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Abstract

Autobiographies written by those living with illness are readily available sources of data that can also aid in the development of a grounded theory. However, existing methodological guidelines do not provide support for the transparent and rigorous use of these texts. This paper describes a number of issues around the use of these texts, and provides an example of how autobiographies were used in a study conducted by the author. A set of steps that can be used by other grounded theorists considering the use of autobiographies as sources of data is provided, in an attempt to advance this aspect of the methodology.

Keywords

Autobiography, Grounded Theory, Extant Data, Guidelines, Reflection

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Autobiographies as Extant Data in Grounded Theory Methodology: A Reflection

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Autobiographies written by those living with illness are readily available sources of data that can also aid in the development of a grounded theory. However, existing methodological guidelines do not provide support for the transparent and rigorous use of these texts. This paper describes a number of issues around the use of these texts, and provides an example of how autobiographies were used in a study conducted by the author. A set of steps that can be used by other grounded theorists considering the use of autobiographies as sources of data is provided, in an attempt to advance this aspect of the methodology. Keywords: Autobiography, Grounded Theory, Extant Data, Guidelines, Reflection

In her description of grounded theory data sources, Charmaz (2006, 2014) makes the distinction between extant and elicited data. Elicited sources involve working directly with participants to “elicit” their experiences for the purposes of a study. Extant sources of data are those that “the researcher had no hand in shaping” (Charmaz, 2006, p. 35), but are nonetheless used in helping to address the research questions of a study. Among the many different types of extant texts are autobiographies of those living with illness, which Charmaz includes in her own work on chronic illness. Glaser and Strauss (1967), in the original guide to grounded theory research, also describe the important role that “library data” can play in theory development. More specifically, in discussing ways to overcome time and resource limitations, they describe “if we can do this with an interviewee or an informant, why not with the author of an autobiography or a novel?” (p. 253). Unfortunately, explicit methods for using and working with autobiographies in grounded theory are not readily available, leaving researchers on their own to devise methods for incorporating this data source into theories.

Broadly speaking, autobiographies are included as a form of unsolicited first-person written narratives. They may occur as hard- or soft-cover books, or digitally as an e-book or series of blog entries that cover the events of a person’s life. Autobiographies are distinct from biographies, or pieces written about someone by another person, or work that might be in response to specific questions posed to that person such as in an interview. The story told by the author, including the depth, detail and events covered, is raw and written without the specific probing of others. A systematic methodological review, conducted by O’Brien and Clark (2010), identified a number of issues with the use of this type of data source in qualitative research. More specifically, in the 18 papers reviewed, O’Brien and Clark focused on the methods used by the authors of the papers and how they addressed the ethics of using this type of data in their work. With respect to institutional ethics approval, the majority of the researchers did not feel they needed such approval as the data they collected were in the public domain. Where the water was more muddied, however, occurred with respect to first-person narratives published in blogs and other personal websites. In these cases, the researchers took a variety of approaches in either concealing or revealing the authors of the works they used, with a tension between the need to maintain privacy and the need to attribute copyright to the material. Considering policies from a variety of sources on ethics for conducting research, O’Brien and Clark believe that ethics approval is not required to use only published or publicly available data. Further, given that the narratives of the authors are a form of intellectual

property, the authors should be recognized as such within research studies. Given the great variety in presenting the methods used working with these narratives, O'Brien and Clark also describe the need for greater transparency of the process of collection and analysis used so that quality appraisal can be completed.

Following the review and suggestions provided by O'Brien and Clark (2010), the purposes of this paper are to describe how autobiographical texts can be used specifically with grounded theory methodology and to provide suggestions for how others can also incorporate this type of data into their own work. Within this description, I outline practical and theoretical advantages and disadvantages of these data sources, drawing on my own experience completing a grounded theory study; and provide six "steps" that could be followed in working to overcome the disadvantages and be transparent with the process used.

An Example of Using Autobiographies in a Grounded Theory Study

As part of my doctoral work, I designed and conducted a grounded theory study investigating how, and why, individuals living with young-onset Parkinson's disease became informed about their disease over time. Following Charmaz's (2006, 2014) flexible methods, I wanted to include autobiographies of those living with the disease as a means of developing depth in the data I collected, and to help ensure I would have sufficient data to develop my theory; especially, given reported difficulties in recruiting those living with this disease in earlier research (Fontenla & Gould, 2003). These autobiographies, which exist in the public domain, were written by individuals living with young-onset Parkinson's disease and had been published between the years 1998 and 2010. Beyond the autobiographies, I also used in-depth interviews, focus groups and an online discussion board to collect elicited data, and spread the data collection and analysis out across four cycles (see figure 1). Such an approach to the study design was purposeful to allow time for concurrent data collection and analysis and constant comparison, essential to grounded theory methodology (Charmaz, 2006, 2014; Glaser & Strauss, 1967).

| YEAR | 2011 | | 2012 | | | | 2013 | | 2014 |
|---------------------------------|----------------------------|-----------------------|--|---------------|---|---------------------|--|-------------------|------|
| MONTH | October | November - January | February - April | May - June | July - November | December - April | May - July | August - April | |
| PHASE | Cycle 1 | | Cycle 2 | | Cycle 3 | | Cycle 4 | | |
| EXTANT DATA | 4 Texts | Analysis | 3 Texts | Analysis | 3 Texts | Analysis | 4 Texts | Analysis | |
| ELICITED DATA | 2 Focus Groups (n = 15) | | 18 Interviews (n = 6) 1 Focus Group (n = 3) | | 18 Interviews (n = 6) 2 Focus Groups (n = 9) | | 11 Interviews (n = 4) 1 Focus Group (n = 6) | | |
| Online Discussion Board (n = 6) | | | | | | | | | |

Figure 1. Cycles of a grounded theory study illustrating incorporation of extant texts

To locate autobiographies, I searched English book titles on Amazon.com during the data collection period, that is, October 2011 to July 2013, using the phrase "young-onset Parkinson's disease." During this period, I was able to locate 28 autobiographies, and from these I chose 14 to represent the diversity in experiences of those living with the disease who had written autobiographies (see table 1). Four autobiographies were read during cycle one, three during cycle two, three during cycle three, and four in the final data collection.

Table 1: Autobiographies used as extant data sources

| Author | Publication | Abbreviated title |
|----------------------|--------------------|-----------------------------------|
| Amodeo, Joseph | 2007 | My Moments of Hope |
| Andrews, Sandy | 2003 | Everyone Has an Everest |
| Dubiel, Helmut | 2009 | Deep in the Brain |
| Fox, Michael J | 2002 | Lucky Man |
| Fox, Michael J | 2009 | Always Looking Up |
| Gordon, Sandi | 1992 | A Personal Story of Acceptance |
| Grady-Fitchett, Joan | 1998 | Flying Lessons |
| Griffey, Joe | 1998 | Parkinson's at Twenty-Nine |
| Harshaw, Bill | 2001 | My Second Life |
| Lightner, Patricia | 2003 | Parkinson's Disease and Me |
| Phan, P | 2004 | My Life Unraveled |
| Secklin, Richard | 2010 | Looking Down the Barrel |
| Webster, Kathleen | 2004 | Living with the Invisible Monster |
| Wenmouth, Richard | 2010 | Life Goes On |

As Charmaz (2006, 2014) describes, it is important to keep in mind that extant texts are written for varied purposes that may or may not be directly related to the topic of the research. As such, through my reading of these autobiographies, I extracted data from them that was relevant to information behaviour, that is, the foci for my study, using a data extraction form that I created for the study. Those interested in reviewing the data extraction form described are encouraged to contact me to receive a copy electronically. Data that were extracted included basic demographic information such as their age when they wrote the book and the age they were diagnosed, information related to their diagnostic experience, supports in their life, and any specific references made to topics or sources of health information desired and sought out. Data extracted from these autobiographies were used to supplement the elicited data that I collected, and were analyzed together using data analysis methods for grounded theory. In other words, the data extraction forms were subject to the same coding and constant comparison as transcripts from elicited data sources throughout the study. The coding was completed using the qualitative software program NVivo from QSR International. Nodes were created for each line or sentence of the extraction forms, which were then compared against nodes from other form and transcripts from the elicited data sources. Over time, as my theory started to focus more on the adjustment process of individuals in relation to their information behaviour, I also

modified the data extraction form to include consideration of evidence related to the adjustment of the authors. In writing up and presenting the theory, I used the term “author” to properly distinguish those who wrote autobiographies from “participants” who played an active role in the study, and to also recognize the authors as the owners of their intellectual property (O’Brien & Clark, 2010).

Advantages and Disadvantages of Using Autobiographies in a Grounded Theory Study

Reflecting on the use of autobiographies in a grounded theory study, generally and in my own experience conducting this type of research, there are a number of important practical and theoretical considerations. In the discussion below, I have grouped these considerations according to the relative advantage or disadvantage that they offer in being included as a data source for this methodology.

Advantages

From a practical point of view, published autobiographies are readily available sources of data in the public domain. The extent of this availability has, no doubt, been increased in recent years with more people using e-book readers, web-browsers, smartphones and tablets to read books (Rainie, Zickuhr, Purcell, Madden, & Brenner, 2012). Indeed, these e-versions of books are often offered to consumers at a reduced price, in comparison to print books, making them more accessible financially as well. Many public libraries also now offer electronic holdings of books that patrons can borrow and read on their electronic devices. In the same vein, the development of these technologies has also made it easier for individuals to publish their illness narratives using electronic formats, coinciding with an increased focus on “the body” and illness narratives (Frank, 2013; Hardey, 2002; Pitts, 2004).

If working with a rare population, or with a population where there are known difficulties with recruitment, using this type of data may be a means of increasing the depth of the data collected. Additionally, as has been described within the context of O’Brien and Clark’s (2010) review, collecting and analyzing this type of data does not require ethics approval as it exists in the public domain. Of course, within a grounded theory study, it is not likely that extant data would be the only type of data collected. Therefore, ethics approval would be required overall, but not for the extant data collected where such data was not previously written by study participants; meaning that insights leading to the development of research questions, or insights after the conclusion of a study to refine a theory or design a future study, could arise from these texts. In comparison to elicited data, another practical advantage of autobiographies is that there is no need to transcribe the narratives, as they already exist in print form.

With respect to theory development, beyond providing access to a specific population, autobiographies increase the diversity of experiences of individuals used in a grounded theory dataset. Such texts usually provide broad coverage of an individual’s life living with an illness, sometimes starting in childhood and working up to the point at which the author has written the text. As a means of increasing the complexity of the theory generated, autobiographies can help to supplement the elicited data collected (Charmaz, 2006, 2014). This speaks to the important role that extant texts can play in increasing one’s theoretical sensitivity to a specific topic. Birks and Mills (2011) define such sensitivity as “the ability to recognize and extract from the data elements that have relevance for your emerging theory” (p. 59), and is described by Kelle (2007) as being a prerequisite for building categories in a grounded theory study. Part of this sensitivity is developed through being reflexive about one’s personal biography and

disciplinary perspectives, but is also developed throughout the research process as one engages with the data (Birks & Mills, 2011; Charmaz, 2006, 2014).

Disadvantages

Beyond the advantages of using autobiographies in grounded theory studies, there are also a number of practical and theoretical drawbacks. In a practical sense, using autobiographies can be difficult if the texts are missing information that would be useful for comparison within the dataset. For example, you cannot ask authors of the autobiographies to fill out demographic questionnaires you might have study participants complete, as they are not participants of the study. You might also need to make inferences about the authors' histories if they are not explicit with details you might need for your study, again, which might facilitate comparisons to be made. Given that autobiographies can be hundreds of pages in length, you might wonder as well if you need to code the entire book at one or multiple levels. Since coding is completed with the elicited data that is collected, how do you negotiate this process with extant data? Another more practical consideration that does not necessarily have an obvious answer is about when to read autobiographies during a grounded theory study. As mentioned above, reading them are a means of enhancing theoretical sensitivity. Thus, should extant texts all be read before or after the elicited data, or should you intersperse your collection and analysis of the autobiographies with your other data sources?

Although an advantage of using autobiographies is the breadth of the experiences of the authors, a disadvantage is that these texts often do not provide the same depth in comparison to elicited sources. More specifically, because the extant texts pre-exist outside of the study, and researchers likely do not have interaction with the authors, you cannot probe into their experiences any further than what they describe in the books. Thus, depending on the specific focus of your research, there may be only limited portions of the texts that would be relevant for your study.

Also, important to consider from a theory-generating perspective, it may be that a certain type of person is more likely to write and publish their illness narrative in the public domain. Such a person, for example, would likely have access to the Internet, would have a certain level of literacy or support from others who are literate, would have the time and state of mind to write and introspect on one's illness experience, and would have the knowledge about self-publishing or the ability to work with a publisher. In other words, there may be socioeconomic and psychosocial influences on who publishes illness narratives in the public domain and who does not. Although publishing these narratives, as I have described as an advantage, has become easier because of changes in technology, such access to publishing does not mean that doing so is universally available to those living with illness desiring to write about their experiences.

A final point to consider with respect to theory development is that context in which the autobiographies were written. For example, the specific experiences being described by an author may be different because of their geographic location and/or the specific period the book was written. However, this would really only be a drawback if you were looking for the experiences of others in similar physical and temporal contexts. In most cases, especially within a grounded theory study, such differences can actually be quite valuable for theory development as it can illustrate the potential influence of physical and temporal changes on illness experiences. In other words, using texts set outside of the context of your study will necessitate reflection on how and why their experiences might be similar or different to those taking part in your study.

Six Steps in Using Autobiographies as Extant Data Sources in a Grounded Theory

In reflecting on the use of autobiographies in grounded theory, I offer a set of steps for others considering the use of this type of extant data within their own grounded theory work.

1) Have a Clear Research Direction

Know what it is that you want to ask of the authors' experiences. Although theoretical insights can stem from autobiographies even before a study starts, once a decision has been made on the direction the study will take, understand what it is you want to know from reading the autobiographies. For example, in my grounded theory study, I was interested in the information behaviour of the authors and how this related to their process of adjusting to the diagnosis over time. When reading the texts I, therefore, had a clear picture of what it was that I was looking for from the texts.

2) Develop a Data Extraction Form

With your initial research question in mind, develop a form you can use to extract data from the autobiographies to make the data easier to work with and analyze. Generally, the data you are extracting from the texts are very similar to the types of questions you might be asking your participants during elicited data collection.

3) Locate Suitable Autobiographies

With your extraction form ready to go, you can set out and try to locate texts to collect your extant data. Just like your elicited data collection, you should have specific inclusion and exclusion criteria that you apply to the autobiographies you find to make sure they fit within the parameters of your study. For example, with my grounded theory study, I found a large number of autobiographies written by those living with Parkinson's disease. However, because my focus was on the information behaviour of those with young-onset Parkinson's disease, I needed to read summaries of the books and, in some cases, read the first several pages to make sure the author was included in my population of interest. It will also be important at this point, in your search, to make sure you are able to identify actual autobiographies from more fictional narratives, which would not be appropriate for use in a study evaluating the illness experiences of "real" people.

There are many different sources that can be used for accessing autobiographies, and they may be available in print or electronic format, or in both formats. As I have described, I primarily used Amazon.com and was able to locate both print books and electronic books that fit my inclusion criteria. However, public and university libraries, and other online bookstores will also provide access to these books. It is also important to note that some autobiographies may only be available in a specific book format, for example, Kindle, so it will be imperative if you are having trouble to use as many sources as you can to locate the texts.

4) Choose the Autobiographies to Include

Once located, you need to decide which of the autobiographies you found that meet your inclusion criteria will be included in your study. If you are lucky enough to have ample texts to choose from, and more than you (and possibly your research team) can read and analyze within the time frame of your study, you need to make some decisions. As this was the case that I experienced within my grounded theory, I suggest trying to include a range of texts

written in different periods and in different locations to add to the complexity of your theory. If possible, through reading the summaries or initial pages of the texts, also try to select those where the authors have different educational and occupational backgrounds. For example, some of the texts I used were written by a stay-at-home mother, a celebrity, a university professor and a police officer, and varied in publication years and geographic locations of the authors.

Of course, once the study is over, you can always return to the books that were not included to see if they spark any additional theoretical insights; but, there will undoubtedly be only a specific amount of time you have to complete your study. Whether completing the study for your masters or doctoral work, or as part of a funded study working as a researcher, there are always time restrictions that limit the amount of data that can be collected and analyzed. From a constructionist point of view, this is not problematic because knowledge itself is seen as context dependent and always subject to change (Berger & Luckmann, 1966; Fleck, 1979). Thus, theories are never really “complete” in the sense that a study will be able to identify all of the possible nuances of a process, nor incorporate additional nuances based on a future context that does not yet exist.

5) Read and Analyze the Texts

For practical and theoretical reasons, I chose to embed my reading and analysis across the four cycles of my study. I found this strategy useful because it meant that I could spread out this work, and could pick and choose when I completed the work to fit with the elicited data I was collecting concurrently. Theoretically, setting up the study this way also helped to ensure that I would not prioritize the extant data over the elicited data in the early part of my analysis and theory generation. Another important reason for setting up the study this way is that the specific questions you ask of the data may change over time as the theory develops, just as the questions you ask of participants will likely change over time and become more specific. In other words, there may be a need to change the components of your data extraction form. As constant comparison is an important part of the grounded theory process, this means that you would not need to re-read all of the autobiographies you included, but only those you had already read up to a given point to then focus in on data related to your developing analysis.

6) Be Reflexive on Use of the Texts

As reflexivity is an important part of the grounded theory process, and qualitative research more generally (Ravenek & Laliberte Rudman, 2013), it will be important to think about how, for example, you used the texts to generate the overall theory and whether you prioritized some texts over others. Other questions and considerations will also be important depending on the foci of a given study. Having this insight will help to improve the transparency of your work, currently cited as a problem with using this type of data in qualitative work (O'Brien & Clark, 2010); and could also help you understand potential directions for additional research on the topic.

Conclusion

Autobiographies available in the public domain are a growing source of data for use by researchers using grounded theory methodology. Changes in technology, and an increased societal focus on the body, have likely contributed to their increased availability. Using such data offers a number of advantages, both practically speaking and in the theory generation process. However, potential disadvantages also exist and must be considered by researchers

using this autobiographies with this methodology. This paper has described one approach used to incorporate these texts across a grounded theory study, in addition to providing six steps to help others increase their transparency and rigor in using these data sources.

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