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Welcome to the eighth volume of the *TRO Research Annual* featuring current research on issues related to therapeutic recreation and highlighting new and innovative ways of approaching therapeutic recreation practice. The TRO Research Annual serves as our vehicle for communicating the current state of research within the field of Therapeutic Recreation. The objectives of the *TRO Research Annual* are as follows:

1. to provide a venue for Canadian and more specifically, Ontario research;
2. to highlight research that contributes to the body of knowledge and scope of practice of Therapeutic Recreation in Ontario;
3. to stimulate the continuous development of TR research to comply with TRO’s Research Standards of Practice;
4. to promote communication between researchers and practitioners; and
5. to highlight professional practice issues in TR and exemplary programs across the country.

This year’s Research Annual showcases an array of articles from practitioners, students and academics. By communicating and celebrating our individual and collective contributions to the development of therapeutic recreation, we showcase the contributions of our profession within today’s healthcare settings for ourselves and the greater healthcare field.

Our professional practice papers begin with the keynote address by Dr. David Austin from this year’s TRO Annual Conference in Toronto. In his address, Dr. Austin described three distinct periods of therapeutic recreation experienced during his career of nearly 50 years. Describing the period of 1990s to today Dr. Austin states that therapeutic recreation in the United States has been in a temporary state of equilibrium. He suggests that TR in Canada is in danger of encountering a similar state in the future. To move the profession ahead he puts forth twelve challenges and opportunities for our field.

Next, Caitlin Pietras describes her experiences as a volunteer with the Black Light Theatre group in Orillia, Ontario and shares the learning, growth and challenges experienced by youth and volunteers as they shape their contributions into a dramatic production. The purpose of Caitlin’s paper is to encourage the TR field to consider the ways drama can contribute to the quality of living for those with whom we work.

Karen Hirshfeld and Tracey Sanford start off our research papers with a report on their non-pharmacological approach to pain management at Providence Healthcare. In their article, they outline the history and development of the in-patient pain management program and share the results of their evaluation to date.

Shannon Hebblethwaite and Jackie Doyle explore the contribution of the New Beginnings Club (NBC), a recreation and leisure based community social support program on the lives of individuals who have experienced traumatic brain injury (TBI), brain tumour, or stroke and their care partners.

Julie Rodier and Susan M. Arai share stories that arose in community leisure and recreation during Julie’s narrative policy analysis of the *Accessibility for Ontarians with Disabilities Act (AODA)* as part of her Master of Arts degree. Nine interviews were
conducted with policy makers, policy implementers, and people with disabilities. In describing their findings, Julie and Sue highlight the need to adopt a critical stance to understanding disability and social inclusion in therapeutic recreation.

Finally, Shannon Heblethwaite and Lynn Curley share a very personal example of reflection through their use of Participatory Action Research (PAR) in therapeutic recreation. Woven into their PAR project, Lynn had the opportunity to reflect on her growing understanding of the research process and its contribution to her own development as a practitioner. Though this experience, Shannon and Lynn highlight the importance of research and evaluation in the practice of therapeutic recreation.

As you read through these articles, I urge you to critically reflect on their application to your own practice and as always, celebrate the contributions of our colleagues in TR.

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Perspectives on Our Profession: A Nearly 50 Year Journey
David R. Austin, Ph.D.

Abstract

In his keynote address to the delegates at the 2011 TRO Annual Conference, David Austin proposed that there have been three distinct periods during his career of nearly 50 years in recreation therapy. The first period was that of the 1950s and 1960s when recreation therapy displayed its passion for caring for underserved populations in hospitals and institutions. During this phase in the development of recreation therapy the profession moved from the simple provision of healthy recreational activities to a clinical approach involving individualized treatment and rehabilitation. The period of 1970s and 1980s saw the professionalization of recreation therapy while the profession continued to deal with its identity crisis. In the period of the 1990s to today recreation therapy in the United States has been in a temporary state of equilibrium. While recreation therapy in Canada has perhaps not slipped into a state of equilibrium, it is in danger of encountering such a period. Recreation therapists in both Canada and the United States must advance the profession or run the danger of suffering a decline. To move the profession ahead, twelve challenges and opportunities are put forth. The author concluded that he believes the profession, both in Canada and the United States, will rise to the challenges and opportunities before it. He portrayed the future of the profession as a bright one in which recreation therapy will be a powerful force in producing a healthier society.

INTRODUCTION

I was born just before our largest generation, the Baby Boomers. Mind you, I’m not a “want-to-be” Boomer myself. In fact, deep down I believe that those of us born just before the Baby Boomers shared in having the same influence on society as the Baby Boomers. We just have not received either the credit -- or the blame for it. It has been written (“Boomers Rocked the Culture,” 2010) that two things will stand out when historians look at the effect of the Baby Boomers on entertainment: those are TV and rock n’ roll.

The Baby Boomers grew up with TVs in their living rooms and the 45s and LPs they played on their record players in their bedrooms. In fact, the Baby Boomers have been credited with inventing pop culture by watching TV shows like “Leave it to Beaver” and listening to the music of Elvis, the Rolling Stones, and the Beach Boys.

Influenced by Elvis, soon the Beatles followed with “I love you, ya, ya, ya.” It seemed that everyone loved the Beatles – along with many other rockers such as Little Richard, James Brown and Bo Diddley. Perhaps due to the influence TV had on them, the Boomers also embraced movies as not just entertainment but as a true art form.

Some thought of the Baby Boomers years of the 1950s and 1960s as the end of civilization as we knew it. Others felt the Baby Boomers were creating a new culture that would emphasize individual expression and rebellion against the morals of their parents’ generation. At any rate, a youth culture developed that had previously not existed. Television, the movies, and the music industry adopted the culture of the
teens of the 50s and 60s and catered to their tastes.

Most of us, who at the time, were in our 20s and 30s began to grow our hair long, facial hair, and to wear flowered shirts, flare leg pants and boots or sandals. Basically, we did whatever we could to set us apart from our stogy old parents. The world would never be the same again, as even today our society continues to embrace TV, rock music, and the movies. And Boomers, now in their mid-60s, still maintain their love for TV, rock and pop music, and the movies.

I use the effect the Baby Boomers had on society to display how the context of the situation had an effect on what happened in society then and on what continues today. Similarly, the context in which recreation therapy has operated has influenced us and our practice. To put something in context is to understand what has surrounded it at the time. I hope to do that today.

Happily, because I grew up in the 1950s and began my professional career in the 1960s, the story of the influence of the Baby Boomers in a way helps set the context for what I was experiencing as a young RT. This was a time of great change in Canada and America and we will see many things were evolving during this time, including our profession of recreation therapy.

**MY CAREER**

I began my career, fresh out of college, in 1963. I was a recreation therapist at Madison State Hospital, a psychiatric hospital located in Madison, Indiana, and operated by the state of Indiana. Incidentally, my salary was $4,900.00 per year (when I told others my salary I would round up to $5,000 because I thought it was a much more impressive salary than $4900!).

As I have written in my newest book, *Lessons Learned: An Open Letter to Recreational Therapy Students and Practitioners*, at the time “I believed the aim of recreation therapy was helping the psychiatric patients at the hospital where I worked to enjoy themselves through their participation in recreational activities” (Austin, 2011, p.1). Thus the context of our treatment echoed that of the distant culture of 19th century reformers such Pinel, in France, whose humanitarian efforts in the treatment of mental illness employed recreation. Pinel’s “moral treatment” emphasized opportunities for patients to take part in recreational pursuits such as physical activities and gardening in a home-like environment similar to those experienced by healthy individuals. In this atmosphere patients were treated with kindness, dignity and respect (Austin, 2002). Our approach at Madison State Hospital in many ways mirrored Pinel’s moral therapy as, in the main; we attempted to provide our patients with a variety of healthy recreational activities. In actuality we were more hospital recreators than true recreation therapists.

My experience in my second position that I assumed in 1965 was quite different. This was at Evansville State Hospital where we followed a strict treatment approach. Here we assessed patients and then the treatment team designed a treatment program that would assist patients to reduce their psychiatric symptoms. Recreation was not just a healthy pursuit as it had been at Madison. Instead, recreation was seen as a “tool for treatment.” In fact, a medical model was employed and the medical process of assessment,
diagnosis, treatment, and prognosis was overseen by the hospital’s psychiatrists. The RTs were a part of the treatment team, but the team was always headed by a medical doctor who wielded ultimate authority.

At Evansville, RT also was no longer without a theoretical basis. We followed a psychoanalytic approach. For example, to help men with aggression, we had them hit a heavy bag or punching bag. Sometimes we went bowling so they supposedly could relieve their aggression by knocking down pins. Dances provided a healthy means to sublimate sexual desires.

Once I began my work at Evansville State Hospital, never again did I experience the practice of recreation therapy without some underlying theory. By the time I went to the University of Illinois to do my Ph.D., in 1969, the behavioral approach of Watson and Skinner had gained standing. We were reinforcing clients for their positive behaviors with M & Ms and similar rewards. The Children’s Psychiatric Center where my wife worked as a nurse used a behavioral approach and reinforcement therapy was particularly popular in institutions serving clients with intellectual disabilities.

During the four years that I was pursuing my Ph.D. at the University of Illinois, coming onto the scene was the humanistic psychology of Abraham Maslow and Carl Rogers. The principle humanistic approach to therapy was Rogers’ client-centered or person-centered therapy. Unlike the mechanistic psychoanalytic and behavioral approaches, the humanistic perspective was one that saw people as having the ability to be rational thinkers and to be responsible for themselves and their behaviors. The medical model was rejected by those following a humanistic approach. The then new humanistic approach of Rogers seemed to be rapidly embraced by those in RT.

The humanistic approach provided a context for recreation therapy practice that fit nicely with the warm, supportive atmosphere that was a part of Pinel’s moral therapy which influenced what was otherwise a nonclinical, theoretical approach found in my first position at Madison. Yet the humanistic approach offered a complete and well organized theoretical rationale for the practice of recreation therapy.

Humanistic psychology rejected what many consider to be the negative and deterministic views presented by the psychoanalytic and behavioral approaches. Humanistic psychologists do not see people as being primarily driven by instinctual urges of sex and aggression or conditioned by the environment in a robotic manner. The humanistic perspective recognized biological drives and the influence of past learning, but it went beyond previous theories to see people as being self-aware, capable of accepting or rejecting environmental influences, and generally being in conscious control of their own destiny (Austin, 2009).

Under the humanistic perspective, humans were perceived to be social beings that have a strong need to belong. Social relationships were thought to be power inducing, with the therapist-client relationship being key in bringing about change in the client (Cain, 2002). The humanistic perspective has also offered a view of people that sees all human beings (including our clients, of course) as ever striving to achieve optimal health and well-being. This optimistic view of humans is one on which RT practice could be anchored (Austin, 2009). As the humanistic approach became widely adopted by those in recreation therapy, university textbooks similarly adopted the humanistic approach for the practice of recreation therapy. Examples are books by Austin and Crawford (2001), and Shank and Coyle (2002) and Bullock and Mahon (1997) (a Canadian I believe). Illustrative is Bullock and Mahon’s
book that focused on topics obviously influenced by the humanistic perspective such as client strengths and abilities, enjoyment, self-determination, and individualized, person-centered care.

Throughout my 29 years as a professor at Indiana University, humanistic psychology continued to prevail as having the most impact on the practice of recreation therapy. Just within the past 10 years, however, a new approach termed “positive psychology” has emerged. It is my belief that the approach of positive psychology has the potential to rival humanistic psychology for the hearts and minds of practitioners. But my guess is that this new approach of positive psychology will not actually replace the influence of the humanistic approach but, instead, extend it.

Let me briefly summarize what I have seen happen in RT practice since I began my career in 1963. We began with largely atheoretical practice, where our role was that of primarily being hospital recreators providing normal recreation activities for hospitalized patients. From there however the profession rather quickly moved to a much more clinical model with the recreation being used as a “tool of treatment” in order to bring about specific therapeutic benefits. I must confess that it was my good fortune to be work within what for its time was a sophisticated clinical program at Evansville State Hospital. Compton (2010) has remarked that in the 1960s in general in our profession the “seeds of individualized treatment” had been planted but many RTs were only beginning to learn how to implement clinical RT programs.

While the psychoanalytic approach initially provided a theory for clinical practice, the profession as a whole moved toward a humanistic approach. Carl Rogers would have a much more powerful effect on RT than would Freud.

The humanistic approach of Rogers would ultimately transcend RT in psych/mental health to widely influence RT practice in the 1970s and 1980s in a growing array of settings in which RT was being found outside psychiatric hospitals and institutions for residents with intellectual disabilities.

THE PROFESSIONALIZATION OF RECREATION THERAPY

In June of 1995, here in Toronto, a group of RTs met to establish the foundations for a national professional organization for RT in Canada. That group gave birth to what would become the Canadian Therapeutic Recreation Association (CTRA). By 1998, CTRA would hold its first conference where the initial elected Board of Directors took office with Colleen Hood as the first president. The formation of CTRA was an indicator of professionalization in Canada. During my nearly 50 years in RT, I have witnessed the professionalization of RT. One part of that professionalization was the formation of national professional associations in the USA.

Just a few years before CTRA was formed, there had been discontent among RTs in the United States with the lack of an independent professional organization for RT. This discontent was a feeling by RTs, similar to their Canadian colleagues, that they should have their own anonymous professional association. Thanks to the leadership of David Park, the American Therapeutic Recreation Association (ATRA) was formed in 1984. I was one of 50 Founding Members of ATRA. Most of us Founding Members perceived ATRA to be an organization that would champion our profession as a health care profession that employed a clinical approach (i.e., involving individualized treatment and rehabilitation).
The organization for RT that preceded ATRA was the National Therapeutic Recreation Society (NTRS). NTRS was a branch or special interest group within the National Recreation and Park Association (NRPA). NTRS has now disbanded but, at the time of the forming of ATRA, NTRS endorsed the Leisure Ability Model authored by Gunn and Peterson (1984). Many in ATRA, perhaps the majority, did not subscribe to the broad, umbrella conceptual model of Gunn and Peterson that defined our practice as the provision of recreation services to persons with limitations. While Gunn and Peterson are to be commended for supplying our emerging profession with a conceptual model for practice when none previously existed, the model suffered from its broad definition of our profession. Our practice was so broadly defined that it was difficult to explain what we did to ourselves, much less to interpret our profession to others outside of our profession. You can see that by the 1980s, RT had begun to attempt to define itself and what it stood for. Unfortunately, in my eyes, we have not yet fully set the boundaries of our profession so we may clearly define it for ourselves and others. Even without a clear definition of RT, I can tell you that we have made some remarkable steps in our professionalization during my career. Many markers of professionalization have been achieved.

Following the publication of Gunn and Peterson’s Leisure Ability Model, a number of conceptual models have been developed (including my Health Protection/Health Promotion Model). We have established a body of knowledge that is displayed in our scholarly journals and textbooks. University professional preparation programs now exist to produce trained professionals to conduct RT (almost no university curricula existed when I began my career). Curriculum guidelines now exist, as well as university accreditation programs for recreation therapy. Ethical standards now exist. Continuing education is offered at the national, regional, provincial, state, and local levels. And we now have a credentialing program administered by the National Council on Therapeutic Recreation Certification. I should add that our profession today also serves diverse client groups in many settings, including those located in our communities. In short, our profession of recreation therapy looks very little like the one that I entered back in the 1960s. We have advanced by leaps and bounds in the professionalization of recreation therapy.

PERIODS IN RECREATION THERAPY

Let me suggest that we have seen three distinct periods during my career in RT. These are the context within which our profession has existed. In the 1950s and 1960s we displayed our passion for caring for underserved populations in hospitals and institutions. During this time we initially based our practice on the intrinsic value of recreation for persons who were ill or disabled and, later, began to see ourselves as clinicians that used recreation as a tool for treatment in individualized care plans. In the 1970s and 1980s we saw the professionalization of recreation therapy even while we continued to deal with our identity crisis of trying to interpret our profession to ourselves and others. In the period of the 1990s to today, our profession seems to be in what I hope is a temporary state of equilibrium.

Systems have three basic directions in which to move. They can grow, decline, or temporarily reside in a state of equilibrium. I would posit that recreation therapy in the United States is in a state of equilibrium – at which point RT must either grow or it will
decline. Because recreation therapy has more recently developed in Canada, I sense that Ontario and all of Canada is more in a growth mode than the United States. However, I believe that RT in Canada must too choose to move ahead or run the danger of suffering a decline.

What has led me to believe that RT in the United States is in a state of equilibrium? Over 30 years ago we met the criteria to be considered an emerging profession (Navar, 1979). As previously indicated, we had a developing body of knowledge, professional literature, university curricula, professional associations, and other markers of professionalization. Some gains have been made since but, in the main, RT in the United States has remained stagnant and in some areas even has shown decline (e.g., a reduced number of research universities with RT curricula). In my mind, this lack of growth resulting in a state of equilibrium has continued due to our failure to define just who we are as a profession, although it seems to me that in the United States we have begun to identify ourselves more and more as health care professionals. Our future, I would project will be one of determining our relevance in health care and in identifying what is unique about us. In doing so I believe we will have to take advantage of many opportunities and react to many challenges. It is to the future that I would now like to turn.

THE FUTURE OF OUR PROFESSION—OUR “2020 VISION”

Just what do we wish for historians to say about us in years hence? This is the question we now turn to as we look toward the future of recreation therapy. Do we wish for historians to indicate that as we entered into the second decade of the 21st Century that recreation therapy resided in a state of equilibrium or ever went into decline? What is our “2020 vision”? We live in transformational times and we need to be focused on the future. To assure our future does not dim but, instead, bright lights shine on our profession, there are a number of challenges and opportunities that we must address. Comedian Dennis Miller used to end his rants on his TV show by saying “but then I could be wrong.” Before presenting my challenges and opportunities I would like to present a short of disclaimer to admit that not all may buy into my views and that is okay. To do that I want to share this quote with you from the book Medicine and Philosophy (Johansson & Lynoe, 2008):

Fallibilism implies tolerance. Everyone needs to hear criticism of his (or her) views in order to keep them valid, and such an insight might ground some tolerance. But as soon as one acknowledges the possibility that one may be wrong – partly or wholly – one has to become much more tolerant. Why? Because then criticism might be needed in order for oneself to be able to improve one’s views. Tolerance is necessary not only in religion and political matters, but also in scientific and philosophical. (p. 5)

With that, here are challenges and opportunities within our profession that I have identified:

To define ourselves.

First and foremost, it is my belief that our profession needs to clearly define itself. A handicap that our profession has endured is that we have too long existed without a clear and unified message that answers the question: “What does your profession do?” The following quote appeared in a textbook:
Members of a profession without a clear paradigm bear an undue burden in attempting to make sense of their life work. Perhaps the most pervasive impact on this paradigmatic uncertainty is the difficulty therapists have had with their own identity. Over the years, many students and colleagues have shared with me their frustration in not being able to explain (to themselves, much less others) what their profession was (Kielhofner, 1997, p.304).

Where do you suppose this quote is to be found? Do you think it comes a recreation therapy book? If you do, you are mistaken. It is from a book on occupational therapy (OT). I share the quote with you to illustrate: (a) the importance of having a clear definition for our profession; and (b) that we are not alone; other professions (such as OT) share the dilemma of lacking a definition that will direct practice and allow them to interpret what they do for others. I should mention that while both RT and OT share the dilemma of lacking clear definitions for their professions, I do wish to state that I perceive RT and OT to be very separate and distinct professions.

To engage in Evidence-Based Practice.

I’m sure you are familiar with Evidence-Based Practice or EBP. EBP has come to the forefront of health care during the past decade. The term EBP refers to basing what we do in practice on research findings and other reliable clinical evidence. The integration of the best available external research and clinical evidence with the recreation therapist’s clinical expertise permits us to deliver quality care. We, in RT, need to follow the trend toward the use of evidence-based practice, while still maintaining our humanistic approach. By the way, do you know where evidence-based practice originated? Right here in Canada. EBP flows out of Evidence-Based Medicine – and the birthplace of Evidence-Based Medicine was McMaster University in Hamilton.

To produce applied research that will provide the evidence for EBP.

I recently learned that today medical knowledge is doubling every 8 years. Doubling knowledge every 8 years seems astounding to me. But in order for us in recreation therapy to have empirical research evidence on which to rest our practice, we must too produce applied research to guide our practice. Our efforts will be further strengthened if we collaborate with other health professionals as we gear up for increasing research efforts.

To develop program protocols.

Recreation therapy needs to develop protocols that can be shared widely with practitioners in the Canada and the United States. Especially relevant will be protocols developed for programs for those with chronic illnesses and disabilities. Particularly needed will be protocols on physical fitness programs for our growing population of elderly clients (remember thousands of Baby Boomers will turn 65 this year) and those who (in staggering numbers) are obese or overweight. Recent research has found that those with intellectual disabilities are particularly prone to be overweight (Rimmer, Yarnaki, Davis Lowry, Wang & Vogel, 2010; Yamaki, Rimmer, Lowery, & Vogel, 2011).

We also will need protocols for social skills training (including leisure education) for those with serious mental illnesses and protocols for stress reduction since the American Psychological Association has reported that most Americans suffer from
“moderate to high stress” (American Psychological Association, 2011, p. 60).

To engage in theory-based practice.

It is my strongly held belief that every recreation therapist must rest his or her practice on a conceptual model. Of course, I recommend my own Health Protection/Health Promotion Model! Whatever conceptual model you choose, it must be founded on a theoretical foundation. Earlier in my talk I spoke of the humanistic approach as forming the theoretical basis for the practice of much of recreation therapy today. In the near future I predict that positive psychology will join humanistic psychology to form the basis for much of our practice. In fact, I believe that positive psychology is simply an extension of humanistic psychology so most of the basic theoretical concepts of the humanistic approach will blend nicely with the newer positive psychology. Elsewhere I have written: “it seems to me that positive psychology will join with humanistic psychology in forming a solid theoretical foundation for recreational therapy practice” (Austin, 2011, p.35).

A large part of positive psychology has to do with the therapeutic benefits of positive emotions. Certainly RT produces past, present, and future positive emotions. Do we not provide our clients with past emotional experiences such as contentment and satisfaction? Do we not offer current emotional experiences such as fun, enjoyment, and happiness? Do we not allow clients to anticipate emotional experiences such as hope and optimism? Such positive emotions also produce “side effects” of first, serving as antidotes for negative emotions and, second, of freeing people up to broaden their thoughts and actions (Austin, 2011).

Based on this, positive psychologist Barbara Fredrickson (2001) developed her Broaden and Build Theory of Positive Emotion. Her theory sees positive emotions as agents that release us to broaden our thought and actions. This frees us up to take more risks or to stretch ourselves. I expressed this concept elsewhere when I wrote: “Stop and think about yourself. When you are happy and feeling good about yourself and the world, are you more optimistic and risk taking than when you are down in the dumps? Of course you are. We all are. That is our human nature” (Austin, 2011, p.36).

Once we open ourselves up to new experiences, we are then in a position to build on our personal strengths and our skills and abilities. This is the “build” part of Fredrickson’s Broaden and Build Theory of Emotion. Thus, based on positive psychology, we and others can readily perceive that recreation therapy is a lot more than “fun and games.” RT, in fact, produces positive emotions that open clients up to new experiences -- new experiences that serve as vehicles for clients to overcome problems or difficulties and develop themselves for the future.

Once more I would like to share something that I have previously written. I wrote:

I think it is important for recreational therapists to recognize that the positive emotions they help their clients to achieve represent far more than ‘fun’ or ‘feel good’ experiences. The positive feelings brought about in recreation and leisure activities are not an end, but a means to an end. This is because positive emotional experiences in activities open doors for clients, doors that lead to help clients to reach their goals of achieving health and well-being. (Austin, 2011, p.36).

In addition to positive emotions, the other two major components that comprise positive psychology are positive strengths
and abilities and positive environments. While time does not permit extensive elaboration on these components, I would bet that you can see that these concepts also fit well within recreation therapy. Do we not take a strength-based approach in recreation therapy? I think so. We are strength-based, focusing on clients’ strengths, not their limitations or pathology. I believe that recreation therapists are some of the best clinicians when it comes to taking a positive approach to clients – an approach of “building what’s strong,” rather than the solely the traditional approach of “fixing what’s wrong” with clients. I truly believe being positive and enthusiastic are traits that most RTs possess. I don’t believe there is any group of helping professionals who do a better job at displaying a positive approach as RTs.

Finally, in regard to positive environments, the third pillar of positive psychology, from our tradition during the early Red Cross days has come our ability to offer clients positive environments in the form of creating warm, supportive atmospheres within RT. I wish we had more time to explore positive psychology as a theory base for our practice. I hope you can see from this brief discussion that it is important to have a theory base and that humanistic and positive psychology offer us a theoretical foundation for our practice.

To provide uniform and rigorous university professional preparation programs.

As a result of my more than 40 years as a professor, I have arrived at the conclusion that while today’s university professional preparation programs are vastly superior to what existed years ago, it is time for them to be made more uniform, more rigorous and more complete. I found that in speaking with RTs from Alberta last fall, at the Alberta Therapeutic Recreation Association Conference, that they too felt university curricula needed significant improvement. One specific area that many RT curricula ignore is gerontology courses – especially courses in gerontology in RT. Yesterday’s Baby Boomers are today’s Elder Boomers, and we must prepare RTs to work with them.

It seems that our profession is not the only one that needs to shore up its university programs. Concerns for more demanding college programs were echoed this winter in the book titled Academically Adrift: Limited learning on College Campuses (Arum & Roksa, 2011). The book reported on an extensive research study of more than 3,200 college students taking a variety of majors at colleges and universities across the United States. The results of the study reminded me of the words of comedian Woody Allen who once supposedly said: “Some drink deeply from the river of knowledge. Others only gargle.” This report showed that on average students spent only 12 hours per week studying and 37% reported spending less than 5 hours per week studying. The researchers concluded: “Students often embraced a ‘credentialist-collegiate orientation’ that focused on earning a degree with as little effort as possible” (p.70). Further, the researchers partly blamed faculty for the absence of effort and recommended that in every course that students need to be assigned a minimum of 40 pages of readings each week and be asked to write at least 20 pages each semester. These hardly seem like stringent requirements to me. How about you?

Ultimately, I believe that we need to make the M.S. degree the entry-level degree for recreation therapists. While waiting the development of the M.S. as our entry-level degree we need to establish opportunities for seamless transition from the associate’s to bachelor’s degrees, to master’s, and Ph.D. degrees.
A final thought on education is that RTs should be educated with physicians and other health care professionals both as students and throughout their careers in lifetime learning opportunities. The prestigious Institute of Medicine of the National Academies of Sciences (of which my wife, Joan, is a member!) has endorsed the idea that continuing education efforts should bring together health professionals from various health professions in order to facilitate team-based health care delivery as it becomes increasingly important. The Institute of Medicine has further endorsed the concept of establishing a national interprofessional continuing education institute for all health professionals (Institute of Medicine, 2009). Wouldn’t it be a tremendous outcome if RTs could be key players in bringing about the establishment of interdisciplinary education at our universities and national CE institutes for all health professionals in our great countries?

To establish repositories to provide practitioners with the latest information on best practices in the field.

Compton (2010) suggested RT needs to establish repositories that hold the latest information on best practices. I too believe that practitioners need to have readily identifiable places to go when they need information. Examples of needs could include things such as assessment instruments and program protocols. Further, I would suggest that the repositories should be university based and government supported.

To embrace the explosion of the new and exciting technology that will be a certain part of our lives.

This will involve buying into electronic health records that are replacing paper-based medical records. It will also mean using technology in assessment and in programs. We are already have computerized assessment instruments and use terms today such as “Wiihabilitation” in our practice. Professor Carmen Russoniello, at East Carolina University, is doing great things in researching the use of video games used in rehabilitation.

Telemedicine allows clients and physicians to connect over the internet. Research (Neale, 2011) has shown that an Internet-based rehabilitation program worked as well as conventional therapy in the recovery of patients with total knee replacements. Perhaps the future may involve similar “telehealth” or “telerehab” methods for RTs and their clients.

“Patient-centered medical homes” is a phrase we are hearing these days. These are technology-driven, using sensors to remotely monitor the person at home (Acohido, 2011), and employ a holistic approach to health care. Why can’t RT find a place in such environments? I am not sure just how recreation therapy will use technology in the future, but I am sure that we will need to as innovation will act to transform health care.

To offer education and training not limited to time and place.

Already recreation therapy newsletters and journals allow practitioners to gain CEUs. At Indiana University, since the early 1980s, recreation therapy education has been provided through a graduate-level video-based distance learning program. I also take some pride in having instructed the first online course in RT when, in 1999, my colleague Bryan McCormick and I taught a course titled “Techniques in Therapeutic Recreation” to three students, one in New York, a second in Utah, and the third in New Mexico. But such offerings are only the
beginning of what we can do when we don’t limit education and training to time and place. The time is certainly right for universities and professional associations to develop professional and continuing education using the newest technologies to better prepare RTs and help them keep up-to-date.

The evolution of mobile and digital technology within education has led to an emergence of interactive, digital content. The increasing popularity of smart devices and iPads enable quick and effortless mobile consumption of content. These technologies are leading educators into the new ways to use technology in their teaching; pulling content, such as e-text and video into their courses and workshops with just a few clicks. Let me end with this thought on not limiting ourselves to time or place in education and training. It has been suggested that “a relatively untapped resource is the use of social media among medical professionals” (Sharp, 2010). How about RTs in Ontario leading an initiative to expand the use of social networking among RTs everywhere?

To develop much greater collaboration between RTs in Canada and the United States.

It has been my pleasure to recently speak at several Canadian conferences. In addition to speaking here in Toronto, last fall I presented at the Alberta Therapeutic Recreation Association Conference in Calgary. And a couple of years ago, I spoke at the Canadian Therapeutic Recreation Association Conference in St. John’s, Newfoundland. As I like to tell my friends, and well actually anyone who will listen: “I’m ‘big’ in Canada!”

I’m not so sure that is true - but I do know that I have learned a great deal from my Canadian colleagues during these conferences. I’ve also been energized by my Canadian colleagues, who have time and again displayed to me their strong belief in the power of our profession to help others. In an article on the Alberta symposium, I stated: “Canadian RTs are extremely welcoming and are rapidly advancing recreation therapy in their country. I hope we in the United States will have continuing exchanges with our Canadian colleagues as they have much to offer us and we too can be helpful to them” (American Therapeutic Recreation Association, 2011).

I believe it would be healthy to have many more opportunities for interactions between RTs from our countries. By inviting me here today the leaders of TRO are making an effort to further relations between our countries. (I hope I haven’t set back that effort too badly!) I would urge the leaders of TRO to continue to play a prominent role in increasing interactions between Canadian and American RTs in order to strengthen and improve RT in both of our counties.

To become a vital part of the transition from health care as disease and illness care to illness prevention and health promotion.

Particularly as health care moves to emphasize prevention rather than simply cure, doors should open for recreation therapy in such areas as: the improvement of mental health; the reduction of obesity, the reduction of alcohol and drug addiction; and the reduction of heart disease. There will be a corresponding prioritization of care and treatment of conditions related to old age as the graying of Canada and America continues. This will involve aging clients living in the community and those in assisted-living facilities, as well as those in nursing homes receiving personalized health care involving both restorative short-term care and long-term, complex care.
And mark my word; the “elder boom” is on its way as we speak. Between now and 2030, the number of elderly Americans will increase from 40 million to 72 million, or from 13% of the population to 20% of the population (Friedman, 2011). Likewise, older Canadians are the fastest-growing demographic in Canada. Canadian elder boomers today account for almost 14% of the country’s 32 million people, and the proportion of aging Canadians will keep rising in the future (CBC News, 2007). Yes, the numbers of elder boomers is growing daily and that growth will bring more and more demands to the health care system. It has been stated that the health care system in the United States is not prepared for the elder boom (Friedman, 2011). I would hazard a guess that the same might be said about Canada.

To become a vital part of the transition of health care from hospital based care to community and home based care.

Another trend will be the continuing migration of care out of the hospital and into community settings. I might add that this trend is nothing new. Even at the turn of the 20th Century, more than 100 years ago, there was great concern that community-based care for older adults and those with chronic illness was being neglected. It has been written that: “The overarching sentiment of the time (100 years ago) was that medicine had to be brought out of the hospital, into the community, and into the home to the extent possible” (The Joint Commission, 2008, p.6).

Does this surprise you? It surprised me. While I have heard cries for more community-based care throughout most of my career, I had no idea that the need for community-based health services was widely recognized late in the 19th Century and early in the 20th Century. A full Century after the initial recognition of the need for community care, The Joint Commission (2008) stated:

The call for hospitals from a century ago echoes today. The rise in the number of patients who are aged and those who are chronically ill, challenge hospitals to extend the parameters of hospital-based care from inside the medical center, to the community and into the home. (p.6)

I do believe that in the near future we will see substantive changes in health care. We must make health care available to people where they live. I can especially see that my area of practice, psych/mental health, should be a health concern that rises to the top in terms of community-based health care. Did you know, as documented by the National Institute of Mental Health (2010), that “mental disorders are the leading cause of disability in the U.S. and Canada”? This is amazing to me since Thorazine arrived as a wonder drug to treat schizophrenia when I was beginning my career in the 1960s. We thought that drugs, such as Thorazine, would perhaps eliminate serious mental illness. Yet the numbers of seriously mentally ill has increased six-fold since Thorazine was introduced (Whitaker, 2005).

Did you know that one in five Ontarians will have serious mental illness or a substance abuse problem during their lifetimes? Did you realize between 15 and 21 percent of children and youth in Ontario have at least one mental health issue? Or that 340,000 adults in Ontario have gambling problems? (Report to the Minister of Health and Long Term Care, 2010). Did you realize that one in 10 Canadians report problem drinking? Did you know that one of five children in North America displays signs of emotional or behavioral problems? Or that one in every eight Canadians will be hospitalized for mental illness at least one in
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their life, more than those hospitalized for cancer and heart disease (Garfinkel, 2002).

A report titled *Respect, Recovery, Resilience: Recommendations for Ontario’s Mental Health and Addictions Strategy*, published by the Minister’s Advisory Group on the 10-Year Mental Health and Addictions Strategy in December of 2010, suggests the first goal to actively promote mental health should be prevention programs. Prevention programs the report indicates should help people to:

- Develop coping skills and constructive ways to deal with anger, sadness, fear and grief.
- Develop stress management skills.
- Do things that build confidence.
- Build and maintain healthy relationships with family members, friends, neighbors and co-workers.
- Find work-life balance.

Are these outcomes that are familiar to recreation therapists? Do they easily fit under the banner of recreation therapy? I think so. And, additionally, I believe that RTs are often in the best position to deliver these outcomes in the community.

A great American and fellow Hoosier Abraham Lincoln once said: “Don’t stand in someone else’s shadow when it is your sunshine that should lead the way.” I believe Lincoln’s words are apropos today for RTs in Ontario. Further, one of the specific strategies found in the report by the Minister’s Advisory Group on the 10-Year Mental Health and Addictions Strategy reads: “Provide wellness and mental health supports for seniors in community settings, such as senior centres and recreation programs” (p.20). Additionally, in light of the fact that: “Research shows that between 80 and 90 percent of older adults living in long-term care facilities have some sort of mental disorder,” (Zahradnik, 2007, p.1) preventative mental health programs for seniors certainly seem to be called for. Again, should not RTs take the role of one of the primary providers of preventive mental health services for seniors in the community? Likewise, shouldn’t RTs be providing mental health care to those in long-term care facilities?

While talking about the aging population it is helpful to refer to a report by the Canadian Mental Health Association (Zahradnik, 2007) that indicated the vital place of long-term care in the Ontario health care system and reminded us of the growing number of persons who are older. The report stated: “While most seniors can expect to reside in the community throughout their later years, a significant number will require institutional care to ensure safety and well-being. The need for long-term care services and support is often greatest for those who are considered the most vulnerable – those who are frail, or have complex health conditions or psychiatric disorders” (p.2).

The report went on to state: “Today, adults over 65 years of age represent 12 percent of the total population in Ontario, but they consume over 44 percent of the province’s health care budget and account for 50 percent of acute hospital days. By 2026, seniors will amount to approximately 21 percent of the population and consume about 60 percent of health care spending” (p.2). Finally, the report states that the growth rate of long-term care beds over next 30 years will be 300% (p.5).

Before leaving the topic of aging Canadians, you should know that the Public Health Agency of Canada states that 60% of older Canadians are inactive (*Physical Activity Guide for Older Adults*, 2009). Yet, physical activity is essential to the health of older adults (Centers for Disease Control and Prevention, 2010). In fact, research has shown that activity energy expenditure is strongly associated with mortality in older adults and will likely improve the health of
older adults (Manini et al., 2006). Thus, it seems evident that Canadian RTs should develop and implement physical activity protocols for older Canadians both in the community and in long-term care facilities.

It seems obvious to me that with increases in physical activity should come a reduction heart disease and other health problems associated with aging. Recent research (Bailey & McInnis, 2011) has shown that physically active video games or exergames, such as those on Wii systems, have potential to get kids up and moving and to bring about moderate to intense energy expenditure. It does not seem a too much of a stretch to suggest that older adults would also gain from participation in such exergames. I hope some RTs will try out the use of active video games with older adults and report their results in the literature.

CONCLUSION

You can see that my own age may have provided a context for my address this morning. Although I don’t really consider myself to be elderly, I guess I might fit that demographic! Comedian Bill Crosby has said: “Old is always 15 years from now.” I can tell you that there is some truth in that statement! If you will recall we began today by talking about Baby Boomers – who we are today’s “Elder Boomers.” And while discussing the movement of health care toward health promotion and illness prevention, as well as the movement toward community-based health care, we just completed talking about how RTs should be prime players in working with aging populations in the community, as well as in long-term care facilities. It seems to me that we “old people” have become an important client group for our profession.

I might add that the US Department of Labor projects that due to the aging Boomer population the demand for recreation therapists will outpace the average for all occupations in the next decade. The Labor Department expects the employment of RTs to increase by 15% from 2008 to 2018 (United States Department of Labor, 2010-11). We also talked about the dramatic changes in RT during my nearly 50 years in our profession. Over my 50 years in our profession, I have witnessed real growth from rather unsophisticated beginnings to a profession that meets all criteria for an emerging profession. Yet to me, it seems that in the United States our profession has become mired in a temporary state of equilibrium.

While my perception is that recreation therapy in Canada is in a growth mode and has not suffered the degree of equilibrium we have in the States, you here in Canada are subject to many of the same forces we have experienced in the States. Thus, I believe our profession, both in Canada and the United States, needs to rise to the challenges and opportunities that we have discussed today. Someone once said, “I know not what the future holds, but I know who holds the future.” I do know that it is us, you and me, who hold the future of recreation therapy. If we are up to the task of meeting the challenges and opportunities ahead, and I believe we are, I see nothing but bright lights shining on our profession of recreation therapy. A quote from Oprah Winfrey perhaps best conveys my confidence in our ability as a profession to rise up to meet our future. Oprah said: “When I look to the future, it’s so bright it burns my eyes.” I believe we are in a wonderful profession that has a bright future and that we are blessed to be in our profession of recreation therapy.

Let me end by quoting from the final chapter of my book, Lessons Learned, the chapter is titled “Cherish the Opportunity to do Recreation Therapy.” I’ve written the following:
I’ve always felt...that we recreation therapists have advantages that most other helping professionals do not enjoy. Our focus on the positive is very unique within the helping professions. We recreation therapists have always been optimists, full of hope, who believe in the capacity of clients to change. We emphasize our clients’ abilities and capitalize on our clients’ strengths to create positive emotional outcomes such as fun, enjoyment, and satisfaction. Because of our positive approach, clients tend to get attached to us. They like us and what we do for them. I hope you...feel very lucky, very blessed to have chosen to become a recreation therapist. Our profession is a special one. It is one that is to be cherished (Austin, 2011, p.133).

Yes, our profession is a special one and we have witnessed great strides having been made by our profession. Yet, certainly, there is much more work to be done. As one who has been actively involved in our profession for nearly 50 years, I’m convinced that we can bring about important advances that will move our profession far beyond where it is today. If the vision we share for our profession is to be realized, it will be because of each of you – and your individual and collective strivings. I wish you the very best of success in your efforts!

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See My Voice: At-risk Youth Share their Message through the Medium of Black Light Theatre

Caitlin Pietras

Abstract

Black Light Theatre is a contemporary style of theatre in which the performers are hidden on a black stage with only florescent props visible under a black light. Using her therapeutic recreation (TR) background and experience with youth, Karen Bell started a Black Light Theatre program in Orillia, Ontario with a group of at-risk youth, filling a void in services to this population and geographical area. The program is driven entirely by the youth’s creativity and participation. The purpose of this paper is to encourage the TR field to consider the ways drama may be beneficial for those with whom we work and begin to conduct research on the use of drama in TR settings. To this end, I provide information on the Black Light Theatre group in Orillia, Ontario. I describe my experiences as a volunteer with the Black Light Theatre group and discuss the process that captures the learning, growth and challenges experienced by the youth and volunteers as they turned their ideas into a full evening production in front of a paying audience.

A story is not something created, but something that needs to be released.

John Francis

INTRODUCTION

Joshua* is a 15 year old boy who comes from a single-parent family. Before becoming involved in Black Light Theatre, Joshua was engaging in self-mutilating behaviour. He was an attention-seeking student with high needs and mediocre grades.

Tanya* is a 17 year old girl with the potential to be a natural leader. At home she cares for a step-brother with an intellectual disability and a mother with an alcohol addiction. Her father is only allowed to visit her in a supervised setting.

These are just two glimpses into the complex lives of at-risk individuals involved in Black Light Theatre in Orillia.

*Names have been changed to protect the identity of the youth

A youth is considered to be at-risk when s/he “engages in behaviour which could lead to mental or physical harm to oneself or others” (Robertson, 1995, p. 5). One way for youth to express themselves in a meaningful way is through participation in drama therapy which is based on the principle that acting out situations can induce behavioural and/or psychological change in a person (Nathan & Mirviss, 1998). The purpose of this paper is to encourage the TR field to consider the ways drama may be beneficial for those with whom we work by sharing information on a drama program adapted by Karen Bell to support at-risk youth in Orillia.

Black Light Theatre is unique in that the actors are hidden in black and are only
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visible through the fluorescent props they hold. This program is youth-driven and the production is based on themes the youth create. Themes are often centred on political issues, community concerns, situations that youth deem to be unjust, abuse or bullying. The project is a transitional piece, aiding to help youth develop self-esteem and discover their strengths and interests. This program offers participants the opportunity for choice, self-expression, meaning, and individuality within a group context.

The program’s unique structure and mix of music, friends and fun are appealing to youth and influences their choice to participate. Individuals who may be resistant to working within a structured framework seem to respond well in situations that encourage creativity. By providing youth with positive ways to spend their time, Black Light Theatre provides an alternative to crime and deviant behaviour. Black Light Theatre also helps youth connect with community programs, groups and clubs by involving volunteers and organizations in theatre productions.

LITERATURE REVIEW

Two common themes can be found in the literature on drama. First, people need to tell stories to make sense of their everyday lives (Landy, 2005). Second, drama gives individuals a voice that might otherwise not be heard (McCann, 2009). Drama-based programs allow individuals to identify and generate strategies and skills for dealing with unpredictable situations and provide a safe and supportive environment in which to practice and evaluate these strategies (Blacker, Watson & Beech, 2008). Creative arts also foster increased communication abilities, improved self-worth, healing, and improved interpersonal relationships (Nathan & Mirviss, 1998). Drama encourages spontaneity, offers youth-at-risk an alternative to drug use, and builds trust and teamwork (Leeder & Wimmer, 2006).

Drama therapy has been shown to be effective for diverse populations with different cultural backgrounds. Studies have examined the impact of drama for individuals with schizophrenia (Yotis, 2006), persons living with dementia (Lepp, Ringsberg, Hold, & Sellersjo, 2003), new immigrants within the school system (Rosseau, Gauthier, Lacroix, Alain, Benoit, Moran, et al, 2005), and male survivors of sexual assault (Mulkey, 2004). Drama workshops have been used in prisons to create a safe and supportive environment in which inmates build skills and develop leadership, a sense of community, self-respect, self-expression, social and language skills, and a sense of achievement (Blaney, 2006). Drama therapy has also been shown to help criminal offenders develop empathy (Vine, 2006) and has assisted incarcerated women in resisting internalized oppressive beliefs (Leeder & Wimmer, 2006).

While there appears to be benefits associated with the therapeutic use of drama, it can also have some negative implications. For example, a recent study conducted with marginalised youth in Toronto found that while performing drama in public teaches critical thinking and social skills through problem solving, it also places participants at risk for the scrutiny and judgement from others (Gallagher, Freeman & Wessells, 2010). Thus, it is important for professionals to understand the potential benefits and disadvantages of using drama and adapting it for those with whom they work.

As I have demonstrated, considerable research has been conducted on drama and drama therapy. However, very little research has been done on the use of drama within the field of therapeutic recreation (see Rafferty, 2008). Despite the paucity of research within the field, 71.4% of therapeutic recreation practitioners who
responded to a survey by Rafferty (2008) believed drama therapy had the potential to be a useful tool. Clearly more research is needed to ascertain the possible benefits of drama therapy for various populations and the findings of this research communicated to TR practitioners. As previously stated, my purpose in writing this paper is to encourage the TR field to consider the ways drama may be beneficial for those with whom we work and begin to conduct research on the use of drama in TR settings.

**BACKGROUND OF BLACK LIGHT THEATRE IN ORILLIA**

A resident of Orillia for over 25 years, Karen Bell, a therapeutic recreation graduate, and faculty member in the Child and Youth Worker program at Georgian College, had observed over the years that unique programs for at-risk youth in Orillia and the surrounding area were extremely limited. After participating in a Black Light Theatre workshop at a Child and Youth Worker Conference in Hamilton, Bell decided to adapt what she learned about its use for individuals with physical disabilities to create an opportunity for at-risk youth in Orillia to participate. I joined the group as a volunteer the second year the program was run, in 2009.

Funding often determines the lifespan of a program. In this case, Bell was able to secure funding with the Orillia District Arts Council (ODAC) for the program so that she could employ Kathleen Hall, a Child and Youth Worker graduate from Georgian College, as the facilitator. Funding was also necessary to book the location of the final performance and to purchase black lights, props and fluorescent paint in order to ensure the props will be seen. Participation was encouraged by the decision not to charge the youth for their involvement in the program. This meant program costs had to be fully covered by both bursaries and/or ticket sales.

Through the partnership with ODAC in the City of Orillia, Bell was able to hold rehearsals at the Orillia Youth Centre free of charge. The Youth Centre was chosen as it is in a central area for Orillia youth to congregate. Many of the Youth Centre staff were familiar with the participants from previous experiences and were therefore a valuable resource to support the program.

Bell utilized her connection to Georgian College, Laurentian University, and local high schools to recruit students to volunteer with the program. Community members were also encouraged to volunteer. Volunteers attended an information session to clarify their role as mentors and determine the time commitment to the program. They were asked to return the following week if they felt it was an appropriate fit for them. It was communicated to the volunteers that due to the nature of the population, the youth need someone who can act as a positive role model, and show commitment to the program by being at practices on time every week. For some of the youth, these volunteers are the only stable thing in their chaotic lives.

Youth for the program were sought through various partnerships within the community, as well as through word-of-mouth from previous participants. Youth that participated were between the ages of 12 to 19.

**BLACK LIGHT THEATRE AS A SITE FOR INCLUSION**

One unique aspect about the program is that every effort is made to include youth and support their completion of the program. Many of these youth have been expelled from other programs or felt as though they did not have a group to which they could identify. Black Light Theatre is one place
See My Voice: At-risk Youth Share their Message through the Medium of Black Light Theatre

where they could express themselves in a healthy and positive way. It is a place where they did not have to worry about their abusive parents, their dad in jail, their mother selling drugs, prostitution, and other stressful life situations a teenager should not have to ever worry about. No one has been asked to leave the program in the three years it has been running. The program operates with a philosophy to “make it work” in order to keep the youth involved.

PROGRAM GOALS

It is the hope of founder and co-facilitator Karen Bell, that the youth involved in Black Light Theatre will continue to be involved with theatre in the future, and become active, contributing members of the community. Some goals of the program include teaching social norms, providing youth with ways to express themselves that do not involve violence, theft or vandalism, linking the youth to community groups, and giving the youth the opportunity to take ownership of a project and see it through to the production. Although the practices build towards the final performance, it is important to note that the program goals and outcomes are achieved during the process itself, and are not solely based on the outcome (performance).

PROGRAM IMPLEMENTATION AND EVALUATION

Black Light Theatre consists of two rehearsals per week, which are each two hours long. The program runs for eight weeks from September to November annually with the final performance held in mid-November. Students begin the program as they start the new school year and complete the program before the start of exams and the busy holiday season.

Each practice session is highly structured. The sessions are broken into short segments in order to accomplish the most in a short period of time. Each session started with a short drama ice-breaker activity. From this, the youth broke into groups. The groups had to be flexible in planning the choreography as sometimes youth would be absent and other group members had to step in to help out. Working with this population, one must expect that youth will come and go from week to week depending on their personal situations. Even if there are only three youth left on the night of the performance the show will go on because Black Light Theatre is not about the final production, it is about the process.

Weekly sessions involve the youth in choosing the music, choosing a message or theme to convey to the audience, making up the choreography to the music, designing and creating props, and then rehearsing over and over again. It is very important to have the majority of the work done early on so that the rest of the practices can be spent rehearsing and making the props. At the end of the night the group comes together to practice one song as a group (usually the entire group performs the opening and closing act together), debrief, and then leave for the night.

Black Light Theatre is evaluated by the youth through a questionnaire after the final performance. The youth reunite one last time at the Youth Centre to watch the video of their performance, which provides an opportunity for them to reminisce, discuss how the program went, and connect again with the volunteers and participants. If youth have trouble reading or writing, the volunteers are available to assist with the questionnaire. Attempts are made to follow up with youth who have dropped out of the program along the way and discuss why they chose not to continue.
DISCUSSION

Going into the program, I admittedly had some expectations and preconceived notions of the population and theatre in general. Black Light Theatre was as much of a learning experience for some of the volunteers as it was for the participants. We learned the importance of active listening, being flexible, and being supportive. Volunteers had to let go of conventional notions of theatre and realize that this was going to be a completely different experience. Most importantly, we had to learn how to step back and give control to the youth.

It was very important to be flexible when programming for youth at-risk. There will always be reactions from the youth that are unexpected, or scenarios that were never anticipated. It is necessary to have a plan, but also to be flexible and then work together as a team to return to the planned path. At-risk youth can be resistant to the ideas of others. It is often through this resistance that most of the learning occurs. I have learned the value of demonstrating to youth that volunteers and program staff are actively engaged in a team endeavour.

In addition to being a positive way for at-risk youth to express themselves, Black Light Theatre is also a great way to connect youth to the community. A sense of community is important to help the youth understand what it means to support one another and be a contributing member of society. Working with various community organizations also brings familiarity between organizations and may encourage youth to volunteer or participate in other community initiatives.

There were many challenges presented to the youth, staff and volunteers. For example, it was often difficult to obtain parental consent to participate. Some youth were not on speaking terms with their parents, and some parents could not read and would throw out the consent forms rather than ask for help. Other parents struggled with addictions which interfered with all aspects of the participants lives. Another challenge facing the youth was to remain in the program from start to completion. Remaining in the program meant being confronted with problems, and talking about difficult issues. Some youth choose to avoid these situations completely by leaving the program.

Tenuous funding presented another challenge. Creative arts programs are often considered frivolous programs without a purpose or proven positive results. Recreation therapists and other allied professionals have to advocate for the youth and the programs offered in order to ensure these services will continue in the future.

Other barriers to the program included the youth’s reluctance to commit. Youth often lacked social skills, were fearful to trying something new, were not motivated to participate, faced bullying, had justice and legal issues, possessed different levels of learning, and had emotional issues (self-harm, drugs, foster families). Despite all of these issues, the strength of the program was found in the ability of youth, staff and volunteers to persevere and emerge as a team. There will always be last minute drama, the youth will forget their marks on stage, and they will giggle when they are supposed to be silent. Things will not go smoothly; they may not even go at all! In the end, when the youth are running around with huge grins, full of confidence and happiness, if only for that one night of the performance, it dawns on you: this is the reason we do what we do.

RECOMMENDATIONS

Drama is an excellent tool to use with both at-risk youth and youth in general. The
Black Light Theatre program is adaptable to any population. It is important to be flexible in the process and not worry if the event is not turning out the way that was planned. Establishing partnerships with the community and developing support networks is crucial to a program’s success. Have fun! Although it may seem like your message is not resonating with the youth, you will be astounded by the results. Conducting research that examines the experiences of youth involved in programs such as Black Light Theatre is vital for funding in the future. Finally, do not be afraid: program facilitators need not have any theatre experience to facilitate or participate in this program!

CONCLUSION

There is no one program that will work for all youth, illustrating the importance for communities to have a variety of diverse programs to serve the population (Bocarro, 1995). While sports and fitness activities have many benefits, they may not address the emotional component to therapy. It has been shown that drama is an effective therapy for many populations (Blaney, 2006; Landy, 2005; Lepp et al., 2003; Yotis, 2006). At-risk youth are one more population that can see these same benefits. By engaging these youth and showing them that they are a valuable member of our community, they are learning important lessons about positive social norms, as well as providing an alternative to violence and anger. I have seen how Black Light Theatre can be effective for at-risk youth and help them to express their innermost concerns and desires without fear of ridicule. For example, Joshua is now employed by a local charity that supports the community. He has matured and is growing into a positive role model. He has been invited to participate in several youth leadership conferences and is still involved with the Youth Centre and local community projects. Tanya is using her natural leadership qualities and is hoping to give back to the Black Light Theatre group next year as a volunteer.

As therapeutic recreation practitioners, we have a chance to make a significant difference in the lives of others. High school is a challenging time of transition, and we have a chance to ease at least a part of this journey by showing our support and allowing the youth to be themselves. It is though our youth that the future lies, and it is up to us to show how it can be a positive and hopeful one.

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At-risk youth participate in “See My Voice”, a *Black Light Theatre* production
(Photo courtesy of Josh Pietras, 2009)

**About the Author**

Caitlin Pietras is a graduate of the Georgian College Therapeutic Recreation program, with an undergraduate degree from Queen’s University in Biomedical Computing. Caitlin is currently using her creativity to plan and implement programs for youth with intellectual disabilities. Caitlin would like to thank her editors and numerous individuals she consulted for their help and support in this project.

**About the program facilitators**

Karen Bell is a graduate of the Therapeutic Recreation program (Recreation for Special Populations) at Georgian College. Karen is a faculty member in the Child and Youth Worker program at Georgian College.

Kathleen Hall is a Child and Youth Worker graduate from Georgian College and enjoys working with youth as an Imagery Consultant with Photo Voice as well as Black Light Theatre.
Surviving and Thriving in a World of Pain: A Non-Pharmacological Approach to Pain Management

Karen Hirshfeld and Tracey Sanford

Abstract

In 2006, Providence Healthcare, a Toronto healthcare facility specializing in rehabilitation, undertook an external peer review process through Accreditation Canada to assess and improve services provided to patients based on international standards of practice. This process concluded with a recommendation to implement a pain management program. In order to address this recommendation, Providence Healthcare implemented a pain management clinic in the community centre as part of the outpatient clinic, instituted the use of new tools to track and measure pain, and began offering Stanford University’s Chronic Pain Management Program and Chronic Disease Self-Management Program through the Scotiabank Learning Centre. Within the field of therapeutic recreation (TR), there is much literature that supports the role of therapeutic recreation in the management of pain (Finch, 2006; Richeson, 2004; Stumbo, 2002, 2006a, 2006b). The purpose of this article is to outline the rationale and development of our in-patient pain management program and share the results of our evaluation to date.

INTRODUCTION

In 2006, Providence Healthcare, a Toronto healthcare facility specializing in rehabilitation, undertook an external peer review process through Accreditation Canada to assess and improve services provided to patients based on international standards of practice. This process concluded with recommendations to implement a pain management program, a falls prevention program and a wounds initiative. In order to address the recommendation to initiate a pain management program, Providence Healthcare implemented a pain management clinic in the community centre as part of the outpatient clinic, instituted the use of new tools to track measure pain, and began offering Stanford University’s Chronic Pain Management Program and Chronic Disease Self-Management Program through the Scotiabank Learning Centre. In addition to accreditation recommendations, the pain management program at Providence Healthcare was created because of issues arising within our hospital. As healthcare staff, we were finding that many patients were admitted longer on the orthopedic and amputee rehabilitation units due to unresolved pain issues which were delaying their healing process. These delays led to an increased length of stay of patients and concern that unrelieved pain was impeding patient therapy goals.

There is much literature that supports the role of therapeutic recreation in pain management as noted by Finch (2006), Richeson (2004) and Stumbo (2002, 2006a, b). All authors state that there is a significant role for Therapeutic Recreation within pain management and it is the responsibility of all clinical staff to address pain and provide appropriate intervention.
Recreation therapy interventions as noted by the authors above can offer an effective non-drug approach to better manage and relieve pain such as cognitive-behavioural and physical interventions. There are many interventions such as relaxation, guided imagery, distraction and humour that can be provided by therapeutic recreation practitioners to assist patients in successful pain management. The purpose of this article is to outline the rationale and development of our in-patient pain management program and share the results of our evaluation to date.

LITERATURE REVIEW

Pain is the number one issue for patients going through the rehabilitation process (Finch, 2006). According to the American Pain Society, 24% of surgical patients do not receive adequate pain relief. This concern is echoed by the Joint Commission of Accreditation of Healthcare Organizations who state that 50-80% of surgical patients do not receive appropriate pain relief. Inattention to pain has severe physical, emotional, medical and social consequences for our patients. Unrelieved pain may increase morbidity, increase the use and cost of medical resources, and mortality (Richeson, 2004). According to Finch (2006):

when pain is left untreated in older adults, there is a greater chance that these individuals will become depressed, lose weight, have difficulty sleeping, become socially isolated or experience impaired mobility and overall function. These types of decreases in one’s quality of life in turn increase healthcare costs. (p.30)

Prior to initiating our program, an extensive literature review was performed. The following review is broken into two themes – the implications of unresolved pain and the role of TR as a non-drug intervention.

First and foremost, Finch (2006) and Richeson (2004) state that there are many implications with regards to unresolved pain, for example, pain is one of the most costly health problems and serious issues in North America. It has also been determined to be one of the top clinical problems for older adults. The authors also state that addressing pain should be the cornerstone of therapy.

Secondly, Finch (2006), Kunstler et al (2004), Richeson (2004), and Stumbo (2002) acknowledge the role of therapeutic recreation within pain management and how it enhances the quality of life and well-being of participants. Therapeutic recreation interventions have shown to be effective in reducing pain symptoms as well as assisting with depression, improved sleep, socialization, and physical mobility. In addition, participants who used non-drug interventions also used fewer analgesics which reduced side-effects and cost for participants. Recreation therapy intervention for pain can also be used as best practices in providing more opportunities to lead an active and healthy lifestyle with pain.

DEVELOPING THE INPATIENT PAIN MANAGEMENT PROGRAM

For the initial screening of inpatients into the pain management program, we utilized an existing Pain Assessment Tool developed by Providence Healthcare as part of its own Pain Management quality initiative. This form asks patients to list areas of pain around the body, indicate a global pain score, outline how and when their pain began, describe the pain in words (i.e. throbbing, stabbing, etc.), identify how long the pain lasts, what techniques make the pain better and/or worse, and identify any
medications taken for pain and their side-effects. By answering these questions, we have been able to determine how someone is managing their pain and if they are an appropriate candidate for our pain management group. This process has also been used to help collect qualitative data for our program, with the Pain Assessment Tool being used as our pre-test / post-test measurement.

We have also utilized the Wong-Baker Facial Grimace Scale called the Universal Pain Assessment Tool. This tool asks patients to identify their current level of pain on a scale of 1-10 (with 1 being “no pain,” and 10 being “worst possible pain”) at the beginning of the group prior to trialing pain management techniques. It was also used at the end of trialing techniques to determine if the strategies were effective in managing pain. We used the Universal Pain Assessment Tool to collect quantitative data to show effectiveness of the non-pharmacological pain management methods outlined in the program.

The program was designed for a group of 8-10 adults per session undergoing rehabilitation. Sessions were developed to meet length of stay issues; the group consists of three 60 minute sessions which were completed within a one week period. Individuals with physical limitations, in particular fine motor skills could participate in the sessions, with sessions modified to meet their needs. In addition, all participants must be able to concentrate for 60 minutes on a cognitive task. In developing our sessions, we focused on our main goal of providing patients with educational sessions on how to utilize non-pharmacological pain management methods to assist with decreasing their pain.

During the first session we highlight relaxation and deep breathing. Participants are given homework, including keeping a pain diary to track their pain, time of day, triggers and how they coped with the pain. To begin session two, we review the last session and share any learning’s from the homework. After that, we concentrate on the role of distraction and humour as a pain management technique. Session three is a review, wrap-up and evaluation of the program and includes a range of mini exercises that involve relaxation, distraction/escapism and humour. The intent of this third session is to provide an opportunity to reinforce all new learned strategies. As a summary, each technique is reviewed and evaluated for personal effectiveness. In addition to the techniques, the sessions also provide education on what is pain, the difference between acute, prolonged and chronic pain, reasons for pain and additional techniques for managing pain such as getting enough sleep, positive attitude, and hydration.

We developed our evaluation tool with the help of our Information and Performance Quality Manager to measure how often participants were using the strategies after being discharged from our group (i.e., frequency) and the ease and effectiveness of strategies. As part of our evaluation, we also asked an open-ended question to determine what participants learned from participation in the group while other questions pertained to the program itself, including how they would rate the program’s effectiveness, suggestions for improvement in the future and whether they would recommend this group to others.

Finally, we developed a marketing plan in order to receive appropriate referrals from colleagues and to provide a general overview for members of our inter-professional team. In-services were presented to the team, descriptive posters and program handouts were distributed and inclusion criteria were discussed. The following section describes the results from
our evaluation tool measuring patient outcomes from the program.

RESULTS

As described above, the collection of data for this program continues to rely on utilizing the following measures: Providence’s Pain Assessment Tool (initial screen), quantitative data using the Universal Pain Assessment Tool (pre-test/post-test), on-going patient feedback during sessions and the completion of a program evaluation form. Since 2008, we have had 119 participants through this program and the following data has been collected:

Pre-Test / Post-Test results

Utilizing the Universal Pain Assessment Tool, it was discovered that prior to participating in the pain management program, 100% of participants (n=119) identified using medication as the only strategy to control their pain. They also described much variance in the type of pain, the duration, frequency, and medications utilized. As a result of experiencing unresolved pain, patients complained of nausea, sleep disturbances, dizziness, constipation, decreased mood and anxiety from medication use.

After participating in the pain management program, again utilizing the Universal Pain Assessment Tool, participants in our group showed an average decrease of 3.93 points on the pain scale. In other words, the learning’s gained from the pain management program contributed to a decrease in pain as experienced by participants. Additional feedback was given from group members and recorded for qualitative purposes. Program participants commented on the use of relaxation, distraction/escapism and humour to alleviate their feelings of pain and their ease of use. Comments included:

“When I was distracted I wasn’t thinking of my pain during the activities.”

“It not only helps my pain but my anxiety.”

“Instead of taking medication, I visualized I was at Disney World with my daughter. When I finished this, I forgot about the pain and went onto something else.”

Patient Evaluation Forms

As an additional follow-up measure, participants were asked to complete the Patient Evaluation Form. The results from this measure are based on 30% of participants (n = 36) who completed the group evaluation form. With regards to using strategies upon completion of the pain management group, 25% of participants used relaxation and deep breathing daily, 50% used humour daily, 42% used distraction and escapism daily and 50% used guided imagery daily. Data from the evaluation forms also collected information on effectiveness of the strategies and the results are as follows: 50% of participants found relaxation and deep breathing and humour to be somewhat effective, 50% found distraction and escapism to be very effective and 42% found guided imagery to be very effective (see Table 1).
We also collected information on the ease of incorporating pain management strategies in daily life. The results are as follows: 50% found relaxation and deep breathing to be very easy, 66% found distraction and escapism to be very easy and 33% found guided imagery and humour to be very easy. Additional feedback was obtained from an open-ended question asking participants what they learned from the group. To date, feedback suggests that participants have incorporated techniques and strategies learned during the pain management inpatient TR group into their daily routines and have subsequently been able to improve the management of their pain:

“I now have a better selection of authentic, realistic pain management tools to use.”

“I sometimes take inappropriate medication and then curl up in a ball. I worry about becoming an addict and continuing this at home...This group has given me strategies to cope and manage my pain.”

“I learned how to breathe properly and laugh.”

“I am proud to have learned more ways to relieve my pain.”

“One thing I learned from this group was the number of different ways to help dissolve the pain for an hour or more. I had actually been doing some techniques without realizing the pain would disappear.”

We encountered several challenges to our data collection such as poor return of the patient evaluation form. Data collection was difficult due to patients not being able to complete this as they might have had an external appointment or were sent to acute care or were discharged prior to the end of group, therefore data regarding effectiveness, ease and usage only
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represented 30% of participants who attended the group.

CONCLUSIONS

Our results for non-pharmacological pain management techniques are positive and relevant for the therapeutic recreation profession. Non-pharmacological strategies are beneficial in pain management, as seen by the decrease in the universal pain assessment tool of 3.93 points for our participants. Patients often require more time to learn and carry over strategies such as relaxation and deep breathing and this is assumed after reviewing results for ease and effectiveness of strategies.

Recommendations for this initiative include partnering with Pharmacy to identify measures on how to determine whether learning non-pharmacological strategies also promotes a decrease in analgesics usage. In addition, there are plans to offer more opportunities for patients to practice their newly learned techniques with staff in order to continue these strategies independently.

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Social Programs for Survivors of TBI and Stroke: Evaluation of a Community-Based Social-Recreation Program

Shannon Hebblethwaite and Jackie Doyle

Abstract
Community-based social-recreational programs play an integral role in the lives of individuals with a wide variety of abilities and disabilities. The New Beginnings Club (NBC) is a recreation and leisure based community social support program that provides services to individuals who have experienced traumatic brain injury (TBI), brain tumour, or stroke and their care partners. This study explores the lived experiences and social needs of TBI and stroke survivors living in Chatham-Kent, Ontario. Further, the research identifies key outcomes related to membership in the NBC program offered in this community. Twenty individuals participated in the study; 8 of these were TBI survivors and 12 were stroke survivors. Structured interviews were conducted and revealed similarities and differences between individuals who had experienced TBI and those who had experienced stroke. We suggest that these community-based social programs have play an important role in the lives of individuals who have experienced TBI and stroke.

INTRODUCTION

Nearly 20,000 people each year in Ontario experience stroke (Smit, 2008). Fifteen percent of people who have a stroke will die, 10% will recover completely, 25% will recover with a minor impairment or disability, 40% will be left with a moderate to severe impairment and 10% will require long-term care (Kirshner, Biller, & Callahan, 2005). Functional disabilities have been linked to a decreased sense of wellbeing post-stroke, specifically related to stroke survivors’ sense of control, perceived opportunities for individual development, and their ability to engage in positive social relations (Clarke, Marshall, Black & Colantonio, 2000). Immediately following a stroke, many survivors experience a considerable amount of their immediate recovery time in controlled, structured healthcare settings. Despite slight shifts from a medical model of disability to a psychosocial model that emphasizes health and ability, much of the focus in acute care and rehabilitation settings remains centred around functional outcomes and rehabilitation (Moreland et al., 2009). In many instances, it is not until the survivor and their supports return home to attempt to engage in “life as usual”, that they more fully understand the impacts of their stroke and their association with the intrinsic psychosocial needs that influence their quality of life. It is for this reason that streamlined accessibility to effective and sensitive community social support programs is vital to facilitate their transition.

Stroke survivors commonly struggle with limitations in activity and social participation, potentially resulting in depression, decline of community engagement, and decreased quality of life (Huijbregts, Myers, Streiner, & Teasell, 2008). Sylvester, Voelkl, and Ellis (2001) suggest that inclusion in recreation through community-based leisure opportunities can empower individuals with disabilities to become valued and active members of their communities. Engagement in leisure that
allows for personal expressiveness has been shown to facilitate adjustment to disability and generate a sense of optimism among individuals who have experienced brain trauma (Kleiber, Reel, & Hutchinson, 2008).

Community-based social recreation programs can help to facilitate inclusion for individuals with a wide variety of disabilities. The New Beginnings Club (NBC) is a charitable, not-for-profit organization operated by the Brain Injury Association of Chatham-Kent (BIACK). NBC is a recreation and leisure based community social support program that provides services to those who have experienced traumatic brain injury, brain tumour, or stroke and their caregivers. The NBC also facilitates linkages to other health and social service resources in the community. The Municipality of Chatham-Kent is a municipality with a population of approximately 110,000 residents, with roughly one-third of the population living in rural areas surrounding the larger cities of Chatham and Wallaceburg. The purpose of the NBC is to provide social and recreation opportunities for individuals with brain injury, brain tumour, stroke, and their caregivers. The mandate of the NBC does not include the provision of regulated health care services.

Historically, people living with a Traumatic Brain Injury (TBI) were the primary target group for NBC services. More recently, the NBC has more assertively worked to integrate people recovering from a stroke within their service. With the growing involvement of stroke survivors and their caregivers, the NBC embraced the opportunity to understand the experience of people recovering from a stroke or TBI in order to evaluate the services and programs of the NBC.

The current study, therefore, evaluates the ability of the NBC program to address challenges faced by its members. Specifically, this study explores the lived experiences and social needs of individuals with TBI and stroke. Further, the research identifies key outcomes related to membership in the NBC program.

METHODS

In order to understand the expectations, needs, experiences and outcomes of survivors of TBI, stroke, and their care partners in relation to the NBC, structured individual interviews and formal survey tools were used to gather information from stroke survivors, TBI survivors, and their care partners. This paper examines the qualitative interview data gathered from these interviews.

Participants included eight individuals who had experienced TBI and 12 individuals who had experienced stroke. They ranged in age from 35 to 95 years. Participants were recruited through the NBC using posters and announcements in the club. It should be noted, therefore, that the participants were a self-selected sample who willingly consented to participate in the research study. Due to limited resources and accessibility, non-active members of NBC were not represented in the study. Similarly, there were a minimal number of participants who exhibited severe communication impairments, such as aphasia, thus creating a gap in understanding the expectations, needs and experiences specifically associated with these stroke survivors.

Information regarding the quantitative data is available from Jackie Doyle.

In some instances, both the survivor and caregiver participated jointly in the project, often because the survivor was not comfortable participating individually. For the purpose of the study, these survivor/caregiver-pairs were counted as one participant since they represented their joint perspective.
The second author conducted structured interviews individually with each participant and recorded their responses on a structured interview protocol form. The participants were asked to describe how and why they became members of the NBC. They were then asked to discuss the impact that the NBC program had in their lives, including perceived benefits of their participation as well as challenges they faced in relation to their participation in the program. They also provided suggestions for improvement to the program.

Interview data were analyzed individually by both authors and compared on the basis of salient themes that emerged from the participants’ responses to each of three structured interview questions: why they joined the NBC, what the most significant impact of NBC was for them, and why they continued to participate in the NBC. Salient themes were developed based on the frequency with which the participants spoke of the issue as well as the perceived impact the issue had on their involvement in the NBC program (Ryan & Bernard, 2003). These themes were then compared between the participants who had experienced TBI and those who had experienced stroke in order to compare and contrast their needs and experiences.

FINDINGS

For both the individuals who had experienced TBI and those who had experienced stroke, three main themes emerged as substantially more salient than other themes discussed by the participants. The participants who had experienced TBI reported that the NBC had an important impact on their lives by providing them with opportunities for socialization, a sense of freedom, and a sense of contribution. The participants who had experienced stroke also reported opportunities for socialization as an important factor, but also spoke about the importance of activity involvement and the opportunity for continued self-enhancement and rehabilitation as central to their involvement in the NBC.

Opportunities for Socialization

Participants in both groups felt that the most important impact that the NBC had was enhancing their socialization within their community. Engaging in social activities, often in a group, decreased the sense of social isolation that these individuals experienced after their TBI and their stroke. One woman with TBI spoke about the challenges of maintaining a social network when asked about the benefits of her participation in the NBC. She stated: “The social aspect of it. All my friends are married with kids, and don’t have time for you. Now where do I go to meet people?”

Participants frequently discussed the importance of developing friendships with other members of the NBC as illustrated by one man who had experienced a stroke: “Friendship. I’ve gotten to know a lot of people here and made a lot of new friends.” The social support gained within these friendships was imperative to the participants’ psychosocial well-being. One man spoke about the central role that the NBC played in this respect as he reflected upon himself and his brother who had had a stroke, stating: “For me when I come here it brings your hopes up. [My brother] just likes coming here, socializing with other people. It takes away the stress.”

Sense of Freedom

For the participants with TBI, freedom of choice was regarded as highly beneficial in helping them manage the stress of a chronic disability. Having the choice to get away from their home environment and engage in
activities of their choosing contributed to their sense of self. It also provided participants time to be away from their care partners, which was viewed to be beneficial to both partners. For example, one woman stated that the reason she participated in the NBC was “because I like it. It gives me a break from my home life.” For others, the NBC offered them one of the few realms of their lives where they had the autonomy to exert their independence by choosing the activities that they participated in while at the club. Poignantly, one woman reflected: “It was the only way I got freedom.”

Sense of Contribution

Beyond feeling a sense of choice and freedom from participating in the NBC, participants with TBI also spoke passionately about the sense of contribution that they gained through their participation. The NBC seemed to be moving toward a more participatory model and actively engaging the participants in the planning, implementing, and evaluating of the program. Participants took great pleasure in helping with the program, particularly in respect to supporting other participants. By feeling that they had made an impact and that their input or talents were valued, their self-esteem and self-worth were enhanced substantially, as evident in the following two examples: “I see I am making an impact or influence. If they can see what I can do with a head injury...they can see to have hope and if they stick to their guns they can achieve it” (woman with TBI): “I am an excellent role model” (man with TBI).

Meaningful Involvement Contributes to Meaningful Recovery

The participants who had experienced stroke cited the opportunity to engage in activities as having a strong impact on their recovery. The wide variety of recreation activities offered at the NBC, including music, Wii, cards, karaoke, crafts, computers, pool, cooking, and games, was one of the main reasons that participants recovering from stroke joined the NBC. One man stated that he continued to participate in the NBC “because the activities are of interest to me.” Another man enjoyed the opportunity to participate in different activities “because I like it. Playing cards and group activities. I do not get that at home.” The chance to engage in these activities expanded the skills, interests, and abilities of the stroke participants and had a positive impact on their sense of belonging in their community after their stroke. This was exemplified by one woman who said, “We sing karaoke and other programs. As I feel much more at home, I slowly add more. It’s opening the world to me again.” The participants who had experienced stroke identified that involvement in the activities offered through the NBC helped in adjusting their leisure lifestyle after their stroke. They gained awareness of strategies to adapt leisure to their disability, and increased their independence and control in their ability to plan and follow through with leisure activities. These activities, therefore, played a central role in their recovery after their stroke.

Continued Self-Enhancement and Rehabilitation

Participants who had experienced stroke also purposefully engaged in the NBC in order to enhance their well-being, both physically and cognitively. They highly valued the opportunity to engage in activities that promoted continued recovery and self-improvement. This was in contrast to the
participants who had experienced TBI who identified more psychosocial motivations for and benefits of their involvement with the NBC. The stroke participants chose activities that specifically focused on physical exercise, cognitive stimulation, as well as those activities that provided them with an opportunity to improve their communication skills. Although not intended as such, some participants viewed the NBC as an extension of the various therapies that they had received in the hospital following their stroke. This is evidenced by one man’s reflection: “I thought it would be a continuation of therapies, and it kind of is. I come on Thursdays for the exercises.” Another woman stated that she participated in the activities in order “to practice my speech. Without that, I have nothing. It’s another world of participating... I participate much more. I was always an outgoing person and with the stroke I withdrew, and now in here I talk more and participate a lot.” Through their engagement in the activities offered at the NBC, the participants gradually perceived an improvement in their abilities. This sense of achievement enhanced their psychosocial well-being and facilitated more engagement in their communities.

DISCUSSION

Akin to findings from previous research (Kleiber et al., 2008; Pang et al., 2007; Smit, 2008), the experiences of individuals who have experienced TBI and stroke support the need for community-based social recreation programs such as the NBC. Participation in recreational activities was a key factor that enhanced the psychosocial well-being for TBI and stroke survivors. This participation, however, varied somewhat between individuals with TBI and those who had experienced stroke. For individuals with TBI, the activities were strongly associated with intrinsic motivations and outcomes. The opportunity to participate fully in the process of planning, implementing, and evaluating recreation programs played a role in the sense of contribution that the TBI survivors experienced. This involvement resulted in increased feelings of freedom and choice while subsequently contributing to a stronger sense of self-worth among the participants. Whether this feeling was perceived through their ability to share knowledge or talents with others, or through the desire to be involved in NBC tasks or responsibilities, the principle of valued, purposeful and meaningful activity was central to enhancing a sense of self-worth. This is further supported in the Stroke Strategy pathways report that outlines the importance of making a meaningful contribution in the recovery from stroke (Smit, 2008). This participatory approach has been implemented with the TBI survivors and, therefore, warrants further consideration when expanding the NBC programming to integrate stroke survivors as well.

For the stroke survivors, physical and cognitive stimulation were more central motives for participation, along with opportunities to enhance communication skills. Similar to the TBI survivors, a crucial element of this experience was the purposeful nature of the activities. This reflects the value of a participatory approach to community-based programming whereby participants are given the opportunity to choose the activities that best meet their perceived needs. These needs, for the stroke survivors, related more to the physical and cognitive domains while the TBI survivors were more focused on the affective domain. The experiences of both groups, however, emphasize the important psychological outcomes associated with their engagement in these recreation activities, including enhanced self-worth and self-esteem.
Despite slight differences in the motivations for participation in the NBC, both groups strongly emphasized the value of socialization in the program. The participants’ need for socialization motivated their involvement in activities and interactions that promoted community engagement and facilitated the development of supportive relationships. Through this socialization, the program created a network of resources available to assist the participants not only to adjust to their disability, but to realize their strengths and abilities.

Participants recovering from stroke, in particular, emphasized the importance of continued self-improvement, both physically and cognitively. Moreover, they reported that involvement with NBC improved self-esteem, assisted with recovery, increased awareness of community resources and improved ability to cope with stroke challenges. This supports previous research that demonstrated a correlation between survivor social support satisfaction and perceived self-acceptance, positive relationships, and environmental control elements of well-being (Clarke et al., 2000). This was an important element of the NBC, given research that suggests the impacts of stroke may significantly impede the survivors’ ability to participate in these activities independently and lead fulfilling leisure lifestyles in their community (Pang, Eng, & Miller, 2007). Overall, findings from this study illustrate that the NBC has primarily met their expectations of opportunities for continued self-improvement and recovery, and demonstrates participant satisfaction in opportunities to engage in positive social supportive relationships and meaningful activity. These findings clearly align with the Stroke Strategy pathway of creating a community environment that supports active engagement and continued recovery (Smit, 2008).

CONCLUSION

This research provided a more nuanced understanding of the lived experience and social needs of the TBI and stroke survivors who were active members in the NBC. Socialization and recreation participation provided the means for individuals limited by physical and cognitive functional deficits, to enhance psychosocial well-being. It facilitated coping through engagement in productive and meaningful activities. With a unique recreation and leisure programming focus designed with the consideration of the specific expectations, needs and challenges of its participants, the NBC plays an important role in the lives of individuals who have experienced stroke and TBI. These findings support the NBC as a suitable model of community programming that assists individuals who have experienced various types of neurological trauma to engage in supportive social and recreational activities to augment their sense of overall well-being. The NBC provides an effective and transferable framework of programs, services and collaborative networks that facilitate experiences self-worth, community, and autonomy. This environment provides a foundation of support to facilitate opportunities to improve quality of life by optimizing psychological and emotional well-being.

The study also supports the efforts of the NBC to open the program to individuals who experience stroke. Considering the potential impacts of stroke on physical and cognitive abilities, self-awareness and self-image, and new limitations and barriers that often accompany a stroke, it would be prudent for the NBC to better understand the process to foster participation by stroke survivors in a community-based social-recreational
program. Correspondingly, the club should focus efforts on creating marketing that more effectively targets these individuals. It is recommended that decisions regarding allocation of resources consider the necessity of fostering promotional and educational relationships with the general public and healthcare and community service professionals, locally and beyond, to ensure an awareness of the NBC resources and their associated impacts and to encourage referrals from a wide variety of sources, including family, hospital interdisciplinary care providers and patient flow coordinators, physicians, Community Care access Centre health care professionals, and other home-care organizations. It is vital that the importance of meaningful engagement in recreation and the values of freedom, choice, control, and a sense of contribution be understood by the community of TBI and stroke survivors, their caregivers, and health care professionals alike. With a unique recreation programming focus designed with the consideration of these specific experiences of TBI and stroke survivors, as well as collaborative program partnerships in the community, the NBC has successfully bridged a supportive social recreation gap in services along the continuum of care within the community of Chatham-Kent.

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Exploring Discrimination and Difference in a Narrative Policy Analysis of the Accessibility for Ontarians with Disabilities Act

Julie Rodier and Susan M. Arai

Abstract

In stories we find meaning and communicate ideas. This article shared stories that arose in community leisure and recreation through a narrative policy analysis of the Accessibility for Ontarians with Disabilities Act (AODA). Nine interviews were conducted with policy makers, policy implementers, and people with disabilities. Narratives described essential stories attached to the AODA that people with disabilities have been discriminated against, the AODA seeks full accessibility and removal of barriers, it aims to create equal opportunities, and that alongside work, play is important in the lives of people with disabilities. Counter-stories revealed the complexity of this policy issue and raise issues of individual choice and difference, and note the challenges of defining concepts such as accommodation, accessibility, equal opportunity, and inclusion. The study highlights the need to consider difference and adopt a critical stance to understanding disability and social inclusion in therapeutic recreation.

INTRODUCTION

The purpose of this article is to share stories about discrimination and accessibility arising from a narrative policy analysis of the Accessibility for Ontarians with Disabilities Act (AODA). As a provincial policy, the AODA was created in Ontario to address systemic discrimination experienced by people with disabilities. The road to creating the AODA has been long, and the path to full implementation even longer. In 1990 policy addressing accessibility was first introduced by Bob Rae, it took until 2005 for the AODA to be proclaimed in legislature by the Liberal Party of Ontario, and full implementation of the policy is not anticipated until 2025. As we make this journey in Ontario, it is important to consider the voices and stories that unfold in the implementation of this policy. The AODA consists of five accessibility standards to be phased in over time including: (1) customer service, (2) transportation, (3) information and communications, (4) built environment, and (5) employment (Ministry of Community and Social Services, n.d.). This study sought the stories of policy actors with experiences in municipal recreation in a mid-size community in Southwestern Ontario and began in May 2009 following the enactment of the Customer Service Accessibility Standard on January 1st, 2008. At that time, this standard was the first to be implemented and compliance was expected for public sector organizations (including municipalities) by January 1, 2010, followed by all other organizations (including private business) by January 1, 2012 (Ministry of Community and Social Services, n.d). Failure to comply was to be met with harsh financial penalties, the maximum fine individuals could face was $50,000 for every day in which the offence occurs, and for organizations the fine would rise to $100,000 for each day of non-compliance (Ministry of Community and Social Services, n.d).
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Services, n.d.). The AODA impacts and defines standards of accessibility in buildings, services, and businesses in both the public and private sectors. In therapeutic recreation, as we think about how to make our services and supports more inclusive and accessible to all persons there is much we can learn from stories told about the implementation of the AODA.

METHODOLOGY: NARRATIVE POLICY ANALYSIS

Narrative policy analysis borrows from narrative and interpretive inquiry and assumes that the whole is bigger than the sum of the parts (Hollway & Jefferson, 1997) and that stories are windows into people’s lives (Riessman, 1993). This article emerges from a study, the purpose of which was: to conduct a narrative policy analysis during the implementation phase of the Accessibility for Ontarians with Disabilities Act (AODA) in a municipal recreation setting to identify the parallel and divergent stories that surround this legislation. The study involved three groups of policy actors: policy makers, policy implementers (i.e., Regional and Municipal staff), and people with disabilities affected by the policy. Policy documents such as the Accessibility for Ontarians with Disabilities Act, the Accessibility Standards for Customer Service, the Guide to the Accessibility Standards for Customer Service, and Hansard Archives (digitized version of the debates of the House of Commons of Ontario) were examined to shed light on the perspectives of policy makers. Policy implementers and people with physical disabilities¹ were recruited for involvement in interviews through snowball sampling to find individuals connected to AODA implementation at the municipal recreation level. As Scott (year) explains, snowball sampling, “assumes that groups of influential in a given field are interconnected: that members know each other, either personally or by reputation, so that if you ask them who the key people are, they will know” (cited in Farquharson, 2005, p. 347). In total, nine interviews were conducted with people with disabilities (n=4; Samantha, Alice, Kevin, and Palma) and Regional or Municipal staff involved in the development and implementation of the AODA (n=5; Kassandra, Lucy, Paige, Janet, and Dakota). Pseudonyms are used to ensure confidentiality of research participants. Semi-structured, in-depth interviews were conducted between May and July 2009 with each lasting between 30 and 90 minutes. Questions focused on participants understanding and experiences with the AODA, impacts of the AODA, and challenges facing the AODA. Interviews were conducted by phone or face-to-face at a location of the participant’s choice, digitally recorded with the participant’s permission, and transcribed verbatim for analysis.

Following Roe’s (1994) approach to narrative policy analysis, this study sought to uncover stories (stories that are repeatedly told), counter-stories (those that run counter to dominant stories), and non-stories (stories that are not present). The analysis of interview transcripts, policy documents and literature unfolded in five steps which: (1) described the social and political context surrounding development and implementation of the AODA; (2) identified essences that arose from the data to create the dominant stories; (3) identified counter-stories and stories absent or missing from

¹ To make the study manageable in size for a Master’s thesis and to limit the variety of stories that could potentially arise, the study focused on the stories of individuals with physical disabilities rather than individuals with a variety of disabilities (e.g., cognitive or intellectual).
the dialogue (non-stories); (4) further interpreted stories, non-stories, and counter stories to create a metanarrative which allowed the multiple voices to be heard; and (5) used the metanarrative to recast the problem of discrimination for people with disabilities. From data analysis, three groups of narratives arose. The first narratives, the focus of this article, explored issues of discrimination and accessibility and how this plays out in the context of leisure and recreation. Additional narratives (not reported on here) included narratives telling the story of creating and implementing the AODA and meanings of disability in the AODA.

FINDINGS: NARRATIVES ABOUT DISCRIMINATION, BARRIERS, AND ACCESSIBILITY

Stories arising from the AODA state that: people with disabilities have been discriminated against; the AODA seeks full accessibility and removal of barriers; the AODA aims to create equal opportunity; and alongside work, play is important in the lives of people with disabilities. In addition to these main stories, the counter-stories reveal the complexity of issues around discrimination and accessibility and the various understandings and experiences of the policy actors, including people with disabilities. Counter-stories raise issues of individual choice and difference, as well the challenges imposed by static and rigid categories and definitions of concepts such as accommodation, accessibility, equal opportunity, and inclusion.

Story: People with Disabilities Have Been Discriminated Against

As stated in the AODA, accessibility standards are meant to break down barriers and increase the inclusion of people with disabilities in society. As noted in the purpose statement, for the AODA, “[r]ecognizing the history of discrimination against persons with disabilities in Ontario, the purpose of this Act is to benefit all Ontarians.” Samantha implied discrimination against people with disabilities stems back to a lack of exposure, noting that, a few decades ago, it was a much rarer occurrence to meet people with disabilities in the community. Palma, another person with a disability, believed that there, “has been enough pressure from the disabled population to say, we’re missing out on a lot of things.” She explained that in the disability community, this desire to be recognized dates back to the beginning of the 1980s with the declaration, in 1981, of the Universal Year of Disabled People.

Many participants noted that discrimination will stop when attitudinal barriers are broken. When asked if attitudes need to change in today’s society, Samantha emphatically responded that negative attitudes caused by ignorance are “one of the biggest barriers as far as anybody with a disability is concerned.” Many participants felt hopeful that there was some progress in changing attitudes. Dakota, a policy implementer, believed that by enacting small changes people will eventually open their minds to accept people with disabilities. She said she can almost see the day when the general public will accept the inclusion of people with disabilities into mainstream society, “I think it’s changing. Just television, commercials, positive things, washroom[s] with you know, it’s a small piece, washrooms with the stalls, just things that weren’t there when I was growing up.” Palma infused conversations about discrimination with a message of hope. She described an initiative to change attitudes by targeting school-aged children as a solution to changing negative attitudes in the future.
Paige also thought that through the accessibility standards for customer service, such as the training component, people gain pieces of information that help to start to erode negative attitudes toward people with disabilities.

**Counter-story: Reinserting voices of people with disabilities—what about choice?**

Discussions about choice also arose as a counter-story to the story of discrimination. During the interviews, participants noted that one way people with disabilities dealt with discrimination was to choose whether they will visit that establishment again. Alice described one of those situations: “If I’m not treated well when I go somewhere I don’t go back.” Similarly, Kevin summarized what happens when he has not been able to access an organization with the expression, “That’s a strike the dog kind of shop for me.” Not going back to establishments that are not accessible is one way that Kevin fights against discrimination.

**Story: The AODA Seeks Full Accessibility and the Removal of Barriers**

In the AODA, the goal described is that by the time the legislation is fully implemented in 2025 Ontario’s businesses and services will be made fully accessible through the removal of barriers which prevent full participation of people with disabilities in everyday life. As defined in the AODA, an accessibility standard shall:

(a) set out measures, policies, practices or other requirements for the identification and removal of barriers with respect to goods, services, facilities, accommodation, employment, buildings, structures, premises or such other things as may be prescribed, and for the prevention of the erection of such barriers; and

(b) require the persons or organizations named or described in the standard to implement those measures, policies, practices or other requirements within the time periods specified in the standard. 2005, c. 11, s. 6 (6). (AODA, 2005)

Further, the Duncan’s resolution which provides principles for implementing the AODA notes that:

The Ontarians with Disabilities Act should require government entities, public premises, companies and organizations to be made fully accessible to all persons with disabilities through the removal of existing barriers and the prevention of the creation of new barriers, within strict time frames to be prescribed in the legislation or regulations. (Hansard Archives, October 29th 1998)

As described in the AODA, a barrier “means anything that prevents a person with a disability from fully participating in all aspects of society because of his or her disability.” Participants also hoped full accessibility would occur one day. Palma truly believed that making things accessible does not need to become a complicated process. Similarly, Dakota believed that if everyone did their part, an accessible Ontario would be possible. As Dakota described, “So if you’re only a little business you should be able to afford a little renovation with a little money.”

**Counter-Story: How do we define accessibility and reasonable accommodation?**

While the AODA strives to make Ontario fully accessible, interviews with
participants revealed another story. When Paige, a policy implementer, was asked if she believed Ontario would one day be fully accessible, she answered, “I never say in my training sessions that Ontario is going to be fully accessible by 2025. I have no delusions about that. It’s going to be a step on the way.” Further challenges arise in defining what accessibility and inclusion means. Alice defined accessibility in terms of inclusion, but questioned: “So, yes they want to be inclusive, but what does that mean?” Palma questioned who gets to define what accessibility is for each and every individual. Similarly, Palma, a person with a disability stated that, for her, access means a variety of things. As participants described, further challenges in defining accessibility lie in the contrast between the full accessibility and the principle of reasonable accommodation. As the third principle from the Duncan Resolution states:

The Ontarians with Disabilities Act should require the providers of goods, services and facilities to the public to ensure that their goods, services and facilities are fully usable by persons with disabilities, and that they are designed to reasonably accommodate the needs of persons with disabilities. (Hansard Archives, November 12th 2004)

If every individual is different, how is it possible to reasonably accommodate for all the different needs? As stated in the Guide to the Accessibility Standards for Customer Service (Ministry of Community and Social Services, 2008): “There is no single way to provide accessibility. Accessibility can often be achieved in a variety of different ways” (p. 25). These vague statements leave space for each organization or business to define accessibility and reasonable accommodation for themselves. Alice noted we will need a good dose of common sense to be able to surmount the obstacles that lie on the road to an accessible province:

And just because someone adds a door opener to make the door be automated, it doesn’t mean that it’s accessible. As soon as you put a pylon or something in front of it, it renders it inaccessible, right? So are you gonna have a policy about people will not put a pylon 3 feet in front of an automatic door? Probably not, right? It’s one of those common sense things that people lack.

Alice noted that unfortunately full accessibility will only be addressed when that particular issue comes up, “I think they’re only challenged to move on something when someone is really taken aback on something and they put up the political, the political fight.”

Story: The AODA Will Create Equal Opportunities

According to the Guide to the Accessibility Standards for Customer Service, quality includes ease of accessing equal opportunities. The AODA was enacted for people with disabilities to have “equal opportunities to fully and meaningfully participate in everyday life” (Hansard Archives, November 12th 2004). In the Guide for the Accessibility Standards for Customer Service (2008) “equal opportunities” means, “having the same chances, options, benefits and results as others” (p. 28). Janet offered us her interpretation of this principle as she saw it applying to municipal recreation. She stated, “Everyone should be able to participate. And that’s sorta how we look at the services that we offer, you know, with the City. It’s essentially mandated that we cannot turn anybody away.”
Counter-Story: Does equal opportunity mean, “if you make a greatly extraordinary effort, yes you can do anything’’?

The counter-story described that whether equal opportunities are presented to people with disabilities depends on the effort that needs to be poured into the experience. Kevin, a person with a disability, described that with a lot of effort, he would be able to access programs, goods, or services he wanted or needed. Palma echoed this thought saying it depended on the person and that person’s life circumstances:

I speak up for what I want. I push a little bit for what I need. And I think that I know what my rights are. And I think that I’m not one to go in screaming and yelling and demanding. I like to go in and propose what it is that I need or I want. Listen to both sides of the story before, you know, making a decision.

Palma believed she is provided with equal opportunities in the community, but through her work with other people with disabilities she has become aware that not all individuals have the energy and time to fight for equality. Alice, a person with a disability, did not believe she has been provided with equal opportunities in community. She explained her point of view in relation to the five accessibility standards areas. She explained she does not always receive good quality customer service from businesses and she has needed to apply for more jobs than “most people” to obtain one. Alice also noted that although transportation services for people with physical disabilities exist, they do not meet her needs for flexibility and spontaneity: “When it comes to transportation, I personally have a problem with using a service like Mobility Plus because I’m more spontaneous than two days notice for booking a ride allows.” The only area in which Alice thought she was provided with equal opportunities was in terms of information and communication; however, she attributed her lack of special needs in this area as a reason for this different experience.

Story: Leisure is Important in the Lives of People with Disabilities

Madeleine Meilleur, the Minister of Community and Social Services, stated that everyone should be: “working together to make our province a more inclusive place for people with disabilities to live, work and play” (Hansard Archives, May 27th 2008). Hansard Archives, digitized version of the debates of the House of Commons of Ontario, offered a glimpse in the discussions surrounding the development and implementation of these two policy documents. Although mentions of leisure in discussions surrounding the development and implementation of the AODA were brief, the message rang clear: leisure was important in the lives of people with disabilities and would be improved by implementation of the policy.

Counter-Story: There is still a lot of work to be done.

Participants described room for improvement and work still needing to be done on the AODA but there was a good foundation laid. Policy implementers noted they try their best to include people with disabilities in their programs. Dakota, a policy implementer, was adamant that the City (Municipality) was fairly inclusive. She explained initiatives were in place to make leisure experiences as close to ideal as possible. Paige, also praised efforts made to improve accessibility at the municipal level. After explaining that she thought community needs for leisure were met, Kassandra also noted that standards were going to push the
municipality further in terms of the provision of leisure experiences to people with disabilities. Similarly, Janet argued that although a variety of programs and services were in place for people with disabilities, she would like to see more added. Participants described that accessibility included more than the types of activities available for people with disabilities. Palma noted it was details such as parking spots and washrooms that made it possible for someone with a physical disability to enjoy an activity at a municipal recreation centre.

People with a disability argued there was considerable room for improvement. Alice noted that experiences at the city level were acceptable for the moment but there was room for improvement. She also noted that in addition to access to a site, other important aspects included transportation and participation to the best of one’s abilities. Similarly, Palma believed that while the foundation for accessibility has been laid, attempts at accessibility do not reach far enough to allow people with disabilities to participate fully. Palma identified a belief among recreation centre staff that programs are accessible, but in fact they are not:

*I think that having staff that has some time availability to work with the person. Whether it’s, you know, that they take longer to fill out the form or they need help in doing, what am I thinking, a craft or whatever is happening at this building. I know one of the things that we work on here is swimming is an issue. I have people that would really like to go swimming. So work has been done to get pools in the community accessible. But, so a person can’t go without support if they need help to change, and then they need help to get into the pool.*

Kevin emphasized this point. He told me he had been to a city park to swim on a hot summer day and found facilities were not set up for a person using a wheelchair. That experience left him feeling embarrassed and discouraged him from going back.

*Counter-story: Does the AODA accommodate differences in people’s leisure experiences?*

When policy implementers spoke about leisure experiences they often commented on people with disabilities experiencing something similar to able-bodied individuals. Dakota described that the ideal leisure experience was having, “a normal day like everybody else.” Similarly, Janet described leisure experiences in an ideal world as, “it’s just everybody is on the same page whatever their abilities are.” Among people with disabilities however, the story that emerged was that leisure was different for everyone, whether the person had a disability or not. When asked to describe her leisure pursuits, Palma immediately launched into a long list of her favourite past-times that included scrap-booking, reading, being a grand-mother of five, travelling, and volunteering. Other participants stated they did not have much leisure or recreation in their lives. As Samantha (a person with a disability) stated, “I haven’t really had any leisure experience.” She later explained that during her free time, she loved to volunteer at various organizations. This love for volunteering was echoed by Alice (also a person with a disability) who stated that for her, volunteering was leisure. Kevin categorized his current leisure experiences as “new leisure” for him, reflecting a change in the kinds of activities he did for fun, as a result of acquiring a disability.
DISCUSSION AND IMPLICATIONS FOR TR

As Roe (1994) describes, the next step in narrative policy analysis is to use the stories and counter-stories presented in the results to create a metanarrative. This step in the policy analysis helps to recast complex, uncertain, and polarized policy issues into a manageable story that allows for divergent policy stories to co-exist (Roe, 1994). The metanarrative that arises around discrimination in this study is as follows:

The AODA was needed to address discrimination, remove and prevent further barriers, and improve inclusion of people with disabilities in community; however, in practice, the emphasis on equal opportunity and reasonable accommodation lessens the ability of this social policy to address the systemic oppression that people with disabilities continue to face. The impact of the policy is lessened by a failure to acknowledge difference and choice rather than just disability categories, equality of outcome rather than just opportunity, and accommodation rather than just access. Examining leisure as a context for the implementation of the AODA highlights the importance of taking into account all aspects of an individual’s experience to move the AODA from unmet promises to the creation of an inclusive society.

The meta-narrative enables us to recast the problem, and in this case, the problem lies in limits the policy continues to place on the social inclusion of people with disabilities. The AODA is touted as anti-discrimination legislation to promote equal opportunities through the removal of barriers (Hahn, 1996). According to Labonte (2004), equal opportunities have become the “mantra of neo-liberalism” (p. 119) and under neo-liberalism, equality is understood not as equality of outcomes, but as the equality of opportunities (Sarrouh, 2002). This emphasis on individual rights, equality, and the idea of equal opportunity is a necessary but insufficient condition to achieve social inclusion. According to the Roeher Institute (2003) social inclusion requires that (1) people with disabilities have access, and (2) they need to have the practical means necessary to participate. The AODA focuses on alleviating the barriers to access, and, therefore, its focus is on the first component of social inclusion; however, it does not readily address the second aspect of social inclusion. Specifically it does not address issues of poverty, and people with disabilities continue to rank high among the people living in poverty in Canada (Arai & Burke, 2010). Further, the emphasis placed on access as “reasonable accommodation” further creates insufficient conditions to reach social inclusion. The idea of reasonable accommodation begs the question, reasonable to whom?

A second challenge within the AODA arises in the way disability is understood and the failure to accommodate a broader notion of difference. Satz (2008) suggests anti-discrimination laws are limited in their mandate because they view disability as a definite identity category. Mabbett (2005) argues that a decategorization of disability is needed to ensure that anti-discrimination laws are successful. As the counter-story suggested, when policy implementers spoke about people’s access to leisure they commented about people with disabilities being “on the same page” and a “normal day” was being able to experience things the same as people who are able-bodied. Similar tensions exist in therapeutic recreation and leisure studies more broadly. Some have argued that leisure experiences for people with disabilities do not differ greatly from those of persons without disabilities because
people with disabilities are human beings first. However, there is a need to consider the individual experience of difference that lie at the intersection of systemic forces of discrimination and individual impairments. Divergences in individual definitions of disability lead to variety of disability experiences (Devine & Sylvester, 2005). Similarly, one of the main stories talks about the difficulty of describing accessibility because everyone is different. Some authors suggest it is crucial to realize that the disability does have a “modifying element” on the experiences (Henderson Bedini, Hecht, & Schuler, 1995). One “modifying element” is that persons with disabilities sometimes have more time to engage in leisure pursuits due to the lower levels of employment (Aitchison, 2003). Further, Aitchison (2003) suggests the idea of leisure as free time “may be problematic for people whose freedom is relative freedom dependent on the support and care of others” (p. 963). Further, people with disabilities often have “fewer leisure resources than the general population” (Aitchison, 2003).

The AODA is touted as anti-discrimination legislation emphasizing accessibility and barrier removal to create equal opportunities for people with disabilities, although counter-stories begin to highlight challenges associated with this focus. To break this cycle of discrimination, we need to extend this conversation to consider social inclusion, rather than the narrow emphasis in neo-liberal theory on equal opportunity. This study allows TR practitioners to examine the deeper issues that are at play in the leisure experience of people with disabilities. These narratives give us much to think about as we attempt to implement various aspects of the AODA into our workplaces. For TR practice specifically it is important to be reflexive and to ask our participants about their understandings and experiences of accessibility, accommodation, and inclusion. Arai and Burke (2010) emphasize that “we must ensure that the voices of the people most affected by the policy are heard in the policy arena” (p. 120). Although policies that include people with disabilities in the policy process can be praised for their departure from the traditional model, it solicits us to ask the question: How far should we go to ensure that people with disabilities are participating in the policy process in a meaningful way? Oliver and Barnes (2006) state that the participation of people with disabilities must not stop at improving the conditions for people with disabilities but that it must be framed as a “wider struggle” that aims to better society.

Second, we can ask ourselves whether we are considering issues of difference in our attempts at social inclusion. Therapeutic recreation seeks to provide people with disabilities with the means to function fully in society (Therapeutic Recreation Ontario, n.d.) and to fully understand interactions at play in the therapeutic recreation process it is crucial to look at social inclusion. For Saloojee (2005), the focus of social inclusion is on the valued recognition and full participation of individuals in the community, so that they can benefit from and contribute to society. Further Saloojee argues that the discourse around inclusion of people with disabilities into mainstream society cannot be separated from that of social exclusion. Consequently, concerns around social inclusion for therapeutic recreation practitioners should be centred on advocating for change around society’s structures that prevent the inclusion of certain groups into society and creating space for individual difference to flourish. It has been argued that recreation can promote social inclusion in situations that go further in the design of programs, structures, and agency than the simple assumption that participation equates inclusion (Donnelly &
Coakley, 2002). Beyond the idea of equal opportunity and reasonable accommodation, concepts crucial to social inclusion include equality of outcome, relationships of social cohesion and accommodation of difference, and real participation and citizenship. Leisure is a “relational determinant of individual and community health” (Arai & Burke, 2010, p. 136); and leisure, like work, is an area of life in which social inclusion and exclusion manifest themselves on a daily basis.

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Enhancing Recreation Therapy Practice through Participatory Action Research

Shannon Hebblethwaite and Lynn Curley

Abstract

Recreation therapy espouses a holistic approach to health and emphasizes the importance of self-determination through leisure. Participatory action research (PAR) is well-suited to the study of recreation therapy with its emphasis on empowering marginalized groups. As part of a PAR project, one recreation therapist reflected on her experience of the research process. By actively participating in the research project and navigating the hurdles that she faced along the way, the recreation therapist found that she was able to reflect more critically on her practice and enhance her skills as a practitioner. Engaging in the research process also served to enhance her credibility among her interdisciplinary team. These findings emphasize the importance of research and evaluation in the practice of recreation therapy.

INTRODUCTION

The importance of person-centred care and empowerment has been well established within leisure studies and in health care (Kitwood, 1997; Pedlar, Hornibrook, & Haasen, 2001; Sullivan, Pedlar & Miller, 2002). A person-centred approach to care emphasizes the needs of the person and focuses on the person’s strengths and abilities, rather than simply on disease and disability (Kitwood, 1997). Key features of this approach include recognition, respect, trust, and mutually empathetic interactions between individuals with disabilities, their families and friends, and their health care practitioners. Community programs tailored to the individual needs of persons with disabilities enhance self-determination by providing more choice and control for these individuals (Lord & Hutchison, 2003).

As a profession, recreation therapy is well positioned to be a leader in incorporating a person-centred philosophy in working with marginalized groups. The holistic approach to health is central to the practice of recreation therapy and is well-documented in the TR literature (Austin, 1997; Carter, Van Andel & Robb, 1995; Coyle, 1998; Lee, Datillo, Kleiber, & Caldwell, 1996). Pedlar, Hornibrook, and Haasen (2001) expand this philosophy and integrate Parse’s theory of human becoming into action research that empowers both recreation therapists and individuals with chronic impairments.

Individuals with chronic health conditions such as stroke often experience decreased self-control when they cannot actively participate in their care. Disempowerment often results, contributing to depression and decreased self-esteem. Person-centred care attempts to address these challenges by emphasizing the person’s strengths and continued capabilities. Community-based agencies appear to be optimally positioned to adopt a more person-centred approach to caring for individuals with chronic impairments. Torjman (2007) suggests that complex social problems are addressed more effectively when communities facilitate collaboration among citizens and professionals.

In seeking to integrate research with practice, participatory action research (PAR)
is well positioned to address the issues of personhood in research participants and to empower marginalized groups (Kemmis & McTaggart, 2005). For example, PAR has been helpful in understanding recreation for people at risk of developing diabetes (Wharf-Higgins & Rickert, 2005), how women with low income participate in community development (Frisby, Reid, & Ponic, 2007) and physical activity (Frisby, Crawford, & Dorer, 1997). In light of the small amount of leisure research that utilizes action research, Hutchison (2008) advocated for an expansion of PAR in leisure research.

Central to action research is the active engagement of participants in order to more fully understand and improve their collective situation (Lewin, 1946). Freire (1982) emphasized the critical component to the approach, suggesting that thinking cannot, and should not, separate itself from action. Given the centrality of the idea that some kind of improvement or change is desirable, PAR is often utilized when exploring the experiences of marginalized groups and can therefore, be particularly useful in evaluating the process of recreation therapy. Although PAR strives to engage these marginalized groups in the research process, limited research has explored PAR as an important avenue to empower recreation practitioners working with these marginalized groups. The purpose of this paper, therefore, is to explore the experience of a community-based PAR project for one recreation therapist working on a Community Stroke Rehabilitation Team (CSRT) with individuals who have experienced a stroke.

METHODS

This paper emerged from a community-based participatory action research project conducted in collaboration with the recreation therapist, Lynn Curley, who is part of the CSRT, and the stroke survivors and their families who have been involved with the CSRT. This CSRT provides support to stroke survivors in the community through a multidisciplinary health care team. Lynn’s role in the CSRT is to work with stroke survivors to provide individualized leisure assessment, collaboratively develop an individual recreation plan, and assist stroke survivors to engage in recreation as a means of addressing individualized goals and objectives (e.g., increasing physical mobility, enhancing self-esteem, decreasing social isolation). The intent of the original study was to critically explore the experience of leisure for stroke survivors who had participated in services provided by the CSRT.

Shannon, a university researcher, co-facilitated the action research process with Lynn. Fourteen stroke survivors participated as co-researchers in the process. The group engaged in open brainstorming sessions to determine the goal of the research and to decide on the methodology that would be used. The participants embraced PAR and set two goals for the research project, which were to: 1) examine the experience of leisure for stroke survivors who had participated in services provided by the CSRT; and 2) develop a means of educating other stroke survivors about the role of leisure in the recovery process.

Using a Photovoice methodology (Wang & Burris, 1997), the participants were asked to take pictures of what their leisure has been like since they experienced their stroke. These photographs were then gathered and used to facilitate discussion among the participants about the role that leisure played in their recovery. We co-facilitated individual interviews with each stroke survivor. These interviews were audio-recorded, with participant consent, and then transcribed verbatim. Detailed field notes and a reflexive journal were maintained throughout this process, acting as data which
further informed the emergent understanding of participants’ experiences. Qualitative data analysis of the interpretive interviews employed the constant comparative method (Glaser & Strauss, 1967) as a means to process the data. Each interview was coded line by line. These open codes were then grouped into themes that represented the various experiences of recreation therapy by the stroke survivors and their care partners.

Once all of the individual interviews had been analysed, we met with all 14 participants together and discussed the major themes that emerged from the interviews. Together, the group then selected the photographs that best represented their collective experiences based on the analysis of the interviews. These photographs were used to create a calendar that could be distributed to other stroke survivors in order to educate them about the role of leisure in stroke recovery. Included with each photograph was a caption that summarized the meaning of the photographs for the participants.

Throughout the process of the research, we both kept reflexive journals in order to reflect upon their experience of the PAR process. The findings discussed here are based on these reflections that were analyzed using the constant comparative method described above. These findings outline the important role that PAR played in Lynn’s experience as a practitioner on the CSRT.

FINDINGS

Based on Lynn’s reflexive journal, it was clear that engaging in the research project was an important journey for her as it added a dimension to her practice that she had not previously explored or implemented. Three main themes emerged as important experiences and outcomes of the research process for Lynn: overcoming hurdles; encouraging critical reflection; and enhancing credibility.

Overcoming Hurdles

Lynn had recently achieved a milestone of working for 25 years in the profession of recreation therapy; yet this was the first formal evaluation in which she had ever participated. Her biggest challenge was overcoming the fear and trepidation surrounding the idea of engaging in research as part of her practice:

I hesitated doing research as I don’t have education in statistics and research methods. How could I do a research project when I didn’t always even understand what I was reading – methods, samples, validity, reliability? Perhaps part of it is the insecurity that I feel about my skills and knowledge as I did not complete my university degree. I thought my work needed to be valid and reliable - just like a standardized tool, therefore, my work could never be a research project. With [Shannon’s] guidance, I’ve come to understand that this clearly isn’t the case. I didn’t understand the ‘whole’ of research. Research is more than numbers and statistics. My work doesn’t have to be perfect in order for a research project to be undertaken.

It became clear that part of this challenge was in feeling confident in her own practice and being secure in knowing that her role as a recreation therapist was a valuable and important part of the clients’ quality of life. Opening her practice to critical evaluation and reflection required substantial courage and a commitment to understanding and enhancing her practice as a recreation therapist. Central to this was a clear dedication to providing quality care to stroke survivors and their families:
The whole research project was intimidating and I had to give my full trust in [Shannon’s] advice, direction, and faith in me that my work was worthy or structurally sound enough to be used as a research project. I had to have faith so I could help my stroke clients.

Once the project was underway and the interviews were being conducted, Lynn’s passion for recreation therapy easily transformed into enthusiasm for research. She became more confident in her skills and abilities, not only as a practitioner, but as a researcher as well:

Having first-hand experience with a research project has been extremely rewarding. I feel more confident in my understanding about the various research methods. It validates the important everyday things that RT does. If I can do research, then everyone can. Our programs and our philosophy fit perfectly with this type of action research.

**Encouraging Critical Reflection**

The research project not only enhanced Lynn’s research skills, but also enabled her to reflect critically on her skills as a practitioner. It became evident that her ability to foster compassionate relationships with stroke survivors and their families was critical to both the success of the leisure experiences that she helped to facilitate and to the research project. Many of the participants commented on her inclusive and supportive approach, often stating, “If it weren’t for you, we would be sitting at home doing nothing”. Through her participation in PAR, Lynn was able to identify strengths and weaknesses in her practice and began to work to enhance her skills as a practitioner, stating:

I’m hoping this will strengthen the role of RT in stroke rehab and will have impacts for services and funding. It has already, albeit a bit slowly, changed the way that I approach my practice as a recreation therapist. I have learned to be more timely and thorough with documentation and recording of events and outcomes. The job is very demanding – the research project has helped me to try to be more complete in my delivery of RT.

This suggests that research is an important, yet often neglected element of practice. Being able to represent her experience as a practitioner and to explain the impact of recreation therapy had for stroke survivors encouraged her to share her knowledge and experiences with funding agencies and other practitioners.

I really look forward to sharing my experience of qualitative research with other recreation therapists and with Stroke Strategy. Ideally, by sharing our story, my stumbling and awkwardness will strengthen RT as a profession but most importantly, it will improve the care provided to persons with disabilities. Clients have told me that RT has been the most important service on the team. Now I have the data to support that claim when I talk to my clients and my team.

**Enhancing Credibility**

Although the process of engaging in research was a challenging one and required the development of new skills and competencies, the development of this research capacity empowered Lynn in her practice. Through the process of becoming more educated about research, she became increasingly passionate about the need for further research in the field of RT. As a means of enhancing her research capacity, she attended a qualitative health research
conference and presented the research project there. She viewed this as a key event in her research journey.

Attending the Qualitative Health Research Conference taught me about the various research methods and details. It also gave me ideas for future research projects. I was very grateful for this opportunity – what a gift. I was very motivated and excited about the endless opportunities for research in RT. I was so proud of myself in being able to understand and ‘talk the research talk’.

It became apparent that Lynn did have the ability to understand the complexities of the research process, despite her initial insecurities about her abilities in this new realm. She then began to realize the importance of continued professional development and the importance of evidence-based practice. This referred to the need to regularly incorporate research and evaluation into her practice.

I need to take more time to read RT journals and various articles that support leisure in order to advocate for increased RT service to my clients. I would like the time to develop my resource handouts supported with current research literature. I need to be able to quote research articles to make a difference with my program managers and the region – just my word and very enthusiastic reports is not enough.

By participating in her research journey, she became increasingly aware of the importance of evidence-based practice and the importance of research in enhancing the credibility of the RT profession. Before starting this participatory action research project, she was concerned that the experience of RT wasn’t being adequately captured by the standard evaluation protocols that the CSRT was using to evaluate the program’s effectiveness. Through her participation in the research process, she became better equipped to advocate for the importance of RT in the rehabilitation of stroke survivors. Rather than feeling left out of strategic decisions being made by the program managers and funders, she now has her own evidence to support the role of RT on the CSRT.

I finally feel like I have a voice, although I still need to work to ensure that this voice is heard. It’s part of needing to constantly advocate for the profession. I feel empowered and more confident having participated in a research project – hopefully I’m more credible in other’s eyes.

DISCUSSION

The findings outlined here indicate the important role that research, particularly PAR, can have in critically reflecting upon recreation practice. The nature of PAR is particularly well suited to the practice of recreation therapy because, like person-centred care, PAR espouses the involvement of the participants in every phase of the process. Integrating PAR with person-centred care weaves together two well-established threads within leisure studies and can play a critical role in strengthening the ties between research and practice.

Involving Lynn as a co-researcher and including her as an equal partner at every stage of the research process contributed to the building of her research capacity. Engaging in reflexivity in the research process encouraged a critical examination of recreation therapy practice and contributed to her personal and professional growth. As an allied health professional and member of the CSRT multidisciplinary team, Lynn’s voice had been silenced due to an inability to communicate the outcomes of recreation therapy for the stroke survivors. Freire
Hebblethwaite and Curley (1982) stated that, in action research “the silenced are not just incidental to the curiosity of the researcher, but are masters of inquiry into the underlying causes of the events in their world. In this context, research becomes a means of moving them beyond silence in a quest to proclaim the world” (p. 30-31). Although health care practitioners are beginning to incorporate a psychosocial approach to their practice, the field continues to be dominated by the medical model and persists with an objectivist approach to both research and practice. In this respect, recreation therapy, in advocating for a more holistic, person-centred approach, exists at the margins. Struggling to fit recreation therapy into quantitative research that was being conducted by the CSRT, the practice of recreation therapy was further marginalized. Through PAR, Lynn began to find her voice and became empowered to advocate for herself, her profession, and the importance of recreation therapy for stroke survivors.

Leisure researchers must not lose sight of recreation therapy and ought to seek to enhance the body of research available to recreation therapists. As Kay (2000) suggested, leisure researchers and practitioners need to be more active participants in the development of social policy. Better integration of research into the practice of recreation therapy can facilitate this involvement. Participatory action research effectively addresses the question of relevance in leisure research by integrating theory with practice and by grounding the research in the experiences of the participants from inception to conclusion (Pedlar, 1995). Incorporating practitioners into the community of leisure researchers and providing them with opportunities to fully engage in research and evaluation can serve to empower them and encourage them to advocate for both the profession and the marginalized groups with which they practice.

Similarly, recreation therapists need to make research and evaluation part of their practice. If they are not to be outpaced by other allied health professions, they must ensure that thorough assessments, goal setting, documentation and evaluation are a routine part of their practice. In order to be active participants in decisions about programs and policies, they must be able to support their practice with comprehensive documentation, including research. This will only become increasingly important as the profession moves towards regulation and licensure. Lynn stated in her reflexive journal, “RT has so much potential to be bigger and better than ever. It’s fun and exciting to be part of the growing journey”. It reminds us of Mahatma Ghandi who said, “Be the change you want to see in the world”.

REFERENCES


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The TRO Research Annual, published by Therapeutic Recreation Ontario, was established in 2002 to provide a venue to communicate information about research studies being conducted in Ontario and encourage further initiatives in research. Manuscripts are accepted based on the judgement of the co-editors and advisors. At this time, articles are edited but not peer reviewed to help encourage practitioners to write about their experiences. No payment is made for articles published in the TRO Research Annual.

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Research oriented manuscripts should contain: A rationale for the study which includes a clear purpose statement and/or research questions addressed in the paper and a review of related literature; A method section which includes sample size, a description of the how the sample was selected and recruited, a description of the data collection strategies used, and a description of the data analysis procedures; Results which highlights the key findings of the study making sure to address the study purpose and all research questions and including any tables, graphs, and figures that help summarize the results; and a discussion of implications for TR practice which describes the contribution the study makes to therapeutic recreation practice and provides specific recommendations for practice.

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Exemplary program papers should include: An introduction which describes the background of the program and provides a clear rationale for the program (e.g., why this program is needed for the particular client group); a detailed program description which includes the purpose of the program, the goals and/or outcomes, the client group to be served, exclusionary/inclusionary criteria (i.e., any criteria for referral to the program), and an outline of the program procedures or content (i.e., specific techniques used or program modules); and finally, a discussion including such topics as the outcomes and experiences of the participants, challenges of implementation, method of evaluation, and specific recommendations for TR practitioners.

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