

Abstract

Objectives: Deep brain stimulation (DBS) is a form of biotechnological surgery which has had considerable success for the motor improvement of Parkinson's disease and related disorders. Paradoxically, this observed motor improvement is not matched with improved psychosocial adjustment. This study contributes to a small but growing body of research aiming to understand this paradox. We conclude by discussing these aspects from a phenomenological and health psychology understanding of decision-making, human affectivity and embodiment.

Design: A hermeneutic phenomenological case study.

Methods: Semi-structured interviews with one woman with Parkinson's disease were carried out paying particular attention to (a) *how* the decision to have the procedure was made and (b) the affective experience in the time periods immediately prior to the procedure, shortly after and one month later.

Results: The thematic structure derived from the hermeneutic phenomenological analysis comprises the following experiential aspects:
Making the decision: 'I was feeling rather at a dead end with my Parkinson's';
Shifting emotions and feelings: 'Terrified, excited, disappointed, overjoyed';
Embodied meaning: 'This extraordinary procedure where they were going to drill holes in my head'.

Conclusions: This research has elucidated the complexity of decision-making, the emotional landscape and specific bodily nature of the experience of DBS. It has suggested implications for practice informed by both existential-phenomenological theory and health psychology.

Introduction

Deep brain stimulation (DBS) is a new form of biotechnological surgery and it is important to understand patients' experience of it; many of us are living longer lives and as biotechnology advances what we think, feel and do about these matters carries existential import.

DBS and Parkinson's disease

There is considerable evidence of the success of DBS in the alleviation of the motor symptoms of Parkinson's disease. However, clinicians do not always observe a corresponding improvement in psychosocial aspects and a growing body of research addresses this paradox. (Agid, Schüpbach, Gargiulo, Mallet, Houeto, Behar et al., 2006; Hariz, Limousin, Tisch, Jahanshahi & Fjellman-Wiklund, 2011; Schüpbach, Gargiulo, Welter, Mallet, Béhar, Houeto et al. 2006; Schüpbach & Agid, 2008). Common to this research is its use of qualitative methodologies to gain insight into the patients' perspective – what *matters* to them. The value of these approaches is particularly pertinent with neurodegenerative disorders like Parkinson's disease because they are defined by heterogeneity with the patient often perceived as a “law unto himself” (Stern, 1990).

DBS is offered when symptoms cannot be controlled with medication or drug induced side effects become too severe. Specific brain structures are targeted in order to reversibly modify functional brain circuits. This involves the placement of electrodes using computerized stereotactic imaging techniques which are connected to thin insulated leads and linked to a neurostimulator, a

device similar to a pacemaker, which is implanted under the skin in the chest area (Okun et al, 2007). When the stimulator is switched on, electrical impulses are produced which are sent to the brain to stop or reduce the signals that produce Parkinson's disease.

At present, research is limited to life post-DBS and findings demonstrate that DBS offers both possibilities and challenges for living. Although many people experience increased confidence due to motor success, their "new life" brings concerns about stimulator dependency and side effects (Hariz et al, 2011). Agid et al (2006) assessed quality of life via interviews with 29 individuals and findings conformed to the emerging picture of marked motor improvement contrasted with poor psychosocial adjustment. How people incorporate their newfound health poses problems for work, marital and social life and sense of self, alongside body image concerns due to the presence of the stimulator. Although a direct role for stimulation is possible, they argued a more likely explanation is experiencing problems of 'reintegration'.

A related explanation is that treatment using new biotechnology is a disruptive biographical experience. Prior to DBS, patients managed the disease in ways that had become habitual and embedded in their daily lives. Post-DBS these strategies are no longer needed. Some people experienced a loss of control which permeates all aspects of their lives (Gisquet, 2008). Initial elation over improved motor abilities is replaced with feelings of bodily alienation and their lives lose meaning. One individual reported, "Before stimulation, every day

was a fight against the illness. Now, my life seems empty without real stake” (Gisquet, 2008, p. 1849).

The prior beliefs and thoughts of individuals considering DBS play a role in decision-making, coping strategies and adjustment processes. An interview study aimed at eliciting the views of healthcare providers concluded that managing patients’ hopes and expectations was complex, further complicated by media reporting of ‘miracle cures’ (Bell et al, 2011). To counter unrealistic beliefs, family and social support networks are vital for the provision of good psychological care and psychosocial education. Clinicians should aim to be open and transparent, informing patients and families not only about the potential for increased mobility but the psychosocial issues outlined above. As the research stands, it seems to be a case of “the doctor is happy, the patient less so.” (Agid et al, 2006, p. 410).

The current picture is one of a mismatch between an improved motor state and an experienced world different from the one prior to surgery. This situation is comparable to that of a diagnosis of Parkinson’s, a time that represents biomedical coherence for the clinician, whilst for the person diagnosed, it is one of experiential incoherence (Pinder, 1992).

This study aims to contribute to a way of doing health science and to a form of health care which places the person at its centre (Williams & Grant, 1998); one that *enables* people to discuss and make choices in a meaningful way, and that encourages health care professionals to listen to the particular

concerns of individuals. Insight into what *matters* for the person contributes to caring practices which are multidimensional embracing a humanizing and technological focus (Todres, Galvin & Dahlberg, 2007).

The value of an idiographic phenomenological psychology case study

Being idiographic

Ashworth and Greasley (2016) describe an idiographic sensibility recognizing the “realization of the inescapability of the personal lifeworld” (p.572).

Robinson (2011) argues that being idiographic is an *objective* which seeks to describe and explain singular events and things in the dynamic context in which they occur. Idiographic and nomothetic methods complement each other and both are forms of evidence-based knowledge (Runyan, 1983).

The value of the idiographic is seen in the move to personalized medicine and also methodologically in approaches ranging from experience sampling methods (Conner, Tennen, Fleeson & Feldman Barrett, 2009); contemporary idiographic science (Molenaar, 2004; Molenaar & Valsiner, 2008); phenomenological qualitative research (Finlay & Molano-Fisher, 2008; Spiers & Smith, 2016) and theoretical discussions of the relationship between the idiographic/nomothetic dyad (Barlow & Nock, 2009; Robinson, 2011; Salvatore & Valsiner, 2010).

The case study

Nietzsche (1974) said that “One should not wish to divest existence of its *rich ambiguity*” (pp. 335, § 373). Case study research aims to provide concrete

contextual knowledge in the form of exemplars which retain and convey the complexity and nuance of real life. Case study research has been described extensively (Flyvbjerg, 2006; Stake, 1995; Yin, 2003) with Stake proposing that a case might be descriptive, intrinsic or instrumental in its aim. Cases can describe a phenomenon in the context in which it happens. Intrinsic cases are undertaken when the case *itself*, in all its ordinariness, is of interest; the instrumental case takes what has been learned about one case and examines other similar cases in light of that knowledge. This case study straddles all three approaches. It provides detailed research-based descriptions of the DBS experience and it has intrinsic interest. We suggest it has instrumental value because the findings can be ‘transferred to’ (Guba & Lincoln, 1989) or ‘recontextualised’ (Morse, 1994). We are guided by the claim that “formal generalization is overvalued as a source of scientific development, whereas ‘the force of example’ is underestimated” (Flyvbjerg, 2006: 228).

The usefulness of case study research is recognised in the health sciences particularly in the study of dementia (Hellström, Nolan & Lundh, 2005; Kitwood, 1997). It is argued that the approach provides researchers with a flexible and viable tool for developing and evaluating theory, interventions and treatment programmes (Baxter & Jack, 2008).

Phenomenological psychology

The focus of phenomenological psychology is lived experience, how individuals experience events, processes and other aspects of their life (see Blinded, in press; Finlay, 2009 and Langdrige, 2007 for a detailed

discussion). Typically, researchers begin with individual narratives of the phenomenon and from these aim to distil an understanding which elucidates, more broadly, the nature of human being/living. As such, phenomenology has been described as an approach which “begins with the idiographic and moves towards the nomothetic” (Churchill, 2014: 4).

Halling (2008) proposes three levels of analysis to bring about this move: researchers examine and reflect upon the specific experience (say, living with Parkinson’s disease); with several descriptions of this experience, researchers scrutinize them for shared aspects which say something about the nature of the experience more generally (such as unwanted feelings of dependency on family and bodily changes which limit activities); finally, in a more philosophical and fundamental vein, they might ask how the possibility of such feelings and change even exist and what they say about the nature of human being (that human beings are relational and embodied creatures).

Willig (2015) has identified a tension when researchers do not wish to (or their data demands they not do so) lose sight of individual experience, yet want to make inferences which have more universal validity. Her solution was to ask focused process and meaning questions of each individual account giving rise to a more fundamental and shared significance. Similarly, Garza (2011) has proposed developing an idiographic thematic narrative which might prepare “the ground for a *comparative or general* level of analysis” (Garza, 2011:50).

We suggest addressing this tension on a case-by-case basis, being open and attentive to ones’ engagement with the data and what it is telling us. This tension applies to both single- and cumulative-cases and our modest aim here

is to offer some inferences for readers to consider if they are reasonable, recognizable and significant.

Methods

This is a hermeneutic-phenomenological exploration of the experience of undergoing DBS. The first author is an experienced phenomenological researcher whilst the second author is a specialist nurse in movement disorder research with experience in conducting experiential interviews. Ethical approval was given by the Department of Psychological Sciences, Birkbeck University of London.

The study contributes to the emerging picture of the psychosocial consequences of DBS with a detailed focus on (a) *how* the decision to have the procedure is made and (b) the affective experience in the time periods immediately prior to the procedure, shortly after and one month later. As far as we are aware, these particular aspects and temporal dimensions have not been addressed previously.

Participant and data collection

Katherine (a pseudonym), a 72-year-old woman was diagnosed with young onset Parkinson's disease thirty years ago and she recently underwent bilateral posteroventral pallidal DBS. Data were collected through semi-structured interviews by the second author in Katherine's home where she lived alone. Katherine was interviewed three times: 3 weeks prior to the procedure, 4 weeks post procedure and a final time at 12 weeks.

Interview schedules were developed for each time period but as is usual in phenomenological research, the schedule was used as a guide and Katherine was encouraged to introduce topics which were relevant for her. In practice, this might mean abandoning, at least partially, prepared questions and allowing the participant to set the parameters for what is important experientially. Table 1 shows sample questions for each interview including ancillaries and prompts designed to elicit further detail and reflection. All interviews focused on how Katherine was thinking and feeling at the time as well as encouraging more reflective sense making.

(insert Table 1 about here)

Each interview lasted 60-90 minutes and provided 5.25 hours of data in total. Interviews were digitally recorded, transcribed verbatim and anonymized.

Each interview was analyzed separately before being treated as a single data set which was subjected to further analysis in order to examine change across the three time periods. Analytic procedure included several stages: multiple readings to aid 'dwelling' in the experience, becoming aware of and reflecting on the researchers' assumptions and preconceptions so that the focus remained on what *Katherine* said; identification of *thematic moments* where *moments* are understood as presenting "an "aspect" or "face" of the phenomenon under investigation – a sort of touchstone moment by which the rest of the data can be rendered sensible from a particular vantage point"

(Garza, 2004). The identified *moments* were marked in boldface type and remained embedded in the interview text; *moments* were copied and pasted into a separate document and organized into thematic groups which represented *initial* understandings of “coherent threads of meaning” (Garza, 2011, p. 47). Themes represent moments which fit together from the perspective of the researcher. Transformation involves a shift from the facts of ‘what happened’ to possible immanent meanings (Wertz, 1985). The end result is a thematic structure which has moved from “the ‘given facts’ (the data as presented) to ‘intended meanings’ (the data as understood by the researcher)” (Churchill, 2014:10). Themes are both data-driven and constituted out of a dialogue between participant and researcher which inevitably partly reflect the researcher’s perspective and focus.

Findings

The thematic structure comprises three experiential aspects: Making the decision, shifting emotions and feelings and thoughts about DBS and embodied meaning. Numbers in parentheses refer to the interview the extract is drawn from.

Making the decision: “I was feeling rather at a dead end with my Parkinson’s”

Katherine described how being asked to consider DBS cast her Parkinson’s in a different light:

I would say I was feeling rather at a dead end with my Parkinson’s I felt that I was getting worse and nothing seemed to be helping very much. I

think I was complaining probably and he [Katherine's consultant] suddenly introduced this idea of deep brain stimulation and because he introduced it, because he was so conservative about operations and new treatments I took it very seriously. (1)

Katherine's use of the phrase "my Parkinson's" is intimate and hints at the relationship between illness and sense of self. "Dead end" evokes the metaphor of illness-as-journey, one which has stalled and reached an impasse and DBS offers the possibility of breaking out of it. However, there is a more painful interpretation, that of having reached the end of life. Katherine is faced with being-towards-death, the awareness that her life is finite. As such, DBS was something weighty and to be given careful consideration.

Katherine felt fearful and alarmed – the disease she had lived with for over thirty years now required her to consider a "radical" form of surgery which suggested that her Parkinson's had assumed a more threatening status:

I felt that I was worse and it made me somewhat in awe of my Parkinson's that it was considered *by him* of all people to need an operation so I was a bit alarmed as well as somewhat frightened of the idea. (1)

DBS had confronted Katherine with death, something she returned to frequently saying, "I feel my body is up against me...I'm fated to die".

Although not unusual for ideas of death and dying to be foregrounded when facing surgery, their presence indicates the relevance of a social network and professional counseling to help patients confront their fears. Katherine talked explicitly about the value of taking part in this study because she had a “clearer sense” and felt “lighter”, having had the opportunity to talk through issues which had helped clarify for her “certain sorts of muddy areas in my brain”.

Although clinicians encourage patients to discuss decisions with family and friends this is rarely straightforward in the complex web of familial relationships. Katherine has a supportive family but their “slightly horrified” reactions meant that rather than sharing her own fears and concerns, she spent time reassuring them:

Yes, I immediately told the children that this had been proposed as something to look into and they were all slightly horrified and most people’s reaction has been one of slight horror so I’ve been spending my time reassuring them rather against my feeling because I don’t feel that reassured myself but it’s better that then have them with their eyes like saucers saying how could you do such a thing? (1)

Katherine’s fears and her own horror were reflected back to her and as a result she decided to keep them to herself:

I want them to know about it but I don't want them worrying more than necessary, it's hard to take comfort from them because I'm trying to protect them so I can't go to them and say I feel terribly weak and frightened because that's too much for them to take. (1)

Katherine does not have a husband and her wish to protect her children as well as herself from peoples' reaction to DBS is likely to have left her feeling alone.

Thinking about dying was part of Katherine's decision-making and it fluctuated:

Dr X said he hasn't had anybody who hasn't been helped a bit which is enough for me and I know there's a risk in having an operation and I think secretly I think I'll die I don't really, I don't know what I think. (1)

It is, it's very heavy then there's the brighter side of me that thinks don't make such a fuss all these people have had it people are queuing up to have it, it can't be that dangerous. (1)

Katherine knew the decision was hers to make but what she says suggests bewilderment and confusion. A more existential reading might say that not knowing what to think is a way of avoiding feelings of vulnerability and awareness of her own finitude. If she *did know* what to think, then these must be acknowledged.

Katherine was clear that she did not simply want 'facts' to evaluate, she wanted to discuss her fears and concerns and receive a human reassuring response. She said of her consultant, "I was looking for confidence and he didn't give it. He didn't not give it but he didn't give it" and reading about the DBS experience of others was helpful. Several times she said how she would have liked the opportunity to talk to people who had had DBS.

Other worries included personality change and visible signs of surgery.

Katherine described a man who had undergone the procedure:

[He had] two sort of things like horns growing out of his head, he looks awful, it's so frightening and that's obviously where they put the electrodes in he looks like a young deer who's growing horns. (1)

Katherine's sense making is imbued with fear about how the procedure might change her appearance which in turn might affect self-perceptions as well as those from others. These concerns contrasted sharply with her hopes for a successful outcome. The possibility of a reduction in her exhausting and embarrassing tremor encouraged Katherine to be "brave", imagining a different life that was tremor free and "wonderful."

Finally, Katherine's perceptions of the surgical team influenced her decision:

He really wanted to find out what I felt about what he was telling me because most surgeons are very impersonal and rather chilling. (1)

The team appeared to work well together without “a feeling of competitiveness between the different levels of authority” which engendered feelings of trust and security in Katherine; she was comforted by the humanity of the surgeon. This particular experience was in contrast to other times when surgeons had been “chilling” and “impersonal”. These perceptions suggest that feelings of reassurance and *safety* which are so important to decision-making are, at least sometimes, absent from surgeon-patient interactions.

Shifting emotions and feelings: “Terrified”, “Excited”, “Disappointed”, “Overjoyed”

Katherine’s interviews reveal a background orientation of fluctuating emotions, moods and feelings. Indeed, one of the most striking things the analysis shows is the complexity and range of emotional states experienced.

Fearfulness dominated and manifested itself in a number of ways: fear about her body afterwards, *“I’m worried about getting water in the holes in my head”* and fear about motor improvement being temporary, *“I’m frightened of the rest of Parkinson’s engulfing me”*. Being engulfed is a powerful image that conveys Katherine’s sense of the disease as insidious, a bodily trespasser that will eventually swallow her up. This fearfulness intermingled with other feelings and Katherine moved from relief, acceptance and finally excitement before the operation through to failure, disappointment and anger afterwards.

Unsurprisingly, Katherine felt relief when she went into hospital for the procedure:

It was a relief to be in and have it happening because I knew I wanted to do it I knew it, equally strongly I was terrified of it but I was there now and there was nothing for it but to get on and it was a relief instead of waiting instead of thinking about it I was not waiting and thinking about it which was easier. (2)

This shift from fearfulness to relief might signify a relinquishing of control or that Katherine had more actively oriented herself towards acceptance. She moved between 'giving up' and a more active acceptance and it seems more likely that our orientations towards the world contain both these elements:

I stopped feeling apprehensive I sort of gave up I decided to just let it go. I had faith in the team who were looking after me and I felt that was enough and I wasn't likely to die though I might and I sort of came to terms with that. (2)

Those of us who have had operations or had loved ones and friends undergo them will recognize this relinquishing of control, this placing of trust in others and an acknowledgment that however unlikely, dying is a possibility.

Relief and acceptance is only part of the story; Katherine described it as also “unreal” and “exciting”:

It was definitely quite exciting and they seemed to know what they were doing and it was quite a relief to be taken over, what else did they do to me oh yes they scrubbed me down with red soap like cleaning a horse after a race and I felt very curious and they put stuff on my hair though they promised me they wouldn't shave my head. (2)

I felt like I was being challenged in some way and I must rise to it and that was quite exciting, it was quite invigorating after all the waiting. ...I'd been sitting thinking about it and suddenly there it was large as life and actually frankly terrifying but also quite exhilarating. (2)

Feelings of exhilaration, invigoration and rising to the challenge seem to provide further evidence that Katherine had actively taken a more positive orientation toward the surgery. Also worth noting is that despite Katherine's relief that the procedure was going to happen, she was unsure about whether or not her head would be shaved suggesting an element of doubt and lack of trust over what she had been told.

Post DBS, Katherine's emotional landscape changed again and was coloured with feelings of failure, disappointment and anger. She could not discern the “dramatic improvement” hoped for and she felt “puzzled and rather dismayed”

and that somehow, she had failed the surgical team as well as family and friends:

I felt I'd failed, the fact that I wasn't immediately dramatically different made me feel I'd failed, I had a huge sense of failure. (2)

Katherine was not only disappointed that the surgery has not worked she was disappointed in *herself*. Her body had let her down and she was not a successful *patient*.

Over time, Katherine began to notice improvement but it took the familiar surroundings of her home to convince her of it:

I left the hospital convinced that it hadn't worked or convinced that it had only worked in a way that was so marginal that the doctors were pretending to be pleased with me and it was only when I got home that I realized how much better I was. (2)

This realization was accompanied by feelings of "being overjoyed", "grateful" and "happy", all of which left Katherine exhausted. Simultaneously, she experienced abandonment expressed as being "slightly cast adrift" as she struggled to get an appointment to discuss her "new body":

I feel I went through this extraordinary ordeal and I'm owed a certain care and not to be able to get hold of them is very frustrating...one

desperately wants support all the time, I mean in a way I've been given lots of support but I need more, I feel frightened. (3)

Once more, the world was a fearful place for Katherine. Although the surgery had been successful she felt in a sort of limbo – her body altered and she faced the challenge of how to live with the changes. The procedure had given rise to considerable emotional fragility indicating the need for psychological support at all stages.

Embodied meaning: "This extraordinary procedure where they were going to drill holes in my head"

Katherine described the procedure of DBS as "odd", "spectacular", "strange" and "mysterious" and that other peoples' reactions were ones of "horror"; it was alien, the stuff of horror movies and novels:

I feel quite squeamish. I imagine that I will lie there asleep then they will get a drill and make a hole in my head on one side and then the other side and then they'll stick iron things into me and then my heart will stop beating and I'll be dead. (1)

Although Katherine knew that the procedure required great skill and precision, she imagined it as a brutal assault on her body ending with her death.

Postoperatively, her sense of her body was foreign to her:

It's beginning to sink in literally and metaphorically what's happened to me. I think in the beginning I was so relieved not to be dead and so relieved I had a good result that I didn't really focus on the reality of having two electrodes in my brain and a battery in my chest, to be honest when you mention it I feel quite frightened. (3)

Attempts to accept her changed body involved imagining what this new body would be like. Although she dismissed her imaginings, they represented attempts to normalize DBS and for it to become part of her narrative:

I imagine that there's one on each side, they told me that they go in like hard spaghetti and then they soften like cooked spaghetti once they're in so they're quite benign they're not like having a metal thing in your head and they've got 4 claws and these claws sort of cling to the affected area and respond via the wire to the battery and the claws are quite small. I don't know whether there are claws or not and if there aren't claws there are sort of projections off the side of each electrode little bumps.

Little sensors?

Yes little markers but this is pure fantasy I don't think it's true, and then I imagine green and red wire going down attached to these two electrodes I'm not quite sure how they're attached because the end of the electrode is in the brain so how can you get the wire there very odd and it's very like an extremely big kitchen wire with two plaited red and green conduits which go in to a battery which is a normal Duracell

battery in my bosom that's how I imagine it, my battery says Duracell on it. (3)

Uncertainty and fear predominated:

Something had happened to my brain, they put two metal rods in it and I wasn't sure what this meant I was going to be like. (2)

I felt my brain had been taken over and God knows what thoughts had been put in it and would I ever be in control of it again and would I know how to handle my new brain. (2)

Although Katherine did not believe literally that she had a new brain, she expressed repeated concerns about how the brain is the "centre of thought" and that "one feels under threat monkeying around with one's brain". She likened the brain to the heart and imagined that "if one had something done to one's heart one would have the same feeling".

Katherine utilized avoidance and rational deliberation to aid adjustment:

It doesn't really impinge very much, that's the interesting thing, there are days go by when I don't give it a thought, it's become part of me and it doesn't seem so evil to have these things in my brain and I can trace the course of the wire into my battery. It's funny I don't know why it frightened me when you asked about it perhaps I try not to think

about it. I think I do try not to dwell on it because you could go fairly crazy trying to think about having sticks in your head but then I've got two artificial hips and an artificial knee so why am I not worrying about that it's the same intrusion and it's artificial. (3)

She started to accept her "new reality" and being at home began to repair a usually taken-for-granted harmony:

Surrounded by my own things I don't feel that estranged I don't feel that sort of different. (3)

There are days go by when I don't give it a thought, it's become part of me and it doesn't seem so evil to have these things in my brain and I can trace the course of the wire into my battery. (3)

The experience of having DBS was a disruptive experience. The seamless connection of being an embodied situated person in the world had loosened, as if Katherine had lost the accustomed moorings which ground her.

Phenomenologically speaking, her way of Being-in-the-world had shifted, a concept which captures how we are situated in the world as temporal, spatial, embodied and relational beings that strive inexorably to make the world meaningful for ourselves (Kearney, 1994).

Discussion

This study has illuminated how the DBS experience is one of considerable emotional and cognitive turmoil. We extend our analysis by focusing on some of the key findings through an engagement with phenomenological and health psychology theories.

Katherine's emotions and feelings were clearly an important part of her thinking illustrating how our emotional and cognitive lives do not exist as separate entities, divorced from each other, but rather "as two aspects of a single, unified experience" (Furtek, 2010, p. 58). Emotions, moods and feelings are "the other side of cognition" and they are the "indispensable ingredients of thought, judgment and evaluation." (Slaby, 2010).

Support for this view comes from work which finds an active role for emotions in decision-making which is dissimilar from more reasoned consideration (e.g. Heilman, Crişan, Houser, Miclea & Miu, 2010; Simon, 1956, 1957). When individuals process information they have access to both an intuitive automatic mode which is "fast, affective, parallel, associative and holistic" and a more reflective deliberative one which is "slower, sequential, rule-based and analytic" (Usher, Russo, Weyers, Brauner & Zakay, 2011). We suggest that Katherine engaged in both types of thinking which has implications for communication between clinicians and patients and future intervention development. The information model of communication assumes a relationship of clinician-as-expert which enables the patient-as-consumer to make the best choice. This model assumes a straightforward connection

between values and facts; health care professionals provide the facts and patients values define the treatment given. In contrast, more deliberative or concordance models (Emanuel & Emanuel, 1992; Wirtx, Crib & Barber, 2006) emphasize communication as a human and moral *dialogue* and that the beliefs, values and desires of the patient are both emotionally imbued and relevant. Katherine's thinking and decision making is not "detached reflection" (Minger, 2001) but lived sense-making (Inkpin, 2016) which necessitates a careful consideration of the first-person perspective.

Phenomenologically, emotional experiences *disclose* and *open up the world* to us, situating us in an "affective space" (Fuchs, 2013) imbuing our world with meaning. Through these experiences we understand what *matters* to us and we use this knowledge to guide our choices: "Acting is only possible in a world of affective affordances which lend a meaningful structure to the field of possible action." (Fuchs, 2013). Katherine's emotions and feelings attune her to the world and reveal its possibilities for actions.

Whilst recognizing the range of emotions and feelings Katherine experienced, we propose that her fundamental orientation to the world is one of fearfulness. The intentional object of her fear is the DBS procedure because she judges it to be potentially harmful. However, Katherine not only feels fear, she *becomes* fearful, an attunement which is not simply concerned with the object, but has developed into something more pervasive and fundamental, akin to anxiety. Her fear is a "terrifying presence" (Ricoeur, 1966, p. 271) because it confronts her with the possibility of death and the fragility of her existence

(Heidegger, 1962). Katherine contains this fear by committing to surgery, accepting her decision and thus transcending the situation through choice and action.

In other DBS studies patients have described themselves as feeling like “Robocop” or an “electronic doll” after the surgery (Agid et al, 2006). Similarly, Katherine was afraid and anxious about the impact of this relatively new procedure and the “reality” of her changed body was difficult to contemplate. In contrast to theories of embodiment predicated on either biological materialism or cultural determinism (Davis & Walker, 2008), phenomenology dissolves dualist notions insisting on a unified body-self-world system and arguing that we are body-subjects rather than body-as-object for me-as-subject. Thus embodiment means that we do not *have* bodies, rather we *live through* our bodies and it is through them that we understand the world (Merleau-Ponty, 1945; Toombs, 1995). Katherine’s imaginative descriptions of the neurostimulator and electrodes invoke a sense of “*unhomelikeness*”; (Svenaesus, 2011) a sense of ‘not feeling like oneself’, of being off-kilter and that one’s body has taken on alien qualities. Katherine’s surgery has not only disrupted the mood of a familiar body to one of unsettled attunement but has fractured the narrative and meaning-structure of her life (Ferguson, 2012; Kayali & Iqbal, 2013). Katherine needs help to understand her new body and to regain a more *homelike* attunement.

Previous studies are agreed about the importance of good information, psychological guidance and familial support when individuals face the decision

whether or not to have DBS. However, what constitutes 'good' information depends, at least in part, on one's vantage point. Katherine was given ample factual information which she largely discarded; she wanted the opportunity to discuss her concerns and have them taken seriously but what she described as "silly" questions went unasked. Active encouragement to discuss such issues is necessary for people to make better informed decisions and dispel misperceptions as well as encourage understanding of the *meaning* such questions have for them. This requires those involved in their care to step outside of their professional role, no matter how briefly, and see how it looks from the perspective of someone like Katherine. A mutually respectful dialogue predicated on a "knowledge for care" and humanizing framework (Todres, Galvin & Hollway, 2009) is one way to address these issues. This is no easy task; even well-intentioned health care professionals determine the rules of encounter and participatory decision-making and concordance is not yet a reality (Borg Xeureb, Shaw & Lane, 2016).

In line with previous studies, Katherine's experience highlights the importance of patient tailored discussion, counselling and emotional support; highly desirable needs but not always realistic or practicable. One possibility is a 'buddy' support system where a nurse specialist and/or psychologist matches prospective patients with those who have had DBS. This is similar to women with breast cancer who receive one-on-one peer support from breast cancer survivors (Ashbury, Cameron, Mercer, Fitch & Nielsen, 1998). Alternatively, there are interactive computer-based systems such as CHES (Comprehensive Health Enhancement Support System) designed to meet

information, social support and problem solving needs (Gustafson, Hawkins, Pingree, McTavish, Arora et al, 2001). Whatever form support takes, it seems clear that it needs to be on-going and run alongside the entire illness/treatment trajectory of the person (Hathaway, 1986; Mazor et al, 2007).

This study has illustrated the value of the case study and a phenomenological approach in health psychology research. Nevertheless, like all approaches, they offer a necessarily partial perspective. A case study can be seen as a starting point from which to develop multiple lines of research and theory. For example, carrying out further cases which can be compared to one another in order to put hypotheses and theory to the test, or integrating various analytic approaches.

Conclusion

This study has contributed to the small body of literature on the impact of having DBS surgery. It provides an exemplar of how the case study can add to the diverse methodological tool kit for health psychology. Its idiographic focus elucidated the complexity of decision-making, the emotional landscape and specific bodily nature of this experience. Theoretically, it has utilized phenomenological concepts and health psychology research to inform suggestions for person-centered care.

References

[Blinded]. (in press). Interpretative phenomenological analysis. In C. Willig., W. Stainton-Rogers. (eds.). *The Sage Handbook of Qualitative research in Psychology*. London: Sage.

Agid, Y., Schüpbach, M., Gargiulo, M., Mallet, L., Houeto, J.L., Behar, C. & Maltête D. et al (2006). Neurosurgery in Parkinson's disease: The doctor is happy, the patient less so? In: P. Reiderer., H. Reichmann., M.B.H. Youdim., M. Gerlach. (eds.) *Parkinson's Disease and Related Disorders*. New York: Springer Wiley, pp. 409-414.

Ashbury, F.D., Cameron, C., Mercer, S.L., Fitch, M. & Nielsen, E. (1998). One-on-one peer support and quality of life for breast cancer patients. *Patient Education and Counseling*, 35, 89-100.

Ashworth, P. & Greasley, K. (2009). The phenomenology of 'approach to studying: The idiographic turn. *Studies in Higher Education*, 34, 561-576.

Barlow, D. H. & Nock, M. (2009). Why can't we be more idiographic in our research? *Perspectives on Psychological Science*, 4, 19-21.

Baxter, P. & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 13, 544-559.

Bell E., Maxwell B., McAndrews M.P., Sadikot A.F. & Racine E. (2011). A review of social and relational aspects of deep brain stimulation in Parkinson's disease informed by healthcare provider experiences. *Parkinson's Disease*. Available at: <http://dx.doi: 10.4061/2011/871874>

Borg Xuereb, C., Shaw, R. L. & Lane, D. A. (2016). Patients' and physicians' experiences of atrial fibrillation consultations and anticoagulation decision-making: A multi-perspective IPA design. *Psychology & Health*, 31, 436-455.

Conner, T.S., Tennen, H., Fleeson, W. & Barrett, L.F. (2009). Experience sampling methods: A modern idiographic approach to personality research. *Soc Personal Psychol Compass*, 3, 292-313.

Churchill, S. D. (2014). Phenomenology. In: T. Teo (ed.). *Encyclopedia of Critical Psychology*. New York: Springer, pp. 1389-1402

Emanuel, E. J. & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *Journal of the American Medical Association*, 43, 51-58.

Ferguson, T. (2012). I am not myself: Understanding illness as unhomelike Being-in-the world. *AMA Journal of Ethics*, 14, 314-317.

Finlay, L. (2009). Debating phenomenological research methods. *Phenomenology & Practice*, 3, 6-25.

Finlay, L. & Molano-Fisher, P. (2008). 'Transforming' self and world: A phenomenological study of a changing lifeworld following a cochlear implant. *Medicine, Health Care and Philosophy*, 11, 255-267.

Flyvbjerg, B. (2006). Five misunderstandings about case-study research. *Qualitative Inquiry*, 12, 219-245.

Fuchs, T. (2013). The phenomenology of affectivity. In: K.W.M. Fulford., M. Davies., R.G.T. Gipps., G. Graham. & J.Z. Sadler et al (2013) (eds.) *The Oxford Handbook of Philosophy and Psychiatry*. Oxford: Oxford University Press, pp. 612-632.

Furtek, R.A. (2010). Emotion, the bodily, and the cognitive. *Philosophical Explorations*, 13, 51-64.

Garza, G. (2011). Thematic collation: An illustrative analysis of the experience of regret. *Qualitative Research in Psychology*, 8, 40-65.

Garza, G. (2004). Thematic moment analysis: A didactic application of a procedure for phenomenological analysis of narrative data. *Humanistic Psychologist*, 32, 120-68.

Gisquet E. (2008). Cerebral implants and Parkinson's disease: A unique form of biographical disruption? *Social Science & Medicine*, 67, 1847-1851.

Guba, E. G. & Lincoln, Y. S. (1989). *Fourth Generation Evaluation*. Newbury Park, CA: Sage.

Gustafson, D.H., Hawkins, R., Pingree, S., McTavish, F., Arora, N.K. et al. (2001). Effects of computer support on younger women with breast cancer. *Journal of General Internal Medicine*, 16, 435-445.

Hariz, M.G., Limousin, P., Tisch, S., Jahanshahi, M. & Fjellman-Wiklund, A. (2011). Patients' perceptions of life shift after deep brain stimulation for primary dystonia – a qualitative study. *Movement Disorders*, 11, 2101-2106.

Hathaway, D. (1986). Effect of Preoperative Instruction on Postoperative Outcomes: A Meta-Analysis. *Nursing Research*. 35, 269-75

Heidegger, M. (1962). *Being and Time*. (Trans. Macquarrie, J. & Robinson, E.). Oxford: Blackwell.

Heilman, R.M., Crişan, L.G., Houser, D., Miclea, M. & Miu. A.C. (2010). Emotion regulation and decision making under risk and uncertainty. *Emotion*, 10, 257-265.

Hellström, I., Nolan, M. & Lundh, U. (2008). 'We do things together': A case study of 'couplehood' in dementia. *Dementia*, 4, 7-22.

Inkpin, A. (2016). *Disclosing the World. On the Phenomenology of Language*. London: MIT.

Kayali, T. & Iqbal, F. (2013). Depression as unhomelike being-in-the-world? Phenomenology's challenge to our understanding of illness. *Medicine, Health Care and Philosophy*, 16, 31-39.

Kearney, R. (1994). *Modern Movements in European Philosophy*. Manchester: Manchester University Press

Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.

Langdridge, D. (2007). *Phenomenological Psychology: Theory, Research and Method*. Harlow: Pearson Education.

Mazor, K. M., Baril, J., Dugan, E., Spencer, F., Burgwinkle, P. & Gurwitz, J. H. (2007). Patient education about anticoagulant medication: is narrative evidence or statistical evidence more effective? *Patient Education and Counseling*, 69, 145-157.

Mendelsohn D., Lipsman N. & Bernstein M. (2010). Neurosurgeons' perspectives on psychosurgery and neuroenhancement: A qualitative study at one center. *J Neurosurgery*, 113:1212-1218.

Merleau-Ponty, M. (1962). *Phenomenology of Perception*. (Trans. Smith, C.). London: Routledge.

Mingers, J. (2001). Embodying information systems: The contribution of phenomenology. *Information and Organization*, 11,103–128.

Molenaar, P. C. M. (2004). A manifesto on psychology as idiographic science: Bringing the person back into scientific psychology, this time forever. *Measurement*, 2, 201-218.

Molenaar, P. C. M. & Valsiner, J. (2008). How generalization works through the single case: A simple idiographic process analysis of an individual psychotherapy. In: S. Salvatore., J. Valsiner., S. Strout-Yagodzynski., J. Clegg (eds.). *Yearbook of Idiographic Science*. Rome: Firera & Liuzzo Group, pp. 23-38.

Morse, J. M. (1994). 'Emerging from the data': The cognitive process of analysis in qualitative inquiry. In: J. M. Morse (ed.). *Critical Issues in Qualitative Research Methods*. London: Sage, 23-43.

Nietzsche, F. (1974). *The Gay Science*. New York: Vintage.

Okun, M.S., Rodriguez, R.L., Mikos, A., Miller, K., Kellison, I., Kirsch-Darrow, L. et al. (2007). Deep brain stimulation and the role of the neuropsychologist. *The Clinical Neuropsychologist*, 21, 162-189.

Pinder, R. (1992). Coherence and incoherence: Doctors' and patients' perspectives on the diagnosis of Parkinson's disease. *Sociology of Health & Illness*, 14, 1-27.

Ricoeur, P. (1966). *Freedom and Nature: The Voluntary and the Involuntary*. (Trans. Kohák, E.). Evanston: Northwestern University Press.

Robinson, O. C. (2011). The idiographic/nomothetic dichotomy: Tracing historical origins of contemporary confusions. *History and Philosophy of Psychology*, 13, 32-39.

Runyan, W. M. (1983). Idiographic goals and methods in the study of lives. *Journal of Personality*, 51, 413-437.

Salvatore, S. & Valsiner, J. (2010). Between the general and the unique. *Theory & Psychology*, 20, 1-18.

Schüpbach WM. & Agid Y. (2008). Psychosocial adjustment after deep brain stimulation in Parkinson's disease. *Nature Clinical Practice Neurology*, 4: 58-59.

Schüpbach, M., Gargiulo, M., Welter, M.L., Mallet, I., Béhar, C. & Houeto J.L. et al. (2006). Neurosurgery in Parkinson's disease: A distressed mind in a repaired body? *Neurology*, 66, 1811-1816.

Simon, H.A. (1957). *Models of Man: Social and Rational*. Oxford: Wiley.

Simon, H.A. (1956). Rational choice and the structure of the environment. *Psychological Review* 63, 129-138.

Slaby, J. (2010). The other side of existence: Heidegger on boredom. In: S. Flach., D. Margulies & J. Söffner (eds.). *Habitus in Habitat II – other Sides of Cognition Vol. 2*. Peter Lang.

Spiers J, Smith JA (2016) Rebirth and change during a liver kidney transplant: an interpretative phenomenological analysis case study. *QMIP Bulletin*, 21, 14-17.

Stake, R. (1995). *The Art of Case Study Research*. London: Sage.

Stern G. (1990). *Parkinson's Disease: The Facts*. Oxford: Oxford University Press.

Svenaesus, F. (2011). Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. *Medicine, Health Care and Philosophy*, 14, 333-343.

Todres, L., Galvin, K. & Holloway, I. (2009). The humanization of healthcare: A value framework for qualitative research. *International Journal of Qualitative Studies on Health and Well-being*, 4, 68-77.

Todres L., Galvin K. & Dahlberg K. (2007). Lifeworld-led healthcare: revisiting a humanizing philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy*, 10:53-63.

Toombs, S. K. (1995). The lived experience of disability. *Human Studies*, 18: 9-23.

Usher, M., Russo, Z., Weyers, M., Brauner, R., & Zakay, D. (2011). The impact of the mode of thought in complex decisions: Intuitive decisions are better. *Frontiers in Psychology*, 2, 1–13.

Van Manen, M. (1998). Modalities of body experience in illness and health. *Qualitative Health Research* 8, 7-24.

Wertz, F. (1985). Method and findings in a phenomenological psychological study of a complex life event: being criminally victimized. In; A. Giorgi (ed.).

Phenomenology and Psychological Research. Littsburgh: Duquesne University Press, pp. 155-216.

Williams, B.W. & Grant, G. (1998). Defining 'people-centredness: Making the implicit explicit. *Health and Social Care in the Community*, 6, 84-94.

Willig, C. (2015). "My bus is here": A phenomenological exploration of "Living-with-dying". *Health Psychology*, 34, 417-425.

Wirtz, V., Crib, A. & Barber, N. (2006). Patient-doctor decision-making about treatment within the consultation: A critical analysis of models. *Social Science & Medicine*, 62, 116-124.

Yin, R. K. (2003). *Case Study Research: Design and Methods* (3rd ed.). Thousand Oaks, CA: Sage.

Table 1. Sample interview questions across the 3 interviews

Questions	Interview 1	Interview 2	Interview 3
Sample	How did you make the decision to have DBS?; What do you think the procedure will be like and how do you feel about it right now?; How do you think your life will be better after DBS?	What was it like for you in the days leading up to the procedure?; Can you tell me everything about the day in as much detail as possible?; How is everything now?	What has life been like since you came home?; Is life different in the way you expected it to be?; What advice and information would you like to have been given?
Ancillary	What information were you given?; Is this different to how you felt when you made the decision?; What are you hoping for?	How did you prepare for it?; Did you talk to anyone in the days leading up to it?; What were you thinking/feeling before and after?	How do you feel about your body now?; What are your hopes and expectations for the future?; Can you give me an image which captures your experience?
Prompts	Could you say a little more about that?; Please could you give me an example?; If I've understood you correctly, you thought X, is that right?		

