

Title

Applying an analytical process to longitudinal narrative interviews with couples living and dying with Lewy body dementia.

Abstract

Narrative research methods invite people to share their experiences via storytelling. There is increasing interest as to how qualitative narrative inquiry can provide greater understanding into the lived experience around health and illness, particularly within the field of dementia. Narrative research is concerned with how humans make sense of and engage with the changes and disruptions of everyday life. However, narrative research is an emerging and evolving field with no single clearly defined approach to data analysis. In this article we provide a methodological exemplar by applying Murray's four levels of narrative analysis to longitudinal narrative interviews completed with couples living with Lewy body dementia. We describe how to analyse connections between the four levels and how to articulate this across different interview time points. This analysis process contributes to methodological knowledge by providing a strategy to connect the personal, interpersonal, positional, and societal levels of analysis. The time taken for in-depth analysis of a co-created, dyadic longitudinal narrative approach requires careful consideration, but ultimately it can provide a richer understanding of the lived experience, allowing for deeper social, clinical, and academic insight.

Keywords: Qualitative analysis, dyadic, longitudinal, personal narratives, narrative psychology, Lewy body dementia.

Introduction

Narrative research methods invite people to share their experiences via storytelling. This may occur through oral, written, or visual accounts (Andrews et al., 2013). There is increasing interest as to how qualitative narrative inquiry can provide greater understanding into people's experiences of health and illness (Wang & Geale, 2015), although this method is less explored within the field of dementia. However, narrative research is an emerging and evolving field with no single, clearly defined approach to data analysis (Meraz et al., 2019). The approach taken is said to depend on researcher perspective, other literature in the field, and the underlying theory used to guide the choice of research topic and questions (Woolf & Silver, 2017). These conceptual perspectives and traditions form the framework for the analysis process and provide the foundation to assess the validity of narrative research (Riessman, 2008). This research is set within an interpretivist, phenomenological experience-centred approach. The aim of this article is to provide an analytical example by applying Murray's (2000) levels of narrative analysis in health psychology to longitudinal narrative data gathered with couples living with Lewy body dementia. Lewy body dementia is a common neurodegenerative dementia which can give rise to an array of physical and cognitive symptoms such as fluctuation attention, visual hallucinations, falls and motor features of Parkinsonism. These complex symptoms can result in particular psychosocial challenges specific to people living with Lewy body dementia and their families (Killen et al., 2021).

Murray's (2000) four analytical levels include the personal, interpersonal, positional and societal (Murray, 2000). We explore how this application can reveal a richer understanding of the lived experience and gain deeper insight into these complex issues. Finally, we discuss how this process addresses the two aspects of validity considered to be important within narrative research: 'The story told by the research participant,' and 'the story told by the researcher' (Riessman, 2008, p. 184).

Living and dying with Lewy body dementia: Demonstrating narrative analysis

To demonstrate the analysis process data are drawn from a PhD project exploring day to day experiences of couples living with Lewy body dementia. Experience-centred approaches acknowledge personal narratives may be fluid, incorporating past, present or future stories, both real and imagined (Squire et al., 2014). Using a longitudinal narrative approach couples were interviewed three times over a six-month period. The qualitative data collection stage consisted of in-depth, open-ended interviewing which was conversational in nature. The stories of one couple are chosen to illustrate the analytical process rather than the overall study results. The study received ethical approval (Social Care Research Ethics Committee: London REC 18/IEC08/0035 30.11.2018) and names and places have been changed to preserve anonymity. Interviews were audio-recorded and transcribed verbatim for analysis. ATLAS.ti 8 qualitative data analysis software was used to organise and structure the longitudinal narrative data collected (Woolf & Silver, 2017).

To ensure methodological rigour and trustworthiness of the study longitudinal interviews with the same participants (triangulation of data sources) were collected (Caldwell, 2014). Repeated listening to the audio recordings and re-reading of transcripts allowed for familiarisation of both structure and content of the narrative accounts (Davidsen, 2013). The study data were initially organised into an overarching descriptive narrative for each couple. This helps to get a sense of the whole before going into more detail of the main chapters and stories. This was followed by the application of Murray's (2000) four levels of narrative analysis, which seeks to illuminate the complexity of health and illness narratives by articulating the personal, interpersonal, positional, and societal levels at work in stories. (Table 1: Murray's four levels and related analytical questions). The final stage involved applying the research questions and connecting the levels to provide more in-depth understanding of the experience of Living with Lewy body dementia.

Table 1: Murray's four levels and related analytical questions.

Level	Health & illness narratives	Narratives portrayed as:	Analytical considerations/questions
1	Personal	Expressions of the lived experience of the narrator.	<p>What stories are being told? Which particular events are noted? Who are the main characters and sub-characters in the story? Where/what is the setting (physical or psychosocial) for the story? Are there divergent perspectives in dyads experience of same story? Which stories reoccur and change over time? What is the under-lying narrative thread of the stories?</p>
2	Interpersonal	A dialogue which is 'co-created' and structured between participants and interviewer.	<p>In what context does the interview take place? How does couple interactions/relationships influence the storytelling? How is it determined which stories fade, or dominate and get told? Is there an indication that the stories are told with an intention to be read or heard? How do the participants articulate which are important stories? Are there messages to be conveyed?</p>
3	Positional	The differences in social position between the narrators and researcher/listener.	<p>Within the interview interaction what roles and social characteristics are known or emerge? How may the characteristics (gender, age, health status, background, role etc) of the researcher affect the storyline? How do the interviewers questions, responses and behaviour influence the story?</p>

4	Societal/ideological level	Shared stories that are shaped by the social context and ideological assumptions within which we live.	How does the social, cultural, and historic context influence the stories? What broader societal (or community based) assumptions, (thoughts, practices, language) are evident?
	Connecting the levels	An integration of the 4 different levels of narrative analysis	What is the narrative thread evident at each level? Is there a connecting underlying narrative woven through each level? What new evidence does it offer?

(Adapted from Murray, 2000; Murray & Sools, 2015)

Developing an overarching descriptive narrative

An overarching narrative in the form of a short descriptive profile was completed. This enables familiarity with the key characters, features and content of the longitudinal interviews, (Murray & Sools, 2015). A single coherent narrative also helps ‘to preserve the flow of the story as a whole,’ and is considered important when the raw data may be disjointed (Bazeley, 2013, p.115). At the time of the interviews Joan was 73 and living with Lewy body dementia at home with her husband Peter. They had been married for over 45 years and the final interview was carried out nine months before Joan died (Box 1: Short descriptive profile).

BOX 1: Short descriptive profile

Joan, a retired teacher first noticed changes to her mobility about five years previously and was given a diagnosis of Parkinson's which she found 'depressing'. Following a significant car crash and a long hospital stay she found herself 'much more dependent on other people', especially Peter. Joan had some problems with her memory, and 'started to see children and other people in the garden' which she said were 'unsettling'. She was diagnosed with Lewy body dementia. 'Well dementia with Lewy Body has been mentioned, Parkinson's with dementia, I don't think anyone's absolutely certain.' Before the second interview at their home Joan had a fall. This resulted in another hospital admission with a fractured hip and recurrent pneumonia where 'things went from bad to worse'. Joan's condition deteriorated, and she was discharged home for end of life care with carers four times a day under NHS Continuing Healthcare funding. This resulted in a lot of medical equipment in the house and frequent visits from community staff. Peter found it difficult to adjust his role as husband and carer and what palliative and end of life care meant for them. For the final visit, Joan's physical and mental condition had improved slightly and she was able to re-call some of her hospital admission and talk about the changes and frustrations for her.

Level 1: Identifying PERSONAL stories

The personal level of analysis narratives closely relates to the phenomenological approach within narrative psychology, where stories are considered to have therapeutic functions, providing shape and order to peoples experiences (Davidsen, 2013). Most commonly this occurs in the reassessment of identity (Frank, 2013), and making sense of the chaos caused by the disruption of illness (Bury, 1982). Within Murray's (2000) approach, stories told by the research participants at the personal level were analysed intact, rather than breaking down into themes. The aim was to ensure the stories remain authentic and 'visible' to aide transparency of the analytical process (Riessman, 2008). Dyadic interviewing allowed for prompting, corroboration, and modification of the narrative interactions. Conducting three interviews with the same participants over time also allows for clarification of stories and personal interpretation (Caldwell, 2014). Collecting dyadic longitudinal data can support the trustworthiness of the analysis process, and subsequent findings (Bjørnholt & Farstad, 2014). The setting, plot, characters, and main event of each storyline were identified and a title was applied to capture the main focus of the story. (Murray & Sools, 2015). Within each story a narrative thread was then identified as 'a means of viewing experiences' (Puplampu et al., 2020, p. 881). Grosseohme & Lipstein's (2016) trajectory approach was applied (Grosseohme & Lipstein, 2016). This was to observe if experiences changed over the three interviews, by applying a time ordered sequential matrix (Table 2: Example personal stories: longitudinal analysis matrix).

Table 2: Example personal stories: longitudinal analysis matrix

Story title	Interview 1	Interview 2	Interview 3
	Narrative thread	Narrative thread	Narrative thread
Healthcare interactions	Advocacy	Frustration	Restrictive, rigid system
Relationship changes	Marital disconnection	Loneliness	Adjusting to being apart
Becoming a carer	Learning through experience	Guilt	Adapting & accepting

(Adapted from Grossoehme & Lipstein, 2016)

The dominant stories for Peter involve his changing relationship from husband to carer, and interactions with healthcare professionals. Peter talks about his relationship in terms of being ‘divorced’ and missing their shared interactions:

PETER: *“it’s again adjusting to our relationship because I said to some people when they’d asked me, it feels like we’ve in a way been divorced, but not, but still living together, because it’s a different feeling between us isn’t it, which is not your fault at all..... I miss what we had, a lot [laughter]. I don’t think it necessarily has quite the same impact in Joan.”* (Story – Relationship changes: Interview 1).

And the sense of frustration this causes:

PETER: *I suppose the other frustrations are um there’s nothing from Joan, it’s not her fault I know that but she’s much more receptive to the carers and things than she is to me....//... I suppose the other things I miss most is just the companionship really, that’s hardest because we’re not sharing anything in the sense of other than me putting a spoon in her mouth, that’s it now really. That’s the only actual interaction we’ve got....*(Story – Relationship changes: Interview 2).

Peter and Joan also talk of frustration with interactions with the community teams and the situation they find themselves in:

PETER: *“part of this healthcare is occupational therapy, and she’s quite adamant that she doesn’t think it will do Joan any good to move out of the bed at this stage. INTERVIEWER: Did she say in what way? PETER: Because they measured Joan’s blood pressure. Now again that was relatively low, although Joan’s had low blood pressure for years but I understand they have a protocol. I find it quite annoying that they’re not prepared to see how it goes rather than say we can’t do it..... Anyway I got angry,... they said we’re not going to be able to move Joan for the foreseeable future, so we’re stuck really. But I said well I’m not prepared to accept that long term....So that’s frustrating,...”* (Story-Healthcare interactions: Interview 2)

Joan expresses this situation as a loss of independence with the use of metaphors with particular reference to the feeling of being a prisoner, of being kept captive in her hospital bed:

JOAN: "I was capable of being able to walk, whereas now I'm mostly being prisoner here. INTERVIEWER: Prisoner here, you mean in bed? JOAN: Mmm. I have all my um meals... JOAN: It's frustrating...Unfortunately she [The occupational therapist] concluded that I wasn't ready to be released." (Story-Healthcare interactions: Interview 3)

Peter and Joan both described her illness within the context of constant change and interruptions 'where the structures of everyday life and the forms of knowledge which underpin them are disrupted' (Bury, 1982, p. 169).

PETER: ".....the thing I miss most is it's difficult to do things together as we would have done before, to get out would be lovely I mean I can but obviously Joan can't but um I think that's what we miss most isn't it, just to go places and do things together." (Story – Relationship changes: Interview 3).

Peter is able to reflect and adjust over the interviews, and by the final interview Peter has adapted his approach to communicating with the community team:

PETER: "I think I told you we had a little bit of a run in the first time [laughter], I got a bit upset, and um shouldn't have done, but this time I kept very calm and I sort of anticipated the outcome anyway, 'cos I thought they're not going to give us the go ahead".

Analysing dyadic interviews at the personal level allows for a deeper understanding of divergent and convergent views on a shared experience (Polak & Green, 2016). However, it is important to observe whose story gets told, and this becomes more apparent when analysing at Murray's (2000) interpersonal level.

Level 2: Exploring co-created stories at the INTERPERSONAL level.

The interpersonal level of analysis is one that is 'co-created in dialogue' and as such is the result of a joint enterprise (Murray, 2000). This level is important in understanding the context, structure and participant roles within which narrative accounts are produced (Wong & Breheny, 2018). It is said that co-created stories can provide a common reflective space that produces rich data, both in terms of expanding and corroboration of a story, and by highlighting differences and disagreements (Bjørnholt & Farstad, 2014).

Peter and Joan were predominantly interviewed together, therefore, the stories are portrayed as shared expressions of their lived experience to acknowledge the “*interdependent relationship between individuals.....as a source of information rather than attempting to control for it*” (Caldwell, 2014, p. 488). Peter is the key narrator, who is keen to tell his story. When analysing which stories fade or dominate it can be seen that Peter influences the direction of the stories:

PETER: Tell [researchers name], you had a visit from an occupational therapist, can you tell her about that? That was last Wednesday wasn't it. Do you remember what she came for? JOAN: Oh she came to see if whether I could sit in a chair, and do various other. PETER: What conclusion did she come to? JOAN: Unfortunately she concluded that I wasn't ready to be released. (Story – Healthcare interactions: Interview 3).

Peter admits that he ‘*sometimes takes over, and that isn't sort of right.*’ This was apparent when Peter interjects:

INTERVIEWER: Can you tell me a bit.... PETER: Sorry, no I was going to say, once the diagnosis had come through, that gave you some access then to a Parkinson's nurse didn't it. JOAN: That's right.” (Story – Healthcare interactions: Interview 1)

Peter says he “find it quite difficult to hear Joan at times’, and Joan does have difficulty in getting her voice heard in the interview setting. By the final interview she does make the point that “*the idea is to have a two way conversation*” when talking to Peter about her respite carer:

INTERVIEWER: Do you find those visits [from the respite carer] helpful? JOAN: Yes, except Katie is so good at talking. PETER: That's an understatement. JOAN: Try to get a word in sometimes. PETER: I can imagine [laughter].JOAN: But the idea is to have....Two way conversation.”

The challenge to “get a word in sometimes” may be due to the physical and cognitive changes associated with Lewy body dementia, differing personalities or Joan being viewed in the role of ‘patient’ or ‘cared for’ person. It highlights the disadvantages of joint interviewing, when the interaction may have the effect of silencing an individual’s account (Polak & Green, 2016). However, the couple’s intimate knowledge of each other may serve as an advantage in expanding conversations:

PETER: Not so easy for you though with youngsters is it. INTERVIEWER: I was going to say how is that when [the grandchildren] come? JOAN: Well I enjoy having them but find I can't, play with them so much because I can't get down and get up, I need some help. PETER: Do you find you miss that? JOAN: Yes.

One of the strengths of analysing Murray's interpersonal level with dyadic interviews is it enables greater understanding of how couple interactions and relationships influence the storytelling and whose story gets told.

Level 3: Understanding social positions at the POSITIONAL level.

Social characteristics and roles are relevant at the positional level of analysis; in particular the role of the researcher, where the issue of power relations is of principal concern in narrative enquiry (Clandinin & Connelly, 2000). Challenges to the integrity of the research can be addressed by considering how perspectives might be influenced by personal, historical, cultural and academic experiences (Creswell & Creswell, 2018). We have backgrounds in community nursing, palliative care, and dementia research. To reduce potential medical influences and improve the credibility and quality of the analytical process people with lived experience of Lewy body dementia were involved in shaping and testing the open-ended questions. Professional socialisation is considered unavoidable (Salisu et al., 2019), so within this analysis the researcher remains 'visible' by retaining the interviewer dialogue within the stories. When analysing how the interviewers questions, responses and behaviour influence the story there is some evidence of the natural orientation toward the clinical interview with the 'probing' questions. For example, when Joan mentions her memory "*can you tell me more about....*" and when they talked about speech and language therapist:

PETER: *"....she was first brought in to look and see whether Joan was having swallowing difficulties. INTERVIEWER: I was going to say do you find that's a bit of a problem, swallowing? PETER: Not too bad is it,"* (Story – Healthcare interactions: Interview 1).

It seems that Peter does not view the researcher in a clinical context, but more of a 'confident' of his frustrations with healthcare professionals *"But um so no we will quietly I'd like this to be treated confidentially [laughed],*

He predominantly uses the research as a vehicle to discuss their relationship and feelings:

PETER: *"it's me trying to adjust to what our life is now like. And starting to and I think I am, realising that we're never going to do as much as we used to do or but I think the things I miss most are those, it's been nice today, you've talked a lot about how you feel, but we really don't do that hardly at all,.....The way our minds work and when they go wrong you can't talk like that and we've really never talked about really have we Joan your condition as such, it's very difficult to say if I start trying to explain what I think is happening, that's not really very kind and um..."*

As a retired professional he gives methodical and articulate accounts in his stories. He takes on particular roles, for example as research participant, questioner, and advocate speaking for Joan. Analysing the positional level at different time points can highlight how the roles for researcher and participants may change and evolve as they become more acquainted. This can show differing perspectives of the same experiences adding to the quality, depth, and richness of the data.

Level 4: the SOCIETAL level.

Societal level of analysis is concerned with the socially shared stories that are characteristic of certain communities or societies (Murray, 2000). Community-based assumptions were considered within cultural, social and linguistic dimensions as this allows for broader understanding of the narrative (Andrews et al., 2013). Peter describes his experience of Joan's hospital admission which is essentially the start of his caring role.

PETER:so many different people turning up, different doctors, you couldn't tell necessarily who would be the best person to talk with. And er I probably I think it's always difficult if you start to challenge the service, I think at that the other patients basically were going to be there and be accepting of what was going on, I wasn't [laughter]. I felt it was important to alert them to what Joan's needs were, I don't think I made myself very popular but er.....If you don't shout, no one listens." (Story – Healthcare interactions: Interview 1).

Peter starts to learn the language of medicine and says he has been 'looking things up', and is particularly concerned about the effects and interactions of the medications Joan is on – "my biggest worry is the interaction of medication which all seem to pinpoint the same part of the synaptic join if you like....." Words such as 'medicines' and 'brain' are frequently drawn on to frame and discuss dementia in the media, and can influence shared beliefs and influences surrounding health and illness (Bailey et al., 2019). Peter's advocacy and caring roles develop over the three interviews. As Joan's condition deteriorates the couple's role of husband and wife move as Joan becomes a 'patient' and Peter a 'carer' and advocate for Joan. By the final interview, his caring skills involve becoming part of the 'medical' team he initially challenged.

PETER: we've had a doctor or a paramedic come and then an ambulance once or twice but then after consideration it's been felt more appropriate to try and help Joan here.... they're quite keen not to take us to A&E which I'm quite happy about - and they've often said that with the consultation of the doctor and then me we'll give you antibiotics here and that's worked. And in fact one of the paramedics that came after my call to the surgery, told me that his actual job was to try and keep as many of 65 year olds and above out of hospital,..." (Story – Healthcare interactions: Interview 3).

The final stage of analysis involves connecting and articulating Peter and Joan's stories across the four levels (Murray, 2000). Evaluating how these levels work together can allow for a deeper understanding of human experience and enhance 'coherence' of the data, (Riessman, 2008). It can lead to a greater depth of analysis and contribute to the wider social narrative (Wong & Breheny, 2018).

CONNECTING the levels of analysis

Finding the connections between these different levels is complex, however by doing so it becomes possible to challenge the dominant narrative and 'develop a new story that enhances alternative knowledge' (Murray, 2000). It is at this stage the data is analysed 'through a researcher's lens with the purpose of understanding the experiences, aided by research and theoretical literature' (Loh, 2015, p. 6). All authors were involved in data analysis as a means of corroboration, and of establishing trustworthiness of the interpretation process. (Loh, 2015).

To connect Murray's 4 levels, this stage of analysis involved applying the following research questions to the data:

- What are the everyday life experiences of people with Lewy body Dementia?
- How do family/ informal carers describe the experience of living with someone who has Lewy body dementia?
- Are there similarities in content (what story is told), experience, and meaning between person living with Lewy body dementia, and the family carer?

Joan and Peter find many aspects of living with Lewy body dementia frustrating. Underpinning the frustrations, the main connecting narrative was identified as 'communication'. The importance of clinician-family communication (Armstrong et al., 2019) and communication between couples (Vatter et al., 2018) has been previously noted for people living with Lewy body dementia. However, applying Murrays levels allowed for deeper insight into the complex issues around communication from theoretical, academic, and clinical perspectives. Intercultural communication theory places importance of the processing of identity (personal, relational, enacted and community) through interactions (Gudykunst, 2005). Communication is key to this process, therefore by applying Murrays levels of narrative analysis communication 'gaps' for Peter and Joan were more readily identified.

Personal level stories highlighted the relationship between communication style, competence, and message strategies, which is important clinically. This was evident when Peter is communicating with the therapy team:

PETER: *"Anyway I got angry, then they started treating me like an infant, why do all these people speak so loudly, this is my question, I didn't say that to them, and then*

they speak to you as if 'are you alright, do you need to sit down'].....(Story - interactions with healthcare: Interview 2).

Communication gaps may also be observed within the couple's relationship:

PETER: *"I suppose the other frustrations are um there's nothing from Joan, it's not her fault I know that but she's much more receptive to the carers and things than she is to me...."*

And in relation to physical features of Lewy body dementia, whereby the voice gets quieter as the condition progresses. This makes communication between Peter and Joan more difficult. Peter says *" I find it quite difficult to hear Joan at times, But Joan was never a loud person....you've got quieter and quieter haven't you? JOAN: Yes. By the second interview he misses what conversation they did have: PETER: "I never get a smile, I never get a um, I don't get any reciprocal.....it might be my fault I don't know, but there's not much conversation going on at all, "it's me that ends up doing the talking,..."* (Story – Relationship changes: Interview 2).

Analysis at the positional level reveals how the research interview acts as an avenue to open up communication between the couple, *"it's been nice today, you've talked a lot about how you feel, but we really don't do that hardly at all,..... we've really never talked about really have we Joan your condition as such,..."*

Exploring societal and cultural perspectives and can illuminate tensions between self, disability and communities (Riessman, 2008). As Peter adjusts to Joan's deteriorating condition, interactions with healthcare professionals became more equal with shared decision making. Peter says they have *'had one or two scares about er pneumonia coming back'* but he monitors Joan's condition – *'I've got monitors and things, I can check her oxygen saturation, I can check blood pressure'*. (Story – Healthcare interactions: Interview 3). Communication between Peter and the community healthcare teams improves as they work together to prevent hospital admissions, which may not be considered appropriate at the end of life (Robinson et al., 2016).

Conclusion

A dyadic longitudinal narrative approach offers deeper clinical and academic understanding of the personal experiences of people living with Lewy body dementia. Applying Murray's four level approach enables a transparent analysis process to reflect the multitude of influences which in turn can strengthen the validity of findings. Two levels of validity are considered important within narrative analysis: the story told by the research participant, which relates to

Murray's descriptive stage, and the story told by the researcher, or the analytical stage. The interviewer remains visible within the text which enables transparency of the analysis process to clarify and confirm the story told by the researcher. To enhance coherence of the story told by the research participant the stories were kept intact rather than breaking into themes, and by completing longitudinal couple interviews some member checking occurred naturally. How people relate their experiences to others is complex, and this approach attempts to integrate the content, structure, and composition of dyadic narrative interviews in a flexible way. This paper provides a structured transparent example of how to connect and integrate Murray's levels of analysis and contributes to the growing body of analytic methods for interpreting stories.

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