

The Impact of Parental Young Onset Dementia on Children and Young People's Educational Careers

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Abstract: The aim of Sikes and Hall's(2018) study was to discover the impact of having a parent with young onset dementia (YOD) on children or young people's educational careers by interview 24 subjects among the ages from 6 to 31 years old (Sikes & Hall, 2018). In this paper, the theoretical perspectives will be identified from the perspective of ontology and epistemology. Methodology and methods will also be discussed. Furthermore, evaluating consistency of the relationship between theoretical perspective and the chosen methodology with the methods conducted is also focused on. Finally, the discussion of ethical issues in the study is also an important part of this paper, not only the ones claimed by the author but also the implicit ones should be considerate.

Keywords: Young People; Influence; Dementia; Research Methods

1. Theoretical perspective

Sikes and Hall (2018) put their effort on study a phenomenon related to social construction from different individuals' unique perspective of world, thus, the paradigm in this research is interpretivism (Collins, 2010). To illustrate the theoretical perspective of a research, it is necessary to identify the ontological and epistemological assumptions applied in it. Ontological stance identifies the nature of reality (Della et al., 2008), to this extent, the research of studying the impact of YOD to children or young people's educational careers is conducted based on different human interpretation of the reality. Sikes and Hall (2018) discovered how the disease influenced children and young people's educational careers through the participants' unique experiences, and drew conclusion on the basis of these experiences. Epistemology focuses on how the knowledge was obtained. The purpose of the study is to privilege the voices which were historically neglected from children and young people who lived with parental dementia. To cohere with the aim and ontological assumption of this study, the authors applied interviews on children and young people who had a parent that suffered from the disease and under this context, the epistemological assumption was also consistent with the purpose of the study.^[1]

From the discussion above, this research consists a set of interpretive material practices such as interviews to make the world visible. Thus, this research satisfied the definition of qualitative research. In qualitative research, the researchers usually study things in their natural context which means they are likely to go into the context and to interact with different participants to examine better understanding of a subject and to collect different angles of a phenomenon (Denzin & Lincoln, 2008). As a distinct form of qualitative research, narrative focused on lives of individuals and write narratives of individual experiences (Connelly & Clandinin, 1990). As a narrative research, the data collection and analysis can be very difficult for researchers since the actual things they are collecting are the self-organised information from the participants (Miller, & Salkind, 2002). ^[2]In this study, as the interviewees had similar background they may share some common points in their stories which may make the process of collection and analysis easier. Moreover, the researched was designed to use purposeful sampling, 24 British in certain ages related to educational career and conducted to unstructured interviews to "situate personal experiences of dementia within the broader social context (Shakespeare et al., 2017)." The small and purposeful sample is required in this study because the in-depth and unstructured interview are beneficial to explore the personal construction of the individual world. What's more, qualitative research is associated to inductive reasoning, inductive reasoning works "bottom-up", begin with specific observation of the world developed to abstract generalizations

and ideas (Neuman, 2003).^[3] In this research, the authors studied the impact from a specific group of subjects and by collecting and analyzing data, moved to suggestions that could improve the current situation for the whole group of children and young people who had a parent with YOD. However, there is no evidence of systematic solutions are provided by the authors, and after the unstructured interviews, no exact patterns or theories of how parental YOD impact on children and young people's educational career emerged. ^[4]

2. The effectiveness of the methodology and methods

According to Coe, researchers need to choose the methodology and methods that answer the research questions most appropriately to make the research be practical and the methodology and methods are required to consistent with the theoretical perspectives of the research. The study of Sikes and Hall (2018) was based on an Alzheimer's society-funded investigation that concerned about similar questions with them and decided to focus on educational careers. The authors put efforts on examine the sample, how they chose the participants and what they required from them. For qualitative research, sampling is not just a sole decision, but a serious of reduplicative decisions through the whole research (Emmel, 2013). It is vital to determine sample sizes and sampling practices to conduct a good research and to budget resources (Guetterman, 2015).^[5] In this study, the sample size was small which made the data collection and analysis more accurate and in-depth. The authors advertised the project on specific website to YOD and recruit voluntarily participants to take part in it. Bernard (2002) indicated that availability and willingness to participate, the skills to communicate experience are very important factors in purposeful sampling. Thus, the method the authors took to recruit subjects is an appropriate one and the snowballing to select the participants reduced the potential bias by the researchers.^[6] Although the method applied to choose sample was rational, it still had limitations: narrative inquires required good communication skills but the participants under 10 were likely to fail on that.

Interviewing is a method that frequently used to conduct qualitative research to collect participants' ideas and experiences, and based on the degree of structuring, this research used unstructured interview. Unstructured interviews do not require predetermined questions or answers, they are more informal, in-depth like conversations.^[7] Punch (1998) noted that unstructured interviews provide a way to understand the complex human experience without limiting the field of inquiry. This research aimed to figure out the impact of parental YOD, but based on the ontological assumption, the realities are various from individuals. The researcher need to acknowledge the whole background and the progress of every participant when they were affected by their parent who suffered from YOD. The unstructured interview may help the author to develop a better understanding of the social reality from the interviewee's perspectives (Zhang & Wildemuth, 2009). From the interviews, the experiences of the participants and the impact of parental YOD to them individually are primary and direct which is useful when analyzing data.^[8] Thus, the use of unstructured interview is effective. However, the authors not focused the general impact of parental YOD but they got a more specific purpose which was to study the educational career impact of spending time with the parent with the disease.^[9] The unstructured interviews seemed too flexible to the aim. As the authors had a target aspect, the questions of the interviews should be more related to educational career. Semi-structured interviews are also open whilst concerned on one or several themes. Thus, changing the unstructured interviews to semi-structured interviews may make the research more effective less overwhelmed.^[10]

To study the impact of the parental YOD to educational career was to collect and analyze the experience and interpretation of individuals who shared similar situation (Overcash, 2003), and in this case, narrative research is an appropriate choice for this research. YOD is a progressive disease and the impact of parental YOD is various from time to time, that's why the research sustained for 18 months. Since narrative inquires are the stories and experiences people tell over time (Casey, 1995), it is suitable for this research to continue. ^[11]

Maxwell (2013) noted that different types of consideration such as description, interpretation, theory, generalization, researcher bias and reactivity could cause different threats to the validity of a research. To consider the validity, the first thing is to discuss the authenticity of the data. The interviews in this research were recorded and transcribed in full, thus, the threats are reduced. However, the authors did not mention the exact questions they asked when interviewing, which may lead to a decrease of credibility of the research. Because the topic of this research is vague and subjective, researchers potential

bias or priori thoughts may appeared in the interviews.^[12] Overall, the choice of methodology and the research design are appropriate for the study. For qualitative research, reliability is closely connected with consistency (Carcary, 2015). The ontological and epistemological consistency is discussed above and to verify the accuracy of data, the researchers need constant comparison among the data. This research continued for 18 months and all the participants are interviewed more than once in different period, thus the comparison can be granted so as the consistency.^[13] So this research possessed the ability of reliability. Most qualitative research studies a specific phenomenon in a certain population but that does not mean the criteria of generalizability is not important. Generalizability is often assessed by the extent to which the finding of this research can be generalized to another under similar circumstance (Kvale & Brinkmann,2009).^[14] Since that the relationship between theoretical perspective and methodology and methods chosen of this research is effective and the findings are valid, the results could be generalized but limited in the study that related to the similar disease like dementia. ^[15]

3. Ethical issues related to the research

Gray (2014) noted that with increasing personal involvement, the relationship and interaction between researchers and participants could be ethically and morally challenged. ^[16-18] In Sikes and Hall's (2018) research, they clearly demonstrated that the "Ethical approval was granted by our university" which means most of ethical aspects were covered and approved, and it is clear that the authors got all the consent of participants include the children under ten. And more specifically, they make the interview about sensitive topics anonymous to further protect the participants. However, the authors considered the children under 10 years old were deemed to have the capacity to consent after spoken to them. This behaviour may make the consent being involuntary. ^[19-21] Moreover, the confidentiality was not presented in the research. It is important to protect the data of participants, and the protection of data of children and young people was even more important in a research process (Greig et al., 2007).^[22] But there is no clear explanation in this research of how they deal with the data or the "stories" of the participants after the study. What's more, participants are also part of the whole research, hence, they should have rights to know different stages and changes of the research including the publication and dissemination (Munhall, 1988).^[23] This research is published on *British Educational Research Journal* but the authors did not mention about getting participants' permission to publish the interviews and the research based on. In additional, the ethical consideration of gender may potentially exist since that the authors did not clearly note that how many girls and boys were selected to conduct the interview, this may cause a potential gender bias to the results of the research.

4. Conclusion

This research focused on the question related to social constructions and the ontological and epistemological assumptions consistent with the paradigm interpretivism. And the methodology and methods adopted revealed it is a qualitative research. Sike and Hall (2018) aims to discover the impact of parental YOD on children and young people educational careers by conducting unstructured interview of individuals who experienced it. The methodology and methods contributed to the process and results of the whole research. The purposeful sample provided an in-depth interpretation of the experience and the unstructured interview gave a whole picture of the impact from different individuals' perspective. By narrative inquiry, the authors collected valid data and better understandings to the participants' situation. There are small limitations in the research design such as lack of exact interviewing questions and ethica issues about confidentiality. The research of Sike and Hall's (2018) is valid and reliable one.

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