

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

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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.

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Accessing the world of people with severe multiple impairments can be difficult in this time of ethical dilemmas. My thanks to the Directors of

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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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