“JUST LITTLE THINGS”:
NURSES’ PERCEPTIONS
OF
QUALITY OF LIFE
FOR
PEOPLE WITH SEVERE MULTIPLE IMPAIRMENTS

CHRIS ATKINS

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ABSTRACT

Notions of quality of life dictate philosophies and policies for services for people with developmental disabilities. There is an abundance of research on quality of life, much of which has influenced the significant amount of study of quality of life for people with developmental disabilities. According to specialist developmental disability nurses, however, this research has little meaning for one group of people with developmental disabilities with whom they work - people with severe multiple impairments. Nevertheless, judgements and decisions about the lives of this group continue to be driven by the idea of quality of life.

While the literature review found that researchers are urged to seek the perceptions of people regarding their own quality of life by asking them, some authors have noted the difficulty in pursuing such a method with people, such as people with severe multiple impairments, who are unable to communicate in the usual ways. Given, then, that it is difficult to directly determine the views of people with severe multiple impairments, this study sought the perceptions of nurses about the quality of life of the people with whom they work.

In order to discover and conceptualise nurses' views, a symbolic interaction perspective was chosen to guide this study and data were analysed using the grounded theory approach. The study was conducted in two stages. Stage One consisted of semi-structured indepth interviews with
expert nurses to explore their perceptions of quality of life for the people with whom they worked. A significant finding in these interviews was that perceptions of quality of life are mediated by interaction. Consequently, Stage Two involved a participant observation study in which the interactions of nurses and people with severe multiple impairments were examined.

Specialist developmental disability nurses have a unique view of quality of life for people with severe multiple impairments. They refer to it as “just little things”, a phrase which masks complex nursing knowledge and skills, and which can be described by four interrelated categories which emerged from the data: humans being, supporting, becoming intimate, and situated belonging. As nurses become more intimate with individuals, they perceive that people with severe multiple impairments are humans being as they wish, and that quality resides in supporting their everyday lives in a context of situated belonging.

This thesis represents a new conceptualisation of quality of life for people with severe multiple impairments, a conceptualisation which may have significance for other groups and, indeed, for the whole quality of life enterprise. This conceptualisation draws on knowledge not usually related to quality of life, that is, knowledge of the body, of the emotions, of identity and of humanness. Such findings demonstrate the power of an interpretive approach in explicating the meanings nurses have regarding quality of life. Further, these findings have implications for how the question of quality of life is approached, for how different ways of thinking about people impact on quality of life, and for the importance of the life in quality of life.
ACKNOWLEDGMENTS

While research and writing can be lonely occupations, the completion of this work would not have been possible without the help and encouragement given to me by so many people over the last ten years.

Ms. Penelope Kearney was always there. She read and commented on so many drafts of the work and challenged so many of my ideas that the thesis is more than it could ever have been without this discourse. Ms. Kay Plymat and Dr. Keith Bennett, my supervisors, assisted me to clarify ideas and to write them down in a way which would be meaningful to others, remaining patient and sensitive and helping me keep my sense of humour. Dr. Jillian Maling and Dr. Judith Christensen both read an early draft of the thesis and their comments helped to guide my path. Dr. Rene Geanellos engaged me in intellectual debate over the years and her insightful comments on the final draft gave me the confidence to finish.

The production of a thesis is the conclusion of the assembling of words, their dismantling and reconstruction over and over again. This was made possible by the patient and endless hours Ms. Ann Crowley, in particular, as well as Ms. Robyn Hopson and Ms. Karen Williams spent at their computers. The words were often inspired by the literature which was made so accessible by an extraordinary librarian: Ms. Margaret MacIntosh. The work was supported financially by generous scholarships from the University of Western Sydney, Nepean, the Edith Cavell Trust, and the Professional Association of Nurses in Developmental Disability Areas (Australia) Inc.

Accessing the world of people with severe multiple impairments can be difficult in this time of ethical dilemmas. My thanks to the Directors of
Nursing in the Department of Community Services who trusted me with the delicate issues in the lives of the people in their care.

Qualitative research can never be the property of the researcher alone; it is the participants who made this thesis a reality. For the time they gave, the trust they had, the thoughts they shared, I will always be grateful. I can only hope that this work will be useful to them as they continue to strive for a place for people with severe multiple impairments.

Finally, as a thesis tends to consume much of one’s life, the practical help and the unconditional love given to me abundantly by my family will never be forgotten.
DEDICATION

For

Joan, Phillip and Kevin

who, first and last, taught me about

people with severe multiple impairments

and

quality of life
STYLE KEY

“Italics” are used to refer to the participants’ words.

Italics are used to refer to my fieldwork notes.

Bold is used for emphasis.
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QUALITY RESIDES IN SUPPORTING

COMPLETING ACTS

Body acts
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- Supporting the comfort of the body
- Supporting the development of the body

Emotion acts
- Assisting with involvement in interests
- Promoting independence in activities
- Encouraging relationships
- Providing emotional security

Identity acts
- Impression management
- Discerning preferences
- Managing resources
- Advocating

SUMMARY

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KNOWING

Knowing the situation
- Knowing through time and experience

Knowing the body
- Knowing the impaired body
- Knowing the individual impaired body

INTERPRETING

Designating aspects of the body and the situation
 Giving meaning to the body in the situation
 Acting on the basis of interpretation of the body in the situation

FEELING

Emotion work

EMPATHISING
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