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 (1936/1970), 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 (Laverty, 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
experience is examined. Therefore, there are differences in the characteristics of descriptive and interpretive phenomenology which is also reflected in how findings are presented. Descriptive phenomenology attempts to describe the essential qualities of an experience, and interpretive or hermeneutic phenomenology seeks meanings and understandings in what people experience. Essentially all phenomenological researchers are seeking to understand what a particular experience is like and what meaning people give to these experiences.

1.2. Phenomenological research

Phenomenological research as a method has flexibility as one of its best features (Garza, 2007) in that it can follow a structured series of steps or it can be less structured and be directed by the experiences being collected (Flood, 2010). Phenomenological researchers analyse the data by looking for themes, patterns or trends, and usually include quotes from the study participants in the findings (Parahoo, 2014). To aid analysis, researchers may employ particular frameworks or follow models such as Amedeo Giorgi’s four steps, explained by Devenish (2002). These are: to firstly get an overview of the sense of the transcript from the phenomenon under investigation; identify meaning units; transform participants’ everyday expressions into psychological language, and develop a description based on the transformed meaning units. Max Van Manen also offers such steps as orientating to the phenomenon, asking specific questions, facilitating the answers by defining reflective modes, consulting the literature, developing themes and writing to produce seamless text (Van Manen, 1990).

Interpretive Phenomenological Analysis (IPA) which comes under the broad umbrella of phenomenological research has become very popular in recent years (Pringle, Drummond, McLafferty, & Hendry, 2011). The method is influenced by the tradition of hermeneutic phenomenology and was developed for research within psychology. The use of “bracketing” is not considered a step in IPA studies (Chan, Fung, & Chien, 2013). In essence, IPA offers an approach that allows for the researcher to explore the subjective experiences of participants, while having a set of guidelines to follow (Smith, Flowers, & Larkin, 2009).

1.3. Aim

This review aims to examine the phenomenological approaches taken within a number of studies that sought to identify the experiences of people with intellectual disability. This group of people have often been excluded from research for a number of reasons, including ethical concerns regarding the extent to which they are in a position to give informed consent, difficulties with information not being provided at an appropriate level, or people being easily coerced into taking part (National Disability Authority, 2009). In phenomenological research in particular, researchers may feel that they may not be able to provide rich enough data to reflect their experiences. These concerns may result in people with intellectual disabilities being excluded from research (Iacono, 2006) and their authentic voices unheard (MacMahon et al., 2015; Niry, Duvdevani, & Doron, 2015), rather than accommodations being made to ensure their inclusion (National Disability Authority, 2009).

While it is acknowledged that there are different qualitative methods that focus on the lived experience, the present paper specifically examines phenomenological research, which uses interviews with people with intellectual disability as a sole method of data collection. The literature that has exclusively involved people with intellectual disability is of particular interest, as it aims to capture their experiences by means of requesting their views and opinions on a range of topics, and negates the need to seek information from others such as family or support staff.

1.4. Results and discussion

The Critical Appraisal Skills Programme (CASP), qualitative research checklist was used to assist in the screening, extracting key data and providing information for the results section from the studies (CASP, 2000).

The checklist’s screening questions identified if the research had a clear aim and if a qualitative methodology was appropriate. More detailed questions then examined the research design, recruitment strategy, data collection, relationship between researcher and participants, ethical issues, rigour of data analysis and statement of findings.

All the questions in the CASP checklist guided the appraisal of the studies. The areas detailed in the results section of this review provided background for the discussion which was based on the key characteristics of phenomenological research. These included philosophy or theory, approach to bracketing, data collection, and analysis and value of the research.

Phenomenological research is important, as it gives value to people’s perspectives and experiences. This systematic review seeks to make a unique contribution, as a first attempt to identify and review the phenomenological research that has endeavoured to give voice to people with intellectual disability.

2. Method

2.1. Search strategy

To ensure only studies which adopted a phenomenological method and included people with intellectual disability were examined, only the following inclusion criteria were applied: (1) interview as method of data collection; (2) papers should be...
published in English in peer-reviewed journals for access and credibility; (3) papers should refer to the population of people with intellectual disability; (4) papers should involve research that seeks the experiences and views of people with intellectual disability only; (5) a phenomenological research methodology must have been applied.

A number of steps were taken to ensure the studies that met the criteria were accessed. Firstly the parameters of the review were defined to determine which terms to use when searching the chosen databases and the years were not limited. The broad terms “intellectual disability” and “phenomenological research” were identified and searched, and then combined to provide an initial result. Databases searched included CINAHL Complete, Web of Science, MEDLINE and PsycINFO. In each database the “headings” functions were used to ensure all possible terms were included. The terms for intellectual disability were “intellectual disability”, “learning disability”, “developmental disabilities”, “mental retardation”, “mentally disabled persons” or “intellectual development disorder”. For phenomenological research, the terms were “phenomenological research”, “hermeneutic phenomenology”, “interpretive phenomenology” and “phenomenology”.

### 2.2. Screening

A first screening of results from the search was undertaken by carefully reading the title of all the papers identified from each of the databases searched. All articles that clearly did not involve interviewing people with intellectual disability were excluded at this stage. This resulted in a total of 65 studies which were then saved to a folder in ‘Refworks’ (a reference management application). Duplicates were then removed, resulting in 44 papers being judged against the inclusion criteria. The process for application of the criteria involved printing a copy of each article and firstly reading the abstract. As a result of the second screening, 16 studies were excluded, as they involved the use of other methods of data collection such as focus groups or participant observation, did not involve people with intellectual disability only, and were reviews or dissertation abstracts. As a result 28 studies were included in the review. Table 1 summarises the sources of the studies and screening process.

### 2.3. Evaluation criteria

The CASP checklist was also used to provide the criterion for evaluating the papers. The checklist’s initial screening questions identified that all the studies had a clear aim and that a qualitative methodology was appropriate.

Based on the checklist, a numbered table was developed to provide key descriptive data including details of the author(s), date and place, research design, participant numbers and level of intellectual disability if specified, data collection, data analysis, confirmation of ethical approval or reference made to ethical considerations, and the main findings of the research. The table is appended to the end of this paper (see Table 2).

To meet the aim of examining the phenomenological approaches taken, the results section firstly provides a brief overview of each of the papers (including reference to ethical approval), and then examines five aspects of the checklist that have particular significance in phenomenological research which have used interviews as the data collection method. They include the influencing philosophy or theory, recruitment and data collection, relationship between researcher and participant, rigour of data analysis and statement of findings.

These five areas were chosen as they relate to the key characteristics of phenomenological research and together provide the basis for the discussion which follows.

<p>| Table 1 |
| Summary details of search strategy. |</p>
<table>
<thead>
<tr>
<th>Database</th>
<th>Search terms</th>
<th>Initial result</th>
<th>1st screening</th>
<th>Duplicates removed</th>
<th>2nd screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL Complete</td>
<td>Mental retardation OR mentally disabled persons OR developmental disabilities OR learning disability OR intellectual disability AND phenomenology OR phenomenological research</td>
<td>167</td>
<td>34</td>
<td>44</td>
<td>28</td>
</tr>
<tr>
<td>Web of Science</td>
<td>Intellectual disability OR mental retardation OR mentally disabled persons OR developmental disabilities OR learning disability AND interpretive phenomenology OR phenomenological research</td>
<td>181</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MEDLINE</td>
<td>Intellectual disability OR mentally disabled persons OR developmental disabilities AND phenomenology OR phenomenological research OR interpretive phenomenology</td>
<td>56</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PsycINFO</td>
<td>Intellectual disability OR intellectual development disorder AND phenomenology OR phenomenological research</td>
<td>83</td>
<td>8</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Table 2
Details of the papers reviewed based on the Critical Appraisal Skills Programme (CASP).

<table>
<thead>
<tr>
<th>No.</th>
<th>Authors and date</th>
<th>Research design</th>
<th>Numbers</th>
<th>Data analysis</th>
<th>Ethical approval</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ditchfield and Burns (2004) UK</td>
<td>Interpretive, Phenomenological Analysis</td>
<td>11 women with mild intellectual disability</td>
<td>Interpretive, Phenomenological Analysis</td>
<td>Part of wider study with ethical approval</td>
<td>Women had very little understanding of the menstrual cycle. Limited opportunities for support or discussion. Expectant mothers strategically negotiated support networks prior to birth of child.</td>
</tr>
<tr>
<td>2</td>
<td>Mayes, Llewellyn, and McConnell (2008) Australia</td>
<td>Phenomenological study, Descriptive</td>
<td>17 women 18–35 years screened to meet criteria</td>
<td>Description based on Van Manen Paper focused on &quot;negotiating a support network for me and my baby&quot;</td>
<td>Yes</td>
<td>Sought practical assistance from those who acknowledged them as most important person in child's life.</td>
</tr>
<tr>
<td>3</td>
<td>Mayes, Llewellyn, and McConnell (2011) Australia</td>
<td>Phenomenological study, Descriptive. Findings taken from larger study</td>
<td>17 women (18–35 years), borderline, mild and moderate intellectual disability</td>
<td>Van Manen Description of each pregnancy from transcripts of interviews</td>
<td>Yes</td>
<td>Becoming a mother for women with intellectual disability involves the support of often one key person from their social network. Women valued post-natal care.</td>
</tr>
<tr>
<td>4</td>
<td>Wilson, McKenzie, Quayle, and Murray (2013) UK</td>
<td>Interpretative, Phenomenological Analysis</td>
<td>6 women with mild intellectual disability</td>
<td>Interpretative, Phenomenological Analysis based on Smiths work with themes identified</td>
<td>Yes</td>
<td>The role of informal support is key. The effectiveness of support depends on how it is perceived by the women. Having a child removed results in mothers needing support, often they do not know why the child was removed.</td>
</tr>
<tr>
<td>5</td>
<td>Gould and Dodd (2014) UK</td>
<td>Interpretive, Phenomenological Analysis</td>
<td>Nine women with mild intellectual disability</td>
<td>Interpretative, Phenomenological Analysis Themes and overarching super-ordinate themes</td>
<td>Yes</td>
<td>Being a parent is associated with some difficult task but is valued and a welcome identity, in particular a strong identity with motherhood. The reactions of others can be negative.</td>
</tr>
<tr>
<td>6</td>
<td>Shewan, McKenzie, Quayle, and Crawley (2014) UK</td>
<td>Interpretative phenomenological analysis, Drawn from a larger study</td>
<td>Eight people with intellectual disability</td>
<td>Interpretative, Phenomenological Analysis based on Smiths work with themes identified</td>
<td>Yes</td>
<td>People with intellectual disabilities have additional challenges in understanding their diabetes. People valued the group analytic therapy, but found it emotionally painful and difficult to identify with others or see positive changes.</td>
</tr>
<tr>
<td>7</td>
<td>Lloyd et al. (2007) UK</td>
<td>Interpretive, Phenomenological Analysis</td>
<td>6 people with Down Syndrome and Alzheimer's disease over 40 years</td>
<td>Interpretative, Phenomenological Analysis following guidelines of Smith and Osborn (2003)</td>
<td>Part of a wider study where ethical approval was obtained.</td>
<td>People with intellectual disabilities have additional challenges in understanding their diabetes. People valued the group analytic therapy, but found it emotionally painful and difficult to identify with others or see positive changes.</td>
</tr>
<tr>
<td>8</td>
<td>Dysch, Chung, and Fox (2011) UK</td>
<td>Interpretative, Phenomenological Analysis</td>
<td>4 adults with mild intellectual disability</td>
<td>Interpretative, Phenomenological Analysis</td>
<td>Yes</td>
<td>People with intellectual disabilities have additional challenges in understanding their diabetes. People valued the group analytic therapy, but found it emotionally painful and difficult to identify with others or see positive changes.</td>
</tr>
<tr>
<td>9</td>
<td>Macdonald et al. (2003) UK</td>
<td>Qualitative Interpretative, Phenomenological Analysis</td>
<td>9 adults, mild intellectual disability</td>
<td>Interpretative, Phenomenological Analysis</td>
<td>Informed consent obtained.</td>
<td>People with intellectual disabilities have additional challenges in understanding their diabetes. People valued the group analytic therapy, but found it emotionally painful and difficult to identify with others or see positive changes.</td>
</tr>
<tr>
<td>10</td>
<td>Pert et al. (2013) UK</td>
<td>Interpretative, Phenomenological Analysis</td>
<td>15 adults with borderline to mild intellectual disability Screening test applied</td>
<td>Interpretative, Phenomenological Analysis Themes identified into positive and negative</td>
<td>Yes</td>
<td>People with intellectual disabilities have additional challenges in understanding their diabetes. People valued the group analytic therapy, but found it emotionally painful and difficult to identify with others or see positive changes.</td>
</tr>
<tr>
<td>11</td>
<td>MacMahon et al. (2015) UK</td>
<td>Interpretative, Phenomenological Analysis</td>
<td>8 men and 3 women (22–44) Undertaking a cognitive behaviour therapy (CBT) anger management programme</td>
<td>Interpretative, Phenomenological Analysis based on Smiths guidelines, themes identified, grouped to reflect relationships between themes</td>
<td>Yes</td>
<td>The CBT intervention was experienced as being both effective and enjoyable. Many benefits of the intervention were reported such as newly acquired skills in anger management and new relationships.</td>
</tr>
<tr>
<td>No.</td>
<td>Authors and date</td>
<td>Research design</td>
<td>Numbers</td>
<td>Data analysis</td>
<td>Ethical approval</td>
<td>Main findings</td>
</tr>
<tr>
<td>-----</td>
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</tr>
<tr>
<td>12</td>
<td>Harker-Longton (2002) UK</td>
<td>Qualitative phenomenological approach</td>
<td>1 adult woman with mild intellectual disability</td>
<td>Analysis involved continual listening to the tapes, transcribing, reading and re-reading descriptions into themes</td>
<td>Yes</td>
<td>Concerns with single participant. Agreed all published quotes</td>
</tr>
<tr>
<td>13</td>
<td>Brown and Beal (2009) UK</td>
<td>Interpretive Phenomenological Analysis</td>
<td>9 adults, mild intellectual disability</td>
<td>Interpretive phenomenological analysis</td>
<td>Yes</td>
<td>Self-harm in this population appears to occur within an interpersonal context. Early trauma significant</td>
</tr>
<tr>
<td>15</td>
<td>McNally et al. (2007) UK</td>
<td>Qualitative Interpretative Phenomenological Analysis</td>
<td>9 adults, mild intellectual disability (19–57 years)</td>
<td>Interpretative Phenomenological Analysis</td>
<td>Yes</td>
<td>Issues were the impact on the participants regarding their feelings of lack of control before and after detention. Lack of understanding regarding acer and punishment</td>
</tr>
<tr>
<td>16</td>
<td>Isherwood, Burns, Naylor, and Read (2007) UK</td>
<td>Interpretive Phenomenological Analysis</td>
<td>6 men ages 19–40 receptive language was sufficient. Interviewed after intervention</td>
<td>Interpretative phenomenological analysis based on Smiths work with themes identified. Themes clustered and integrated into master themes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Cookson and Dickson (2010) UK</td>
<td>Qualitative Interpretive Phenomenological Analysis</td>
<td>11 adults, dual diagnosis of intellectual disability and schizophrenia</td>
<td>Interpretive phenomenological analysis</td>
<td>Yes</td>
<td>People with ID make sense of their diagnosis in different ways but are not dissimilar to others</td>
</tr>
<tr>
<td>18</td>
<td>Mason, Timms, Hayburn, and Watters (2013) UK</td>
<td>Interpretative Phenomenological Analysis</td>
<td>11 adults with intellectual disability from self-advocacy group</td>
<td>Interpretative Phenomenological Analysis</td>
<td>Yes</td>
<td>Friendships have a significant role in the lives of people with ID but there are significant negative aspects resulting in stress. Staff having the control over activities minimises choice</td>
</tr>
<tr>
<td>19</td>
<td>Sullivan, Bowden, McKenzie, and Quayle (2013) UK</td>
<td>Interpretive Phenomenological Analysis</td>
<td>Ten people with intellectual disability 6 male 4 female</td>
<td>Interpretative Phenomenological Analysis based on Smiths work with themes identified, reflective diary and supervision</td>
<td>Yes</td>
<td>Close relationships, including touch and sexual behaviours are important. Negative perceptions surround sexual behaviours</td>
</tr>
</tbody>
</table>
While issues of ageing for women with ID were found to be complex they were mainly described as positive. A positive attitude and self-perception help women to cope with difficulties. Work, physical changes associated with ageing and daily supports. For people with ID the image of becoming older is similar to what society expects. Supported living means accepting and leisure, friends and family are important. A general fear of getting old makes them more like others.

Data analysis involved Consent discussion and open talk held with participants including the freedom of participation. Also feeling that becoming older makes them more like others While issues of ageing for women with ID were found to be complex they were mainly described as positive. A positive attitude and self-perception help women to cope with difficulties. Work, leisure, friends and family are important. A general fear of getting old People with intellectual disability believed they faced with and were aware of stigma.

<table>
<thead>
<tr>
<th>No.</th>
<th>Authors and date</th>
<th>Research design</th>
<th>Numbers</th>
<th>Data analysis</th>
<th>Ethical approval</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>Kahlin, Kjellberg, Nord and Hagberg (2015) Sweden</td>
<td>Phenomenology based on the philosophy of Merleau-Ponty</td>
<td>5 men and 7 women between the ages of 48 and 71 with moderate to mild intellectual disability</td>
<td>Descriptive phenomenological analysis method. Descriptions analysed using Giorgi’s method. Themes and sub-themes developed</td>
<td>Yes</td>
<td>Participants identified with the physical changes associated with ageing and daily supports. For people with ID the image of becoming older is similar to what society expects. Supported living means accepting and expecting support. Also feeling that becoming older makes them more like others</td>
</tr>
<tr>
<td>21</td>
<td>Niry et al. (2015) Israel</td>
<td>Phenomenological approach</td>
<td>19 women with mild to moderate intellectual disability sample. Number determined by theoretical saturation</td>
<td>Data analysis involved identifying themes</td>
<td>Consent discussed and open talk held with participants including the freedom of participation.</td>
<td>Yes</td>
</tr>
<tr>
<td>22</td>
<td>Jahoda and Markova (2004) UK</td>
<td>Phenomenological study</td>
<td>28 adults – mild intellectual disability</td>
<td>Interview transcribed and analysed based on work of (Edgerton, 1967, 1984)</td>
<td>Yes</td>
<td>Time spent with participants prior to study Signed informed consent obtained from guardian and participant</td>
</tr>
<tr>
<td>23</td>
<td>Hall (2009) USA</td>
<td>Phenomenological</td>
<td>14 adults (21–35 years) mild/moderate intellectual disability</td>
<td>Phenomenological (Moustakas) significant statements into meaningful units and themes</td>
<td>Time spent with participants prior to study Signed informed consent obtained from guardian and participant</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Gilmartin and Slevin (2010) Republic of Ireland</td>
<td>Phenomenological approach</td>
<td>13 adults, with intellectual disability</td>
<td>Colazzi’s 7-stage process of analysis</td>
<td>Yes</td>
<td>Amount and quality of social inclusion depended on transport, living arrangements, involvement in activities, interaction in work and community, friendships, abilities and family support.</td>
</tr>
<tr>
<td>25</td>
<td>Umb-Carlsson and Lindstedt (2011) Sweden</td>
<td>Phenomenological approach</td>
<td>21 adults – moderate, mild intellectual disability</td>
<td>Empirical phenomenological psychological method using five analytic steps</td>
<td>Yes</td>
<td>Self-advocacy groups affect change in services and also empowered individuals</td>
</tr>
<tr>
<td>26</td>
<td>Kenyon, Beail, and Jackson (2014) UK</td>
<td>Interpretative Phenomenological Analysis</td>
<td>Eight participants, assumed to have mild intellectual disability 7 women 1 man</td>
<td>Interpretative Phenomenological Analysis based on Smiths work with themes identified</td>
<td>Yes</td>
<td>Supports changing the focus from the group to the individual and the general essence of Q of L are around well-being and themes of social adult status, control of life, personal safety, social belonging and self-chosen solitude</td>
</tr>
<tr>
<td>27</td>
<td>Davidson, Smith, and Burns (2014) UK</td>
<td>Interpretative Phenomenological Analysis</td>
<td>Five people with ID who had been given a cognitive assessment by a psychologist</td>
<td>Followed IPA methods reporting the findings according to the phases of assessment Followed IPA methods but identified the analysis as being more descriptive and less interpretive</td>
<td>Yes</td>
<td>Findings concerned awareness of difference, understanding of labelling and coping responses to sigma</td>
</tr>
<tr>
<td>28</td>
<td>Pestana (2015) UK</td>
<td>Interpretative Phenomenological Analysis</td>
<td>Eight people with mild intellectual disability</td>
<td>Followed IPA methods reporting the findings according to the phases of assessment Followed IPA methods but identified the analysis as being more descriptive and less interpretive</td>
<td>Yes</td>
<td>Participants did not understand the purpose of assessment but trusted clinicians and reported benefiting from the experience</td>
</tr>
</tbody>
</table>

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3. Results

3.1. Overview of research studies

Phenomenological research has been used in the selected studies to investigate a range of issues that concern people with intellectual disability and those that support them. Here, they have been grouped according to the focus of the research, beginning with five that concern women in particular, one regarding parenting for both men and women, eight that focus on various aspects of physical and mental health, three on the experience of being detained, two studies in areas of friendships and relationships, two on ageing and seven that consider issues relating to quality of life and identity.

Concerning women in particular, researchers sought to investigate their understanding and information needs regarding the menstrual cycle (Ditchfield & Burns, 2004). Four studies focused on being a mother, seeking to examine how women negotiate supports prior to having their babies (2), how they perceive their identity as a mother (3), what supports women need when they become mothers (4) and the impact of having their children taken into care (5). Parenting and the impact of having an intellectual disability was the focus of one study which sought to explore the experiences and perceptions of both mothers and fathers (6). The researchers sought to understand if parents saw this as having an impact on their parenting role.

Physical and mental health issues were the subject of a significant number of studies including the experiences and impact of living with dementia for people with Down syndrome (7), and seeking to understand what life was like for people coping with diabetes (8). Views in relation to therapies such as group analytic therapy (9), cognitive behaviour therapy (10), and an anger management intervention (11) were sought to identify their impact on people with intellectual disability. Self-harm was investigated in a case study dealing with one woman’s view of self-injurious behaviour (12) and then examined further in two studies who investigated people who self-harm and live in secure services (13, 14).

Being detained was the common theme in three studies. The first explored the experience of being held for compulsory assessment and treatment under the UK Mental Health Act (15). Offending was linked to studies concerned with people held in a secure setting, and how they made sense of their offending behaviours (16), or how they understood their diagnosis of schizophrenia (17).

Friendships and relationships were explored in studies which investigated how people experience and make sense of friendships (18) and their perceptions and experiences of close and sexual relationships (19).

Ageing and the experiences of ageing provided the focus for two studies. One explored the impact of living in group homes on people’s experience of ageing (20), while the second aimed to investigate how women articulated their views of getting older (21).

Social inclusion and identity were dealt with in seven studies that looked at a number of topics that related to quality of life. One examined how two groups of people moving to independent living from their family home or residential care coped with social stigma in their everyday lives (22). Another sought to understand how to enhance the social inclusion of young adults by writing descriptions and identifying themes from their experiences, confirming the importance of awareness and self-advocacy to enhance inclusion (23).

A study on how people experience being a member of a self-advocacy group (24), and an examination of what quality of life means for people with intellectual disability (25), also made reference to inclusion and empowerment. Having a diagnosis of intellectual disability and how people with intellectual disability experience this, was the subject of one study (26).

The exploration of how having a cognitive assessment influenced self-identity (27), and research examining self-concept (28), both sought to understand how people with intellectual disability perceive themselves.

All of the studies noted that ethical approval had been sought and given with consent being the most significant issue raised throughout the reviewed studies. As can be seen in Table 2, examples are in one case the careful approach taken by screening to ensure people had the ability to consent (24), and in others by providing information in alternative formats such as pictures or symbols (8, 18). Extra time was taken to ensure participant understanding (2, 14, 15, 20, 21, 22), with participants in one study being given an opportunity to recap on what would be involved in agreeing to participate (1). Further individual approaches such as reading the information to those with poor literacy (14), or taking an incremental approach to consent (4), show an overall commitment to taking an ethical approach in the studies. A further impact on ethics which is addressed later is the rigour which is applied to data analysis to ensure that a true account is given of the study participant’s experiences.

3.2. Influencing philosophy or theory

There is evidence of different philosophical or theoretical influences informing the choice of method by the researchers in the reviewed studies. Eighteen were identified as displaying the appearance of Interpretive Phenomenological Analysis (IPA), and 10 as Phenomenology or a Phenomenological approach (see Table 2).

The largest number of studies used IPA, which is gaining significant popularity in the United Kingdom (UK), with all 18 studies that adopt this method being UK-based. A variety of justifications were identified for using IPA. These were, variously, that: its use is increasing in health psychology (1); it has been used in a number of studies with adults with intellectual disabilities (4); it is suitable for a small sample (8); the method is both phenomenological and interpretive, trying to represent participant’s views and researcher’s stance (6, 10, 16, 18); and finally, that it is a systematic and practical
approach (7) suitable for exploring subjective perceptions (7, 19, 27, 28) and for in-depth analysis (17). Some authors discussed the benefits of IPA for exploratory research (13, 16), or where there is limited existing research (19). Macdonald, Sinason, and Hollins (2003) discussed the use of qualitative methods and the variety of underlying epistemological positions that a researcher may employ. Four studies identified a qualitative approach as suitable, rather than an explanation of IPA as such (8, 9, 11, 15).

While all followed the guidelines for IPA studies, one study (13) discussed the necessity of “bracketing” during data collection and also during analysis. While this is not a feature of IPA studies, the researchers appear to differentiate between the approaches taken during data collection where pre-existing ideas and assumptions are suspended, and during analysis which they identify as being “interactive”. This shows that the researchers were influenced by both the descriptive and interpretive traditions, indicating that they may have overlooked the complexity of IPA. Reference was not made to any particular philosophical or theoretical influences in studies, however it is accepted that IPA is grounded in interpretive perspectives (Finlay, 2009).

Of the 10 studies identified as Phenomenology, or as using a Phenomenological approach, four (2, 3, 12, 25) identify directly with the philosophical influence of Husserl who initiated the phenomenological movement. Two were identified as descriptive phenomenology, where “bracketing” was a feature (14, 24). Both Australian studies identified with the work of Van Manen (2, 3). Two Swedish studies make explicit reference to the phenomenology of Husserl (20, 25), with one also drawing on the philosophy of Merleau-Ponty who was influenced by both Husserl and Heidegger (20).

One study referred to feminist research and its use of qualitative methods (21), with others more focused on literature associated with people with disability (22, 23). Half of the studies focused on approaches offered by particular writers when undertaking phenomenological research, rather than positioning the study within the descriptive or interpretive (hermeneutic) traditions (14, 22, 23, 24, 25). In general all studies make reference to the characteristics of descriptive phenomenology.

### 3.3. Recruitment and data collection

Recruitment in phenomenological studies uses purposeful sampling as the participants must have experienced the phenomena being examined (Creswell, 1998; Parahoo, 2014). All of the studies included in this review met these criteria. Researchers all described the recruitment strategy adopted, and indicated inclusion or selection criteria, often seeking the support of key staff to identify those that met the requirements. Everyone recruited people who had sufficient verbal skills to give descriptions of their experiences, with 20 stating the participants had a mild or moderate intellectual disability. There was variation overall in the numbers recruited in the studies, ranging from 1 to 28, and with an average of 11 participants. The number of participants in the IPA studies ranged from 4 to 15, with an average of 8. This would appear to reflect the diversity evident in qualitative studies generally, and in particular the small numbers recommended for IPA.

Data collection as specified in the criteria for this review was undertaken by interview only. Of the reviewed studies, 27 referred to a semi-structured interview with the one case study (12) using a series of interviews based on the topic under investigation. Most referred to an interview schedule, others identified an interview guide (21) or protocol (23) with two indicating the use of a topic guide (10, 22). In one study, researchers received training so they were familiar with the interview protocol (10). The use of open-ended questions was highlighted in a number of studies (3, 4, 5, 6, 9, 13, 15), with the majority making reference to the need to be flexible with the interview schedule or guide.

One study by Macdonald et al. (2003) included in its appendices a copy of the interview schedule, which involved detailed questions on group analytic therapy. Of interest is the level of detail in the questions posed, which showed that the researcher was conducting a structured rather than a semi-structured interview. Niry et al. (2015) also took a very structured approach, basing their interview guide on an international study of ageing that involved over one hundred questions. Just one study identified beginning the interview with a global question, but this was also followed by an interview guide which ensured that particular areas associated with positive quality of life could be explored (25). Some researchers such as McNally, Beail, and Kellett (2007) made reference to identifying themes not addressed in their interview schedule. The use of prescriptive or detailed interview schedules or guides could have the potential to limit the ability of the participant to be open, and reduce their opportunity to give an account of their experience.

### 3.4. Relationship between researcher and participants

The relationships between researchers and participants are important aspects of any qualitative research, but are of particular concern when dealing with people with intellectual disability. Difficulties of responsiveness and acquiescence are common. People with intellectual disability may have comprehension and memory problems, finding it difficult to respond to subjective phenomena. They may have a tendency to respond positively or to appear agreeable to the interviewer (Emerson, Hatton, Thompson, & Parmenter, 2004), or have difficulties verbalising experiences (Lloyd, Gatherer, & Kalsy, 2006). Issues such as the status of the interviewer or the framing of the interview questions may affect the data (Emerson et al., 2004), in addition to the influence of interview schedules or guides as mentioned earlier.

Examining the role of the researcher in the reviewed studies, there is evidence of significant attempts by many to adopt techniques that will maximise the success of the interviews. In some studies the researchers referred to the importance of building rapport (7, 11, 16, 17), with others using techniques such as inviting personal questions (2, 14) to make people feel...
at ease. In one case the interviewer spent three weeks observing and interacting with the participants to get to know more about their communication skills and preferences (20), and in another an average of 12 h was spent getting to know the participants prior to the interview (22). Generally, the attempt was made to keep interviews relaxed and conversational, and the venue for the interview carefully chosen to ensure participants felt at ease.

A number of the studies made reference to the challenges of interviewing people with intellectual disability (2, 20). Some detailed techniques included ensuring vocabulary was clear and simple (5), complex language was avoided (14), or pictures used to support understanding (20). During the interview, researchers ensured prompts were non-directional (13) with efforts made not to guide the interviewee (14, 15, 22, 23).

This willingness by researchers in some of the studies to focus on the relationship with participants may have positive or negative effects. It could add to the richness of the data collected, or possibly add to the potential for acquiescence or wanting to please the interviewer. Umb-Carlsson and Lindstedt (2011) make reference to this in their discussion, drawing attention to the benefits of having experience with people with intellectual disability identifying a risk for preconceptions. To counter this and ensure rigour, the method of data analysis will be of significance.

3.5. Rigour of data analysis

Managing the data and the method of analysis are included in a process of ensuring rigour. Managing large amounts of data is an issue in all research studies; in qualitative research, while the number of participants may be low, the amount of data collected can be significant and require the use of data management tools. Common to all the studies was transcription of interviews, with field notes also transcribed in some. In one case not all interviews were recorded and instead notes were taken by the researcher (12). Qualitative data analysis software was not identified as a feature in the majority of the studies, with only two (6, 14) using N-Vivo which is a qualitative software package that can be used to “… store and analyse the interviews” (Duperouzel & Fish, 2010, p. 609). Data was analysed as expected in the IPA studies, as the researchers were guided by the approach developed by Smith and applied the stages recommended.

Studies described as Phenomenology or Phenomenological research varied in their approach to analysing the data, reflecting the influences of writers who themselves have built upon phenomenological philosophy. Steps of analysis based on the work of authors such as Van Manen (2, 3), Colazzi (24), Moustakas (23), Burnard (12) and Edgerton (22) reflect their influence. The Empirical Phenomenological Psychological (EPP) method which is composed of five analytic steps was used in the Quality of Life study (25). The reviewed studies have shown that methodologies in phenomenological research can be combined and altered as well as interpreted by the researcher (Carter & Little, 2007). In qualitative research generally, there is no single guideline for researchers to follow to establish rigour (Armour, Rivaux, & Bell, 2009). Therefore, the approach must be one that allows for reliability and validity to be evident through constructive procedures during the course of the study (Morse, Barrett, Mayan, Olson, & Spiers, 2008), and show sufficient understanding of the level of rigour required (Laverty, 2003). Morse et al. (2008) expand on this by explaining that for work to be valid, the application of the method must be clear so that the researcher’s findings and claims can be legitimated with built-in verification strategies that ensure rigour.

The reviewed studies reflected the lack of set guidelines with a variety of methods used. Ditchfield and Burns (2004) make reference to traditional methods of judging rigour as “… not applicable to qualitative research…” (p. 26). Independent audit or analysis was used to establish rigour in a number of studies (1, 8, 10, 13, 17), or to identify if the analysis was systematic and logical (7). Others evaluated the themes that emerged from the data by using an independent assessor (4, 28) or co-researchers (12), or sought participant feedback to ensure accurate representation of their views (6, 14). The approach of using a research team or second author was employed to ensure interpretation was valid and reliable (11, 17, 24, 25), while some used a combination of methods (18, 19, 23), with one study monitoring validity by keeping a journal in addition to checking coding with the other researchers (26).

3.6. Statement of findings

As with all studies, reporting in phenomenological studies needs to allow for the reader to understand the findings and in particular how the researchers have interpreted the participants’ experiences (Maggs-Rapport, 2001). It is here that the methodological decision-making of the researcher becomes evident, reflecting the phenomenological philosophy or theory which informed the phenomenological method applied. The statement of findings itself should reflect a phenomenological approach, as the researcher attempts to uncover the essential elements of the experiences of people with intellectual disability.

In the majority of the studies, findings were detailed using themes, with one using self-concept domains to “cluster” the themes (28). This clustering of meanings into themes broadly reflects the approach taken by phenomenological researchers (Creswell, 1998). With the individual themes, discussion took place either generally or using sub-themes often supported by direct quotes from the interviews (again as usual in phenomenological research).

Of interest in ten of the studies (5, 9, 12, 14, 18, 19, 20, 21, 25, 27) was the fact that the authors included all or some of the researcher’s questions as well as the participants’ responses. This may contribute to giving the reader more insight into the nature of the interview, and is useful in understanding the prompts used by the researcher.

In 24 studies, there was a separate discussion in addition to the findings, and limitations were detailed in 14. Discussion or conclusions highlighting the findings and their importance in practice were identified (1, 2, 3, 8, 10, 11, 12, 14) or referenced...
(13, 15, 16, 20, 21, 22, 23, 25) in the majority of the studies. Some identified clinical or practice implications (4, 6, 7, 17, 18, 19, 27), and others made recommendations for practice or services (5, 23, 24) and staff training (1). The need for further research was mentioned directly in eleven studies (1, 3, 10, 11, 12, 13, 15, 18, 20, 21, 25), with others speaking more generally about the need to promote collaboration between people with intellectual disability and those who provide services to them. All the reviewed studies presented their findings as expected in phenomenological research.

### 4. Discussion

#### 4.1. Philosophy or theory

The different philosophies and theories that influenced the studies are reflective of the many approaches available to phenomenological researchers. Finlay (2009, p. 8) in her paper debating the different phenomenological methods, took the position that “…phenomenological research is phenomenological when it involves both rich description of the lifeworld or lived experience, and where the researcher has adopted a special, open phenomenological attitude which, at least initially, refrains from importing external frameworks and sets aside judgements about the reality of the phenomenon.”

She continues to explain that for a phenomenological method to be “sound” it should have an appropriate link to a phenomenological philosophy or theory, and the method applied must be “justified and consistent”. In the reviewed studies, the varieties of approaches that can be taken to phenomenological research were evident. Influencing theorists were not a feature of the IPA studies, indicating that researchers are perhaps comfortable with the prescriptive nature of having a series of steps to follow, yet still taking an interpretive approach. Within these studies, there were differences in approach in areas such as how the interview was conducted and findings presented. In general, all eighteen studies adhered to the principles of IPA.

There were differing levels of evidence of influencing philosophers and theorists in the 10 studies more broadly defined as phenomenological. Of significance in these studies was the finding that some researchers draw on philosophy and theories from both descriptive and interpretative perspectives. An example is the study investigating the mother identity for people with intellectual disabilities (3). Researchers identified firstly with Husserl’s descriptive phenomenology, and then used a process described by van Manen to find the essential structures of how women assume the mother identity. The main influences were drawn from descriptive phenomenological philosophy and theories.

While the diversity of approaches in the reviewed studies reflected different influences, researchers need to be cautious in choosing a method merely due to features such as local popularity rather than what may suit the research question. While choosing an approach that may provide structure and guidelines such as in the IPA studies researchers could be challenged to consider more pure interpretive techniques such as those offered by interpretive or hermeneutic phenomenology. In hermeneutic phenomenology the findings do not claim to rigorously present everything that was found, but instead are led by Heidegger’s philosophy of identifying those things that need to be thought about (Harman, 2013), and allowing readers to be drawn into thinking about the subjects from their own perspective.

In understanding the world of people with intellectual disability, methodologies such as Heideggerian hermeneutic phenomenology allow the researcher to dwell in their world while attempting to uncover meanings that may not be clear or are hidden (Ironside, 2005). Therefore it has the potential to go further by getting a deeper understanding of the lived experiences of people with intellectual disability.

#### 4.2. Approach to bracketing

The approach to bracketing plays a significant role in how phenomenological research studies are conducted. To apply bracketing (or what is often termed “phenomenological reduction” based on the work of Husserl), researchers focus on the experience and then describe how it is constructed. Heidegger, while taking an interpretative approach, allows for identification of what is described as “pre-understandings”, which represent the researcher’s previous experience of the phenomenon. As researchers are already in the world, an interpretation of that world already exists which is not possible for them to ignore (Heidegger, 1962). These pre-understandings may cause the researcher to look at things in a particular way or with a particular perspective which can hide the phenomenon from view (Van Manen, 1990). So while not bracketing out their experiences, the method requires the researcher to acknowledge and examine their pre-understandings, and present an interpretive account of the world of the participants. Therefore this method, while taking account of the researchers’ background, ensures that he or she is restrained by the participants’ voices which must be made visible (Benner, 1994), while understanding that the participants provide the primary means of understanding the phenomenon through their experiences, descriptions, interpretations and meanings.

For researchers who are investigating the experiences of people with intellectual disability, bracketing may prove a difficulty as it is usually researchers with a particular interest in this group who will undertake research. The reviewed studies reflected this – the results highlighted the relationship between the researcher and participants, with most researchers having previous experience or working in the area of supporting people with intellectual disability. The guidelines in IPA may cause confusion, as was evident in one study where the authors referred to the use of bracketing. According to the original source (Smith et al., 2009), the researchers attempt to suspend any pre-existing ideas about their topic rather than bracket or put aside their experiences completely. Therefore the approach advocated in interpretive...
phenomenology, where people acknowledge their previous experiences and accept this may impact on the research, may be
the best approach. Researchers can state their own situation and be honest in showing that they have an interest in an issue
or intervention that impacts on people with intellectual disability, and the reader can then take this into account when
examining the findings and recommendations.

4.3. Data collection (the interview)

According to Kvale and Brinkman (2009), a phenomenological interview is structured in a way which aims to understand
the world of the participant from their perspective, and obtain descriptions of their experiences of a particular phenomenon.
People with intellectual disability can be very open about their experiences and appreciate opportunities to discuss their
lives, and therefore make significant contributions as participants in research (Emerson et al., 2004). However there is also
the concern that people with intellectual disability cannot provide rich data due to their cognitive limitations. This was
addressed in a number of the reviewed studies. Some researchers did not have concerns, saying that their participants
provided extensive and detailed transcripts (12), “…talked openly and added insight to our understanding of their situation”
(Brown & Beal, 2009, p. 512), and gave accounts that were both rich and descriptive (14).

In contrast, others such as McNally et al. (2007), while promoting the rights of people with intellectual disability to
express their views and opinions, stated that “The data obtained was probably not as rich as…from the general population.” (p.
52) and Niry et al. (2015) noted that, “Their verbal ability to express their feeling was limited…” (p. 226).

Despite some reported challenges, the importance of giving this group an opportunity to describe and give meaning to
their experiences was a key feature of the reviewed studies. Researchers wanted to help to add to the body of knowledge
regarding many important aspects of the lives of people with intellectual disability, and support input into decisions that
affect them directly. Duperouzel and Fish (2010), for example, stated that people with intellectual disability are; “…rarely
asked about their experiences of self-injury and felt they had little say in the care they received” (Duperouzel & Fish, 2010, p. 614).
Research as “giving voice” to the perspective of people with intellectual disability and the need to listen to their voices was
an underlying feature of much of the reviewed work.

Data collection through the use of interview only (based on the reviewed studies), would indicate that people with a mild
or moderate intellectual disability can be recruited as research participants, but this participation can be influenced by how
the interview itself is conducted and the impact of interview schedules and topic guides. In the IPA studies reviewed, while
adhering to its main principles all adopted different approaches for the interview. All identified an interview schedule or
topic guide and the use of prompts during the interview. Just one study provided a copy of the interview schedule (9).

In their study, Macdonald et al. (2003) asked people with intellectual disability about their experience and satisfaction
with group analytic therapy. By using a very prescriptive interview schedule, the researchers found the participants had
difficulties understanding some of their questions, and this was reflected by the participants themselves. Structured
interviews would appear to contradict the approach advocated in IPA, and potentially influenced the themes which emerged
in the studies. As all studies used some form of schedule, it would help in ascertaining their impact if researchers considered
including them when reporting on studies.

Making a further important observation, MacMahon et al. (2015) made reference to the possibility of including people
with intellectual disability in the design of interview schedules and conducting interviews or focus groups themselves. This
was also referred to in the case study in which the authors supported the view that people with intellectual disability should
be involved in all aspects of the research process and preferably as co-researchers (12).

In supporting a more inclusive approach to research, there is an argument to be made in favour of a less structured
approach to data collection so that the uniqueness of each experience can be truly reflected. A positive effect of a less
prescriptive approach is that if the participants can guide the interview, they may relay experiences they have not previously
spoken about (14) and benefit from a more flexible approach to data collection (18). In hermeneutic interviewing for
example, the researcher is encouraged to take an approach that allows the participant to guide the direction of the interview
while still focusing on the topic. Often there is just one question that asks the participant about their experiences of a
particular phenomenon, and the subsequent interview is guided by the participant’s replies rather than any predetermined
questions or prompts. This approach has the potential to identify aspects of the experiences that are of particular significance
to people with intellectual disability.

4.4. Data analysis and value of reviewed studies

People with intellectual disability have been included as participants in phenomenological research and the willingness
of researchers to include this group of people in research studies is commendable. To understand the experiences of people
with intellectual disability, hearing their views is essential rather than depending on the views of others such as staff or
therapists. The results of the reviewed studies have the potential to help people with intellectual disability, as they have been
equipped to reflect the impact of certain interventions, conditions or important life events. For the application of research,
those methods which highlight how the findings can help inform practice, or make reference to particular clinical
implications, have the potential to make most impact.

The approach to analysis in terms of influencing philosophies or theories and rigour of application can have significant
impact on the findings and the value of the research. Approaches that guide researchers through a series of steps are popular
but must also be chosen with care. Choosing a method of analysis that can add to the value of the research, such as Heideggerian hermeneutic phenomenology, ensures that there is no pre-conceived plan and that there is no claim that the findings presented are “objective, simplified, scientific concepts of truth” (Smythe, Ironside, Sims, Swenson, & Spence, 2008, p. 1391). The findings can be interpreted by practitioners and others within the context of what is best for people with intellectual disability:

“The quest of Heideggerian phenomenology is not to provide answers, for that shuts down and closes thinking. It is rather to invite readers to make their own journey, to be exposed to the thinking of the authors and to listen for the call on their own thinking.” (Smythe et al., 2008, p. 1393)

Thinking and engaging at an intellectual level can result in increased awareness and understanding among staff who support people with intellectual disability (1, 2, 3, 12, 23, 26), particular guidelines for practitioners (4, 11) or information to assist them in understanding participants needs (8, 9, 16, 17, 18, 19, 27, 28). There is also the importance of highlighting the need for opportunities to be involved in their care and plans for the future (7, 14, 24), and challenge stereotypes of people with intellectual disability (25). There is additional value in showing that people with intellectual disability can have similar experiences to other groups (21) and can benefit from similar interventions (10) or supports (20).

Being involved in decisions about their lives is about improved quality of life and having the ability to have as much control as possible. Research can help highlight situations which result in powerlessness (13), lack of control (15), or a feeling of potential stigmatised treatment (22), as reported in some of the reviewed studies. A note of caution may be necessary, as generalisations from the research conducted within the wider population may not apply to people with intellectual disability, who may require different approaches dependent on their particular needs (Lloyd, Kalsy, & Gatherer, 2007). In addition, while it is not the remit of this review to evaluate the efficacy of particular therapies or interventions, those studies that looked at these areas show that qualitative research methods have a role in identifying their potential benefits.

4.5. Conclusion

Generally, the value of results in phenomenological research with people with intellectual disability is dependent on the correct application of the recruitment and data collection method, the relationship between researcher and participants, the rigour of data analysis, and how findings are stated. In addition, an area that requires further examination is how research findings are disseminated. This is a challenge for all researchers, but in particular for those who wish to ensure people with intellectual disability can benefit from research outcomes. Researchers need to examine how the findings can be shared with people such as policy makers and practitioners, who can utilise them in their practice (Sandelowski, 2004).

The diversity of potential users of these studies requires a willingness to use different ways of dissemination such as reports written in plain language supported by appropriate illustrations. Methods in addition to academic publications and conferences must be considered, with a focus on presentation and translation. Therefore both scientific and communication concerns can be addressed and the widest audience reached, while still contributing to traditional academic forums (Keen & Todres, 2007). This would address the need to translate research into practice, while also giving a “voice” to people with intellectual disability (Lewis & Porter, 2004) who may traditionally have been marginalised (Northway, 2010). For people with intellectual disability, involvement in research should not be just about being participants in research, but also being informed of the findings and how they may impact on them.

5. Implications for future research

Implications for future research concern both the choice of method and how research is disseminated. For people with intellectual disability being part of the research process is important but having research shared in a way that is understandable and meaningful to them is of equal importance. Researchers may need to address this by considering alternative ways of ensuring people hear about their findings and are supported to understand any implications. Methods such as creating an easy-to-read version of the study or making a video to explain the findings may be some possibilities to ensure people with intellectual disability understand research findings and the potential impact on their lives.

Future researchers should consider the benefits of Heideggerian hermeneutic phenomenology when seeking to understand the experiences of people with intellectual disability. All phenomenological approaches involve working with the data to ensure the emergence of common themes or essences. However, Heideggerian hermeneutic phenomenology may have particular benefits for working with data from people with intellectual disability. While it may appear counter-intuitive to undertake a hermeneutic study with people who may not have the same verbal ability as others, the process itself can counter any concerns researchers may have. Smythe et al. (2008) explain:

“The process of doing hermeneutic phenomenology is represented as a journey of “thinking” in which researchers are caught up in a cycle of reading-writing-dialogue which spirals onwards.” (p. 1389)

This journey takes into account that researchers most likely have previous experience with this group, the interview is not dependent on structured schedules or guides, and analysis is not constructed by inflexible steps or guidelines. This approach fits with the main characteristics of participatory research, which promotes the inclusion of marginalised groups and...
requires the researcher to be willing to highlight important issues (Northway, 2010). Smythe et al. (2008) argue that being human is complex, and we need to search for what is seen and unseen while provoking thinking about the particular experience that is being investigated. In practical terms, this may mean that rather than prompting people with intellectual disability to answer a series of questions, instead the researcher merely asks about their experience and listens for both what is said and unsaid.

Therefore this review hopes to advance the use of this methodology, given the value it has in allowing the voices of people with intellectual disability to be heard, while challenging researchers not to attempt to “… prove or disprove, not to provide irrefutable evidence…” (Smythe et al., p. 1391), but instead create discussion and questions about issues of concern to people with intellectual disability.

References


Hall, S. A. (2009). The social inclusion of young adults with intellectual disabilities: A phenomenology of their experiences. Journal of Ethnographic and Qualitative Research, 4(1), 24–40. Retrieved from http://jwvweb.wiuweb.onweb.com/jwv/jwvart.html?recid=0bc05f7a67b1790e54b937a3e010a6d00b957235a0b93b27c1e19768019595728edc&fmt=HPDF, http://www.wiuweb.onweb.com/jwv/jwvart.html?recid=0bc05f7a67b1790e54b937a3e010a6d00b957235a0b93b27c1e19768019595728edc&fmt=P


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