



Review article

People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection

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ABSTRACT

This paper presents the findings from a systematic review which investigated the use of phenomenological research interviews in studies involving people with intellectual disability.

A search of four electronic databases and the subsequent application of inclusion criteria resulted in 28 relevant publications. Selected articles were reviewed and key data extracted using CASP guidelines, with findings presented by examining the influencing philosophy or theory, the method of recruitment and data collection, the relationship between researcher and participants, the rigour of data analysis and finally a statement of findings.

The results show people with mild and moderate intellectual disability, included as participants in phenomenological research investigating a range of issues that are important in their lives.

A critical discussion focuses on the main characteristics of phenomenology and points to implications for further research. Creating awareness of research among people with intellectual disability is important, and finding the best way to ensure findings are disseminated in accessible formats is recommended.

Researchers are also challenged to consider Heideggerian hermeneutic phenomenology as a method with the potential to fully explore the experiences of people with intellectual disability.

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What this paper adds

- The paper contributes to revealing the ways people with intellectual disability can be participants in research.
- It highlights particular aspects of the methodology and dissemination which, if improved, may enrich the inclusion of people with intellectual disability in research and increase the value of studies with this group.
- The authors take the position that Heideggerian hermeneutic phenomenology is a suitable method to ensure the lived experiences of people with intellectual disability can be fully explored.

1. Introduction

Qualitative research allows for the detailed investigation of individual experiences, where researchers seek to understand the perspective of participants and the influence of the context in which an experience occurs (Hennink, Hutter, & Bailey, 2010). There are a number of techniques that may be applied in qualitative research, including participant observation, interviewing and focus groups (Schutt, 2011). Selecting a methodology will require finding an approach that suits the research question but also one congruent philosophically within the context of the research and the participants involved. The most common qualitative approaches are phenomenology, ethnography and grounded theory. Phenomenology is concerned with how people experience a particular phenomenon, ethnography considers how people behave in relation to their environment, while in grounded theory hypotheses or theories emerge from the data (Parahoo, 2014). This systematic review examined the use of phenomenological interviews in studies involving people with intellectual disabilities.

1.1. Phenomenology

Phenomenology is based upon the work of the philosopher Edmund Husserl (1859–1938), which was then developed by his student Martin Heidegger and is grounded in the academic disciplines of philosophy and psychology. There are a number of different phenomenological research schools with methodologies that have been influenced by Husserl's descriptive and Heidegger's interpretive approaches (Flood, 2010).

Phenomenology can be defined as “...the study of lived experience.” (Van Manen, 1997, p. 9). It can be explained further as:

“Researchers search for essentials, invariant structure (or essence) or the central underlying meaning of the experience and emphasize the intentionality of consciousness where experiences contain both the outward appearance and inward consciousness based on memory, image and meaning.” (Creswell, 1998, p. 52)

The main characteristics of phenomenology can be explained firstly as attempting to describe the participants' experiences of a phenomenon and gain an insight into their world. Researchers conducting descriptive phenomenological research then use a technique of phenomenological inquiry called “bracketing” where their previous experiences, personal beliefs or biases are put aside during the study.

Husserl proposed that bracketing was needed to ensure the phenomena could be seen clearly, while in contrast Heidegger felt people could not put aside the influences of their previous experiences (Lavery, 2003). However phenomenological methodologies generally adhere to the concept of “reduction” which involves researchers having an open mind and returning to; “...the original sources of peoples experiences.” (Heinonen, 2015, p. 35) to ensure the uniqueness of each

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