

A Voice of Travail from A Chronic Pain Patient: The Lived-Experience of A Withdrawn Disability Living Allowance

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Abstract

This study described the lifeworld of one ‘chronic pain patient’, Shelly whose disability living allowance (DLA) was withdrawn. The aim is to explicate the existential impact of this withdrawal when she presented her lived experience of this phenomenon in her narration. As I listened to Shelly’s problem soaked narratives through a relatively unstructured interview, an emerged behind the scene voice of travail became louder through the narratives. The existential phenomenological analysis reveals an experience of erosion of Shelly’s sense of identity, a daily toil and laborious lived body in the context of her life activities and relationships. The narratives also revealed the patriarchal approach of ‘the system that be’ that were compounding and even making the voice of travail louder, eroding autonomy, promoting feeling of helplessness and suffering. These findings were discussed in the context of previous studies. Following the discussion, a reflexive account of the research relationship and how the process of analysis has impacted on this researcher was provided to promote a more transparent accounting of the relational centred methodology and how I came to my interpretation. Findings from this research lend support to the idea of the ontology that fully embodied and integrate with our being in the world, bridging the gap and weaving together a new way of understanding the body-subject and how it experiences and copes with its vulnerability in the world

Key words: Chronic Pain, Disability Living Allowance, Life world, Travail, Embodiment

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Introduction

The wave of austerity and unfavourable economic climate which swept across Europe towards the end of 2009 (Norman & Uba, 2015) led the United Kingdom government to embark on budget cutting and a series of sustained reductions in public spending in 2010. This austerity measure has continued up to the time of writing this article, with the aim of reducing the budget deficits and public debts through closure programmes to either abolish or withdraw funding. The first focus was public bodies funded by the government known as quasi-

autonomous non-governmental organisations (Quangos) and later, incapacity benefits, organisations such as the National Health Service (NHS), leading to varied consequences (Morris, 2010; Hills, 2015). The Disability Living Allowance (DLA)/attendance allowance advisory Board, and the Appointments Commission were returned to Whitehall departments (Morris, 2010).

Some researchers have presented arguments that justified the government’s closures and benefit cut programmes. Allen & Radev (2006) presented that keeping the Quangos promotes lack of transparency and lack of accountability for the tax payers’ money.

It was also reported that in the UK, about 3,000 people go on to the incapacity benefit scheme every week and a mere 300 ever return back to work (Frank & Chamberlain, 2001; Phillips, 2006; Waddell & Burton, 2006). Specifically, the Taskforce on Pain in the work place have argued that benefit payments could compromise the motivation to return to work and recommended that medical benefits for Chronic Pain (CP) should cease at six weeks in order to encourage early mobilisation and return to work (Ministerial Task Force for Health, Safety and Productivity- MTFHSP, 2004). These forms of arguments have led to the setting up of a stringent definition of disability based on substantial limitation in a major life activity, similar to what happened in the US and Canada in the past (Friedland, 1999).

The issue of cuts to benefits for disabled people is not a popular topic among the people and was well contended (Action for M-E, 2016; Morris, 2010; DeGood & Kierman, 1996). However, the Department of Work and Pension (DWP) announced the scrapping of the DLA and an introduction of a new support programme, arguing that £2 billion in savings is expected from ending the DLA (Age UK, 2013). Hence, from April 2013, a new benefit called Personal Independent Payment (PIP) replaced the old DLA (The Disability rights, 2013) and it came to force on February 2013, under part 4 of the welfare reform act, 2012. This led to the reassessment of people obtaining the old DLA and new applicants by the new disability assessors trained and commissioned to carry out this assignment under the DWP (Age UK, 2013).

Although the eligibility criteria for the DLA have not changed for the PIP, it has now become more stringent as disability is now based on substantial limitation in a major life activity (DWP, 2013) similar to the US definition (Friedland, 1999). Eligibility criteria also demanded claimant 'to have had these limitation/difficulties for 3 months and expect them to last for at least 9 months' (Tu & Ginnis, 2012; DWP, 2013) with the exemption of only the terminally ill who are not expected to live more than 6 months (DWP, 2013). Concerns were raised that this way of defining disability could invalidate the eligibility of those with fluctuating disability or whose conditions are episodic and might not fit the orthodox ways of body construction as well/unwell, healthy/unhealthy, abled/disabled

(Action for M-E, 2016; Lightman, Vick, Herd & Mitchell, 2009).

As the PIP came into force, the guidance note stated that claimants will be regularly assessed to re-establish their eligibility and identify the help needed (DWP, 2013). Hence, people living with chronic pain and other chronic conditions were re-assessed, leading to many losing their DLA status as they could not fit well to the new disability definition.

The current study focused on the lived experience of withdrawn DLA of a person living with a chronic pain condition. Chronic pain is a condition characterised by persistent or episodic nociceptive pain of a duration or intensity that adversely affects the function or wellbeing of the patient. Chronic pain is defined as pain that persists or recurs for more than 3 months over a 6-month period (IASP, 1986 & 2016). It is estimated to exert the highest cost of economic burden as a major cause of disability across the world (Phillips, 2006). It is also regarded as the most common medical cause of long term sickness absence annually (Phillips, 2006; Allen, Hubbard & Sullivan, 2005) and could have a profound negative impact on the quality of life of the Chronic Pain Patients (CPPs) in addition to its economic impact (Eriksen, Jensen, Sjogren, Ekholm & Rasmussen, 2003). Without adequate treatment, the CPPs are often unable to work or even carry out the simplest of tasks leading to problems such as depression or stress (Eriksen et al., 2003; Ekman, Jonhagen, Hunsche & Jonsson, 2005). Moreover, the condition might fluctuate and may not fit well within the framework of able/disabled and healthy/ill whereas other types of disabilities could be inferred from an inability to function on a daily basis in the work place or elsewhere (Beatty, 2005).

The struggles of the CPPs to legitimize their chronic illness and achieve a sick role have been well documented in literature. Werner, Isaksen and Malterud, (2004) interviewed ten women who were CPPs about their condition, they revealed how they perceived skepticism, distrust and struggle for the medical legitimisation of their condition as they sought treatment. A systematic review by Newton, Southall, Raphael, Ashford and LeMarchand (2013) showed how feeling of disbelief (also known as de-legitimation in literature) could lead to emotional distress such as depression, guilt and anger among the CPPs. The CPPs could also perceive challenge to their integrity which could subsequently affect their

individual's self-identity, as well as isolation resulting from loss of relationships (Newton et al, 2013). There is however a gap in literature particularly in the UK regarding the impact of the withdrawn DLA from the CPPs who were previously found eligible for it.

The current study explored what it is like for a chronic pain patient (*Shelly) whose DLA was withdrawn.

Method

The central question of this research project is: how does a chronic pain patient who has been entitled to Disability Living Allowance perceive the withdrawal of their benefit; and how does this affect the account of their sense of self or identity?

The study adopted a qualitative method with the specific aim of understanding how a chronic pain patient is thinking and feeling about the policy change that she directly experienced/affected her. A relational centred, existential phenomenological research method was adopted (Finlay & Evans, 2009; Finlay, 2011). It focuses on exploring the lived world of one woman, to understand the process within two phenomena, that is, the experience of having benefit withdrawn as a chronic pain patient; and to provide the researcher's own reflexive process as impacted by the experience of the woman. Although the main focus of this study is to describe Shelly's experience, as a reflexive researcher, the researcher also provides information on how her own psychological process creates opportunity for further exploration of Shelly's experience. This process of phenomenological inquiry is in line with phenomenological and existentialist approaches, which allows for this very personal way of working with the client's predicaments. Thus promoting close resonance with client's experiences and needs (Creswell, 1998; Finlay & Payman, 2013). Attempt was made to stick close to Shelly's experience, but yet not limiting it only to the empirical as I sought to capture both her experience and the research process as it unfolded in an embodied, experiential relational way (Finlay & Payman, 2013).

This research follows an idiographic approach, making no assumption of inter-subjectivity or shared realities across different individuals who might also be in the same condition. This opposes the positivistic oriented nomothetic approach by which

impression and interpretations are based on averaging data obtained from large samples where resulting statistics can only apply to an average person, not to a particular individual.

Bracketing

As a clinical psychologist who also received training in pain psychology, I have worked within a pain management clinic and have some knowledge of clinical and psychological features of chronic pain syndromes. My usual practice tends more towards positivistic orientation using scales/inventories and psychological measures to assess feelings, thoughts, emotions, beliefs and other psychological states of my clients. I then would consider this information in the context of a clinical interview, conducted before formulating hypothesis and establishing the aetiology of my clients' problems. In my role as clinical psychologist, my interview techniques will usually be carried out with some preconceived ideas and theoretical underpinnings. I am quite aware that this orientation is contrary to the research method adopted for this study. I had to work hard to "bracket" these presuppositions and my natural, positivistic and reductionism epistemology in order to attend genuinely and actively to my participant's views and feelings. My trainings as a psychotherapist and a qualitative researcher significantly assisted me on my effort to 'bracket' and be attuned to my co researcher (Shelly).

Literature was delayed till after data collection in accordance with Hamil and Sinclair's (2010) suggestion to avoid phrasing questions or analysing data for themes already existing in the literature. Chan, Fung and Chien (2013) suggested that this will help to address the problem of researchers' pre-understanding of the research questions and subsequently enhance 'bracketing'.

Ethical approval

Ethical approval for the study was obtained from the ethics committee at Manchester Institute of Psychotherapy. After ethical approval, the potential co-researcher was sent information sheets and a consent form and was afforded an opportunity to ask questions about the study before she confirmed her agreement to participate. She was assured of anonymity, confidentiality and the right to withdraw at any stage of the study. At the beginning of the interview, a verbal consent was also obtained from the participant. Detailed process of withdrawing the transcript was provided on the information sheet.

My co-researcher was informed of an opportunity for one psychotherapy session, which had been arranged for her with a qualified psychotherapist without charge as compensatory for her time, if she wished. A mutual place for the interview was also agreed on before the interview.

Participant (co-researcher)

Shelly, a 47-year-old Caucasian lady, is an acquaintance that I met in a charity cafeteria where I used to volunteer to serve. She had become a friend and will freely discuss her family problems, pain problems, as well as her current visits to the hospital and her doctor's impressions with me. Undoubtedly, a mutual trust became established between the two of us as she began to see me as someone who listened to her and whom she could share her problems with. I believe that this might have promoted her free attitude to share her personal and interpersonal details in the discussions that emanated from this interview.

My co-researcher is a mother of one daughter (aged 24years) and she has two grandchildren (boy and girl). She has the diagnoses of Fibromyalgia, sciatica back pain and asthma. She had been on Disability Living Allowance (DLA) for over ten years before a ruling in 2013 'took her off' the DLA list. She is currently on employment and support allowance (ESA) and has been placed on trainings at different locations.

Data collection- interview

Prior to the interview, an information leaflet and an informed consent form were completed by the co researcher who also provided a verbal consent. An in-depth interview guided only by the topic of the discussion was adopted for this study. This method is deemed useful to enable the researcher to have complete data, tone and implied meanings. Questions asked were open ended intended mainly as cues to elicit talk from the woman. The interview lasted for 90-minutes and was recorded with the co-researcher's consent. The woman was debriefed after the interview. A week after the interview, my co-researcher also dropped a written poem for me to further express her feelings and thoughts (appendix 1). This poem formed part of the materials analysed below.

Analysis

A relational phenomenological analysis (RPA) was adopted to analysis the data. The tape was listened to

and transcribed to text which was then hermeneutically analysed. The transcript was read a number of times by which point the investigator became very familiar with the material. The transcripts were examined for identity related themes, some resulting from the woman's direct account. As this process continued, the researcher continues to engage in interpretative analysis with the text and transcript in an attempt to unravel the meanings contained in the woman's account and how this account impacted on the researcher. I had endeavoured to pay close attention to what was explicitly and implicitly communicated by my co researcher as she constructed a narrative around her meaning of her DLA withdrawal and her experience with the 'system that be'.

Results and discussion

Broad theme: A voice of Travail

Travail is a word that comes from the Latin word, *trepalium*, meaning "instrument of torture". Thesaurus on line and Oxford dictionary (2014) described it as 'to work strenuously, especially when arduous or involving painful effort, toil, tribulation or agony or anguish. While the closest English word is toil, travail means you are not just exerting monumental effort but suffering as you do so'. It seems that I clearly and loudly heard the voice of travail echoing in the voice of my participant as she described her experience of benefit revocation in this project. Shelly was asked about what the revocation of her DLA means to her now. She responded by querying "the point in life" and described herself as being "at the bottom of the sea, drowning" in conversation below:

Seriously, I do, yeah. Of course I do. I've been trying to keep my head above the waters, but feeling like I'm drowning. I think I'm at the bottom of the sea and I'm drowning.

Shelly's hyperbolic metaphor of being 'at the bottom of the sea drowning' touched the existential issue of life and how she is struggling to keep alive. As if choked, this was echoed again in her poem (appendix 1) when she said, "*their policies are burning me,*" "*can't you ease up a little and allow us to breathe and heal?*" How long the struggle, the labour or toil will be to keep alive 'at the bottom of the sea' or in the struggle 'to breathe' is hard to imagine. Her next conversation further described her experience and how she feels about it. Shelly resonated

“I just want an end to it. Sick and struggling, exhausting and tired, trying to just get on with life”.

Shelly also showed her feeling of helplessness and anguish as she further described her experience of the withdrawn benefit this way;

“I have nowhere to turn, as I get disfigured by the state”.

Now that the benefit is withdrawn, she is *“a lamb in a jungle, tied up in a post and just left there”* to *“become a super lunch, a super food for the lions and tigers.”* Chronic pain itself has its own challenges for Shelly, as it exerts its debilitating effect and limits her ability to engage in meaningful occupations, leading to diminished quality of life (Newton et al, 2013). Studies showed how it causes stress on all components of a person’s life including family, health, psychological status, spirituality and socioeconomic circumstances. It might appear sensible that Shelly’s narratives show laborious struggle to keep alive if the impact of her chronic pain is combined with the impact of the benefit withdrawal. Shelly’s story presented the State as the “torturer” and herself as “the instrument of torture”.

Should the government be labelled ‘torturer’ for striving to save money and ‘rehabilitate’ the people previously living on benefits back to work? Previous studies have shown strong empirical evidence in support of back to work programmes for people with musculoskeletal chronic pain (for example, Waddell, Burton & Kendall, 2008; Waddell et al 2006). These studies also showed that the principles of remaining at work could be applied to most people with common musculoskeletal disorders and this could have significant positive impact on their psychological wellbeing (Waddell et al 2008; 2006). It can be argued that the government’s duty is to save money especially at this period when the government is battling with increased national debt and the recovering of the collapsing economy.

But while the policy sounds beneficial to the nation, how is this to Shelly? Shelly, standing from an alienated position, described her agony and laborious trial under the heavy hand of ‘their burning’ policy. Other major issues promoting travail for Shelly are further illustrated in the four major subthemes uncovered from the interview which will be discussed in turn.

Subthemes:

1. Paternalism ideology promoting travail.

A significant theme from Shelly’s narrative centres on how her relationship with the state could be captured by Paternalism Ideology (PI). PI is defined as the interference of a state or an individual with another person, either with or against their will with a claim that the person interfered with will be better off or protected from harm (Dworkin, 2010). Below is Shelly’s narrative of how she has been on benefits:

“, they put me on sickness benefit. I was on it for, I could say twelve-years actually, for I was on sickness benefit, due to the fact of being ill...

Yes, I was on Sickness benefit and income support as well. Which didn't give me a great standard of living at all but at least, I could at least pay one or two bills”.

Forrat (2012) described state benefit gesture as soft paternalism where the state assists the disadvantaged through the provision of public housing, and gives money to the poor in the form of various benefits. Classical neo-economists (Beaulier & Caplan, 2007) were the prominent critics of the welfare state as they felt that soft paternalism divides the society into the elites and the masses, where the latter need guidance and protection and the former are capable of providing it (Murray, 1990; Hernstein & Murray, 1994; Sowell, 1996 & Chavez, 2002). They argued that the welfare state perversely harms the very people it is intended to help. The classical neo-economic viewpoint appears to be the far right. Beaulier et al, (2007) argued that giving money to the poor reduces their incentive to enter the work force, has ill-effect on their judgement, promotes self-control problems and failure to acquire experience, and eventually left people at lower class level. They thereby suggested a reduction of the size of welfare benefits, limiting their duration, restricting eligibility, and even abolition.

Shelly’s next narrative appeared to deviate from the above arguments as it seemed the benefits have helped her to a point where she has been pursuing an online degree programme but had to stop it after her DLA status was withdrawn.

“But it's like, you know, I was doing a degree to get myself up so that I could eventually come off the benefit one day, may be going into teaching mathematics. But that was my dream, they've kicked the dream from underneath my feet. They sent me to “Learn –Direct” ..., for me to do some training with

them or whatever. And it's compulsory and if I don't go, I'm going to lose all my benefits, So I'll be left with nothing.So they bag you up into a corner, they'll bully you and you are already not well. So, what will this do, this exasperates the problem you've got. So no wonder you know, I'm just gonna feel down and depressed, and feel like what the heck is this all about. So, yeah.....”.

Shelly's narrative here appears to show how the state could move from the soft paternalism to the hard one and how she also defied the reasoning and critical arguments of the classical neo-economists (Murray, Hernstein et al, 1994; Sowell, 1996; Chavez, 2002). She was pursuing pre-degree programme so that she “can eventually come off the benefit one day” but had to stop to create more time to enable her meet the conditions for receiving the ESA from the government. Shelly's DLA seems to be for survival since she has no other means or source of income and she called the absence of her DLA a ‘hard time’. To Glaeser (2006), the welfare programme is like the state giving more choice to the citizens and withdrawing the choice could be more costly and intrusive. Therefore, Shelly's DLA withdrawal might have opened Shelly up to this cost and intrusion. But the replacement will fall well within the hard paternalistic orientation defined by Glaeser (2006).

It sounds puzzling that Shelly was not supported with her dream of earning a degree, but this fits with the idea of a new paternalistic welfare state, which assumes that service users lack certain capacities and require supervisory programs to guide them towards self-sufficiency (Ben –Ishai, 2012). This is incompatible with the obligation of a “Just state” (Ben-Ishai, 2012) that fosters autonomy. Shelly used the word ‘compulsory’, and the metaphor “*bagged you to a corner and bully you*”, and another metaphor, “*because I'm jumping through their hooks and I have to do whatever they tell me to do*” to describe her relationship with the state. The last metaphor depicts a helpless fish in pain, on the hook of the fisherman to be disposed as the fisherman wishes. Shelly's rich use of metaphor described the state with the characteristic of hard paternalism, thus confirming Glaeser's (2006) idea that soft paternalism involving welfare, will later increase support for hard paternalism.

It's hard to know whether the state-sponsored programme that Shelly was co-opted to will achieve

its set goals, but what is clear from this data is the evidence of her struggle to keep up with the state's expectation against her will because Shelly's original dream has been “kicked off underneath her feet”. Shelly traced her current psychological status of ‘feeling down and depressed’ to her experience with the state as though in ‘dèjà vu’ when she said ‘so no wonder I'm just gonna...’. There is also a sense of alienation and persecution by the power that be, still reinforcing the idea of hard paternalism. She said:

“Yeah, I'm getting punished for being ill. That's what I have said from the beginning. I'm being punished for being ill. I'm a criminal for being ill. I am guilty I'm ill. I'm just waiting for them to pass more sentences.”

It appears she felt she was receiving punishment from two angles, referring to her pain and the state that is also ‘punishing’ her ‘for being ill’. Here is her description of this metaphorically;

“Yes, and they are punishing me for having the illness. Yeah. “I'm between the devil (is this her pain?) “and the deep blue sea” (is this the state?).

This depicts her as an ‘object of torture’, echoing the voice of travail.

The ambivalence relationship of my co-researcher to her DLA/ESA also ‘leaped out’ in the excerpt above like ‘I hate you (that is, ‘you are not enough’), don't leave me’ (‘but I need you’) phrase (Kreisman & Straw, 2010). On one hand, she felt really sad that her DLA has been stopped, but on the other, she laboured hard to meet the criteria for ESA which appears not enough for living. She recounted about her present situation

“I have to do away with some things to buy food. I have to do away with gas and electricity. That means there has been some few weeks I have to do away with Gas and electricity and I have no gas to cook. I've not got anything to cook. It's just robbing Peter to pay Paul. You know, Ermm.. I have got phone to pay and every fortnight, I have to pay my phone bills and then on top of that pay the rent. So that week, I might be left with like £20 to £30 to last for two weeks. And it's not a case of I'm going on partying on a Friday and Saturday if I could. I'm not buying any luxury, I don't buy, you know, there is nothing that I buy that is considered as any kind of luxury or whatsoever. Just normal things. Pay the bills. That's it.... (Silence). I'm trying not to get into debt with the bills because the last thing I need is the

bailiff hanging out at my door.... because that really will be the end. ...”

Without the next major theme identified from Shelly’s narrative, one would wonder what her motivation to continue with such insufficient amount for sustenance is rather than seeking a job.

2. Embodiment (Disappointing Body).

The phenomenological definition of embodiment defines it as an effect where the body, its sensorimotor state, its morphology or its mental representation play an important role in information processing (Korner, Topolinski and Slack, 2015; Glenberg, 2010). This framework calls for unification and the analysis of those processes arising from the recurrent, dynamic interactions of behaviour, brain, bodily processes and changes in the physical and social world. It has its philosophical route in Merleau-Ponty’s (1962) phenomenology of perception which proposed that the body is our general medium from having a world. There is the assumption that thoughts, feelings and behaviours are grounded in bodily interaction with the environment (Glenberg, 2010). The collection of themes below describes how Shelly experienced her body phenomenologically as well as how this interacted with her behaviour, thoughts and feelings to promote her travail.

Body creating barrier to employment

As Shelly was experiencing a persistent pain condition which has gone sciatica, she described her body as creating a barrier to employment or ability to remain on job in this narrative. Shelly’s thought is presented in her statement below;

“Often, yeah, I mean I’ll love full time job, I’ll love it, but I know that I can’t do it, because my health won’t let me, so I’m limited to few hours a day, and it’s about finding that kind of job.”

This is because of the uncertainty she often feel from her body:

And then, how am I going to do it, because I can’t say it’s between the hours of whatever and whatever, I am feeling okay, and in which day I’m going to be really in pain and be feeling uncomfortable and not feeling great whilst I’m doing whatever I’m doing”.

On how the health condition affected her, she narrated how she braved her pain to do things but ending up amplifying the fluidity of her body and her discomfort. She described how hard to predict

what is best to do without experiencing tremendous pain in her excerpt below;

“Because (of) my health condition (it) is hard for me to do anything for any long period of time, I can’t sit down for any long period, I can’t stand up for too long, I can’t walk for too long. Er, mmm it’s a mismatch of all these three things, sitting down, standing up and walking that be. I can stand up for five minutes and walk to two metres, then you are able to walk, and then.....”

Again, she described this uncertainty regarding her body’s ability to carry out actions dictated by her nervous system (Konner et al, 2015);

“.....yeah, that is it. Yeah. Because you can see me today, I can be walking, feeling a little bit okay. And then the next time you see me, I could be holding on to the walls, trying to drag my feet along. So, then the wall becomes my best hold because I had to hold onto it to get to anywhere I need to go”.

This narrative explains why she has been on the DLA for 12 years as her condition does not seem to fit the work environment expectations. Patel, Greasely and Watson’s (2007) reported perceived overarching barriers to return to work among unemployed chronic musculoskeletal pain patients to include financial and physical uncertainty, as well as their pain condition. Shelly seems to have described a disabling pain condition that will require a special provision to fit the work environment. However, Siebers (2011) noted how difficult it may be for a ‘disabled’ person to fit in to the work environment if they will require special provision that will make the ‘business owners bend over backwards to accommodate access that able bodied persons take for granted’.

The bodies-at-odds/body Fluidity

In an attempt to further understand what it is like to be Shelly, she provided further insight to what goes on in her body daily;

“Shooting pain, sometimes... you try to massage it, and the pain..., it’s like you are not relieved from that pain. ...you usually getting, let’s say 10 being the worst pain and 0 being none, but you are either getting 5 or you getting 10. Walking up the stairs, my God man, it’s like. ... I feel like mountaineering. My God! It’s only stairs. I use to walk or run up to 50 stairs and I feel nothing. Now I can hardly finish walking up one stairs! You know, you have pain in your chest because you get asthma as well. You try to cope with that, and then you get one thing going, then another thing going, then another, then

another, just bugging you down and just stopping you from, even trying to move normally, you can't.

Shelly's narrative described someone with the diagnosis of fibromyalgia, a condition characterised by a widespread pain and tenderness; and which legitimised her right to DLA for about 12 years. Despite medication, she still experienced 'sciatic' back pain which "causes lots of pain most of the time". Shelly's narrative described a body that is disappointing and "at odds" with her expectations (Vicks et al, 2010; Thomson, 1997). Scarry (1987, in Smith, 2006) described the journey that a fibromyalgia patient might have gone through to obtain a doctor's diagnosis of the condition as laborious. It appears she must have been relieved when her physician labelled her condition, since fibromyalgia has no organic causation (Scarry, 1996 in Smith, 2006). However, getting fibromyalgia diagnosis is one thing; living with the condition is another. Since the medical knowledge and practices are built upon the conceptualisation of the body as a material functioning system, consisting of muscles, bones, tissues, nerves and chemical substances (Boyd, 2012; Bullington, 2009), this therefore makes a condition with no organic causation difficult to treat. Bullington (2009) found it puzzling to see how people turn to the health care system to seek help for a variety of psychosomatic/psychosocial problems, allowing their bodies objectified and to be treated like a malfunctioning machine without considering their lived experiences.

In line with Leder's (1990) and Phinney's (2002) observations that chronic pain can thwart the meaning and reordered the life stories of sufferers, Shelly's story showed how her illness condition has "thwarted and reordered" her meaningful life stories. Shelly described how she "used to walk or run up to 50 stairs and feel nothing", but now, her chronic pain condition has placed the painful body in focus, rupturing the natural connection of the body to the world and diminishing her articulation of self and the world. The body that was once taken for granted to the point that it disappears from immediate awareness has now become visible and unfamiliar (Leder, 1990). It appears that Shelly would benefit more from a therapeutic process that could re-insert the body into the flow of experience, where the body disappears into its natural science in order to allow the world to once again unfold (Bullington, 2009).

Shelly's description of her condition has also amplified what researchers have previously been observed as common experience of people living with chronic pain conditions with regards to the fluxing body (Lightman et al, 2009; Fisher, Emerson, Firpo, Ptak, Wonn, & Bartolacci, 2007 & Friedland, 1999). In a world that emphasise categorical orientation or what Longhurst (2001) called binaries of the body as, for example, able/disable, health/ill, this might create a dilemma and generate controversies around the individual who is experiencing a fluxing or fluctuating body. The description of the body as either/or creates a situation described by Lightman et al (2009) as bodies-at-odds. This creates discomfort because the individual possesses the ability to live sometimes as healthy, sometimes ill, sometimes able, and sometimes disabled. In essence, Shelly's narrative showed a contending sense of self outside the mainstream culture and her own culture due to the issue of the unstable body (Sandahl, 2003). Unfortunately, little attention has been paid to the fact that many people experience fluctuations in impairment or episodes of wellness within disability studies and disability-related policy and legislation (Phinney, 2002; Lightman et al, 2009; Siebers, 2011).

3. Sense of self-worthlessness and loneliness

Pertaining to her sense of self, Shelly described herself as a 'no class person', a 'nobody', a 'nothing'. 'Sense of self' and her 'feelings' became inseparable.

I am a no class person. That is how I feel. I am a no class person.....

Previous studies also noted the narrow medicalised view of the suffering of individuals living with chronic pain and how often they experience a sense of loneliness as they observe their former self-image crumbling away and without the simultaneous development of a new image (Charmaz, 1983; Cannella, Lobel, Glass, Lokshina & Graham, 2007). It appears Shelly's DLA was serving as a form of recognition of her suffering from her pain condition, validating herself and helping to save her sense of self from total collapse. Now that the benefit is withdrawn, her sense of self plummeted and she saw herself as worth 'nothing'.

4. Insensitivity- what employer is going to employ you?

Shelly sarcastically recounted her disappointing experience of not been able to secure a job due to the insensitivity of employers towards her health problem, she asked;

"What employer is going to employ you? Cause they just want workers, they are not interested in your health, so to find that certain number of hours per day to do the work, I'm looking but I've not find in much look"

However, the most prominent insensitivity felt by Shelly appeared to be from the state health assessor whom she said did not show her any recognition:

*"They sent me to see a medical professional, which didn't acknowledge anything that I was saying. ...Just typing away on the computer.... She didn't look at me. She didn't listen. They just made up their own mind and basically signed me off, Ermmm, and she wrote up to the *DSS and got me signed off. She said I was fit for work.....And clearly my medical record says that I am not fit for work. But this lady thinks I am".*

....."The whole situation of it all right from the very start that they send me to the health care professionals, the obnoxious arrogant attitude from her, the obnoxious and arrogant attitude from the judge, and just..... you know, I'm ill, I'm not a criminal. So, they make you feel that you are nobody".

Shelly described a feeling of not been accounted for by the judge, the state agents and the medical assessor who authorised the removal of her 12 years old benefit without considering the implication of this on her. Her description of the health professionals here appear to fit the paternalistic way of working by medical professionals decried and detested by Coulter (1999) and Glenton (2003). These authors commented that medical professionals reproduce knowledge which support their social position as educated experts and justifies the treatment they give to patients with no consideration of the agentic position of the patients. Anndale & Clark (1996) called this type of positioning 'patriarchal model of thinking and behaving'. Shelly responded to this by feeling let down by the system; that 'nobody listens'; and subsequently that she has 'nowhere to turn,'; 'trapped in a system she cannot fight.' Anndale et al (1996) and Luke (1974) noted that the pervading patriarchal models of thinking and behaving could become inherently dominating,

controlling and objectifying and lead to power display

Reflexivity

The use of a relational phenomenological approach enabled me to capture the richness of the lifeworld experience of how a policy adopted for the generality of a society affected the lived experience of an individual. As data continued to emerge from the researcher-participant relationship, I was aware that a co-creation was taking place in the embodied dialogical encounter (Finlay, 2009). I was aware that the intersubjective space between us was allowing each of us to impact one another causing an intermingling in the pre-analytic participation as we both actively engaged in an interactional encounter (Finlay, 2009). Adopting the principles of Finlay's relational phenomenological approach where I engaged in open presence, embodied intersubjectivity, dialogic co-creation and the entangled selves to understand another's (Shelly's) personhood has brought new realities to me about how 'the power that be' could use hard and soft paternalism, to generate impact that could create and maintain unhealthy dependency within the society (Jones, 1996; Coulter, 1999).

Considering the difficulty of my co-researcher to break her circle of 'torture', I had noticed a discomfoting feeling at one point during the interview, an aroused feeling where I felt the helplessness of having "nowhere to turn" in the face of 'burning' circumstance. As my feelings of discomfort escalated, this dialogue ensued between me and Shelly,

R: *I really felt like crying when you said that...*

Co researcher: *Yeah (eyes turned red, position adjusted) ... Oh don't cry because you let me cry as well. You know, it's one of those things....So, yeah.....*

I was aware that what I said could have re-directed the focus from Shelly to me as I empathise with her. But I was glad that instead of this, it seemed to help her to experience her inner and repressed emotion. The process of my reflexivity and supervision revealed how my own childhood experience of hardship and difficulties in my early academic journey had suddenly emerged as a parallel process as I listened to the narrative of my co-researcher. This has brought alive the complexity of the intersubjective space where the past selves surface to interact with those present. Rather than becoming

preoccupied with my own emotions and experiences, I have stayed close with my co-researcher as our dialogues brought new realities into being from her lived experience. We seemed to become entangled where the “feel like crying” became a commonality, bringing the question, ‘was the crying mine or hers’ or ‘was it for me or for her’. This is where reflexivity, adequate supervision and use of bracketing become essential tools in relational phenomenological approach (Finlay, 2009). However, the significant issue here is that it appears that this interpersonal dialogue with my co-researcher seems to meet a fundamental need to experience shared reality in me. It seems the commonality of an inner state has been appropriately motivated and there is a successful connection of shared reality (Echterhof, Higgins & Levine, 2009).

Conclusion and recommendations

The themes from Shelly’s narrative showed how the withdrawal of her DLA and her enlistment in the government’s programme has not ‘rehabilitated’ her, but has instead increased her pain and kept her on within the system for longer. This at the end will seem to cost more than any financial saving in line with previous researchers’ observations (Good, 1992; Glenton, 2003). As a therapist who adopts transactional analysis in my approach of working with clients, the recurring theme from Shelly’s narrative of not being heard, being punished, not acknowledged or understood seems to fit into the description of the parental injunction of ‘don’t exist’ and ‘don’t be important’ toxic messages from the Parent ego states (Goulding & Goulding, 1976) and classified as part of the survival injunctions in TA terms (McNeel, 2000). Bollas (1987) proposed a similar concept of lived relationships that leaves shadows in our living body from how we were handled as a baby, how we were attuned to. The end result of this injunction could be depressive/suicidal thoughts or feeling of worthlessness (I don’t matter) and an existential life position of You are Okay, I am not Okay (the victim positioning) with the childhood decision/belief of ‘I am never going to be heard’ and a sense of hopelessness.

This idea has been noted to underlie fibromyalgia and other chronic pain conditions. Appel-Opper (2008a,b) noted that ‘some childhood experiences will be ‘unthought’ and ‘unsensed’ by the person concerned, but remain living in the body waiting to be heard by some-body’ and manifest itself as psychosomatic problems. The whole Shelly’s

experience appears as an impasse (Goulding & Goulding, 1976), a circle of woe, unending movement from sorrow to woe, a voice of travail. I conclude, like Appel-Opper (2008a) that in this impasse condition, ‘there is also something like a hope, ‘a healthy striving’ in the body that one day ‘some-body’ will be able to listen, to see the invisible and just to be there’.

It is interesting that my participant has never been referred for psychological intervention or psychotherapy. This has implication for the need to include psychotherapeutic services within pain management. I believe that the state will benefit more from promoting autonomy and involving the individual in the decisions that concerns them than the use of power. Lukes (1974) argued that the use of power may avert open grievance or actual conflict, but the latent conflicts which consist in a contradiction between the interest of those exercising power and the real interest of those they exclude remains. Like Tomasini (2013) reiterate, there is need to consider the idea of the ontology that fully embodied and integrate with our being in the world, bridging the gap and weaving together a new way of understanding the body-subject and how it experiences and copes with its vulnerability in the world.

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Appendix 1

My co-researcher's poem handed over to me after the interview.

Poem written by Shelly the co-research

*Hard times are here, I have nowhere to turn,
as I get disfigured by the state.
Their policies are burning me, they don't
care, (it) is our fate.
Don't be ill (unwell) in this country, they
sweep you all the same
You for your illnesses are to blame
I hope someday things will have to change,
and people treated with dignity again.
Is it not the responsibility of the policy
makers to include everyone?
Yet folk like we (us) are made a victim.
Can't you ease up a little and allow us to
breath and heal?
After all we are human and we do suffer and
feel.*