Using Grounded Theory Method to Capture and Analyze Health Care Experiences

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Abstract

Objective: Grounded Theory (GT) is an established qualitative research method but few papers have encapsulated the benefits, limits, and basic tenets of doing GT research on user and provider experiences of healthcare services. GT can be used to guide the entire study method, or applied at the data analysis stage only.

Methods: We summarize key components of GT and common GT procedures used by qualitative researchers in healthcare research. We draw on our experience of conducting a GT study on amyotrophic lateral sclerosis patients' experiences of healthcare services.

Findings: We discuss why some approaches in GT research may work better than others, particularly when the focus of study is hard-to-reach population groups. We highlight the flexibility of procedures in GT to build theory about how people engage with healthcare services.

Conclusion: GT enables researchers to capture and understand healthcare experiences. GT methods are particularly valuable when the topic of interest has not previously been studied. GT can be applied to bring structure and rigor to the analysis of qualitative data.

Many researchers and research teams that are predominantly quantitative in orientation may find that qualitative methods are needed to answer some or all of the questions they seek to answer in their study. This article seeks to enable such researchers to conduct qualitative research and data analysis with the help of the Grounded Theory (GT) method, one of the most widely used and established qualitative methods. We give practical advice pertaining to each step of a research project, and illustrate these with the help of examples from a recent study that we conducted, and also hypothetical examples of research scenarios (the latter are in italics).

The need to apply qualitative methods in conducting primary research and in analyzing data can arise for a number of reasons. First, the parameters of service user and provider experiences might be poorly understood, which in turn makes the design of survey and other quantitative research instruments impossible. Second, there might be good grounds to argue that the existing quantitative research instruments are not valid or reliable, or not suited to the particular context where they are to be applied. Third, the research team might need to gain a fine-grained understanding of processes behind patterns in their data; for instance, there is a correlation between the location of services and level of satisfaction with services, but why is this the case? In each of the above scenarios, qualitative research methods are prerequisites for good quantitative research, yet quantitatively-oriented researchers and teams frequently lack the toolkit necessary to conduct qualitative research that stands the chance of gaining acceptance with rigorous qualitative peer-reviewers. Quantitatively oriented teams might also have access to qualitative data that they would like to analyze and

make sense of, but lack the analytical tools to do so (for a detailed introduction to qualitative data analysis, see Bradley, Curry, and Devers 2007).

The purpose of the article is to demonstrate that while the task of conducting a qualitative project and analyzing qualitative data is not easy, the challenges of undertaking good qualitative research are not insurmountable for quantitative researchers (or indeed inexperienced researchers with a qualitative orientation), provided that an established method, in this case GT, is followed and carefully documented.

Qualitative Research

Unlike quantitative research approaches which excel at testing hypotheses derived from existing theories, qualitative research provides rich descriptions of phenomena and generates hypotheses about phenomena (Sofaer 1999). Qualitative research is useful to describe novel, poorly understood phenomena and to engage in causal inference, hence being of particular help when building new theory or adjusting theory that has been shown to be deficient (Hurley 1999).

Qualitative research methods explain processes i.e. 'what is going on here' or patterns of human behavior. Qualitative research helps researchers in health care / health services to understand how social practices and patterns in healthcare are created and what meaning these practices have for people within specific and/or varied contexts. Qualitative research is conducted in uncontrolled or 'naturalistic' settings (Lincoln and Guba 1985). The most frequently used method of data collection is the in-depth semi-structured interview, hence our focus here on interviews. As for most other

domains, participants of qualitative health care research tend to be key stakeholders who have first-hand experiences of and insights into the particular phenomenon under study; it is important to treat them as the *only* experts on their own experience.

What is Grounded Theory?

Broadly speaking, GT is a systematic set of techniques and procedures that enable researchers to identify concepts and build theory from qualitative data (Corbin and Strauss 2008). More specifically, GT is concerned with psycho-social processes of behavior and seeks to identify and explain how and why people behave in certain ways, in similar and different contexts (Charmaz 2006; Corbin and Strauss 2008; Dey 2008). GT is primarily inductive which means that researchers move from the specific to the general in order to explain phenomena in the qualitative theory-generating process. Deduction and abduction have a role in building theory (Charmaz 2009; Corbin and Strauss 2008; Timmermans and Tavory 2012). For instance, a GT study might employ analytical categories that are deduced from the early data collection phase and the literature (e.g. medical practitioners in rural areas tend to prescribe more drugs), or seek to probe into a number of possible explanations for phenomena (e.g. is this because rural patients have more complex medical conditions? or because practitioners in rural areas have different educational backgrounds?). The distinguishing feature of the GT approach to these questions is its openness to multiple explanations, in all cases derived 'ground up' from the data.

GT is a commonly used qualitative method in health research (Pawluch and Neiterman 2010). GT is typically focused towards building theory (Strauss and Corbin 1998). Data is compared with data, otherwise known as 'constant comparison'

(e.g. inaccessibility of clinics has featured in seventeen out of twenty interviews to date, with some variation the reasons why clinics are seen as inaccessible; in three interviews it did not feature, seemingly because all three participants lived within two miles of a clinic). Grounded theorists not only code data for concepts (e.g. older adults recognise the importance of preventative approaches to health, most commonly mentioned being the winter flu vaccine) but also identify relationships between concepts/categories (i.e. variables) to build substantive theory (e.g. social class features as the strongest explanation of the likelihood of seeking flu vaccination in our sample).

The following sections outline methods and procedures used in GT research. Sampling, data collection, and data analysis in GT occur (ideally but not necessarily) in tandem but each is detailed separately here. Readers might be interested in all these aspects of GT research, or might want to skip to the data analysis section if they are working with an existing dataset. We draw from our experience of conducting a GT study on healthcare experiences among people with amyotrophic lateral sclerosis (ALS) where we aimed to explain how and why people with ALS engage with healthcare services. ALS is a rapidly progressive, highly disabling, and terminal neurological disease (Hardiman, van den Berg, and Kiernan 2011). The study was motivated by the argument that rudimentary questionnaires about healthcare services do not adequately reflect domains of care that are important to people with ALS (Foley, Timonen, and Hardiman 2012a).

How Should I Sample in Grounded Theory Research?

Different types of non-probability and non-randomized sampling are used in GT. Typically, grounded theorists purposively select participants who they believe can offer valuable insight into the topic under study (Morse 2007; Sbaraini et al. 2011). Ideally, a GT study employs theoretical sampling. This means starting by interviewing a small number (sometimes just one or two) people whose characteristics are relevant to the study, and selecting further participants on the basis of the information gathered from the early interviews (e.g. in a study of maternity care services use among immigrants of African origin, starting with participants who fit this broad selection criteria before starting to purposively select some who are Muslim, others who are Christian, because early interviews suggested the importance of religion in inclination to access services). Occasions arise when researchers encounter problems recruiting participants and for practical purposes might, in addition to purposive sampling, resort to convenience sampling where participants are in close proximity to the researcher. Regardless of the sampling strategy, sampling in GT should always be trained at illuminating theoretically relevant aspects and dimensions of a phenomenon (e.g. the characteristics and views that explain likelihood of seeking maternity services before birth).

In our study, we had a (national) ALS population-based register to sample from and we did not encounter problems recruiting participants in order to capture a broad range of healthcare experiences among people with ALS. We had no need to resort to convenience sampling and sampling from the Irish ALS population-based register enabled to us sample without pre-defined geographical location. However, in many instances, researchers don't have population-based registers or similar databases available to them, and qualitative researchers (including GT researchers) might

sample from multiple sources (e.g. migrant rights groups or places of worship in the case of the above example of accessing maternity services).

It is not possible to know, at the outset of a GT study, the exact number of research participants that will be sampled. This is because theoretical sampling is driven by concepts or categories (i.e. variables) that emerge during data analysis and the need for further elaboration of these categories in order to develop theory. For example, in our study, when we identified that aging and parenthood shaped how participants made decisions about their care (Foley, Timonen, and Hardiman 2014a), we sampled participants for variation in these contexts (e.g. people with ALS at different life stages, and those who had dependents and those who had no dependents). However, for pragmatic reasons such as assuring research funders, it is often necessary to give an indicative number of participants even though this might not be the final number.

Sampling 'hard-to-reach' population groups can be challenging, especially in studies that broach sensitive topics such as death and dying, or healthcare experiences of people who have stigmatized conditions. For example, gatekeeping by different groups (most typically different healthcare providers and professionals) can impact on recruitment in palliative care research and restrict researchers' access to people who could potentially offer valuable insight on these experiences (Ewing et al. 2004). Inevitably these obstacles can restrict GT researchers, where developing theory is supposed to guide who they sample and where they go to sample. Nonetheless, all efforts should be made to access participants who fit the theoretical sampling criteria, including the use of alternative sampling routes. Sampling ceases in GT studies when categories are well described and dimensionalized (Corbin and Strauss 2008); this is

known as 'saturation' of the data. Saturation is not dependent on the *amount* of data that has been collected and analyzed but rather occurs when no significant new insights are emerging (i.e. additional interviews are not generating novel data / data necessary for fleshing out the categories that have already emerged).

How Should I Collect Data in Grounded Theory Research?

Qualitative interviews with individual participants are the most commonly used methods for data collection in GT research. Data collection in GT can also incorporate observational methods at one point, over time and in similar/different contexts. Indeed, multiple types of data (e.g. archival material, written sources) can be used as data. However, due to limited space available here, we confine our outline to interviews only. Interviews in GT studies can be unstructured (where questions asked in the course of the interview are not pre-determined prior to interviewing) or semi-structured (where all participants are asked some key open-ended questions that are intended to structure the interview).

Unstructured interviews are suited to enquiry that embarks on a very poorly understood topic, and/or intends to extract the basic parameters of a phenomenon with the view to maximum openness to what might be the aspects of it that matter most. In the ALS study, we took the unstructured approach because we had established, through a literature review, that little was known about how and why people with ALS engage with healthcare services (Foley, Timonen, and Hardiman 2012b) and we were open to the possibility that parameters of ALS care as agreed by service providers might be very different from the parameters of care from the service user perspective. Our study topic was broad (i.e. service user healthcare experiences in

ALS) and we did not set out to focus on any particular domains of ALS care. Hence, most interviews began by inviting participants to talk about their experiences of healthcare services since ALS came into their lives. Where necessary and fruitful, participants were 'prompted' when they struggled with phrasing a particular experience. Additional information on issues that were particularly pertinent to individual participants was pursued spontaneously (in the course of the interview) by adding questions that elicited this additional information ('probing'). Furthermore, as data analysis (that proceeded in parallel with data collection) progressed and began to yield a conceptual and theoretical framework to explain the ALS healthcare experience, some new questions were asked of subsequent research participants in order to be able to refine the concepts and theory.

However, most GT studies in health care research use pre-prepared interview guides (i.e. semi-structured interviews). Here, grounded theorists should use short interview guides (with opening, central, and closing questions; typically no more than 10 questions in total) to help focus the data and expand on key components of the experience(s) under study (Charmaz 2006). All questions should be 'open-ended' i.e. not in any way prescriptive of what the answer might be (e.g. "can you tell me about your first visit to the clinic?" rather than "was your first visit to this clinic a positive or a negative experience?"). The use of interview guides in GT can also facilitate greater consistency in data collection between experienced researchers in research groups where multiple researchers within the group conduct the interviews (for an example of a team conducting GT research, see Conlon et al. 2013).

GT methods are also suited to focus group data collection and analysis (Hennink 2014; Hernandez 2011). Focus groups enable participants to respond to ideas shared by other members of the group and might encourage participation where participants are reluctant to be interviewed on their own (Kitzinger 1995). Focus groups however, also have limitations. The quality of data generated from focus groups is very much dependent on the composition of the group (preferably 3-5 participants per group) and on the group facilitator's skills in modulating the group. Ideally, focus groups should be conducted within or as close as possible to the relevant naturalistic setting (e.g. an extended care facility where participants live and operate in communal surroundings).

Duration of interviews in GT research vary but ordinarily interviews last around one hour (the range in duration can be considerable, varying by individual participants' health, and other circumstances). Interviews are usually audio-recorded and transcribed. Qualitative interviewing requires good listening skills, astute observation (including attention to nonverbal cues) and the ability to react sensitively to participants. Some questions should be sufficiently general to cover a wide range of participants' experiences, others narrow enough to explore experiences specific to each participant (see 'prompting' and 'probing' above).

As for other qualitative methods, careful compilation of field notes is important in GT research. Field notes in GT studies might contain some early analytical note taking but essentially (and distinct from memos, see later) describe the interview setting and record observations (Corbin and Strauss 2008). In our research, the first author compiled field notes to record relevant considerations (e.g. tone, mood and coherence of the respondent) that shaped how each interview was conducted. Field notes also

serve to jog the researcher's memory in studies where the fieldwork phase takes a long time, and help to contextualize the interview for an analyst who did not conduct the interview (e.g. it might be very important to know, from the field notes, that a particular participant lived with their adult child, a contextual fact that might explain several statements in the interview that would otherwise remain perplexing).

How Should I Analyze Data in Grounded Theory Research?

As stated, in GT, data is collected and analyzed data in tandem which in turn generates data and guides subsequent interviews. We followed well-established coding procedures in GT (Corbin and Strauss 2008).

First, we broke data down into discrete parts that represented segments of raw data. These segments (otherwise known as indicators) comprised words, phrases or large blocks of data that we abstracted under conceptual headings (e.g. "this segment is about the participant being trustful of his physician at a specialized ALS clinic; I will code this as 'trusting clinic physician'"). We coded for similarities and differences in the data which involved constantly comparing indicators and concepts with new data that in turn led to new concepts (e.g. "several subsequent participants disclosed being trustful of healthcare professionals at the clinic – I have decided to label this as "trusting ALS clinic"). In GT, this is known as 'open' coding. We coded data in terms of basic psycho-social processes. This was done by looking closely at what participants described themselves as doing, feeling, and being. To this effect many lower level concepts were labelled using gerunds i.e. the verb form that functions as a noun e.g. trusting (Charmaz 2006). We coded for *process* which means how participants acted in response to different contexts (Corbin and Strauss 2008). This

means we identified conditions which shaped participants' experiences and then captured different and/or similar contexts that could add meaning and variation to categories that were emerging in the data (e.g. based on the above analysis, we sampled participants who had never accessed services at the ALS clinic).

We began to make tentative propositions about the relationships between emerging categories and about how variation in context might shape participants' experiences. In GT analysis this is referred to as 'axial' coding. By exploring tentative relationships between concepts (subcategories) and categories, subcategories described categories in more detail. During coding, the first author wrote reflexive and theoretical memos (written records of analysis). Memoing is an important component of GT method (Charmaz 2006; Corbin and Strauss 2008; Glaser 2014). In our study, the first author recorded methodological insights, and theoretical comparisons about the data which together guided sampling and theory building. For example, in a early memo entitled 'making decisions in the context of family', she made comparisons between how different family contexts were impacting on participants' decisions about care and then sampled participants who had varying degrees of family support available to them. As we continued to sample and analyze data, it emerged that family context also encompassed how participants themselves sought to provide support to their family and that their parenting roles at different life stages influenced how much support they sought to provide to their family (Foley, Timonen, and Hardiman 2014a).

The final coding phase in GT research, known as 'selective' coding, involves the identification of a core category that incorporates other categories, or supersedes them

in explanatory importance. The relationship between categories constitutes substantive theory (in our case, theory about how people with ALS engage with healthcare services). We continued to refine the main categories (including the core category) and the relationships between categories after interviewing had ceased. Here, insights from theoretical memos were expanded to compile additional theory building memos about the data. This final stage of theory building helped synthesize the relationships between categories that explained how and why people with ALS engaged with healthcare services. For example, loss emerged as the core category in our data which consisted of loss of control, loss of parenthood, loss of the future, loss of expectations, loss of independence, loss of hope, loss of participation, loss of identity and loss of normality. We identified the relationship between loss and control: participants felt they had no control over loss in their lives and exerted control in healthcare in response to loss of control (Foley, Timonen, and Hardiman 2014b).

GT researchers ordinarily use diagrams as well as memos to assist them in data analysis. During selective coding, the first author developed and iteratively refined an integrative diagram which helped to establish relationships between categories. The purpose of developing and refining the integrative diagram was to provide a graphic description of the substantive theory and illustrate the relationships between concepts and categories (including the core category). It is important to note, however, that all data in a GT study do not have to 'fit' neatly into the theoretical frame. Similar to quantitative research, there are exceptions to patterns in the data. The explanations that ensue from analysis might not apply to all cases.

Can I Apply Grounded Theory to Data Analysis Only?

Ideally, GT is applied throughout the research process i.e. from conception of research questions to concurrent sampling and data analysis. However, GT also allows for the use of GT coding procedures after most or all of the data has been collected. Sampling is done on the basis of concepts in the data and so a researcher can sample theoretically in existing data (Charmaz 2006; Corbin and Strauss 2008). For instance, project timelines and division labor within research projects might lead to separating data collection and analysis. Situations might also arise when 'target' participants are only available to the researcher at a particular point in time and so researchers might conduct a number of interviews without analysis in between. Although coding data after some or most of the data has been collected means that data is unlikely to be 'saturated', analysis should still begin with the earliest interviews together with (where available) field notes compiled during the data collection phase. Here, coding procedures are the same as procedures employed in GT studies that collect and analyze data in tandem (see previous section on data analysis). In studies that complete data collection prior to analysis, researchers still compare data with data and search for patterns and psycho-social processes in the data (Corbin and Strauss 2008). It is important to note that memos and diagrams are also central methodological components of studies where GT method is applied to the data analysis stage only, and are undertaken at each stage of analysis to record comparisons between data, expand on emerging categories and build theory. Data analysis using GT method is shaped by what the qualitative dataset consists of and how it has been collected.

Do I Need to Use Computer Software in Grounded Theory Research?

Qualitative researchers (including grounded theorists) often use computer software programs to assist them in their research [e.g. NVivo, Atlas.ti] (Hutchison, Johnston, and Breckon 2010; Hwang 2008). Software programs for qualitative research enable researchers to store, organize, and retrieve data, and link data to data, and are particularly useful in studies with large amounts of data and in studies that combine multiple modes of data (e.g. text, audio and visual). Most software programs for qualitative analysis now allow for visual coding, in text editing, contextual annotating and hyper-linking of the data to other documents or multimedia support.

Although computer software programs for qualitative research are universally described as 'Computer-assisted Qualitative Data Analysis Software' (CAQDAS), the term assisted means how data is electronically stored, retrieved and linked. They do *not* perform the 'thinking' of GT researchers who code, categorize and theorize the data, and derive hypotheses from the data (Weitzman 1999). It is important to stress that the use of CAQDAS is *neither necessary nor sufficient* in GT (or any qualitative data analysis). In other words, it is possible to undertake high-quality analysis with the help of 'manual' analysis only (e.g. annotating transcripts, cutting and pasting in simple word-processing programs or even in paper), and using a software program is not going to yield good analysis *per se*.

Health service researchers who employ GT method often use CAQDAS (e.g. Patel and Riley 2007). Qualitative researchers (including grounded theorists) have described the pros and cons of using CAQDAS (e.g. Bringer, Johnston, and Brackenridge 2004; Corbin and Strauss 2008). We found that a software program for qualitative analysis helped us demonstrate what we did and how we did it. Linking

codes to codes, and codes to memos, and annotating data, enabled us to 'track' our analysis of the data and record how we decided on sampling procedures. Nonetheless, we reiterate that CAQDAS should not be seen as an essential tool for GT research. Qualitative research is interpretative which means that data is conceptualized by human beings.

By what Criteria is Grounded Theory Research Evaluated?

There are numerous sets of guidelines for judging qualitative research in health care research (e.g. Mays and Pope 2000; Quinn Patton 1999). Terms such as 'validity' and 'reliability' are used in qualitative research but they hold somewhat different meanings than they do in quantitative research. Valid means that the procedures of a study and instruments used, can in fact tap into the phenomenon under investigation. Reliable means that another researcher can in principle obtain similar results using the same method and procedures. GT research (as for other qualitative research) should also be judged based on the 'credibility' and 'trustworthiness' of the findings. These refer to the extent to which the findings are an accurate account of participants' experiences and of the researcher's role in the research. Credibility of the findings is also judged by the documented methodological steps taken by the researcher(s) (i.e. by the account of how the data was analyzed and how theory developed). In qualitative research, this is known as an audit trail (Devers 1999). GT researchers need to provide a detailed account of all the steps taken so that their research design can be *replicated* by other researchers in different contexts / countries.

More specifically, the quality of GT research should be judged by how well the data has been contextualized and 'saturated' for variation in context and meaning. Contextualized and 'saturated' data means that the data captures the complexity of the phenomenon under study and is therefore likely to be highly applicable (i.e. relevant) to the practice setting. 'Sensitivity' to the data is also important in GT research. 'Sensitivity' means how in tune the researcher is with data that infer meaning (Corbin and Strauss 2008). For example, how much did questions arising during data collection arise through analysis (i.e. induction) and to what extent might some of the interview questions have been based on preconceived ideas or existing knowledge about the data (i.e. deduction)? As mentioned, some analysis and extrapolation in GT research can be deductive in nature, but GT analysis should primarily be inductive i.e. take seriously the exhortation to seek to understand phenomena 'from the ground up'.

Variation exists in GT in terms of how and when researchers verify their analysis. Some choose to return to participants and validate the accuracy of codes, categories, and developing theory (Charmaz 2006). In our study, we did not conduct a second interview with participants largely on the grounds of rapid progression of ALS for the majority of participants. However, after we identified a core category (i.e. loss) we validated the data by returning to all data and scrutinized the data for meaning that had inferred loss. Here, we found that the experience of loss permeated all interviews and was *the* central experience for participants and shaped how they engaged with healthcare services. In our study, we discussed coding and emergent findings on a regular basis which helped guide subsequent sampling and analysis. Multiple researchers in GT team research often code the same data. 'Inter-coder reliability' in GT research does not mean that different coders must have coded data identically. Rather, inter-coder reliability involves discussion on different and similar

interpretations and is likely to enrich and fine-tune the analysis that ultimately converges on a shared interpretation.

How Do I Present Findings in Grounded Theory Studies?

Some publishers and journals have specific guidelines for submitting qualitative research (e.g. BioMed Central 2013). A number of papers also provide guidelines on presenting qualitative data on health care research (e.g. Malterud 2001; Tong, Sainsbury, and Craig 2007).

However, there is no one set of guidelines for presenting GT research. GT research for journal publication typically includes an introduction that explains the purpose (i.e. aims and objectives) of the research. Most journals also require a literature review section that is presented before study methods and findings (although this might be quite short, and mainly for the purposes of illustrating the gaps in knowledge/theorizing). A methods section should outline the key methodological steps and choices (broadly in the order in which they were presented in this article). The methods section should also include some account of the reflexive role of the researcher(s) and how the researcher(s) impacted on the research process (e.g. in our research, the first author had worked in the clinical field and so her background shaped how some participants responded to her).

Findings are presented in the form of categories supplemented by excerpts from the data (i.e. participants' quotations) and diagrams that support the explication of the data and link the evidence to the conclusions. The iteration between data and analysis (i.e. conceptualizing, theory generation) should be clear. In current publishing culture,

strong engagement with pre-existing literature is expected and the discussion section is an appropriate location for this. Concluding remarks should account for the strengths and limitations of the study and make clear the implications of findings to healthcare and the practice setting.

Conclusion

GT is a valuable research method to capture and understand healthcare experiences. GT can identify and explain variation in healthcare experiences. GT is rigorous and credible but also 'do-able' and pragmatic. GT is also a flexible qualitative research method and can accommodate to the scope and resources of a given study. The inductive nature of GT lends itself well to understanding key processes in healthcare from the participant perspective.

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