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A Semi-Structured Approach to Photo Elicitation Methodology for Research Participants With Intellectual Disability

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Abstract

Using photo elicitation with participants with intellectual disability is a creative approach to inclusive research as the method promotes research participation. Through the photographs that they take, individuals with intellectual disability convey their thoughts and experiences, without the high cognitive demands that are typical of many other data collection methods. People with intellectual disability rely on environmental support to function optimally in everyday life situations. This is also the case for their functioning in research situations. This article provides a novel contribution to photo elicitation methodology, as we share our experiences from using a semi-structured approach, which offers support and guidance to research participants with intellectual disability in the empirical phase of the research process. We discuss the benefits and challenges such a new approach could introduce. The article concludes that provision of adequate support is a prerequisite for successful research participation for individuals with intellectual disability, and our semi-structured approach offers a suggestion on how to deliver this support.

Keywords

methods in qualitative inquiry, participation action research, photo elicitation, photo narrative, photo voice

Introduction

Photo elicitation is a creative method that can actively engage people with intellectual disability in research. The method allows individuals with intellectual disability to move from a relatively passive role in research toward more active participation; people with intellectual disability change their position from being passively scrutinized ("research on") toward being empowered explorers of their own life situation ("research with"). Yet, the impairments that are typical of intellectual disability may require careful considerations on how to conduct this type of qualitative research, to ensure that research participation becomes a positive and empowering experience for this group of vulnerable individuals.

Intellectual disability is a neurodevelopmental disorder characterized by significantly below average intellectual functioning and adaptive behavior (Word Health Organization, 2020). The impairment in intellectual functioning typically results in difficulties with verbal reasoning, abstract and logical thinking, planning, problem-solving, and understanding complex ideas (Luckasson & Schalock, 2013). As a consequence of these difficulties, research participation may be challenging for people with intellectual disability, and special measures must be taken to ensure a good match between the capacities of the individual with intellectual disability and the demands of the research situation.

In this article, we investigate how the support of a semi-structured approach to photo elicitation may alleviate some of the possible hindrances in research participation. We explore this question based on experiences from a previous photo elicitation study with adults with intellectual disability (Garrels & Sigstad, 2019), in which the purpose was to look into their motivation for participating in the labor market. We share our experiences with using file folders with predefined topics during data collection as a means of offering support and guidance to participants with intellectual disability in the empirical phase of the research process. Thus, this article provides a novel contribution to photo elicitation methodology, as we describe the use of file folders as a semi-structured approach to the data

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collection. A semi-structured approach may seem to stand in contrast to the traditional use of photo elicitation, where the original intention is to give research participants a free and independent starting point in research. However, based on our own experiences with using file folders as a means of support in a photo elicitation study, we discuss how this semi-structured approach may contribute to greater confidence and mastery during research participation for people with intellectual disability. Based on our understanding of the challenges that people with intellectual disability typically encounter, we further argue that this support may result in more comprehensive descriptions, as it may facilitate the participants' conveying of abstract thoughts and ideas.

In the introduction of this article we further present how photo elicitation may be a useful method to include people with intellectual disability in research. Then, we describe how file folders were used as a semi-structured approach in our previous empirical study with adults with intellectual disability. Based on experiences from this study, we finally discuss the benefits such a new approach could introduce, as well as potential challenges in light of participation in research.

Photo elicitation is a participatory research technique which allows researchers to analyze participants' responses to images that are shown during the research process. As a research method, photo elicitation is placed within the tradition of visual research methods, which includes a range of visual approaches, also including photovoice and video ethnography. The underlying idea of photo elicitation is to insert photographs into the research interview, so that different kinds of information may be evoked than through the use of words alone (Harper, 2002). As Harper (2002) describes, "When two or more people discuss the meaning of photographs, they try to figure out something together," and this may provide an excellent starting point for qualitative research interviews. Epstein and colleagues (2006) also recommend the use of photo elicitation as an "icebreaker activity" for deeper discussions, as the photographs may help building rapport and increase the participant's engagement in the research interview.

Within photo elicitation, photographs may be researcher-produced, participant-produced, or they may be co-produced by the researcher and participant (Lapenta, 2011). With participant-produced photographs, participants may be more actively involved in the research process, as they are put in charge to take pictures that document various aspects of their lives. This type of respondent-generated image production is also known as reflexive photography (Harper, 1988). The photographs produced by the participants act as a starting point for interviews, and the interview is guided by the participants' interpretation and explanation of their own photographs (Lapenta, 2011). Through participant-produced photographs, the point-of-view of the person holding the camera is captured, and researcher bias that is otherwise embedded in the selection of images and interview questions is reduced (Lapenta, 2011).

As Weiss and colleagues (2017) suggest, photo elicitation is considered an efficient method to empower people with intellectual disability and to capture their experiences. Since visual research methods do not rely significantly on cognitive ability, they may be especially useful to capture the lived experience of people with intellectual disability (St.John et al., 2018). Photo elicitation allows participants to show their worlds visually, and the method poses fewer demands on verbal fluency than many other inclusive research strategies do. As Booth and Booth (2003) state, photography as an activity emphasizes action over cognition, and the photographs can help to concretize abstract issues, making it easier for people with intellectual disability to convey their experiences to others. The use of visual aids during interviews may therefore be advisable, as this kind of support may help to illustrate the topic of conversation. Due to the visual component that is added to the discussion, even individuals with limited verbal communication skills may be given the opportunity to participate actively in research studies (Tajuria at al., 2017). The photographs may facilitate more critical dialogue in the subsequent interview, and they may also contribute to richer and more detailed in-depth information (Akkerman et al., 2014). As Lapenta (2011) suggests, the photographs may help convey content that words can only approximate. This implies that, with photo elicitation, the perspectives of persons that were previously mostly excluded from research because of challenges with verbal communication, can now be explored.

In participatory action research studies that use photography as a means of collecting data, it is common to give research participants free rein when taking photographs.

However, for research participants with intellectual disability, visual research methods are not always unproblematic, and they may not be as empowering as hoped for. For instance, Overmars-Marx and colleagues (2018) found in a comparative analysis of nine photovoice studies involving participants with intellectual disability, that all the studies adopted an open instruction procedure, allowing participants to take any photographs that they wanted. This absence of instruction may be considered in line with the idea of participant empowerment and autonomy that characterizes inclusive research and participatory action research (Evans-Agnew & Rosenberg, 2016). Yet, in their analysis, Overmars-Marx and colleagues (2018) identified several challenges during the photographing stage, such as participants not wanting to share the photographs that they have taken, participants forgetting to take photographs, the photographing taking much longer than planned, the omission or under-representation of certain themes, and difficulty with photographing negative and/or abstract matters. One of the included studies (Booth & Booth, 2003) also reports on one of the participants no longer wishing to be involved in the project after having experienced some difficulty during the photographing.

We question whether some of these challenges may stem from the cognitive impairments that characterize intellectual disability. For instance, not wanting to share photographs, the photographing taking much longer than expected, or "forgetting" to take photographs may be expressions of uncertainty or a sense of low self-efficacy concerning the task at hand, or it may be an indication that the research participants

have not properly understood the instructions that were given. That is, there may be a gap between the capacities of the research participants with intellectual disability and the demands that the research situation poses. If this is the case, participation in research may be experienced as too complicated, and a lack of mastery may steer people with intellectual disability away from any future research participation. Therefore, specific accommodations to the research method may be desirable when conducting visual research studies with participants with intellectual disability. This is also suggested by Di Lorito and colleagues (2018), who claim that people with intellectual disability are likely to require specific supports in order to facilitate their inclusion in research studies. Significant adjustments may be necessary and in line with a so-called relational understanding of their condition, which posits that a proper "fit" between support needs and supports is pivotal for the optimization of functioning of people with intellectual disability (Schalock et al., 2010; Wehmeyer et al., 2008).

Example of Using File Folders in a Photo Elicitation Study: A Semi-Structured Approach

We conducted a photo elicitation study with seven adults with intellectual disability to explore their motivation for participating in the labor market (Garrels & Sigstad, 2019). Our sample consisted of four women and three men, aged 21–58 years old, employed in two sheltered workshops and three competitive employment workplaces. We opted for participant-generated photographs as a methodological approach to the data collection process, as we were interested in gaining more detailed descriptions from the participants than qualitative interviews alone would offer. By including persons who usually have difficulties in expressing their thoughts verbally, we wanted to explore the possibilities that photo elicitation entails. However, based on our previous working experience with people with intellectual disability and our knowledge of the impairments that characterize the condition, we chose to offer some support to our participants to guide them more smoothly through the photographing activity. We believed that this support would bridge the gap between the participants' capacities and the demands of the research situation, so that their functioning and their experience of participating in the research project was optimized.

Participants in the study were provided with an easy-to-operate Polaroid camera. Furthermore, they were also given guidelines for which topics to center their photographs around. These topics were presented in a file folder with plastic pockets, where each pocket was labeled with a specific topic, such as e.g. the best thing about my employment, lunch time, colleagues, work tasks, my favorite activity, not so fun activity, the most important workspace, my employer, etc. Participants could then place the photos they had taken in the respective pockets. The file folder served primarily as guidance, and we did not pose restrictions on what could be photographed or how many photographs could be taken. We agreed with the participants that they would take pictures for 1 week, after which we scheduled time for an in-depth interview with them. During the interviews, we utilized the photographs as a starting point for conversation with the participants. Both the topics in the file folder and the pictures provided structure to the interviews by delineating themes for the interview questions, in addition to functioning as visual support for the conversation. Thus, both the photographs and the topics were used as a "stimulus" for the interviews, and they formed a basis for contextualizing and more in-depth storytelling about the photographs. In other words, this approach to photo elicitation can be called semi-structured. We used a deductive starting point based on our own pre–understanding and the existing knowledge base (Laverty, 2003), from which the various topics in the file folder were developed. Participants then took photographs from their own perspectives, which implied a more inductive approach. During the interviews, the file folders combined this inductive and deductive perspective. They provided a semi-structure to the interviews, while at the same time opening for topics and approaches that were unknown to us in advance.

Findings

We will now present three findings regarding the use of file folders as a semi-structured approach to photo elicitation: (i) the file folders may provide useful support in framing the photographing activity; (ii) the use of predefined topics may help participants with intellectual disability to convey a more comprehensive and in-depth narrative; and (iii) the file folders may function as augmentative communication aids during the consequent interviews.

Support in Framing the Photographing Activity

According to the comparative analysis by Overmars-Marx and colleagues (2018), studies that use participant-generated photographs generally do not put restrictions on the number of photographs that participants can take, and this may lead to considerable variation in the quality and duration of the subsequent interviews. In our study, the number of photographs that the participants took ranged from a handful to roughly 20. Some participants were meticulous in taking one photograph per topic, while others varied more in the number of photographs that they took for each of the topics. Despite the variation in the number of photographs, we experienced that the file folders helped participants to frame the task of taking photographs. The predefined topics provided support for what to photograph, and the plastic pockets in which participants could place their photographs also gave an indication of when the activity could be considered completed, namely when each pocket had at least one photograph. Hence, the file folder may provide useful support for possible challenges with executive functioning, such as planning and time management, that people with intellectual disability may face (Danielsson et al., 2012).

However, we also encountered that participants did not take photographs for all the topics that were mentioned in the file folder. In itself, this was not problematic, as it allowed us to ask follow-up questions during the interviews about the absence of certain photographs, and we could gain valuable information that way. However, during the interviews, we also experienced that the topics had not always been clearly understood by all participants, and this may have created an unfortunate barrier for their research participation. For example, one participant did not understand the meaning of "favorite activity," as he was unfamiliar with the word "activity." Therefore, this pocket in his file folder remained empty, and the participant's lacking comprehension did not surface until during the interview. This informs us that for future studies, it is important to use even simpler language in describing the topics. Moreover, it may be helpful to go through the file folder with each participant prior to the photographing, to make sure that each topic is understood.

Support in Capturing Abstract, Negative, and Neutral Themes

Akkerman and colleagues (2014) address the issue that negative and neutral themes as well as more abstract topics may go under the radar with studies that use participant-generated photographs, as participants with intellectual disability may have difficulty representing these themes through photography. We found that the specific topics in the file folder guided our participants to illustrate a wider range of aspects of their job situation, as they were also encouraged to take photographs of certain negative or more abstract aspects (e.g., "Something I don't like very much at work"). At the same time, participants were still able to bring their own insights and ideas into the research, which became clear from the variety of photographs that participants took for one and the same topic. For instance, for the "lunch time" topic, some participants took pictures of their food, while others took photographs of the leisure activities that they did during lunch, and still others documented the lunch area.

Even though the file folder provided guidelines for which topics to photograph, participants still experienced the freedom to highlight what they considered to be the most important aspects of that topic. Thus, we found that the use of a file folder with predefined topics guided participants to illustrate abstract aspects as well as positive, negative, and neutral experiences. At the same time, the support did not seem to interfere with their possibility to contribute with personal content and to give direction to the research study. In our experience, providing topics to the participants may function as a useful support to overcome challenges with abstract thinking that are characteristic of intellectual disability (Luckasson & Schalock, 2013). Thus, the file folder functioned as a framework for possible research topics, but participants maintained the freedom to fill in this framework in a way that they found personally relevant.

The File Folder as an Augmentative Communication Aid

Hollomotz (2018) recommends the use of concrete reference tools, such as picture cards or other visual support, as particularly useful strategies to facilitate communication during interviews with people with intellectual disability. In our study, the use of file folders helped to concretize the interview content. Participants made active use of the photographs they had taken, not only to share their personal experiences, but also to explain more clearly to the researchers the message that they wished to convey. On several occasions during the interviews, participants browsed back and forth through their file folders with photographs and they used the photographs actively to clarify the message that they wanted to convey. This is illustrated by the following interview excerpt where the participant describes one of the tasks that she excels in:

Interviewer:	And this is some kind of packing assignment, I believe? (*interviewer points to a picture*)
Interviewee:	Yes, this is where we put on the labels. I'm very good at that, so . . . (*browses through the file folder*) . . . those two over here (*points to a new picture*).
Interviewer:	Yes, those are the same, yes.
Interviewee:	Yes, it's the same candy, but there I've done everything, it's those labels.

In this example, the participant makes active use of the photographs that she has taken to describe the different phases of the packing process, from bagging candy, to labeling the candy bags, to obtaining a finished product. Undoubtedly, it could have been cognitively challenging for the participant to relate the content of these work tasks chronologically by means of verbal language alone. However, with photographs neatly organized according to topic in the file folder, the participant experienced useful support in communicating her line of thoughts. Thus, the file folder functioned as a sort of augmentative communication aid, which supported and extended the participant's expressive language skills, so that a richer content could be shared. The photographs themselves, but also their organization in a file folder with labeled topics, helped strengthen the communication between the researcher and the participant with intellectual disability.

Discussion: The Bathwater and the Baby

Photo elicitation as a research method could be situated within the field of participatory action research, which emphasizes authentic research partnerships and active participation throughout the research process (Heffron et al., 2018). However, with photo elicitation, research participation is restricted to the data collection process. Some of the aims of "ideal" participatory action research are to avoid the replication of traditional power relations during the research process, and to give a voice to underrepresented groups (Dorozenko et al., 2016). However, with regard to people with intellectual disability, we wish to caution against throwing away the baby with

the bath water. While it is important to advocate for the inclusion of people with intellectual disability in research as in all other aspects of society, we cannot ignore the impairments that are typical of intellectual disability and the resulting need for support.

Many participatory researchers in the disability field may strive to erase difference and undo societal wrongs, and they may feel tempted to diminish their own role in the research process, in order to elevate the role of the co-researcher with intellectual disability (Walmsley, 2004). Yet, merely ignoring the cognitive challenges or hiding the need for support may be counter-productive for the research participation of individuals with intellectual disability. Walmsley (2004) encourages researchers to be clear about what they do to include participants with intellectual disability and how they do it, as this could demystify the participatory action research process. Almost two decades later, we find that this call for transparency in participatory action research is still valid, maybe especially so when it comes to the type and amount of support that is provided.

Indeed, with our introducing of file folders with predefined topics into the photo elicitation methodology, we questioned whether we were moving too far away from the idea of empowerment, autonomy and non-directiveness that characterizes this method. Yet, as Cluley (2016) states, people with intellectual disability lead their lives with support, and hence, we should not shy away from providing support in research either. People with intellectual disability form a very diverse group with various degrees of support needs, depending both on their individual capacity and the environmental demands. For most individuals with intellectual disability, research participation is a relatively new situation, and this may cause them to feel uncertain about what is expected of them. By presenting a semi-structured approach to photo elicitation, our intention is initially to show how it is possible to take care of participants with intellectual disability and their current challenges, so that participation in research can be a mastery experience for those concerned. Within a relational perspective, this is about searching for what helps to narrow the gap between environmental expectations and individual capacities (Schalock et al., 2010). Given that persons with intellectual disability constitute a group that is often excluded from research, it is a matter of contributing the necessary support so that their participation is enabled. Therefore, we encourage a flexible approach to photo elicitation methodology that allows support when needed. We also claim that this support does not necessarily diminish the autonomy of participants with intellectual disability in the research study. Instead, the provision of support is likely to turn research participation into a positive experience for individuals with intellectual disability, as it may help them feel in control of the task that they are put to. The resulting feelings of mastery and self-efficacy during research participation may then decrease the risk of attrition and increase the likelihood that people with intellectual disability will participate in new research studies when invited.

Conclusion

Photo elicitation is a visual research method that may give a voice to individuals who may struggle with expressing themselves in other, more traditional ways. The method does not pose high demands on cognitive and verbal ability, and therefore, it may be especially suited to include people with intellectual disability in research. However, people with intellectual disability form a diverse group, and many of them may need more explicit support also during their participation in photo elicitation studies. In our study, we provided guidance to our participants by predefining the topics for what to photograph in a file folder with plastic pockets.

As we see it, this support forms a semi-structured approach to photo elicitation, and the supplement of file folders with predefined topics provides adds value to the methodology in several ways. The file folder offers guidance and instruction to the participants, so that the task of taking photographs becomes more clearly defined. Furthermore, the predefined topics direct participants' attention also to negative, neutral, and abstract themes which otherwise may go under-represented. Finally, the file folder with its topic labels may function as augmentative communication during the subsequent interviews. To guarantee that the file folder with its topics works as intended, it may be advisable to talk through the topics together with the participants in advance, so that their comprehension can be checked. The support that this semi-structured approach provides may contribute to a greater sense of mastery and self-efficacy for people with intellectual disability, thus making research participation a more empowering experience for them.

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