

“WHAT CAN’T BE CURED MUST BE ENDURED”

Living with Parkinson’s disease

Virginia Eatough

Introduction

This hermeneutic–phenomenological study offers an understanding of what it means to be a person living with Parkinson’s disease. It does so through a close examination of the lifeworld of a woman with Parkinson’s whom I call Elsa. The lifeworld or *Lebenswelt* is “the realm of immediate human experience” (Halling, 2008: 155) which is constituted out of shared human structures or fractions which are implicated in all our experiences. These fractions include our embodied natures, our relationships with time, the various activities we are committed to and care for, our moodedness or attunement and the fact that we inhabit a world with and of others (Ashworth, 2016). They can be seen as heuristics, links in the existential chain (Van Der Bruggen & Widdershoven, 2004) which elucidate and clarify lifeworlds. Furthermore, “Each fraction is there for any phenomenon whatsoever, though some fractions may be weightier for the meaning of a given phenomenon than others” (Ashworth, 2016: 23).

The central argument presented here is that understanding the lifeworld of someone with Parkinson’s can strengthen and enrich relevant healthcare practices and policies in order to improve peoples’ well-being. (Van den Berg, 1972; Svenaeus, 2000; Toombs, 2002). First, this requires broadening our ideas of what constitutes evidence to include detailed research-based descriptions of people’s lifeworld experiences rather than simply service users’/patients’ views about healthcare services (Todres, Galvin & Dahlberg, 2007).

Second, it involves making use of phenomenological concepts and phenomenologically inspired theories to help develop a form of care and attention to well-being which has at its centre this lifeworld; that world which *matters* to the person and which an exploration of can illuminate their lived experiences. One such example is the existential theory of well-being proposed by Todres and Galvin (2010, also Chapter 8, this volume), which aims to reach beyond more traditional understandings of well-being (equating with health but not illness for example). They suggest that specific forms of well-being such as physical, emotional, economic and so forth presuppose a fundamental experiential structure of well-being, at the heart of which lies what they call a “unity of dwelling–mobility” (2010: 5). This dwelling–mobility is the deepest experiential possibility of well-being, one which contains within it multiple possibilities of well-being within a person’s lifeworld:

The essence of mobility lies in all the ways in which we are called into the existential possibilities of moving forward with time, space, others, mood and our bodies. The feeling of this “moving forward” is one of energized flow.

The essence of dwelling lies in all the ways that we existentially “come home” to what we have been given in time, space, others, mood and our bodies. The feeling of this “coming home” is one of acceptance, “rootedness” and peace.

(Todres & Galvin, 2010: 5; Chapter 8, this volume)

In what follows, I hope to illustrate the value of a lifeworld approach and of phenomenological theories and concepts. Moreover, I hope to achieve this through a focus on *one* person’s lifeworld. There is a discussion to be had on the merits (or not) of this form of idiographic methodology which will not be discussed here. Suffice to say, that the view held here is akin to John Bayley’s (2012) view of Tolstoy’s characters which is that people are both completely particular and completely general.

A lifeworld

At the time of the interviews, Elsa was aged 82, lived alone and had been diagnosed with Parkinson’s three years previously. Her experience is no longer one of a taken-for-granted world, a world of often unthinking engagement with her body, other people, objects, activities and so on. Rather the disease has and is transforming Elsa’s lifeworld and to illustrate this change, I focus on four lifeworld fractions, namely embodiment, relations with others, self-understanding and project because they carry weight in Elsa’s descriptions of her life.

The embodied presence of Parkinson’s

Phenomenologists are concerned with the body as it is lived (*Leib*) rather than the body of physiological mechanisms and chemical interactions (*Körper*) (Merleau-Ponty, 1962) and *Leib* is “one’s animate body with its ‘inner life’ and ‘point of view’” (Hanna & Thompson, 2003). Elsa’s embodied perspective is now shot through with the pervasive presence of Parkinson’s, which she describes as “constantly in my head” – a significant phrase pointing to how cognition is a deeply embodied and situated activity. Tremor is one such bodily presence which moves in and out of Elsa’s awareness:

If I get cold the tremor is more pronounced. There are times when I’m not aware of the tremor at all, perhaps I’m engrossed in a film or a play or a book, lovely escape route all of them. So, I’ve had that sort of relief, perhaps that’s what you meant. There are times when I would not know that there’s anything wrong with me, and that’s lovely.

Tremor is accentuated when Elsa is cold but diminished or even disappears when engaged in pleasurable activity. Most of us will have experienced when the pain or inconvenience of a minor injury, headache or toothache, for instance, fades into the background when focused on a task and the pleasure or relief it can bring.

In contrast, other aspects of Parkinson’s do not so much fade or hover in and out of Elsa’s awareness; rather they are stubbornly present. Housework requires her to “be conscious of every move” and getting dressed is no longer an effortless daily activity:

I can tell you that getting dressed is a burden unlike what it used to be. You seem to be fighting everything. I think my very early experience of Parkinson’s is when I discovered I was quarrelling with buttons. It [*sic*] wouldn’t do what I wanted then you get suits that don’t do what you want to and shoes that don’t lace up the way you want. So you have a running battle with all these inanimate objects, you see? So getting undressed is an adventure, getting undressed at night is a bigger one still, because you are hopping about, one leg into the pyjamas, yes, that’s great, how about the other leg, oh yes.



Elsa invokes a battle metaphor which highlights the meaning these struggles have for her. In a very real sense, inanimate objects such as buttons and laces are experienced as animate and purposive. Similarly, Elsa’s “tottering” requires mindfulness:

But that is my biggest fear that I will totter, because that’s one of the difficulties at night struggling into the pyjamas and then finding myself suddenly stuck up against the cupboard because I am trying to get the other leg in.

This tottering is more than a symptom of Parkinson’s; rather it is an expression of how Elsa *lives* the disease. It has become her way of being-in-the-world (Phinney & Chesla, 2003).

Elsa’s body has been rendered obtrusive by the disease and constant vigilance and concentration is required as she goes about her daily life:

ELSA: Well, I have learnt to be very careful, especially in the kitchen and I have got rid of a pair of slippers with smooth soles and now have these.

INTERVIEWER: Those slippers have got grip I can see.

ELSA: That’s right, because that I think it’s what enabled me to totter and fall, that was in the kitchen you see and it’s a blow to one’s pride, it takes you by surprise you know, if you’re not in control, it’s a bit daunting.

The natural decline of motility means that greater awareness is needed to carry out mundane household tasks. Such restrictions are part of aging and are typically met with acceptance that one’s body will increasingly impose unwelcome limitations. However, Parkinson’s disease makes the task of aging more arduous because in a very real sense the disease renders one’s body unknowable. Both old age and Parkinson’s have rendered Elsa’s bodily movements slow and tentative, making her body visible in contrast to the invisible and ‘absent’ body (Leder, 1990) we enjoy in health. Her body can no longer be taken-for-granted; rather it is experienced as something she *has* rather than something she *is* (Van Der Bruggen & Widdershoven, 2004).

By wearing slippers with grips, Elsa attempts to regain some sense of unreflective movement, to experience her body as less conspicuous. Those involved in the care of people with Parkinson’s can assist in these attempts to become at ease with one’s changing body, to develop strategies which make it more familiar again and which encourage flow and restrict over-thinking.

For Elsa, pleasurable activities, which in some way define who we are, are integral to our projects and connect us to the world, are no longer harmoniously embedded daily practices:

I used to walk – well, it wouldn’t mean much to you – but from here to my mother’s at X. That’s quite a few miles, it would take me an hour to get there. And I did that for the sheer joy of doing it, I did all my best thinking when I was walking. But now my thinking is restricted to the next paving stone.

Undoubtedly, Elsa’s age has limited her ability to walk long distances. Nonetheless, Parkinson’s disease not only restricts how far she can walk but has removed the joy and sense of freedom it brought. Walking is a source of deep enjoyment for many people; it can feel elemental, evoke a sense of positive well-being and is beneficial to maintaining good health. These aspects are diminished because of Elsa’s need to focus on a reduced microscopic world – the next paving stone. This vigilance is existentially charged because it highlights how the freedom to engage in fundamental life-enhancing activities is severely curtailed.

The changing nature of Elsa’s body is characterized by what Svenaeus (2000) calls “unhomelikeness”, a sense of no longer inhabiting seamlessly a familiar world. Her body has become conspicuous and in doing



so it is no longer capable of skilled flow of action. Elsa has lost what Heidegger (1962) describes as our typical way of being-in-the-world: unreflective “ready-to-hand” coping and engagement in smooth habits and practices. This is similar to accounts of people with dementia when dementia is understood as a deeply embodied breakdown and not simply as a disease of the brain: “The everyday grace of engaged activity is lost . . . what has in the past been transparent, seemingly ‘thoughtless’ activity is now revealed as a reflective act” (Phinney & Chesla, 2003: 296). One consequence of these bodily changes is the imposition of unwanted aid objects into Elsa’s home giving rise to distress, resentment and helplessness. These feelings are most keenly experienced over “a bath which sat in the bath”:

INTERVIEWER: Are you ok? You look as if you are in a bit of pain there.

ELSA: No, I’m just reliving, this is painful to me because she’s a nice person [healthcare professional] and she was doing her best for me, so we get this thing attached to the bed, which I hate, still hate it, bang the head on it now and then. Hmmn . . . she sent someone in to put in a rail. That is really the best thing she did, I mustn’t detract from her kindness. And I had this lavatory guard (laughs) but the worse [sic] thing that happened was that she sent Mediquip with a bath which sat in the bath. That arrived one Friday, hard on its heels came X, that’s the name of the rehabilitation officer. She wanted to demonstrate to me how it worked. She did. And as the demonstration proceeded I got more and more uneasy, that’s why I’m looking like this.

INTERVIEWER: What was your unease about?

ELSA: Having that thing sitting in my bath and turning the place into a nursing home rather than a home.

Although this event happened some time before the interviews, it has the power to evoke negative feelings still, so much so that Elsa was perceived to be in pain. The new and unwanted bath was experienced as invasive, transforming her *home* into something impersonal and unfamiliar.

The relational presence of Parkinson’s

Halling (2008: 1) succinctly reminds us “To live is to live with other people.” Living with Parkinson’s has had a profound effect on Elsa’s relations with others, and as with the physical world there has been a corresponding diminishment of her social world. To a large extent, Elsa has withdrawn from her relationships with family and friends because of a perceived imbalance between what they can do for her and what she can do for them. For example, she no longer accepts invitations to dine with friends: “The fact that I no longer feel I can entertain and then I don’t like accepting hospitality because I can’t reciprocate. I’m told that’s not relevant, you know, but I feel it is.” Not being able to contribute to the easy exchange of ‘give and take’ in the way she once did is a significant loss for Elsa and points to a shortfall in the relational duality which is at the heart of meaningful human relationships.

In part, Elsa’s social world is shrinking because she is on her guard against “pitying looks” and friends “feeling sorry” for her. She says clearly, “I just don’t like the idea of being labelled, as that’s the person who has Parkinson’s.” Recognition that friends wish to help gives rise to uncomfortable feelings:

INTERVIEWER: And what’s that like for you, knowing that people do things that they probably wouldn’t have done in the past?

ELSA: Well, I accept it but inside myself I think it’s a pity that they feel obliged to do that. I have more sympathy with the disabled, the blind and the deaf, I am one of them now, I’m not normal anymore, and that’s a blow to one’s pride.

Having Parkinson’s has led to a tangible shift in how Elsa perceives herself. Its persistent presence has led to unwanted and negative changes in Elsa’s most significant and enduring relationships; to such an extent that

the fleeting company of strangers/acquaintances is experienced as more enjoyable. With strangers, she can experience the value of feeling equal which arises from not knowing about her condition:

ELSA: That's all right; I can meet them on equal terms because they don't know about my condition. And I kid myself; I hope that it's not obvious. Although people are very kind to me.

INTERVIEWER: Strangers are kind?

ELSA: Yes. (laughs)

INTERVIEWER: In what way?

ELSA: I never, I keep my fingers crossed on this, I never get on a bus that's full without somebody leaping up and giving me their seat. Now, I know I look feeble or I look old, I don't know which it is but I'm very grateful for the kindness of strangers.

Elsa embraces the kindness of strangers with a real sense of warmth and gratefulness. She is able to accept this level of generosity because she believes it has been given because of her elderly appearance and associated infirmity and not her Parkinson's. She shows her ease at being an elderly woman who is accepting of a societal act, which represents respect to those who are aged and inevitably less able-bodied.

Many studies report the importance of good social relationships for the maintenance of health and well-being (Antonucci, 1990; House, Landis & Umberson, 1988). Graham and Bassett (2006: 345) point to how "The tender balancing of acts, needs and intentions can make reciprocity difficult to negotiate. Some have difficulty receiving, especially those with a past history characterized as 'giver' rather than 'receiver'." This appears to be true for Elsa. Moreover, there is growing evidence that receiving nonreciprocal support is harmful because of feelings of indebtedness, lowered self-esteem and loss of self-respect (Väänänen, Buunk, Kivimäki, Pentti & Vahtera, 2005). Thus, family therapy and counselling which draw attention to how throughout one's life there are 'inevitable dependencies' (Fineman, 1995) which reflect our deep interconnectedness with others would seem one way to help people like Elsa whose struggle to maintain independence has meant a withdrawal from those most dear to her.

Elsa's relationships with healthcare professionals are characterized by tensions reflecting Elsa's changing, less powerful agentic sense of self and her evolving status as a 'patient'. Despite this, it is notable how Elsa's relationships with caring professionals are alive and meaningful for her in contrast to those with family members and longstanding friends which appear increasingly distant. The former is characterized by an emotional richness and involvedness suggesting that, at least in part, Elsa is more at ease with them.

Within this highly specific relational context, Elsa alternates between being grateful and yet resentful of the help she receives. At times, these feelings almost completely straddle one another:

I think that all that is being done for me, is with the aim of improving my quality of life. If you saw B [physiotherapist] you'd feel the same I think. He's very positive and he makes me feel like I am doing alright – I know I am not – but he assures me that I am. So I try and hold onto that. . . . He's played havoc with my life, I can tell you. The whole of this year I haven't been able to call my soul my own because he comes on Wednesdays and Fridays, so there's not much I can do either side of his visits.

The tone is light-hearted but clear: Elsa appreciates the support but this is set against a discernible resentment of its invasiveness which is especially directed towards the various assessment processes involved. Elsa experiences these as things that are 'done' to her and she is left feeling undignified and vulnerable:

"Can you get on the bed?" So I got on the bed on top of the duvet, I was like a stranded whale then. I couldn't get off. The result of that was that she got a fitment for the bed, which I didn't

want. I told her I didn't want it. "Well, just try it" she said. Very nice person. "Just try it" she said. I had to do it out of decent feelings and there it remained.

Being asked to demonstrate her physical skills is experienced as being asked to 'perform':

ELSA: I would say there are times when I resent having to perform, walk to the wall, come back, walk backwards, walk sideways . . . it's a bit demeaning.

INTERVIEWER: What do you mean by that?

ELSA: I mean that I don't like having to do things to please other people.

INTERVIEWER: I see.

ELSA: You know, that's the first thing they want you to do, it's to walk. And unless they are exceptionally sensitive, that can be something you'd rather not do.

Elsa's descriptions speak of a complex mix of humiliation, umbrage, respect and a wish to please and these relationships are characterized by delicate negotiations:

We're doing tai chi together. He's [physiotherapist] doing his best to restore my balance. But that other bit of me says "you can do as much as you like but if my balance is going, it's going. However, I'll do anything you tell me dear, because you're a nice fellow and I don't want to hurt your feelings." (laughter)

Tension is palpable and fluid and tempered with a wry humour as Elsa navigates between valuing advice and 'knowing what is best for her'. Her age and generation may account, at least in part, for her need to please and be respectful when faced with those 'in authority'. In the attempt to determine 'what is best', acknowledging the *experiential expertise* of the person with Parkinson's can contribute much to the development and maintenance of positive relationships with the healthcare professionals they encounter.

Fine and Glendinning (2005) suggest that dependency in old age is perceived as shameful in some way, a personal attribute to be alleviated. They propose that 'care' and 'dependency' be seen as multi-faceted intertwined phenomena rather than as a relationship of opposites signifying power/powerlessness respectively. This involves thinking about seeking and receiving care as a positive adaptation strategy (Baltes, 1996) one which involves an ethic of care that establishes a relational practice, and which supports the notion of a "complex, life-sustaining web" of connectedness between caregivers and those being cared for (Tronto, 1993). Caring practices founded on reciprocity and mutual obligation with some sense of 'equivalence' cannot be overestimated; in their absence people like Elsa experience a severely weakened sense of belonging and shared interdependence (Graham & Stephenson, 1992; Lewinter, 2003) which shrinks further their already diminished lifeworld.

Self-understanding and projects in a Parkinsonian lifeworld

As one gets older one becomes all too aware of unwanted shifts and changes in our lives and which have an indelible effect on oneself and the people, activities and things we care for. Previous care and commitments to these projects have to be revised and our lives refashioned or even transformed. Elsa's changing body and relationships are testimony to how the 'double whammy' of old age and Parkinson's disease means that her taken-for-granted "being able to be" (Carel, 2008) is challenged. She has to work out a new way of being-in-the-world and those involved in her care face the task of helping her to do this and to envision new possibilities for living. Elsa has been thrown into the world of Parkinson's and this thrown-ness requires her to seek its significance, to make sense of it, so that she might continue to pursue projects that are meaningful for her.



One way Elsa does this is to actively reflect and *place* Parkinson’s in the context of her life. For instance, she is reluctant to attribute loss of energy and balance solely to the disease:

INTERVIEWER: So you have noticed a change in the level of your energy?

ELSA: Oh yeah, not half. But then you see, when you get to 80, you don’t know if it’s because you’re 80 or because you’ve got a condition. (laughs)

INTERVIEWER: Right.

ELSA: I tried that with the Parkinson’s nurse but she didn’t seem to agree with me.

INTERVIEWER: Right, what would she have said?

ELSA: Well, she more or less conveyed that any troubles that I’ve got are Parkinson’s. . . . I tried to convince her that if I go off balance that’s the sort of thing that happens when you are 80 anyway, she wouldn’t buy it.

There is clear resistance in the phrases “I tried to convince her” and “she wouldn’t buy it” which indicates something is at stake in terms of Elsa’s perception of herself. Impression management is fundamental to our relations with other people and requires sensitive handling especially by those in the caring professions. Elsa wants to be and to be seen to be *more than* the disease; she does not deny the disease rather she is attempting to integrate it into her life and acknowledge that change is inevitable:

ELSA: I’m sure they [her sons] must be quite sad to see me now compared to that dragon that used to run up and down the stairs. I’m just a different person and that’s what illness and old age can do to you, it seems to me. I think you go through different phases all through your life, you are the child, and you are the sulky adolescent, and you might be the young bride, or the mother, or the grandmother, you know, each phase becomes a different person in you.

INTERVIEWER: How would you describe the phase you are in now?

ELSA: (Laughs) Grumpy old woman.

INTERVIEWER: You say that with a smile.

ELSA: Yeah, well, I think you need to take these things like that. I’ve done very well. That is one of my attitudes. I have done very well to get to 80 with so very little to bother me.

The metaphor *dragon* suggests that Elsa perceives her younger self as a formidable personality that illness and old age has eroded. Yet, the description of herself as a “grumpy old woman” retains vestiges of this resilient tough self. It echoes a television programme in the UK, *Grumpy Old Women* in which older female celebrities discuss topical issues. Invariably, the women are feisty and spirited. If Elsa is aware of this she might be (un) consciously identifying with such women, helping her to manage this late life stage with resilience.

Acceptance and “gritted teeth” is another way Elsa manages her Parkinson’s. Elsa was a teenager during WW2 and it is perhaps not surprising that her way of thinking about the disease is stoical:

What can’t be cured must be endured. That was a constant saying of my mother’s. She lived to 98 and a half and I pray to God I don’t. Accept. I think that’s the only way to deal with challenges, accept and do what you can about them.

Of course, Elsa’s acceptance could be taken to signify that she is resigned in the face of the disease; however it seems to me that the better interpretation is that it reflects the accumulated awareness of a life that is being lived and reflected on.

Finally, old age and chronic illness bring the future into sharp focus. A diagnosis of Parkinson’s disease dramatically changes any future one might have envisaged:



Oh I cried because I know it's (pause) one of the things that seem to be underlined, is that it's progressive, so I was frightened at what the future might be, living alone. I've got two sons but I don't want to be a burden to them – who does?

As Elsa correctly identifies, elderly people do not want to become a burden. This phrase is so commonplace that all too often we fail to appreciate what it *means* to the person who fears becoming one. As already noted, relationships and roles are no longer founded on a taken-for-granted give and take; rather they are perceived as skewed and characterized by a one-sided dependency. Feeling an inconvenience means that one's *worth* is eroded, that one's existential legitimacy and self-belongingness is under threat (Craig, 2013).

For Elsa, and other people living with Parkinson's, the range of existential possibilities is pared down; one has to come to terms with unwanted limitations and unrealized projects and develop new ways of being. Understanding what it means to inhabit this world of diminished possibilities is a crucial aspect of their care. This care includes support and guidance for how to make room for and accept vulnerabilities, involves thoughtful actions and encouragement to try and restore well-being possibilities so that their lives, as far as is possible are not impoverished:

To help restore well-being for a person whose physical movement is very limited, a helper may focus on the well-being possibilities of facilitating contact with greater spatial horizons through accessing beautiful and expansive sights, smells and sounds; to help restore well-being in an ill person isolated in intensive care, a mere human touch or voice may be the intersubjective welcome that is needed to invite the person out of their sense of isolation.

(Todres & Galvin, 2010: 5; Chapter 8, this volume)

One does not need to be ill to understand how, for example, the experience of walking through woodland, up mountains or on a beach is an expansive one that deepens our embodied connections to the world and others. As we saw for Elsa, walking has always been a source of pleasure, a "sheer joy" which enabled her "best thinking". If someone concentrated on the next paving stone for her, her world could and would expand again. An awareness and understanding of Elsa's loss can lead to a form of care which aims to enable an enhanced experience of well-being. After all, there is a reason we bring flowers to those whose worlds have literally shrunk, whether to a hospital bed, a living room or a front gate.

Concluding comments

In this chapter I have engaged in a hermeneutic-phenomenological reflection of one person's experience of living with Parkinson's disease. Hopefully I have conveyed, at least in part, how Elsa has made sense of this experience, and in turn, how I have interpreted this meaning-making. In my view, understanding something of Elsa's lifeworld can be insightful for the understanding of other people in similar predicaments. I have suggested that there is a need to develop caring practices which conceive of well-being as the multiple possibilities described by Todres and Galvin at the outset of this chapter. For example, carers of people with Parkinson's disease can reflect on how to magnify their contracted spatial horizons by bringing the outside world to them – perhaps bringing beautiful and scented flowers or placing a favoured armchair by a window. Such things aim to *enable* people like Elsa to grasp their existential possibilities so that well-being might flourish and a sense of existential legitimacy be maintained (Craig, 2013). In the face of old age and Parkinson's disease which inevitably looks towards death, many things can be done to help access well-being possibilities which render life more liveable and meaningful. In other words, we should aim to bring "our ways of knowing into closer harmony with our ways of being in the world" (Buttmer, 1976).

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