
Centre stage diagrams: a new method to develop constructivist grounded theory – late-stage Parkinson's disease as a case exemplar

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Abstract

A recent advance to the 'classic' grounded theory approach of Glaser and Strauss' seminal work has been the development of constructivist grounded theory. While constructivist grounded theory has significant utility, centre stage diagrams were developed by the authors to help integrate 'storied meaning' and diagramming into a method of data collection, analysis and theory development/presentation. Centre stage diagrams are co-constructed by the researcher and participant and use the participant's own life course, language and conceptual visualization of their subjective experience and are created over prolonged engagement. Centre stage diagrams are reached by the researcher and participant mutually engaged and interacting with two inter-related questions: i) *what* is the centre stage storyline in the lived representation of the phenomenon under study? and ii) *who* is centre stage in that lived experience? Our work in late-stage Parkinson's disease is used to illustrate this approach to theory building and generating constructivist grounded theory. Centre stage diagrams have potential for development as a practice tool and/or as an independent research method.

Keywords

centre stage diagrams, collaborative inquiry, constructivist grounded theory, late-stage Parkinson's disease, methodological development

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Introduction

Beresford's (2005) notion of the 'politics of knowledge' has focused attention on the importance of practice perspectives in building an evidence base for health and social care. The increasing recognition of the authoritative and expert voices of patients and their families as service users has led to increasing calls for qualitative researchers to use the participant's experience as the key contribution to the research act and to the dissemination of findings (Hodgson and Canvin, 2005; Keady et al., 2007a, 2007b; Nolan et al., 2007; Williams and Keady, 2008a, 2008b). Such collaborative work requires the creation of what Bradbury and Reason (2003) have described as 'living' knowledge.

Within the classic grounded theory approach as originally described by Glaser and Strauss (1967), this quest for more transparent user involvement in theory generation was taken up by Charmaz (2000) who emphasized the importance of fully engaging with experience so that the 'mutual creation of knowledge by the viewer and viewed aims towards interpretive understanding of subject's meaning' (p. 510). Within this approach, therefore, it is the participant's construction of their experience that sits at the heart of the theory building process and research enterprise, a movement away from the objectivist stance in classic grounded theory (Glaser and Strauss, 1967) to an interactive, subjectivist one where mutual interpretation and agreement are keys to unlocking and presenting human experience. In an attempt to create the 'intimate familiarity' (Charmaz, 2000: 521) from which the subjective worlds of the participant(s) and researcher can engage in such a mutually dialectal exchange to generate 'storied meaning' within constructivist grounded theory (Charmaz, 2000, 2006), the authors developed centre stage storylines as a method of data collection, analysis and theory development/presentation.

In this article, the properties of centre stage diagrams will be illustrated by reference to a single case example drawn directly from a recently completed 3-year constructivist grounded theory study involving people living with late-stage Parkinson's disease (PD) and their carers (Williams, 2010; Williams and Keady, 2008a). As we will shortly explain, it was during these encounters that the centre stage diagram ideas were piloted and empirically tested/validated by participants, i.e. those living with late-stage PD and their carers. It is the participant's engagement with the centre stage diagramming, ideas, and their endorsement of it, that allows us the platform to share this approach with any measure of confidence. However, before this is considered further, we will briefly outline the main features of classic grounded theory (Glaser, 1978; Glaser and Strauss, 1967) and the later development of constructivist grounded theory (Charmaz, 2000, 2006) as it was Charmaz's insights that gave us the impetus, motivation and opportunity to create the method of centre stage diagramming.

Grounded theory: classic to constructivist approaches

In the Preface to their seminal text written over 40 years ago now, *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Barney Glaser and Anselm Strauss wrote the following: 'Our book is directed toward improving social scientists' capacities for generating theory that will be relevant to their research' (Glaser and

Strauss, 1967: vii–viii). At its heart, the classic grounded theory approach embraced the entire scientific quest with concepts playing a central part in theory building. This was spelled out in the strategic method of comparative analysis which Glaser and Strauss (1967) originally saw as a general approach ‘just as statistics exist for the experimental methods’ (p. 21), with the addendum that both approaches use the logic of comparison. Glaser and Strauss (1967) believed that grounded theories exist to ‘take hard study of much data’ and that the inter-related role of theory within sociology was to (p. 3 slightly abridged): enable prediction and explanation of behaviour; be useful in theoretical advance in sociology; be usable in practical applications; provide a perspective on behaviour; and guide and provide a style for research on particular areas of behaviour.

Consequently, Glaser and Strauss (1967) saw the role of theory in sociology as a strategy for handling data in research which provided modes of conceptualization for describing and explaining within a substantive area of inquiry. Grounded theories are usually mid-range in their formulation, have a practice focus and are applicable in a diverse number of settings, which perhaps explains why, over the years, the approach has appealed so much to health and social care professionals (Arden, 1999; Chenitz and Swanson, 1986; Cowley, 1991; Wilde et al., 1993). Thus, in classic grounded theory, the researcher attempts to give the data a more general sociological meaning, as well as to account for, and interpret, what has been found (Glaser and Strauss, 1967). The purpose of the constant comparative method, which underpinned the use of concepts, was to explain, predict and seek relationships within data, as Glaser (1992) himself later stated in this straightforward summary:

Using [the] constant comparison method gets the analyst to the desired ‘conceptual power’ quickly, with ease and joy. Categories emerge upon comparison and properties emerge upon more comparison. And that is all there is to it. (p. 43)

Therefore, in classic grounded theory, both theory and theory development are grounded in empirical data and in acts of everyday social life, although it is important to emphasize that it is not the data which are important, but the conceptual category (or conceptual property of the category) that is generated from it. As Glaser and Strauss (1967) explain, a concept may be generated from one datum which then merely becomes one of a ‘universe of many possible diverse indicators for, and data on, the concept’ (p. 23). Crucially, in classic grounded theory, it is the indicators that are then sought for comparative analysis, and there are seen to be four stages in this process: i) comparing incidents applicable to each category; ii) integrating categories and their properties; iii) delimiting the theory; and iv) writing the theory. To operationalize these four processes, it is envisaged that the researcher must interact with those being studied and strive to interpret their social world and meanings. Accordingly, conducting interviews, transcribing text and detailing, storing and referring to theoretical memos are central to the process of undertaking the classic grounded theory method; indeed, Glaser (1978) later viewed the writing of theoretical memos as the ‘core stage’ in the process of generating theory, with memos defined as ‘the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding’ (p. 83).

While the contribution of classic grounded theory to the canons of research and practice cannot be underestimated, and whose influence continues to be exerted to this day (<http://www.groundedtheory.com/>), Charmaz (2000) was to subsequently label this approach to generating grounded theory as ‘objectivist’ as it privileged researcher knowledge over lay knowledge (of the experience under study) held by the participant. After all, within classic grounded theory, it is the emergent theory, or the emergent properties of that theory, that need to be constantly compared and tested, not the quality of the relationship between researcher and participant. Charmaz (2000) effectively questioned this moral and ethical standpoint and called for a more inclusive approach to generating classic grounded theory, one which sought to construct the realities of the participants (own) lives using their symbols and life language as the cornerstone of theory generation. Moreover, as Dey (2007) noted, ‘narrative inquiry can play a critical role in grounded theory’ (p. 185), thus further opening the door for more inclusive ways of advancing the approach.

To achieve this paradigm shift, Charmaz (2000) suggested that the principles of constructivism – stakeholder involvement and partnership working – should be added to the mid-range theory-building properties of classic grounded theory (Glaser, 1978; Glaser and Strauss, 1967) to produce a new approach of representing and grounding grounded theory through ‘storied meaning’. This development was termed constructivist grounded theory (Charmaz, 2000). Here, concept generation was still theorized to be integral to the production of a constructivist grounded theory, but the very nature of the relationship meant that concepts would be discovered on a conjoint basis, rather than the researcher alone searching for the theoretical saturation of codes and categories across a comparative data set (Charmaz, 2000). While these ideas held promise, the authors sought to uncover such ‘storied meaning’ and engage participants as co-researchers in their condition, utilising diagramming (Charmaz, 2000, 2006) as a platform for engaging participants in data generation, focused coding and the process of theoretical coding with the researcher. The sections that follow illustrate how the authors have attempted to develop, refine and test centre stage diagramming as a method within constructivist grounded theory for this purpose.

The study

We will now visually represent the use and application of centre stage diagramming through the couple-based exemplar of Joan and Peter drawn from our 3-year constructivist grounded theory study on late-onset PD, a study that explored adaptation, coping and storied meaning from within a biographical discourse. While the main thrust of this article is on methodological development, in the couple-based case example of Joan and Peter that follows, it is salient to provide a brief overview of the study design and PD.

Parkinson’s disease: an overview

There are over 120,000 people in the United Kingdom (UK) diagnosed with PD and one person in 100 over the age of 65 is affected, increasing to one in 50 for those aged over 80 years (Bell, 2003). PD is recognized as a neurodegenerative and incurable chronic

illness that has a major impact on health and requires substantial personal and social adjustments (Playfer, 2002). PD is a progressive condition and the symptoms become increasingly difficult to control as the disease advances, especially motor complications, fluctuations in the effectiveness of therapeutic treatment and dyskinesias (Stocchi, 2003; Verhagen, 2002). Hoehn and Yahr (1967) classified PD along five stages, with stage 5 indicating severe disabilities and the loss of independence. In the presented study, 'late-stage' describes the worsening condition of a patient as the course of the illness progresses and in relation to Hoehn and Yahr's (1967) scale, late-stage is located between stages 3 and 4. At stage 3 people with PD have mild to moderate physical disabilities progressing to more severe disabilities at stage 4.

To date, the literature reveals a paucity of studies that have engaged people living with PD in an appraisal of their own lived experience (Hobson et al., 2001), especially in its later stages (Williams and Keady, 2008a), although it has been known for some time that in PD the wellbeing of carer and cared-for are closely related (Hobson et al., 1999). Increasingly, research has identified the importance of exploring the most important issues for people with PD, including an emphasis on the centrality of psychological adjustment and the need for psychological interventions (Holloway, 2007; Schenkman et al., 2002; Secker and Brown, 2005; Wressle et al., 2007). A key feature of maintaining lower levels of depression, anxiety and stress in PD is the nature of support, its quality and the number of close relationships (Simpson et al., 2006).

Methodology and methods

Sample

The study involved the participation of 13 people with late-stage PD and their family carers, located at the time of initial recruitment between stage 3 and stage 4 (Hoehn and Yahr, 1967). Participants were aged 60–89 years and the interviews ($n = 101$) have been conducted longitudinally between June 2007 and September 2009 with interviews and subsequent centre stage diagramming conducted in the person's home (Williams, 2010). Recruitment was organized from the caseload of two specialist Parkinson's disease nurses working in North Wales, UK and one Consultant Geriatrician. We will use one couple-based case example (Joan and Peter) from the study sample to demonstrate how centre stage diagrams were constructed and their utility as an applied method of developing a constructivist grounded theory (Charmaz, 2000).

Data collection and analysis

The study sought to develop a constructivist grounded theory that mapped the experiences of people with PD and their families as they attempted to manage and adjust to the transitions involved in the later stages. It is here where the development of centre stage diagramming was refined and tested to form the bridge that linked storied meaning to engagement in the research act to produce a constructivist grounded theory. Gubrium's (1993) approach to generating life story was used as a prelude to producing centre stage diagrams with the storied meaning found in the response to questions such as 'What were

the most important turning points in your life?’ and ‘What is your “philosophy” of life?’ Gubrium’s (1993) approach to understanding life story provided a series of questions that engaged participants in being reflexive about their life experiences and enabled a life story to be built that presented a platform for understanding the personal or a shared philosophy of participants and identified any significant past events prior to focusing on the impact of PD. Integrating Gubrium’s probes to life history taking facilitated the exploration of participants cognitive schemas (Rodwell, 1998) and meanings. As Pruchno (1992) notes ‘meaning is not necessarily made on the spot but develops in relation to the retrospective and prospective attention given to it’ (p. 581), and at all times participants were involved in producing diagrams about these issues even though this was problematic owing to the coordination difficulties that are associated with late-stage PD. Participants were seen initially every month to complete the storied narrative and initial exploration of their late-stage PD then subsequently visited every month, 2–3 months or at a negotiated interval. The longitudinal series of interviews that underpinned the case study work with Joan and Peter is shown in Box 1.

Box 1. Sampling frame

Number of Interviews	Date	Duration	Joint/Single Interview	Location
Interview 1	28.05.07	1.5 hours	Joint led by Joan	Home
Interview 2	14.06.07	1.5 hours	Joint led by Joan	Home
Interview 3	28.06.07	1.5 hours	Joint led by Joan	Home
Interview 4	01.08.07	1.5 hours	Joint led by Joan	Home
Interview 5	06.09.07	1.5 hours	Joint led by Joan	Home
Interview 6	05.02.08	1.5 hours	Joint led by Joan	Home
Interview 7	25.2.2008	1.5 hours	Joint led by Joan	Home
Interview 8	15.4.2008	1.5 hours	Joint led by Joan	Home
Interview 9	03.03.09	1.5–2 hours	Joint led by Joan	Home
Interview 10	21.04.09	45–50 mins	Joint	Home
Interview 11	06.07.09	45–50 mins	Joint	Home

In many respects Joan presented a complex case of late-stage PD with many symptoms that were not only distressing but also required careful management during the course of the interviews. In particular, during the course of the interviews from 2007–9, the greatest difficulty she faced was overwhelming fatigue, neurological pain, severe tremors and stiffness which often required the interview to be paused while Joan had a rest or received an Apomorphine injection and/or ‘boost’ from the Apomorphine pump that was used continually as part of her medication regime. As her condition deteriorated, the difficulty of completing interviews was increased with the onset of other symptoms, including memory difficulties and depression. The interviews were completed as a dyad with Joan and Peter; however, the diagramming was done with Joan leading the task and ‘directing’ what was centre stage while both Joan and Peter provided a rationale and additional commentaries and ‘fleshed out’ the issues. The role of the primary researcher undertaking the interviews (SW) was to clarify, check and confirm the contents of the

diagram with both participants and follow-up any apparent gaps or dissonance that emerged from either the interview and/or diagramming. In this way the diagram provided the basis for further conceptual and discursive clarification.

Storylines have been used extensively in narrative-based work such as by Plummer (2001), Sandelowski (1991) and Strauss and Corbin (1998). This emerges from the basic element of 'story' in narrative traditions and the development of its presentation and disclosure through storylines, plots and themes (Plummer, 2001). These may be a feature of the narrative-as-told by research participants or the narrative-as-interpreted by the researcher to enable the story to be organized and developed into a pattern with an embedded meaning (Plummer, 2001). The narrative-based researcher has a repertoire of conceptual 'tags' to organize people's storied lives, including seeking out nuclear episodes, plots with epiphanies, a thematic cluster of episodes and the literary device of a beginning, middle and end (Plummer, 2001). Storylines, plots and themes in many respects are closely linked in narrative-based work as part of its architecture supporting the analysis of complex dynamics in stories and delineating *how* events, incidents and characters of a life story are organized, disclosed, have agency and act as part of the uncovered (narrated) story (Williams and Keady, 2008b).

In our work the centre stage diagrams primarily explore two inter-related questions: i) *what* is the centre stage storyline in the lived representation of the phenomenon under study? and ii) *who* is centre stage in that lived experience? These storylines are supported by subsidiary processes that consist of descriptions, additional diagrams or commentaries on the centre stage diagrams that focus on identifying *how* the centre stage storyline is supported/accomplished and *when* the centre stage storyline occurs. The 'centre stage' is also both a visual and metaphorical concept. The centre of the stage is where the person locates the main issues/life storylines and then uses the length and breadth of the page to position others/issues/challenges around the centre; visually, the farthest away from the centre stage, the least impact this has on the centre stage storyline, unless the person indicates otherwise. So, a centre stage diagram is literally represented on the centre of a page with the person then in control about relationships that extend to/from it, and/or in documenting how things link together in their diagram, or not. Lines become important, circles can represent continuity or the all-embracing nature of the condition, broken lines can represent discontinuity and a bold, thick line can represent a strong affiliation to the subject area. The diagram therefore provides an immediate visual narrative, one that can be compared as the centre stage storyline(s) change as the relationship and encounters develop over time and new events occur in people's lives.

The centre stage work involves participants in all phases of data collection and also in the data analysis, producing a co-constructed grounded theory that has movement, direction and dimensional attributes owing to the visual representation of storied meaning spun around a centre stage storyline, or a number of centre stage storylines. At all encounters, diagramming – and theorizing – was entered into willingly by participants and the personal satisfaction that completing a representative picture of their experience had upon those taking part, including, of course, the researchers, was compelling.

All necessary ethical approval to conduct the study was provided by the appropriate research ethical committee in North Wales and NHS research governance group.

Findings

Joan and Peter: a brief life story

Joan was diagnosed with PD in 1989 and referred to a Movement Disorder Clinic in North Wales involved in the study in 1994. Joan had experienced a difficult ‘diagnosis story’ that led to a prolonged period of crisis in adjustment with little explanation of how the diagnosis of PD would impact upon her and her husband’s lives. However, the medical management had improved when her care was transferred to a locally based consultant and access to the Parkinson’s disease nurse specialist (PDNS). On consenting to take part in the study in 2007, Joan had a complex regime of medication as part of the management of her disabling PD, including limited mobility (requiring aids), poor swallowing, hypersalivation, facial and other stiffness, tremors, spasms, extreme fatigue and neurological pain in her legs. It was evident that Joan’s condition had deteriorated over the years and during the course of the study continued to experience a decline and suffered a stroke and bowel problems that required surgical intervention. Her husband Peter was the main carer and also supported Joan’s mother who lived nearby and had dementia. Joan and Peter had two daughters, and a number of grandchildren, with one daughter living in the area who increasingly became involved in supporting her parents towards the end of the study. During the study period (2007–9) both Joan and Peter provided emotional support for their daughter during a difficult period in her life.

The initial interviews with Joan and Peter used Gubrium’s (1993) life story framework and started by asking them to start wherever they wished and to identify important turning points in their life. From the discussion, a life story emerged which highlighted the importance of the ‘diagnosis story’ and a philosophy and meaning of life that involved prolonged periods of anger, learning and the importance of ‘fighting it’.

Centre stage diagramming generation (August 2007)

The construction of the first diagram (see Figure 1) illustrates *what* is centre stage in Joan’s life and became a crucial marker in uncovering the complexity of Joan and Peter’s life with PD. For Joan, the act of diagramming using the centre stage ideas helped her to articulate her day-to-day experience of adjustment and story its meaning. As can be seen in Figure 1, Joan placed her PD symptoms squarely in the middle of the page, an act that represented her first centre stage storyline.

The notion of having the mid-point of the page as the ‘centre stage’ and assembling relevant issues in relation to ‘*what*’ and ‘*who*’ is part of the centre stage storyline technique was grasped very quickly and with some enthusiasm by Joan. Peter liked its simplicity and they started to use the diagram as a prompt, or ‘prop’, for developing what the issues meant to them in their lived experience as part of the interview. The narrative that was built around the ‘prop’ of the completed diagram uncovered hidden aspects of their life that had not been discussed in the three previous interviews (28.05.07–28.06.07); this comprised of the emergence of ‘*memory*’ and ‘*isolation*’. An important feature of the diagramming was how Joan and Peter described the dynamic interrelationship between issues such as ‘swallow’ and ‘speech’, or the ‘tremor/spasms’ and the terrible ‘shocking pains’ in Joan’s legs.

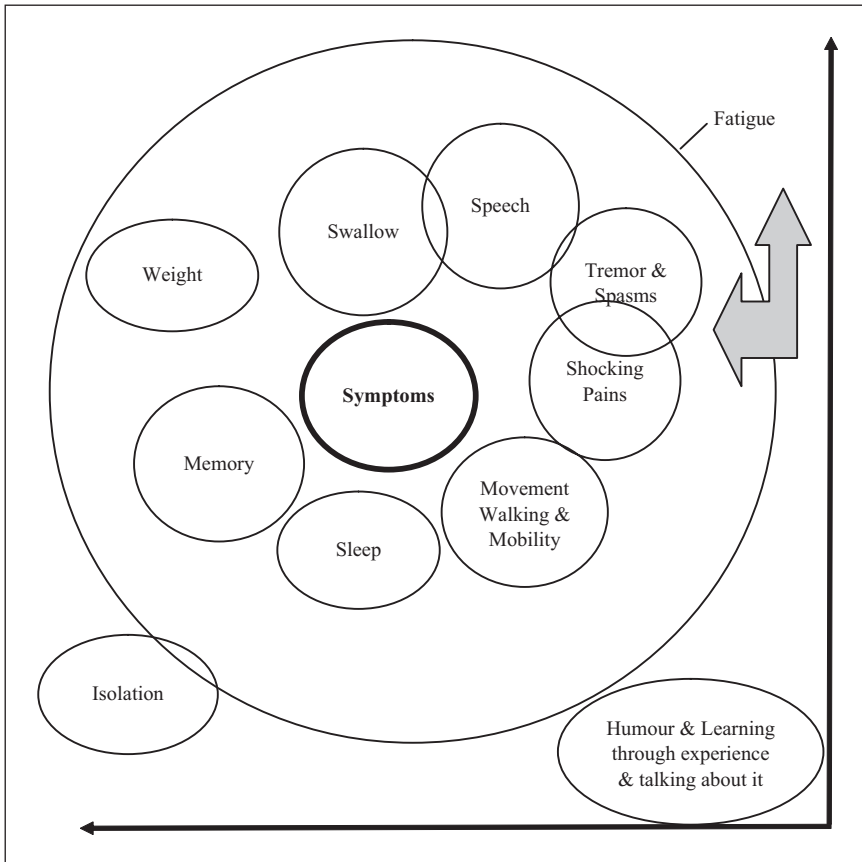


Figure 1. What's Centre Stage: Joan (August 2007)

Note: As part of diagramming the language of participants were used and this included a number of abbreviations / terms which will form part of future figures, as indicated below:

Key:

Physio: Physiotherapist

PDNS: Parkinson's Disease Nurse Specialist

OT: Occupational Therapist

GP: General Practitioner

SLT: Speech and Language Therapist

Consultant: Consultant Physician

As can be seen in Figure 1, symptoms of greatest importance in 2007 were *movement, walking and mobility*. The *shocking pains* of neurological pain in the legs and a whole body *tremor and spasms* were also associated with pain as indicated by the overlapping or linked circles. The majority of experiences were clustered around the middle of the diagram and centre stage, including *memory* (poor short-term memory and 'can't think of a word') as well as substantial difficulty with disturbance to *sleep* and *weight* loss. The experiences of impaired *swallow* and *speech* difficulties, including severe problems with the volume and strength of Joan's speech, were a constant and centre stage feature. Joan

recounted the difficulties involved with having to ‘struggle’ with her speech, take care with swallowing and the difficulties of choking on food. All these experiences were embedded in the overarching symptom of overwhelming *fatigue* which Joan drew as an enveloping circle. In particular, the constant tremor exacerbated the fatigue as Joan felt ‘wiped out’ by the effort of doing the most simple of tasks.

Fatigue had an effect on all the symptoms described as centre stage and often made the experience of each respective symptom feel subjectively worse. The arrow in Figure 1 connects *fatigue* as a symptom which exacerbates the *shocking pains* and *tremor and spasms* to a significant extent. Collectively, these symptoms result in *isolation*, described as difficulty accessing previous life patterns due to mobility difficulties, tremor and spasms, but also an altered sense of ‘being a person’. This was illustrated through Joan struggling with her identity as a ‘wheelchair user’ and that, in the words of her husband ‘[Joan] had difficulty accepting going out’.

Offstage to the right-hand bottom corner, but spreading out to encompass *what’s* centre stage, is *humour and learning through experience* and *talking about it* which is inter-linked to managing *what’s* centre stage. Peter summarized this during an interview as being ‘a little bit of trial and error over the years really’ (01.08.07). As Figure 1 demonstrates, the diagrammed role of *humour* highlights its central role as a coping strategy within Joan and Peter’s relationship with each other and PD. The learning process was difficult and required constant re-construction:

No, Parkinson’s affects every bit of your life, yeah. I said to myself ‘Right, it’s got a piece of my life but it’s not having any more’ but of course it doesn’t listen, it slowly takes another bit and you think ‘Well, OK, I’ll give in, you can have that bit [laughs] but I’m keeping some for me . . .’ [pause] and that’s why I sit with a needle for hours trying to thread it. (Joan: 01.08.07)

The sense of *isolation* is equally important as with *humour* and *learning through experience*. The difficulties of going out, being seen as different due to tremors (such as mistaken for being ‘drunk’), having to use the wheelchair and ignored as well as losing friends that ‘fall away’ as the illness progressed. It also encompassed mood and the days when Joan sat in the ‘bad chair’ suffering from depression as well as the chronic ‘deep sorrow which never goes away – continuous grieving for life’s normal contents, which you take for granted thinking they will remain with you forever growing with you in the future’ (Joan’s reflections: 01.08.07).

In the context of ‘*who*’ is centre stage, Figure 2 identified those that supported (their) adjustment to their PD as at August 2007; it is noticeable that Joan and Peter located themselves as together (in the sense that they shared the same circle) and in the centre of the stage – others revolved around the centre, largely equidistant from one another and from Joan and Peter. As such, the ‘*who*’ as centre stage diagram in Figure 2 provides a source of reflexivity for participants as well as the researcher and develops insights into how the couple manage their day-to-day lives with PD and, more importantly, with one another.

In contrast, Figure 3 shows how Joan and Peter constructed professional involvement in their day-to-day lives – the broken line to the speech and language therapist is a literal

representation to that support, while the physiotherapist is seen as ‘distant’ but an important link nevertheless. The other professional relationships are self-evident and Joan and Peter continue to place themselves as together and not separated by professional involvement in their life.

The completion of the ‘what’ and ‘who’ centre stage diagrams in August 2007 highlighted the dynamics of maintaining stability, support structures and networks for

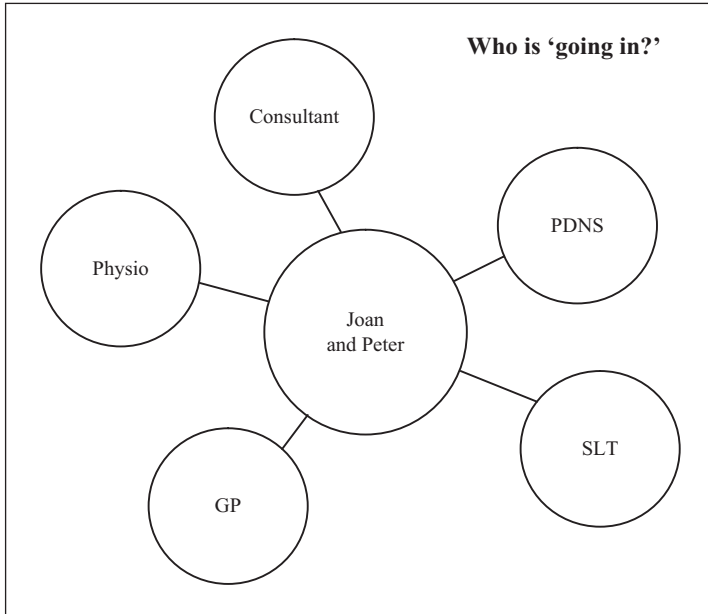


Figure 2. Who is Centre Stage: Joan (August 2007)

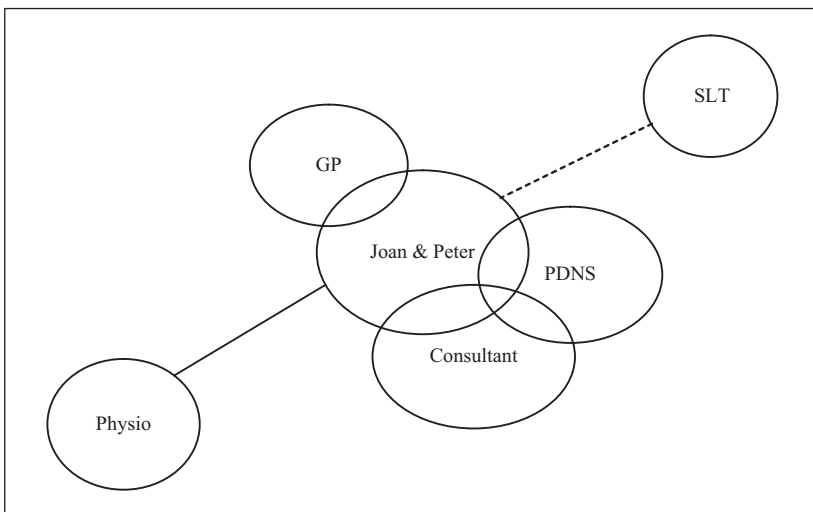


Figure 3. Relationships with Professionals: Who is Centre Stage: Joan (August 2007)

Joan and Peter, representing the categories that distilled their subjective experiences. As part of the data analysis process, SW discussed the diagrams with Joan and Peter and ‘fleshed out’ how they contributed to understanding their story of life with PD. Each centre stage circle was explored in turn and notes made which identified their properties and importantly the inter-relationship between each circle. These insights allowed the interviews to further explore *how* such structures were accomplished and *when*; such additional information supported the centre stage storyline accounts and are beyond the scope of this article. The process of ‘fleshing out’ the meanings as well as describing the events or people in each circle underpinned the dialectic co-construction of what was the nature of their experience at different points in time. In addition, SW identified his perspectives in theoretical memos (Charmaz, 2000) and shared these ideas as part of the analytical discussion with Joan and Peter.

The ‘*what*’ and ‘*who*’ centre stage storylines were to change around two years later.

Centre stage storyline generation (April 2009)

In the later part of the study a series of new symptoms appeared in the life of Joan and her carer Peter, including for Joan a devastating stroke, an acute bowel problem and consequently increasing chronicity (see Figure 4). Diagramming these changes was completed within the interview and required ‘going back and forth’ between the interview-based discussion and adding to the diagram. Joan’s fatigue was extremely disabling and resulted in the session being ‘broken up’ into a series of discussions with a break. Joan suffered excessive tremors and required a ‘boost’ of Apomorphine with severe spasms ‘kicking off’ [Joan’s explanation of this aspect of her symptoms].

The diagram in Figure 4 depicts the altered state of ‘*what*’s’ centre stage and indicates important changes in the process of adjustment from two years ago. Figure 4 abbreviated major changes that Joan experienced, such as numerous hospital admissions, and focuses instead on the three ‘core’ experiences of *life with PD*, *stroke* and a *colostomy*, represented as shaded circles. However, the basic shape of the previous diagram was largely retained with the coping mechanism of *humour and learning* retaining its importance with the addition of ‘*accepting it*’.

Compared to the previous diagram illustrated in Figure 1, *speech and swallow* felt as one experience but has been pushed out from the centre, replaced by other more dominant experiences (as considered by Joan). However, there were times when *speech and swallow* also moved into the centre stage, as indicated by the broken arrow. Significantly, as part of the PD, *memory* was now a major problem, far more than other physical symptoms such as *mobility*. As Joan remarked, ‘it bothers you a lot’ and her short-term memory was significantly worse by 2009, so much so that she resorted to ‘writing things down’ as an aid to remembering and coping. There were also difficulties for Peter in worrying that Joan ‘can’t remember, shuts down completely and can’t remember what [she’s] talking about’ (21.04.09). The inter-linked nature of experiences were slightly modified with *pain* now a separate experience with the *tremor and spasms* retaining their significance, but associated with changes such as *balance* [a new experience to be recorded as centre stage] and *mobility*.

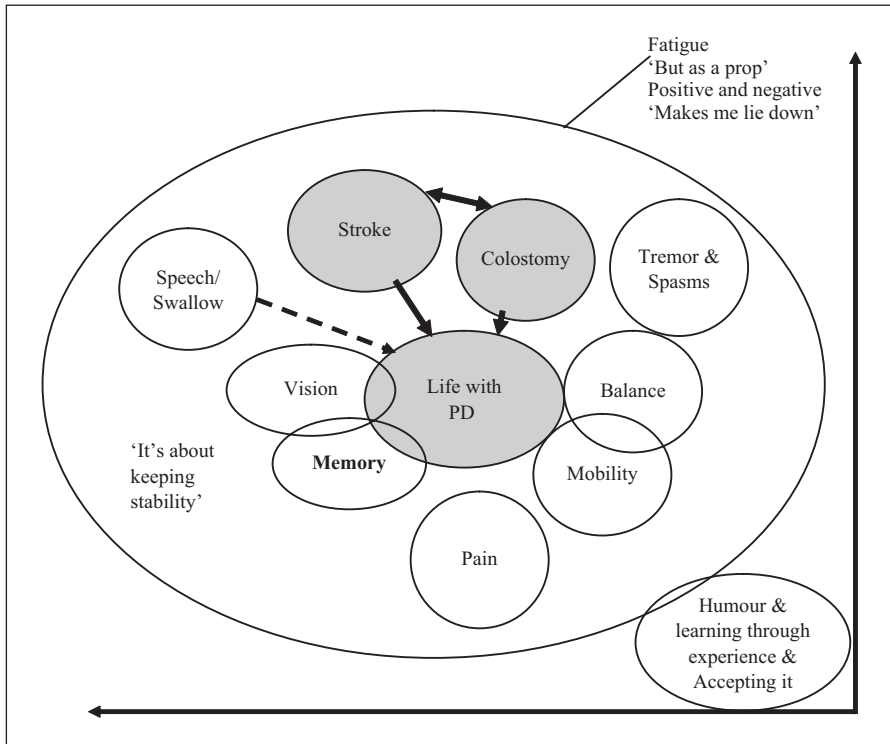


Figure 4. What's Centre Stage: Joan (April 2009)

For Joan, the impact of the stroke combined with the PD resulted in an increase in difficulties with moving around with assistance and a lack of confidence. The issue of *vision* emerged as a particularly troubling experience as a direct result of the *stroke*, but it also impacted on the experiences of *mobility* and *balance* related to the PD. Joan had double vision and impairments in the left eye with added complications from the side-effects of her complex range of medication. Previously (in 2007) her ability to read books had been important in coping with her PD, and now the difficulties with her vision had been 'accepted' only by her carers enabling Joan to use the internet in her spare bedroom-called the 'craft-room'-with its computer and arts materials. A refuge from her symptoms.

As Figure 4 also reveals, the interrelationship between the experiences of symptoms drawn from the *life with PD* and *stroke* event was clearly marked out by arrows and there was the added difficulties of managing the *colostomy* from the bowel operation which required her carer to manage changing the colostomy bag and caring for the site as a result of both the PD and stroke. Yet *fatigue* still embedded these experiences but in an altered state. Joan described how fatigue had become an adjustment 'prop' with both negative and positive aspects. The negative aspects carried over from Figure 1, although as a 'prop' it had a positive impact by forcing Joan to build-in more frequent rest periods to her day resulting in a more successful adjustment to her condition.

Figure 4 also revealed that *humour and learning* remained important ‘offstage’ experiences, but now focus on ‘*accepting it*’ rather than ‘*talking about it*’ and centred on ‘*keeping stability*’ among the three experiences of *living with PD, stroke* and the *colostomy*. The issue of *isolation* no longer featured in the diagramming, although, from an observer perspective, it seemed that Joan was experiencing greater isolation following her stroke due to her avoidance of going out, her fear of falling and feeling ‘unsafe’ unless using a walking frame in the house. Joan’s *fatigue* remained extremely disabling and even going out in the wheelchair was used only ‘when required’ for appointments. Joan’s life was now largely focused on being ‘house-bound’ as she was attempting to accept this by focusing on its role in ‘keeping stability’ and access/use of the internet now had ‘opened another door’ (21.04.09) for her; a technological aid that reduced her sense of isolation.

The dynamic between Joan, Peter and the multidisciplinary team is presented quite differently to the original diagram in 2007. In the ‘*who*’ is centre stage diagram of 2009 (Figure 5) there is a striking change in the positioning of the *PDNS, Consultant, GP* and *physiotherapist* as being ‘offstage’ rather than at the centre of the diagram. This is despite Joan and Peter’s perception of their ability to influence or alter the situation as being ‘very limited’. It is a paradox and yet the professionals retain a problem-solving and reassuring role in the life of Joan and Peter, focused on ‘being there’ and providing a ‘backup’; however, in reality, the professionals have little to contribute in the couple’s experience of being in a ‘cul de sac of adjustment with the PD and life following a stroke’ (21.04.09). The initial diagram on ‘*who*’ is centre stage (Figure 2) now includes the time-limited, but important, ‘off-on stage’ role that the stoma nurse, occupational therapy and the immediate post-discharge team had all played following Joan’s discharge from hospital.

The diagramming in Figure 5 also shows Joan and Peter represented as separate, inter-connecting circles in the centre stage of the diagram [with the experience of PD] rather than as a unified single circle as in previous diagrams. This graphically illustrates Peter’s role as ‘a carer’ and Joan’s role as being ‘cared-for’. This was noted as a particular shift in the researcher’s (SW) memo and discussed as part of the analysis.

A further modification to the previous diagram (Figure 2) was the presence of Joan’s mother who lives with dementia situated in an ‘offstage’ position. Once more, Peter had taken a more explicit caregiver role and provided practical and emotional support. As Figure 5 also reveals, Joan and Peter, as with all participants in the study, included a variety of other supportive personnel, such as friends and neighbours, who were infrequently discussed in the narrative account. These had been a ‘hidden’ part of their lives but became increasingly important in the centre stage diagrams as Joan was now housebound and had increased disabilities. A negative aspect of receiving support and help from neighbours, friends and professionals was the ‘stress’ it caused Joan, having to cope with managing these relationships and getting others to understand her condition and requirements, such as the fatigue. In particular, the diagramming identified the centre stage role of Joan and Peter’s daughters [a new feature in the diagram] but this was also associated with an increase in stress which had had a negative impact on Joan and her PD. The stress was caused by relational tensions between the two daughters and the new role of the ‘centre staged’ daughter (1) in taking over the main supporting role to her father as she lived nearby.

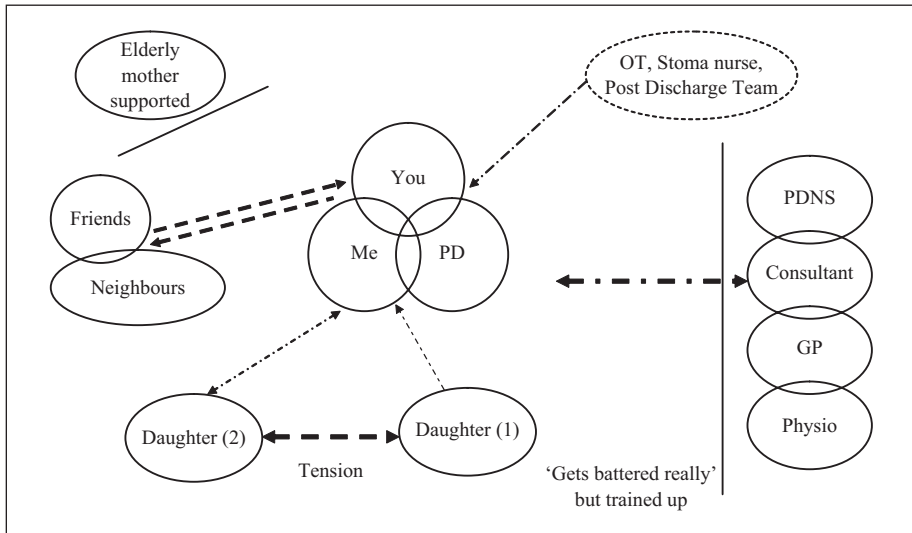


Figure 5. Who is Centre Stage: Joan (April 2009).

Note: Me: Joan, You: Peter.

The role of the couple's daughters is central to illustrating a new pattern of adjustment and is an important addition to the previous diagram in 2007. As Figure 5 shows, the main support for both Joan and Peter is their daughters as events have re-shaped daily life following a stroke and a colostomy. The daughter (1) living locally has learned to manage the colostomy and volunteered to be 'trained up' to change the bags, look after the site and help out with her father. Joan notes that she now 'gets battered really' in terms of increasing demands for help. Previously, daughter (1) required much support and assistance. The second daughter is remote, living further away and since the change in roles there had been an increasing tension between the two daughters. The centre stage diagram (Figure 5) is now dominated by intra-family support and complex relational issues.

Discussion

At the end of the study, Joan and Peter reflected that the diagramming had been 'useful for thinking about things' and that it was good to 'share feelings' and look at PD 'from another point of view . . . otherwise [we] lie in our own cocoon' (06.07.09). The generation of centre stage diagrams pivoted on an interplay between the talk of a narrative-based interview and the act of diagramming built on the researcher's ability to create a close relationship with participants as a pivot for constructivist grounded theory work (Charmaz, 2000). The process of centre staging requires reflection-on a life with PD and partnership between participants and the role of the researcher as facilitator. Such a strategy was based on the Blumerian principle of gaining access to participants worlds and understanding the 'assumptions underlying the data by piecing them together' (Charmaz, 2000: 525).

The drama-language inherent in the centre stage method was readily grasped by those living with late-stage PD and the research encounter became a collaborative theoretical journey with the locus of control being shared with participants. The centre stage techniques described in this article enabled analytical and reflexive work to be completed with participants through diagramming as part of the interview and engaged participants and the researcher in a shared process of theoretical coding as the study progressed. The diagrams provided a visual starting point for understanding the categories that emerged, their relationships and how they worked in people's lives (Charmaz, 2006). As a technique, it presents an opportunity to 'open up' grounded theory beyond 'zombie categories' that represent well-used or past categories that 'mask a different reality' (Plummer, 2005: 358). It also recognizes that 'research – like life – is a contradictory, messy affair' (Plummer, 2005: 357) and whenever possible researchers need to provide participants with the tools to construct and generate their own storylines. Arguably, the role of researchers is to provide participants with an opportunity and techniques to provide 'transforming knowledge' based on the 'interpretive rendering of worlds we study rather than an external reporting of events and statements' (Charmaz, 2006: 184). In many respects centre staging provides horizons of self-understanding (Randall, 1999) as participants share and reflect upon their experiences with the researcher and both gain a different view so that the 'story reflects the viewer as well as the viewed' (Charmaz, 2000: 522).

The aim of using centre stage diagrams is consistent with the technique outlined by Strauss and Corbin (1998), but embraces the call of Charmaz (2000) to re-engage with the raw data in constructivist grounded theory. Rather than 'stand back', using centre stage diagrams as a method enables the participant(s) to move forward and stand with the researcher in moving from identifying the story, defining the descriptive story and formalizing a 'storyline memo'. This was vividly captured in the series of figures described in this article, particularly figures 1 and 4, where the level of thought and movement that went into the creation of these diagrams had a flow, energy and fluidity that was not far removed from the creation of a substantive grounded theory, with 'stability' as the basic social process that both explains and transcends the data. This theoretical development enabled the researcher (SW) to build a dialectic discussion with participants using the diagrams as the 'centre stage' for the conceptual work that brought participants into the activity of shared focused and theoretical coding (Charmaz, 2006), and mapped how their realities shifted, or changed, in response to which processes were being explored. Indeed, Glaser (1992) himself argues that grounded theory and identifying a storyline is based on 'persistence, patience and emergence' (p. 78).

Centre stage diagrams rely on the act of identifying storylines and performance over time. Diagramming has an established role in grounded theory work (Charmaz, 2006; Glaser and Strauss, 1967; Strauss and Corbin, 1998) with the key attribute being that 'diagrams should flow, with the logic apparent without a lot of explanation' (Strauss and Corbin, 1998: 152). We would concur that a central activity is engagement with participants' subjectivity as stated by Charmaz (2000, 2006). In our approach, the views of Strauss and Corbin (1998) that diagramming should enable the researcher to gain distance 'forcing him or her to work with concepts rather than with details in the data' is

turned on its head. Instead, the process of centre stage diagramming involves participants and the researcher gaining 'closeness' to the data and engaging together in conceptual work from an early point in the research encounter, and it addresses the aim of gaining a shared and co-constructed understanding of chronic illness (Ironside et al., 2003). Furthermore, unlike Strauss and Corbin's (1998) vision of diagrams as valuable tools for integration, we would suggest that centre stage diagrams are central to 'uncovering' and later 'integration' of the emergent theory. Here, we were influenced by the simplicity of using 'chapatti' or venn diagrams as part of centre staging as the circles denote different sizes in symbolic relationships to each other. Mikkelsen (1995) describes their utility in depicting participants sense of relations as well as events and the ability to 'weight' allocated to individuals or groups stating 'it is a subjective, not an objective, delineation' (p. 80).

In centre staging, the use of venn diagrams is modified by using the notion of a 'stage' and asking participants to not only use size and weighting, but also the centrality of issues, people or events in being 'centre stage'. Again, this complex notion was readily grasped by all participants in the study and broken down into understandable constructs that we all identify with: a broken line means a fractured or broken relationship; a strong line reflects a strong relationship and so on. Indeed, we would suggest that modifying the centre stage diagrams to have a role as a practice tool, and measuring performance through diagramming, holds real promise as a future approach.

However, the primary difference in centre stage diagrams as they were depicted in this article is that the storyline is not solely restricted to the researcher as 'analyst'; rather, it involves participants in co-constructing the(ir) storyline in the area under study. The act of centre staging moves the researcher away from processual or conceptual maps that may produce 'overly complex architecture that obscures experience' (Charmaz, 2000: 525) and, instead, highlights the importance of accessible visual representation and relationship building between the researcher and participant(s). Furthermore, in contrast to a traditional usage of storyline in the analytical stages of grounded theory, we assert the centre stage storyline (based on narrative work) is best placed at the start of the theoretical journey and the initial immersion in the data to obtain a 'general sense' and seeking out of the descriptive story. The centre stage storyline can then subsequently be revisited on an ongoing basis and subject to constant comparative analysis and revision. The diagrams provide a means of sharing the act of coding with participants and in many respects represent what Charmaz (2000) describes as 'action codes' which provide insight into people's actions and situations and facilitate comparison as part of the 'chain of theory development' (p. 515).

As we have previously highlighted, we believe it is important to situate the search for centre stage storyline(s) within an interview that has a biographical account and is approached using straightforward questions, i.e. 'what', 'who', 'how', 'when' as this delimits the complexities and re-contextualizes them in a way that makes sense to the individual (or other combination of participants) approaching diagramming. It is this platform that allows the centre stage diagram to emerge and co-construction to commence, based on the storied meaning that the phenomenon under description holds for the participant(s). In addition, the act of memoing by the researcher provides a

theoretical trail that links the 'action codes' emerging from the centre stage storylines to the development of a clearer account of interrelated processes. Importantly, the visual representation of a storyline through the centre-stage technique enables a temporal sense of adjustment to change and a sense of self (or selves) to be mapped. The constant comparison of generated storylines identify connections between events and provide a 'self-correcting data collection process' (Charmaz, 2000: 522) as participants and researcher re-visit centre staging. The opportunity for reflecting on change highlights the importance of reflexivity in grounded theory work (Hall and Callery, 2001), but facilitates a shared reflexive account to be developed between the researcher and participant.

Finally, the development of centre stage diagrams through storylines seeks to address the relationship between the conceptions and 'interpretive act' of the participant and researcher that lie at the heart of an inquiry. Denzin (1989) identifies this tension of the researcher's view of the world as abstract, relativistic and generalizing while the participant engages in common-sense concepts that seem to be 'natural, practical, simple and literal, ad hoc and accessible' (p. 9). Storylines may provide 'meaning bridges' in the analytical process, but they also contribute towards drawing together what are first-order (everyday life) and second order (abstract) concepts (Denzin, 1989). Centre stage storylines 'tells the story about people, social processes, and situations' (Charmaz, 2000: 522) and enable a narrative to be developed as part of the 'flow of experience and making it intelligible' (Randall, 1999: 13). Arguably, the method of using centre stage storylines addresses the constructivist 'hazard' of overemphasizing the individual (Charmaz, 2000: 531) by enabling a constant comparison of diagrams across a sample of participants which, in the wider study of late-stage PD (Williams and Keady, 2008a), included the contribution of 13 families. Such a data set enables the identification of wider basic social processes and transcendent meanings.

A key aspect of using centre stage diagrams through is that it 'celebrates firsthand knowledge of empirical worlds' (Charmaz, 2000: 510) and allows the interview as a digging tool (Denzin, 1989) to achieve the constructivist grounded theory aim of uncovering participants' unstated assumptions and implicit meanings and provides a visual space for 'private thoughts and feelings' to emerge (Charmaz, 2000). While the centre stage diagramming method has been described in this article by reference to a constructivist grounded theory study of late-stage PD, it can extend to other long-term conditions such as dementia, stroke and rheumatoid arthritis, with the practice applications of centre stage diagramming and/or its usage as an independent research method, still to be developed.

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