

Volunteers as Partners: Fostering Client-centred Care

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Abstract

This study provides insight into the experience of volunteering from the perspective of community members with disabilities who are involved in educating occupational therapy students. Setting the stage for the study is a first person perspective highlighting the personal significance of volunteering as an educator of health care students. This qualitative research study used semi-structured interviews to discuss volunteerism and the lived experience of disability. Four common themes emerged: personal development, advocacy, education and the dynamic relationship. These themes are illustrated in the Volunteer Experience Model and discussed in relation to other volunteering opportunities and experiences found in the health care literature. This study provides evidence for further research relating to teaching roles for people with disabilities.

Key Words:

volunteers, occupational therapy, students, disability, client-centred care

Introduction

This article describes the viewpoints of volunteers involved in an occupational therapy course titled *The Lived Experience of Disability* at a Canadian university. The course was designed to promote the development of empathy and deepen occupational therapy students' understanding of disability with the aim of understanding and adopting the concept of client-centered practice (Jamieson, Krupa, O'Riordan, O'Connor, Paterson, Ball, & Wilcox, 2005). Volunteers actively engage in educating students about their lives by assuming an educator role in this dynamic relationship. Occupational therapy is a health profession concerned with promoting health and well-being through occupation. "Occupation includes everything that people do during the course of everyday life, including the occupations through which people look after themselves, enjoy life and contribute as members of society" (Canadian Association of Occupational Therapists, 2003).

In *The Lived Experience of Disability* course, pairs of students are matched with a volunteer community member who has a disability. Volunteers assume a mentoring role by meeting with students regularly over a six-week period, engaging in different activities and roles in a variety of venues. Meetings may include touring a volunteer's home to identify accessibility issues, chatting at a downtown café while observing the reactions of community members, meeting the volunteer at their place of work or leisure, using the transportation system or engaging in experiential opportunities such as using mobility devices in the community. Meetings are planned to convey to students the activities and roles assumed by volunteers in their daily lives. They provide students with a realistic view of the experience of living with a disability, as

volunteers involved in the course impart their knowledge within community settings. Through journaling and tutorials, students reflect on these educational experiences. Past research using this approach has demonstrated the importance of partnership to student learning and has focused on the lived experience from the students' perspective (Borcherding & Baldwin, 2001; Paterson, O'Riordan, Jamieson, O'Connor, Krupa, & Wilcox, 2000). The purpose of this research was to examine the essence of volunteering from the viewpoint of 14 volunteers involved in *The Lived Experience* course. To set the stage and to provide some context, one of the authors of this manuscript Debbie Docherty, an experienced volunteer and advisory committee member in the course, provides her own following viewpoint:

As a volunteer in this course over the past 8 years, I have experienced the predictable benefits of volunteerism, including a sense of personal contribution, fulfillment, involvement in my community and intellectual stimulation. There are also unanticipated benefits. The most gratifying experiences have been the teachable moments: that instant when the student and I, through conversation and demonstration reach a point of common understanding, at a deep level, of the experience of disability. This "ah ha" moment leaves me with the certainty that understanding has occurred at a significant level. I am not the paid professional educator burdened by the design of the curriculum or evaluation of the student in a formal academic sense. I cannot overstate how liberating it is to be freed from the administrative constraints of the course. I am

however responsible as a volunteer, to engage with the students, to share openly my experience of living with a disability and to offer feedback to both the students and the course instructor about how I think the students interacted with me. While feeling positive about giving of myself and my time, I am simultaneously contributing to the enhanced learning and competence of the very health care professionals I will need to rely on. Over the years of volunteering I have refined my tutoring style, and challenged the students through experiential activities and discussions about their biases or expectations regarding the abilities of individuals living with a disability. In our society individuals living with a disability are too often marginalized. Their involvement in and contribution to the civic and social life of their community is dismissed, curtailed or discounted. This occurs both through attitude (negative biases about the competencies of individuals living with a disability) and the built environment (which prevents physical access to those with mobility or visual impairments). This course provides a unique and meaningful opportunity for volunteers to engage in an activity that gives a sense of purpose to their lives.

Methodology

This study was conducted as part of a large action research project called, Queen's University Inter-Professional Patient-centred Education Direction (QUIPPED) seeking to create an inter-professional educational environment. The purpose of the exploratory action research

project was to enhance the ability of learners and faculty to provide patient-centred care, while recognizing the contribution of the health care team within a respectful and collaborative framework. Action research is "iterative, rigorous and collaborative, involving a focus on both organizational development and the generation of knowledge. Its iterative characteristic implies a cyclic process of intervention, with the conduct of ... several cycles of activities that are designed to address the problem(s) experienced in the organizational setting" (Davison, Martinsons & Koch, 2004, p. 68). The research discussed in this paper was one of many activities carried out in this 33-month action research project from 2005-2008.

Participants

Participants were recruited from volunteers involved in *The Lived Experience of Disability* course. Of the 17 volunteers involved in the course, 14 consented to participate, representing 82% of potential participants, ranging in age from mid-twenties to mid-sixties. Participants experience a diversity of disabilities including physical and mental health challenges. Participants were divided into three groups based on their level of experience in the course: new volunteers (seven), experienced volunteers (five) and experienced volunteers who were also members of the course advisory committee (two). The advisory committee, including three experienced volunteers and the course coordinator, works collaboratively in planning and making decisions about all aspects of the course. The groups were formed in order to determine whether or not the length and depth of involvement impacted the volunteering experience.

Confidentiality, risks and benefits were discussed with participants before commencing the interviews. Participants

were assigned a number from P1 to P14 to identify and label the data collected, ensuring confidentiality. Ethics approval was obtained from the university's research ethics board.

Data Collection

A qualitative methodology was employed utilizing semi-structured interviews to collect data by allowing participants to narrate their volunteer experiences (Figure 1). Interview protocols recommended by Krueger and Casey (2000) provided helpful guidelines.

A research advisor was present to assist as needed. Interviews, held in a quiet, non-threatening environment with refreshments provided, were 60-90 minutes in length. Transportation was arranged for participants if necessary. An interview guide (Figure 2) was used to facilitate discussion among the participants. Interviews were taped and transcribed, and field notes taken. Member checking was utilized as the participants reviewed the transcripts to verify accuracy. Redundancy was achieved

as later interviews confirmed themes that emerged from earlier interviews.

Analysis

Open coding was used to capture the themes described by participants. Researchers independently read and coded the transcripts to achieve triangulation. Transcripts were also read and coded by the research advisors. Brainstorming sessions occurred between the researchers and advisors to discuss inter-relationships between codes and determine common themes. Every effort was made to ensure trustworthiness as advocated by Krefting (1991). A conceptual model was developed to illustrate the themes that emerged from the participants' narrated experiences.

Findings

This study was exploratory in nature, and the findings may not be inferred to any larger group or population other than the participants in this study. Four major themes emerged from the volunteers' narratives: personal development, advocacy, education and dynamic relationship.

Figure 1. Conceptual schema of data collection.

ROUND 1

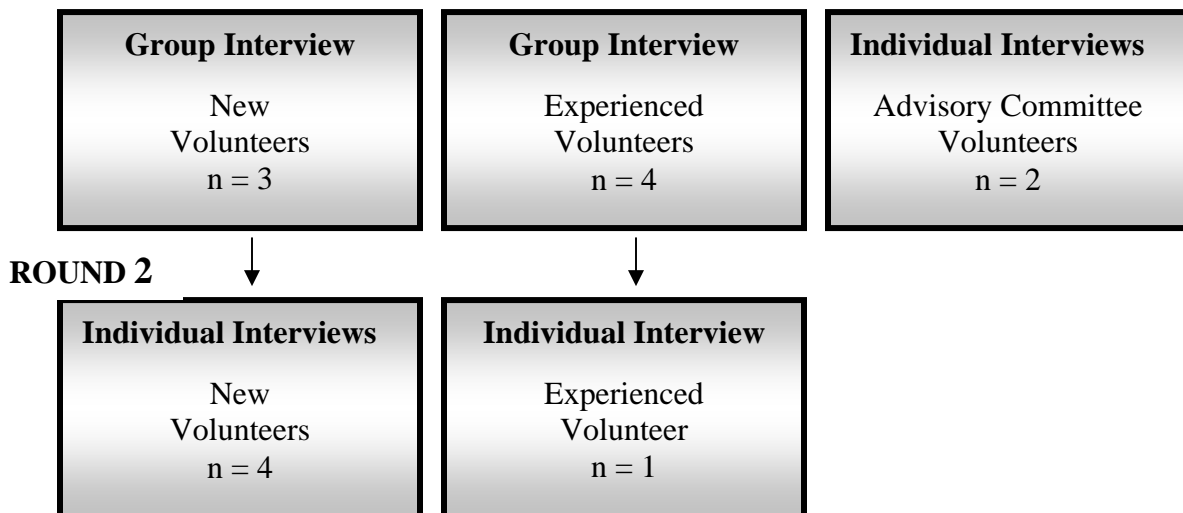


Figure 2. Interview guide.

The interviews will begin with a brief introduction to the purpose of the study and how the information gathered will be used. Participants will be informed of confidentiality and of their right to refuse to answer any questions and/or withdraw from the study at any time. Volunteers will also be provided with all necessary contact information should any questions arise after the interview is complete. *Duration:* Approx. 60-90 minutes

1. How did you become a volunteer for “The Lived Experience of Disability” course?
2. How long have you been a volunteer for the course?
3. What was your motivation to become involved and/or continue in the course?
5. What do you enjoy about volunteering for this course? What are the challenges?
6. How would you describe your role in the course?
7. How have your experiences with students affected your overall view of volunteering?
8. How do you feel you are contributing to students’ understanding of disability? Please provide an example.
9. How does change in a student’s perspective of disability affect you?
10. How do you feel your participation in the course affects your overall view of disability?
11. Do you feel that this experience has changed you? How?
12. Has this experience changed your perception of your own life or the lives of others?
13. How did you become involved in planning the course with the instructor? *
14. What do you enjoy about the planning aspect of the course? *
15. How do you feel your participation in planning affects the course? *
16. How does this participation affect your overall volunteer experience? *

* Questions for volunteers advisory committee members

Personal Development

The first major theme that emerged was the concept of personal development. Changes that occurred within the participants as a result of their volunteering experience with the students were discussed. Participants expressed an increase in their level of confidence, self worth and self-awareness through self-reflection, as well as enhancement in their sense of contribution to community. One beneficial outcome expressed by some participants was an increase in confidence level in either their personal lives or ability to share their experiences of disability with others. For example, one participant said, “I think that having more confidence about being able to

use my disability as a teaching tool was heightened”.

Participants also reported that being a volunteer made them more aware of their own disability, how they function and the depth of the challenges they encounter in their daily lives. Discussing their experiences with students facilitated an appreciation for their current situation and reflection on what they have been through in their past. One participant said: “students give me a new opportunity to consider my life in a new way this year versus last year, in relation to how is your disability affecting you now”.

Another aspect of the personal development theme was the feeling of contributing to the community. Participants

viewed this experience as making a difference in their lives, the students' lives and influencing their communities. One participant said, "I feel really positive about myself. I feel I've made a difference. . . . not all of us are going to be like super-human volunteers . . . but most of us do little things many times and that's what I hope I am doing".

Advocacy

The second major theme that emerged was the concept of advocacy. Participants spoke about taking this opportunity to advocate for themselves and other people with disabilities. Creating a positive image of people with disabilities was identified as a key component of the experience. Participants aimed to portray this image while interacting with students. One participant discussed the importance of projecting this image to students: "One of the greatest things is knowing that you will hopefully change someone's perspective or ideas of what they think someone with a disability's life is all about".

Participants also expressed that society tends to develop myths or misconceptions about people with disabilities. Volunteers discussed the importance of ensuring that students realize people with disabilities are not defined by their disability. One participant said, "Disability doesn't define your life. You know, it's a piece of you just like blond hair and green eyes . . . it's something that defines your personality a little bit but it's not everything that you are". Another said, "They get to see us being successful in whatever it is that we are doing . . . the disability is one thing and one part of how I define myself but clearly it's not everything".

Finally, participants expressed the importance of utilizing this experience to change perspectives of disability. They

perceived this opportunity of spending time with students as a way to advocate for people with disabilities. One participant discussed the importance of changing students' perspectives of disability: *Instead of getting angry it makes me think at least someone is out there with a different mindset. It may be a small step but it's an important step in changing the world so that people are treated equally and people will help those who ask for it without question.*

Education

The third theme was education. Participants discussed their role in teaching and challenging students, as well as the influence they have on future health care professionals. Participants noted the importance of practical experience for students. One participant stated, "I feel very strongly they can't rely on textbooks . . . they can just use them as guidelines. Every individual they deal with is different . . . they must be aware of that and always think outside the box." The volunteers expressed that witnessing the lived experience of disability enriches student learning and provides insight into disability in a way that textbooks or professors cannot.

One of the highlights of the volunteer experience was presenting students with a challenge to determine their response to a particular situation. The challenges often involved students taking part in simulated activities to show them what it might be like to have a disability. One participant said:

I borrow a couple of wheelchairs from a medical supplier and we go to the mall for a couple of hours and the students push themselves around in the wheelchairs to get the perspective of how people can

sometimes treat you when they know you're disabled.

The education theme also involved student learning. Many participants felt they took on the role of a teacher when interacting with the students. This role added meaning to the overall volunteer experience of participants. One participant discussed taking on this educator role: "I liked the set up of the course. It allows people with disabilities to become teachers and engage students in all kinds of different social interaction." Participants discussed the importance of this volunteer experience in influencing how students are going to practice as occupational therapists in the future. They felt the education they provide to students would give them the tools required to work with people with disabilities. One participant remarked: "The people that we are working with are going to become professionals . . . and being able to influence the outcome of their experience and how they will treat the people that they work with in the field is rewarding."

Dynamic Relationship

The fourth theme was the dynamic volunteer-student relationship. Many of the participants discussed the mutual learning that occurred between them and the students. The experience was not merely volunteers imparting information, but rather a shared exchange with students. One participant talked about this dynamic relationship and said, "There is a sense that we have all got something to learn from each other." Furthermore, the participants enjoyed the socialization that occurred as a result of this dynamic relationship. "I love being with bright young keenly interested people . . . I get more out of it I think than I give."

Differences among New and Experienced Volunteers

Minimal differences emerged between the new and experienced volunteers, including the members of the advisory committee. Differences were noted in the challenges faced by new volunteers. They felt uncertain about students' personal and professional background, as well as what to expect from the experience. The main challenge for experienced volunteers was creating new learning opportunities for students, as well as themselves, to avoid repetition or boredom.

The Volunteer Experience Model

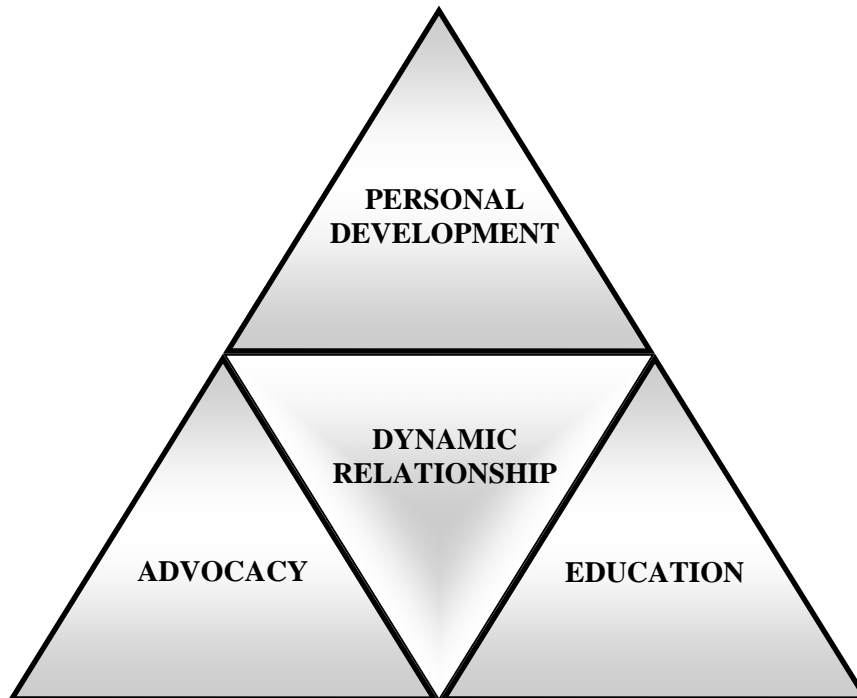
The Volunteer Experience Model (Figure 3) illustrates these themes and demonstrates that the dynamic relationship between students and volunteers is central to their experiences. This model is a visual depiction of the narrated shared experiences of the volunteers engaged in this study. The placement of the triangles is essential in understanding the overall volunteer experience. The personal development triangle is placed at the top of the model because it is the individual component of the experience. From an individual perspective, personal development refers to the internal changes that occurred as a result of the volunteers' involvement with students. These changes enabled an increase in self-confidence, self-worth, self-awareness through reflection and a sense of contribution to the community. When viewing the volunteer experiences from a systems level perspective, the concepts of advocacy and education emerged. Therefore, advocacy and education are placed at the bottom of the model and refer to the system changes. System changes are thought to be changes that occur to both the student and to the future health care system. Participants saw this experience as an opportunity to create a positive image of

disability and to change students' perspective of disability. The importance of the volunteers' role in teaching future health care professionals and the impact this would have on the students' future practices in the broader health care system were also discussed. Ultimately, it was believed that through advocacy and education, the volunteers would influence the manner in which students practice as professionals. Thus, these changes in the students would have a positive effect on how they interact with individuals with disabilities in their future practice.

The dynamic relationships component is placed in the center of the model to depict

how the other three components are influenced by this interaction between volunteers and students. The dynamic relationship was described as the shared learning that occurs between the student and volunteer. The participants often commented on the significance of the educational and social aspects of their visits with students. Both aspects were considered strengths in the experience. The volunteers enjoyed getting to know students on a more personal level, while also being provided with the opportunity to engage in activities that promoted learning.

Figure 3. The Volunteer Experience Model.



Conclusions

This research contributes to the growing body of knowledge on the importance of engaging in volunteering activities, as well as the benefits associated with volunteerism. More specifically, this research provides insight into the volunteers' experience and provides support for future research on volunteerism as an occupation for persons with disabilities at both individual and systems levels. A Volunteer Experience Model was developed to illustrate major themes that emerged from participant accounts with a prominent finding being the dynamic relationship between student and volunteer. This concept is important to future practice as it suggests that therapists can be taught as much from their clients as they can teach their clients. This data reflects experiences from a specific group of individuals within a specific setting. Future research initiatives could examine the application of the Volunteer Experience Model to other volunteer groups and settings.

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Beth Morgan completed her undergraduate degree in Kinesiology at McMaster University, Canada in 2003. Much of her time outside of school was spent working for local agencies that support adults and children with various disabilities. Her Master of Science in Occupational Therapy degree was completed in September 2006 at Queen's University, Canada and she has been working as an occupational therapist at Bloorview Kids Rehab since graduating. She is currently working with the Spina Bifida/Spinal Cord team and Seating Services.

Heidi Hunter completed a Bachelor of Arts (Honours) in Psychology at Wilfred Laurier University, Canada. Prior to pursuing a Master of Science in Occupational Therapy at Queen's University, Heidi spent 4 years working with persons with intellectual disabilities. Currently, Heidi is working as an occupational therapist in a community setting for Comcare Health Services and is focused on taking the lessons learned from the volunteers in *The Lived Experience of Disability* course and applying them to enhance her daily practice.

Samantha Anstey graduated from Brock University, Canada with a Bachelor of Arts in Community Health. She worked as a rehabilitation assistant with the paediatric population before graduating from Queen's University in 2006 with a Master of Science in Occupational Therapy. As a student, Samantha participated in *The Lived Experience of Disability* course and contributed to the QUIPPED Project. Currently, Samantha is working at Rehabilitation Solutions as a member of the Hand and Upper Extremity Specialty team.

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Dr. Margo Paterson is Associate Professor and Chair of the Occupational Therapy Program, School of Rehabilitation Therapy, Queen's University, holding a Master of Science in Community Health and Epidemiology from the Queen's University and a Ph.D. in Health Sciences from the University of Sydney, Australia. Margo was co-principal investigator with colleagues from medicine, nursing and other disciplines on a \$1.2 million Health Canada grant for the Queen's University Inter-Professional Patient-centred Education Direction (QUIPPED) project.

Debbie Docherty completed a Bachelor of Arts/Bachelor of Social Work before enjoying 33 years as a social worker. Late in her career, she completed a Master of Social Work from McGill University. She also discovered the joys of volunteer teaching at Queen's University in the Faculty of Health Sciences, along with participation in an Occupational Therapy course, *The Lived Experience of Disability*. Debbie's credibility in this regard has been earned through a 20 year course of living with Multiple Sclerosis that forced a somewhat early departure from paid employment but led to a satisfying second career as a volunteer.