

Exploring life history methodology in chronic illness: a study in Relapsing Remitting Multiple Sclerosis

AUTHORS

Therese Burke

RN, MSCN
PhD Candidate, School of Nursing, The University of Notre Dame, 160 Oxford Street, Darlinghurst, NSW, Australia
therese.burke2@my.nd.edu.au

Joanna Patching

RN, BA(Psych), MLitt (Psych) PhD
Associate Professor, School of Nursing, The University of Notre Dame, 160 Oxford Street, Darlinghurst, NSW, Australia
Joanna.patching@nd.edu.au

Both authors made a substantial contribution to the manuscript. Therese Burke designed the study, performed the interviews, developed the thematic data analysis and composed the initial manuscript. Joanna Patching supervised the study data collection and assisted with thematic data analysis, manuscript design and review.

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KEY WORDS

Relapsing Remitting Multiple Sclerosis, chronic illness, lived experience, life history, ethnography

ABSTRACT

Objective

The aim of this study was to gain insights into the lived experience of a chronic disease, Relapsing Remitting Multiple Sclerosis (RRMS). Selecting the most effective methodology to reflect the life span proved challenging. However, the life history approach proved to be a data-rich methodology for this study and is explored in detail in this paper as a qualitative nursing tool.

Setting

This study recruited participants through a state based Multiple Sclerosis organisation in the community.

Subjects

Thirteen participants living with RRMS were purposively recruited, ten female and three male, to discuss their lived experience. Participants were from diverse backgrounds and were at various stages of disease progression.

Primary argument

Ethnography and life history is an under-utilised methodology in nursing research. However, the life history approach was used effectively to collect data to explore the life trajectory of living with a chronic illness. Semi-structured interviews and Braun and Clarke's (2006) method of thematic data analysis ensured a systematic, robust exploration of the lived experience of RRMS. The study developed eight key themes and over 70 subthemes, providing clarity into the experience of living with RRMS.

Conclusion

Employing the life history approach to living with RRMS reflected the ebbs and flows of life, themes intertwining and changing positions of importance according to life events, whether directly or indirectly related to RRMS. Life history proved to be an effective method to gain a greater understanding of chronic illness and although often overlooked in nursing research, may represent an excellent methodology choice for nurse researchers working in other areas of chronic illness.

INTRODUCTION

Multiple Sclerosis (MS) is a progressive inflammatory disease of the central nervous system (CNS) with the most common form of MS at diagnosis being RRMS, affecting 85% of people living globally with the disease (Compston and Coles 2008). Recent data from Multiple Sclerosis Research Australia (MSRA) suggests that there may be 25,600 people living in Australia with MS (MSRA 2018). RRMS is characterised by unpredictable relapses (exacerbations or attacks), which usually last several weeks before the individual returns to baseline functioning (Lublin et al 2014). There is currently no curative treatment for RRMS, although recently there have been major advances in more efficacious treatments called disease modifying therapies (DMTs) to control relapses and possibly prevent future disability (Stuve and Racke 2016). Aside from a highly variable disease state and multitude of possible neurological symptoms, MS can also cause numerous secondary and tertiary effects. Issues may develop in highly personal areas of intimacy and sexuality, mental health, relationships and employment.

Although there exists an abundance of literature examining many different aspects of MS and MS symptoms, there is a paucity of literature exploring the whole life experience of living with MS, and more specifically, RRMS. The aim of this study was to gain insights and understanding into the lived experience of RRMS, so that nurses may have a deeper understanding of the patient experience and be able to plan and adjust their nursing care accordingly. To address these specific aims, the study sought to answer the research question ***“What is the experience of living with Relapsing Remitting Multiple Sclerosis?”***

Exploring the literature for a suitable method for data collection and later data analysis that would span as much of the life trajectory as possible proved challenging. Using a qualitative approach to understand the experience of living with RRMS would ensure the participant remained at the centre of the research process, and their lived experience the focus of the research. However, beyond that, there were very few studies (especially in recent times), which replicated methods in data collection and analysis in the speciality of MS. The aim of this paper is to explore life history as an interesting and effective methodology for qualitative nursing research in chronic illness. Full study results from the research have been published elsewhere (Burke 2019).

The study most alike the current study in terms of participant numbers and focus (Miller 1997) was published prior to any disease modifying therapies being available and reflected a completely different prognosis than in modern times. Miller's (1997) study asked 10 participants living with RRMS “What is it like for you living with RRMS?”. Hermeneutic phenomenology was used to analyse the transcripts and 12 themes were developed to describe the experiences of living with RRMS including the importance of social networks, coping with RRMS, control, uncertainty and conflict. Miller's (1997) study however, only concentrated on the present time of living with their illness, not the entire life trajectory, posing questions as to whether previous life events influenced this chronic illness and vice versa.

Other studies have used various methodologies in phenomenology to explore single cases of women living with RRMS (Fawcett and Lucas 2006; Finlay 2003), or most recently a study exploring the life world of six young women living with RRMS (Beshears 2010). However, the focus of the research was centred on the present time, and no male participants were included in the studies. There was only one narrative found in the literature review for the current study which explored living with MS using a life history approach (de Chesnay et al 2008). This short narrative presented an abbreviated story to teach others about overcoming obstacles in chronic illness (de Chesnay et al 2008).

DISCUSSION

Choosing a research methodology for the current study

The research question in the current study required a methodology that would gain deep, rich insights and understanding of the experience of living with RRMS. In seeking to understand and interpret meaning within context, the study also sought to be inductive (develop findings directly from the study data) and to seek both patterns and differences in data. The individual voices were important to hear, as well as the group voice of the entire data set. Finding individual meaning and understanding in stories from patients is fundamental to the caring and compassionate culture of nursing, and something nurses strive for in daily practice (Munhall 2012). Additionally, nurses are often attracted to qualitative research as they value the richness of deep understanding and the perspective of the individual living with chronic illness. Finding a data collection method which considered the people living with RRMS as the experts (Windle 2011) was also important to consider as a component of the ontology and epistemology beliefs underpinning the current study.

Ethnography methodology

Ethnography is a research methodology which involves the process of learning about people by learning from them (Roper and Shapira 2000) and has its historical roots embedded in social and cultural anthropology (Holloway and Todres 2003). The goals of ethnography are to describe, interpret and understand characteristics of a particular social setting, taking into consideration the diversity and multiplicity of voices from key informants, the experts who have rich knowledge of the subject under research (Holloway and Todres 2003). Essentially key informants who represent the culture under study discuss their lives, so that others can better understand the culture (de Chesnay 2014). Ethnography has a place in health research, particularly with its focus on the emic, or the patient perspective (Morse 2012), being holistic, contextual and reflexive (Boyle 1994).

Ethnography takes on many forms and has been adapted for use in different settings, depending on the goals of the research. Early ethnographers spent long amounts of time in the field, known as 'fieldwork', getting to know the study participant/s and encouraging them to share their life stories, often forming personal relationships in the process (de Chesnay 2014). Often in recent times, economic and time constraints are considered to inhibit such long encounters between researchers and study participant/s, especially in the field of nursing. In keeping with the important aspects of traditional ethnography (insights, understanding and culture), focused ethnography developed, wherein researchers attempt to learn about certain conditions by asking about the experiences of those living with the condition (de Chesnay 2014; Cruz and Higginbottom 2013).

Life history as a form of focused ethnography

The life history is a "retrospective account by the individual of his or her life in whole or part, in written or oral form, that has been elicited or prompted by another person" (Watson and Watson-Franke 1985, pp.2). This involves a person choosing to tell about the life he or she has lived, told as completely and honestly as possible (Atkinson 1998). The terms life history and life story are sometimes used interchangeably (Plummer 2001), but there is a subtle difference. Life history is defined as the life account told by a person to the researcher (de Chesnay 2014) whilst life story is the narrative analysis created of the person's life from the life history told to the study researcher (Atkinson 1998). Focused ethnography, in particular life history, has recently become more popular in health research generally, as it is an effective method to gain information from a culture that may not necessarily have direct contact with one another (Morse 2012), as is often the case with people living with a chronic illness.

Life history in nursing

Life history in general is an underused methodology in nursing, but is perfectly suited to the profession, as nurses have always valued the stories and insights patients are able to provide to improve understanding of their world (de Chesnay 2014). Hagemaster (1992) advocated the use of life history in nursing research, and although still developing, more nurse researchers have used life history over the last two decades to investigate social, psychological and illness inspired phenomenon. Nursing studies using focused ethnography have been used to explore illness in homeless youth (Ensign and Bell 2004), investigate health in immigrant adolescents (Garcia and Saewyc 2007), explore recovery from eating disorders (Patching and Lawler 2009), report the experiences of community mental health nurses (Spiers and Wood 2010) and to examine the experiences of a rare chronic health condition, lymphangiomyomatosis (Haylen 2015; Haylen and Fisher 2014).

Given its ability to provide a comprehensive holistic examination of the subjective life experience, the life history approach was chosen as the most appropriate design for the current study, for the purpose of identifying important themes experienced by individual people living with RRMS, which may also be experienced by their peers in similar situations (Field and Morse 1985). A great advantage of life history is that it retains the whole individual story and locates it in a wider social, cultural and historical moment (Plummer 2001). Life history examines events and how they impact individuals and their life trajectory, revealing turning points, epiphanies and transformations that may occur over the course of the life living with disease (Haylen and Fisher 2014). It also provides a way of understanding the meaning of illness and how this meaning might change over time.

Using life history in researching chronic illness reflects the complexity of the human experience it is examining (de Chesnay 2014), presenting an ideal methodology to gain insights and understanding. Being less time consuming than traditional ethnography, focused ethnography in the form of life history, is more practical for most nurse researchers. However, there are challenges inherent in using this methodology, including deeply personal narratives which may affect the researcher/s emotionally, and the fact that the interviews and follow-up can be time consuming and prolonged.

Conceptualising life history in the current study

As suggested by de Chesnay and Fisher (2014), the purpose of the life history is to collect a focused history around a disease to document the story of each participant, but being careful not to frame this within a broader ethnography of all people living with a disease. The life history approach in the current study reflected the cultural and social contexts of each participant, allowing them to approach their life history in any way they chose, not necessarily in chronological order or centred only on their RRMS diagnosis. Interestingly, many participants talked of other events in their lives being just as pivotal or more so, than their RRMS illness diagnosis. Others revealed life events and happenings which later played a significant part in coping with their chronic illness.

In life history, the researcher and the participant come together as collaborators, composing and constructing a story (Atkinson, 1998). This was consistent with the ontology and epistemology of the current study with a strong focus on the emic (patient) perspective. Fostering a good relationship between the researcher and study participant is important in life history research, as it involves establishing a close relationship between the two (Plummer 2001). Developing a trusting environment and good rapport early in the process is essential to a successful study outcome.

Life history and study methods

Study participants were purposively recruited through a local, state based MS organisation using a flyer to contact the researcher if people living with RRMS were interested in participating in the study. Fourteen people expressed interest and requested further information, thirteen people were subsequently enrolled into the study and interviewed, and one person declined further involvement without giving a reason. Study recruitment followed the natural preponderance of RRMS, with ten females and three males agreeing to be interviewed. Participants were asked to choose a pseudonym for the study process to protect their identity and any potentially identifiable information (about significant others and health care professionals) was removed from the study transcripts. Approval for the research was obtained from the University of Notre Dame Human Research Ethics Committee (reference number O16002) with particular attention to participant confidentiality and managing potential distress to participants recalling past life events.

Semi-structured interviews have the purpose of obtaining descriptions of the life world of the participant with respect to interpreting the meaning of the described phenomena (Kvale and Brinkmann 2007), making it especially suited to life history research. Semi-structured interviews have some pre-defined questions built-in to the interview, however the researcher is also permitted to probe further and ask additional questions as the participant responds, often leading to the collection of powerful data in the form of insights, experiences and perceptions (Peters and Halcomb 2015). Semi-structured interviews were the chosen data collection method for the life history approach, performed in person and individually, with just the researcher and study participant present.

Interviews were performed at a location of the participant's choosing, and mostly occurred in the home of the participant and less commonly in a public location such as a park or café. At the commencement of the interview, participants were provided with a verbal overview of the study, outlining the study aims. Each participant was then invited to tell their life history, in any order they wished, and covering anything they wished to, with particular thought to the question "What is the experience of living with RRMS?". This consistent approach ensured the information gathered was rich and participant centred. Although predominately unstructured in nature, the interviews were categorized as semi-structured for two reasons. Firstly, reflection questions were provided to study participants a week prior to the interview to give some direction to the information that was sought. Secondly, the RRMS component of the research question gave particular direction about the topic to be explored as part of the interview.

Reflexivity in the study as a component of ethnography

Reflexivity fits into the wider perspective of ontology and epistemology (Berger 2015) examining the role of the researcher in the generation and construction of knowledge and assisting the researcher to act without bias (Holloway and Galvin 2016). Unlike quantitative research where an objective stance is necessary, in qualitative research the active role of the researcher is valued and appreciated as an important research tool (Braun and Clarke 2013). However, it is important that the researcher makes visible personal reflexivity as a form of quality control within the research (Braun and Clarke 2013), where the aim is for "empathic neutrality" (Ormston et al 2014).

The majority of study participants had been cared for by an MS Nurse as part of their life journey with RRMS, with the MS Nurse valued by participants for their skills, knowledge and support. Belonging to the 'MS Nurse club' most likely held some definite benefits for the principal researcher in terms of rapport and trust, gaining instant entry into their life-world. Participants felt comfortable to discuss any issue they wished disclosing insights into sensitive issues, such as parenting, sexuality, relationships, hopelessness, mental health, compromised care and fear. This enabled new understanding into living with RRMS and exposure of concepts

that have been reported infrequently, or have not been reported at all in the specialty. Additionally, having an understanding of the symptoms of MS (particularly participant fatigue) helped to manage the interviews by organising breaks and rest when necessary.

At times, the life history interviews contained highly emotive content and there was difficulty for the principal researcher to disengage from the data, with vulnerable feelings surfacing as interview transcripts were re-listened to and re-read many times as the thematic analysis progressed. Several of the interviews were emotionally intense, some participants had suffered neglected childhoods or had been subjected to tragedy, and others suffered mistreatment by health professionals. Constantly re-living these discussions to develop codes and themes often invoked sad and heart-rending emotions for the researchers. However, an earlier article by Tanner (2009) exploring experiences listening to sad situations during qualitative doctoral work proved very helpful in facilitating an effective mental health plan for the study researchers during this process.

Life history and the study findings

As a chronic illness, the life journey of RRMS takes many twists and turns; it is never a linear journey, but rather one of continual flux, which is mainly due to the innate unpredictability and uncertainty that comes with the diagnosis of RRMS. This is also the case for many other forms of chronic illness. The great advantage of using the life history approach is that it reflects the entire life journey; with and without disease. Using this process uncovered many aspects of each participant's life, which may have had an impact on their later journey with RRMS. In particular, many participants described events in childhood, which gave rise to their later development of resilience, such as childhood neglect, other illness and migration from non-English speaking countries. This resilience was then helpful to the study participants in later life, drawing on coping skills to help them through the difficult and challenging times of RRMS. The process of telling the life history to the researcher also helped participants to understand themselves in a different way, with many participants openly recognising their achievements in overcoming difficulty and challenge.

Study themes were developed from the data, with eight key themes telling the story of living with RRMS as a chronic illness over the life span. Commencing with "Piecing Together the Puzzle" of symptoms at the beginning of the RRMS journey in the years prior to and during diagnosis, followed by "(Re)defining ME now that I have RRMS" and coping with the diagnosis, "Battling the Demons" that followed diagnosis, relapses and symptoms, for some the experiences of "Surplus Suffering" from others, and negotiating "High (In) visibility" of the symptoms. Eventually study participants were able to gain control by "Taming the Beast", learning "The DMT Dance" managing their medications and side effects, and ultimately "Holding Hands with Hope", expressing hope and practising purposeful positivity. Although presented theme by theme in a logical succession, the study findings did not always follow in sequence and definitely did not always "end up" with hope and positivity. Instead, the eight key themes intermingled with each other to reflect the ebb and flow of life. They tell the story of possible stops along the life journey of RRMS and the constant moving backwards and forwards when negotiating and managing living with a chronic illness. Nurses involved in all areas of nursing care from community, surgical care, other medical specialities, emergency, midwifery and mental health may encounter patients living with MS and benefit from insights into understanding the journey of patients to plan care which is patient centred, individualised and holistic. Specific clinical recommendations have been published elsewhere to comprehensively address specific areas of care (Burke 2019). The nurse can also experience greater job satisfaction and fulfilment with a deeper understanding and insight into illness.

As noted life history author Plummer (2001, pp.7) reflects, "life is in fluctual praxis, always in flow and ever messy." Using ethnographic methodology, and the life history method in particular, to uncover the study themes worked skilfully with the "messy" life trajectory of RRMS, a chronic but unpredictable disease. Additionally,

the inclusion of subthemes in the data analysis gave the added ability to “drill down” even further into each theme, identifying more specific features of a theme under the same central organising concept, but with subtle differences. This helped to give the study findings more structure and subsequently guided the development of recommendations for clinical practice (Burke 2019).

CONCLUSION

Using life history methodology to explore the lived experience of a chronic illness gave this study much more emotion and insight than would have been achieved by simply asking pre-determined interview questions in a structured format, or by presenting participants with a survey or questionnaire of topics that the researchers felt were important. Instead, life histories flowed naturally for the study participants, forming stories and presenting an abundance and wide range of themes.

Life history gives voice to the ordinary members of a culture as they cope on a daily basis with the joys and challenges of life (de Chesnay and Fisher 2014), and was embraced by thirteen participants living with RRMS in the current study. The use of this focused ethnographic methodology worked cleverly with the ebbs and flows of living with a chronic illness, to reveal many themes and subthemes exploring the lived experience of RRMS. As RRMS is most commonly diagnosed in young adults, it represents a long period of time to live with a chronic illness. Using the life history approach generated rich and detailed data about the experiences of living with RRMS and unearthed some extraordinary insights, which subsequently led to the development of clinical recommendations for nursing practice. This under-used ethnographic methodology could be very useful to consider in other nursing studies researching chronic illness in the future.

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