

CHANGING MINDSETS THROUGH 'LIVED EXPERIENCE' :
AN EXPLORATORY STUDY OF A PARTNERSHIP IN OCCUPATIONAL
THERAPY EDUCATION

A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF
A MASTERS DEGREE IN OCCUPATIONAL THERAPY

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March 2005

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ABSTRACT

It is critical that educators responsible for training future health professionals implement teaching strategies that prepare students for relevant service provision. People with a disability perspective have, in recent times, criticized occupational therapy services for being insufficiently informed by the perspectives of disabled people and have called for increased collaboration with consumers in designing services to meet their needs.

This study was undertaken to explore the experience of all the participants of a teaching partnership between an occupational therapy (OT) educator and a 'disabled expert'.

The 'disabled expert' participated in the teaching partnership with an occupational therapy educator in a first year OT lecture series focused on basic activities of daily living. A case study design was used to provide in-depth qualitative information that would provide relevant contextual detail, as well as capture the essence of the experience.

The 'disabled expert' contributed to teaching through sharing her 'lived experience' of disability whilst the OT educator facilitated student learning within occupational therapy theory. Students were invited to contribute by sharing their experiences through journaling.

Data was collected from student reflections and from field notes following observation, personal reflection, and discussions with the 'disabled expert'.

Findings were analysed from data collected from all the participants. Analysis of student reflections revealed two major themes. The first theme suggested that the experience was characterized by the need to 'wrestle' with learning that challenged students both personally and professionally. The second theme explored how the learning experience contributed to 'crafting' students into future therapists. An overarching theme emerged as the interface between these two themes was considered. Central to this overarching

theme was the experience of disjunction and the formulation of a response to disjunction.

Perceptions by the educator suggest that the 'disabled expert's participation brought opportunities for 'doing', contribution, connection and well-being.

Findings from the educator perspective were presented in terms of reflections on the 'juggling act experienced', the personal learning and development and the resource implications of the process.

Results indicate that, whilst the learning opportunity undoubtedly created rich learning potential, it was resource-intensive and dependent on high levels of personal commitment by participants. Skilled facilitation, and investment by participants to serious reflection and feedback were all pivotal in maximizing the potential of the learning opportunity. It is recommended that the 'partnership approach' be extended to other areas of teaching, but that caution be exercised in the implementation and monitoring of such a partnership.

ACKNOWLEDGMENTS

Firstly, to Lauren, thank you so much for the inspiration you have been to me throughout this study. I have learnt so much personally, both about the experience of disability and about the art of teaching through the journey that we have taken together. Thank you for your willingness to risk a new way of doing things. Thank you for what you have given to us in such an enriching way. It is difficult to capture the essence of your contribution in a few words. You made us question, you made us laugh, you made us cry, but most of all you made us feel your sense of hope, and helped us to understand your resourcefulness and resilience in the face of your day to day challenges. We hope our practice as therapists bears witness to the many things that you taught us from your 'lived experience'.

To the first year Occupational Therapy students 2004 – thank you for the spirit with which you embraced your learning. Thank you for the time taken to reflect on your experience, and to give us feedback, which has helped us to understand more about your learning.

To Helen, my supervisor, thank you for helping me to keep calm and focused. Thank you for your encouragement, your organized approach, your 'beady eye' for detail and your support of the whole process.

To Lana van Niekerk, and my colleagues from UCT Division of OT , thank you for setting the high standard of teaching, practice and research that you have done in the past few

years. I know that this study was able to come into being largely due to the ethos in the department.

To my husband, Tony and my two sons, Christopher and Daniel, a special thank you for your patience and support in helping me get to the end of this road. For giving me both the time and space to make it all happen, a big thank you!

To Christopher, extra special thanks for your computer wizardry that made the computer do as it was told!

University of Cape Town

USE OF TERMINOLOGY

According to Marks (1999) language both produces and disguises meanings. As such language is both a symptom and cause of a disabling society. It is acknowledged by the researcher that names and labels are important in the politics of disability. The researcher supports the rights of people with disabilities to be able to express their own goals and preferences and to contribute to service delivery.

The researcher acknowledges that use of the term 'disabled expert' may be seen by some as problematic in that it is not desirable that people be labeled by their disability (2003, American Psychological Association). In this study the term '**disabled expert**' is used to acknowledge the particular 'expertness' that is acquired by a person who has 'lived experience of disability'. This type of knowledge is different from that which is gained through training and work experience. Knowledge of the 'lived experience' of disability makes an important contribution to the clinical reasoning process used by health professionals in decision making. The person involved in this study was not referred to as the 'disabled expert' during classroom sessions with students. Consent was obtained from the 'disabled expert' to use such a term in written material pertaining to the study and no objection was raised to it being used. Permission to use the first name of the 'disabled expert' was also sought to allow for greater fluency of written material.

The following **terminology relating to disability** reflects thinking embodied in the Social Model of Disability (Cradock 1996, Finkelstein 1993, Oliver 1999, cited in A. Turner *et al*, 2002 p. 259).

A lively debate presently rages over the appropriate labels to describe people who have a disability. Disabled activists promote the use of the term 'disabled people' to emphasize that society has disabled them from living a full life. The term '**disabled people**' implies that people are disabled by other factors, namely environmental, sociopolitical and economic barriers, and by negative attitudes within organizations and society at large which prevent equal opportunities.

Others prefer the term '**people with disabilities**', which they feel emphasizes that they are people first and their disability is secondary (McConkey & O'Toole, 1995). In this study the importance of seeing the person first and foremost as person rather than as person with a disability is recognized as are the social dimensions of disability.

Impairment: refers to the medical or health problem. It may be referred to as the functional limitation caused by physical, mental or sensory impairment (Tregaskis, 2002)

Acknowledging the multi-faceted roles of myself as researcher, occupational therapy educator, facilitator, coordinator and observer, I have chosen to use the term '**educator**' to refer to myself in my role as teacher. I do, however, occasionally use the term '**researcher**' when referring to work that is directly related to the research process, rather than the teaching role. '**Educator**' and '**researcher**' are therefore the **same person**.

CHAPTER 1 : EVOLUTION OF STUDY

1.1 PERSONAL EXPERIENCE

The decision to study the impact of a partnership between an educator and a person with a disability evolved over some years. I qualified in occupational therapy in the early 1980's at a time when the movement advocating for the rights of disabled people was just beginning to gain momentum internationally. Rapid progress has since occurred, leading to the development of new policies and attitudes worldwide in response to dissatisfaction that had been growing amongst disabled people. The Disability Movement succeeded in challenging many of the long-held traditional ideas about disability, treatment and rehabilitation. Some claimed that medical and allied health professionals were partly responsible for the existence of these traditions. Disabled peoples' organizations have taken issue with service providers over the dominance of professionally-controlled welfare services and over alleged attempts by professionals to restore disabled people to 'normality' and to 'independence' (Watson & Fourie, 2004). The Disability Movement has confronted the collective experience of exclusion and built a strong political and social movement which continues to drive change in the health professions.

Much of my training was limited to a 'medical model' approach in which the focus was on curative and rehabilitative care, a process driven largely by the health professional. Many strides have been made by activists in the Disability Movement to counter the traditional power of this 'medical model' approach. The consequent promotion of the 'social model' of disability began to influence the extent of participation of people with disabilities in service planning.

This is one of the significant changes in the past two and a half decades that has influenced occupational therapy. In addition, momentous political and legislative changes in South Africa since 1994 (advent of democracy) have motivated occupational therapists locally to examine critically the services they are providing. With these developments has come a renewed focus on occupation and on initiating partnerships and networks that support our professional goals. This has resulted in practice developing in many new contexts.

Through my own studies as part of the Masters degree in occupational therapy, I have become more aware of the important debates that have evolved with representatives of disabled people over the design and provision of service. I have become more aware of the need for collaboration. There has also been lively debate about the role of disabled people in research and about the nature of the relationship existing between the different groupings. I have also been influenced by the revival in occupational therapy in celebrating the transformative power of occupation and in exploring the link between occupation and wellbeing.

I have begun to question the way forward given my new awareness arising from exposure to these debates. This is perhaps a natural progression as a result of my personal reorientation in thinking. Furthermore, as an educator, I have also been challenged to consider possible implications for student training. I believe that teaching must be informed by practice, and must also reflect current occupational therapy thinking.

1.2 FUNDAMENTAL TENETS OF OCCUPATIONAL THERAPY

Fundamental beliefs that have influenced occupational therapy philosophy include belief in the individuality of human beings and their inherent capacity to be in charge of their own destiny and to make choices concerning their future (Turner, 2002). Such beliefs are reflected in the attitudes that therapists have towards the people they work with, and the ways in which they work with them. Integral to practice is the belief that not all people require the same interventions; each person's opinion or view holds value and it is important to be able to facilitate him/her to identify his/her needs in order to be able to organize appropriate intervention (*ibid*).

This implies an understanding of the client-centered approach to service, which values dynamic and interactive partnerships between disabled people and those responsible for service delivery (Hagedorn, 2000). Such fundamental beliefs affect and dictate the relationship developed with an individual, which should be based on mutual, respectful collaboration. The value of an appropriate occupational therapy approach lies, therefore, in its sensitivity and responsiveness to the client's expressed needs and not in the therapist's assumptions. Watson and Fourie (2004) suggest: "If we want to help people change their occupations and the way they live, understanding their actual state of affairs is far more important as a starting point than our assumptions" (p.23).

The therapist adopts an optimistic view about the person's ability to shape his/her life and works with the person to identify the areas seen as important to fulfilling his potential. Collaboration and communication between client and health professional is seen as integral if the client is to make informed decisions about intervention that

will promote adaptation and maximum well-being. In a collaborative environment, the client has the option to either pursue or decline participation in therapy.

1.3 THE LINK BETWEEN TEACHING STRATEGIES AND OCCUPATIONAL THERAPY VALUES

Increasing recognition of the part the client has to play in decisions about therapy, implies that occupational therapists train students in ways that demonstrate respect for the value of the 'client-as-expert' of 'lived experience'. Teaching strategies have not always kept pace in fostering the kind of practice that the profession seeks to promote to remain true to its' philosophy. Little has been written about the experience of teaching partnerships between health professionals and disabled people in student training or the impact of this type of teaching strategy on students, health professionals and disabled people themselves. Attempts to change teaching strategies need to be monitored to determine the benefits for student learning and to highlight any risks or difficulties that occur during the process that may impact on decisions regarding training.

1.4 EVIDENCE NEEDED ABOUT THE EFFECT OF USING A PARTNERSHIP APPROACH

A study documenting the experience of participants involved in a 'partnership teaching approach' between a health professional and disabled person could provide information to guide further initiatives in occupational therapy or other health professions.

The experience of partnering health professionals in teaching as 'disabled expert' is a perspective that may also be of particular relevance to disabled people in the community who may consider participating in formal health professional training programs.

In addition, students involved in such a teaching partnership would gain awareness about disability as a result of the input that could be framed within occupational therapy approaches to service. It was anticipated that such a learning approach would facilitate the development of a client-centered approach to problem-solving in self-care. Such a learning approach students would likely facilitate the development of a client-centered approach to problem-solving. Students would also begin to form a clearer understanding of the contribution an occupational therapist could make in working with people with disabilities in one or more specific areas. Whilst other benefits of undertaking such a study would undoubtedly surface, they could not be predicted with any certainty.

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CHAPTER 2: BACKGROUND INFORMATION INFORMING STUDY: LITERATURE REVIEW

2.1 OVERVIEW

In this chapter literature from the field of higher education, occupational therapy and the disability rights movement has been reviewed.

The intention is to focus specifically on current strategies used to train undergraduate occupational therapy students and the response of disabled people to these strategies.

Literature pertaining to changes in disabled person-therapist partnerships and the application of the client -centered approach was reviewed. The researcher also reviewed literature exploring the relationship between health and occupation and the participation of disabled people in programs to train health professionals.

It is acknowledged that these are all very broad fields of study and the literature review does not attempt to be exhaustive. The researcher has attempted to select and synthesize relevant literature according to a number of themes identified as being relevant to the study.

2.2 EXTERNAL PRESSURE FOR CHANGE IN HEALTH PROFESSION SERVICE AND EDUCATION

There is an increased recognition by health professionals of the contribution that people with disabilities in the community are able to make related to decisions about health and rehabilitation services (Coleridge, 1993). Many professionals in the health sciences have trained in institutions with a strong traditional clinical orientation to service, with their understanding of health revolving around the ideal of the flawless

body as the ultimate in well-being (Tighe, 2001). This approach to disability, known as the 'medical model', has been widely contested recently by those who refute the significance of impairment in the global meaning of health (Barnes & Mercer, 2004). In a response to this, the social model was developed, which instead focused on promoting an understanding of disability removed from health (*ibid*, 2004). The social model focuses on the experience of disability as a form of oppression. It considers a wide range of social and material factors and conditions, such as family circumstances, income, and financial support, education, employment, housing, transport and the built environment, and more besides (Barnes, 1999, cited in Kitchin, 2001). Whilst not denying the impact of impairment, there is an attempt to understand the wider circumstances of disabling barriers and attitudes that demean or exclude disabled people.

This increased presence of proponents of the Disability Rights Movement, has led to a call for an equalization of the power relationships between health professionals and people with disabilities and for the involvement and empowerment of the latter. Marks's use of the term 'disabling professions' (1999), reflects her concern pertaining to the extent of control seen to be exercised by professionals working with disabled people. According to Barnes and Mercer (2004), a further grievance of disabled people was the takeover of disability organizations by non-disabled people. People advocating for rights for disabled people no longer wanted disability seen as a 'personal tragedy' and began exploring the social interpretation of a 'disabling society'. There are, however, others involved in the debate, who see the social model focus as incomplete and perhaps as potentially destructive as the medical model was limited (Watson N., 2004). Watson, whilst acknowledging the value of the social model, criticizes it for "oversimplifying the complexity and diversity in disabled peoples' 'lived experience' " (*ibid*, p.103).

Dialogue between health professionals and disabled people is essential for the two sides to move forward together. In the past two decades, people with disabilities have, in increasing numbers, begun taking leading roles in the planning of services internationally. Growing numbers of people with disabilities are themselves becoming professional therapists and carers (Coleridge, 1993). Tregaskis calls for disabled people to form strategic alliances with non-disabled people (2004, p. 68). She calls for developing communication and negotiation skills between disabled and non-disabled people in order to tackle social exclusion through the formation of 'engagement' and alliances (*ibid*, p. 79).

This demands a new approach to the relationship between consumers and providers of health services, which in turn, suggests the adoption of different approaches in the training of health professionals.

There is also pressure from people with disabilities to adopt a more emancipatory approach to research that involves them (Stubbs, 1999). The problem of dual accountability in disability research is acknowledged (Kitchin, 2000). A conflict of interest is described in that the educator is accountable both to academia and to the disabled subjects involved in the research, which results in an altered dynamic in research relations. There is broad acknowledgement in these circles that ownership of the research needs to be shared and negotiated and that a 'plurality of methods and methodologies' should be accepted (Mercer, 2004, p.119). In Kitchin's (2000) study of research issues and disabled people, the body of disabled people interviewed supported the use of inclusive methodologies in research with disabled people, calling for action -orientated, empowering research which did not result in the alienation and sense of oppression often experienced in 'expert-led' research.

Hammell (2002) proposes that the research base that informs practice should itself reflect a client-centered orientation, demonstrating efforts to include clients as collaborators throughout the research process.

2.3 COLLABORATION BETWEEN HEALTH PROFESSIONALS AND DISABLED PEOPLE TO IMPROVE SERVICE PROVISION:

The occupational therapy profession is committed to providing services that are client-centered in their approach. Research by Braithwaite (2003) supported this need for partnership. Braithwaite (2003) described the need for people with visible physical disabilities to constantly juggle the need for instrumental social support against receiving unwanted help on a daily basis. Every disabled person interviewed in her study indicated that they received much more assistance than they wanted or needed. They also often received assistance that was not helpful in terms of its timing or delivery. She acknowledges the difficulties encountered by non-disabled people in providing help in such a way that reduces 'social cost' for the people they are trying to help. Study findings showed clearly that people with disabilities strongly prefer to be the initiators and controllers of interactions involving their own assistance wherever possible (*ibid*). In recommendations to non-disabled people to guide their response when help is needed, Braithwaite (2003) suggests:

"organizations should provide training opportunities for non-disabled people who will be interacting with people who are disabled to help them make choices that will maximize the rewards in these helping situations for both disabled and non-disabled interactants" (p.23).

Occupational therapists believe that individuals are unique and 'expert' in their own lives and they are therefore responsible for ensuring that services are based on the values and insights of those served. (Clark *et al*,1993). By encouraging clients to be active participants in their own rehabilitation, therapists demonstrate the value they place on client choice, empowerment and client support in taking risks. 'Client-centered' practice is an approach to providing occupational therapy, which embraces a philosophy of respect for, and partnership with, people receiving services. The client, in collaboration with the therapist, determines therapeutic goals, participates in the implementation of intervention and the assessment of outcome (Law *et al*, 1995). This collaboration between client and occupational therapist can be viewed as a partnership. Client-centered practice recognizes the strengths that clients bring to the therapy encounter, the benefits of a client-therapist partnership and the need to ensure that services are accessible and fit the context in which the client lives (*ibid*, p.253). Client-centered practice necessarily leads to changes in power so that clients have more input in defining the focus of the intervention process.

Whilst the term 'client-centered' or 'person-centered' is frequently used in occupational therapy contexts, use of the terms does not necessarily imply a transfer of this intention into truly client-centered practice (Law *et al*, 1995). According to Clark *et al* (1993), there is a gap between client and professional perceptions about desired treatment outcomes and in the content of writings between the two groups.

With partnership come the appreciation of, and respect for cultural diversity, vision and values, personal roles and the appreciation of the critical influence of the environment. A partnership should enable issues to be explored jointly and allow for trust and learning to result from the interaction. Within the client-therapist relationship the client's

experiences and knowledge are thus central and carry authority. Service is then constructed from a range of options to meet the needs of the client. The therapist may make a contribution to the range of options possible through professionally acquired knowledge of resources, interventions and through learning arising from clinical experience. Throughout the process the therapist listens to and respects the client's values, adapts the interventions to meet the client's needs and enables the client to make informed decisions.

In a review of the service process, Mary Law et al (1995) described evidence that, through respectful and supportive treatment, information exchange and practices enabling client-professional partnerships, client satisfaction is increased. An individualized flexible approach to occupational therapy intervention, where the client contributes to defining goals of intervention, has been shown to lead to improved occupational performance outcome and improved satisfaction.

2.4 OPTIMIZING STUDENTS LEARNING : STRATEGIES IN OCCUPATIONAL THERAPY EDUCATION

"Once the pupils come to you, their minds are only half formed, full of blank spaces and vague notions and oversimplification. You do not merely insert a lot of facts if you teach them properly. You take the living mind and mould it"
(Highet, 1947, p.10)

2.4.1 Current widely used teaching methods in occupational therapy:

"The incremental body of knowledge about how students learn has prompted a move within the higher education system itself to create educational environments that are more conducive to learning" (Savin-Baden, 1997a, p.447).

These developments have encouraged the implementation of methods that are more active and designed to help students derive meaning from their learning that will benefit their service delivery. Problem-based learning emerged in the 1960's owing to the perceived limitations of teacher-centered and subject-based learning (Reeves *et al*, 2004). Since then, moves towards adult-centered learning and interactive learning environments continue to place learners in a different relationship with knowledge and professional practice (*ibid*). Long-term advocates of problem-based learning stress that it is the only known method for preparing future health professionals to be able to adapt to change, to learn how to reason critically and to enable a holistic approach to learning. It is critical for attaining integrated, cumulative learning (Bruhn, 1999).

Savin-Baden (1997a) cites three reasons for using problem-based learning methods i.e. for developing reasoning skills; for defining skills in the context of 'own' experience; and for enabling skills of independent inquiry. It is suggested that problem-based learning has implicit within it the idea of reflection (*ibid*). This is because it appears to be an approach that requires students to use skills and life experience in their learning process.

Higget (1947) cites the example of a pathologist, Osler, who introduced the technique of teaching by using the 'patient as text'. "Instead of discussing an illness in theory, he explained it at the bedside of a man who was suffering from it" (p.215).

These methods have asserted that there are a number of advantages to learners, such as increasing the retention of information, developing an integrated knowledge base and increasing learner motivation in comparison to more traditional approaches. Evidence within OT is accumulating slowly, with indications that approaches such as problem-based-learning have improved clinical reasoning and the professional behavior of students (Stern, 1999, cited in Reeves, 2004).

2.4.2 The influence of teaching methods on performance of first year occupational therapy students

A study which investigated the factors influencing the occupational performance of poorly performing first year occupational therapy students at a South African university, highlighted teaching methods as one of six themes that was found to influence student performance (Ramukumba and Gravett, 2004). The researchers reported that students need to perceive the connection between their learning content and the profession for which they are training (*ibid*). If the content of the subject was perceived to be relevant, students tended to select deep approaches to learning and were more motivated to study. Students also felt that they learnt better and understood more during practical classes as opposed to theory classes. They reported that the practical classes provided opportunities to reflect on what they were doing instead of memorizing material. Recommendations from this study suggested the importance of creating an environment in which students are encouraged to ask questions. Reflection on learning, sharing from previous life experience, interactive discussions and support in learning, were all viewed as important for the construction of deep, personal understanding (*ibid*). If students' life experiences were drawn upon, they tended to feel welcomed and could make use of their existing knowledge and experience when constructing new personal knowledge. It was concluded that, by encouraging deep approaches to learning, students' performance would hopefully improve as they would feel more involved in their learning. It was recommended that educators strive to create a learning climate in which students do not feel anxious or threatened as this is more likely to lead to deeper learning (*ibid*).

University work is most often tasked with helping students to choose a deeper approach to learning, which is characterized by vigorous and critical interaction with the knowledge content, whilst surface approaches focus on information reproduction

and passive acceptance of information and memorization aimed at meeting assessment criteria. It is desirable that at university, students make sense of their learning and understand realities. Typically it is hoped that there will be integration of knowledge around the subject and ultimately an ability to apply the knowledge in new situations. Adopting deep approaches is acknowledged by educationalists to require time for reflection, thinking and the internalization of knowledge.

Norton refers to work by Marton and Saljo who in 1976 published an influential paper introducing the idea that when university students undertook an academic task, they could adopt either a learning approach focused on understanding (deep learning) or on reproducing of knowledge (surface learning). They believe student's study activity is the outcome of the interaction between the student and his/her environment (<http://www.ltsnpsy.york.ac.uk/LTSNPpsych/Specialist/Norton/Introduction.htm>).

According to Entwistle (1981, cited by Houldsworth and Hodgson):

“orientation and approach should not be viewed as fixed attributes of an individual, but as variable depending on context and situation. The assumption is that learning is not a thing – a concrete object, but an individual experience, influenced by the context which it occurs and the way the individual experiences and interprets the world”

2.4.3 A call for change in teaching strategies

There is an ongoing need for opportunities in experiential learning, for the promotion of constructive relationships, and for deep, effective student learning. This goes beyond the usual methods, in which simulation or role-playing exercises may be implemented. These so-called “quasi-disability exercises, are often viewed by students as interesting and amusing. French, however, suggests that evidence from literature indicates that this type of experience does little to develop awareness of the life experiences of a disabled person (1992, cited in Scullion, 1999). French

(1994, cited in Scullion, 1999) furthermore suggests that disabled people are dissatisfied with their contact with health professionals and their educational systems. Scullion (1999) urges that 'quasi-disability' exercises be used with extreme caution and not in isolation. It is suggested that professional education represents one key front on which to promote disability with dignity in partnership with disabled people.

Attempts to change teaching strategies need to be monitored to determine the benefits, costs and risks to those involved in the learning process. There is currently little evidence documented about the impact of teaching partnerships on either the students or those responsible for the teaching program.

2.4.4 The contribution of reflection to the development of clinical reasoning skills:

According to Alsop (2002, p.204):

"learning is likely to be aided by reflection, whether it emerges through reflection-on-action (Schon, 1983), experiential learning (Boud, 1983) or critical debate (Reynolds, 1998). Reflections may be thought of as the images of our experiences, revisited for the purpose of learning".

2.4.5 Modeling a Client- centered approach in teaching

Albert Einstein once said "*Setting an example is not the main means of influencing another, it is the only means*". (www.ntlf.com/html/lib/quotes.htm)

In research by Banks (1992), professionals described partnership as holding non-directive, non-authoritarian and collaborative attitudes. For them, partnership involved believing that people have a right to select and shape the

help they receive, being willing to let go of the expert role, valuing empowerment, and focusing on strength and ability.

Self-help group members, in the same study, described an ideal professional as one who respected their dignity, treated them as a colleague, valued their experiences and opinions, and consulted them on anything affecting their lives (*ibid*, 1992). Katz (1993, cited in Banks, 1992, p. 81) concluded that “a mutually respectful partnership with acceptance of legitimacy and uniqueness on both sides, seems the desirable way ahead”.

2.5 OCCUPATION AND WELLBEING

2.5.1 Teaching (through ‘lived experience’) as occupation

Occupation may be regarded as the unique medium of occupational therapy. The American Occupational Therapy Association published a Position Paper in 1995 in which they defined occupation as the “ordinary and familiar things that people do every day”, noting that this definition underplays the “multidimensional and complex nature of occupations” (*ibid*, p.1015).

In the present study, the ‘sharing of lived experience’ is seen as an ‘occupation-as-end’ i.e. referring to the complex activities and tasks that comprise the roles of an individual.

“Occupation – as – end ‘achieves its therapeutic effect from qualities of meaningfulness and purposefulness” (Trombly, 2002, p. 257).

Occupational therapists propose that occupation is a basis for health (Turner, 2002), and it is therefore important to look at what happens when occupational behaviour is underutilized as a result of disability. A state of occupational deprivation may exist when a person cannot undertake what is meaningful to him (*ibid*). There is evidence

that loss of occupation and role have a negative effect on a person's health and well-being. Boredom, frustration, monotony and a restricted lifestyle are reported to be the major feelings associated with loss of occupation (*ibid*).

Occupational therapists are committed to enabling people achieve satisfying occupational lives in several ways. Evidence from research is beginning to demonstrate the link between occupation and the maintenance and restoration of health.

"When roles and occupations are lost, not only is physical and psychological health affected. Peoples' daily lives are made up of routines and habits that reflect their roles and occupational needs, motivators and responsibilities. Habituation may be seen to hold together the ordinary fabric of our daily lives" (*ibid* p.37).

There is little written about the disabled person's experience of sharing 'lived experience' in a teaching partnership in a training facility. This sharing of the 'lived experience of disability', which the educator views as an 'occupation', needs further exploration in terms of the experience of the person who 'shares lived experience' for the purpose of student training. In serving to expand the person's occupational repertoire, the experience of sharing 'lived experience', may have potential to restore some of the loss experienced as a result of disruption to usual occupations.

2.5.2 Exploring the link between occupation and well-being:

The uniqueness of occupational therapy lies in its focus on occupation as central in promoting health and well-being (Wilcock, 1993). The OT profession, according to Wilcock (1998), has a unique understanding of occupation and the relationship between what people do and who they are as human beings. It was not until the early

between what people do and who they are as human beings. It was not until the early 20th century that the fundamental link between health and occupation in daily life was articulated. The active process of occupation is a basic human need since it enables human beings to develop as individuals and as members of society. (Wilcock, 1993, cited in Townsend, 1997). At its simplest, occupation is seen as an innate drive to fulfill the needs through which humans survive.

" Needs are seen as physiological phenomena that provide motivation and, as such, cause humans to be occupational by nature. Needs reward the use of capacities through providing the drive for the pursuit of satisfaction, fulfillment, belonging and pleasure. Needs are also seen as a means of preventing disorder through drives for exploration, thought, communication and understanding" (Turner, 2002, p. 27).

Townsend (1997) describes our potential, as active human agents, as lying in the variety of ways to occupy life. She believes that :

"if we release ourselves from viewing occupation merely as work, then we can consider the "contemplative, creative, pragmatic, utilitarian, enlightening, emancipatory, empowering or other transformative potential in occupation" (p. 19 -20).

Townsend proposes that the potential to transform ourselves and society comes through occupation. She surmises that the transformative potential in occupation lies in recognizing that occupation is an active process through which people both experience and organize power (*ibid*).

Occupational therapists strive to help people to transform their lives by facilitating talents and abilities not yet in full use through enabling them to 'do' and to 'be'. In so doing they become part of the process of 'becoming' (Wilcock, 1998c). To achieve well-being, individual people or communities need to be enabled towards what they

are best –suited and wishful to become (*ibid*). Wilcock (1998b) suggests that there is much still to be explored in understanding the relationship between occupation and health. Furthermore it is suggested that occupational therapists be prepared to test their beliefs in the power of “becoming” that they believe people gain through both “doing” and “being”. Whilst occupational therapists are often mindful of the development of human potential through occupation, documentation of this phenomenon is underreported and is often confined to therapeutic settings.

2.6 SUMMARY

The review of literature suggests that teaching strategies in occupational therapy should demonstrate the philosophy of occupational therapy through the way in which it is taught.

The occupational therapist is also concerned that any participant in a teaching program derives meaning and experiences well-being through the engagement in ‘occupations related to teaching. This concern is an understandable consequence of having an ‘occupational focus’ and believing that occupation can be health-promoting.

CHAPTER 3: METHOD OF INQUIRY

3.1 PROBLEM STATEMENT:

Little is documented in the literature about the use or effect of partnerships in occupational therapy training. Whilst it is possible that these approaches have been attempted before in various forms, the experience of participants in such learning programs is unclear.

3.2 PURPOSE OF THE STUDY:

- To contribute to understanding about the experience of partnership strategies in the training of students in the health professions.
- To contribute to the OT profession's understanding of the 'disabled expert's' experience of engagement (through partnership) in the occupation of teaching health profession students through the sharing of 'lived experience'
- To document the resource implications of implementing a partnership approach in teaching and the lessons learned from the process.
- To understand more clearly the benefits and risks to all participants in using a partnership approach in teaching.

3.3 RESEARCH AIM:

The aim of the study was to provide an in-depth understanding about the participants' experience of a teaching partnership between an OT educator and a 'disabled expert' in a first year occupational therapy lecture series on Personal Life Skills.

3.4 OBJECTIVES:

- To explore the experience of first year students during a partnership approach in teaching during a specific lecture series (PLS)
- To determine how the 'disabled expert' experienced engagement in the occupation of "sharing lived experience" during the lecture series
- To identify unanticipated consequences of a partnership approach to teaching on student learning
- To explore the educator perspective on sharing the teaching experience with a 'disabled expert'.
- To extract the lessons learned from the partnership experience for future teaching.

3.5 STUDY DESIGN

3.5.1 The Choice of Study design: Case Study

A case study design was selected using qualitative research methods. Stake (1995) describes case study as being the study of the particularity and complexity of a single 'bounded' case (p.47). Whereas some, such as Stake, consider the 'case' an object of study and others a methodology (Merriam, 1988) a case study is essentially an exploration of a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context. An intrinsic case study approach was selected to explore the 'uniqueness' of this case. A single program such as this lecture series represents a 'within-site study' (Creswell, 1998).

The design of this study was in the qualitative /interpretive tradition as I sought to describe recurring patterns of meaning and experience from the perspectives of participants in the lecture series. "Qualitative" methods allow the researcher to study selected issues in depth, openness and detail as they identify and attempt to understand the categories of information that emerge from the data. (Terre Blanche M & Durheim K, 2002). "Subjectivity is seen as essential to understanding" (Stake, 1995, p.47). Understanding' requires what is referred to by Stake as "thick descriptions' conveying to the reader 'particular perceptions of the actors" (1995, p.43).

Description of the specific context in which the research was undertaken, is regarded as a distinguishing feature of this method of research (Creswell, p.63). Stake (1995) calls for researchers using case study methodology to 'look at a sweep of contexts, temporal and spatial, historical, political, economic, cultural, social and personal"(p. 43) In this study, the 'context' refers to the physical and philosophical setting of the Division of Occupational Therapy at the University of Cape Town, Faculty of Health Sciences. The changing global context of the Disability Rights Movement and OT formed the macro context. The micro context was taken to mean the specific context for teaching and the contextual features relevant to the situation of the 'disabled expert', the students and the educator.

The study was exploratory in nature, offering investigation into a relatively under-researched and under-documented area of teaching. As such a more flexible design guided the implementation of the research process. The study was not positioned in

any particular 'theoretical camp' prior to data collection. However, after analysis, findings were interpreted in relation to existing literature and theoretical frameworks.

3.5.2 Other participative research methods considered:

In making decisions about methods, I considered the potential influence of the research process in this study of participation of both the 'disabled expert' and the students. Current trends in research involving disabled people, point to the desirability of liberation or empowerment of co-researchers (Stubbs, 1999). The nature of this study could have allowed a cooperative inquiry between the educator and the 'disabled expert'. A full co-operative inquiry was deemed not feasible within the constraints of this study, but I valued shared decision-making with the 'disabled expert' and sought to research the process in ways that were empowering. However, the methodology used in the study and ultimate control of decision-making about the extent of cooperation remained in my hands for practical reasons relating to constraints in time. This is therefore not congruent with co-operative inquiry which requires engagement of all participants in all decisions regarding the research process (Reason & Bradbury, 2001).

3.5.3 Extent of participation by 'disabled expert' in study

Participative research is possible in many different ways. Rowan (cited in Reason and Bradbury, 2001) describes pure quantitative empirical research at one end of the scale (where the educator is alienated and role-bound) whilst at the other end of the scale there is full involvement of all subjects in the research planning process, data collection and interpretation/ presentation of outcomes. In this study, I involved the 'disabled expert' in much of the thinking which evolved both before and during the

study. Impressions and findings from the study were discussed at intervals with the 'disabled expert', thus involving her at selected points of the cycle.

As the study evolved, it became clear that the 'disabled expert's voice was critical for articulating the meaning of the experience from her perspective. This is an opinion supported by Kitchin (2000). In response to this, I asked her to contribute to writing her perspective on the experience.

Whilst I managed data and the process of analysis, integration of the interpreted data was discussed with the 'disabled expert' during the writing-up process.

The standard research cycle with its unavoidable steps from evolving the research question to implementation and communication of findings are all stages for potential participation of the participants of the study. I made conscious decisions to involve the 'disabled expert' at different stages of the research cycle, but mostly during the planning and implementation phase.

3.6 RESEARCH PARADIGM:

One of the distinctive characteristics of qualitative research is its emphasis on interpretation (Stake, 1995).

I worked within an interpretive paradigm which allowed opportunity for understandings to emerge about the case and its unique context. I was aware that meanings were likely to be highly variable across contexts of human interaction, and did, therefore, not set out to make the findings generalisable. Instead I sought to produce a detailed and rich description of the particular context, with representative 'raw data' presented so that the reader could make decisions about transferability into a comparable context.

Interpretive methods are methods that try to describe and interpret people's feelings and experiences in human terms rather than through quantification and measurement. Researchers working in this tradition assume that people's subjective experiences are real and should be taken seriously. They assume that the experiences of others can be understood more clearly by interacting with them and listening to what is said. (Terre Blanche & Durrheim, 2002). I was also mindful that the level of immersion in the study as participant, as well as researcher, I would, by the end of the process, come to a position of offering a personal view.

3.7 GAINING ACCESS:

I had access to the setting as a result of regular ongoing teaching commitments within the Division of Occupational Therapy, where I have been lecturing since 1990. The role as researcher was negotiated with the Head of Division and with first year course coordinator. A proposal was submitted to the Ethics Committee, Faculty of Health Sciences, University of Cape Town, for approval before commencement of the course.

3.8 STUDY POPULATION:

The study population included all registered first year students in the Division of Occupational Therapy, Faculty of Health Sciences at the University of Cape Town during 2004. See Appendix B for details regarding the student profile. All students participated in the lecture series, consent for publication of their work was optional. Systematic sampling was used to collect reflective data from the students. Ten students were selected alphabetically to hand in reflections for review after each

session. (Katzenellenbogen *et al*, 2002). Each student had two opportunities to have their reflections reviewed by the educator. Once the reflections had been received, maximum variation sampling of the material was done to obtain the broadest range of information and perspectives on the subject. In selecting suitable participants, I looked for subjects who had different experiences or who appeared to think differently about the topic (Terre Blanche & Durrheim, 2002). Extracts that were considered to be Information-rich were used for further analysis. The study also involved the educator and the 'disabled expert' who collaborated in the teaching partnership for the Occupational Performance Personal Life Skills lecture series. The process used to select the 'disabled expert will be described further in the next section.

3.9 CHOICE OF LAUREN AS 'DISABLED EXPERT':

NOTE: From this point the 'disabled expert' will, for ease of reading, be referred to as 'Lauren'.

I first met Lauren whilst visiting the Disability Unit at the University of Cape Town six years ago. At the time Lauren was employed there, and we had struck up a conversation which was to lead to the development of a relationship that extended over a number of professional and personal fronts. I had been involved in the teaching of Personal Life Skills and recognized how much she could contribute to students' understanding about self care and the experience of disability. Lauren responded with enthusiasm to an invitation to speak on a once-off basis to students. She then returned each year to address the first year group. Student feedback was always very positive. Sporadic contact continued between us over the years and we began to speculate some months ago about extending her participation in the

program, using her 'lived experience' as a form of 'case study' throughout the lecture series.

Lauren as 'teacher':

Lauren's involvement in the lecture program was sought for a number of different reasons. Perhaps the most important reason was that, in spite of facing an uncertain future, Lauren continues to live a full and productive life with her family in her community despite the life-changing impact of Multiple Sclerosis (MS). Her involvement was also convenient as she lives close to the University, as well as to the educator. She had also had previous successful teaching contact with students in the Faculty of Health and Rehabilitation Sciences.

The fact that she had MS was relevant, as it is a condition that may affect an individual's physical, mental and social health and well-being. Lauren's self-care is affected in a number of important ways by this, which is of professional concern to occupational therapists. Most aspects of her care either require assistance or assistive equipment. She also has adopted many new ways of doing basic activities. It is not the condition per se that is important in this teaching situation, but rather the impact of the condition on Lauren's everyday occupations that provides the important focal point for teaching.

Continuous problem-solving and clinical reasoning are essential if an occupational therapist is to help someone like Lauren be able to live as independently as possible. Therapists must use a strong client-centered approach if intervention is to reflect the individual's values, beliefs, needs and priorities, respecting the person's choice as to when and if, he/ she accepts advice (Campion, 1996, cited in Tipping, 2002). Students need to learn how to implement this approach practically as they

about issues related to self-care. Being able to learn from Lauren was seen as an important starting point.

Lauren has access to regular support and information and remains connected with latest developments in MS through her access to the internet. She communicates with other people who have MS. She uses her gift of being able to communicate eloquently about her experience of living with, and managing life with MS.

She has demonstrated many of the qualities described by Hightet (1947) of a good teacher – including humor and good relationships with the audience. She delivers her message in an appealing and captivating manner.

An important reason for inviting Lauren to participate in the program was the evidence I had seen of her diverse coping strategies and adaptations that she has developed over the past two decades. Lauren's particular strengths, abilities and resources were identified as having enabled her adaptation. Much of what she has learnt over two decades is valuable to service providers. Perhaps even more important than this though, is Lauren's high level of conscious awareness of the kind of issues that concern the health professional. Perhaps most significant was the high level of motivation that she had expressed to expand her teaching opportunities.

Lauren seemed the perfect choice for 'disabled expert' to share her 'lived experience'.

Exposure to a 'real case' was regarded as having the potential to engage the student's attention in a deeper way and in so doing, facilitate integration of the complex factors that influence clinical decision-making in issues of self-care.

3.10 CLARIFICATION OF THE ROLE OF THE RESEARCHER IN THE STUDY:

“The case researcher plays many different roles and has options to how they will be played” (Stake, 1995, p. 91). The multi-faceted role of the researcher in this study included that of educator, student evaluator and facilitator. As such it is acknowledged that I consciously made decisions about how much emphasis to give each role. I made choices about responsibilities and how they would be fulfilled and monitored. The role of educator involved planning and delivering information, facilitating opportunities for learners to access information and most importantly, the prompting of ‘stories’ and the creation of conditions deemed necessary to facilitate learning. I was also responsible for student evaluation.

I participated fully in the teaching sessions in that I was ultimately responsible for the final outline, the structure and logistical aspects of the lecture series. In ensuring objectives were met, I invited the participation of Lauren as a form of ‘case example’ to give students opportunity to engage in realistic problem-solving exercises based on Lauren’s life experience. I involved Lauren in the planning stages of each lecture to ensure that she was prepared for the kind of issues that might arise and to ensure we could match content to objectives. We spoke about her experience and explored situations she would share. Some flexibility and spontaneity was allowed to enable use of any learning opportunities that arose during lectures. As educator, I assumed responsibility for the transmission of occupational therapy skills, knowledge and principles on a broader level, whilst giving autonomy to Lauren in areas of her ‘lived experience’ of disability.

Personal background as educator.

I acknowledge the influence of exposure to the debates of the Disability Rights Movement and to the specific culture of learning/ practice that exists in the Occupational Therapy Division at the University of Cape Town. (Refer to contextual information provided in section 4.1)

I have no personal experience of disability, but have worked with people with disabilities for some years. My clinical experience in occupational therapy has mostly involved working with people with chronic problems such as Lauren experiences. This has possibly influenced my teaching to some extent through the experience I am able to share. I consider myself to have a particular empathy and concern for people with chronic problems as a result of physical impairment because of my own clinical experience.

I am also aware that my previous teaching in the same lecture series (PLS) over the past 10 years has resulted in the accumulation of thoughts and impressions that may have influenced the interpretation of data.

3.11 STEPS TAKEN PRIOR TO COMMENCEMENT OF THE STUDY:

- Written consent was sought from participants, including all first year students participating and Lauren (refer Appendix C1 and C2). Students were informed about the planned project and about their role as participants. Lauren's level of involvement was negotiated with her and the Division of OT, as it involved an extension of her previous teaching commitments and was the first time that there was to be joint partnership carried through the entire lecture series. It also involved additional payment.

- A rough framework for the lecture series was designed to meet my identified objectives (guided by curriculum planners in the Division of Occupational Therapy).
- The lecture series design was reviewed with Lauren and refinements were made following joint 'brainstorming'. It was decided that we would have additional meetings between Lauren and myself prior to each session to recap objectives and issues to be raised during the session.
- The method of data collection and sampling was planned. Relevant literature was selected and reviewed.
- Students participating in the study were asked to complete a screening questionnaire (see Appendix D). This was done for the purpose of providing an overview of the student profile, so that student experience could be drawn on in class discussion. The profile of the students may have been relevant to the interpretation of data.
- The researcher designed an observation template to record happenings in each session (refer Appendix E).

3.12 DATA COLLECTION:

My intention in data collection was to explore as widely as possible the experiences of the participants during the lecture series. There was no intention to disturb the context in any way. I attempted to collect material in different ways and from diverse sources so as to understand the experience from multiple perspectives.

3.12.1 Observation:

Participant observation was done during both visits to Lauren and in all teaching sessions held. I interacted within the setting with participants as a complete “insider” throughout the course.

Videotapes were made of each session for thorough review by the educator after the session. I designed an observation template (see Appendix E) as a method of keeping a record of happenings in the field in a more structured way. Whilst viewing the video, I also asked myself the following questions and wrote reflective memos as suggested for discovery analysis (McMillan & Schumaker, 2001):

Did I learn anything new about my research topic today?

How can I best describe this to someone who was not here today?

What were my feelings and responses to the session today?

What were the major issues and concerns having completed the session?

Did anything unanticipated arise today?

Was anything not covered that needed to be included at a later stage?

Were objectives of the session met? Were there any issues to be

addressed in the next session as a result of identifying gaps in the teaching?

3.12.2 Student Reflections

After each session 10 students were asked to hand in their reflections of the session for review. These questions were based on those designed in the Occupational Therapy Division for other reflective exercises (refer to Appendix F).

Readers may wish to refer to the sampling strategy outlined in 3.8.

I decided to use this sampling method to ensure that each student had opportunity to have his/her voice heard. Issues of domination and marginalization in the group

setting may be problematic when researching experience that is shared by a group. The purpose of reflection was explained to the students. Students were encouraged to keep their reflections from each session for their own learning. Each student had two opportunities to have their reflections reviewed by the educator. Students were reminded to hand in reflections after the session but were not penalized for non-compliance. I clarified that whilst marks would not be awarded for reflections, comments would be made on student work as a form of feedback and to encourage dialogue between educator and student. Copies of the reflections were made for analysis. I informed students that Lauren would also have access to the reflections to permit some feedback for her. Reflections were gathered the week following each session.

3.12.3 Personal field notes:

Both descriptive and reflective notes were kept from the initiation of the study. They included ideas that evolved as I began to analyze the material. Much of the information noted stemmed from observation of Lauren and following informal conversation with her and her carers. Any moments of particular insight were noted. This was ongoing throughout the study period.

3.12.4. Review of Lauren's published/ unpublished books

Lauren has mentioned aspects of her teaching experience in her two published books. A brief review of her published books and a chapter from her most recent (as yet unpublished) book was done to add to my analysis any material pertaining to the occupation of 'sharing lived experience'.

3.13 TRUSTWORTHINESS AND RIGOR

The practices associated with trustworthiness traditionally include triangulation, member checking and reflexivity (Savin-Baden, 2002, p.191). Savin- Baden (2002) argues for what she refers to as “honesties”, a “more moral category which enables us to engage with the fragility and the instability of people and their contexts, their data and the management of their data.”(*ibid*, p.192).

In order to develop such ‘honesties’, various actions were taken. These included situating myself in relation to the data and to the participants, voicing my mistakes, and reviewing research that is used in interpretation in a critical way (*ibid*, p.192). I needed to engage with the study’s data in a way that engaged the multiplicity of truths and honesties that emerged from different participants. I needed to make the process open to scrutiny and to realize my role in the management and interpretation of the data(*ibid*).

Furthermore, for the research to be both credible and trustworthy, I needed to share explicitly how the study had evolved. When writing up the research, I clarified the ways in which meaning had been interpreted and the use of language needed to be accessible to all. Savin-Baden suggests that the” notion of ‘honesties’ helps us avoid the prejudice ‘for similarity’ and ‘against difference’ in data interpretation “(*ibid* p.191).

3.13.1 Reflexivity

I situated myself in relation to the participants. Subjectivity needed to be made explicit as the experience and background of the educator are important influences on the

research relationships, collection and analysis of data. How I experienced and understood the situation being studied was affected by my own history which was interwoven through former contact with that of Lauren. It was important for me to consider any assumptions about the potential impact of the experience prior to the commencement of the course, mainly because of my exposure to Lauren's 'once-off' sharing in the same lecture series in previous 1st year lecture series.

3.13.2 Triangulation

This was addressed through using different methods of data collection. Findings were viewed separately, then the findings were integrated to form a more complete picture of the experience for the different participants. Different strategies may yield different insights about the topic of interest and were assumed to increase the credibility of findings (Mc Millan & Schumacher, 2001).

Triangulation of data sources (searching for convergence of information) and data collection strategies maximized the probability that emergent associations were consistent with a variety of data. To find regularities in the data, I drew together different sources, situations and methods to see whether patterns emerged. In this way negative cases could also be detected (*ibid*).

3.13.3 Prolonged contact:

Strategies to increase credibility included prolonged contact with students through the course (which was taught over 6 months). This minimized the students' ability to exhibit contrived behaviors for the benefit of the educator (*ibid*).

The existence of a lengthy working relationship with Lauren prior to the study, suggests that there was already a measure of stability and consistency in the

relationship. Any inconsistency in her response would have been likely to be detected by me.

3.13.4 Member checking:

This was done with both the student group and Lauren so that I could present interpretations to them and clarify what I had ascribed to my analysis of 'their' perspectives. Member checking was done once the course was complete and after a preliminary analysis had been done. I presented my preliminary interpretation of data to the students as feedback during the annual course evaluation feedback session run by the first year coordinator.

Schwandt (1997, cited in Dickie, 2003, p. 54). suggests that :

"member checking is not profitably viewed as either validation or refutation, but is simply another way of generating data and insight"

3.13.5 Recording data:

Use of mechanically recorded data was valuable in ensuring the accuracy and detail of my recall of the teaching sessions. Raw data in the form of verbatim quotes, is deemed important in the presentation of the findings so that the reader could better understand the nature of the data.

3.13.6 Participant review :

I discussed my synthesis of student reflections and the interpretations I had made about their experience and the learning program with Lauren at intervals. I invited her to comment on the findings.

3.13.7 Transparency of process:

I sought to be explicit about the choices made during the research process.

3.14 STRENGTHS AND LIMITATIONS OF STUDY:

A particular strength of the study was my familiarity with the teaching environment and lecture series. A further advantage was a pre-existing relationship with Lauren through previous teaching experience together. I believe I had a good understanding of the nature of both her difficulties and assets.

The teaching situation was also not unfamiliar to her as she had done a number of 'once-off sessions' with students in previous years in the same lecture series.

A limitation was that I also participated in the course. As a result, my observation (in researcher role) during the session was compromised. I did not want intrusion from the video camera to stifle the students' contribution, so used observation of the students during the class without the benefit of being able to view their non-verbal responses after the session. There were many potential angles to the study that could have been selected instead. Likewise there were many other potential ways of collecting data. These may have yielded different findings.

Findings from case studies are not easily transferable. They can, however be generalized to some extent dependent on the accuracy of the description of the context and research process followed (Kelly, 2002).

I believe that in this study the reader can decide on the transferability of the findings into another context as a result of the contextual details provided.

My dual role as educator/researcher may have influenced the responses of the students in their reflections. As young students they could perhaps be influenced to

give the kind of responses that they thought that I expected. In this regard, I assured them that their responses would be likely to differ and that there was no correct or 'better' response. I also confirmed that no mark would be awarded for the reflections but that comments would be given. It was important that summative evaluation was done with independent criteria for marking. Students were told this. Reflections were not part of formal student evaluation.

3.15 ETHICAL AND LEGAL CONSIDERATIONS

Approval for this study was obtained from the Research Ethics Committee, Faculty of Health Sciences, University of Cape Town.

3.15.1 Consent

I explained the organization of the lecture series as a partnership between the educator and the 'disabled expert' and requested participation of the students in exploring the partnership approach. Students were aware that this was an untested method of teaching this lecture series. Written consent was sought for their work to be used in any publication. The educator made herself available to answer any questions arising. There was no attempt to coerce students into divulging personal information on the screening form or to make their work available for publication. However, explanations were given on repeated occasions about the purpose of the information. Consent was also sought from Lauren. Permission was sought from both Lauren and the students to videotape the teaching sessions.

(Refer to Appendix C1 and C2).

3.15.2 Anonymity and confidentiality

The anonymity of the 'disabled expert' was impossible to ensure, but the use of her name and any sensitive information was negotiated with her prior to any publication of data. There was no opposition to using her name in publication of material. Each of the student forms / documents was coded with a personal identification number. Only the educator had access to these codes. Students were given the assurance that participation in the study was voluntary and that they could withdraw from the study requirements (in terms of making their work available for use in analysis) at any time without risk to their performance evaluation. It was, however, made clear that it was compulsory for students to participate in course-related assignments and summative evaluations. No student names were published in the writing-up of the study. Only Lauren and I had access to individual student reflections. Whilst some aspects of these reflections were shared with the class, no names were ever linked with comments, issues or concerns raised. No extracts were read out in class. Students were urged repeatedly to keep personal information shared in the class by Lauren, confidential.

3.15.3 Competence

I have an honorary lectureship in the Occupational Therapy Division, UCT and have been responsible for the PLS lecture series for the past 10 years.

I have also recently completed the coursework from the Masters Program in Occupational Therapy at UCT (2004), and so am confident that my knowledge of international trends affecting occupational therapy is reasonably current.

3.15.4 Beneficence and non-maleficence

I assured the students that participation in the study would in no way affect their grades as assignments/ exams would be marked according to specific criteria independent of the study. Non-participating students were only identifiable by an assigned number on their reflection sheets. Attempts were made to reassure students about the usefulness of the study.

It should be acknowledged that I was concerned that the sharing of the 'lived experience' could possibly evoke unanticipated emotional responses from students, considering their age and relative lack of previous exposure to the 'disability issues' covered. I tried to pay particular attention to this possibility and to address issues as they arose, either through class discussion or through responses to reflections. Students were offered the opportunity to speak to me, Lauren or the class coordinator should they wish to address any issue on a personal level.

Likewise, Lauren shared information which rendered her personally vulnerable due to the depth of sharing/ and the public nature of the sharing. I tried to ensure that each situation was sensitively handled and followed-up through discussion with her after the session.

There was a risk that Lauren's health status would change during the study period. She was given the assurance that withdrawal from the course on the grounds of poor health would be possible at any stage of the process. Findings were reviewed with Lauren at intervals during the study. This was done to minimize the possibility of harm arising from any unexpected or negative findings. Careful attention was given to the rights of participants to have their identities protected. The educator took care not to publish errors or to manipulate data to establish a more desirable outcome.

It was clear from the beginning of the partnership that Lauren valued participation in the lecture series. An important ethical issue for me was the need to ensure that an 'open agenda' between all participants was upheld at all times. This was critical to prevent any tendency to clarify or discuss 'difficult issues' pertaining to the 'disabled expert' with students 'behind her back'. Students were reminded regularly of the commitment to openness and the need to handle any discomfort in a direct way. Opportunity was given to voice different opinions and both Lauren and I tried to sustain a non-judgmental attitude.

3.16 ANALYSIS OF RESEARCH DATA:

Stake (1995) suggests that there is often no clear point at which data collection ends and analysis begins. Initially there was more focus was on the accumulation of material, and as this faded out, the analysis gained in momentum. At an early stage I compiled a description of the profile of the student group and attempted to describe the context in which the teaching partnership occurred. Whilst it was not possible to describe every aspect of the case, an attempt was made to make sense of certain observations of the case by both watching the videotapes taken during the session as closely as possible and thinking deeply on what information was relevant. Sometimes significant meaning was found in a single instance, but mostly important meanings re-appeared.

In this study inductive analysis was done with the categories and patterns emerging from the data. There is much art and intuitive processing to the search for meaning and it is usually an untidy process (Stake, 1995). According to Stake (1995),

“analysis is a matter of giving meaning to first impressions and to final compilations. We take our impressions, our observations apart, giving meaning to the parts. Not beginning, middle and end, not those parts but the parts that are important to us. “(*ibid* p.71).

My ultimate intention was to consider the issues that would help decide the worth of this method as in occupational therapy education, and to extract the important lessons that were learned through the process.

“Two strategic ways that researchers reach new meanings about cases are through direct interpretation of the individual instance and through aggregation of instances until something can be said about them “(*ibid*).

During this research a combination of analysis and synthesis was used. Many questions drove my analysis as I began identifying emerging categories, patterns and themes in the data.

Terre Blanche and Durrheim (1999) suggest that a key principle of interpretive analysis is to stay close to the data, to interpret it from a position of ‘empathetic understanding’. It was necessary for me to move both towards, and then away from the material at times to ensure that what has become familiar for me did not lose its strangeness or its nuances. A delicate tension and balance was required to ensure that I stayed close enough to the context so that others familiar within the context would recognize it as true. However, at the same time I had to maintain enough distance to recognize new perspectives. Terre Blanche and Durrheim (1999) write about this tension as being an integral part of interpretive research. They suggest that looking back on an experience may be productive in the disclosure of new meaning.

Through the process of data collection, a detailed description of the case emerged. Analysis of themes or issues and an interpretation of assertions about the case by the educator enabled the final interpretive phase of the case study, in which the 'lessons learned from the case' were extracted and reported. This is a process described by Creswell (1998, p.63).

3.16.1 Steps in analysis

"Analysis and interpretation are the heart of the sense-making process" (Dickie, 2003, p. 56). I have used the process suggested by Dickie (2003) to describe how the data was analysed, to tell the story of the research process and how I came to the conclusions that were made.

I found the following steps helpful as a starting point in what was a rather untidy process of reflection, analysis and synthesis (Terre Blanche & Durrheim, 1999, p. 141).

3.16.1.1 Familiarization and immersion:

I read and re-read reflections by the students and notes recorded in my fieldwork journal. I watched videotapes on the sessions and brainstormed ideas about issues that came to mind as I did this. I completed the observation grid immediately following the session whilst I viewed the videotape. These were used for reference purpose during the analysis and for modifying teaching sessions.

In reading through some of the student reflections, I tried to gain some sense of the 'whole'. I did this to enable me to utilize student feedback and to address any gaps or issues as they arose. I took each data set (reflection) and marked out possible codes

as I asked myself the question “What is this about?” “What is important about this piece of data?” The notes recorded in personal field journals were important in capturing these preliminary ideas, which were retrieved at a later stage of analysis.

3.16.1.2 Inducing codes

During the coding process, I broke down the body of each student reflection into labeled meaningful pieces, with a view to clustering the bits of coded material together in broader categories. I coded phrases, sentences, ideas, identifying these textual bits by virtue of their containing material relating to the themes under consideration.

3.16.1.3. Forming Categories

The codes and categories changed and were merged to a point of redundancy. A comparison across categories was done to check for overlap. Central to the idea of pattern finding is the notion of repetition. The search for repeatable regularities is central to interpretive enquiry (Kelly, 2002).

I defined these categories of meaning to ensure that the information could be grouped accurately. Once final categories were established, I searched for broad themes emerging from the data which could explain the experience of the students as they participated in the sessions.

3.16.1.4. Elaboration

Exploring themes more closely is referred to as elaboration. The purpose is to capture the finer nuances of meaning not captured by the original and rather crude coding system (*ibid*). At this stage it was necessary to consider and re-consider the material

to be able to give a thorough account of what was going on from my material collected.

Questions were important in helping me to understand the data. Refer to Appendix G for a list of the type/ nature of questions that drove my analysis of the different perspectives.

3.16.1.5 Interpretation

The final step involved interpreting the data using themes as subheadings. I wrestled with the data at this point, needing to create some distance in order to get new clarity. The two major themes that emerged provided a means to explain the experience of the students. I then mulled over the interrelationship that seemed apparent between the two themes. An overarching theme emerged which helped me to explain the essence of the student experience. I created a schematic figure to draw together my findings. Finally I looked for any examples that might contradict the findings. I then synthesized the findings from all perspectives to get a picture of the 'whole' process.

At this stage I began to spend more time in serious reflection on how my personal involvement had colored the research. I asked myself how I might have influenced the structure and style of interactions, the student reflections, and how my decisions made had influenced the findings.

In this research I considered it important that I did not simply summarize the way that people already understood their experience. I saw it as important that I play out what Kelly (2002) referred to as the '*insider-outsider dialogue*' in my own mind as I tried to be true to those voices of the participants in the study, whilst at the same time answering my research question. I attempted to understand and interpret what I had heard from the participants.

3.16.2 Reaching conclusions:

Writing, collecting data, reading theoretical work, analyzing data happened more or less simultaneously. Findings are presented from the perspectives of all participants in the lecture series, namely the educator, the students, and 'disabled expert', Lauren. I have analysed data collected from the students in the form of reflections, and from field notes made from observations or informal discussions to derive these different perspectives. I have discussed my findings in relation to existing literature and theory.

Once findings from all the perspectives had been analysed, I then stepped back from the 'individual perspectives' to attempt to integrate the various perspectives together to create a picture of the 'total experience' and so that important lessons for teaching could be extracted from the experience.

3.16.3 Leaving a Research Trail

My intention was always to share with the readers enough contextual detail to allow them to imagine the situation as it was experienced. Dickie (2003, p.49) issues a 'plea for sharing the magic and the effort' of the data analysis process. I experimented with a number of schematic representations of my data as I tried to make sense of findings.

I wanted readers to understand the process of analysis I had used to discover patterns in the data. I referred to existing literature in education and health to help gain understanding about what had been found. The process of interpretation continued as I wrote until it finally reached a point where I felt that I had achieved a satisfactory sense of the essence of the experience of the participants from the data that I had collected. Kelly suggests this is the point at which the analysis reaches a

point of saturation (Kelly, 2002). I used questions by Comstock (1994) suggested by Kelly (2002 p. 435) during this final stage of drawing conclusions from my analysis. Ultimately, I attempted to present cautiously the lessons learned from the case study. It was not always a simple or orderly process. My hope was that my experience could enable others to learn from the case, an expressed intention of case study research (Creswell, 1998).

CHAPTER 4: CONTEXTUALISING THE STUDY

4.1 IDEOLOGICAL SETTING FROM WHICH THE EDUCATOR EMERGES:

The Personal Life Skills lecture series, which is the focus of this study, is part of the first year module in Occupational Performance within the Division of Occupational Therapy in the School of Health and Rehabilitation Sciences at UCT

The researcher acknowledges that the development of the lecture series has, in the past decade, been influenced by the prevailing ethos in the Division, as well as by the educational methods encouraged.

I referred to the Self Review Portfolio document (Van Niekerk & Duncan, 2004) to familiarize myself with the formal educational philosophy upheld by the Division. The document conveyed the philosophy of the Division - that knowledge is relative and provisional. Learning is understood to be social and interactive. It involves actively transforming knowledge and being transformed by it through exploration, action and reflection between educators, learners and learning systems, for example contexts, people and texts (*ibid*).

The work of the Division of Occupational Therapy has sought to deconstruct the previous dominant professional role in favor of partnerships with all clients. The curriculum has undergone a major transformation in the past fifteen years with educators adopting a renewed 'occupational focus'. Occupation is viewed as the occupational therapist's unique contribution to health and well-being.

The themes that are introduced into teaching in the first year curriculum include human occupation as "end", the human as "occupational being, and occupation as "means".

Students are introduced to learning through reflection and clinical reasoning to become critical thinkers.

Reflection is seen as important, not only to develop personally, but to ensure that the profession moves forward in such a way that results in best service for clients (Alsop, 2002)

As therapists have begun to challenge the “uncomfortable fit “of the medical model, it has become essential to engage with other frameworks of practice and research. (Roberts, 2002). This shaping of change is enabled to take place as long as reflection on current practice is prioritized by both therapists and students. Reflective practice has been used in undergraduate occupational therapy education in the Division of Occupational Therapy to trigger reflection-on-practice and reflection-on-teaching experiences.

In the UCT OT course there is also opportunity for students to spend time in service learning placements which are structured to assist students to help to integrate theory and practice. Two of the curriculum outcomes identified for the first year students are:

- 1) to appreciate the dimensions of occupational performance across the lifespan and
- 2) to recognize the importance of components of micro context as determinant of occupational behavior.

Didactic teaching and rote learning is kept to a minimum and a combination of teaching methods like problem-oriented learning groups, tutorials, self-study tasks and workshops are included. Reflective writing and critical appraisal opposed to rote reproduction of facts is highly valued as a means of introducing students to the

clinical reasoning process which is essential for practice as Occupational Therapists. (Van Niekerk and Duncan, 2004).

The Division has shifted in its focus somewhat from the medical model of disability towards a social model in which social and physical environments are viewed as contributing towards disability. However, there is an appreciation of the issues that are not resolved by social manipulation or action alone and which are individually experienced.

The educator acknowledges the influence of such thinking in the planning of a lecture series focusing on the 'lived experience' of a disabled person.

In PLS, Students are encouraged to develop their problem-solving capacity and knowledge base in order to develop competence as a resource person. Sensitivity and understanding is required, as well as practical support in decision-making. Of equal importance to problem-solving with the client, is the consideration of what the condition means to the person in terms of their particular life roles and developmental stage of their life, given the supports and constraints unique to them. During the teaching, students are given opportunity to participate through sharing accounts from personal experience of both difficulties and coping strategies. They are also demonstrated certain techniques (e.g. transferring, wheelchair use), introduced to assistive equipment/products and challenged to consider ways of changing the method of performance or aspects of an environment that may be constraining performance.

4.2 PERSONAL LIFE SKILLS : THE LECTURE SERIES

To the non-disabled person, many, if not all, of the activities of daily living are non-problematic; they are simply taken for granted, performed with hardly any awareness that they are being performed at all. This contrasts vividly with the experience of people who are disabled in some way. To them, some, and frequently all, activities of daily living are a problem and continually challenge energy, ingenuity and character (Locker, 1983).

Personal Life Skills (PLS) forms part of the learning module on Occupational Performance during the first year of study in occupational therapy at UCT.

It is a lecture series that focuses on these basic activities of daily living – the range of difficulties that may be experienced in different circumstances, and the broad possible strategies that an occupational therapist might implement to facilitate a person's day-to-day performance of these activities in his/her context. The nature of the problem varies from person to person and problem solving becomes an ongoing necessity until a routine that meets the client's needs and expectations can be implemented. Fore-planning and "thinking it out" are valued as the therapist and disabled person weigh up options and alternatives within the limitations of available resources. Attention to managing efficiently the mundane practical problems of everyday life releases time, energy and money for constructing a more satisfying existence based on access to social and other opportunities(*ibid*).

In PLS, students are introduced to basic self-care tasks such as feeding, dressing, toileting and hygiene and difficulties that arise as a result of health or other difficulties.

Access to the physical environment and access to transport form part of the broader problems contributing to mobility impairment and restricted use of community facilities. Communication (in its broadest sense) is also addressed in this lecture series, seen as important in the exercise of social and occupational choices. The expression of sexuality as it relates to disability and relationship is briefly explored. The ordinary activities related to the management of a home and family impose multiple challenges on both the disabled person and his/her family and are important concerns addressed by an occupational therapist in client intervention.

Previous methods of teaching Personal Life Skills have involved problem-solving related to "imaginary" cases or cases known to a student. It has also involved brief exposure to video footage of different people with disabilities and occasionally once-off exposure to sharing of "lived experience" by a person with a disability. This 'real-life' exposure has always been regarded by students as a highlight of their learning in this lecture series. The educator has previously used a combination of didactic teaching, video material and class discussion around student experience of people with disabilities to inform interactive class discussion. Readings that supplement learning have also been given. Students have been required to complete an assignment following a once-off contact with a person with a disability. Occasionally there has been opportunity given for simulation of disability e.g. attempting to master personal life skill tasks assuming one-handedness or visual impairment.

Refer to Appendix H for more detail about the content of the full lecture series.

4.3 LAUREN'S CONTEXT:

Lauren lives with her parents in their family home in Newlands. She belongs to a very close family, having two brothers, who despite living away from Cape Town, enjoy regular contact with her. She speaks about their families with special pride. Whilst she has not ever married, she did have a close companion for some years.

Lauren is from a Jewish background, which introduced cultural and religious issues into the lecture series, and provided opportunities for learning about diversity. This was valuable for student learning as the cultural environment can influence the way the individual deals with the challenges of increasing disability (Tipping, 2002).

Lauren has two helpers at home who come in a few days each week. They form an integral part of her life through the assistance they give her in her daily activities and the support they provide. Again, having had personal experience of 'helpers', this adds another dimension to sharing that was relevant.

Lauren has a very special and loyal companion, formally known as 'Professor Fred Huggins'. He is a service dog trained by the Guide Dog Association of South Africa and is inseparable as companion and helper to Lauren. Speaking about him in her book, she illustrates the special bond they enjoy:

"Of course he is far more than a sum of his uses. I have found multiple sclerosis to be exceedingly isolating. Fred just helps to make life better. Unconditional love served in abundance" (Singer, 2001, 37).

Lauren as person:

Of her proposed title 'disabled expert', Lauren's wrote in a local magazine about her involvement:

When I first heard that I immediately thought, "An expert? Brilliant! Forget disabled."
(Shape, July 2004, p.32).

This gives readers a small glimpse of Lauren's character – lighthearted, teasing and spirited. I also know Lauren to have a sharp intellect and a gift of communication. Lauren energizes others and is, at the same time energized by engaging with them.

Now in her early forties, Lauren has been living with Multiple Sclerosis (MS) from the age of 16 years. MS is the most common cause of neurological disability in young adults. Onset of the disease usually occurs between the ages of 20 and 40 years and tends to affect women more than men (Tipping, 2002).

According to the National Multiple Sclerosis Society (2004):

MS is a chronic, progressive neurological disorder which results in widespread damage to myelin, a protective sheath surrounding nerve fibers of the central nervous system. When myelin is damaged, this interferes with messages between the brain and other parts of the body. For some people, MS is characterized by periods of relapse and remission, whilst for others it has a progressive pattern. Managing symptoms is the key to living with the condition as currently there is no cure for the condition. Common symptoms include pain, deadening fatigue, problems with sight, mobility and coordination, incontinence, cognition and depression. (National Multiple Sclerosis Society, 2004)

MS is a permanent and degenerative condition, unpredictable in its course and requiring ongoing adaptation and increasing compensation and compromise to manage one's day to day functions. The nature of the condition is uncertain and may also result in cognitive and psychological manifestations. Life expectancy is not significantly reduced in people with MS, but due to MS's progressive nature, it nevertheless has a great impact on individuals throughout their lifespan (*ibid*).

Lauren has significant mobility problems which prevent her from walking more than a few meters with support; so much of her day is spent in her motorized scooter, which she fondly refers to as the "Stealth". Fatigue and poor mobility in her lower limbs are significant symptoms of her condition and she requires help from her parents and trained caregivers. Parasthesia and tremors often aggravate her mobility difficulties. Lauren is not able to use public transport easily and spends much time in her home environment as a result of this. She requires either her wheelchair or motorized scooter when going out. Her fatigue is a debilitating problem that affects all aspects of her being and doing.

Mundane activities that most people take for granted have become ongoing problems for Lauren as her physical abilities have dwindled.

Lauren has written widely about her experience of MS. She described in her book about MS, her feelings after diagnosis:

"And with that I felt I had immigrated to a new country. The signposts had all changed and the language was different" (Singer, 2001, p.4). Lauren describes MS as "a mischievous beast which is sometimes quiet then it taps me on the shoulder. I'm still here, it says. As if I could ever forget" (*ibid*, p.6).....

It can affect every aspect of one's life. The psychological effects of living with a chronic illness, which may get worse, or it may not, quickly or slowly, are immense. Each individual copes with it differently. Each individual has a different package to unwrap...MS is more than a challenge. It can fundamentally alter the way a person is able to grapple with the usual complexities of life. MS is an illness of chronic uncertainty and change, of unpredictable loss and adjustment. (ibid, p.7).

As a result of the progression of MS, Lauren was unable to pursue her post-graduate studies at university. Whilst for some years she led an active working life at the university, she was medically boarded some years ago. She is now self-employed doing private consulting and writing books. She keeps herself active in both her family and community and has numerous interests.

4.4 DESCRIPTION OF THE PHYSICAL AND INTERPERSONAL CONTEXT OF TEACHING

Contextual details were included because it was considered an important feature of the climate that was consciously created to both maximize learning and foster an atmosphere that would facilitate interaction.

The first session in which Lauren was introduced to the students took place in the comfortable living room of her family home in Newlands. It is a spacious room with a double door opening up onto a deck overlooking a tree-filled garden. The group had been split in half to accommodate the large number of students. I did not divulge any information to them about Lauren prior to the session. Both groups met in the same week, each for a 1 ½ hour session. I arrived early to ensure that all was ready for the first session. Fred, Lauren's service dog, a golden retriever, lay

sprawled on the carpet, seemingly unaware of the imminent student invasion. The busload of students was met at the door whilst Fred bounded out to add his welcome. Whilst some were delighted to see him, others seemed a little hesitant and some even a little unnerved as he weaved his way through them. Lauren waited on her scooter inside, putting the group at ease as she welcomed them in. Most students sat on the floor or perched on chairs and tables around the room as introductions were done by the researcher and the course outlined. Lauren sat in the front of the room. I introduced Lauren briefly and described the approach to the lecture series. The room remained quiet with all eyes on Lauren as she began to share. The subject of her condition – multiple sclerosis was not brought up initially. Students were asked to introduce themselves and Lauren shared a little about her family and working background. The students did not know quite what to expect and were very tentative initially, but her engaging and dramatic style of sharing kept the students riveted. It appeared initially that there was some reluctance from students to voice personal opinions. Fred was a great ice-breaker especially during this initial contact. Once Lauren had shared a little about her family and life, she began to tell them about her experience of MS.

Following the success of these two early visits to Lauren's home, I had some concern that the environment of intimacy created at home would not be able to be matched by the more formal teaching venue. It was an unnecessary concern as by then the students' interest had already been harnessed. They seemed relaxed, and engaged spontaneously with us both as they entered the venue. These remaining sessions were held in a regular teaching venue in the School of Rehabilitation and Health Sciences, a large, rather 'clinical' venue which is familiar to the students. It seats close to 70 students in a formal arrangement with lecturing staff in the front

facing the students, who sit in rows. Although seating is not fixed, it was difficult to re-arrange a large class in a less formal way. The venue was accessible for Laurens' mobility equipment. Lauren came to the class in either her motorized scooter or in her wheelchair and spoke to the students from the front of the class with myself alongside her, often sitting on one of the front desks to encourage less formal interaction. We chatted in a relaxed fashion to students as they entered the venue. In so doing, an inviting and relaxed ambience was created. Fred joined the class on a number of occasions, causing quite a stir and much hilarity when he helped himself to some unsuspecting student's lunch.

Whilst the lesson plan did have a basic structure, an attempt was made not to stifle the flow of discussions by insisting on keeping too rigidly to the schedule. I usually introduced the session with some overall framing of the intended content and would then invite Lauren to join in the session to share her related 'lived experience' at points throughout the session. There was regular interaction between us throughout the session. Students were invited to comment or share their experience and they were challenged to reflect on issues as the session progressed. The atmosphere, whilst still having some elements of a more formal teaching environment, allowed students the freedom to engage with either Lauren or I at any point in the class. As may have been anticipated in such a situation, certain students participated freely, offering their contributions with confidence, whilst others listened intently, but were more reserved or tentative in their interactions. The classes were generally very well attended and students were for the most part attentive.

The sessions ran for an hour and a half, with students given a short break midway through the lecture. This was also important for Lauren who has severe energy

limitations as a result of her condition. At times some flexibility was required to ensure that Lauren did not become too fatigued as her speech tends to become slightly slurred when tired. I assumed a coordinating role, prompting sharing around particular issues and ensuring that the discussions kept on track to meet the objectives of the session. As issues around disability are very diverse, it was sometimes necessary to draw the conversation back to the topic at hand. Clarification from an occupational therapy perspective was done by me. Lauren and I both broadened the discussion to include some possibilities/ alternatives for clients with other conditions/ from other contexts. References for resources were often given – either of suitable literature or websites related to the course information. Local equipment and service providers were named.

4.5 STUDENT PROFILE:

Sixty-two students were eligible for participation in the study.. It was apparent that, although this was a young and fairly homogenous group i.e. mostly female school-leavers from an urban environment, most of the students had been exposed to people with disabilities, albeit in very different contexts. It was noted that, whilst the range of exposure to disability was broad in the class as a whole, individual experience of disability was highly variable and their concepts about the scope of occupational therapy was somewhat limited. It was evident that students needed to be encouraged to share experiences in order for each to gain maximally from the teaching. (Refer Appendix B for a more detailed profile of the student group).

CHAPTER 5: FINDINGS AND REFLECTION ON FINDINGS: THE STUDENTS' PERSPECTIVE ON THE EXPERIENCE OF THE TEACHING PARTNERSHIP

5.1 Overview: Through their reflections, students revealed many thoughts, feelings and insights about their experience. Two major themes and an overarching theme emerged from the data analysed.

WRESTLING WITH SELF AND 'OTHER'

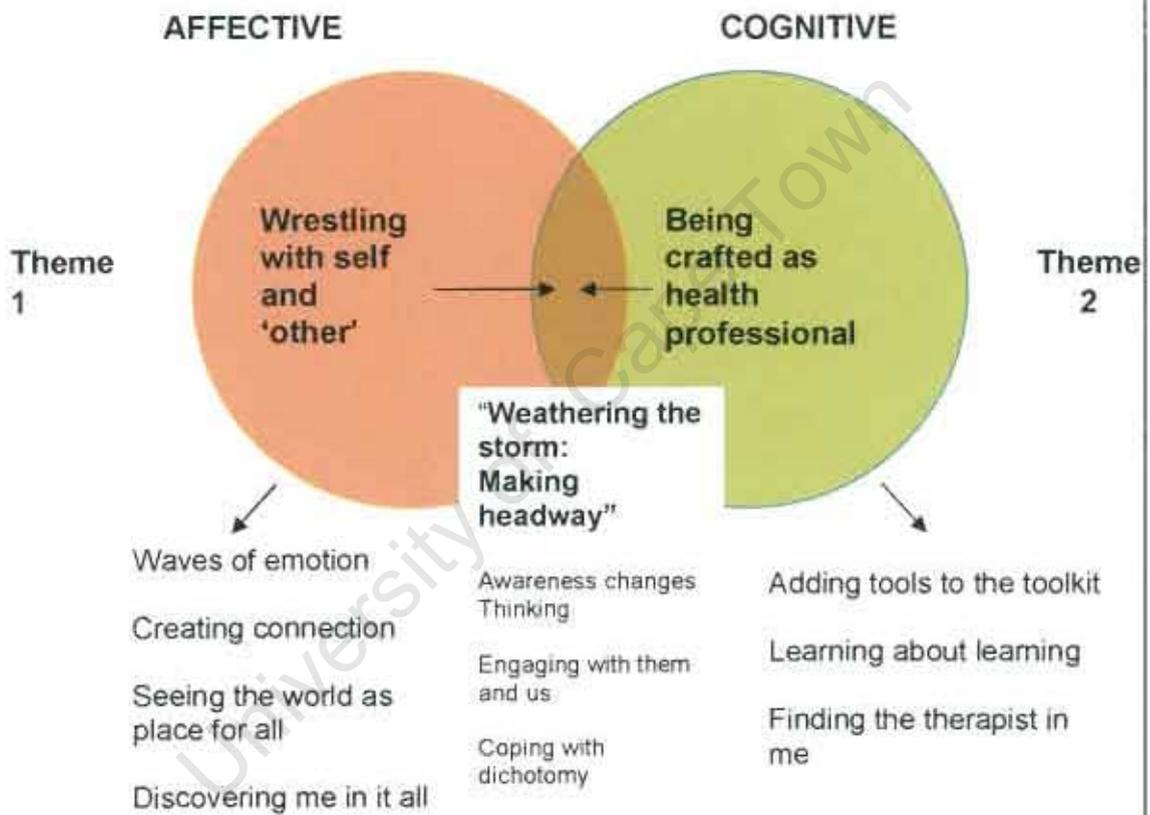
BEING CRAFTED INTO HEALTH PROFESSIONAL

Figure 1 overleaf illustrates the two major themes emerging from the study. The first theme embodies the concept of 'wrestling with self' and 'other' as students were exposed to new ideas, emotions and debates, which they then had to 'wrestle with' to understand what it meant for them.

The second theme explores the 'crafting' of an occupational therapy identity, that came into being through exposure to 'lived experience'. These two themes, whilst distinctive in important ways, are also interconnected. This will be explained in my reflection on the findings.

The overarching theme (weathering the storm; making headway) was identified as the two themes were considered alongside one another, the first having a strongly affective overlay and the second more of a cognitive overlay. It must be said that this was a broad overlay and not entirely distinct to each theme. It does, however, illustrate the strong emotional content that is inherent in the learning process. The intersection between the themes represented a 'space' in which students experienced some level of discomfort and a need to make 'shifts' in thinking.

FIGURE 1: ANALYSIS OF STUDENT PERSPECTIVE



5.2 THEME 1: WRESTLING WITH SELF AND “OTHER”

“my eyes have been really opened this year, I have never really considered what having a disability really entails until now”

‘Wrestling’ emerged as a theme as I considered the strong affective content flowing through student reflections in response to Lauren’s sharing. In making connection with her, and identifying with her experiences, many began seeing the world as a place for all and were personally challenged as they began to discover themselves in this new world. Wrestling involves a process of struggling with a difficult problem. Implied in ‘wrestling’ is the act of confronting, ‘grappling with’, ‘coping with’, and applying oneself to the task at hand. During this process of ‘wrestling’, students needed to reconcile many conflicting images, thoughts and feelings as they began expressing a personal response to this challenge from ‘beyond self’. They began to think about their place in this ‘new world’ that was manifesting itself to them. The categories that contributed to this theme will now be considered and the process of ‘wrestling’ illustrated with raw data from student reflections.

5.2.1 Waves of emotion

“I felt very moved and I got quite emotional at times when I heard Lauren speaking about her situation and the difficulties that she has to face in her day to day life”

Emotional content seemed to wash through the student reflections. The metaphor of waves seemed fitting as emotions fluctuated from emotional ‘crests’ to emotional

'troughs' as students sought to process and respond to their experience of Lauren's sharing. These emotional responses were often coupled with projective identification. An emotion may be defined as an instinctive feeling as distinguished from reasoning. It suggests instinct, intuition and 'gut feeling', the experience of sentiment from the heart.

Sympathy.

Sympathy was a dominant emotion expressed during the earlier stages of the lecture series as students were confronted with the realities of Lauren's life situation.

However, as the students' became more conscious of the robustness of her personal coping strategies and attributes, this emotional response was less often manifested:

"Initially I was aware of having to contain strong feelings of sympathy for Lauren. This was especially true when Lauren spoke of the fact that there was nothing worse than not being able to toilet herself. Also the fact that Lauren has not been able to have children evoked pity from me."

Uncertainty:

"I felt a bit unsure of how to relate to her as I cannot begin to understand what she has been through as I have never been through it myself. I'm hoping as time goes by that I'll be able to put aside my fears and insecurities and try to focus on understanding the situation and the person rather than relating it to my own situation"

Feeling overwhelmed:

"when I see and hear about just a small amount of the difficulties that Lauren faces each day, I become overwhelmed with the thoughts of what difficulties disabled people in poor or disadvantaged communities are facing"

Fear:

Fear was expressed in response to students asking 'what if it were me?' How would I be able to cope.

"The thought scares me (of not being able to communicate).

Communication is key in my life. I can't take my ability to communicate for granted. I must help those who can't."

Discomfort:

Self-care, by its very nature, involves occupations that are private and are most often shared within more intimate or 'caring-for' contexts. It was evident that some aspects that Lauren shared generated feelings of discomfort, shock and perhaps even repulsion in some of the students who may not have explored these kind of issues so frankly before.

"Another issue that really evoked strong feelings for me is incontinence. Lauren spoke about a particular incident when her incontinence pad leaked and she wet herself. She said it was the most 'revolting' feeling, but her mindset had to change into thinking it's really not so bad".

Some students reflected on how they might respond if they were confronted with this problem when working with a client.

"I didn't think I'd feel very comfortable if someone urinated while I was working with them. It will be difficult for me to be natural if an incident like that takes place".

This student struggled with the level of Lauren's disclosure:

"What made me feel slightly uncomfortable was that she shared many personal intimate details in our class, it made me feel really uncomfortable for her."

Distress:

Evidence of distress filtered through reflections following some of the sessions:

"I almost cried when I saw (referring to the video of a program made about Lauren for TV some years back) how well Lauren used to walk and move around and to see how MS has affected her".

Another student wrote of the same video:

"I can't imagine how shattering the memory must be for her"

Having to confront practices that were 'culturally foreign' precipitated further emotional response.

"I have grown up in a loving family and am comfortable hugging both my guy friends and girlfriends and family etc. I couldn't see it any other way. So what Lauren said about not being able to touch boys/guys/ men horrified me"

Whilst these may be described as more negative or unfavorable emotions, they were countered by more optimistic and positive emotional responses to Lauren's humor, warmth, and spiritedness e.g.

"I also felt very hopeful that someone who is physically less fortunate than myself can be so at peace with herself"

"I now see that I have a lot to offer people in order to help them find the best quality of life"

5.2.2 Creating connection

The second category within this theme refers to the sense of 'being connected' in relationship with Lauren as the students began to learn more about her life and share something of their lives with her.

This student captured sensitively the essence of a therapist's connection with a client:

"I almost felt honored that Lauren was willing to be so open with all of us, this must have been and must still be a very difficult thing to deal with and must make you feel helpless when you start to lose your grip on something so intimate and personal (referring to hygiene). It made me realize as an occupational therapist how intimate our profession may actually become with our clients."

This student showed evidence in her reflection that she was forming a connection with Lauren through identifying with the situation described:

"in many ways I can empathize or even sympathize with Lauren, as I have struggled with a degree of incontinence since I can remember...I know how hard it can be to cope with the embarrassment and how stressful it can be..."

As students listened to Lauren's stories, some began to be 'drawn into' or to identify with her experience. As they did this, they drew closer to her and she to them. They began to imagine what she must be experiencing, to ask questions, to take on challenges, to measure their personal experience alongside hers, to offer opinions and to engage with her stories, whilst sharing their own. The world of Lauren became more merged with the world of the students as the 'connectedness' strengthened. Connection implies a link or relationship evolving between people. It implies a bond or a form of interdependence. To 'identify with' someone means "an understanding of, or a 'feeling the same as someone else' It suggests a sense of oneness, interchangeability or closeness, which is related to connection.

5.2.3 Seeing the world as a place for all

"Listening to Lauren made me more aware that people with disabilities are regular human beings"

Debates about possible responses to the challenge of disability brought a realization of the demands it would impose on personal resources, and precipitated the need to view the world in a fresh, new way.

"It really stuck when Lauren said it is not only her that has MS, so do her family and friends"

Sharing opened up debate and the option of reckoning with problems from multiple perspectives. For most it was a stimulating and very 'individual' experience. For some it exposed memory from past experience, this amplifying their responses to learning. Some students began to appreciate how disability itself could transform a person's life. They began to wrestle with how they might respond to the same challenges if in a similar position. Students were encouraged to probe their innermost beings as they contemplated the experience of being part of this new and very different world. How might they one day respond as therapist to people whose lives were so fundamentally changed? At the same time, how different were these 'others' really?

5.2.4 Discovering 'me' in it all

"I could just blame the media, the fashion mags, the top models, but in the end it is just about me accepting who I am and being satisfied with what I have to give (this is a journey not only disabled people have to take.)"

Identification with Lauren's difficulties gave students the impetus to discover parallels in their own situations.

"listening to her talk, I wondered how I would react if I found out that I had a disability. I never really thought much about independence I have in things like going to the toilet or walking around the house."

They reflected on their healthy and privileged status, many wrestled with values, priorities, issues of culture, life goals and aspirations. By doing this, students were stretched as questions of identity and of selfhood, personality, character, distinctiveness and uniqueness came surging to the fore. Students spoke about themselves in a number of ways.

The depth of responses evoked in this quote is clearly evident:

"I was deeply moved by her incredible story and experiences with Owen (partner). I think every girl in the world has dreams for somebody like him that will love you and all of you...."

This student began to identify her values, see her emerging personal place in the therapeutic process.

"I think communication is the key, knowing what the client's feelings and needs are, not letting your own views of independence take over".

"She really made me question myself in terms of my life, goals and aspirations. I thought about how I always moan about my life and disappointments and fail to see the good in it, and at times forget how blessed I am."

5.3 THEME 2: BEING CRAFTED AS 'HEALTH PROFESSIONAL'

“the knowledge I gained from today’s session will definitely help me on my path to becoming an occupational therapist...”

Becoming a health professional is inextricably linked to what I view as a process of being 'crafted'. Being 'crafted' has connotations of being hand-shaped in a painstaking and creative process. It implies molding together the values, capacity, skills, talents, dexterity and spirituality of students ; in essence it reflects the emerging and shaping of student as both reflective learner and competent health professional. There is a link apparent between 'being crafted' and 'becoming'. There are strong cognitive elements underlying this theme, as opposed to the affective elements underlying the first major theme.

“the whole time the assistive devices were being explained, my thoughts were on my grandmother who is going in for a knee operation. I was gathering information that I could pass on to my grandmother”

The categories contributing to this theme included the skills and attitudes that students identified as being important to their preparation for being a practitioner.

5.3.1 Adding tools to the toolkit

“this helped me to realize that each individual suffers from unique difficulties and it is therefore important to build a good relationship so that he/she feels comfortable to share all the things which are affected by the disability or

impairment, and then as OT, it is essential that you look at all the possible ways which you could change, adapt the environment or setting in order to minimize the difficulties”

Personal Life Skills is a lecture series intended to build theoretical knowledge and understanding and to impart basic practical ‘know-how’ related to self-care. It requires comprehension of the values that underpin concepts such as independence. It is expected that, through the lecture series, learning will be such that students will be able to begin acquiring the tools for working with clients in different contexts. Certain attitudes are also instilled during this process. It is anticipated that students begin to learn both how to ‘do’ and how to ‘be’ in an occupational therapy setting.

In their reflections, students confirmed the relevance of their learning to their becoming therapists. The experience gave them new appreciation of the power of the client’s voice in the interaction with therapist, they began to grasp something of the nature of the therapeutic relationship and the importance of effective communication. They learned about the reality of risk/ safety issues in client’s lives and about the modifications that could be made to the environment. . The experience was perceived to be a powerful learning space, where students learnt not only about many resources, but they also received tips useful in caring/ problem-solving, they learned that there is not only one way to do something, and that the OT can draw on many others to support therapeutic goals.

The following shows some of this learning that was experienced by the students:

We should ask our clients about their priorities:

"I learnt that as therapists we shouldn't always assume that we know what to do to help others, but we should ask our clients. I really think this will be useful later, especially as a student as we rarely have the right answers"

We should resist losing hope:

"...and even if you think a patient may have no chance of progress, you should never squash self-motivation or optimism because there is always potential for change and change doesn't have to be recovery, but rather a better quality of life."

There is much that can be done to improve a situation:

"Seeing the adaptations that were made to Lauren's house made me aware that there are a lot of things that can help someone who is disabled to normalize their environment"

There is not only one way to solve a problem:

"Just because they say "this is the way to take a bath, it isn't necessarily the only way to take a bath"

Safety issues are an important consideration in therapy

"another thing that really stuck out for me was the issue of safety for a disabled person e.g. when going to an auto bank, and the difficulties associated with concentrating as well as seeing if there are any dangers lurking, or how to get help in an emergency"

Assistive devices require careful consideration of the person's resources and abilities:

"It (Dragon Dictate computer software program) is very expensive and therefore not available to all. It must also require somewhat of an art to function fully and therefore could not be used by a disabled person with lower cognitive function".

The work of the OT is multi-faceted, but there are others to support his/her work:

"I can see how OTs try to battle the workload on their own and don't stop to think that someone else may be better able to do whatever you do. This point challenged me because from experience at school I found myself taking too heavy a load.."

Learning had psychological dimensions and was related to coping and adaptation.

Students learnt from considering the personal resources that Lauren uses e.g. the concept of denial, a defence-mechanism which Lauren described that she often used to help her to cope:

"it was interesting talking to Lauren about denial and how it plays a huge role in all of our lives and not just when you're faced with what she is"

This understanding of the association between attributes and coping strategies also contributes indirectly to professional competence.

"I certainly did not expect to find such a pleasant, strong-willed woman with an unfaltering optimism. I found her attitude towards her disability realistically optimistic in that she knows her limitations, and strengths and works with them in a positive way to ensure a fulfilling life"

Students formed powerful images of Lauren through the way she shared her 'lived experience' with them. Whilst acknowledging that her life had changed and that she still had some real difficulties, she was able to impart how she applied her personal resourcefulness to manage her difficulties.

This student's comment captures the essence of Lauren as the students experienced her in their learning:

"MS is part of her but it doesn't define her".

"The video of Carte Blanche (TV program) that was shown to us, really gave me a wakeup call on how Lauren's condition has deteriorated over the years. This frightened me a great deal, however once the video had been switched off and Lauren began speaking, my entire thought process and emotions did a round about turn. Lauren was not feeling sorry for herself nor was she going to let her deterioration get her down, she was going to continue to hold her head up high and continue with leading her life in a way that makes her happy"

Practical skills, which are part of self-care, are dependent on practice and repetition which naturally require more time. Whilst some techniques were demonstrated, there were not opportunities for skill to be developed or refined in any way. The lecture series was more about 'becoming' through 'seeing', 'listening' and 'mulling over', rather than actually 'doing'.

5.3.2 Learning about learning:

Becoming a learner is part of becoming a professional. Understanding about ones' personal experience of learning is a first step in becoming a lifelong learner. One of the questions asked in the reflection guide (see Appendix F) suggested students evaluate the teaching strategy used in the lecture series. Through doing this, students also reflected, albeit less consciously or directly, on their own learning process and style. Students wrote about what they enjoyed in the process, what helped them to learn better and contrasted this method of learning with more familiar methods

experienced. They challenged the weakness and limitation they perceived in traditional didactic learning approaches.

They reflected on important dimensions of their preparation to 'become' a health professional. The following quotes demonstrate some of the student growth as they began to identify how they were learning from their experience.

'learning through reflection'

"another quote I found interesting was that 'you don't learn from experience, but from reflection on experience. This gave writing this journal more meaning and purpose."

'Actually seeing' and 'experiencing' and 'hearing from' makes learning come alive

"I think that this has been one of the most interesting and beneficial lectures throughout our whole course so far. Having Lauren, a person experiencing the challenges that we are taught about, teach us is a very effective way to learn. For the first time I can see practically how OTs get involved in someone's life"

"a key moment was when Lauren was talking and had to stop because she was too tired and couldn't find the words needed. She spoke of it happening but I recognized how real the problem was when it actually happened. There is so much value in Lauren being in our classes – the problems she faces are not just theory. They become real when we sit and hear her talk about them."

Learning is a lifelong process

“once again I learnt that our learning never stops. We always have to read new things and search for new treatments..”

Not needing to know it all“

“Today Lauren revealed that having a disability also has unpredictable moments just as all people have those moments, of not knowing what to do in a particular situation. This made me realize that as humans we all cannot do everything expected of us, just as disabled people can't do activities which their disabilities deprive them of.

Absorbing what needs to be learned to become a professional

Lauren's ability to deal openly, comfortably and honestly with some very personal issues drew much comment from students. It showed them the importance of needing to build skills in coping with the personal intimacy demanded in dealing with issues of self-care. For Lauren it is an important enabler that helps her to get the assistance and access to the resources that she needs.

“Lauren is really open and allows us to get an insight into her feelings and thoughts about the disability”

Lauren's gift in communication were also identified as key by many students to her coping skills. The relationship between recognizing the need to develop good communication skills and the ability to both give and receive quality care and service was evident.

5.3.3. Finding the therapist in me

Throughout the sessions, students had the opportunity to think about themselves in their future role as therapist. As they reflected on how they might one day think and act in this role, they began to visualize themselves as therapist:

“all the assistive devices we were shown will be helpful to remember when we work with clients. Another thing to remember is to be stage-appropriate – only tell them what they need and are able to hear at a particular stage of their disability”

5.4 OVERARCHING THEME: WEATHERING THE STORM; MAKING HEADWAY

The overarching theme was identified as I considered the two themes emerging and the relationship between them during the students' experience. There were two opposing dimensions to this overarching theme, one which concerned the dark, somewhat traumatic and potentially disempowering experience and the second which was a move towards feeling more positive, enlightened and hopeful about being able to respond to the heavier side of the experience.

This quote reflects on some of the 'darker', more difficult aspects of the learning experience:

“I think we could do an entire course on the matter and still not know enough”

This student captures a 'lighter' side to the experience through the following revelation:

“Listening to Lauren also made me more aware that people with disabilities are regular human beings. They have their own lives that they are trying to get on with despite their disability and they are no different from anyone else....when you hear it firsthand you find that suddenly you become more aware of it”

As students wrestled with the affective response to what they had been hearing and seeing (theme 1), and as they simultaneously sought to make sense cognitively of their learning (theme 2), it became apparent to me that students were engaging with different forms of 'disjunction'. In essence they had been catapulted from their zone of comfort into a space (represented by the intersection of the 2 circles in figure 1), which challenged them to feel and think on deeper levels. In some sense this represented a storm raging around them. It was an uncomfortable place to be and some students began to look for a way through this discomfort into a place where they might glimpse the light.

"...because my entire perception of mobility helping devices and people that are in need of them has changed. Before hand I felt sympathy for these specific people....I now feel more capable of talking to people with disabilities in a manner that I would speak to any other person, I now feel empathy instead of thinking 'shame, that poor lady is in a wheelchair, she must have a difficult life.'"

'Making headway'

In contrast to this, as the teaching experience progressed, student writing started to reflect the essence of 'making headway'. Reflections were characterized by more hopeful statements, suggesting that students have moved forwards to a position of greater understanding, that they had grasped some key elements of sound practice and felt they could do this after all.

"Each client is so different and unique. I think it is a huge challenge to treat clients but I think that's why OT appeals to me. I am looking forward to one day

treating a patient and seeing the results that they are improving. I think the satisfaction you must get is indescribable. I am also looking forward to building a relationship with my clients and having them help me while I help them."

Three categories emerged from the two contrasting dimensions of this overarching theme. Each will be described with verbatim quotes to substantiate them.

5.4.1 Awareness changes thinking

As students wrestled with gains in knowledge and understandings, some became more consciously aware of how limited their exposure to disability and its related issues had previously been and how much stereotyping characterized their thinking about disability. They began to identify ways in which they were changing as a result of this increased awareness. The student reflections suggest that they enjoyed a process of 'being informed', 'enlightened', 'becoming familiar with', 'mindful of', and 'alert to' the stimuli arising from their experience.

This growing awareness through the development of new knowledge and insights challenged some of the students' deeper assumptions about disability and the stereotyped ideas they held. This student reflected on her stereotyped thinking :

" I usually thought that people like this go to special schools then to varsity, afterwards graduate but I'd never heard of them doing so much with their lives. I never knew they would long so much for their own families, doing what other families do – like seeing your child's first steps, taking them to school, having a husband..."

In this space that had facilitated learning opportunity, students could re-think their view of the relationship between the person and the experience of their disability.

They could forge new links between the 'who they are' (as client) with the 'what they do' and 'what they wish to become' and then explore this in relation to the 'so, how do I get there' and 'how do we come into it'. 'Thinking through' was central to the process.

Students saw that MS was not Lauren's whole life. They saw the many important aspects in the environment that influence her choices and her quality of life. As one student so aptly shared:

"Key moments in the lecture were moments such as those when we got to learn about Lauren when she wasn't disabled"

Some of the increased awareness came with the exposure to new knowledge

"These are all problems I would associate with a baby. I never realized that the action of eating could wear a person out."

Awareness of the limitations of 'playing disabled for a day' stimulated serious reflection as for many students, this had been their only form of experience of disability personally.

"I also realized from this that when you have a disability – it is with you every day, all the time. I think as an able-bodied person it is almost impossible to imagine this even when pretending to be disabled; it is never the same"

Growth in awareness emerged in response to questions or challenges posed during the sessions dealing with issues such as sexuality and incontinence:

"The truth is that sexuality is almost more important to a person with a disability than a person without. Sexuality is so important for identity and esteem. It is a part of belonging... just because you're in a wheelchair your sexuality doesn't stop"

This growth in awareness is fundamental to the development of attitude, which is an important part of training that runs parallel to knowledge and skills development.

With the exposure to 'lived experience', students were challenged to transform their attitudes towards 'other' and to begin to grapple with the wide-ranging inconsistencies and uncertainties that confronted them. This process, in turn, awakened students to greater self-discovery and exploration of their emerging professional identity.

5.4.2 Engaging with 'them' and 'us':

As students came to know more about Lauren, the realization of 'sameness' became clearer as they compared Lauren's life issues, values and attributes with their own. In doing this, they were able again, to develop a stronger sense of their own identity.

This is in part illustrated by the following quote:

" Meeting with Lauren is breaking down so many of my mindsets (which I hadn't even realized I had) and teaching me so much about human nature in general and about people with disabilities, and that is what they are, people with the same desires, hopes, issues feelings and sensations as me"

I believe that students were encouraged to engage in a real way with concepts of diversity, loss and adaptation. They began to question their assumptions about people and disability, and to challenge their own concept of "normality". Students

began to question both if, and then how they were different, and to reflect on how they responded to any perceived difference.

5.4.3 Coping with dichotomy

Some of the disjunction experienced by students was as a result of dilemmas that are inherent in therapy. Confronting the paradoxes and tensions became necessary as awareness developed. Returning to the image of a storm, one can imagine this experience of the students as being one of being in the midst of winds raging in opposite directions.

Perhaps the most noticeable disjunction occurred through the challenge to position self somewhere on the continuum between 'healthy' and 'disabled'. Lauren repeatedly challenged students about whether they were like her or whether she was like them. Students were enabled through self-discovery to step out of the 'them' and 'us' mindset that so easily develops during training.

"To some extent I think disabilities, or people with disabilities have been stigmatized. You think that only people from underprivileged areas or families develop disabilities, but this is not the case"

Managing the emotional closeness that is generated in the client-centered relationship is another contributor to disjunction as students seek a position between professional objectivity and the intimacy that accompanies empathetic relationships.

Finding the balance between learning from the texts and from the client was another potential source of conflict.

Awareness of difficulties arising from disability were countered by increased awareness of the unexpected good that can come from disability. Students were reminded constantly of the tough aspects of living with a disability, but also encouraged by being made aware of the opportunities that hardship brings for personal growth.

They were shown that problems relating to disability don't necessarily have to be 'fixed' or 'cured', they can be integrated into ones' life and managed through planning and support. These are examples of more 'enabling' disjunction.

Some students reflected on ways that occupational therapists can help, others reflected on ways they could hinder the person's adaptation.

This apparent 'simplicity of occupational therapy was reflected by this student:

"the most prominent part for me in the lecture was as OTs you don't need to necessarily come up with this hugely complicated and professional structure to assist a person, but often how simple things found in the person's environment are much more helpful to the person."

In contrast, this student reflected on the complexity of responding to disability, doubting her capacity to go beyond her own personal response to Lauren's shared experience:

"I felt quite overwhelmed in that I don't know how I would help someone in the situation when I'm an OT, but I'll get there." An understanding of what the

therapist can do and when she needs to draw on the skills of other people, is also an important potentially 'disabling' disjunction.

" I feel right at the bottom of a very steep learning curve"

Examples of reflections that suggested 'enabling' disjunction are as follows:

"a key moment was when Lauren was talking and had to stop because she was too tired and couldn't find the words needed. She spoke of it happening but I recognized just how real the problem was when it actually happened."

"We discussed what made up Lauren, the person. It was good to see that we were all starting to learn more about her and integrate our theory into our experiences"

As students sought to reconcile all these conflicting images and ambivalent thoughts and realities, I observed a pattern emerging that is best described as an oscillation – a 'blowing hot and cold', an experience of ambivalence and faltering confidence in the personal transition students were making. Coping with multiple dichotomies inhibits students from experiencing a smooth learning path. Some experience this polarity as a simple mismatch, others more like a chasm or a gulf. How it is experienced will affect how a student responds to it.

5.5 REFLECTION ON FINDINGS:

The space between the two intersecting circles in Figure 1 was identified as the space where learning occurred. It was a space characterized by the students' experience of disjunction, in which they needed to 'weather the storm', which alternated with the experience of 'making headway',

5.5.1 Shifting away from disjunction :

Disjunction is viewed by many to be the starting point of learning (Savin-Baden, 1997b, p.534). It is a term used to refer to “a sense of fragmentation of part of, or all of, the self. It is characterized by anxiety and confusion, and a loss of sense of self which often results in anger and frustration” (*ibid*, p.534). It captures some of the ‘trauma’ or ‘darkness’ experienced during the learning process. Opportunity to relate what they were learning to their past experience contributed to the disjunction encountered as they realized the poverty of their thinking, which then created the impetus for change and learning. The student began to develop a personal stance in relation to his learning.

The interplay between the affective and cognitive dimensions of the experience provided a fertile space for potential ‘development’ and ‘learning’ to be experienced. What students gained through their learning may be something akin to ‘experience’. According to Hasselkus (2002, p. 4) “experience results when pre-conceived notions and expectations are challenged, refined or disconfirmed by the actual situation” .

Through experiencing disjunction, the students were challenged to move away from their discomfort by confronting the challenge facing them. Savin-Baden (1997b) suggests that disjunction can be ‘enabling’ or ‘disabling’ and that it is experienced in different ways by different students at different times as they are exposed to different learning situations. Shifts away from disjunction always seemed to be related to a greater sense of integration (*ibid*, 1997b). This movement (or transition) is caused by a perceived challenge to the person’s life -world and a shift away from current way of understanding.

Discomfort in any situation usually demands a personal response and I believe this was what ultimately transpired for many students in this space of learning. There was evidence of a shift in thinking, a realization of how different it all is from what they had thought before their exposure to Lauren's experience. According to Savin-Baden (1997 b, p. 533), "...transitions are not linear but recursive. They involve visiting and redefining experiences, rather than necessarily refining them". In my analysis of student findings, this negotiation of transition was not a linear process, rather students may have experienced alternating glimpses of the 'light' and 'dark' as they tried to 'make headway'. Having Lauren share her story throughout the course gave students a valuable opportunity to glimpse the light as indicated by this quote:

"Having Lauren at the lecture just makes everything we learn in it seems much more real. No offense to the lecturer, but it is so much better to have Lauren say 'I would like to use this, I have trouble doing this' than to have a lecturer say 'a physically impaired person would...' Lauren being at the lecture made me see things in a new light."

In this space students could begin to formulate a personal response in their own time, devoid of the pressure of clinical decision-making and action. This was a particularly important space for reflection as it is outside of the need to 'do' and so students can wrestle with 'being' and 'becoming'. In this space students could confront their personal 'turmoil' at the heart of the experience. Lauren's 'sharing' served as a catalyst to the developing awareness. Had the climate for learning been different, the experience of disjunction may have been quite disabling for some students. Disturbing evidence suggests that the incidence of negative stereotyping has been

found to increase during medical training (Oliver, 1996). Likewise, French (1996a, cited in Scullion, 1999) found that empathy towards disabled people decreased during medical training whilst cynicism increased amongst students. Much of this may be due to disabling disjunction experienced during training. In this study, because the environment was supportive, the students experienced a form of mentoring through the process of 'weathering the storm' and 'making headway'. However, it is acknowledged that the journey of each student must be regarded as unique. It depends on many variables such as their commitment to serious reflection or their ability to integrate their past experiences into their learning.

5.5.2 Laying the foundations for professional competence

This experience of disjunction and the consequent response to it may be seen as one of the 'disabling' or 'enabling' factors that relate to the development of competence.

The barriers to achievement of competence in client-centered practice cannot be underestimated, especially for students. It is a difficult process for qualified therapists and even more challenging for students.

Whilst learning through 'lived experience' was not always directly related to becoming a therapist in terms of overt knowledge and skill development, it permitted lateral development that could lay the foundations for professional competence and the emergence of professional identity.

A simple definition of competence involves having the necessary skill or knowledge to do something successfully. In occupational therapy, competence includes attitudes, reasoning skills and a broad range of observable patterns of behavior necessary to deliver a professional service (Duke, 2004). Implied in the development of the student's competence (as a result of training and experience), is the evolution of an identity of him/herself as both learner and health professional. As students absorb

new knowledge and understand more fully what skills, competencies and attitudes are required of them to become health professionals, they grapple with theoretical concepts and frameworks, practical issues, personal and social development. An understanding of the responsibilities of the professional role begins to emerge. There is a sense of the student in a process of 'becoming'.

Fidler (1983, cited in Wilcock, 1998c, p. 251) describes the process of 'becoming' as having three dimensions, becoming competent, becoming I, and becoming a social being. In all these scenarios, she alludes to the notions of potential and growth, of transformation and self-actualization. 'Becoming' implies a shift, a sense of a future and is a process that is individually experienced. (*ibid* p. 51). It suggests personal transformation that is necessary for the development of competence.

Understanding about 'continuing development' is critical in the development of competence to practice (Duke, 2004).

5.5.3. Relating to 'other'

People with disabilities represent a strongly ingrained "other" in many societies.

Attention to disability in western society has been dominated by biological, social and cognitive sciences (Mitchell & Snyder, 1977, cited in Hasselkus, 2002). Disabilities have long been regarded almost exclusively as debilitating phenomena that require medical intervention to restore what may be regarded as 'normality'. This focus on the body has exerted a major influence on our views of disability and health, and allied professionals are to some extent dependent on maintaining these views for our professional survival (*ibid*). Mitchell and Snyder (*ibid*) view health-related professionals as partly responsible for the relentless focus on limitation, dependencies and abnormality, which it is claimed, perpetuates these notions of

disability, whilst ensuring survival of health professions. I suggest that the students may also have strongly defined disability as 'other' and in this way.

The term "abled gaze" is used to refer to the culturally determined perspective that people without disabilities have of people with disabilities in our society. It refers to a position of power (Davis, 1997, cited in Hasselkus, 2002). The person who is 'gazing' puts self in the 'norm' position, perpetuating the social categories of able/disabled and the division of the world into normal and different (*ibid*).

It is clear that Lauren made an impact in terms of allowing students to break away from the usual framework of 'sameness' and 'difference'. Lauren helped students to see the world more as a place for all kinds of people possessing a great diversity of bodies and minds, all of which may be normal in their own way, and able to contribute in different ways. By engaging in such a forthright way early in training, perhaps students were able to ask the questions that Reeve et al (2004) suggest are part of the 'curiosity' of response that non-disabled people struggle to conceal when interacting with disabled people and which contribute to the psycho-emotional dimensions of disability .

5.5.4. 'LIVED EXPERIENCE' : CATALYST TO STUDENT DEVELOPMENT

During the process of analyzing student reflections, it became clear that the findings could be considered in the light of the developmental stage of young adults. It should be noted that this was a fairly homogenous students group, ranging in age from 18 – 25 years.

A theory of psychosocial development during the college years, developed by Arthur Chickering will be used to attempt to make sense of the findings on a broader level. This theory was originally conceived in 1969 and revised by Dr Linda Reisser in 1995. (Reisser, 1995). It relates learning to movement through stages in a sequential manner. As individuals move through the stages they are faced with crises or life tasks. Anxiety over these crises incites the need for individuals to resolve the conflict within themselves. This may be seen as akin to the disjunction experienced by students as they sought to harmonize the cognitive and affective dimensions of their learning.

Chickering's theory of identity development :

Chickering suggests that the major developmental problem that students face is that of establishing identity. Chickering's theory centers around seven vectors of identity development (Reisser, 1995). He highlights the strong emotional thread influencing development at this age.

As I examined these vectors I recognized at once the overlap between what students had reportedly experienced through the lecture series and the stages captured in these seven vectors. It became apparent that the experience of students was intimately related to the development of their personal and professional identity. Whilst three of Chickering's vectors featured more prominently, I will identify how each of the seven vectors was manifested in the students' reflections. I will discuss the three dominant vectors, namely the development of competence, the management of emotions and the development of identity in more depth.

5.5.4.1 The development of competence

It is difficult to comment conclusively on student competence as the sense of competence has a subjective component and is not easily observable (Reisser, p. 507). It involves how students feel about their overall performance and the worth of their accomplishments, based on how this relates to expectations of themselves and professionals involved in training.

As I began to deliberate about competence, the conscious competence learning model facilitated my understanding of the cyclical nature of this journey that accompanies the development of new skills (<http://www.businessballs.com>). The origins of this adult learning model are uncertain.¹ The simple version of the model explains the process and stages of learning that are negotiated in learning a new skill, behaviour, ability or technique. Applied to occupational therapy, as students learn and master the requirements of their profession, they pass through four stages which they then repeat many times throughout their lives as they encounter new challenges and contexts in their work.

It is reported that educators commonly assume students to be at stage 2, and focus effort towards achieving stage 3, whilst often students are still at stage 1 (*ibid*). The educator **assumes** the student is aware of what he /she does not know and still needs to learn. Students at stage 1 are sometimes ignorant about this and will not be able to address achieving conscious competence until they have greater insight into their own incompetence (*ibid*). It is suggested that it is essential to establish

¹ Some believe WC Howell was responsible for Conscious Competence in its modern form – apparently the model can be found in W.C Howell and E.A. Fleischman (eds.), *Human Performance and Productivity*. Vol. 2: Information Processing and Decision Making. Hillsdale, NJ: Erlbaum; 1982.

incompetence (*ibid*). It is suggested that it is essential to establish awareness of a weakness or need prior to attempting to move students from stage 2 to 3.

In this study it was apparent that students quickly began to reflect on their own lack of awareness. Many students used phrase such as 'did not know', 'been unaware of', had never thought ..' in relation to the issues that they were hearing about.

As evidenced by the progression of thinking in student reflections, it is my opinion that learning through "lived experience" enabled significant movement through the early stages of the competence cycle through the experience of disjunction. Students were spurred to shift initially from a position of 'unconscious incompetence' to the more challenging and uncomfortable, sometimes overwhelming position of recognizing 'conscious incompetence'. In this stage the person becomes aware of their deficiency in skill and realizes that by improving in this area, they will improve their effectiveness. The person ideally makes a commitment to learn and practice new skills (*ibid*), which facilitates transition. This was perhaps seen in their efforts to break through the 'storm' to positions of new understanding.

It is also likely that there was development of 'conscious competence' – understanding some of the ways in which an occupational therapist may problem solve with a client.

Through their reflections they were encouraged to engage in critical thinking and reasoning, which contributes to the development of 'intellectual competence' (*ibid*).

Changes in ways of knowing and reasoning was encouraged through the stimulation of thinking, problem- solving, the creation of new linkages and connections, the development of opinions and communication of ideas. Responsiveness to learning from many sources needs to be nurtured and integrated into critical reasoning. At an early stage of student training, the 'patient as expert' is perhaps a favored position to assume in a client-centered approach. This may, however, also make students feel

'helpless' at early stages and contribute to 'disabling' disjunction. In time, a position of balance will hopefully be achieved in recognition of the unique contributions of both. It appeared from analysis of reflections that students had been facilitated in development of 'interpersonal literacy', a term used by Reisser (1995) to refer to skills of communication and collaboration with others.

5.5.4.2 Management of emotions.

"Emotional development involves being connected with a full range of feelings, understanding what causes them, differentiating between levels of intensity and learning to counteract toxic feelings with courage, hope and enthusiasm"
(Reisser, 1995, p 507)

I believe the 'normal development' that occurs during the 'student years' is complicated by exposure to disability issues. The lecture series nevertheless provided a forum for bringing 'feelings' to the consciousness of students. It was instrumental in spurring students to recognize and articulate their emotions as they responded to what they were seeing, hearing and thinking.

Some social model accounts draw on psychoanalytic concepts in helping to explain the construction of disabled people's oppression. (Marks, 1999). It is relevant to consider emotions expressed by students in relation to the emotional energy which Marks believes is behind so many 'non-disabled' people's responses to the subject of disability. It has been argued that in challenging oppression disabled people need to be cognizant of the struggle within non-disabled people between the 'ego' - which contains emotions of sympathy, care and pity and the 'id' - which contains anxiety, fear, anger and hate. It is referred to as a 'hidden hate' and is regarded as potentially destructive, linked with a fear of difference and the preservation of self (Casling, cited in Tregaskis, 2002). Marks (1999) questions the emotional pay-off which non-

in Tregaskis, 2002). Marks (1999) questions the emotional pay-off which non-disabled people gain from participating in 'altruistic' or 'caring work'. She writes about existential anxieties that may be habitually repressed and about how disability has come to represent these feelings (*ibid*). Marks also describes a number of defence mechanisms that people may use to manage unacceptable or difficult feelings that arise from exposure to disability. These are viewed as key ways to understanding disablist prejudices as one begins to understand the unconscious fears and fantasies underlying discriminatory attitudes and treatment of disabled people. Whilst this is an area that may indeed be relevant in the emotional responses demonstrated by the students, an in-depth consideration of these features was considered to fall beyond the scope of this work.

5.5.4.3 Through autonomy toward interdependence

Many students acknowledged this core of interdependence that is required of a therapist in her interpersonal interactions in practice. Students were encouraged to reflect on their perceived independence and interdependence before Lauren's perception of her independence was addressed.

A lot of preliminary work was done to establish this concept which is so foundational to occupational therapists.

5.5.4.4 Developing mature interpersonal relationships.

Relationship in the sessions modeled this to some extent and by nature of the issues discussed, provided a forum for debate and the potential for establishing deeper-level communication.

Reisser (1995) acknowledges that:

“relationships provide powerful learning experiences about feelings, communication, sexuality, self-esteem, values and other aspects of identity. What and how we teach can have a powerful impact on student attitudes.” (*ibid*, p.507).

Two components of the vector are tolerance and capacity for intimacy. Both involve the ability to accept the uniqueness and diversity of individuals and the need to appreciate commonalities and diversity. This was reflected in the wrestling within self and in relation to ‘other’ in the first theme presented. Varying degrees of tolerance were expressed. Tolerance may imply the willingness to suspend judgment, to refrain from condemnation, to attempt to understand different ways of ‘being’. Students were helped to understand how stereotyping can be detrimental.

Relationships take time to develop, so it is important to view this as evolving slowly. I believe the lecture series provided a good opportunity for relationship-building with a ‘disabled person’ in a context removed from treatment or rehabilitation.

5.5.4.5 Establishing identity

Reisser (1995) proposes that any experience that helps students to define “who I am or “who I am not” can help to solidify a sense of self. In this vector, students gain a greater sense of self, become more familiar with their identity and may begin to accept themselves for who they are. Personal issues become easier to discuss and personal values come to the fore. The lecture series certainly provided a stimulus for students to begin to clarify their own values regarding some important life issues.

Reflective moments and revelations help students to discover more about themselves and their chosen professions. During the process of finding a personal stance, students tended to make comparisons between their own and Lauren’s experience. Students began to understand the values held both personally and by occupational therapy. This is a critical part of evolving both personal and professional identity. It

also serves to prepare them more fully to respond to new ideas and concepts or conflicting values/ beliefs.

“By providing students with opportunities to understand the ‘interlocking parts’ of feelings, beliefs, values, priorities and the mind/body complexity, they are more able to develop a coherent sense of self, critical to personal stability and integration” (Reisser, 1995, p. 509).

5.5.4.6 Development of a sense of purpose and integrity.

I suspect that development in this last vector in which vocational plans are clarified, priorities shared and lifestyle choices made evolves over many years. However, some students did reflect tentatively on their future careers as occupational therapists.

The development of integrity involves developing a personalized value system, whilst learning to respect the systems of others (Reisser, 1995). In this lecture series I believe the students’ experienced growth in personal value systems and that they started internalizing some of the values that are held by occupational therapists. They also were exposed to Lauren’s value system. It is hoped that this will help them to practice one day in ways that respect these different values.

Conclusion:

Reisser (1995) calls for educators to keep student development in the forefront of learning programs. This experience afforded opportunity to do this. I view this opportunity firstly, to ‘become aware of’, and secondly ‘to grapple with all these ‘issues’ as important components of both the learning process and student development. This experience of disjunction precipitated a personal response – a discovery about self and an unlearning process, prior to re-learning. The exposure to Lauren’s ‘lived experience’ through the lecture series had been an opportunity for

both 'enabling' and 'disabling' disjunction. In this sense there was a 'storm' of feeling and of sometimes overwhelming stimuli 'raging' during this experience of disjunction. Development of personal and professional identity is perhaps an inevitable consequence of this transition.

Learning alongside Lauren has permitted students to make a significant link between good relationship, personal skills and effective occupational therapy, this requiring both personal and professional development of the students. This emerging understanding is perhaps key to the development of student competence.

CHAPTER 6: EDUCATOR'S PERCEPTIONS OF LAUREN'S EXPERIENCE OF THE TEACHING PARTNERSHIP

6.1 Overview:

In this chapter I will present my perception of Lauren's experience of sharing 'lived experience'. Lauren was employed by the university as a 'disabled expert' for the duration of the course, and as such, the occupation of 'sharing lived experience' could be viewed as what occupational therapists classify as a "productive pursuit". As I observed Lauren's engagement in the planning process, watched her sharing her 'lived experience' with students, discussed the sessions with her afterwards, reviewed her writing, and reflected constantly on all of this, I formed impressions about how she appeared to be experiencing her participation and what it meant to her. I will present these impressions and reflect on them in this section.

According to Hasselkus (2002), 'meaning' may largely be considered as an 'inside thing'. It is real because it is experienced, but it is not easily described and especially not by someone else. I was mindful of the limitations of attempting to derive meaning from what I could only observe or hear as outsider. It is impossible to portray fully the meanings of events and relationships in other peoples' lives. Meaning does, however, have both personal and shared dimensions. Having worked alongside Lauren throughout the duration of the course, I will attempt tentatively to share my perceptions of how I believe she experienced the partnership. I used an occupational perspective to frame the impressions.

One of the ways I have tried to understand the meaning of this teaching experience for Lauren has been to listen to her stories about her life (throughout our collaboration) and to

understand how this occupation forms part of an ongoing story. Through these stories and the new shared story we created together through our teaching partnership, where each of our stories became superimposed on one another, I have been able to come to some understanding of what this experience may have meant to Lauren.

As I attempted to draw together my observations and understandings about the experience for Lauren, I also reviewed existing literature about occupation to explore possible different dimensions of the experience of the occupation. Lauren also gave me some of her own reflections that she had written during the course of our partnership. I will present verbatim extracts from her writing as I discuss my perspective on her experience.

I acknowledge that this was always a messy process of trying to uncover what Lauren was saying about her experience of teaching the students. I believe that this occupation cannot be considered in isolation and that the broader narrative of her life needs to be considered. In addition, being an occupational therapist means that I have years of thinking and personal views/understanding about occupation and its power, which has formed my perceptions.

I have specifically chosen a different method of presenting this perspective (as opposed to student perspective) as I wanted to integrate many 'bits' of information from different sources to describe this experience of occupation.

6.2 Recognizing Lauren's teaching as part of her working 'life story' :

In a chapter in her unpublished book (Singer, 2005), Lauren writes about her former experience of work and how this was transformed through having MS. After working for a time at the University of Cape Town in the Department of Russian Studies, it closed, and

she gained employment at the Disability Unit at UCT. Lauren writes extensively about the pleasure and stimulation derived from working at the University, and was therefore devastated when her job came to an end with her medical boarding some years ago.

In her book, Lauren wrote about the loss of her employment at UCT:

“ I continued to work at the best of my ability but that clearly was not good enough. I was advised to take early retirement due to ill health. I was staggered. Distraught. I knew that multiple sclerosis affected the way that I worked, but I had never thought I would be considered incompetent”.

The impact of this loss of employment was clearly devastating to her perception of self and prompted her to draw deeply from within to restore what had been lost in her occupational life.

“I felt as if I had been discarded” (Singer, 2001, p. 34).

This gives important insight into the meaning of work-related activities to Lauren. She needed to make other plans for a new ‘work future’. Part of this involved a decision to make MS work for her:

“ When I was medically boarded from the University, another friend of mine advised me to make Multiple Sclerosis my career. I was shattered at the time, but what he said lodged in my mind. I have taken an extremely debilitating and frustrating illness and made it serve my purposes. I have worked with it and not against it. I have been able to turn setbacks into stepping stones”.(Singer, 2005)

6.3 Multiple Sclerosis becomes Lauren's career

I have seen Lauren begin to establish this 'career in MS' through the speaking engagements she has taken on, the consultancy work (about disability), the writing she has done, and through her teaching work with students. I do believe this is part of the reason for her enthusiasm to participate in the lecture series. Her pleasure in participation has been manifest not only during my interactions with her, but reveals itself through her writing as the following extract suggests:

"...my love of teaching which has also found a fascinating and highly fulfilling outlet" – referring to the work done with OT students (Singer, 2005)

6.4 Her experiences of working now:

Wilcock's (1998c) portrayal of occupation as a synthesis of 'doing, being and becoming', is also a framework that I have found helpful in piecing together my impressions of Lauren's experience with the students. There was an obvious 'doing' dimension in Lauren's situation, a 'being' which enabled the particular 'doing', as well as a sense of 'becoming' that manifested itself through the process of teaching.

I will attempt to explore these impressions through four themes that emerged as I reflected on my field notes and impressions:

Doing outside home

Being connected

Giving something back

Living out the life meant for me

6.4.1“ DOING” OUTSIDE HOME

“Doing” for Lauren is physically demanding and energy-consuming and many things are difficult or impossible for her to ‘do’. As a result she spends much time at home ‘being’ dependent on others for assistance with ‘doing’. A notable exception is her writing occupations, but these are solitary. I believe Lauren’s love for writing has a significant relationship to her ability to share of her ‘lived experience’, she speaks as one who has reflected deeply on her situation, and it is this habit of ‘being’ that makes her so able to ‘do’ in this context. I had a strong sense that the storyteller is an integral part of who Lauren is. Telling it ‘live’ adds another dimension to fulfilling her passion. She spoke to me on many occasions about how important it was for her to speak to people. It is one of the important ways in which she can ‘do’.

She enjoyed telling other people about her ‘doing’ e.g. she wrote a letter to a local popular magazine about her teaching experience with the students. She has also spoken about her involvement on the local radio talk program (Cape Talk) This would indicate that she is energized and motivated by the experience of ‘doing’. As I listened to her speak about her experience, the impression gained from how she referred to her ‘doing’, was that this was both pleasurable and fulfilling to her. However, the physical aspects of the ‘doing’ seemed to be quite challenging and energy-consuming.

6.4.2 BEING CONNECTED

'While they were chatting over tea, the students asked more questions. What is the hardest thing about living with Multiple Sclerosis?'

'The loneliness I think. It is a scary illness,' Lauren confided. (Singer, 2003, p 19) This is an extract from Lauren's book written through Fred's (service dog) eyes. A simple statement such as this reveals the major impact MS has had in Lauren's life.

A letter written to a popular magazine in which she speaks about her participation in the lecture series suggests the importance of this desire to be linked with others:

"I loved the lecture series, because, above all, I enjoy connecting with people when I know I am still contributing to society" (Shape, July, 2004).

Sharing her 'lived experience' has, I believe, made it possible for Lauren to connect with others – in this case with the student world. It has fostered an intellectual and social connectedness with the teaching world, and it has enabled physical and social connection outside of her usual environment. It has given her another point of being able to connect with others 'outside', through relating her experience to them.

Lauren indicated to me that she felt part of the world, that she was, through her teaching, able to *"share in what the world was saying."*

Again, the satisfaction derived from the connection through occupation was highlighted:

"I find so many fulfillments in speaking to these students; there is so much to learn".

She spoke about the reciprocal nature of being involved, the sense of being able to both 'give and take'.

"It is so easy to become completely self-absorbed, but working with the class has given me the opportunity to go beyond myself".

According to Hasselkus (2002, p.98), "connectedness and relatedness are generally considered positive states of being in life". "To be connected is desirable, and to be connected with oneself, one's world and with a purpose in life, is to be spiritually healthy" (*ibid*, p. 9)

6.4.3 GIVING SOMETHING BACK:

"During this life stage (the middle years), knowledge, attitudes and values are passed to the next generation, a process which Erikson (1967) terms 'generativity'. This takes place at a formal level within society's institutions and at a personal level within families or when contributing to the welfare of others. According to Erikson, where people fail in the attempts to be generative, they may feel a 'pervading sense of stagnation and personal impoverishment' (cited in Johnson, 2002, p. 268, 269)".

"It will be an exciting thing. I will feel that I'm contributing. I would like to help them learn to become Occupational Therapists" (Lauren).

Lauren, in her feedback to students (for their class meeting), wrote
"I believe that our lectures together will have a lasting impact, not only on you but on me too"

In the extract from her latest book, Lauren writes:

" It is my firm belief that all students in the health sciences should have an opportunity to explore the concept of healing. Coming to an understanding of the people behind the illnesses they are treating , is crucial".(Singer, 2005, unpublished)

All of these quotes suggest that the occupation of teaching is highly valued by Lauren, and she perceives a role for herself, a way in which she can contribute to her society.

I believe it is important to consider Lauren's life stage when one considers her experience of participation. During the middle period of life, the main area of productivity is employment, with careers reaching their peak in terms of responsibility. The sense of being able to make a difference characterizes this life stage (Johnson, 2002) Whilst there was possibly some incentive to participate as a result of remuneration, I believe that meaning for Lauren extended well beyond this. Hasselkus (2002) suggests that it is the experience of the 'dance of the occupation' that is important, not the occupation itself or the outcome.

Occupation, in addition to having end-products, is also comprised of process – the experience of being involved in an exciting new project, designing an evolving course, challenging the students in different ways.

Studies give evidence that loss of occupation and role have a negative effect on a person's health and well-being (Turner, 2002, p 35). Turner cites boredom, frustration, monotony and restricted lifestyles as the main feelings associated with loss of occupation. This may be compounded by feelings of uselessness and alienation from society. One way in which some of the impact of occupational loss may be counteracted, may be through developing a new role in teaching programs where students are taught through exposure to 'lived experience'.

I believe that some of the sense of pleasure gained from the experience was perhaps due to a sense of being able to challenge the students and facilitate new insights. She wrote in her feedback to the students:

"I know that it has not always been easy for the students...Inevitably I spoke about things that were uncomfortable to hear. Incontinence is not a topic for a lunchtime chat! We have discussed and questioned some pretty tough subjects."

Lauren seemed to get enjoyment from reading student reflections, which were, on the whole, very affirming. However, it was just as gratifying for Lauren when a student wrote about her reservations about what she saw as Lauren's indiscretion regarding issues of sexuality—purely because it revealed a response, a challenge to the sharing.

The following statement by Lauren suggests the shift in students' thinking which she anticipated:

"at the moment they (students) see problems, they are going to be seeing solutions to problems"

The possible 'ripple-effect' of her teaching was important to her:

"having the knowledge that you're contributing to their (other disabled people) happiness, that they (students) will assist somebody somewhere. That's why this is so important"

Here it is evident that sharing of 'lived experience' is indeed highly valued by Lauren in terms of what it contributes to the learning of others. Lauren has verbalized the importance of the experience of the shared teaching to her on many occasions and expressed gratefulness for the opportunity. In feedback to the students, Lauren wrote:

"I have been privileged to read some of the responses to the lectures. I have been moved by the sensitivity shown. If the reports were just patronizing comments of how 'sorry' the students were for me, I doubt that I would have been able to continue".

I believe that the “uncensored” feedback students gave Lauren through their reflections added significant meaning to her experience. It was important to her that students moved beyond an emotional response to her disability.

I believe that through her sharing, Lauren was able to channel the telling of her stories in such a way as to provide a practically helpful training opportunity for students. Her sharing had a unique purpose and contribution, it was not something that could have been done by someone else in the same way. The challenge to make sense of her difficulties for the students by transforming her experience of disability into something useful was, I believe gratifying in many ways for her personally.

On one occasion Lauren’s mother confirmed my view of the importance of the teaching for Lauren. She used the words “it is so good for Lauren to feel useful”.

6.4.4 LIVING OUT THE LIFE MEANT FOR ME

In addressing these dimensions of Lauren’s experience, McColl’s (2003) work on spirituality and occupational therapy was helpful in understanding the manifestation of ‘spirituality’ in occupation. Spirituality is accorded three facets: an intrapersonal (relationship with self), an interpersonal (relationship with others) and a transpersonal (relationship with natural world and a higher power) facet . I see all of these facets as part of Lauren’s experience of the occupation of ‘sharing lived experience’.

As I thought about if and how Lauren was ‘becoming’ through teaching, I looked at the data I had and integrated this with literature written by Hasselkus (2002), Townsend (1997) and McColl (2003) about occupation and its relationship to self-discovery and transformation, spirituality and creativity.

6.4.4.1 Self-discovery and personal growth through occupation:

According to Hasselkus (2002, p.17), "occupation is a strong enabler for knowing one self". I believe that Lauren's contribution and the interaction and feedback that formed part of the experience, enabled her to see herself in new ways. It strengthened her self-identity through allowing perceptions of increased contribution and competence. I believe that the sense of "having a voice" that was considered seriously has given Lauren a new sense of self, a new sense of respect and of greater influence. The impact of her sharing of "lived experience" could be read in student reflections, whilst the expression and responses of students to stories that she shared could be witnessed.

Lauren was able to engage with the students in debate and discussion about difficult issues and in so doing, she became exposed to new ideas and expanded images of herself and her adaptive process. Student reflections provided much personal affirmation as they commended her many attributes. I believe that her self esteem must have been increased through seeing herself referred to in such positive ways.

Through her teaching Lauren was able to share about other meaningful aspects of her occupational life. This sharing of her inner self with students in the world outside gave her an opportunity to express and reaffirm for herself something of her authentic self.

Not all aspects of self -discovery were necessarily pleasurable e.g. Lauren expressed negativity about her physical image on viewing herself in the video we had made

"I'm so fat, I'm so much like a blob, I don't like my nose. Do I really look like this?"

Through the experience Lauren perhaps viewed herself physically and in other ways through the eyes of others. This expanded perception of self may be considered in relation to the Johari window, a model describing the process of human interaction that is familiar to many occupational therapists. This model, created by Luft and Ingham,

illustrates how self-disclosure and feedback increase personal and interpersonal awareness (Duen Hsi Yen, 1999) . I believe that her self esteem must have been increased through seeing herself referred to in such positive ways in student reflections, and that she may have experienced opportunities for personal growth. At the same time, as the relationship with the students evolved, Lauren was in turn, able to disclose more of herself to the students.

Personal growth and change through the process of reconstructing an occupational identity was, I believe, an important dimension of Lauren's experience, especially in the light of her previous occupational losses. 'Being productive' really matters to Lauren, it provides meaning and forms a central part of who she has been in the past, and how she continues to work out her life in relation to her faith. Debate about occupational identity is very new in occupational therapy but is considered "central to understanding meaning in occupation" (Unruh, 2004, p.294).

The opportunity to share about some issues, although not altogether a new experience, required honesty, vulnerability and an openness. This was experienced as difficult at times during the lecture series. It appears that being able to do this generated feelings of having personally grown, it suggested that Lauren felt a sense of achievement in being able to do this. Lauren referred to being able to talk openly as a "*mark of confidence that I could talk about my feelings*".

It was sometimes my concern that Lauren found some of the issues quite emotional and challenging to address. One such example occurred when she viewed a video clip of herself (made for a TV program 10 years ago) with the students. The deterioration in her physical condition was quite marked and her personal response was visible. Likewise

physical condition was quite marked and her personal response was visible. Likewise sharing about a past intimate relationship, whilst very valuable for the students, required a lot of courage and evoked a lot of both painful and happy memories. Discussing the humiliation of incontinence had moments of discomfort and awkwardness for all, something that was acknowledged and addressed as such. Whilst mentioning the discomfort associated with this level of sharing, it was perhaps this opportunity to turn the 'shameful' into something 'useful' that could have made her feel some sense of achievement.

I believe that her participation has awakened new possibilities for her writing as she uses her experiences with students to generate new stories. It perhaps helped her continue to shape an 'occupational identity', thus helping her 'becoming'. This is a term used by Wilcock (1998c, p.251) that holds 'notions of potential and growth, of transformation and self-actualization.

6.4.4.2 Experiencing spiritual well-being through occupation:

The Canadian Association of Occupational Therapists gives central place to spirituality in the client- centered model, viewing it as an

“essential component of the individual which is in dynamic interaction with the mind and body. Spirituality is seen as the individual's view or purpose of his or her life” (CAOT, 1991, p. 58)

On many occasions Lauren alluded to the fulfillment and enjoyment she was experiencing through her participation in the lecture series. This ability to share face to face has perhaps been even more enriching in a more immediately fulfilling way than her 'sharing through writing'. Lauren often appeared animated, radiant and energized by her participation and it is these very qualities that Peloquin (1997) associates with meaningful occupation.

Lauren very often conveyed to me how important she saw her potential role in helping to train the students through sharing with them. She once spoke to the students about wanting to “create a bridge” between her and them, to help them to see how much they were like her, rather than how much she was like them. She told me that she felt “honored” to be able to participate. She spoke about wanting to help students to *‘be able to help people with their vision of themselves’, ‘to marry a past vision with a future vision’*. In this way Lauren was not only concerned with students but with the clients that students would one day be able to reach through the opportunity of therapy.

Spirituality refers to thoughts, feelings and actions concerning the meaning that is made by individuals of their daily life (CAOT, 1991). According to Trombly (2002, p. 258):

“.....meaningfulness arises from a person’s sense of the importance of participating in certain occupations..... Meaningful activities remain in a person’s life repertoire.”

I believe that Lauren derived meaning through the experience, manifested in her expressed desire to continue teaching and to extend her interaction with students.

In this lecture series, it is my sense, however, that meaning was derived from the process of the ‘sharing’ about the experience between Lauren and I, and through this sharing that new meanings were created from the experience for us both.

6.4.4.3 Fulfilling part of personal destiny:

The following extract from her unpublished book (Singer, 2005) implies that Lauren’s view of the opportunity to do this work (sharing ‘lived experience’) that she values is part of a bigger picture, perhaps even forms part of a sense of destiny.

On one occasion Lauren raised the issue of her return to South Africa :

"Isn't it interesting? – what turned me to come home (from living in Israel). I couldn't understand what my body was telling me – time to go home, go where you 'll get support and be able to handle things. My mind interpreted what my body was feeling. Sitting here with you now is part of the reason why my body was telling me to go home. I can contribute in a way that I couldn't have in Israel".

"...but that could not have happened without looking deeply into myself. There are building blocks that enable all of us to take our lives and make the most of what we have with each setback I could say "But hey, this wasn't meant to happen". Perhaps it was. "

"whilst MS is a major factor in my life and I wish it wasn't there, but I don't think I could have done the same sort of things without the MS" .

These words allude to a sense of her involvement in the lecture series being linked with a sense of personal destiny. I also see it perhaps as part of constructing a positive life story – engaging in an occupation that is inherently meaningful, evokes a sense of passion and feeling that becomes an important focus in one's occupational narrative.

On one occasion Lauren used the words *"repair of the soul"* and spoke about the course being a trigger to many other things that have meaning in the context of her faith. This could indicate that there has perhaps been some healing of the hurt caused by previous losses.

6.4.4.4 Exercising creativity

It is recognized that the re-organization that tends to occur after a disrupting life event may ultimately result in a new and transformed state of being (Hasselkus, 2002, p. 126). The state of "creative chaos" may become a source of creativity, which in Lauren's case has manifested in writing, and now is extended through sharing of her stories in person. This creativity becomes a potential source of inner healing and another tool for coping with adversity. When thought of in terms of creative potential, illness in one's life may become an 'honored state of being'. Lauren speaks about feeling a sense of pride that she has been able to learn from her disabilities in a positive way. New material for her books through new involvements, enriches and expands her future possibilities as writer, enlarges her capacity for 'becoming'.

According to Hasselkus (2002, p.128), *"creativity arises from our physical and social worlds, and from the sensitivities and thinking processes of our inner selves"*

Initially Lauren expressed some uncertainty about whether what she was sharing was what she was 'supposed to be' sharing. I saw this changing as the lecture series progressed. Creativity suggests dimensions of inventiveness and requiring the use of imagination. Much of the creative fulfillment was derived from input into designing the course and thinking about issues from her 'lived experience' that could be shared. She particularly enjoyed sketching scenarios for the students and encouraging them to engage in problem solving. I believe this was an empowering part of her experience.

As the course progressed, both of us became more conscious of the many experiences that could be drawn from to enhance learning. One such example was the experience of going shopping from the perspective of the therapist and Lauren. Another would be the

different considerations in choice of a wheelchair or scooter (from the perspective of the user or the carer). It was discussions around these kinds of possibilities that brought creativity into the process. We consciously thought about innovative ways that student learning could be enhanced together.

Reference to feelings of warmth and a 'lifting of the spirit' that happens when creative moments are experienced, generating feelings of excitement and anticipation, almost a restlessness of creative energy (Hasselkus, 2002, p. 123). I believe that Lauren experienced this at different times - a 'spiritual electricity' (*ibid*). On occasions Lauren would phone me with an idea that had flashed into her mind about the course, and at times she would even drive the planning process ahead. The course provided fertile ground for 'creative moments' (*ibid*). Bodine (1999) cited by Hasselkus (2002, p.124) describes the creativity of everyday life as a "happy energy" – something that was often manifest in my partnership with Lauren.

6.5 CONCLUSION:

In conclusion I believe that Lauren's experience was one in which she felt pleasure and a sense of meaning, fulfillment and reward through being able to engage in an occupation that she deemed of purpose both to herself and others. It had difficult, uncomfortable and painful moments, yet participation appeared to extend her use of her inherent abilities, it offered her new opportunities to experience personal growth, expanded her concept of herself, and gave her opportunities to 'go beyond herself' and feel connected. This occupation was particularly meaningful because it seemed to play some part in her sense of personal destiny. It seemed to help her to make sense of her purpose in having MS. This has been confirmed by Hammell (2004) who cites evidence from a study identifying four dimensions of occupation that are found to contribute to the experience of quality of life following a 'biographical disruption': meaning, purpose, choice/control and self-worth (p.

302). The significance of finding meaning through occupation is addressed as being fundamental to all who have experienced 'life disruption' which has left them with a lack of purpose in everyday life. (*ibid*)

Engagement in personally meaningful occupations, contributes not solely to perceptions of competence, capability and value, but to the quality of life itself (*ibid*, p.302)

I believe that a restoration of a valued occupation of choice (working/ tutoring students) provided the opportunity for a return to her familiar routines and contexts within the university. This had always been an important part of Lauren's life and there was a special sense of victory, I believe in returning to the university as 'worker'.

Coming to work with OT students may have contributed in promoting improved health and well-being. These are complex concepts, influenced by many variables, and their relationship to occupation is not conclusive, although it is evident that there is a relationship between occupation, health and well-being (Hasselkus, 2002, p.69).

During the course it was observed that there was some improvement in both Lauren's health and her apparent well-being. She in fact, stopped her monthly visits to hospital once the course began, indicating that she did not want it to impact in any way negatively on her opportunity to teach.(She was having cortisone treatment that would sometimes cause a slight setback for some days). She also seemed to be able to walk further distances.

As her physical health is dependent on many variables, it is not possible to assume that improved health is due to her participation in the lecture series. However, I believe that through her active involvement and through the choices she was given, her well-being was positively influenced. When I gave her my chapter to read on the analysis of the findings, she responded by saying that she felt 'bowled over and honoured' by what had been written. "I really feel like I did something valuable".

CHAPTER 7: EDUCATOR PERSPECTIVE ON THE PARTNERSHIP EXPERIENCE

7.1 Overview

On review of my reflective logs I identified a number of recurring issues that I believe help to portray my personal experience of the partnership. As I reflected on my diverse roles during the learning experience, the overriding theme was that of a 'juggling' act. I needed constantly to keep a 'bird's eye view' of what was happening at all times. Throughout the process there were many aspects that needed attention for the learning opportunity to be maximized. Some of these aspects involved planning, others involved making accommodations, others a way of 'being'. As educator I was particularly mindful of my 'educator responsibilities' - the need to frame students' thinking in an occupational therapy way and to make sure that content matched objectives.

I had not anticipated the personal growth and learning that I would experience through the process. Much of the personal gain was possibly due to the research process itself which demanded meticulous attention to details and which therefore ensured that I was well prepared for each session. I found the experience of partnership energizing and anticipated each session keenly, especially once the uncertainty and anxiety of the first few sessions had passed. I did, however, find the lecture series demanding in terms of energy, and costly in terms of time and commitment. I definitely played a different educator role from any other I have previously undertaken. I had feelings and thoughts related to this new role and I sometimes experienced it more as a therapist, rather than an educator. I reflected often on the link between my role as educator and therapist.

I reflected on my feelings and impressions about these multiple roles, attempting to understand what contributed to my response to the experience. I spent many hours thinking

through the process, thinking about what was happening and evaluating the merits of the experience for all of the participants. I tried to understand what was contributing to the apparent success of the learning opportunity and the fact that it seemed to be an empowering experience for Lauren. I thought about the importance of having clarity in terms of expectations and roles for the different participants.

My experience could be summarized into four main themes:

Being in sync together – ‘thinking comfortably together’

Practicing what you preach

Process as a learning curve

‘Nuts and bolts’

I will comment on my experience throughout by reference to relevant literature.

7.2 “BEING IN SYNC TOGETHER – “THINKING COMFORTABLY TOGETHER”

There were two aspects of this theme, each of which will be discussed briefly.

7.2.1 The importance of rapport between educator and ‘disabled expert’

The fundamental component underlying a positive experience of this teaching partnership was the rapport that existed between co-presenters. At one point in the fieldnotes it was written that “we think very comfortably together” and “I think we are speaking the same language”. In a simple way, these two quotes illustrate perfectly the essence of the connection. Park and Burgess (1924, cited in Trombly, 2002) describe rapport as a “response to one another that is characterized by immediacy, spontaneity and is sympathetic in nature”. This description captures my experience of the relationship between Lauren and I. Having ‘rapport’ implies a close relationship in which people understand each other and communicate well.

In many ways, collaboration with Lauren has been a strong echo of my work in a therapeutic setting. Teaching alongside a disabled 'expert' who is sharing about their challenges in daily living, brings into the foreground the instinctive interactional reasoning that is so important to clinical decision-making. It makes sense for therapists to teach like this.

Similarities between role of teacher and that of a clinician have emerged. The educator role may be viewed as an empowering one with respect to students, similar to the one that therapists strive to develop in their relationships with clients. Likewise I believe that the rapport that existed between Lauren and I, was similar to what has been referred to as "therapeutic rapport" (Tickle-Degnen, 2002), except that it was manifested in a teaching rather than a therapeutic setting.

Definitions of therapeutic rapport allude to the quality of the experience involving a deep and effortless concentration, where one is challenged by the interaction yet skillful in meeting the challenge. The encounter is deeply satisfying and feelings demonstrated towards one another, are positive for the continued interaction. It is characterized by a sense of moving forward towards a joint goal, enjoying a "mutual and collaborative exchange" between equals. Positivity has been an energizing feature of our time spent together in this common pursuit, each of us bringing something different and complementary to the teaching situation. Sharing between us has also extended to other topics of common interest, family, life, work and health issues. The working alliance has been an easy and spontaneous one, characterized by an attitude of both giving and receiving by each in different ways.

I believe that conveying warmth in the relationship was critical in allowing the depth of mutuality and intimacy that was experienced to transfer into the class sessions. Initially I felt a bit vulnerable and somewhat intimidated by the thought of having a 'client' listen in to all my teaching. However, as the process continued, I became clearer of how best to share knowledge and experience in ways that could be understood both by her and the students. It might have been more difficult if Lauren and I had experienced conflicts or problems in our working relationship.

7.2.2 The need to relinquish some control in teaching: "holding the reins loosely"

It was really important for me to be conscious of the control that I was privileged with in the lecture. Issues of power have potential to arise in any partnership and may result in the build up of tension over time. Partnership always requires a commitment to understanding one another's experience and perceptions, something which is only possible through regular communication and respectful attitudes. Likewise, a commitment to shared decision-making is sometimes difficult to implement because of the time and energy required for this process. Sometimes the differences in style between the sharing of 'lived experience' and the provision of more theoretical frameworks was quite challenging to integrate in ways that did not disturb the flow of the session or the intimacy created by sharing of personal experience.

The power of the educator to steer the class can be a major limitation or enabler in the kind of learning opportunities that are permitted. It is necessary to remain attentive to the issues under discussion, in order to relate them and focus them on the topic for the session.

Optimizing the use of the time available was an important part of the management that was required in the sessions. Whilst definitely aware of letting go of overt control of the session

in allowing the discussions to flow naturally, I believe it was critical for an OT educator to be present to draw some order to what could have become too much for students to integrate. Whilst there were endless avenues of discussion that might have emerged in each session, it was important that I had clarity about where the students needed to focus their thinking. I attempted to use the sessions to respond in ways that reflected the values inherent in occupational therapy. I was conscious of steering Lauren towards sharing experiences that might be relevant to the session and of broadening the discussions.

It was also necessary for me to make a mental note of areas not able to be addressed due to time constraints. Relinquishing control did mean that on some occasions it was not possible to address the issue adequately from the perspective of other people who may have had different experiences.

7.3 “PRACTICING WHAT YOU PREACH ”

I was conscious during the sessions of how important it is to model that which is held to be of professional value in occupational therapy to the students in the teaching situation. I was conscious of my need to be a role model as I related to them in dual roles as educator and occupational therapist. I felt pressure to ‘do’ and ‘be’ in many ways.

7.3.1 Opportunity for modeling and practicing relationship: “witnessing the doing”

One of the key features of this partnership was the opportunity for students to witness a relationship between a disabled person and an OT. In addition, having opportunity to forge a relationship with Lauren provided a special opportunity for students to do the same in a supportive environment. Yerxa (1973, cited by Tickle-Degnen, 2002) describes the relationship as needing “mutual and collaborative exchange”; suggesting that the therapist allow him/herself to feel real emotion as he enters into mutual relation with the client. I experienced some pressure in my responses to Lauren being under constant scrutiny from

the class. Forming of relationship is recognized as an important part of the therapist's use of self in the treatment process. Allowing time for students to form a relationship with Lauren themselves, encouraged them to engage on a deeper level with the material through the development of connections and links between the different areas over time.

7.3.2 Being empowered and empowering others: experiencing a “win – win situation”

Concepts of empowerment and enablement are fundamental to occupational therapy (Rebeiro, 2001). Throughout the partnership I was aware of how potentially empowering this opportunity was for all the role players in the learning program. It was a challenging process as ways were sought to ensure that the partnership gave due recognition and credibility to the “lived experience” as well as to the expertise and contribution of occupational therapists and the life experience/ prior knowledge of students. I became aware that empowerment is a gradual process, that it takes time, energy, commitment and support on an ongoing basis. It requires confronting both risk and challenge and acknowledging the possibility of failure. A shift in the balance of power towards the ‘disabled expert’ can undermine the sense of contribution made by the educator as the disabled person gains in influence. It requires conscious attention to the different kinds of learning taking place to ensure that both have opportunity to contribute uniquely in the situation. As coordinator, one has power to either include or minimize attention to issues arising. Difficult issues are hard to address in front of a ‘disabled expert’ as are criticisms that the ‘disabled expert’ might have about therapy.

It was clear to me that there couldn't be a ‘them and us’ situation. I became challenged about the ethics of discussing the difficulties of clients with students in the absence of the disabled person. I resolved that any issues should be made explicit during sessions and

tried to challenge students to engage openly. Ethically the situation could have become uncomfortable if I felt more detailed information was necessary for students, which could have increased Lauren's discomfort. Should a cognitive or emotional issue have become apparent, this may have presented difficulties for me. It also became clearer to me that it requires patience, sensitivity, and conscious decisions to negotiate a situation and relationship in ways that not only benefit everyone involved, but serve to empower.

Most times I would feel a sense of anticipation before the class, and energized afterwards, despite being physically and emotionally quite drained.

Empowerment can come through recognition of what each could contribute from a different perspective and a respect for that difference. The interaction that Lauren and I enjoyed after sessions deepened our own commitment to the partnership and generated new ideas. I found participation to be gratifying on many levels.

7.3.3 Reflections in teaching: the choice of disabled expert

I have become more conscious of the underlying motivations that led me to invite Lauren to partner me in teaching. In this way I am practicing a reflective approach in evaluating the teaching strategy, one of the components of which is my choice of 'disabled expert'. Whilst I thought I had thought it all out prior to the lecture series, I became more aware of my motivations for choosing Lauren through ongoing reflection.

I believe choosing Lauren had to do with the image that she portrays of disability – one that is first and foremost, appealing. It embodies a spirit of positivism, a sense that there is a future, that it is possible for active living to be enjoyed in the presence of MS. Lauren possesses, what I understand to be 'a sense of coherence' as used by sociologist,

Antonovsky (1993, cited in Hasselkus, 2002). He suggests that to possess a sense of coherence is to view one's world as comprehensible, manageable and meaningful. In addition to this, the fact that Lauren's experience of disability highlights so well the combination of individual limitations with socially imposed restrictions enables comprehensive problem-solving. The fact that Lauren has a "chronic condition" results in issues that relate to both impairment and disability, e.g. her severe energy limitations affect her in specific ways, and are compounded by the barriers that other wheelchair users confront daily.

Occupational therapists need to be concerned with issues of impairment in addition to issues of disability if they are to be aware of the broad range of strategies available that may help clients.

In Tighe's study of women's' perceptions of health and disability, mention is made of Schaefer's work (1995) which suggested that women with chronic illness negotiate loss whilst making discoveries about themselves. This concurred with her discovery that women 'worked at' fixing their bodies and experiences into the limited societal understanding of a body. They then, paradoxically, seemed to reach a deeper understanding of disability and themselves through this work (Tighe, 2001, p.73). I believe that something similar may be said about Lauren as she has come to understand and share both the limitations and the possibilities that having MS has brought into her life.

I believe that the fact that Lauren writes about her experience influenced me to view her as reflective by nature and therefore well- positioned to share what she has learned. She has a high level of conscious awareness about the impact of MS on her life roles and on her sense of purpose. I feel that she was very quickly able to assess the potential in the lectures and what would be useful to students. A big factor was Lauren's preparedness to

share her vulnerabilities with students despite them being strangers. An example of such vulnerability was when Lauren shared about the death of her dreams of having children, and the great disappointment not only personally felt, but shared by her family – she described it as *“sorrow I can’t do anything about”*.

Being able to share on a “feeling” level is critical to the success of sharing lived experience. In the past Lauren has addressed a number of students and other groups about MS. The fact that she can articulate her needs and that she, for example, recognizes the role of denial in coping, and can express the pressures placed on her to deny the reality of the experience, make challenging interaction in the learning situation possible. I am concerned that this particular image of disability may have implications for students as they develop their clinical repertoire in the future. As they become aware that not all disabled people have the same capacity nor will to adapt or come to terms with their disability, it is possible that some disillusionment may be experienced.

A major contributor to Lauren being suited to the job of ‘disabled expert’ is the fact that she has had many years of living with MS, and has had time to make many adaptations.

Whilst Lauren lived up to my unconscious expectations of image, I am left wondering how different it would have been if the image that I had anticipated had not been sustained throughout the lecture series. I also do wonder how different the contribution and potential benefit would have been given a different ‘case’ study.

I was conscious that although MS is essentially a condition affecting physical functioning, it also has psychosocial dimensions which broaden the scope for sharing beyond physical problems.

Lauren demonstrated unusual ability to communicate with others and was successful in drawing them closer to her. Lauren is a gifted storyteller and teacher. She demonstrates many of the twelve principles which Miller suggests characterize storytelling, in the way that she shares her 'stories' In the words of Miller (URL: <http://www.ccat.sas.upenn.edu/emiller/12principles.html>): "Storytelling in itself is so often about coping and survival, about finding a place in the world ". This quote could not reflect in a more accurate way Lauren's real life story.

I became aware of how important stories are to learning as I thought about Lauren's contribution. Healthy, respectful and productive relationships are founded on people listening to, understanding, and knowing each others' stories. As Frank Smith says:

"Thought flows in terms of stories – stories about events, stories about people, and stories about intentions and achievements. The best teachers are the best storytellers. We learn in the form of stories." (URL: www.ntf.com/html/lib/quotes.htm)

These qualities of a good storyteller are affirmed repeatedly throughout the student reflections and are major enablers, in my perception, of the success of the partnership. Lauren's attitude towards rehabilitation may be summed up in a quote from her writings:

"So I can't be cured. Whatever treatment that might have been beneficial in the earlier stages of MS to slow down the progression, would have moot benefit now. So what do I do? Rehabilitation has a wonderful ring to it. Something to do to make my functioning better, my life more manageable. Faced with my changing reality I had to build around myself a support system"...." A team to equip myself for my future with MS." (Singer, 2001).

Most importantly Lauren demonstrated her motivation to inspire future therapists in their dealing with people with chronic illness. Her personal attitude is reflected in these extracts from her personal journey :

“ no matter my disabilities I had never seen myself as disadvantaged by them. Inconvenienced, yes. Made incompetent, no. I had always been able to compensate from any problem I encountered. And so I would again. I would relearn to separate the symptoms from the inner me. I would find my new path. And walk it.”(ibid)

7.4 PROCESS AS PERSONAL LEARNING CURVE

As I went through the process I realized that my experience was characterized by multiple learning opportunities, all of which were personally enriching.

7.4.1 Personal learning through “lived experience”:

Through my experience, I learnt much from Lauren that was useful both from a teaching and practice perspective. Lauren used her heart, mind and soul to teach. She was very affirming of students as they ventured to contribute. Whilst able both to challenge and confront, she balanced this with an approach that encourages student participation. She used humor to many ends, to lighten the mood when discussions become too heavy, to relax the students and to surprise and challenge them. Variation of tone, pace and volume all the time added interest.

Despite many years as an occupational therapist, my own awareness of what it means to be disabled, was developed. New appreciation of the limits of teaching from a educator perspective was gained and greater conviction of the need for learning from the experience of those receiving service. Realizations that I could not share what Lauren

could become apparent. At best an educator can share from her personal experience with clients or from her own experience. However, this falls far short of what Lauren was able to share. Of particular benefit was the power inherent in the natural unfolding of meaningful stories that are part of a wider narrative of Lauren's life. The emotional response to disability, an integral part of the experience of disability is much better shared by the person who has been there.

The experience was to me as if on a journey. I became more acutely aware of how important it is to listen, not to judge, and to journey alongside Lauren. I became more aware of how much the disabled person brings to treatment and more aware of the need to allow Lauren to experience the potential empowerment of her position as teacher. I realized how much power the therapist can assume in a relationship. Lauren is very solution rather than problem-orientated. Many therapists have a deeply embedded orientation towards problems rather than assets. They often believe they are the experts in problem-solving, and may underestimate the capacity of the disabled person in this role. The danger of making assumptions continues to challenge qualified therapists.

Lauren stressed the importance of learning to instruct others well and the importance of learning how to cope with unanticipated difficulties, accepting that they will occur and learning how to manage the crisis calmly. Therapists may be in danger of overstressing the need to perfect certain skills at the expense of learning to cope with unexpected events. The importance of building a framework for guiding actions and directing choices in a crisis situation may be more important. I became more aware of how students need to learn how to be enabling to disabled people.

I also became more conscious of how privileged occupational therapists are to be invited into the most personal and intimate of spaces in client's lives and how this should

be respected. Listening through the student's ears helped me to appreciate this in a new way.

7.4.2 Challenged by assumptions about student knowledge:

I became aware through reading of student reflections just how many assumptions I had made about student knowledge and understandings. I realized that this unconscious making of assumptions may be seen as similar to the assumptions that therapists may make about clients. Providing the forum and sufficient time for student interaction at this early stage of learning to clarify any misunderstandings, and to relate issues to their own experience, is absolutely critical. This is easy to overlook or underplay with the many issues that do arise and create a pressure on the time available. I was surprised by what many students did not know about disability. Collating data from the student group perhaps led me falsely to assume that the students had more knowledge and experience than I had appreciated. I realized that it could not be assumed that students would necessarily have confronted any of the concerns of occupational therapists.

7.4.3 Learning from reflective practice

The experience confirmed the importance of reflective practice, not only in therapy, but also in teaching (Alsop,2002) I witnessed the value of all the participants reflecting on the experience and the personal growth it enabled.

Reflection for all of the participants enriched our experience together immeasurably. It is through reflection that one is able to appreciate the fullness of ones' learning experience. It is through the reflections of others that one is able to take learning a step further. It made for greater collaboration in learning. It revealed assumptions and exposed innermost emotional responses. It encouraged us to ask more questions, and in so doing, I believe that it facilitated deeper level learning. The quality of reflection was highly dependent on the questions used to frame the reflections. It was dependent on long, hard thinking and on challenging what one had experienced in order to make sense of it.

Lauren and I also engaged in a great deal of reflection together as we enjoyed discussions stimulated by the students' written work, which gave us a common stimulus for reflection.

7.4.4 The importance of feedback for all participants: "looking backwards to move forwards"

Reflecting on the experience has led me to understand how important feedback was in the process. Feedback from Lauren served to encourage my commitment to the partnership approach. Likewise a full class of keen students was in itself very affirming to me as educator. I had a strong sense that the students were enjoying the input through the level of attention they were giving, the thought provoking questions asked, and the obvious emotional responses to what was shared. This again was important feedback. I found it personally rewarding to witness the pleasure and challenge that Lauren experienced through her engagement with the students. I enjoyed seeing her so involved in the planning of the lecture series.

I noticed how Lauren seemed to gain in confidence through access to student reflections. She remained sensitive to picking up on issues raised by myself and the students as occasion allowed. An important component of reflection is responsive feedback to the student and through this, the creation of an avenue to take the issue further or to reassure the student or respond to queries. It was encouraging to hear from Lauren that she was also learning from the students. Their feedback formed an excellent basis for discussion and planning.

At the end of the course, I was able to give to the students feedback directly from Lauren and from my provisional analysis of their reflections, which I believe gave them a sense of their learning process.

7.5 “NUTS AND BOLTS “

A significant part of my experience was related to feeling responsible for all the practical details of organizing and running the course. This was different from any other teaching experience I have had and placed an additional load on me. I also needed to maintain a high level of awareness of what was happening from many perspectives and needed to intervene sometimes to get the session moving in the direction desired. It involved making lots of choices and taking action where necessary.

7.5.1 Creating a climate to maximize rapport and learning for teachers and students: “setting the scene”

The program demanded that the climate be conducive to developing intimate and honest communications. I was conscious of allowing students to voice their opinions freely. It was especially important to encourage the more tentative students. I was aware that as facilitator of the lecture series, I had control, which could have stifled Lauren’s contribution, e.g. by not allowing a silence when it was necessary or by making light of some issue to make it less uncomfortable. I believe that the situation called for a high level of sensitivity to non-verbal responses. I was aware that I did not always succeed in doing this. I particularly recall a situation when Lauren showed a short excerpt from a video made for a local TV program some 10 years ago. It was difficult to be confronted with just how devastating the impact of MS had been on Lauren’s mobility. Many of us were moved by the experience. I however, was conscious at the time, of my response of attempting to underplay the impact. In so doing, I hoped to alleviate some of the discomfort being experienced. Sometimes silence was an important response to what Lauren had shared, however a shared silence is sometimes more painfully experienced.

I was aware that Lauren, through her ability to share on a very intimate level could draw students into her inner space. As an educator I felt there were more constraints on myself in this level of sharing, but this is possibly to be expected given my involvement in student evaluation and ongoing teaching.

As the lecture series progressed, interactions between Lauren and I became more spontaneous and less formal over time. Initially I had felt the need to keep a slightly more rigid structure but was later able to relax more as the unanticipated learning opportunities became more evident.

Initially I experienced some apprehension about how Lauren might be experiencing the focus on the most intimate aspects of her life. This presented something of a dilemma to me and required that I remain observant non-verbally and responsive throughout. I discussed these issues with Lauren throughout the lecture series. No amount of planning prior to the sessions can fully prepare one for the questions or issues that might arise. The complexity of the relationships evolving and emotions expressed in the classroom were unpredictable.

One session was less successful in maintaining the students' attention. In this session, which was the first after a longish break, an attempt was made to illustrate with video material the challenges that Lauren deals with in terms of communication. Whilst the material was relevant, the audiovisual equipment was inadequate for the size of the class, making it difficult to see and hear. In hindsight, the exercise was also too passive, which led to a lapse in the attentiveness and engagement of many students, reminding us of the fragility of the climate and the need to sustain the interactive component.

7.5.2 Logistical challenges: “putting it all together “

It was necessary that I facilitate the sessions to optimize student learning through the most efficient use of the available time. Familiarity with the lecture series material made this easier. It was essential that thorough basic planning was done before each session and that space be left for maneuvering using the ‘sharing of the lived experience’ as a form of ongoing case study. Participation in the course required that Lauren be transported to and from the session. There is time and effort involved in this commitment, given that Lauren is not able to drive and her mobility is severely challenged whilst her energy reserves are also low. I was fortunate in being in a position to be able to fetch her. This may not have been possible for lecturers in other situations. We lived geographically close to one another and only a short distance from the teaching venue. The double lecture period was an ideal period of time given Lauren’s energy limitations, but even without this limitation, the intensity of the sharing would make any longer period too personally draining.

The time factors increased my participation time by at least 1 ½ hours for each session, which included the time taken for communication prior to sessions together. On one occasion we experienced difficulty with the electronics of the scooter which meant an unscheduled stop at a local auto-electronics dealer after the session. This understandably required additional time and such difficulties had to be anticipated. Additional time was also spent in follow-up after the session and in ensuring that feedback in the form of reflections were made available for Lauren. Negotiations around the teaching content, which is critical to true partnerships, is costly in terms of time and this must not be underestimated if a program is to be successfully implemented. Likewise, the collection of additional audiovisual material to supplement sessions took extra energy and time to compile.

Negotiating the traffic in a busy shopping centre whilst trying to manage the dog, Fred, operate a video camera, and at the same time, ensure Lauren's safety at the intersections, was one of the more challenging dimensions of my experience. The ever-present threat of the possibility of Lauren's health status changing was a concern for me. At the start of the lecture series, Lauren was undergoing cortisone treatment in hospital on a regular monthly basis. She also indicated that she was experiencing depression. I recall feeling some anxiety that we might not be able to proceed as planned. Multiple Sclerosis is associated with some unpredictable emotional and cognitive decline. Research shows that cognitive disturbances can occur quite early in the course of MS as a result of widespread plaques of demyelination, which may significantly affect the person's emotional status (Berrol, cited in Heller et al, 1989). Likewise, the progressive and debilitating nature of losses may exacerbate emotional disturbances (*ibid*, 1989). This is confirmed by Lauren :

"Sometimes my short-term memory becomes faulty. Sometimes I may become garrulous – there may be a degree of disinhibition (as if I had had a little too much to drink). Sometimes it may be difficult to order my thoughts. I may blurt out a complete non-sequitur. At times it may be difficult to motivate and initiate thoughts and actions" (Singer, 2001).

Facing this type of difficulty caused some personal stress in the experience and contingency plans were considered. This involved more work for me as educator. One of the ways around uncertainty was to create audiovisual material of two of the aspects that were due to be covered. Part of the reason for doing this was to have 'shared experience' recorded should there be some reason that Lauren be unable to participate for health or other reasons.

As educator, I had to remain flexible in approach and method. The relative inflexibility of timetables could be problematic if disrupted due to unforeseen events. I ensured I had a contact number for the students in case of a delay.

In addition I sometimes found the pressures of a set timetable quite limiting. Teaching with Lauren made it more difficult to keep the content confined to PLS. I became more aware of just how integrated all the areas of a person's life are and how much disability issues are an integral part of discussion. It became much harder for me to compartmentalize the work.

I was able to use the two sessions in which Lauren was not able to participate (not for health reasons) to introduce other self-care issues that did not have particular relevance to Lauren's situation.

It was a concern that there was some compromise necessary in having one 'case study'. Providing an in-depth understanding in one context, was done at the expense of broader exposure. OTs work with many different clients, so I had to trust that the students would learn in ways that would enable them to transfer knowledge to other clients. The response of the students in their feedback session reassured me that this was not a major concern for them and they felt that they had benefited from the continuity.

7.5.3. Accommodations : "enabling it to happen"

I became more aware of the accommodations needed to enable full participation by the 'disabled expert'. Fatigue is a major constraint, requiring that participation be limited to once per week because of the energy demands in getting to the university and participating for the full session. This also meant structuring the lecture series so that routine could be maintained for her within the given timetable.

Lauren's speech can become impaired with fatigue and so as educator, sensitivity to the changes in her speech is required. It was necessary to ensure that her energy was conserved to the point that she would be able to manage the mobility and transfers to and from the car to get home. Conscious planning was done for a later start in the practical sessions, to ensure time for Lauren to get ready physically for the session and not to compromise her energy through rushing. I was also conscious of spacing her contribution in discussions to conserve energy for the duration of the session. It was necessary to have prepared backup material for use should difficulties have been experienced.

On a practical level it was necessary to arrange permission for 'disabled parking' and for her to bring her service dog to the hospital. It was necessary to ensure that access within the teaching environment was not a barrier. These accommodations were shared with students, presenting an unanticipated learning opportunity.

7.6. Reflections on roles and responsibilities of participants

I reflected in depth about the role of the different participants in the experience. This ongoing 'thinking through' characterized my experience. I thought through how best to use Lauren's 'lived experience', I thought about what else needed to be included apart from 'lived experience', I thought about how to structure the lecture series and each session to optimize learning.

I thought about how students were contributing to Lauren's experience, how they were experiencing their learning. I responded to them through adopting a facilitatory role.

I watched the participants carefully so that I could respond to any uncomfortable situations timeously. I was also looking for opportunities to encourage students to share from their own experiences and to contribute in other ways.

In hindsight, having multiple roles in the process helped me to counter the possibility of feeling a little 'disempowered' through the attention given to Lauren's sharing. Instead I was aware of how much an educator can contribute to the process through facilitation. An important part of the teaching was involving Lauren in discussion about the direction each session would be taking. I believe it created opportunity for Lauren to consider some of her possible input prior to the session and perhaps to prepare her emotionally to share on some of the more intimate issues. It was important for me to share the OT focus and then to hear how she might assist student learning.

7.7 The influence of ethos in Division of Occupational Therapy

As I mulled over the apparent success of the learning experience and my positive feelings resulting, I became aware of the importance of the prevailing ethos in the Division of Occupational Therapy. This ethos actively encouraged the adoption of an innovative teaching method. There could have been multiple barriers to this method of teaching (with its many variables affecting success), which could have severely hampered attempts to establish and sustain the partnership. This program was able to be implemented as part of a broader curriculum which demonstrates the value that the institution places on current global and national debates influencing trends in OT and disability. The partnership might perhaps not have had the same significance isolated from such a context.

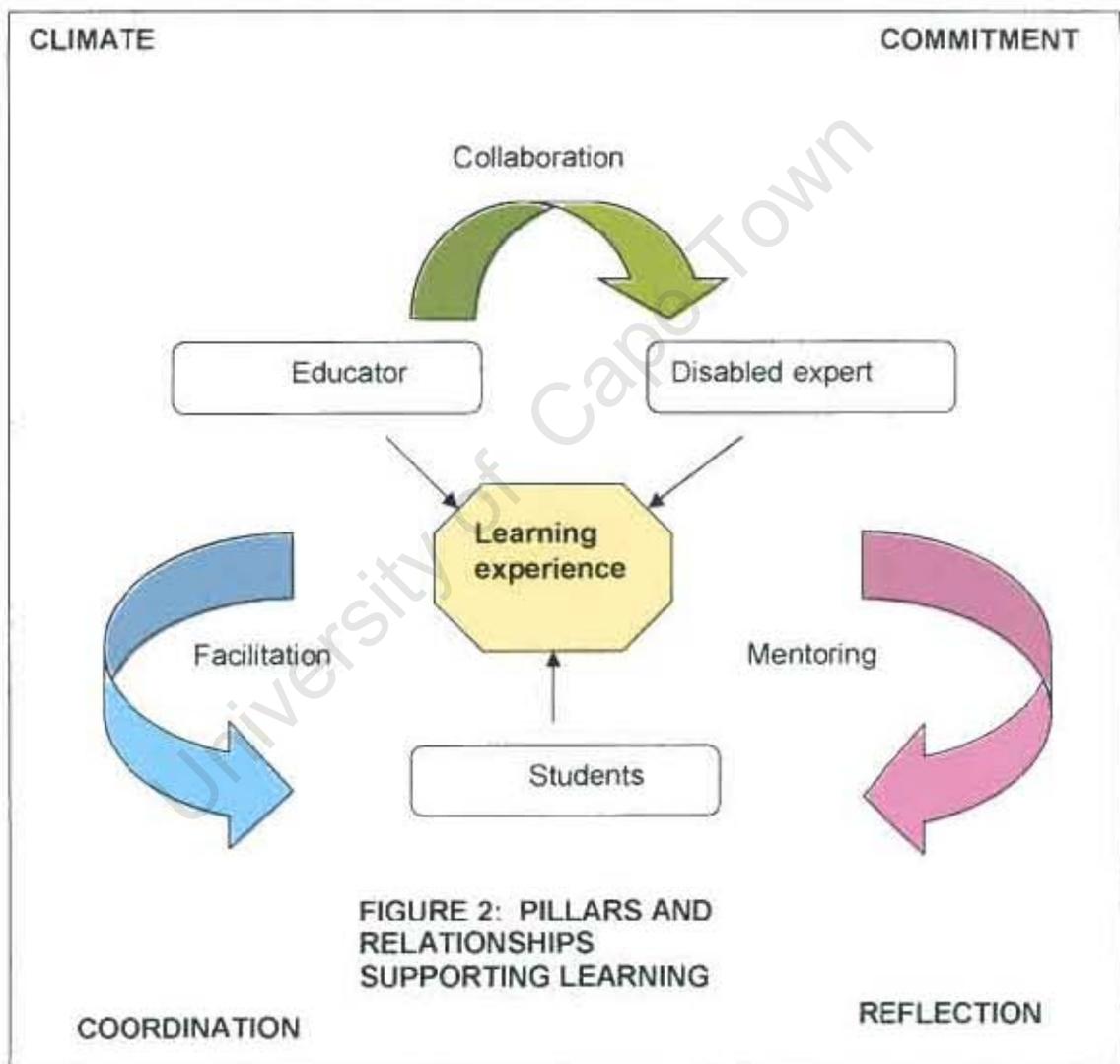
7.8 Conclusion

The experience was very enriching for me personally. Whilst demanding from an organizational perspective, I had a deep sense throughout that this form of teaching was making perfect sense. It was rewarding to witness students relate to Lauren and

challenging (in a positive way) to decide how best to draw on her stories to help students to better understand the work of an occupational therapist.

CHAPTER 8: EXTRACTING LESSONS FROM FINDINGS

As I analysed the data, it became clear that the different experiences of participants should not be detached from one another. The following model was designed to illustrate the interactive, dynamic nature of the relationships between the components/ participants that affected participants' experience of the lecture series.



The rich learning context created by the partnership had the potential to create diverse opportunities for all the participants. It is suggested that a 'synergy' existed, by this is meant a 'cooperative working together' which produced a total effect that was greater than the sum of the individual contributions. This energy that comes from the cooperative relationships enhances the effectiveness of the dynamic whole.

However, for the context and opportunity to be maximized, there were four pillars that emerged as foundational to the learning context. These four pillars included the climate created for interaction, the demonstrated level of commitment by participants to the program, the coordination implemented and the depth of reflection encouraged. These in turn, supported the development of ongoing reciprocal relationships between the participants in different forms – including a 'mentoring' relationship between Lauren and the students, collaborative partnership between Lauren and I and a facilitatory relationship between the students and me.

Falardeau and Durand (2002) suggest an alternative conception of client-centered practice – one that puts accent on interdependence, partnership and negotiation. In their words :

"Negotiation means establishing a bond with the other person, in an atmosphere where listening is as important as expressing your views. It is a perpetual back-and- forth between the therapist and the client. It is an exchange that goes beyond the established power struggle."....."There is no definitive recipe. Negotiation requires constant attention, a strong desire for understanding and a will to go in-depth. (p 139).

They describe a possible client-led (type 1) and an interaction-led (type 11) client centered approach. In the interaction led type of practice recommended, there is emphasis on decision- making that reflects both the priorities and feedback of the client together with the influence and experience of a therapist in a negotiation

process. This perhaps best describes the “collaborative relationship” demonstrated to the students through a ‘give to’ and ‘receive from’ process during the sessions (*ibid*).

On reflection, it appeared that Lauren fulfilled a mentoring role with students. According to Daloz,

“a mentor supports (provides a safe environment in which the student can risk development); challenges (creates a cognitive dissonance encouraging the learner to develop new understandings) and helps the learner to apprehend new realities in a more comprehensive way”

([URL:http://www.isn.curtin.edu.au/tlf/tlf2001/martinp.html](http://www.isn.curtin.edu.au/tlf/tlf2001/martinp.html))

All these relationships were found to be important to the learning process. A weakness or disruption at any point of this interactive process could have impacted on the success of such a learning program and on the experience of participants. I have attempted to summarize the experience of the program in terms of this framework.

A **commitment** to the concept of transforming the traditional ‘professional-led’ teaching process was necessary to potentially transform the way students engaged with the learning matter. This commitment was embedded within a philosophy of education that reflected concepts of empowerment and enablement of people. Commitment was particularly strong in this program from the ‘disabled expert’ who demonstrated great drive and personal initiative throughout the process. The commitment of the students was also very consistent, with high attendance at lectures noted throughout the sessions. It must be borne in mind that all were aware of the research dimension which may have influenced levels of commitment positively as a result of a perception of feeling singled out for special attention.

The quality of **coordination** is believed to be a factor affecting the program. Inherent in this teaching approach were losses, gains and risks for the educator. As the major coordinator of the process, the educator has the privilege of creating and maximizing opportunity for the other participants through choices made about structure and design of the course. This suggests that there was a facilitatory relationship with the students and a collaborative relationship with the 'disabled expert'. On reflection, I believe that the course was carefully structured and that the 'disabled expert' was well prepared for the sessions and given appropriate, timely feedback from the student reflections. Sufficient time was given for regular communication between educator and 'disabled expert'. Students were also well informed about the role that they were to play in the process. Written feedback was given to their reflections and queries addressed.

An **enabling and affirming climate for interaction**, was judged to be a fundamental contributor to the experience of the participants. It was consciously and unconsciously created by both educator and the 'disabled expert' as well as by the students. It was vital to ensure sharing by the 'disabled expert' and to encourage spontaneous and thoughtful responses from the students. The 'disabled expert' needed to be sensitive to educator needs e.g. to meet deadlines or objectives, whilst the educator needed to attend to any accommodations necessary.

The climate during this program was conducive to a deep level of sharing of information by the 'disabled expert'. I believe that this was made possible by the attitudes of friendliness, respect, interest, compassion, seriousness and responsiveness shown by the students during the course. They often expressed their gratefulness to Lauren both verbally and in their reflections which gave her the level of comfort and assurance to continue with the program.

During one particular session, there was a lapse in the student's concentration which definitely impacted on the climate and the feelings generated in all participants. This made us aware of the particularly sensitive area of climate, which may in itself be the major driver of a successful process. Rebeiro (2001) highlights the importance of the environment in enabling occupational performance. An affirming social environment together with opportunities for choice and opportunity was described as being key to improved participation and performance (*ibid*, p. 88). She describes a 'just right' environment that was safe, relaxing and comfortable, and as a result, enabling (p.87). This study supports findings that link environment with performance.

A rigorous commitment to personal **reflection** and **feedback** at all levels was another integral cornerstone to a successful partnership approach. All participants have the potential to gain from regular personal reflection in this process. Personal reflection enables feedback to be given which is essential for an evolving learning program to develop in ways that are beneficial to all the participants.

Reflection was an issue that the students seem to have approached with maturity – whilst reflections that were handed in for review may not have been representative of other reflections (i.e. those not required for marking), I believe that students were challenged by what they heard and their responses to the sessions suggest that they thought carefully through their experience. Alsop suggests that "reflections may be thought of as the images of our experiences, revisited for the purpose of learning" (2002, p. 203). She suggests that reflective activity offers a spiral approach to learning by allowing us to gain new insights into our experiences through revisiting our memory of events (*ibid*). She describes the intentional and serious effort required by reflection, and this certainly speaks of my experience in the process.

All participants had opportunity to both contribute to, and gain from the potentially dynamic learning program. This approach to teaching was dependent on interaction and input from three sources: 'OT input' from the educator, personal 'lived experience' from the 'disabled expert' and the existing knowledge and personal experience of students as they responded to input given, and shared from their previous life exposure.

In order for the learning to be optimal, the educator needed to make choices that honored the contribution of the 'disabled person' as 'expert of lived experience'. She needed to encourage sharing through prompting and opportunity. There were also choices to be made that invited student response. I believe that in our program there was sufficient opportunity given to the 'disabled expert' to share from her 'lived experience'. If anything, it is my impression that her 'case' was given precedence over most other examples/ cases in all the sessions, which I believe honored her contribution sometimes at the expense of other possibilities. Students did not always have as much time for sharing from their personal experience as would have been liked.

CHAPTER 9: CONCLUSIONS AND RECOMMENDATIONS

In this chapter I will draw final conclusions about the experience and explore some of the broad implications for students, future 'disabled experts' and for health educators. I will describe implications in the form of responses to further questions that I raised after completing the analysis. Recommendations arising from the findings will then be presented.

9.1 IMPORTANT FINDINGS LEARNED FROM PARTNERSHIP

The following points capture the essence of what was learned during this process:

The partnership experience was experienced as a 'juggling act' by educator.

All participants endorsed the use of this teaching strategy. However, experience of individuals is variable and unpredictable.

Students experienced disjunction during the learning process, which prompted change and offered opportunities for both personal and professional development. Gains are not predictable, nor can they be generalized.

Lauren's experience was predominantly a positive one, with multiple benefits being derived, despite heavy personal demands.

The experience confirmed the benefits of an educator working together with a person with a disability in the field of OT education.

The experience confirmed the benefits of an educator working together with a person with a disability in the field of OT education.

The joint partnership strategy in this context has unique benefits in promoting a 'deep learning approach'.

The process of teaching in partnership is a fragile one and has some risks inherent in it. Success is also dependent on the program being compatible with the prevailing ethos in the teaching department

The choice of 'disabled expert' and the rapport experienced with the educator and students, is critical to the participants experience of the teaching approach.

The process is labor and resource-intensive (particularly for the educator).

9.2 IMPLICATIONS OF STUDY:

The following questions were seen as crucial in considering the merits of the teaching partnership:

Do the study findings support the participation of disabled people in formal training programs for health professionals?

Do the benefits derived from participating in such a program outweigh risks to the 'disabled expert'?

In what way is this partnership approach providing a unique contribution to promoting a 'deep learning approach'?

How practically feasible is this approach for an educator to implement given that it is resource-intensive?

9.2.1 Do the study findings support the participation of disabled people in formal training programs for health professionals?

The value of the client's perceptions are essential to the continued development of OT service as they help to expand our knowledge of what clients want and how they experience our services. This program showed clearly the unique contribution made by the 'disabled expert' as 'case study'.

Literature does, however, suggest that when health professionals collaborate with disabled people, a power differential may sometimes influence the partnership. It is clear that if disabled people were to be involved more widely in teaching programs, preparation for this role might itself need to be part of an empowerment initiative.

9.2.2 Do the benefits derived from participating in such a program outweigh risks to the 'disabled expert'?

An important finding was the multiple benefits that Lauren appeared to derive from her involvement. The personal demand on the client who chooses to share aspects of 'lived experience' with relative strangers (students) is heavy and it is vital that there be such benefit if sustainability of such a program is to be achieved. Whilst the benefits for others may not be the same as they were for Lauren, I believe it was a potentially empowering opportunity which resulted in significant personal gains for her.

of the important outcomes for the client who is involved in the sharing of 'lived experience'.

I have also considered the relationship between student reflections and Lauren's motivation. Lauren was very positively influenced by the nature of the student reflections. This could have been different in the absence of feedback from reflections or should the reflections have not been so complimentary. The educator acknowledges the risk in this for the 'disabled expert'. Uncertainty about participation in the longer term is another risk which may impact negatively on the 'disabled expert', especially considering the personal investment already made to the partnership.

What may be of particular relevance to the benefits is the stage of adaptation of each person sharing. Lauren is at a stage where she is seeking to gain a deeper understanding of the meaning of her experience of MS. In her case there is a sense of MS having been integrated into her life experience. There was particular maturity of insights to her sharing, making it perhaps easier for students to respond to her than if she had been in one of the earlier stages of adaptation. This is a very important factor to be considered in choice of person for sharing. There may even be detrimental consequences for the 'disabled expert' if sharing is required at another point of the adaptation. There is also uncertainty about the possible long-term impact of repeating the experience each year.

9.2.3 In what way is this partnership approach providing a unique contribution to promoting a 'deep learning approach'?

Students adopting a 'deep' learning approach appeared to be one of the positive outcomes of using this strategy. This supports findings by Houldsworth and Hodgson, who have identified three features that promote 'deep' learning – the 'realness' of environments, the facilitation and interaction occurring during the learning, and the organisation and management approach. I believe that the 'realness' of the context and experience, as well as the interactive component in this study, facilitated enhanced a deeper learning approach. (URL: <http://www.pedagog.lu.se/personal/sb/papers/Phenomenography>) . Gains in depth may be at the expense of range, but will likely strengthen the personal attributes that students bring to their training and introduce them to develop the collaborative skills to practice responsibly and reflexively. This lecture series provided students with opportunity to confront their attitudes towards important disability issues that will impact on later practice.

Stereotyped thinking may even be perpetuated by health educators as they reinforce thinking learned from their own experience gained through medical model approach training. There is less likelihood of this happening when the teaching is shared.

Learning extended beyond PLS as students learnt much about disability issues and human resourcefulness and resilience.

Reflections such as these suggested multiple opportunities for students to grapple with some important personal and life issues.

I believe that the empowerment of students, by facilitating their psychosocial development, is akin to the empowerment and client-centeredness that is valued in the occupational therapy profession.

I believe that the empowerment of students, by facilitating their psychosocial development, is akin to the empowerment and client-centeredness that is valued in the occupational therapy profession.

9.2.4 How practically feasible is this approach for an educator to implement given that it is resource-intensive?

It is clear from the study that this collaboration is a resource-intensive method of learning. There needs to be a regular monitoring of the process to ensure that the learning opportunity is beneficial to all participants. Additional remuneration needs to ensure that the 'disabled person' receives appropriate recognition of their contribution to student learning. The process is costly in terms of time and energy for the educator, however, it is felt that these extra costs are easily justified when considering the range of benefits to all participants.

This partnership experience has value in that it demonstrates in practical and understandable ways this most fundamental philosophy held by occupational therapists – that of keeping the client's voice central to the decision making process. It should not be compromised if at all possible.

9.3 LIMITATIONS OF STUDY

9.3.1 Limitations of Case Study Method

Findings from single case studies are not a strong base for generalizing to other cases (Stake, 1995). However, people can still learn much that is 'general' from single cases. I made conscious choices in the presentation of the research to enable the reader to be able to gauge accuracy, completeness and bias for themselves. Basic

comparisons with other situations can be drawn by giving attention to the contextual information. Raw data was given so that alternative interpretations could be considered. To enable readers to make naturalistic generalizations, attempts were made to give information about myself in the process, and to be explicit about my choices made.

9.3.2 Limitations of data collection method:

There are limitations to the amount of data that can realistically be analyzed. It was important to select the bits worthy of more attention for focus. This was my personal choice which can be seen as a limitation given my lack of experience in qualitative research. In hindsight, the focus on the experience of all participants was too wide for in-depth qualitative data analysis. However, the benefits of gaining clarity about the 'whole' may be viewed as a starting point in gauging the experiences of participants. More in-depth analysis of each perspective would deepen understanding about the experience of participants.

The use of student written reflections is only one method of gaining information from students. A focus group could have been used, which may have revealed different information. The personal journey of one student could also have been followed which would have yielded still different findings. The likelihood of eliciting negative feelings about the course was possibly unlikely although opportunity was given through the questions framing reflections. Students may also have been inhibited in committing negative opinions in writing for fear of this impacting on their summative evaluation. Some students who perceived themselves to have lesser writing skills or confidence may have been disadvantaged in the depth of their reflections. The

guidelines for reflection also have a significant effect on what is written and therefore available for analysis.

A further issue concerns the students that did not submit reflections – would these students have gained from the program to the same extent? It was not compulsory for students to hand in reflections, although the majority did. The question arises whether only those that take the time to reflect and receive the feedback really learn?

By analyzing a large number of student reflections, one loses sight of the individual journey of a single student. I am mindful that each student's experience was likely to have been different.

Likewise, in learning about Lauren's occupational experience, I could have done in-depth interviews, which may have yielded different information. Lauren did not reveal much about her perception of working with me as the educator in the teaching program. It is my opinion that she perhaps viewed me still as much in control of the program and that as such I have influence on her continued involvement. This may have been a constraint in what she felt able to share with me.

9.3.3 Breadth of learning experience compromised

A limitation in this program is the focus on a single client 'context', selected from many others that could have expanded their understanding about contexts that were more different from their own. There is some sacrifice to be made in terms of the breadth of exposure to different kinds of issues. This is especially relevant in a context such as in South Africa, where Lauren is not representative of the majority of the population in terms of socio-economic privilege, educational, cultural or language background. Poverty is considered the country's biggest challenge and it has a

service orientation to accommodate populations as well as individuals (Watson & Schwartz, 2004). I am aware that working with such an 'individual' case does not in any way meaningfully address this more recent broader focus. Therefore, from this 'personal' level of understanding, there must be a shift towards a community and societal level of understanding – i.e. from a 'private to a public perspective' (*ibid*, p. 56). However, I don't believe that this negates the value of the understanding of the personal perspective. Many disabled people have recognized that the social model of disability, whilst acknowledging societal barriers to disabled people, falls short of addressing needs arising from the 'individual' perspective. Both perspectives need to be addressed by occupational therapists.

A further concern is the exposure to one particular phase of the transition process.

9.3.4 Unpredictable learning outcome:

The long-term impact of exposure to this learning is not able to be predicted from this study. Ideally one would want to know whether this kind of approach to teaching will impact positively on student clinical practice, the ultimate goal of student training.

9.3.5 Impact of greater diversity of the student profile:

This student group was fairly homogenous and so it was not possible to ascertain the impact of greater diversity on the perceptions and ultimately the learning experience of the students.

9.4 RECOMMENDATIONS:

9.4.1 Expanding the approach:

From the findings of this study, I recommend using 'disabled experts' in other learning contexts. It is a method that can be used in other divisions/departments in the Faculty of Health Sciences. For example, all students in health-related fields would benefit from the opportunity to learn from shared 'lived experience' to deepen students' appreciation of the need for a client-centered orientation, which is central to many aspects clinical practice. This program requires time outside of the pressures of clinical management.

9.4.2 Marketing the teaching approach:

It is really important to recognize fully the integration that is necessary between personal awareness, knowledge, attitudes, experience and professional skill. Recognition by educators of the added dimension that 'lived experience' brings to the learning situation will drive the implementation of such a partnership in teaching.

An important recommendation would be that this partnership approach needs to be marketed if it is to expand. Groups representing people with disabilities could be targeted in addition to representatives from training institutions who are responsible for curriculum design and planning. Particular care must be taken in nurturing the process and to avoid exploitation.

9.4.3 Resource planning and provision

Additional financial resources need to be made available if this kind of teaching partnership is to be undertaken as it is a costly process in terms of professional time. Roles and responsibilities need to be negotiated. A readiness to enable participation through accommodations is also necessary.

A register of people willing and able to be involved in such programs could be developed. The support of the Division and health faculty should be sought and feedback about partnerships could assist in raising awareness. Clinicians could be helpful in selection of potential 'disabled experts'. Lecturers would benefit from additional training to utilize these methods.

9.4.4 Time for reflection and feedback

An important part of the course requires that students have enough time for reflection and for sharing of their learning journey. It is felt that students might benefit from a closer look at their own emotional responses generated from their exposure to disability. Marks (1999) suggests that people have a number of unconscious fears and fantasies that arise as a result of exposure to disability. Whilst the emotional experience of impairment and disability is a complex area to explore, students may benefit from considering attitudes held, feelings evoked and motivations expressed. Provision needs to be made for enabling this kind of personal growth. Students may benefit from creating a portfolio of reflections which would help them to document and account for their personal development through the learning process.

9.4.5 Monitoring the process

The educator needs to monitor what students are learning from the opportunity. The adoption of a flexible approach ensures that modifications can be made as the course progresses.

9.4.6 Student Evaluation

There needs to be flexibility in the examination style used. In this study students were examined by means of a prepared question relating to their experience. They were permitted to bring a mind-map to the examination as a prompt.

9.4.7 Best stage to use this approach

I believe that this partnership approach is perhaps best used where there is opportunity for relationship to develop over time. The depth of learning cannot be replaced by once-off exposures to the disabled 'expert.' It would be beneficial if students were given the opportunity to re-connect with the 'disabled expert' at a later stage in their training once they have had more exposure to different kinds of issues regarding disability and coping strategies. The same 'disabled expert' could join the same group of students as they continue their learning over the next 3 years and build further on what has already been gained.

9.4.8 Further research

There is much further research that could be generated about the impact of this teaching process. One such study could investigate the impact of the course on student's ability to practice a client-centered approach in therapy at a later stage. Further research could consider the emotional responses to the program and the

ways in which students deal with this emotion. Further focus could be given to the impact of repeated sharing of 'lived experience' on the 'disabled expert' as courses are repeated each year. Empirical evidence needs to be generated that can be used to substantiate the unique contribution to training that the disabled person sharing 'lived experience' makes. Documenting the personal journey of individual students through the course would be another way of studying the impact of the experience on personal development. The disabled expert's perception of working with the educator is another angle that could receive more focus.

9.4.9 The need for caution in using a partnership strategy in teaching

This study suggests the need for caution, as careful choice, meticulous planning and excellent communication are critical to the success of the program for all participants. It is an opportunity that should not be misused as it could have a disabling impact especially at this sensitive stage of learning if not carefully managed. Having said this, I think it is particularly appropriate strategy of teaching at an early stage of training because professional attitudes are not yet firmly embedded and students are receptive to change and growth and at this point.

9.5 FINAL COMMENT :

Among the major outcomes of the Decade of Disabled Persons was the adoption by the General Assembly, of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993.

(www.independentliving.org/standardrules/StandardRules2.html)

Although not a legally binding document for governments, the Standard Rules represent a strong moral and political commitment to take action to attain

equalization of opportunities for persons with disabilities. It is a central theme of the World Programme of Action. Rule 19 (preconditions for equal participation) is concerned with ensuring adequate training of personnel involved in the planning and provision of programs and services concerning persons with disabilities.

“States should develop training programs in consultation with organizations of persons with disabilities, and persons with disabilities should be involved as teachers, instructors or advisers in staff training programs.”

Such a statement suggests that the involvement of disabled people such as the ‘disabled expert’ in this teaching program, should become the ‘norm’ rather than the exception. Equalization opportunities need to be developed on small levels like this within Occupational Therapy training, as well as on many other broader levels, to enable disabled people to contribute input that will help to ensure appropriate service provision. Already disabled people in Africa are, through their own organizations, beginning to address inequality . These groups could be approached to have some input into student training. This would be a fitting contribution to the African Decade of Disabled People (2000 – 2009).

It has also frequently been argued that having personal experience of an event gives a dimension of knowledge that others cannot fully share. This program gives students- in- training invaluable insight that can only be gained from shared ‘lived experience’ integrated into more formal occupational therapy education frameworks.

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APPENDIX A GLOSSARY OF TERMS USED IN THE STUDY

Partnership

This term is used as a means of describing an evolving working relationship between the health professional and the 'disabled expert' in meeting course objectives set for student learning through shared participation in teaching.

Human occupation

It includes the total range of productive, purposeful and meaningful occupations in which people participate. The area of human life with which occupational therapists are concerned. (Hagedorn, 2000)

Occupation is everything people do to occupy himself or herself, including looking after himself or herself (self-care), enjoying life (leisure) and contributing to social and economic fabric of their communities (productivity). (Law *et al*, 1997).

Occupational Performance

Occupational performance is generated by the interaction of the individual mental, physical, socio-cultural and spiritual skill components within an environment (Hagedorn, 2000).

Actions executed, usually within patterns and habits, which form the normal and expected content of a person's existence and are aimed at meeting that individual's needs. (Turner, 2002)

Personal Life Skills

Is a term used by occupational therapists at UCT to describe those activities necessary for maintenance of self within the environment. In some Occupational therapy texts it may be referred to as self-care and care of others. It includes basic activities of self care, mobility, communication, issues related to sexuality and the performance of activities seen as fundamental to participating in society. In this broader sense these activities include house cleaning, childcare, money management, shopping and use of community facilities. It does not include paid employment or leisure occupations. With the exception of eating, many of the components of self-care are usually performed in private and within an individual's personal style, manner and standard. (Turner et al, 2002, p. 28)

Client -centered practice

Collaborative approaches aimed at enabling occupation with clients who may be individuals, groups, agencies, governments, corporations or others. Occupational therapists demonstrate respect for clients, involve clients in decision making, advocate with and for clients in meeting clients' needs, and otherwise recognize clients' experience and knowledge (Canadian Association of Occupational Therapists, 1997, p.47)

Competence

Competence is acknowledged to be a complex concept that is not static. A concise definition of it is elusive. An attempt to define student competence in occupational therapy students indicated that observable behaviour, clinical reasoning, continuing

development and professional and personal attributes were all components of the definition. Self-awareness, risk assessment and reasoning skills were identified as major influencing factors on competence. (Duke, 2004, p. 206)

Projective identification

A term introduced by Melanie Klein to refer to the unconscious process of projection of one or more parts of the internal object into another person. What is projected may be an intolerable, painful or dangerous part of the self of object. It may also be a valued aspect of the self of object that is projected into the other person for safekeeping. The other person is changed by the projection and is dealt with as though he or she is in fact characterized by the aspects of the self that have been projected. (URL:

<http://www.health-dictionary.com/mental-health-terms-details/Projective-identification>).

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Reflective Practice

Reflective practice is defined as "thinking about experiences in practice and viewing them as opportunities to learn, whilst recognizing that one's knowledge is never complete" (Kinsella, 2001, as cited in Roberts, 2002, p.238). Reflective practice involves activities in which individuals engage to explore their experiences in order to lead to new understandings.

ABBREVIATIONS:

PLS	: Personal Life Skills
OT	: Occupational Therapy
UCT	: University of Cape Town
MS	: Multiple Sclerosis

APPENDIX B: STUDENT PROFILE

Of the 62 eligible students in the first year group, 58 of these signed consent for their work to be used for the purpose of publication. Students were all asked at the start of the course to complete a screening form which would provide information about the students' experience of disability, either personal, social or through some work-related activity. The researcher considered that previous exposure, or the lack of it, might have influenced the responses and reflections of students. Interaction between students and teaching staff is a valued component of the course, and it is helpful to be aware upfront of the range of experiences of any student group so that meaningful contribution may be encouraged. It was also anticipated that variables such as age, gender, previous training might all impact on the response to the learning situation. Forty-eight forms were returned, some with missing data, especially as it related to personal experience of disability or disability in the family. It is possible that students were reluctant to disclose this kind of detail at such an early point of contact in their course, and this choice was respected. Some students wrote that they were unclear about what constituted a disability, a topic that was then discussed briefly in one of the sessions.

Following is a brief profile of the student body.

- The student body consisted of 61 female students and 1 male student. Age of the students ranged between 17.11 years and 23.9 years at the commencement of the course.
- 6 students chose not to disclose information about any personal experience of disability.
- Disabilities that had been experienced by students were all of a temporary nature, mostly as a result of orthopedic injuries, with only one indicating experience of a problem of a more long-term nature (attention deficit disorder).
- 3 students did not respond to the question asking about experience of disability in the family
- 25 students responded with varied experience of having a family member with a disability. These disabilities were fairly wide-ranging, including arthritis, amputations, diabetes, stroke, polio, obsessive compulsive disorder, bipolar disorder, intellectual impairment, head injury, deafness and blindness.
- 11 students shared experience of living with a close family member with a disability. This included learning disability, amputation, arthritis, head injury and back problems.
- 34 of the students disclosed some former experience of working with people with disability. 4 students did not respond to the question. This experience included : voluntary work (19students), job shadowing (7 students) at places such as an organization for Riding for the Disabled

(SARDA), Adams farm (intellectually impaired), Open air school, Entabeni and Somerset hospital (people with illness or disability or recovering post surgery), and in services for people with spinal cord injuries and sight difficulties. Some of the students referred to their service learning placements e.g. Valkenberg (for mentally ill). Each of these students has 3 five- week blocks of service learning once per week during their first year of training in OT. At the commencement of the course, students had all been involved in one service learning placement.

- 30 students (i.e. almost half of the group) reported having had previous social contact with a person with a disability. Only 7 students indicated they had had no former contact with disabled people, 8 had had occasional contact and 22 had experienced more regular contact through their involvements.
- When questioned about their ideas about future possibilities/ interests for work, 25 students indicated a primary interest in pediatrics, 4 indicated a preference for work with adults with physical disability, 9 for adults with mental dysfunction and 8 indicated a leaning towards community work. 12 students did not express preference, either because they were unsure or preferred to keep an open mind.

It was thought that this possibly reflected students' limited understandings of the broad scope of OT roles/service.

- Reasons given for studying OT: the majority of students (14) expressed a desire to be of help to people in living better lives; 5 indicated that they would enjoy the challenge and reward of working with people with disabilities or difficulties; 5 expressed a love of working with

people; and 5 described a desire to make a difference to people who were disadvantaged. A number of students indicated that they liked the fact that the profession was well suited to the integration of multiple interests and talents. This question was asked to get some idea of the thinking of students around OT as a profession prior to the exposure to issues during the course.

APPENDIX C1

26.03.2004

Dear Student

Consent for Participation in Study

As you will be aware, I am the lecturer responsible for teaching the first year module "Occupational Performance – Introduction to Personal Life Skills". For the first time, the course has been designed so that learning opportunities are structured in the form of a shared partnership between myself, as occupational therapist/ lecturer and a so-called 'disabled expert'. The course will involve the sharing of the so-called "lived experience" by a 'disabled expert'. As students, you will be invited to interact with both myself and the 'disabled expert' so that a dynamic learning environment may be created in which realistic and creative problem solving around daily life issues can be explored.

As this is a new method of presenting the course, I will be undertaking an evaluation of the impact of this partnership strategy throughout the duration of the course. This will involve ongoing observations by myself of interactions during the class and will involve some in-depth review of selected assignments or other work related to the course. The study will be looking at perspectives of the experience from both teachers as well as the student body. Audiotapes/ videotapes may be done of some sessions. Whilst participation in course related assignments and examinations are compulsory, consent for your work to be used in the study is voluntary. You will in no way be disadvantaged in your evaluation should you decide not to allow your work to be used in the study. No student names will be used in any publication of information. Signed permission will be sought for videotaped/ audiotaped material to be used in any presentation of information. All participating students will be required to complete a

screening form which will serve to provide some personal background and indication of your previous experience of disability and OT.

The exposure to such a partnership in teaching offers exciting possibilities for you as you start your training in the complex ways in which an occupational therapist works. Your participation in the study will help to inform future OT teaching programs and may help to broaden the involvement of disabled people in our training programs.

If you are willing to participate in this study, please sign this form and return it to me as soon as possible.

Thank you for your assistance.

Mrs. M. Linegar

Student name:.....

Signed consent.....

University of Cape Town

APPENDIX C2

26.03.2004

Dear.....

Consent for Participation in Study

As you know we will be developing a partnership in the teaching of the first year OT students Occupational Performance (Introduction to Personal Life Skills) course this year.

I would like to ask for your consent to participate in the evaluation of the impact of the teaching on all the participants in the course. This evaluation will form the basis for my mini -dissertation for a Masters degree in OT. It will involve the analysis of observation data, audio-tapes and selected video-tapes of sessions as outlined on your timetable. I will spend time in preparation with you before each teaching session, and would value any comments, impressions or feedback that you wish to share with me after each session.

I would be grateful if you would agree to be interviewed by myself as part of the study. This may take 1 ½ - 2 hours of your time. I will also be reviewing selected tasks, assignments and examinations of students that are set during the course. Should your health be in jeopardy at any point of the study, you may choose to withdraw from the study and teaching commitments.

I am most grateful for your willingness to play such a potentially valuable role in our teaching program and would like to assure you that any information that is published will be done so only after you have had opportunity to

review findings with me. Naturally you reserve the right to remain unnamed in any publication of findings should you desire this.

I trust that you will find the experience rewarding, thought -provoking and that you will be enriched by your extended participation in our program. Your input will be most valued in any future planning.

Kind regards,
Margi Linegar

Signature of consent:.....

University of Cape Town

Does any member of your extended family have a disability of any kind? (e.g. siblings, parents, grandparents, cousins). If yes, how would you describe the disability? What is your relationship to that person?

Have you ever spent time living with a person who has a disability? If yes, what was/ is this like for you? Were you involved in their day to day care?

Have you had any other personal experience of helping/ working with a person who has a disability? If answer is yes, describe the contact briefly.

You may include any work- shadowing experience you have had.

Have you had any social interaction with people with disabilities in your community?

If yes, describe in a few sentences how you feel about your experiences of interacting with people who have a disability.

What would you say was your main reason for studying to become an Occupational therapist? Do you have an idea of what kind of work you would like to do as a therapist e.g. work with adults with physical disabilities, mental or psychiatric difficulties, community development work, pediatrics?

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APPENDIX E: EDUCATOR OBSERVATION TEMPLATE

SESSION:

Date:

Environment:

Brief description

Observations of Lauren engaging in teaching/sharing

Observations of students' response:

Interest as gauged by non-verbal communications:

Engagement with disabled person. Comments/ challenges/ questions

Engagement with educator. Comments/ challenges

Key moments as observed by teacher (highlights):

Concerns about session:

Logistics/ content/ emotional response/ conflict/frustrations

Comments on working relationship between professional and disabled person as experienced by professional

Meeting of objectives for session:

Objectives for session:

Actual Work covered:

University of Cape Town

Key aspects to remember to pick up on for content:

Additional Insights from health professions teacher

University of Cape Town

APPENDIX F: AHS 108: GUIDELINES FOR REFLECTIONS

- Can you identify key moments during the lecture that had particular significance for you?
- Were there particular aspects of today's lecture that made you see things in a new light?
- Were you aware of any strong personal feelings that were evoked during or after the session? If so, please explain briefly.
- Was there anything that you observed in this session that you think may be useful for an OT working with clients?
- Was there anything that came up during the session that bothered you?
Were you able to deal with/resolve this in the session?

APPENDIX G: QUESTIONS ASKED DURING ANALYSIS

PROCESS:

- Which categories are dominant in reflections? What could be accounting for this?
- What are the major issues or concerns emerging on a broader level?
- What is contributing to the students' obvious enjoyment of the sessions?
- Is there anything from reflections that is standing out strongly?
- Is there anything that I think has been omitted or under-reported?
- Are there any negative experiences or feelings being expressed in the reflections?
- What accounts for so much emotion expressed and personal identification with Lauren?
- What are the student reflections telling me about student training in OT?
- How did the guidelines for reflections influence the data?
- Did the depth of reflections change over time?
- What are the students telling me about how they prefer to learn?

Questions like the following drove my analysis of my perception of Lauren's experience:

- What am I observing as Lauren participates in the class?
- What is Lauren saying to me during our discussions that give me clues to the meaning derived from participation in the occupation of teaching ?

- Is anyone else from Lauren's family saying anything about Lauren's response to her involvement?
- What is Lauren saying through her writing about her experience with students?
- What do her actions tell me about the meaning she derives from the partnership?

Questions asked during analysis of my own perspective:

- What am I feeling during the process of teaching through partnership?
- What is contributing to the apparent success of the teaching?
- What 'extra load' is there on myself as a result of the teaching method selected?
- What difficulties arise from 'sharing the teaching stage'?
- How is my relationship with the students affected?
- How is the teaching different from previous teaching of the same lecture series?
- What am I learning from the process of sharing teaching?
- What planning is necessary to ensure that the lecture series goes smoothly?
- Would I do want to use this approach again. Why/ why not?
- How are the student reflections affecting me?
- How is Lauren's participation affecting what I think about the process of shared teaching?

APPENDIX H : PERSONAL LIFE SKILLS LECTURE SERIES

**OBJECTIVES: TEACHING PARTNERSHIP BETWEEN EDUCATOR AND
'DISABLED EXPERT'- 'LIVED EXPERIENCE'**

Session 1: Visit to Lauren's home

- To introduce students to 'disabled expert' – Lauren, within the context of her home, family and environment.
- To introduce students to basic issues relating to independence.
- To introduce ways of learning about being disabled – 'playing disabled for a day'; learning from 'lived experience'.

Session 2: Self care and "lived experience" of disability. Feeding, dressing

- To introduce components of person, occupation and environment and to explore their relationship to occupational performance (related to Lauren and her occupations/environment).
- To differentiate definitions related to Occupational Performance, activities of daily living and personal life skills.
- To introduce strategies/ therapeutic options used by an Occupational therapist in intervention for problems relating to Personal Life Skills.
- To identify the influences that an Occupational Therapist must consider in the decision-making process.
- To problem solve with Lauren / OT different strategies to cope with difficulties in feeding and dressing.

Session 3 Self care: Bathing, toileting, incontinence

- To increase awareness about difficulties relating to Lauren's experience of bathing, toileting and incontinence.
- To problem solve strategies with Lauren/ OT for coping with difficulties identified.
- To increase understanding relating to the cost of disability.

Session 4 Self care: Sexuality and relationship

- To increase awareness of sexuality as it relates to the broader spectrum of people with disabilities.
- To expose students to Lauren's experience of sexuality.
- To encourage personal reflection on issues relating to disability and sexuality.
- To identify ways in which an OT might best prepare her/himself to cope more comfortably with issues arising from clients' sexuality-related needs (emphasis on the development of attitudes, interpersonal skills, and reflection on experience)

Session 5 Self care : Communication

- To understand the Occupational Therapist's broad view of problems and intervention strategies relating to difficulties in communication
- To increase awareness about the difficulties experienced by Lauren in her ability to both give and receive communications including reading, writing, relating, watching TV, using a computer, telephonic communication.

Session 6 Barriers to independence

- To identify barriers that impact on the life of people with disabilities (attitudinal, structural and physical) with special emphasis on environmental / barriers.
- To increase awareness of these barriers as they apply to Lauren's situation.
- To increase awareness about strategies that aim to eliminate or reduce the impact of barriers

Session 7 Mobility equipment

- To demonstrate practical use of mobility devices and wheelchair
- To demonstrate variable components of mobility equipment
- To teach students how to make choices/decisions relating to the use of mobility equipment including wheelchairs, seating and walking aids.
- To apply these understandings to Lauren's need and use of mobility equipment.

Session 8 Mobility – lifting and transfers. Mobility outside of the home. Travel

- To demonstrate use of lifting and transfer techniques that are used to lift and move people with disabilities
- To demonstrate appropriate methods for assisting Lauren in being lifted and transferred safely and efficiently from wheelchair
- To increase awareness about issues related to use of public transport and disability

- To increase awareness of difficulties encountered by Lauren in driving and use of public transport/ travel

Additional objectives throughout the course:

- To develop students' understanding of role as resource person and problem-solver in Personal Life Skills Intervention
- To increase awareness related to safety issues in all aspects of intervention
- To introduce/demonstrate assistive equipment relating to different Personal Life Skills activities
- To consider choices made in the light of enabling/ disabling factors and personal attributes
- To foster client-centered approach in intervention for personal life skills

METHODS USED IN TEACHING :

- Home visit
- Interactive discussions between Lauren, OT lecturer and students
- Sharing of 'lived experience' of disability
- Reading from "written" experiences of disabled people, published journals
- Demonstration of equipment and assistive devices available (catalogues)
- Video material relating to mobility equipment and lifting/ transferring
- Video material relating to the use of sign language
- Video material prepared with Lauren to show difficulties relating to barriers and strategies for enhancing communication (computer soft ware).
- Recommended useful internet websites relating to Multiple Sclerosis and assistive equipment
- Power point presentation of assistive equipment used by people with disabilities and used by Lauren at home

- Sharing by students of personal accounts of experience of disability or interaction with person with a disability

Additional Input during the lecture series: 2 sessions

Lauren was not able to be present during these sessions.

Objectives:

- To increase understanding about the influence of disability on the ability to perform household tasks
- To understand the impact of disability on the ability to raise children.
- To increase understanding and intervention options for the Occupational Therapist related to the impact of intellectual or psychiatric impairment on personal life skills

Methods used included:

- Video material
- Sharing of 'lived experience ' of visual impairment as it relates to self care, the care of home and family (person with a disability)

EVALUATION

- Review of reflections submitted after sessions
- Examination question June
- Prepared question (mind map) related to learning from sharing of lived experience by Lauren