Methodological Issues Related to The Rapport and Data Collection while Qualitative Researches in Special Andragogy Areas

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Abstract

Qualitative research on the disability cultures and environments that support or perform lifelong education of adults with disabilities in Poland are carried out intensively since the late 90s of the twentieth century. This paper clarifies the dilemmas and delicate issues while the rapport process of qualitative research and associated with collection of the data on socially vulnerable groups, disability cultures and adults with intellectual mental, physical disabilities or psychiatric disorders. The concepts were generated on the basis of secondary analysis of the qualitative research projects led by 18 beginner researchers, students of the undergraduate or graduate studies in Education or Special Education at Nicolaus Copernicus University in Poland.

Keywords: Rapport, Qualitative Data Collection, Dilemmas, Andragogy, Disabilities, Qualitative Methodology, Qualitative Researches.

I. Introduction

Qualitative researches having its roots in cultural anthropology were developed in the world since the nineteenth century. Polish interest of educators and special educators in implementing qualitative research orientation while researching vulnerable groups dates substantially since the late 90s of the twentieth century. Although there were earlier attempts of the action research in such groups in 1955 by W. Szuman from Torun. She was a special educator and special adult educator who undertook participant observation of two boys raised up to 5 years of age in extreme isolation. The fact that qualitative researches are needed in the areas of disability studies while exploring any sensitive, intimate issues wrote years ago B. Glaser and A. Strauss [1] in their study of consciousness of dying. The need for qualitative research in relation to public health research, disability saw in the world U. Flick [2] M. Angrosino [3], and of the investigation of vulnerable groups wrote M. Hammersley, P. Atkinson [4]. In addition, about relationships and needs of bonding cultural anthropology, sociology and qualitative research in disability wrote D. Kassnitz and R. Shuttleworth [5] and Poland, among others A. Rzepkowska [6], [7], E. Zakrzewska-Manterys [8] and author of the article B. Borowska-Beszta [9], [10], [11].

II. Literature Review

Collection and analysis of data in environments, cultures of persons with various disabilities is a repeatedly difficult task. An experienced researcher knows that issue not only means meeting the standards of ethical reasons for data collection in the cultural scene. The area of potential tension is almost any attempt to build rapport, ties and agreements in the field as well as the data collection. It never is no assurance that the investigator will realize the objectives of the research.
There is also no certainty that the researcher will get the cultural knowledge of what he founded. This however, can happily carry obtained results in the direction of fuller precise definition and understanding of what is happening in the field. About the need of meeting ethical standards write world and Polish qualitative methodologists, among others T. Rapley [12], U. Flick [2] M. Angrosino [3] J. Creswell [13] D. Jamielniak [14] D. Kubinowski [15], [16] B. Borowska-Beszta [10], [11]. Written consent for the research is a key requirement and a key matter in the study of vulnerable groups. Not only for authors mentioned above ethical data collection will be preceded by a prepared, written consent form with the necessary elements, such as giving the subject, theme (even sketch) and to precise information on anonymity, arrangements in the context of how the data will be collected (audio, video). It is also necessary information about coding the personal data and on how personal data will be secured by the researcher. There is also need to express requests of the possibility of inclusion post-coded and transcribed interviews to the final report. It is also good to remember about asking for agreement on everything concerning the type of data collection. These problems and issues are evident in procedural terms and the collection of data in any cultural scenes as well as in environments of people with disabilities. However building rapport and collecting the data in families of persons with disabilities or any internally coherent disability culture, despite the best procedural preparation from the ethical or practical research skills in qualitative methodology, generally tends to indicate unpredictable problems related to both participants of studied cultural scenes or the researcher him/herself. Below I present the analysis of problems in building agreements and rapport in the fields and collecting qualitative data in opinions of 18 beginner researchers and participants in my undergraduate and graduate diploma seminar and whose research projects were undertaken in the disability cultures in Poland. I analyze the data in relation to the problems in the field contained in 12 undergraduate research projects, 5 graduate research projects and also cite one voice from ongoing project, encoding the personal data of the researcher as "J. Justyńska".

III. Qualitative Data Collection Dilemmas - Research Review

Among the various dilemmas waiting for a researcher in cultural scenes of adult with disabilities are those associated with the specificity of the cultural scene and lying on the side of the investigator. Below I examine the problems together, because of their complexity.

A. Petulance in conversations with parents or families. The delicate issues of adaptation to disability, the future and the death of parents, and the sexuality of adults with intellectual disabilities

As the first of the major problems that arise when collecting data in the families of people with intellectual disabilities I would indicate as topic petulance issues, associated with the time of adaptation to parental roles and especially mothers to motherhood. The problem of adaptation to motherhood in general undertook a many of researchers in Poland and in the world. The interesting and dramatic picture presented in 90s sociologist E. Zakrzewska-Manterys [17] describing the moment of receiving a diagnosis of intellectual disability and Down syndrome of her son Wojtek. The collection of data in the situation of disability and single motherhood of an adult son, writes in the report a case study S. Kaczmarek [18]. The author points out that data collection was difficult and required great delicacy of researcher. Below is an excerpt of the interview.
Figure 1. Answers of the mother - informant after asking her about the reactions and the beginnings of adaptation to diagnosis about the child's disability. Personal data coded.

The author continues "in my research I decided to use just the collection of data by interviewing. On this field I met many difficulties. The fact that a participant in my research I knew for years was embarrassing for me. I knew I could count on a high degree of openness and total sincerity but the questions prepared by me, which concerned a very personal spheres of life could trigger emotions that would adversely affect the course of the interview and have influence on the mood of the participant. I had to during questioning make decisions about which of the issues being interviewed can deepen and which I had to leave, because they were too sensitive. The recordings, which I received were very quiet."[18] However, the biggest trouble turned out to S. Kaczmarek was that she built a bond and excessive emotional involvement with interviewed female and also awareness of consequences for construction of the reliable conclusions. The author writes "I was afraid that the strong emotional bond that was formed between me and the interviewed female during the recorded conversations affect my credibility in interpreting the results [18]. Another issue associated with petulance when collecting data from families with adults with intellectual disabilities is the issue of future planning for adult children after the death of his/her parents. K. Gondek [19] pursued the case studies of two families with adults with intellectual disabilities about securing the future of adult children after the death of their parents. K. Gondek writes "while long procedure of recruiting the purposive sample of families, one mother decided to quit and as a reason said that in fact she has not initiated any deeper thoughts about the passing process, death and securing the future of her child. She said that the information I gave about the interview are for her unsatisfactory. However, in a short agreement building process and small talk with this mother I got the impression the topic has prompted her to considerations about passing and somehow frightened, so decided not to participate in the study. Another discomfort accompanied by interviewing participants who agreed to participate was my little knowledge of participating in the research family R2 (coded as family 2). As indicated by M2 (mother in second family), a topic related to disability of son is for her painful experience. I suppose that talking with previously unknown researcher and externalizing their thoughts on such a sensitive and delicate issues as death was embarrassing, difficult and required courage on the part of my respondents. Also in R1 (coded as family 1), despite my prior knowledge of the family, M1 (mother in first family) admitted: "I will say this, because I can, because I think that this subject is a rather difficult"[19]. Another sphere of petulance while interviewing in Polish families is a delicate issue of sexuality of adults with intellectual disabilities, which causes difficulties in recruiting purposive sample. K. Wojciechowska [20]
implemented case studies on issues of sexuality in three families with adults with intellectual disabilities. The author writes "a study that I conducted have proved difficult to implement. First and foremost concern was finding the relevant interlocutors. To find them I wrote with requests to different institutions that had to deal with people with intellectual disabilities who lived in different cities. For each facility I volunteered and gave a written request to grant me the data and contact with people willing to give me an interview. If the institution found no one willing to participate in my research I moved to another institution and the procedure of recruitment started from the beginning. Eventually I obtained contact information with three families. The problem in the implementation of research has indicated the hollowness of some administrative staff to which I wrote. Despite promises, I did not receive telephone contact or I came for appointments, which were not remembered. It happened also that I received assurance that aid will be granted to me, that did not come to fruition. Another limitation was recording the interview. People, after reading the topic of the researches as sexuality of adults with intellectual disabilities refused to participate. I heard that the topic is too intimate. I put a lot of effort in translation, why do I need the data"[20].

Among the difficulties attributable to the interviewees, representing family members of persons with disabilities is the issue of adaptation to disability by parents even having an adult child, which can indicate additional difficulty when collecting data. The interesting situation, which I would call symbolically "symbiotic interview" in the field, mention two young researchers E. Piwowarska [21] and K. Kowalik [22]. Symbiotic interview is in my opinion the rare interview context in other vulnerable groups but not so rare in disability cultures. This is an interview in which while interviewing the adult with intellectual disability his/her mother or other member of family speak or whisper the answers instead of informant. This phenomenon causes consternation of the investigator who is experiencing double dilemma: she/he would like to collect reliable data and have voices of people with intellectual disabilities, and secondly barely internally and psychologically agrees to fostering dependence of life of adults with intellectual disabilities. E. Piwowarska [21] in a report and a case study of an adult male with intellectual disabilities, writes that the interview was carried out in the presence of the mother of an adult male with a mild level of intellectual disability, although she agreed freely for his independent participation in interviews. Paul, had no problems in verbal communication. Such a " symbiotic interview" marked by a control of his freedom of expression, caused discomfort in beginner researcher. An adult male with only a mild level of intellectual disability was constantly verbally dominated by his whispering mother. Therefore it was not possible to achieve what really thought 23-year-old male with intellectual disabilities. The researcher was initially surprised because she saw in this situation much dependence of an adult male from the mother. Below is the excerpt from the interview with Paul.

"Eve: With whom do you spend most of your time?
Paul: With parents.
Eve: Okay. I understand. And with whom you spent the most time when you were little?
Paul: (Inhale) (Pause)  
Mother: (whispers) with my mother.
Paul: With mom, with mom.
Mother: My dad worked.
Paul: Mom, dad and all."
Another problem constituting the difficulties of data collection in families or with adults with intellectual disabilities are the areas of other “special sensitivity” which can cause unpredictable reactions. Sometimes it may be a conflict of concepts and conceptual apparatus, which is used by the researcher and this preformed in studied cultural scene. Sometimes the parents and the family or community, do not accept the terms which are used by the researcher, which can be a source of tension constructed slowly during the build of the rapport and realization of interviews. A special problems that occur rarely are some risk of increased discomfort in the study of cultural scene which are growing proportionally to the sensitivity and petulance of a studied problem. It happens however if the problem is at the right moment being seen or positively explained to the research participants, collecting the data would be possible. A similar problems of “symbiotic interview” while collecting the data from an adult male with intellectual disability, working in the open market writes K. Kowalik [23]. Researcher illustrates the conditions of the interview as follows: "during the interview with the sixth informant were present all the time his parents. To my question, whether the parents are to remain present during the interview, respondents replied in the affirmative way. Twice, however, the informant’s mother interrupted the speech given by him. After completing the interview by the informant with disability his mother underwent a critical assessment of his statements during the entire interview, suggesting that the answers could have been more thoughtful. It was a problematic situation because it has placed in the embarrassing situation my informant, and also me as a researcher for whom getting all the data was valuable. Eventually, I managed these difficulties and realized the full study on satisfaction with work-life adults with disabilities "[22]. About unexpected aggression against researcher by the father of siblings with profound intellectual disabilities, I found out by accident a few weeks ago. Junior researcher J. Justyńska (anonymized personal data), whose qualitative project is still in progress. She conducts two case studies of lifelong support in families and adults with profound intellectual disabilities. The researcher constructed a matrix of an interview to get to know the opinions of parents and families about the everyday support of two siblings. When she asked questions about the values of family, informant, a male with higher education degree, the father of adults with intellectual disabilities began to be arrogant, cynical and even verbally aggressive towards a researcher who tried quietly to move to the next questions. Informant unexpectedly challenged the legitimacy of the purpose of the interview and follow-up questions. Then he found and called her research “idiotic”. The researcher after returning from the area, pointed out to me above problems and mental exhaustion that she was insulted. I want to add that this individual researcher is experienced in the in the field of practice, because she is also the sister of an adult brother with intellectual disability in profound level and therefore she has the necessary grounding and delicacy in the field. However even good awareness of similarity of problems had no reduced the informant’s fury in this single interview. Research is still continuing.

B. Recruitment of purposive sample
Another problem while collecting data in the disability and special andragogy areas are related to recruitment participants to the research and completing the purposive sample. J. Laskowska [23] investigated the friendship between females with moderate intellectual disabilities in daily occupational therapy workshop. The author writes "during the research I conducted, I did not meet any restrictions, after a small detail, while sampling of the purposive sample. One exception was only the fact that not every female that I proposed an interview, accepted my proposal. This situation occurred because they were not sure if their personal data will be encrypted "[23]. A. Dudek [24] analyzed the quest for "normalcy" of adolescents with intellectual disabilities in the opinions of parents. The researcher wrote that "the only limit my research I have encountered was having trouble finding people willing to grant me interviews. Many parents, with whom I interacted, after hearing the questions regarded the that there are too many, and they do not have time to talk to me, and that these questions are too personal or too difficult. However, with the help of director of a primary school in my town, I managed to find people willing to answer questions in an interview. They also had nothing against that interviews were recorded and then transcribed"[24]. D. Łysoniek [25] believes that "the difficulty in the study was that at the outset of their conduct. I did not get permission to carry out research in stationary care and educational facility in Grudziadz. The reason for disagreement by the general manager was explained that participants did not agree to record of the interviews. Then I had to start looking for people who would agree to an interview recorded on an audio file. The search took me some time, because my requirements of purposeful sampling were quite high. I cared for on a group consisting solely of males. In addition, 10 males with intellectual disabilities of mild level in age from 18-24 years old. Another difficulty was that often during conversations with informants we heard the school bell, which in some way distracted my callers. The second issue was the fact that during school breaks there was a big noise, which undoubtedly also interfered with the conversations "[25]. Another researcher M. Sumińska [26] writes, "it turned out to be a big challenge for me to meet with the methodology of the study. Throughout any stage of the research I was convinced that my knowledge in this area is poor. Despite the constant study of literature I still felt hunger and need for improvement in this area. Another limitation was to reach the subjective perspective view of marriage and the family presented by people with intellectual disabilities in mild level. This was due to the acquisition of confidence of people invited to participate in the study who want to share their life's plans in the sensitive area of family and marriage"[26]. K. Lachowicz [27] is a researcher who undertook the ethnographic studies in a boarding school for youth and adults with intellectual disabilities. The researcher writes: "my difficulty with studies already started at the search area to find the appropriate informants. I managed to find a girls willing to talk, but the boys was harder to find, because they are a minority in the dormitory. I found four informants, while the fifth caused the difficulty, because of staying for a short time in boarding school, he did not know the answers to most questions. Sometimes informants had very big problems with speaking, pronouncing and did not want to be recorded. Another difficulty with interviews was that some people wanted to save their answers only as written notes without recording them. I found that recording caused a lot of stress for them. Interviews I conducted with people with intellectual disabilities in mild and moderate levels and then transcribing all talks was intensive labor, associated very often with the pronunciation and minor speech disorders of my informants" [27].

C. Organizational problems of the data collection and preparation of the researcher:
Another problem in field studies in cultures and environments of disabilities are those related to organization of data collection processes. E. Zadka [28] examined educators in her ethnographic research the issue of intimacy among adolescents and adults with intellectual disabilities the residents of the dormitory. The author wanted to answer the question whether and to what extent intimacy can be associated with taboo. The author wrote "a key issue during my research was mainly related to finding willing people with whom I could do interviews. Unfortunately educators from the dormitory with a significant reserve came up to my research. Some of them claimed that intimacy was a difficult subject and some discouraged much the fact that interviews are recorded. Another difficulty was to adjust to the proper time which a teacher had. Often the problem was to find the day acceptable to me and informants. I believe that an important limitation of the research was also to find a suitable location for the interview. It happened so that the interview was conducted in the hallway at common-room, because there was no other available space in the facility and my informants also had a limited time. During the interviews, I was often too much focused on asking questions in order, checking whether everything is properly recorded, not on answers"[28]. Another researcher P. Mazurek [29] writes, "the first difficulty was to adjust to the time limit granted by informant while interview. The problem was impossible to determine an appropriate date and ensure it. Changing the date of the interview meetings took place three times. The fourth time I was finally able to determine an appropriate date, time and place. I realized interviews in Warsaw, in “Golden terraces” a huge shopping center at 15:00. Because the physical distance between my informant and me was 220 km, I decided completely to fit the specified date and other requirements of the female I intended to interview. Another problem was recording the interviews. In the place where I led the conversation, I was for the first time, so I did not know "quiet corners" of the Warsaw shopping center. "[29]. Another researcher K. Sokołowska [30] believes that "while conducting interviews in the next room, held classes for people who attend karaoke, causing jamming audio recordings. When conducting one interview behind the door of the room where I held it, a lot of people made noises and a few times I had to stop the interview, and then repeat the question or my informant had to repeat his/her answer. Some of my informants also had speech difficulties or disorders, which also sometimes made impossible to me a thorough understanding of spoken content. Before carrying out a recent interview with an informant at a meeting I was going to take the bus. However, this bus had an accident on the road. For this reason, I was forced to call a cab. This situation has forced me to incur additional financial costs "[30].

D. Researchers’ worries a refusal to participate in agreed tasks by participant:

Denials are not uncommon in the work of the investigator performing the qualitative fieldwork in socially vulnerable groups. It happens very often what I can confirm as a field researcher since 1999. Denials or refusals are accepted because participants have the rights to refuse the participation in the study in any moment, which is usually one of the points of informed consent. A certain trouble is when research participants refuse to perform the tasks they have given prior consent. This problem appeared in the ethnographic study by N. Łaszewska [31]. The researcher developed the study with female students of the University of Nicolaus Copernicus. Her informants had physical disabilities and needed wheelchairs or were using crutches. The researcher wrote about issues of refusals regarding the execution of tasks by the participant. The author wrote "the restrictions that have occurred on my part I can certainly include any concerns with the first contact with potential participants in my research and possible rejection, which
could happen. As it turned out they were wrong and caused anxiety but also delayed making the first step towards establishing contact with potential informants. I would also like to draw attention to the difficulties stemming from the study area and more specifically by their participants. During the interview, I asked my interlocutors for exemplified by drawing their free time. Informant coded as Artist (1) stopped contact with me. After three unsuccessful attempts to contact the informant and asking her for the drawing, I stopped by this endeavor "[31].

E. Missed issues and other problems in collecting data while interviewing adults with physical, intellectual disabilities or psychiatric disorders:
The researcher K. Kowalik [22] investigated the satisfaction with vocational life of adults with disabilities. The author wrote "while conducting research on satisfaction with life encountered several limitations, which I would like to raise as the issue. During the interview I encountered a few difficulties. I could not previously obtain information about the nature of the disability of some of my informants. Same interviewee refused to tell exactly and precise the type of their disability. Some gave only information about the circumstances of its origins and the consequences that flow from it. They were happy to answer questions related to their work. The formal diagnosis of the levels of their disabilities was shown to me by a few informants during the interview. I had to carefully learn the disability of the informants from other sources as managers in the workplace, where informants worked"[22]. P. Ramowska [32] said, "the first difficulty that I met while in the field work was associated with the room in which I conducted interviews. The place was bleak and dark, a bit overwhelming. While gathering the data, I noticed some participants with intellectual disabilities in moderate level felt discomfort caused by recording conversations recorder in the phone. Every informant formally agreed to record a conversation, but I have observed in them embarrassment associated with this situation. I tried to create a welcoming atmosphere for my participants to feel comfortable and willingly talked with me. Another disadvantage with whom I met while interviewing was associated with not understanding the questions by the participants of my research. In one of informants (coded as: Admirer) I noticed a lack of focus on the conversation because it was taken over the situation related to the male who stopped her interest. Sometimes I had to modify the questions of an interview and make participants to understand better my intentions. Very often asking one question, I received an answer to the next. Another difficulty, which I saw interviewing adults with intellectual disabilities was to disperse informants caused by entering into the room other participants of day support center. Another problem was related to the internal safety. One of the participants (coded as: Romantic) after short explanation wanted to be ensured, that I certainly do not share the recording with anybody. She asked again and again despite my earlier assurances and detailed common reading of the consent form. Another female informant coded as: Shy was very embarrassed during the interview. At first she did not want to talk. The biggest difficulty for me was to talk with contestants in such a way as to gather the data. Sometimes I had to precisely change the order of questions and inquire about important issues, which was difficult for me. I must admit that when conducting the first interview I was much stressed that I was able to overcome during subsequent discussions with female informants with intellectual disabilities. Being a qualitative researcher, I never thought that I would be faced with so many difficulties. Collecting data in the field using ethnographic interviews was for me a completely new, but very nice experience "][32]. M. Wolska [33] investigated the way in which see their lives chances 10 adults with psychiatric disorders and mental illnesses, participant of day support
center in Torun. The researcher wrote: "in this study could be seen several important limitations: informants coded as: Mark65 whether Martin39 and Mary63 were not too receptive, on topics related to family and simply refused to answer treating casually to turn specifically to answer these questions, which for some reason seemed to them interesting. Sometimes communication problems occurred, the researcher had to explain the questions. Sometimes that additional intellectual dysfunctions caused unwillingness of respondents to express themselves on topics related to level of their education "[33].

IV. Discussion
The cited above own experiences in the areas of research by young qualitative researchers as the most indicated a problem with recruitment of purposive sample to research. The specificity of data collection in the cultures of disability and socially vulnerable groups, particularly adults shows the need for solid preparation and understanding of the principles of qualitative research. That's what I notice as an additional problem, not mentioned by the researchers is linked to the omission in the reports of these difficulties, which were reported verbally to me as the coordinator of the research during the projects. It turned out that although studies were sometimes deeply imprinted with unique content and experiences in one of the researchers who collected knowledge about the life of student with congenital amputation of limbs made reevaluate her life, but the same time made no any mention of this in the final report. Another of the researchers, while collecting data informed me several times of her constant consternation regarding mutual relations between educators towards young females and males in a stationary center a dormitory for youth and adults with intellectual disabilities, also did not mention this in the report. Very rarely happens that a researcher had no problems in the area, however, such data were also included in final reports. Usually I found them in these reports of novice researchers, who previously before beginning of the research projects, had an access to the cultural scene or informants and had already stabilized level of confidence. There were also works in which investigators did not mentioned about the problems in the area, stating that "there were no major problems." Such information entered in the final report N. Nowogrodzka [34], who completed her micro ethnographic research and spoke to 10 parents of autistic children about the progress of their children after behavioral therapeutic treatment. I suppose, in this case, the subjective feeling of difficulty in the field by researcher could be smaller and that same topic concerned the issue of capacity development rather than thorny issues of failures and burdens caused possibilities, so despite the burdens experienced by parents of children with autism in this case data collection proceeded smoothly.

V. Conclusion
Implementation of qualitative research and collecting the data in families and support environments of adults with disabilities requires knowledge and preparation. It is not certain, however, that the investigator will not experience a completely new, difficult situation, which uniquely defines the reality in cultural scene. Certainly less experienced and novice researchers should openly demonstrate great delicacy in conversations with family members of adults with disabilities. However this is important to notice, that beginners do not have any influence on what stage of acceptance of disability in the family is a mother, father or siblings of the adult with disabilities, what constructs various responses to even most delicate way of interviewing.
Families, parents experience phases of shock, denial, grief, acceptance apparent or actual acceptance to the child's disability. Sometimes they did not accept child’s disability even for very long time to the stages of his/her adulthood. That which is particularly useful for beginners binds qualitative researchers with the necessary attitude of flexibility for unexpected situations and different emotional states of speakers, members of the families.

When it comes to conversations with adults with intellectual, physical disabilities or adults with psychiatric disorders there is needed awareness of their potential and limitation of functioning and subjective adaptation to life challenges which may be causing different consequences related to refusals to speak about particular experiences. Interviewing adults with intellectual disabilities we can face problems with their verbal communication different abilities, which are deeper in adults with moderate and severe intellectual disabilities. We face also lower attention potential which influence entire verbal data collection. We should also be aware that many of adults with intellectual disabilities can communicate but they need our attention to subtle forms of their messages. I conclusion there is very important to remember of ethical standards and not to exploit research participants. What we experience emotionally as field researchers studying and trying to understand the phenomena of human disability is difficult to conclude in the article and requires further field and common learning.

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