

Abstract

Purpose: Although relatively unknown within the field of rehabilitation, qualitative longitudinal research is ideal for rehabilitation and disability research that aims to understand health-related challenges over time. We describe the strengths and challenges of longitudinal qualitative research using two concrete examples.

Materials and Methods: Qualitative longitudinal research often involves in-depth interviews of participants on multiple occasions over time. Analytic approaches are complex, summarizing data both cross-sectionally and longitudinally. We present two detailed analytic approaches used in research with people living with HIV in Zambia and Canada.

Results: Our experiences provide three recommendations. First, development of the initial analytic coding framework should include both inductive and deductive approaches. Second, given the large quantity of data generated through longitudinal qualitative research, it is important to proactively develop strategies for data analysis and management. Third, as retention of participants is challenging over time, we recommend the use of a consistent interviewer over the duration of the study to promote a trusting relationship.

Conclusions: Longitudinal qualitative research has much to offer researchers and can provide clinicians with insights on the challenges of living with chronic and episodic disability. The flexibility in analytic approaches allows for diverse strategies to best address the rehabilitation and disability research questions and allow for insights into living with disability over time.

Keywords: qualitative longitudinal research; HIV and disability; HIV and rehabilitation

Introduction

Recognition of the unique contribution of qualitative research to the understanding of health and disability has increased over several decades. Numerous articles and books have introduced rehabilitation clinicians and researchers to qualitative methods, although approaches have largely focused on cross-sectional as opposed to longitudinal research [1,2,3]. Qualitative longitudinal research is more commonly associated with anthropology, sociology, and social policy research traditions (4), but has untapped potential for addressing questions in rehabilitation and disability. Qualitative longitudinal research is more than just individual “serial” interviews, as it allows one to examine processes of change over time (5, 6). While longitudinal quantitative methods are well established and provide answers to important public health, epidemiological and clinical questions, qualitative longitudinal research is comparatively unknown in health research. Longitudinal qualitative methods are ideal for rehabilitation and disability research which aims to understand the experiences and consequences of health-related challenges over time, with particular attention to nuances of complex phenomena.

The primary aim of qualitative longitudinal research is to study changes that occur over time and the processes associated with these changes [5,6]. Whereas quantitative longitudinal research seeks to measure the extent of change, the aim of qualitative longitudinal research is to understand how and why change occurs (6). Results obtained from qualitative longitudinal research is different and can complement results achieved through cross-sectional analyses (7)

and the social reality of living with chronic conditions. The literature demonstrates diverse approaches to analyses and methodologies, such that longitudinal qualitative approaches have been variably described within the tradition of phenomenology [8], as narrative analysis [9] and using case histories

[10]. As with all qualitative research the form of data collection can vary; in many qualitative traditions personal interviews are typical (11, Creswell) and it is this approach we focus on in this paper. The duration of the studies varies and can occur over months, years and even decades (12; Corden and Miller, 2007). The number and time between interviews will be dependent of the research question (12).

While longitudinal qualitative data sets provide an opportunity for innovative analytic approaches, there are a limited number of studies that provide detailed descriptions of the analytic methods and strategies to manage longitudinal data. Furthermore, there is diversity among these analytic approaches. For instance, Pinnock et al described a “multi-perspective” study in which they conducted four interviews of people living and dying with chronic obstructive lung disease, their caregivers and their health providers to understand their support and palliative care needs over time [13]. The analytic approach compared and contrasted the interviews in three ways: 1) serially, across individual patients, caregivers and health providers; 2) by patient, within patient/caregiver/health provider “sets”; and 3) by group, within integrated “patient sets”, “caregiver sets” and “health providers sets”.

In another approach, Eilertsen et al offered a detailed description of an analytic approach of interviews of six women who were interviewed 12-14 times over a two-year period post-stroke [14]. Their analysis within participants and across cases described the use of flow sheets to track identified themes. In their three phase analytic process, the initial phase focused on individual experiences; the second phase identified patterns, similarities and differences for all participants; and the third phase examined trends within themes and possible connections. Overall, the latter two approaches are unusual and the literature describing longitudinal qualitative approaches to analysis within health and rehabilitation research is relatively young.

Our program of research focuses on understanding the disability experienced by people living with human immunodeficiency virus (HIV). Disability associated with HIV is recognized as chronic and episodic in nature [15,16,]. Given the fluctuations over time and associated uncertainty that result from episodic disability, understanding of this phenomenon will be incomplete if research designs are only cross-sectional. We therefore conducted two longitudinal qualitative research projects, one in Canada and one in Zambia, exploring the experiences of people living with HIV. The purpose of this paper is to describe in detail the two analytic approaches to qualitative longitudinal research used in our rehabilitation research, and to reflect on the challenges and strengths of each.

Analytic Approaches

I. Disability Experiences of Older Adults Living with HIV, Ontario, Canada

This study sought to understand the episodic nature of disability experienced by people living with HIV and its consequences. We conducted a series of four semi-structured interviews with 24 men and women living with HIV, 50 years and older, at five-month intervals, in Ontario, Canada. All interviews were conducted by a research associate with experience in interviewing vulnerable populations. We used a rehabilitation theoretical framework, the Episodic Disability Framework, to guide the semi-structured interviews [15,16,]. During the first interview (Round 1) we asked participants to describe their health challenges including: 1) physical, cognitive, mental and emotional symptoms and impairments, 2) difficulties carrying out day to day activities, and 3) challenges to social inclusion. These challenges were then explored in detail, probing about the episodic nature of the challenges, uncertainty or worrying about future health, and the intrinsic and extrinsic contextual factors affecting the challenges. We also explored the living strategies and social supports that participants used to address their health challenges and uncertainty related to aging with HIV. To understand the episodic

nature of HIV, in subsequent interviews we explored the specific health challenges identified in Round 1 and asked the participant to consider what changes occurred (if any), how these occurred and how these changes affected their functioning, disability and health. Our longitudinal study design allowed for emergent themes to be discussed with participants over time as, in addition to exploring specific challenges identified in previous interviews, participants also were able to identify new challenges that arose over time.

Interviews were audio-recorded and transcribed verbatim. The transcripts were entered into NVivo 9 [17] to manage and organize the data. After the completion of the Round 1 interviews we developed a code book to guide our analysis. The code book was developed based on an open coding procedure of three transcripts [18]. Two investigators independently carried out line-by-line coding of each transcript. Following the initial coding these investigators finalized the code book by reconciling discrepancies and combining codes. The remaining Round 1 transcripts were then independently coded by two investigators from the research team using the code book. Using the coded transcripts at Round 1, we developed in depth summary profiles for each participant.

To examine the episodic nature of each participant's disability over time, we coded the data using a structured approach guided by the Episodic Disability Framework. Each investigator reviewed the summary profile and the Round 2 transcript of a participant and documented any changes that had occurred since Round 1 in specific areas consistent with categories in the Episodic Disability Framework (i.e., symptoms and impairments, difficulties with day to day activities, challenges to social inclusion and uncertainty). Investigators reviewed each participant's cross-sectional summary profile from Round 1 and coded changes that had occurred (i.e. no change, improved or worsened) and/or new symptoms

that emerged across each of the dimensions of disability on a summary form specifically designed for this purpose. We repeated this same process with the Round 3 and Round 4 transcripts (see Table 1 for example of summary form). Next, using the summary forms, we developed an in-depth summary of each participant's experiences over time. The result of this step of the analysis was an in-depth longitudinal summary profile that described the episodic nature of disability experienced by each participant over time. Summary profiles for each participant were completed by two investigators (one who conducted the interviews and one other investigator) and amalgamated into one overall profile for each participant. Having the interviewer code all the transcripts allowed for notation of contextual details of the interview. In the final step, we compared the longitudinal summary profiles of participants to document similarities and differences in the episodic nature of disability experienced by participants over time. This comparison resulted in the identification of common trajectories of episodic disability [19].

II. Sepo II Study, Lusaka, Zambia

The Sepo II Study sought to understand how the experiences of functioning, ability and health and episodic disability change over time for 35 women and men living with HIV in Lusaka, Zambia. We conducted a series of three semi-structured interviews with women and men living with HIV and on anti-retroviral therapy at approximately six-month intervals. Most of the interviews were conducted by a Zambian social scientist with expertise in interviewing. A small number were conducted by a Zambian co-investigator who is a British social scientist resident in Zambia. Each interviewer followed the same participant over the three rounds. This timing was long enough to allow time for changes in “functioning, disability and health” and/or contextual circumstances to occur [20] but short enough to maintain study momentum and maximize participant retention [21]. Like the Canadian study, the

interview guide was informed by rehabilitation frameworks, the International Classification of Functioning, Disability and Health (22) and the Episodic Disability Framework (15,16,). The Sepo II Study is part of a broader program of research and advocacy to advance the field of rehabilitation in the context of HIV in sub-Saharan Africa [23,24,)

In the Round 1 interview, participants were asked to share their experiences (both affirmative and adverse) of living with HIV and anti-retroviral therapy related to their body's functioning, day to day activities, and their relationships at home, at work and in their communities. The interview guides for Rounds 2 and 3 were similar to Round 1 but modified based on an inductive approach to reflect back on the concerns raised in the previous interview(s) and any changes that may have occurred to existing or new challenges. Between Rounds 1 and 2, three new codes were added and one was removed (duplicative), and between Rounds 2 and 3, no additional changes were required.

Interviews were transcribed verbatim and translated into English as necessary. Analysis was conducted both cross-sectionally after each interview round and longitudinally (over time) using a collaborative analysis process by an international team of researchers (based in Canada, Zambia and South Africa) and knowledge users [25]. NVivo 10 [26] was used to manage and organize data and facilitate analysis. To manage the enormous amount of data that longitudinal qualitative study designs generate we developed analytic building blocks that organized, described and synthesized data in various ways. These building blocks included the original verbatim transcripts; code datasets (i.e., all data coded in a particular coding category for each round of data collection); code summaries (i.e., 1-3 page summaries created by team members to describe core findings within each code for each round (leading to 3 summaries for each code); and thematic summaries to support specific longitudinal analysis.

A coding framework and worksheet for the initial cross-sectional analysis of Round 1 data was developed through an inductive descriptive process. Three research team members inductively reviewed the data from 3 transcripts and added descriptive categories to segments of text. These categories were then discussed with a subset of the research team and organized to develop a draft coding framework. This coding framework was piloted independently by three research team members using three transcripts and the coding was compared to ensure consistency of interpretation and to identify missing categories. The final coding framework included a clear definition of each code to increase the likelihood that the codes were applied consistently across the research team.

Each team member participated in the collaborative coding process during all three rounds of analysis [26]. For each round, transcripts were coded independently by 2 members of the research team, a coding worksheet was completed, and all coding was entered into NVivo 10 (i.e., not just where there was concordance). Where possible, research team members were given the same participant's transcript to code in each of the 3 rounds.

To create the coding summary, one team member created a 1-2 page cross-sectional summary across participants by code for each round. Codes were assigned to team members based on individual researcher interest and expertise. For Rounds 2 and 3 a structured code summary template was developed. The template included 3 parts to complete: 1) a summary of the data for the code in that interview round; 2) a comparison of the current round's summary with the summaries from the previous rounds; and 3) key messages and ideas that would benefit from more in-depth analysis in the future. The descriptive summary included the main ideas discussed by participants; reflections on gender and

age; any surprises in the data; areas where there was disagreement or contradictions in the data; patterns (same or different); reflections on previous summaries; and, considerations for analysis.

We approached longitudinal analysis of the data in two ways. First, we reflected on the themes emerging from analysis of individual rounds to identify issues that may reflect change over time or other aspects that would benefit from a longitudinal perspective. For these specific issues, we revisited the data and the code summaries with a focus on this theme to consider patterns or changes that occurred over the three rounds of data. An example is the issue of stigma raised across participant narratives. There were no questions in the interview guide that asked explicitly about stigma, however, the inductive approach to codebook development allowed for us to recognize stigma as a common issue in the transcripts and to code it across the three rounds. For the longitudinal analysis, we revisited the data coded in the stigma category (or code) across the three interviews to identify patterns and shifts. In addition to broad patterns among the dataset, we were able to reflect on the individual trajectories of participants by following the codes for specific participants across the coded datasets.

The second approach we used for longitudinal analysis was a structured approach to analyze the data guided by the three components of the International Classification of Functioning, Disability and Health Framework (ICF) - impairment, participation and activity (22). Using this rehabilitation framework allowed us to analyze the experiences of disability over time by participant. For this analysis, Excel was used to organize and manage the data. Within one Excel file, individual sheets were created for each participant based on a template that had three columns (one for each round of data) and rows that were organized by the three components of the ICF (22). Full transcripts were reviewed for each participant across the rounds and relevant content was identified and copied into the worksheet. Short

forms were also used to denote changes over time (N = new issue, S = issue remained the same between rounds, C = issue had resolved, B = issue remained but was better than before). While this table was very useful for longitudinal analysis to understand experiences of disability over time, it could also be used for cross sectional analysis within each round. An example from one participant is presented in Table 2.

Discussion

Qualitative longitudinal research aims to understand processes and changes that occur over time [4,5] and complements results achieved through cross-sectional analysis [7]. Our varied approaches to the longitudinal analyses were influenced by our research questions and purpose. The Canadian study was specifically focused on understanding the episodic nature of the disability experienced by people living with HIV, triggers of disability and uncertainty. Thus, there was a focus on the individual's experiences. Though similar, the Zambian study analysis generated broader thematic findings after each round of interviews through coding across participants to identify issues that would benefit from a longitudinal perspective. The broad perspective was important in the context of constrained resources and high HIV prevalence and to reach findings that had policy implications. Others have noted that the analytic approach will depend on whether the emphasis is on understanding the individual experience or on a broad thematic approach to build cross-cutting themes [12]. In this paper we highlight how the data were summarized in different ways to best support the aim of the study.

One advantage of longitudinal qualitative research, that is particularly salient to disability research, is the ability to highlight how participants' experiences are influenced by environmental or contextual factors over time [15]. For example, in an analysis of the older women in the Canadian study, we identified how weather was an important influence on mobility and social participation [27]. In the

Zambian study, which was conducted in a resource constrained setting, it was important to collect information during each round of data collection on contextual factors that may influence experiences of disability, for example, information on financial stability and vulnerability; relationship status and strain; number of individuals living in the household; and access to supports (e.g., medical support; psychological support; material support including clothing, food, money; and, practical support).

We provide three key recommendations for those interested in pursuing longitudinal qualitative research based on team consensus following review of the analytic processes from both studies.

First, we recommend that development of the coding framework include both inductive and deductive approaches. The Canadian study used a more structured deductive approach in which specific health challenges related to the dimensions of the episodic disability framework (impairments, day to day activities and challenges to social inclusion) were systematically tracked and changes coded. In the Zambian study, there was a more inductive approach which identified broad themes that changed over time. Once these themes were identified, the data were revisited and an in-depth analysis undertaken to identify patterns in changes that occurred over time. There are risks to both approaches: a structured approach can serve to focus on details rather than the whole person whereas, with the large amount of data, an open inductive approach can make it challenging to focus on key findings. Including research team members with diverse expertise can help ensure the balance between ensuring that the team is open to new ideas and knowing when to make decisions to focus on specific codes and theme development.

Second, it is important to develop strategies to deal with the analysis of a large amount of data. A key challenge is the time-intensiveness of qualitative longitudinal research due to the necessity to track

individuals over time and the volume of data to be analyzed [5,6,9]. We agree with Murray [12], who noted the importance of effective planning from the outset to avoid data overload. Dividing the analysis among team members was key to the success of both projects. Strategies to ensure consistency in understanding and assigning codes are key to ensuring trustworthiness. In both studies, we had two investigators complete each analysis and summary document with any major discrepancies between them discussed and resolved. With concurrent cross-sectional and longitudinal analyses over multiple data points, the use of summary documents and data collections forms help to track and monitor data and was an important strategy for data management. These allowed us to track how dimensions of disability changed, improved or worsened over time. The participants had complex lives and lived with multiple morbidities, with the analyses often tracking over 20 areas of disability. These forms were also necessary to complete the longitudinal summary profile of each participant at the end of the process. One cautionary note: the use of a data collection form may focus attention on previously identified areas, thus investigators need to be open to new challenges that arise over time.

In the Canadian study, the in-depth summary profile developed for each participant at the initial interview allowed us to synthesize a large amount of data into a profile that was an important reference point for subsequent interviews when trying to track change over time. Both approaches used multiple investigators to share the burden of analyzing a vast amount of data. The tracking and organization of the process becomes increasingly more complex with the addition of team members and a skilled study coordinator is required. The size of the team depends on the goals of the study. As the Zambian study included a greater focus on capacity building with students, junior partners and non-academics, there were up to 18 team members involved in the collaborative data analysis process.

Third, we were mindful of the challenges of retention of participants over many months from the outset of the study. The use of a consistent interviewer over the duration of the study allowed for the building of a trusting relationship over time (one person conducted all the interviews in Canada, while in Zambia one person conducted approximately 95% of the interviews). This promotes discussion of sensitive issues that may not have been revealed in a single interview [12]. We attribute this, and the skill of the interviewers, to our excellent retention rates of 100% in the Canadian study and 89% in the Zambian study. Having a consistent interviewer also meant there was one person who was familiar with all the participants' stories. This allowed the interviewer to compare and contrast experiences over time, which was particularly important when documenting contextual cues such as mood and affect which would not be apparent on the written transcripts. While this is important in any study using interviews to collect data, we feel this is particularly important when examining change over time as it contributes to the trustworthiness of the data.

Qualitative longitudinal research, by its design, has strengths that can enhance the credibility of results. The prolonged engagement with participants over multiple interviews allows trust to develop and richer data to be obtained resulting in the emergence of "thick" description (28, Morse). Given the prolific nature of the data generated through multiple interviews often the research teams are large. While large research teams come with their own challenges, use of diverse team members allows for investigator triangulation (29, Krefting,). Larger teams also necessitate the development of a clear coding system and code definitions to ensure that coders had the same understanding of codes; this is another important strategy to enhance analytic rigor (28, Morse).

In addition to the challenges described above, we would add that the unfamiliarity of health funding agencies with longitudinal qualitative methods meant it was necessary to provide detailed rationale and description of the analytic processes to convince funders of the meritorious contributions of longitudinal qualitative research to understanding a chronic and episodic illness.

Conclusion

Longitudinal qualitative research has much to offer researchers in disability and rehabilitation and can be particularly useful in understanding the dynamic nature of chronic and episodic disability. The flexibility in analytic approaches is one of the strengths of qualitative longitudinal research, allowing for diverse possibilities and strategies to best address the research questions. We share our analytic approaches and lessons learned to advance the dialogue and promote longitudinal qualitative research to better understand our patients' and clients' perspectives.

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Declaration of Interest

The authors report no conflicts of interest.

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