

Reflections on the Process of Conducting Secondary Analysis of Qualitative Data Concerning Informed Choice for Young People With a Disability in Transition

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Abstract: Secondary analysis of data is seen as a way of maximising the utility of existing research in a non-intrusive way and provides an efficient research strategy at a time of financial constraint. However, there are few examples from the published literature of social science researchers conducting secondary analysis of qualitative data sets. This article reflects on the process of reusing interview transcripts, carried out with young people with a learning disability and their parents on the subject of life choices, held in a United Kingdom qualitative data archive. Secondary analysis of qualitative data, while presenting certain challenges, has much to offer the research community, and is a particularly valuable resource for qualitative research postgraduate students.

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1. Introduction

The analysis of qualitative data can prove to be a daunting task for a student (COFFEY & ATKINSON, 1996). Creating a sizeable qualitative data set can also be challenging for students with limited time and resources. Having access to a qualitative data archive provides opportunities to develop skills and knowledge that may not otherwise be available (MITCHELL, 2014). This article offers reflections on the secondary analysis of archived interview transcripts with young people with a learning disability and their parents on how life choices are informed. Secondary analysis of qualitative data was carried out using thematic analysis to inform my primary research study for a Master's degree dissertation on the process of choice-making for young people with a learning disability in transition to adulthood. [1]

The re-use of interview transcripts from a national qualitative data archive provided direct access to the stated beliefs of young people with a disability and their parents. Secondary analysis of this dataset helped to gain insights into the

lives of this population and contributed to the generation of hypotheses for a primary research project on informed choice for young people with learning disabilities. The archived data set also offered opportunities to learn from the interview techniques and communication strategies with young people with a disability employed by the original researchers. [2]

This article provides a brief overview of the social policy issues impacting on informed choice for young people with disabilities in transition from child to adult services. Some aspects relating to the secondary analysis of qualitative data are outlined. I then describe the secondary analysis of archived interview transcripts held, in the <u>Timescapes archive</u> by the University of Leeds, UK, undertaken as part of the research project contributing to a Master's degree dissertation. The article concludes with reflections on the strengths and challenges for postgraduate students attempting secondary analysis of qualitative data. [3]

2. Background

2.1 Informed choice for young people with disabilities in transition

One of the policy challenges for health and social care services is the increasing number of young people with complex disabilities and high support needs who are making the transition from children's to adult services. Transitions are recognised as being problematic for agencies and frequently leading to poor outcomes for disabled young people (MacINTYRE, 2009; MITCHELL, 2012). [4]

Self-directed support and personalised services are seen as the means by which individuals and families can have choice and control about the way support is provided to them, with information of good quality, given at the right time, in the right format is seen as a precondition for choice (BAXTER & GLENDINNING, 2011). The legislation underpinning self-directed support (SDS) in Scotland is based on key principles, including informed choice, and is not as focused on promoting individual budgets as it is in England (MANTHORPE et al., 2015). [5]

Choice plays an important role in a person's quality of life (SMYTH & BELL, 2006). However, people with disabilities frequently report a lack of choice and control regarding many decisions, including not being given a choice in who provides formal social care support (BOND & HURST, 2009). Disabled young people with cognitive and communication difficulties face additional challenges to meaningful engagement in decision-making (MURPHY & OLIVER, 2013). There is a gap in the literature regarding how informed choice is realised in the context of self-directed support for disabled young people in transition. [6]

2.2 Secondary analysis of qualitative data

Secondary analysis can be defined as the (re)using of data produced on a previous occasion to obtain new social scientific and/or methodological understandings. The re-use of previously collected qualitative data can be carried out to generate new hypotheses for exploring in different contexts (IRWIN, BORNAT & WINTERTON, 2012), supplement one's own primary data (IRWIN & WINTERTON, 2011a), reveal new methodological insights (MEDJEDOVIC & WITZEL, 2005), generate new findings (GILLIES & EDWARDS, 2005), and gain further insight on hard to reach populations without further intrusion into vulnerable populations (LONG-SUTEHALL, SQUE & ADDINGTON-HALL, 2011). It can also provide a valuable resource for teaching purposes (CORTI & BISHOP, 2005) and be a cost-effective approach to research in austere times (COLTART, HENWOOD & SHIRANI, 2013). [7]

Secondary analysis should not be considered an easy option as a research strategy:

"Secondary analysis is a challenging undertaking. It is time consuming. It requires great persistence in ensuring an adequate understanding of details which may be tacit for primary researchers. [...] However, as many insightful secondary analyses stand testament, there is a depth of social scientific insight and progress which can be achieved" (IRWIN & WINTERTON, 2011b, p.14). [8]

Debates on the challenges of secondary analysis tend to be focused on two methodological issues: the original data not fitting the new research questions, and the lack of direct access to the detailed contextual knowledge about the circumstances of the data collection possessed by the primary researcher. Some commentators however argue that the difference between the use of primary and secondary data is only one of degree, as all data is to an extent re-contextualised and made sense of (HAMMERSLEY, 2010; HAYNES & JONES, 2012). There is a danger that overplaying the proximity to context can emphasise description rather than explanation (IRWIN, BORNAT & WINTERTON, 2014). [9]

While there has been a limited contribution to the knowledge base in the use of secondary analysis with grounded theory techniques (SZABO & STRANG, 1997; WHITESIDE, MILLS & McCALMAN, 2012) more information is needed about the process, strengths and challenges of using secondary analysis with other methods of qualitative data analysis. This article adds to the literature on secondary analysis by reflecting on the use of thematic analysis with archived data. [10]

2.3 *Timescapes* qualitative longitudinal data archive and the *Choice and Change* project

The *Timescapes* archive, part of the United Kingdom Data archive, was created to hold interview data from the Economic and Social Research Council programme of work centring on seven qualitative longitudinal research projects with shared interests in life course transitions. The *Timescapes* archive is hosted by the University of Leeds in the United Kingdom and is available for secondary analysis by researchers. In 2012 interview data, with study participants' consent, from the Department of Health Research Programme from 2006 – 2011 carried out by the Social Policy Research Unit, University of York: "*Choice and Change*: Extending Choice and Control Over the Life Course—A Qualitative Longitudinal Panel Study" (MITCHELL, MADDISON & BERESFORD, 2011) were added to the archive. The *Choice and Change* project examined the realities of choice in the context of changing circumstances, including changes in illness, disability or from other social transitions. [11]

The original *Choice and Change* study included 27 young people with a disability including degenerative health conditions and their parents and focused on the processes by which choices are made within families, exploring the respective roles and experiences of young people and their parents (MADDISON & BERESFORD, 2012). Data from 20 of these 27 cases were archived with *Timescapes*. [12]

3. Secondary Analysis of the Archived Interview Transcripts

The secondary analysis focused on the data relating to the subset of young people with a disability with combined learning disabilities and degenerative health conditions. The aim of my own research project was to explore the phenomenon of informed choice in relation to young people with a disability in transition from child to adult social care supports, seeking to find out more about the role of parents and professionals in supporting young people with a disability with significant life choices, and to identify the facilitators and barriers to informed choice. The *Choice and Change* dataset offered a good fit with my research questions as to how young people with disabilities were informed about significant life choices especially at a time of transition from childhood to adulthood. [13]

IRWIN and WINTERTON (2011b) caution against sampling from within project data sets as there is a risk that this further decontextualises data. However, with regard to my own research questions, it seemed relevant to limit the cases included in the secondary analysis to have some commonality in terms of the young person having a learning disability, and to select cases where both the young person and their parent(s) interview transcripts were archived. There was also the pragmatic necessity to limit the number of interview transcripts to be included in the secondary analysis. The original research study involved regular interviews with both the young person and a parent or carer over a two to three year period, but not all interviews were archived. [14]

I was interested in how young people with cognitive impairment accessed and made use of information regarding choices, and I wished to examine the differing perspectives offered by these young people and their parents. This left a cohort of six young people with a disability and their parents (mainly, but not exclusively, mothers) to be included in the secondary data analysis. One case consisted of two young disabled people from the same family, resulting in six young people with a disability and their parents included in the sample from five households. [15]

After an initial reading of the transcripts, consideration of the research questions, and the pragmatics of completing a small-scale study in a tight time frame, the use of thematic networks (ATTRIDE-STIRLING, 2001) was seen to offer an appropriate analytical tool for this type of qualitative research. Thematic networks visually illustrate the main themes contained in a text, based on thematic analysis which seeks to explore and describe the themes in the text at three different levels: basic themes: lowest order themes such as a statement of a belief; organising themes: middle order themes that organise the basic themes into clusters of similar issues; and global themes: overarching themes that group organising themes together to present a summary of main themes. A thematic network analysis consists of three broad stages: 1. the reduction or breakdown of the text; 2. the exploration of the text; and 3. the interpretation of the exploration. [16]

The decision to use secondary data as a research strategy was informed by prior literature review which suggested that the *Choice and Change* project addressed research questions that were complementary to my own research interests. The *Choice and Change* project examined themes of the role of carers in supporting choice, the perceived response of service providers to user choice, and the impact of choices on independence. My own interests were focused on how choices relating to social care supports for young people with disability were informed during the period of transition from child to adult social care services. [17]

I approached the primary data with an expectation that the interview transcripts would provide rich information that could generate new hypotheses for exploring in a subsequent research study of young people with a disability in transition, reveal methodological insights into research questions and interview techniques, and gain insight into the lived experience of a vulnerable population. The re-use of qualitative longitudinal data was also seen as an efficient way to complement a small-scale research study carried out by an inexperienced researcher with access to limited resources. [18]

Qualitative data analysis software (QDSA) such as MaxQDA or NVivo were not available to me. The advantages of these over manual analysis methods in terms of efficiency, analytical flexibility and transparency are set out by KAEFER, ROPER and SINHA (2015). However, the benefits of QDSA need to be offset against the financial cost of software packages and the time commitment required to learn how to use the package. It could be argued that without the aid of a computer programme, the researcher requires to be more immersed in the data, thus encouraging the imaginative work of ideas alongside data management. [19]

The approach adopted to managing the data was, after reading the relevant background literature, to formulate a number of emerging questions such as "who is involved in choice?", "what aided decision-making?", "decision-making style (self/with others)?", etc. I saved all the interview transcripts as *word* documents, printed these and read each on more than one occasion, highlighting extracts of text and making notes in the margin as I progressed. The scripts were re-read and extracts of texts relevant to each question were cut and pasted into a word document created for each individual question. For example, under the question "who was involved in the choice?" the following extract was placed: "[Interviewer]: And when you talk and think about your new school, who's helped you make a decision to go there? [Young Person]: Mum." [20]

Themes within data can be identified in an inductive way emerging from the data themselves, or in a deductive way driven by the researcher's theoretical interest in the subject (BRAUN & CLARKE, 2006). The approach taken in this study could be categorised as a blend of deductive and inductive approaches as described by Anneliese CANNON (2012). Data analysis was determined by both the research objectives (deductive) and multiple readings and interpretations of the raw data (inductive). Thus the findings were derived from both the research objectives outlined by the researcher and findings arising directly from the analysis of the raw data. [21]

Having initially broken up the data under the seven areas related to the research questions, the next step was to read these extracts, looking for patterns and regularities, to identify basic themes such as "emotional support from mothers aids informed choice". However, I was also looking out for contrasts and paradoxes. Whilst one of the findings from the original research was that young people welcomed parental involvement in choice-making, there was one young woman included in my sub-set who was distinctly critical in general of parental involvement in the decision-making process for young people with disabilities. This led me to look more closely at the interview data to question accounts given that appeared on the face of it to be supportive of parental involvement in decision-making. For example, one set of parents stated that they had not involved their son in the decision as to who his social care worker should be as they knew what his answer would be and they did not wish to worry him by suggesting that he could have a choice in this matter. [22]

Basic themes covering similar issues such as *emotional support from mothers*, and *trusted professionals enabling choice* were clustered into the organising theme of *emotional support from trusted others*. Looking across organising themes such as the latter and *agency/empowerment* led to global themes such as *empowerment and support* being identified. [23]

4. Reflections on the Use of Secondary Analysis of Qualitative Data

The Choice and Change data set held in the Timescapes archive was felt suitable for secondary analysis after reading the published report that focused on the choice-making processes for young people with a disability and their families (MITCHELL et al., 2011). My own research interests covered similar themes in terms of how choices about social care supports are informed for young people with a disability in the context of personalised services and self-directed support. The correspondence between the primary and secondary areas of enquiry ensured that there was a good fit between the primary dataset and the secondary research questions (LONG-SUTEHALL et al., 2011). The qualitative data held in the Timescapes archive contained transcripts of interviews with young people with disabilities and parents on the process of making significant choices. [24]

There is widespread acceptance that the interpretation of data is a reflexive exercise through which meanings are created rather than found, and recognition that the role of the researcher in the analytic process should be made visible (MAUTHNER & DOUCET, 2003). The use of secondary data does not preclude immersion in the data, with reflexivity and the "analytic imagination" having a role in interpreting such data (JAMES, 2013). Amanda COFFEY and Paul ATKINSON, (1996, p.141) suggested that "our influences on the sort of data we collect and what we do with them, and our hypotheses about what our data are telling us, pervade the conduct of research". [25]

Initial reflections on the archive data set were one of disappointment at the gaps in the archived data compared to the complete data set generated by the study. Some of the participants in the original study had no interview data archived, and in some cases there were only partial data included from the three waves of this longitudinal project. There was no information given as to the nature of the missing data, or an explanation as to why this data was not included. It may have been that interviews were not archived due to confidentiality and informed consent issues, or in some cases participants may not have agreed to be interviewed during all three phases of the project. [26]

Access to the *Timescapes* archive was relatively straightforward with log-in details and a password being made available after completing the registration form. The *Timescapes* web-site was easy to navigate and an archive administrator was available to answer any queries. The archived *Choice and Change* project material does provide some very limited contextual information on participants such as a brief outline of the young person's disability, home circumstances and their ongoing and anticipated future choices, but does not come with extensive fieldwork and background notes, as is the case with some other projects in the *Timescapes* archive. This lack of detailed contextual information could be seen as a weakness of this particular dataset. The contextual information provided for individual interview situations is generally limited to a brief comment stating who was present, why some interviews were interrupted or cut short and any communication difficulties presented by the

young person. The following contextual note from one interview provides an example of the kind of information provided:

"The [Young Person] YP is non-verbal, she vocalises but this is not discernible. Mum was present and periodically chips in assisting me in interpretation and providing explanation. I provide a running commentary. The tape is paused a couple of times whilst the YP has suction to clear her chest, at one or two points the machine can be heard on tape. The YP's carer is also present but does not speak during the interview." [27]

However, the settings for the interviews were not given. Also, it was not made clear why some young people required support of another person to communicate their views, and why in some interviews this support was provided by paid carers, rather than parents or independent advocates. Pauses are included in the transcripts without attempts to explain the meaning or emotions signalled by such silences and there are no descriptions of body language offered. [28]

Despite these reservations, the interview transcripts contained rich detail, and they were found to be emotionally engaging. THOMSON, MOE, THORNE and NIELSON (2012) discuss the emotional texture of secondary analysis and conclude that affect and emotion "travel" between persons and over time as the secondary researcher tries to grasp the meaning of what took place in a particular interaction. At times I was touched by the resilience and fortitude of the individual young person, and I was also frustrated by some parents' apparent lack of awareness of the rights of the young person to have a voice in making choices. As a social worker I was particularly disturbed by one extract which seemed to indicate the interviewer minimising one young person's account of being frequently called "useless" by her father, by the interviewer saying that the father would have been "joking". [29]

The research interview has been described as a social encounter whose meaning is negotiated between the participants, and the interview can be shaped by the personality of the researcher (SCOTT, HINTON-SMITH, HARMA & BROOME, 2012). My emotional reaction to the interview transcripts revealed that the drama between the interviewer and interviewee can also be played out between the reader and the dialogue contained in the transcripts. I became immersed in the data as I read the interview transcripts and progressed through the analysis phase. Similar experiences were reported by Nollaig FROST et al. (2010) where they describe the reactions of four secondary analysts to an interview transcript as developing relationships with the interviewer and interviewee. JAMES (2013) explains how the secondary data analyst makes sense of the transcripts within the context of their own perspectives and in some part this results in the sharing of the worlds of the interviewer and interviewee. This chimes with my own experience where I found myself developing mental pictures of the interview setting and the people involved. I drew upon my own lived experience of having a sibling with learning disabilities and my professional role as a social worker. [30]

One major weakness posed by the use of secondary data is the absolute dependence on the written record. There is no opportunity for the secondary analyst to ask supplementary questions, or to clarify answers provided by the research subject. The verbatim recordings in the Timescapes archive contained only limited detail on tone of voice, body language, the physical setting, and the interviewer's perceptions about what is being said. Such nonverbal and paralinguistic elements according to Dikaios SAKELLARIOU, Gail BONIFACE and Paul BROWN (2013) are valuable resources in telling a story and should be captured through audio recording and field notes. [31]

Thematic analysis, which requires dislocation of text from its original context, could have been particularly problematic in secondary analysis as the researcher is further removed from the original data. Amanda COFFEY and Paul ATKINSON (1996) caution that when we chop interviewee accounts into separate coded segments, there is a danger of losing the sense that they are part of a larger narrative. However, repeated close readings of entire interview transcripts and reading across transcripts helped to keep me grounded in the data as a whole and enabled the generation of middle-range theories that could be further explored and tested in subsequent research studies. [32]

This small qualitative study based on secondary analysis of longitudinal data from the *Choice and Change* project proved useful in a number of ways. The archive interview transcripts provided evidence of the diversity of experience for young people with a disability in how choices are informed and made. Analysis of the secondary data-set provided justification for further research into how young people with disabilities make informed choices by revealing examples that challenged the original findings and by offering opportunities to explore in more depth the concept of informed choice. [33]

The need for good interview skills, using a suitable communication tool was made clear from the transcripts. The issue of parents or paid carers being present and helping the young person to communicate raised some questions about the validity of the interview data. However, Dikaios SAKELLARIOU et al. (2013) caution that avoiding joint interviews might silence individuals who rely on others for communication. [34]

5. Conclusion

The archived interview transcripts provided rich descriptive information which were emotionally engaging. Hypotheses were generated from the archive data in terms of the role of parents and professionals in providing information to support choice for young people with a disability. The analysis of secondary data offered insights into a vulnerable population and saved unnecessary intrusion into people's lives. [35]

The use of archive qualitative data for secondary analysis can be a rewarding and valid research strategy, especially for students for whom access to a

substantive source of data is not otherwise possible. Thematic analysis provided a useful approach for analysing qualitative secondary datasets. [36]

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