Working with cerebral palsy students: A personal perspective

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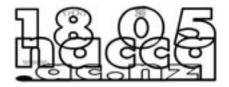Auckland, New Zealand
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ABSTRACT

This paper documents some of the techniques and lessons learnt while conducting interviews with cerebral palsy students when researching the use of technology in education. Consultation in the form of conversational interviews proves to be a valuable part of this research but care needs to be taken as to not offend or belittle these students. Gaining their trust and becoming their friend opens up another world of views that many believed was not there. Many of the usual rules do not apply and working in this area will stretch even the most hardened researcher – both emotionally and academically.

1. INTRODUCTION

Attitudes towards people with cerebral palsy are fraught with misconceptions, but with more and more disabled students being introduced into the mainstream of education, I felt this topic needed to be addressed. Being the father of a child that was diagnosed as having mild cerebral palsy from being a "blue" baby, I was curious about the apparent naivety and discrimination that may result from having misconceptions. My son, although clumsy and uncoordinated as a small child, is now a normal teenager with all the issues that teenagers have today, and with an above average intellect. However, many students who suffer from cerebral palsy are not so fortunate and have difficulty with movement and communication. As a teacher of technology and a researcher of education, I believed that I was in a position to have a positive affect on the lives of these students. But how was I to approach this?

I then spent considerable time in the library - as many researchers do - but this time it was in the health and sciences section reading up on cerebral palsy. After reviewing many books on the subject, it was apparent that one of the biggest hurdles that parents, caregivers and people with cerebral palsy have is the perception that able-bodied people have towards them. The fact is that most people inflicted with cerebral palsy have a normal intellect and some are even superior (Bleck, 1987).

I am neither a medical doctor nor a qualified therapist, nor have I undertaken my research as a parent of a cerebral palsy child. I have taken on the task as an academic and, as such, have attempted to apply academic methodologies to my study. This was not always easy. Established interviewing techniques do not apply when dealing with people who struggle with communication. I spoke to many of my peers, who are well versed in qualitative data gathering, but none of the advice I received prepared me for what was a daunting, yet rewarding task. However, having overcome these apprehensions, I feel honoured to have met these students and gained their trust enough for them to share their thoughts and feelings with me during the interviews. The research was rewarding yet challenging, enjoyable yet humbling, and at the same time provided a valuable insight into the views of another sector of our society - views that are often overlooked.

2. METHODOLOGY

The Hawthorne effect (Roethlisberger & Dickson, 1939) suggests that the act of doing research often changes the outcome. This is particularly apparent when working with students with disabilities. One participant during an interview stated:

"I am proud to be part of your research study…."

How much affect on this has on the overall result of a study is difficult to document. Therefore, for the purpose of any research, participant observation techniques should be used to gather, record and document the data, including:

• Gaining acceptance and developing rapport with the students.

• Gathering data from informal conversational interviews.

• Including the views and perceptions of the author.

• Using both active and passive voice to document findings.

3. INTERVIEWING

The interviews are often in the form of an informal conversation with each student. The questions should be covered without reading them from notes, and without making it less of a conversation; this can be achieved by rehearsing the questions and weaving them into a casual conversation. Practice with a colleague. After the practice conversation, ensure that each question can be answered accurately from knowledge gained from the conversation. Care needs to be taken not to misinterpret the response, and where the interviewer's interpretation is applied to the answer, this needs to be made clear in the transcript.

On occasions the caregiver or parent will often answer for the student when speaking is difficult and a talking machine is not used. Again, the interviewer must be aware of any interpretation that has been applied by the third person. If the student does use a talking machine, be patient in waiting for the student to answer as it sometimes requires a great amount of effort by the student to use the machine. Be aware of this especially if you ask for clarification of an answer. Again, the interview should be a conversation and not a question and answer process. With a conversation, the rapport developed with the student will provide far more enriched answers than a normal interview. For example:

By this time I had won the trust of the student: he wanted to share a secret with me. He said that while he was flying over New York, he had flown into the Twin Towers and crashed. He said:

"I am not a bad person, I just wanted to see if it would work. Please don't think I am a bad person."

He appeared to be tied between wanting to experience the world that the computer simulators enable him to do, and being accepted by what he termed as "real people". I assured him that I did not think he was a bad person (Kearney, 2005).

The conversations should not be recorded, but recorded notes can be taken after each session detailing the student's answers, and the observed emotions and perceived body language by the interviewer. Recordings during the interview can often be inaudible and therefore a pointless exercise. Notes can be made during an interview but care should be taken neither to distract the student nor to appear discourteous. Patience is required while waiting for some students to be able to formulate or even verbalise their answer. Looking away to take notes can appear to be uncaring, so this should be avoided; notes can be scribbled where possible. You will need to concentrate and not be distracted. This will help the student be aware of your genuine interest in what they are saying, and will also enable you to recall the events after the interview.

A structured conversation with the student's teacher, parent or caregiver can be completed after conversations with each of the students. Student answers and the observed emotions of each student can be discussed with them, noting their comments and reaction to these. Once the interviews are completed and notes and recordings are transcribed, a thematic analysis can be undertaken to identify patterns throughout the interviews. This can often be done manually without using computer software such as Nudist, because of the small sample size.

4. WRITING

I strongly suggest that the resulting report is written using solely first person, or both third and first person narrative. Stirling (Stirling, 2003) suggests that the choice of using an active (first person) voice depends on the personal preference of the author. However, throughout my studies, I have always been advised that academic papers must be written in a passive voice (third person).

Stirling states that "there is a strong swing back to the active voice with Lord May, the President of the Royal Society, quoted as saying that he regarded the use of the passive voice in a research paper as the mark of second rate work" (2003, p9). Sheldrake writes that "most scientific journals accept papers in the active voice and some, including Nature, positively encourage it" and that "the active is better at communicating what scientists actually do. Above all, it is more truthful." (Sheldrake, 2001, p1-2). Verbal communication is not the only way that these students communicate. Often their excitement or physical movement will provide much of the answer. This non-verbal communication is interpreted by you, the interviewer, and can often be a personal opinion. I have found that working with these students can also be very emotional and third person narrative does not do justice to the thoughts and feelings that result from these conversations.

Third person appears to be encouraged throughout academic institutions. But this does not preclude the use of an active voice. The Princeton Writing Center suggests that "in academic writing, when a writer has only a weak, unsubstantiated assertion to make, the passive voice appears to cover up the lack of a stronger one" (1999, p2). It is possible to write in third person using an active voice; in fact my institution suggests this in the guidelines for writing publications. For example; "these figures suggests that" rather than "it is suggested by the figures", the latter appearing that the researcher does not wish to be held accountable for the findings. However, when reporting on research with people, it is imperative that the researcher documents their own informed opinion and I suggest that this can be written with an active voice, in first person.

5. DISCUSSION

Various themes are evident throughout my interviews with these students, however one theme is predominant. These young people are very aware that they have disabilities and need special care to be able to cope, but all of them have a desire to be accepted by what they consider as "normal" people. They wish to be able to experience things that many of us take for granted; kick a ball around, drive a car or fly a plane, or even play computer games. For example:

Allan had some use of one hand, and although verbal communication was difficult, he appeared to be comfortable with a computer mouse. His desire was to be able to play Microsoft Xbox games, specifically multi-player games. He suggested that playing with others was important socially. He said that:

"games provide fellowship."

Both the staff member and I were surprised that he should choose such a word as fellowship, but it appeared to be important that he used this word (Kearney, 2005).

The staff member went on to say that these students will never kick a ball around outside with their brothers and sisters, something they would dearly love to be able to do.

Multiplayer computer games provide a social environment that would benefit these students. None of the students that I have spoken to wish to have software written specifically for them; whether it be educational software or custom written games. That would just highlight their disabilities and continue to treat them as different. What they have all suggested is devices to help them be accepted as normal. Whether this is a talking device to assist them with communication, or a device that allows them to play the same computer games that we do, they just wish not to be different. For example:

Shaun plays (Mid-Town Madness) for two to three hours at a time and often likes to just drive around rather than play the game as it was designed. He said that he sometimes like to pretend that it is a driving test and obey all the road rules, something that players do not normally do in car games. He would stop at red lights, drive on the correct side of the road and often follow another car just to see where it was going. He said that driving correctly:

"makes me feel like a real person."

I was taken back by this statement and needed a moment to gather myself. I wanted to reassure him that he was a real person but I was unable to find the words (Kearney, 2005).

Many cerebral palsy students are now mainstreamed in educational institutions. This is to

enable the student to feel accepted in the community, to help the community accept them. This is far from an easy task, yet as technology researchers we are in an ideal situation to assist this sector of our society. Two projects currently underway at Unitec involve both hardware and software which enable cerebral palsy students to play both console and computer games.

Project 1 involves the creation of a configurable game controller for games consoles such as xbox and playstation. Although there are one or two devices on the market for one-handed control, they appear to be designed for an able bodied person and not a person with motor disabilities.

Project 2 centres around car simulators and the emulation of a car driven with hand controls only. This work involves both hardware and software, and can be utilised as a training aid as well as entertainment.

Computer technology was invented to make peoples lives easier. Many of us would laugh at that statement when we appear to have to work twice as many hours to earn the same wage, and we use computers every day. However, as researchers in the technology sector, we are ideally placed to enhance the lives of anyone with a disability, and not just those with cerebral palsy. Unfortunately, most of our lesson plans do not include content that addresses this and I believe that this needs to change. In web design class we encourage students to use cascading style sheets. This technology will assist with the formatting of web pages but it also alienates people with poor eyesight by prohibiting the ability to enlarge the text. In multimedia class we encourage the use of the mouse without giving a thought to blind users who are restricted to the keyboard. In business skills class, we encourage creative transitions between powerpoint slides, without thinking of those users who may suffer from the viewing of flashing or flying characters. Very few programming applications have a voice interface, and I have yet to see one with a pathfinder connection (communication device for the disabled).

Development projects, whether commercial or students work, do not have to solely cater for this sector of our community. But, all development should at least consider that their target market may not all be able-bodied "real" people. Usability testing should not only include users with computer skills, but also those who struggle to use a computer, whether it is from lack of knowledge or lack of physical ability. To do this however, may take time and consideration, and much more interviewing, but will undoubtedly enhance the products usefulness.

6. CONCLUSION

Throughout my research, I have found working with cerebral palsy students to be rewarding and fulfilling. These students have no preconceived ideas of how they view the world, and just "tell it like it is". However, you must win their trust and allow them to open up their lives and share with you. By treating them as normal people, and not patronising them nor talking down to them, you will be rewarded with rich and often unexpected responses. These students have a "disorder of movement" (Stanton, 1992) caused by a damage to the brain, they are not stupid. I am continuing my work with these students in the hope of providing them with tools and techniques that will improve their quality of life.

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