Is it possible to use Interpretative Phenomenological Analysis in research with people who have intellectual disabilities?

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Evaluating the use of Interpretative Phenomenological Analysis in research with people who have intellectual disabilities.

Abstract

Background: This paper examines the appropriateness of using Interpretative Phenomenological Analysis (IPA) in research with people who have Intellectual disabilities (ID), focussing on quality.

Methods: We conducted a systematic search to identify published studies. We assessed the quality of the studies using a bespoke framework, adapted from previous reviews, and articles on indicators of 'good' IPA work.

Results: Twenty eight papers were reviewed. The studies were of varying quality: 6 (22%) papers were rated as 'good' quality; 16 (57%) were 'acceptable', and 6 (21%) were 'poor'. This ratio was comparable to that found in assessments of IPA papers in other domains, suggesting that issues of quality reflect researcher competence, rather than challenges with the population.

Conclusions: IPA can be an appropriate methodology to use with people with ID. We encourage researchers to develop more detailed analyses, to provide more transparency about their sampling strategies, and more detail of the characteristics of their samples.

Keywords: Interpretative phenomenological analysis, quality, Intellectual disabilities, qualitative research, learning disabilities.

Evaluating the use of Interpretative Phenomenological Analysis in research with people who have intellectual disabilities.

A study by Beail and Williams (2014) reported a significant increase in the number of research articles using qualitative methods which were published in three major intellectual disability journals, over the first decade of the 2000s. They noted a marked increase in studies that involved people with intellectual disabilities as participants. A more recent special edition of a journal focussing on qualitative research (Rose & Stenfert Kroese, 2018) has highlighted the growing interest in qualitative research with this group. This includes the involvement of people with intellectual disabilities not only as qualitative research participants (e.g. Larkin et al., 2018; Williams, Thrift & Rose, 2018), but also as members of the research team (Theodore et al., 2018; Unwin et al., 2017).

Previously, researchers have been cautious about qualitative methods in this field. In part this may have arisen from a view that people with intellectual disabilities present challenges to qualitative researchers: “inarticulateness, unresponsiveness, a concrete frame of reference and problems with time” (Booth & Booth, 1996). Researchers may also have been concerned about whether participants with intellectual disabilities are able to give informed consent (Iacono, 2006) to a form of research which may have more complex ethical implcations (e.g. direct, but anonymised quotations will appear in the final report). Much research which ostensibly explores the experiences of people with intellectual disabilities has relied on proxy perspectives (e.g. from carers or staff; Dillenburger & McKerr, 2010; Hatton & Emerson, 2009). Gradually, however, there has been a constructive turn towards adaption, so that methods of recruitment, consent-taking, data collection, and so on, are better able to involve people with intellectual disabilities in meaningful qualitative research. Early work in this area by Atkinson (1998) advocated the importance of helping people with intellectual disabilities to think about their own circumstances, and acknowledging that they are experts in their own experiences.

Given that the term “intellectual disabilities” can include people with varying intellectual and functional abilities (Scanlon, 2013), it is important that research in this field is based on clearly-situated sampling. Studies which include a heterogenous range of intellectual ability are possible, but they are very challenging. This is partly due to the need to provide different solutions to all of the ‘involvement features’ described above, and partly because of the difficulty of showing how themes map onto the different contexts and experiences associated with different profiles of intellectual ability. Well-defined and reasonably homogenous samples may be more appropriate for many research questions, allowing the researcher to focus on a particular context. This can make it easier for readers to understand the implications and context of the analysis. One qualitative methodology which aims to do this is Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). This review aims to evaluate the use of IPA in research with people with intellectual disabilities.

Interpretative phenomenological analysis (IPA)

IPA is an approach to qualitative inquiry which is widely used in applied psychology (Harper, 2012). IPA draws upon the hermeneutic and phenomenological traditions to focus on how *the researcher* makes sense of how *participants* make sense of a salient experience (Smith et al., 2009). It combines these interests via an idiographic commitment to understanding *particular* experiences, *in context* (Larkin et al., 2006). Successful IPA (Smith, 2011) balances these three components, grounding an analysis in enough case-level detail for the reader to be able to understand the context of the participants’ concerns, whilst drawing out the core claims which participants make about their experiences, and also offering a more interpretative perspective, to transcend the explicit claims of individual voices within the data and provide a psychological insight into the phenomenon.

To meet these commitments, IPA researchers tend to prefer in-depth verbatim data (rich in descriptive or reflective content, or both) from relatively small samples of participants, organised around a shared perspective on the topic of interest, to achieve a degree of homogeneity. More recent developments within IPA include emphases on the contribution which can be made by case studies (Smith, 2007) the gains which can be made by combining several homogenous samples within in a more complex ‘multiple perspective design’ (Larkin et al., in press), and the use of visual data alongside verbatim content (Boden & Eatough, 2014).

IPA has the potential to make an important contribution to the field of intellectual disability research. As an approach it provides an opportunity to hear the concerns of research participants and to understand these concerns in the context of a more interpretative ‘birds’ eye’ view from the researcher. This is a domain where there is much to learn about the development, needs and preferences of people with intellectual disabilities, in different contexts. This may be particularly important for evaluating the acceptability of services and interventions, or developing more nuanced approaches to supporting the interpersonal lives of people with intellectual disabilities. Good IPA work can contribute to this learning.

Evaluating the quality of IPA research

There is no consensus – and there are many concerns – about the use of quality criteria for the evaluation of qualitative research studies (Smith & McGannon, 2018). While many guidelines and frameworks do exist which claim to be applicable across a range of methods (e.g. Tong et al., 2007; Elliot, Fischer & Rennie, 1999; Morrow, 2005; Yardley, 2000), all of these are embedded with epistemological and methodological assumptions which are appropriate for some methods, but not others. Rather than import a framework which does not meet our needs, in this paper we evaluate IPA's use in the field of intellectual disability research, with a bespoke framework.

In a previous systemaic reveiw of IPA's contribution to health psychology research, Smith (2011) defined the functional features of a high quality IPA paper: a clear focus; strong data; rigour; sufficient space to elaborate themes; interpretative analysis which is beyond descriptive; discussion of both convergence and divergence of data; well-written. These are pragmatic criteria designed to detect whether a paper is 'good enough' in IPA terms, rather than checklist for researchers to follow. Smith rated 27% of the papers as good, 55% as acceptable and 18% as unacceptable. He concluded that the results were "respectable" given that IPA is a relatively new methodology.

In a methods chapter on IPA, Larkin and Thompson (2012) offer a slightly more elaborate framework for evaluating IPA, which combines similarly pragmatic features for recognising 'good enough' work, with some aspirational elements. They proposed that a "good" piece of IPA research will have the following features: appropriate data from appropriate informants; idiographic focus; transparent data collection; a focus on how things are understood; a balance between phenomenological detail and interpretative detail; appropriate use of triangulation, audit or credibility checks; extracts to support commentary; contextual detail with regards to extracts, research and participants; attention to process, and engagement with theory when presenting the analysis.

In this review, we draw on both of these frameworks to develop a bespoke set of evaluative criteria (see below).

Aims

This review has the following aims:

- Evaluate the quality of IPA research conducted with people who have intellectual disabilities.
- Identify any challenges to the development of good quality IPA research conducted with people who have intellectual disabilities.

Methodology

Search strategy

Three electronic databases (MEDLINE, PsycINFO and CINAHL) were searched. A combination of 'subject heading' searching and free text searching was used across the three databases. The main search terms for free text searching focussed on Intellectual Disability (Learning diff*, Mental retardation, Learning disab*, Mental deficien*, Intellectual Disab*) and IPA (Interpretative phenomenological analysis, Interpretive phenomenological analysis). All the terms were exploded to ensure that more specific versions of the umbrella terms were also included in the search. Free text searching also known as keyword searching was also used. The different variations of the terms including truncations were combined using the Boolean operator OR. They were then entered in parenthesis to the subject heading searching and combined using AND.

The databases were searched with no date restriction and this was conducted on 1st November 2017, generating a total of 363 papers. The inclusion and exclusion criteria (Figure 1) were then applied to generate the final papers included in this review.

Insert figure 1 about here

In total, 29 studies met the inclusion criteria for this review. Two of the papers were different analyses which appeared to be drawn from the same sample, in the same research study by the same author (Pestana, 2011; Pestana 2015). To avoid duplication, we included the earlier of these two papers in the review. This review therefore covers a total of 28 papers.

Quality evaluation

The following steps describe the process of developing, populating and implementing a quality guide specifically designed to evaluate IPA for research with people with ID.

Developing the quality guide

The specific focus of Smith's (2011) evaluation was on the features which distinguish acceptable, unacceptable and good papers from each other (figure 2). The framework in Larkin and Thompson (2012) only makes recommendations for good papers. These are combined in Figure 2. A more general quality checklist for qualitative research by Yardley (2000) is also often discussed in the context of IPA research (e.g. Smith et al., 2009). Yardley argues that there are four main areas to consider when evaluating qualitative research: sensitivity to context; commitment and rigour; transparency and coherence and impact and importance.

Insert figure 2 about here

Populating the guide

Taking into consideration quality issues raised by Smith (2011), Larkin and Thompson (2012) and Yardley (2009) our quality guide was populated by six main areas:

- **Theory:** relates specifically to Smith's (2011) focus on whether a research paper adheres to the theoretical principles of IPA.
- **Informants:** relates to "sensitivity to context" in Yardley (2009), such as 'does the research take into consideration whether the research methodology is appropriate to the participants?' As the specific focus of this paper is on using IPA with people with intellectual disabilities, we also added a column to record information about the level of disability reported for samples in each study.
- **Transparency:** relates directly to Yardley (2009) with regards to "transparency and coherence". Transparency is especially important for those evaluating research to consider whether it is clear how the research was conducted and evaluated. It is worth noting that this guide has separated Yardley's criteria of "transparency and coherence" into two categories. It was decided that there are specific issues relating to IPA (such as number of themes) which could not be captured under transparency.
- **Coherence of analysis:** takes into consideration specific IPA issues raised by Smith (2011) such as the evidence base for the themes.
- **Focus:** maps onto Yardley's criteria of "impact and importance" and also Smith's (2011) and Larkin and Thompson's (2012) recommendations that good papers are clearly-focussed, and engaged with theory.
- **Trustworthiness** was also added as quality marker as Larkin and Thompson (2012) suggest that it is important that IPA researchers demonstrate that they have taken cerdibility issues into consideration (such as the appropriate use of triangulation).

The six main areas were used as headings for the structured tool designed for this study. A shortened version of the tool is shown in Figure 3. Details to consider when evaluating the research were posed as both concrete questions (e.g. how many participants?) and more open ended questions (how were the participants engaged in the research?).

Insert figure 3 about here

To aid more novice researchers, it was decided that it would be helpful for each heading to have some indicators as to what would constitute good, acceptable or poor application of each of the quality domains. For example, with regards to theory, a ‘good’ application of theory would be demonstrated through all theoretical principles of IPA being implemented appropriately, ‘acceptable’ application would mean the researchers made a good attempt and ‘poor’ application of theory would mean that the research is not consistent with the theoretical principles of IPA.

Giving each paper an overall rating

An overall rating of good, acceptable or poor quality based on Figure 3 was ascribed to each paper via the following process:

- The quality guide was systematically completed for each paper, with a researcher assigning a rating for each domain.
- Each completed quality guide was assessed individually using the characteristics of the three quality categories outlined in Figure 2. For example, if a paper was rated as ‘poor’ for theory, then it is likely that the whole paper would be rated poor because it “was not consistent with the theoretical principles of IPA”. Each quality domain (theory, informants etc.) was considered when assigning an overall rating. This step in the rating process was deliberately not designed as a

prescriptive process as rating papers is complex and requires readers to consider all aspects of the research holistically. For this reason, a point's based system was deliberately not used.

- Each paper was reviewed in turn and assigned an overall rating, using the new synthesised criteria designed for this study. A selection of the papers were also blind-rated by another rater to obtain a measure of reliability.

The papers were then assigned a poor, acceptable or good label based the application of Figure 3. It is important to note that 'poor' in this context indicates a poor example of IPA according to IPA's stated principles, rather than a paper which has no merit, or which may not meet more general standards for qualitative research.

Reliability of the measure

Seven papers were rated by two independent raters on the measure. The percentage agreement for the assessment of the papers was 86% agreement. For the categories within the 7 papers, agreement was 79%. For each of the components agreement was as follows: Theory 100%; Informants 79%; Transparency 75%; Coherence of analysis 64%; Focus 86%; Trustworthiness 86%. Cohen's Kappa for all of the components of the 7 papers was significant (Kappa = .565, $p < .001$).

As a further check on reliability a Masters student examined the same seven papers using the measure. Her overall assessment of the papers agreed completely with one of the previous raters and disagreed with the other rater on one paper in relation to their overall quality suggesting that reliability between raters was robust.

Quality characteristics of the 28 papers reviewed

Six papers were rated as poor (Baum & Burns, 2007; Judge et al., 2010; Lewis et al., 2016; MacDonald et al., 2013; Merriman & Beail, 2009; Pestana,2011). None of the 'poor' papers implemented IPA concepts adequately, meaning that they did not adhere consistently to core commitments of phenomenology, hermeneutics and idiography. Secondly, all of the poor papers lacked some transparency with regards to the stages of the research. Thirdly, none of these papers explained the interview schedule and its development. Fourthly, these papers lacked sufficient data extracts to support the themes presented. Finally, none of them reported on any methods employed to demonstrate trustworthiness.

Sixteen papers were rated as 'acceptable' (Anslow, 2013; Brown & Beail, 2009; Dysch et al., 2012; Gould & Dodd, 2014; Kenyon et al., 2014; MacMahon et al., 2015; Malik et al., 2017; McRitchie et al., 2014; Mitchel et al., 2006; Monteleone & Forester Jones., 2017; Newberry et al., 2015; Robinson et al., 2016; Rushbrooke et al., 2014; Sullivan et al., 2016; Shewan et al., 2014; Wilson et al., 2013). All of these papers subscribed to the theoretical principles of IPA. It was clear that IPA was an appropriate methodology for their aims. These papers varied in terms of whether they adhered to the other quality markers.

The remaining six papers were rated as 'good' (Clarkson et al., 2009; Cookson & Dickson, 2010; Dinwoodie et al, 2016; Roscoe et al, 2015; Rose et al., 2015; Stenfert Kroese et al., 2016). These papers met the majority of quality criteria but there were some exceptions, which included specifying the level of intellectual disability of the participants, and a lack of homogeneity in some samples.

Results

Four of the papers investigated the experiences of parents with intellectual disabilities (Baum & Burns, 2007; Gould & Dodd, 2014; Shewan, et al., 2014; Wilson, et al., 2013). Seven of the studies explored the experience of receiving psychological therapy (Anslow, 2013; Lewis et al., 2016; Merriman & Beail, 2009; MacDonald et al., 2003; MacMahon, et al., 2015; Roscoe et al., 2015; Stenfert Kroese et al., 2016). Three studies looked at the experiences of people with intellectual disabilities as inpatients in hospital (Brown & Beail, 2009; Clarkson et al., 2009; Cookson & Dickson, 2010). Three further papers looked at the experience of diagnosis and disability (Dysch et al., 2012; Kenyon et al., , 2014; Monteleone & Forrester Jones, 2016) and two at relationships (Rushbrooke et al., 2014; Sullivan et al., 2015). Other papers explored the experience of: bereavement (McRitchie et al., 2014); aging (Newberry et al., 2015), retirement from daycentres (Judge et al., 2010); trauma (Mitchel et al., 2006); fire setting (Rose et al., 2016); mental health (Robinson et al., 2015); ethnic minorities (Malik et al., 2017); self-concept (Pestana, 2011) and identity (Dinwoodie et al., 2016).

Smith (2011) argues that IPA research should have a clear focus: the topic should be specific and not broad. A specific focus, and a commitment to capturing context and detail (idiography), requires a homogenous sample. All papers rated as either good or acceptable papers also had a clear research focus, with the exception of Kenyon et al. (2014). This paper explored the experience of people being diagnosed with an intellectual disability. The majority of the participants in the sample had been “diagnosed” to have an intellectual disability whilst they were still in school. The mean age of the participants was 47. This raises the question of the current importance of the diagnosis itself, for many participants, as well as their ability to remember an experience that may have occurred over 30 years previously. More explicit reframing of the focus in terms of the continued significance of the diagnosis might have been more meaningful: in the analysis section, the authors reflect on the process of ‘coming to terms with diagnosis’ for example, which might have been a better statement of the study’s focus. When the research topic is not of immediate importance to the participants, it is likely to impact on their ability to engage with the research process, and impact on the quality of the data.

Smith et al. (2009) do not advocate an ideal sample size, but suggest that 6-10 participants for those with more experience using qualitative methods. They add that larger sample sizes may be appropriate when the quality or depth of data is more variable. The sample sizes for the papers in this review appeared in line with this recommendation, with the exception of four papers. Judge et al. (2010), Monteleone and Forester Jones (2016) and McRitchie et al, (2012) recruited 16, 15 and 13 participants respectively. The main challenges of managing larger sample sizes in IPA are: *a.* meeting idiographic commitments and *b.* maintaining depth of analysis.

In 13 of the papers, the homogeneity of the sample was either poorly rationalised, poorly achieved, or both (Dysch et al., 2012; Judge et al., 2010; Kenyon et al., 2014; MacDonald et al., 2013; Malik et al., 2017; Monteleone & Forrester Jones, 2017); Robinson et al., 2016; Roscoe et al, 2015; Rushbrooke et al., 2014; Sullivan et al., 2016; Wilson et al., 2013). Sampling strategies which do not articulate the shared perspective upon the phenomenon of interest not only violate the idiographic philosophy of IPA, but also impact on the researcher’s ability to formulate theories (Smith, 1999). Many of the researchers overlooked the importance of homogeneity with regards to the participants’ level of intellectual disability. Studies sometimes assumed the participants to have an intellectual disability due to their eligibility to receive input from community intellectual disability services.

All of the studies engaged their participants through individual face-to-face semi structured interviews. Malik et al., (2017) used both individual interviews and a small focus group. Only nine of the papers gave a good account of how the interview schedule was developed. Most of the papers made references to the interview topics only (e.g. Rose et al., 2015; Sullivan et al, 2016). However Mitchell et al., (2006) attached the interview schedule as an appendix. The advantage of attaching an interview schedule is that it improves the transparency of the research and helps the reader to explore whether the interview has been adapted in any way to accommodate the needs of people with intellectual disabilities.

In IPA, the rigour of the analysis process is reflected in authors attending to both the breadth and the depth of the themes derived (Smith, 2011). The research process underpinning this must be transparent. Most papers included details about the procedure of the analysis, including information about the *process* of coding (though rarely about the *focus* of coding, which is more useful to a reader). The number of themes varied between the papers, from one super-ordinate theme with 3 sub-themes (Shewan et al., 2014) to 6 super-ordinate themes and 17 sub-themes (Lewis et al., 2012). Generally, smaller numbers of themes allows for greater in-depth elaboration, if those themes have a sharp focus.

The elaboration of themes is vital in qualitative research. Smith (2011) suggests that in some cases, researchers are better off using a paper to develop a subsection of their themes in an elaborate fashion rather than presenting them all superficially. Smith (2011) recommends that, as a rule of thumb, we might expect to see evidence from at least half of the sample underpinning the reporting of any major theme. Given that a theme might not speak to the whole of a sample, we have interpreted this as 'half of the participants *contributing to* a theme should also contribute to the reporting of that theme.' The poor papers in our review often fail to develop themes via discussion of sufficient data extracts.

The quotes in all of the papers appeared distinctly different to IPA papers that included non-disabled participants. The extracts were often brief and decontextualised, such as “makes me hot” (Dysch et al., 2012). Some of the papers had longer excerpts, such as “All the babies were crying and I could not get to sleep. Kept moving me from one room to another I didn’t know where to put my face, when I saw them babies” (Mitchel et al., 2006). Interviews with people with intellectual disability often involve more scaffolding from the researcher, and a more conversational, dyadic style. In the papers in our review, however, the contributions of the researcher were often invisible. Quotes in the papers rarely exceeded two or three sentences.

IPA requires researchers to be interpretative, and extend the account beyond the explicit claims of the participants. All of the good papers had sufficient numbers of extracts to support some interpretation. Each had also attempted to provide both descriptive and interpretative analysis. For this reason, data extracts were not taken purely at face value, and were not left to ‘speak for themselves.’

When an IPA paper investigates the experiences of more than one participant, it is important for researchers to demonstrate the concerns of individual participants in the context of themes which explore shared experiences (Smith, 2011). This is a difficult skill to master. Smith (2011) believes that this is the “hallmark” of good IPA work. The distinct features of the “good” papers in comparison to the “acceptable” papers were that they were able to demonstrate convergence and divergence effectively. Out of six good papers, five were able to demonstrate this. For example, Clarkson et al. (2009) states “Six participants made reference to…” This is a simple stratgegy for contextualising the representativeness of a theme. The paper also explores individual experiences. A simple indicator of this is often the use of pseudonyms (rather than participant numbers), allowing the reader to keep track of who is who. A stronger indicator is time taken to step aside from the main narrative and explore cases where a single participant might strongly exemplify – or contradict - a thematic point. Some of the better papers also provided evidence of triangulation, audit and credibility checks (e.g. Stenfert Kroese et al, 2016).

Specific Issues relating to using IPA with people with intellectual disabilities

It is a common approach for people with intellectual disabilities to have proxies present during research interviews to support them with communicating with researchers (Whitehurst, 2006). Some of the papers explicitly stated that carers were present in some of the interviews to support the person with an intellectual disability (Anslow, 2013; Roscoe et al., 2015; Rushbrooke et al, 2014). Anslow (2013) acknowledged that methodologically this was supportive in allowing people to take part in the research who might have otherwise struggled to do so. There are IPA methods papers (such as Palmer et al., 2010) which discuss strategies for analysing data where there are mutliple speakers, but the papers in our review did not report that they drew upon these strategies.

Cookson and Dickson (2010) reported that the participants in their study presented with limited vocabulary. Regardless of this, Cookson and Dickson (2010) were able to apply an IPA approach very effectively. This suggests that if IPA is applied appropriately, verbal articulacy should not be a stumbling block. Similarly, Brown and Beail (2009) noted that one of the limitations of their paper is that there were concerns that the participants might struggle with interviews due to their limited verbal abilities, and thus that the data would not be “rich”. Despite these concerns, the authors went onto conclude that the participants were open, and shared valuable insights into their experiences. Often concerns about ‘richness’ can focus on the limitations of vocabulary, expressive language or reflective capacity. Rich data take many forms, however, and in phenomenological research, detailed descriptions (or processes or events, for examples) can be an important form of ‘richness.’ Eliciting rich descriptions from participants takes patience, imagination and planning from the researcher (e.g. see Petitmengin, 2006)., but it does not necessarily require an extensive vocabulary or extraordinary level of reflective insight from the participant.

Some papers, especially more recent studies, have used different communication devices to aid conversations between participants and interviewers. For example, MacMahon et al., (2015) used visual prompts of people and places, along with activities, that related to the intervention they were evaluating. Anslow (2013) also specified that some participants used additional communication methods such as Makaton. Whilst this is specified, the way in which Makaton has been incorporated into the analysis has not been recorded.

Discussion

This paper describes a methodology for appraising IPA research for people with intellectual disabilities, which appears to be reliable, and which suggests that it is possible to conduct good quality IPA research with this population. This review rated 6/28 (22%) papers to be of good quality, 16/28 (57%) as acceptable quality and 6/28 (21%) to be of poor quality. In comparison, Smith (2011) rated 27% of the papers he reviewed to be of good quality, 55% to be of acceptable quality and 18% to be of unacceptable quality. It appears that the proportion of “acceptable” papers are roughly equivalent in both fields. Given that just over half the papers in this paper and in Smith’s (2011) review were rated as “acceptable” it seems that reviewers and editors still have some way to go in terms of gatekeeping for consistently good quality IPA research. However, we do wish to underscore the point that papers rated ‘poor’ in terms of meeting their IPA commitments may still have other merits.

The tool that was developed to review the papers seems to provide a useful framework. While there was some disagreements between raters, it did seem to have reasonable reliability and to provide a clear focus for identifying an acceptable paper.

It is important to consider how the term “intellectual disability” was conceptualised in the studies we reviewed. Many authors devoted very little space to describing the ability levels of their participants. One of the reasons for the lack of information may be related to the recruitment process, as the majority of the participants were recruited through staff in health services. The organisations therefore acted as gate-keepers and may have their own assumptions and judgements about whether people with intellectual disabilities are able to take part in research or not. Lee (2003) found that “gatekeeper” organisations can sometimes block access to participants when discussing sensitive topics. Another possibility is that qualitative researchers had reservations about categorising their participants in terms of more formal measurement data. Unfortunately, a consequence of this is that it is difficult to see whether the experiences of people with more severe intellectual disabilities are reflected in the findings of these papers.

Despite the term “intellectual disability” appearing in the keywords of many papers, a closer inspection revealed that while the researchers were labelling their participants as having an intellectual disability, the appropriateness of that label was not always clear. It is vital that future researchers improve transparency regarding the characteristics of participants recruited into their research otherwise we may fall into the trap of either generalising from people with varying presentations or that we run the risk of recruiting people into research who may be in services but may not necessarily meet the definition of intellectual disability.

All of the studies collected data using individual interviews. Malik et al. (2017) did include a small focus group as part of their work. Focus groups may help less confident participants to engage in research, through peer support (Cambridge & McCarthy, 2001). In other fields, IPA researchers have been working with group data (e.g. see Palmer et al. 2010) and visual material (Boden & Eatough, 2016), and these developments may be helpful in the field of intellectual disability research.

The studies in our review tended to decontextualise quotes from their participants, and to remove the researcher's elaborating role in the interviews from the quotes which they presented. More nuanced and insightful analysis could be offered, if IPA researchers considered coding and discussing *sequences* of their interview data, rather than bite-size extracts. Some of the strategies in Palmer et al.'s paper on focus groups (2010) are also helpful for keeping track of interviews with more complex interactional dynamics, and may be adopted here.

Interview schedules were only available for a minority of papers that were reviewed, so it is difficult to comment on whether the researchers adapted their interview techniques or used any novel approaches to engage the participants with the research. People with intellectual disabilities may require additional scaffolding through additional questions from the researchers to guide and support them through the research which suggests that particular care needs to be taken when designing interview schedules. Whilst peer reviewed journals have stringent limits on word count, the degree of detail regarding interviews varied significantly. The papers with the better analysis sections tended to have more transparency with regards to the topics covered in the interview too. This may be because the reader could draw links between the questions asked and the types of responses given by the participants. The whole process was integrated and future researchers would be strongly encouraged to give more details on data collection. Without this information it is difficult to judge the quality of the interview and its impact on the analysis.

It is important that IPA researchers produce themes that transcend the structure of the interview schedule (Smith et al., 2009). In some of the papers, the themes derived were very closely linked to the research questions asked, and had not been developed far beyond the level of ‘topics’. This majority of the papers’ analysis sections were descriptive rather than interpretative, because the level of analysis needed for a good IPA paper was not conducted or not reported. It is possible that the researchers struggled with interpretative commentary on short prose, but as noted above, there are strategies available for dealing with more sequential forms of interactional data. This requires the researcher to plot the development of meaning in the interplay between researcher and participant, producing interpretative commentary across several exchanges. IPA also seems to be often carried out by novice researchers and this lack of experience may result in difficulties with interpretation of the data.

Implications

Good qualitative research can enrich our understanding of the meaning and context of events and processes. Good IPA offers as an experiential and idiographic perspective on the world. IPA can be an appropriate methodology to use in research with people with intellectual disabilities. We encourage IPA researchers in the field of intellectual disability to:

- provide more information about data collection methods
- to be more creative in their approach to data collection
- to develop more detailed and interpretative analyses
- to present analyses which engage with longer sequences of data
- to provide more transparency about their sampling strategies, and the characteristics of their samples.

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Figure 1: Criteria for inclusion and exclusion

Inclusion criteria	**Exclusion criteria**
✓ Adults over the age of 18 with an intellectual disability ✓ Explicit explanation as to how participants were assessed as having a intellectual disability ✓ Data derived from individual interviews or group interviews ✓ Published in English in a peer reviewed journal ✓ Explicitly stated that IPA was used to interpret the data.	× Views of carers or staff × Views of people with intellectual disabilities in conjunction with views of people without intellectual disabilities such as staff views. × Data analysed using IPA and other research methods

Figure 2: Key features of good, acceptable and poor IPA papers.

POOR PAPERS	*The paper fails on one of the four criteria for acceptable. It may be:* • *Not consistent with theoretical principles of IPA;* • *Insufficiently transparent for reader to see what was done;* • *Not of sufficient interest; and* • *Poorly evidenced* • *Insufficient extracts from participants to support the themes being illustrated;* • *No explanation for how prevalence of the themes was determined; and analysis is crude, lacks nuance* *Predominantly what lets a paper down is the poor evidence base. Typical ways this can occur:* • *Large number of descriptive/superficial themes from a large number of participants;* • *Each theme has short summary and one or two extracts without interpretation;* From Smith (2011) p. 17
ACEERPTABLE PAPERS	*Must meet the following criteria:* • *Clearly subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic.* • *Sufficiently transparent so reader can see what was done. Coherent, plausible and interesting analysis.* • *Sufficient sampling from corpus to show density of evidence for each theme"* From Smith (2011) p. 17
GOOD PAPERS	*Paper must also clearly meet all the criteria for acceptable* • *Well focused; offering an in-depth analysis of a specific topic;* • *Data and interpretation are strong; and* • *Reader is engaged and finds it particularly enlightening."* From Smith (2011) p.17
	• *Collecting appropriate data from appropriately selected informants* • *Some degree of idiographic focus balanced against what is shared within a sample* • *An analysis that: transcends the structure of the data collection method (e.g. the schedule for a semi-structured interview); focuses on how things are understood rather than what happened; incorporates and balances phenomenological and interpretative work to develop a psychologically relevant account of the participants engagement-in-the-world* • *Appropriate use of triangulation (can be via methods, perspective's, data, analysis, field world) or audit and/or credibility checking (can be via respondents, supervisors, peers, parallel sample) to achieve trustworthiness* • *Appropriate use of extracts and commentary to achieve transparency (claims should usually be substantive engagement with, and commentary on some longer extracts of data* • *Appropriate level of contextual detail- for the excerpts, participants, researchers and study* • *Attention to process: including analytic and reflexive components* • *Appropriate pitch and engagement with theory (in making sense of the* • *analysis"* From Larkin and Thompson (2012) p.112

Figure 3: Structured tool including quality criteria developed for this paper

Research paper title

Research question and research aims

1.**THEORY**: Good Acceptable Poor

Good: Clearly subscribes to all of the theoretical principles of IPA in a coherent fashion: it is phenomenological, hermeneutic and idiographic.

Acceptable: Attempts to subscribe to the theoretical principles of IPA but some areas are not clear. Some evidence of the research being phenomenological, hermeneutic and idiographic

Poor: Not consistent with theoretical principles of IPA

Phenomenological: is the study sufficiently grounded at looking at what the experience is like for the person? Or does it simply look at what happened. Is the question more than "what people talked about". Are the researchers looking at the meaning?

Hermeneutic: How does the participant make sense of their experience? How does the researcher make sense of the participant making sense of their experience? Is there sufficient interpretation of meaning

Idiographic: concerned with the particular depth of analysis. How has an experience been understood from particular people in a particular context? Does it link to theory?

2.INFORMANTS: Good Acceptable Poor

Good: Appropriate data from a homogenous sample of participants relevant to the research question

Acceptable: Appropriate data from participants which has enabled the researchers to make some attempts to answer the research questions.

Poor: Inconsistencies in data collection and lack of information on participant selection, unable to conclude if the participants are a homogenous sample.

Notes: Make references to the homogeneity of sample.

3.TRANSPARENCY: Good Acceptable Poor

Good: Sufficiently transparent so that the reader can see the all the stages of the research process.

Acceptable: Appropriately transparent, lacks detail in some areas of research methodology

Poor: It is unclear what stages were undertaken, the majority of information is missing

4.**COHERENCE OF ANALYSIS**: Good Acceptable Poor

Good: Sufficient sampling from the corpus. There appropriate extracts from at least half the participants for each of the themes presented.

Acceptable: Appropriate sampling from corpus to show density. Most of themes have extracts from at least half of the sample.

Poor: the themes are not evidences well. Mostly large number of themes which may be superficial from a large number of participants. Analysis lacks interpretation and there is little or no commentary

5.FOCUS: Good Acceptable Poor

<u>Good</u>: The paper has a specific focus. The research question is interested in something that is of significance to the participant's life and is answered by the research?

<u>Acceptable</u>: The paper has some focus but it is not specific. The research question has some significance to the participant's life but is not specifically important.

<u>Poor:</u> The paper lacks a strong focus. It is questionable as to whether the research topic is of interest to the participant. Findings not related to question asked.

Notes:

6. TRUSTWORTHINESS: Good Acceptable Poor

<u>Good:</u> Appropriate use of triangulation or audit and/or credibility-checking to achieve trustworthiness.

<u>Acceptable</u>: Some attempt of using triangulation, audit or credibility

<u>Poor:</u> No use of triangulation, audit or credibility checks

Triangulation Audit Credibility check