‘My sister won’t have a normal life forever’: Can Bronfenbrenner’s Systems Theory account for personal and family experience with chronic health difficulties?

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ABSTRACT

Because chronic illness, by definition, continues indefinitely it thus becomes part of the individual’s identity. This qualitative investigation focuses on Lola (a 30 year old female who contracted meningitis in 2010 after revision spinal surgery), her close family unit and their collective experiences of chronic illness.

The main aims of the study were to uncover the impact of chronic illness on one individual and her family and to explore this in relation to Bronfenbrenner’s systems theory.

Three semi-structured interviews along with four narrative accounts were conducted and analysed using thematic analysis. From this, four significant themes were identified, these being: Loss; Denial; Stigma and Stereotypes and; Blame and Responsibility.

These findings were in accordance with previous literature into chronic illness and chronic pain with associations being made to Bronfenbrenner’s systems theory.

KEY WORDS: CHRONIC ILLNESS CHRONIC PAIN FAMILY SYSTEM THEMATIC ANALYSIS BRONFENBRENNER
### Figure 1. Timeline of Illness Progression

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<tr>
<th><strong>December 2009</strong></th>
<th><strong>January 2010</strong></th>
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<tr>
<td>Pain experienced in back of upper left thigh and hip. Assumed a pulled muscle.</td>
<td>Visited A&amp;E after limping in work. Discovered a slipped disc and high level of infection in bloods. 26th – L4/5 discectomy (3 month recovery period)</td>
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<th><strong>March/April 2010</strong></th>
<th><strong>June 2010</strong></th>
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<tr>
<td>Pain returned and experienced a burning experience. Visited A&amp;E again and another slipped disc was found along with scar tissue</td>
<td>MRI scan showed recurrent prolapse to L4/5 and operation was scheduled for 4 weeks.</td>
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<th><strong>October 2010</strong></th>
<th><strong>Mid November 2010</strong></th>
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<tr>
<td>19th – new MRI showed L1/2, L2/3 and L3/4 also bulging which resulted in a more complex 9 hour operation. Spinal cord torn and spinal fluid began leaking affecting the dura. Membrane from hip used to stop leak as spinal cord cannot be stitched. 20th: severe vertigo like symptoms from loss of fluid. Lumbar puncture was not possible as membrane would tear. Placed on intravenous antibiotics 25th: meningitis detected (infection spread directly to the brain through spinal cord). Already being treated.</td>
<td>Sent home</td>
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<th><strong>March 2011</strong></th>
<th><strong>December 2010/January 2011</strong></th>
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<tr>
<td>Episode of mild to moderate depression. Brain scans carried out which found five major areas of the brain that were damaged</td>
<td>Recovery period</td>
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<th><strong>June – December 2011</strong></th>
<th><strong>February 2011</strong></th>
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<tr>
<td>Remained stable but had regular appointments with pain management team (CBT) and monthly MRI scans to monitor deterioration.</td>
<td>Pain and numbness in neck, shoulder and arm. Hand became swollen. Diagnosed with thoracic outlet syndrome.</td>
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<th><strong>October 2012</strong></th>
<th><strong>May 2011</strong></th>
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<tr>
<td>More discs bulging above metal frame in back. C5/6 moderate degenerative change/bulge C7/8 cord indentation related to fainting as oxygen supply can get cut from brain. Referred pain from shoulder responsible for migraines.</td>
<td>Nerve conduction studies due to numbness.</td>
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<th><strong>January 2012</strong></th>
<th><strong>February 2011</strong></th>
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<tr>
<td>Tested for diabetes due to fainting and dizzy spells. Glucose levels abnormally high even with fasting blood test. Tested liver function. Diagnosed with an autoimmune disorder. Bloods still infected as brain unable to regulate blood count and white blood cells extremely high. Diagnosed with rheumatoid and osteoarthritis, not thoracic outlet syndrome (similar symptoms) Diagnosed with oestomalacia (consideration of bone marrow transplant) and Addison’s disease. Began to wean off morphine and on to fluoxetine.</td>
<td>Pain and numbness in neck, shoulder and arm. Hand became swollen. Diagnosed with thoracic outlet syndrome.</td>
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Introduction
An intended outcome of this research was to uncover how Lola and her family cope with her chronic illness. Objectives of the study included:

1. Examination of Bronfenbrenner’s systems theory in relation to Lola to explicate her subjective experience of chronic ill health
2. Investigation of Lola’s subjective well-being, both eudemonic and hedonic
3. Examination to uncover the impact of the diagnosis and subsequent illness on Lola’s close family
4. Exploration of any coping mechanisms adopted by Lola and her family system, from which a coping model could be created and applied to others living with chronic health difficulties

Spine Surgery
Chronic back pain has been linked to cases where disabling symptoms occur in 30% of surgeries (Trost, France & Thomas, 2009). When long term pain and lifestyle deteriorations become too severe, surgery may be offered to patients. During lumbar surgery, incidental tear of the dural sac and subsequent cerebrospinal fluid leak is possibly the most frequently occurring complication (Tafazal & Sell, 2005).

Some research claims no long term adverse effects of dural tears, despite suggestions that disruption of the dura cannot be considered as a benign event (Huang & McGrail, 2006). Along with revision surgeries (Wang, Bohlman & Riew, 1998), Baker et al (2012) found that age, lumbar surgery and elevated surgical invasiveness are significant risk factors for unintended durotomy. Although these risk factors provide some indication of who may become symptomatic, it is difficult to foresee. When complications occur, some cases can lead to long term problems post-operation. These include severe headaches, persistent leak (durocutaneous fistula), pseudomeningocele formulation, nerve root entrapment, meningitis and arachnoiditis (Hannallah, 2008). Symptomatic patients also may experience a chronic pain condition (Mendel et al, 2008).

Similarly to the experience of Lola in this case study, Todd et al (2008) conducted a case report on an individual that contracted meningitis after undergoing a discectomy at L4-L5 for weakness and pain. Three days after the surgery, the patient reported neck pain, photophobia and fever: likened to the effects of vertigo caused by a dural tear. Cerebrospinal fluid (CSF) examination uncovered a pattern for aseptic meningitis, leading to the conclusion that, although rare, meningitis following a discectomy needs to be a vital prior consideration. In the general population, this incidence occurs in 11 in 100,000 people per year (Nath & Berger, 2004) which shows how unfortunate Lola has been.

Chronic Illness
Chronic illness is defined as ‘any disorder persisting over a long period that affects physical, emotional, intellectual, vocational or social functioning’ (Shiel & Conrad Stoppler, 2008, p229). These disruptive events draw on cognitive and material resources (Bury, 2008), continuing indefinitely and often becoming part of the individual’s identity (Lubkin, Morof & Larsen, 2006).

For those diagnosed with chronic illness, there is a need for acceptance of its presence and to modify their lifestyle to discover coping strategies (Berk, 2013).
This implies a need to integrate the illness into one’s lifestyle and acknowledge a shift in identity (Telford et al, 2006). Conrad (1990) believes that further research needs to:

‘examine relationship with family members, friends and work associates, ...how people adapt to physical discomfort, what it is like to make routine visits for medical care, how medical personnel and others appear to patients, and what strategies people use simply to ‘get by’ in their lives.’ (Conrad, 1990, p. 1260).

From this, Conrad (1990) focused on the difference between an outsider and an insider perspective on chronic illness. Outsiders are external from experiences and view the individual as an object to be affected, ignoring the subjective reality of the sufferer. In comparison, an insider is concerned with the subjective perspective of the person living with the illness. Strauss and Glaser (1975) adopted the insider perspective by focusing directly on chronic illness and how those involved managed to live as normal a life as possible. Illness is suggested to be an undesirable psycho-social phenomenon that accompanies physiological problems (Eisenberg, 1977). The emphasis therefore is on psycho-social aspects, which implies a need to investigate chronic illness from this insider perspective.

**Systems Theory**

Because chronic illness can impact the individual, the family and the social system to which they belong (Koehler et al, 2009), the systems should be considered holistically. Martire et al (2004) found a high correlation between patient outcomes (depression, anxiety, relationship satisfaction, disability and mortality) and family outcomes (depression, anxiety, relationship satisfaction and caregiving burden) relating to chronic illness.

Ecological systems theory (Bronfenbrenner, 1979), depicted in **Figure 2.** comprises four system types that structure development (Ahuja, 2010) and covers roles, norms, and rules. The model includes the following interrelated (Darling, 2007) systems: The ‘microsystem’ is the person’s immediate environment (ie family); the ‘mesosystem’ is the set of connections between the microsystems (ie. interactions between home-work); the ‘exosystem’ largely impacts the behaviour choices within the microsystems; however the person has no influence upon it (ie. Parent’s workplace); and finally, the ‘macrosystem’ involves the larger culture (Bowman et al, 2007). Much of Bronfenbrenner’s work was based in child development, however it is argued to be applicable throughout the lifespan as the systems remain relatively constant (Fingerman & Bermann, 2000). It is an aim of this investigation to discover if system’s theory can be applied to the experiences of an individual with chronic illness and their family as Patterson and Garwick (1994) focused on a family systems framework to explicate the reciprocal relationships between chronic illness, structure and functioning of the family system.
Well-Being

Cella and Nowinski (2002) suggested that outcomes within the healthcare system can be condensed to three measures: how long the patient lives (survival); cost (the economic impact of the illness); and how well the person lives. The last is considered to be a subjective concept covering ‘impairments in activities of daily living, subjective life satisfaction, happiness and the overall value one places on life’ (p.S11). Because of this, health-related quality of life (HRQoL) is now an important factor to consider for the chronically ill. Chronic illness and pain may lead to anxiety and depression, which may result in ‘low health-related quality of life’ (Otto et al., 2007). Bach et al (2010) found that patients with chronic pain scored significantly on mental distress (including depression), obsession-compulsion and anxiety.

Related closely to QoL is subjective well-being (SWB). Cummins (2010) defined this as a positive state of mind that includes total life experience. SWB is not an absolute state but is a relatively stable mood state dependent again upon the individual’s outlook. Significant correlations have been uncovered between ‘self-esteem, affective balance, and psychopathology’ from which it can be inferred that QoL and SWB are more directly associated with our ‘inner’ rather than social world (Thorup et al, 2010). Hansson and Bjorkman (2007) similarly related traits including locus of control\(^1\), self-efficacy, self-esteem and sense of coherence in life.

\(^1\) Where a person attributes the cause of a happening. Those with an external locus of control lay cause for illness with factors that are outside of their own control, such as destiny, a higher power, or
Family Impact
Chronic illness is not a phenomenon unique to the person diagnosed, but affects all those involved with the sick individual. Medical advances within recent years have increased independence from institutional health care, and much care is now delivered to the patient within the home (Armistead et al, 1995), so their illness becomes an ‘ordinary feature of family life and development’ (Cole & Reiss, 1993, p.8). Consequently the family may be subjected to social, economic or psychological stressors.

A burden of responsibility is often then placed on the spouse as the chronically ill becomes dependent upon others (Gignac et al, 2000). Revenson et al (2005) investigated the spouses’ psychological well-being and their adaptation response when met with illness-related stress. It was found that with increasing severity of illness, the spouses who had a greater network of support experienced fewer depressive symptoms. Later research by Baanders et al (2007) supports the notion of this impact by stating that;

“Living with a chronically ill person has an impact on the partner's life that goes beyond the consequences of caregiving” (p.305).

Coping Mechanisms
Among the chronically ill, problems may lie in areas such as coping with depression, anxiety, restrictions within work/social life and pressures that may influence self-esteem (Symister & Friend, 2003). Coping is defined as a person’s efforts to manage taxing demands that are seen to exceed one’s own resources (Walker et al, 2008).

There are many theories to consider which account for the adaptation to major life transitions in regards to the onset of chronic illness. The main theory can be categorised in to a stage based model (Kubler-Ross, 2005) that has an impact on palliative care and proposes that the person adapts by progressing through a series of stages to eventually achieve a sense of acceptance of the illness. An alternative theory (the task-model theory), emphasises the process by which the individual restructures their own lifestyle tasks and tailors their routine to a more manageable model (Samson et al, 2008). Both of these notions are heavily criticised as each places the individual in to categories which they may not fit (Corr et al, 2003).

The Chronic Care Model (CCM) (Wagner et al, 1999) (Figure 3.) can be applied to all and shows that with chronic illness a pressure is placed on individuals as well as the healthcare system (Dotts et al, 2003) so a contributing effort from either side is necessary to maintain an ideal lifestyle. Benign interactions between educated patients and the health care systems may lead to improved clinical outcomes.

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simply coincidence. In comparison, a person with an internal locus of control believes the illness has occurred through their own behaviour systems, for example previous health actions.
Methodology
Design
A qualitative approach was selected in this case study (Bagner et al, 2004) as it allowed for personal accounts to be told and for those with chronic illness to be given a voice and be seen as real people with real experiences (Pierret, 2003). Paterson (2004) indicated that living with and adapting to chronic illness is a continuous process which varied considerably when either an 'illness-in-the-foreground' or 'wellness-in-the-foreground' mind-set was central. This reflects the ideology that individuals may experience chronic illness in a way which is fitting for them. Qualitative data gained is by nature, highly subjective and opinion based to the specific individual and their circumstance (Sale et al, 2002).

Participants
Interviewees were obtained via opportunity and snowball sampling (Langridge, 2004) arising from the central person, who was previously known by the researcher. In all, 7 participants (1 male, 6 female) were recruited. This consisted of; the chronically ill individual, Lola, a 30-year old mother of a 4-year old daughter, who previously worked within the mental health sector; her live-in partner, Adam, age 32, who currently works full time in a manual labour occupation; Lola’s mother, aged 50 who also has a 9 year old daughter that participated; her aunt, a 46 year old in a managerial position and two of her cousins; Emily, 24 and Stacey, 21. To provide the reader with a personal familiarity of participants, cameo sketches are included (Appendix 1.).

Figure 3. The Chronic Care Model (Wagner et al, 1999)
For the purposes of this study, self-selected pseudonyms were used to refer to, Lola, Adam and the two cousins. The others will simply be referred to by their familial link to Lola. This ensures their confidentiality and anonymity remains evident throughout the research.

Arguably, Lola has a distinct multitude of conditions so she became an exceptional case to investigate to uncover the ways in which the chronic illnesses have affected her lifestyle and impacted those close to her. This transition into living with chronic illness began only three years ago and it is clear that her life has already changed dramatically. To depict this fully for the reader, a timeline representation Figure 4. Spinal Diagram of her diagnoses is included as Figure 1 with a spinal diagram Figure 4 to provide context and a glossary (Appendix 2.) to explain some of the less commonly known medical terminology.

Data Collection
Semi-structured interviews, or guided/ focused interviews (Willig, 2008), were used to collect data for three of the participants; mother, aunt and Stacey. The three interviews conducted were based on a set of unseen semi-structured interview prompts (Appendix 3.) which allowed for rich data to be obtained. Through this flexible structure, interviewees were able to lead the conversation and provide as much detail as they wished to and the interviewer could follow up on interesting points made (Barriball, 2006). Interviews were conducted at a place of the interviewee’s choosing, which in all cases was their own residence after working hours. Each was carried out on a one-to-one basis to ensure they felt able to express themselves freely and without consequence. The three interviews were recorded using a Dictaphone and immediately transcribed.
During a period of illness, an interview process was unthinkable with Lola and in turn, Adam as it may have caused unnecessary distress. With this, the researcher altered means of data collection. Lola and Adam were separately provided with their set interview prompts, by email, and asked to provide a diary or narrative accounts which reflected their personal experiences. They were each given one month to complete the narratives, to make the process as less demanding as possible, due to the unforeseeable ill health. As noted later by the researcher, under the time constraints and pressure of an interview, the rich data from Lola would not have been as extensive. Emily, one of Lola’s cousins also participated in this narrative form as a result of availability. Finally, Lola’s 9-year-old sister contributed by means of a story where she describes her experiences of her sister’s illness.

**Data Analysis**

Content and thematic analysis was used to analyse data from the transcripts. Braun and Clarke’s (2006) guidelines were adhered to for thematic analysis (Guest, 2012) and the transcripts were repeatedly reread and interpreted by the researcher. The themes were noted after discovering patterns throughout the data (Ezzy, 2002) and colour coding transcripts. The final themes uncovered are all interpreted through the reviewed literature and all are related back to Bronfenbrenner and ecological systems theory.

**Ethical Considerations**

Good ethical control was vital to the study due to the sensitive subject. Approval was gained through a supervisor at Manchester Metropolitan University, along with an Ethics panel, after the completion of two ethics forms (Appendix 4.). The potential for psychological harm was necessary to consider as with semi-structured interviews it is difficult to know what realms the interviewee may stray in to and if this then may become uncomfortable for them. Every attempt was made to counteract this by doing the following: The interview process and their participation in the case study was fully explained to them; they were made aware of their right to provide as much or as little detail as they wished to, even to the extent of refusing a question if they felt it too intrusive; and finally they were required to read and sign consent forms (Appendix 5.) prior to the interview process taking place. This explained their role in the study and their rights of participation as well as the contact details of the researcher in order to ask any questions.

As mentioned prior, Lola and Adam contributed to the study through a narrative, diary style account of their experiences due to an unforeseeable ill-period for Lola during the time of data collection. Unnecessary distress may have been caused if the researcher were to pursue the interview line of investigation therefore; the collection methods were adequately modified.

On the whole, contribution to any form of research can be deemed a burden to the individual because of the time required and the emotional anguish that may be caused, especially in terms of qualitative investigations. All participants were given a full explanation of the research intentions and the influence their involvement could have in regards to informing others of personal experiences with chronic illness.
Following the process, participants were fully debriefed and their right to withdraw their data was also explained. Here it is worth noting that participants did contact the researcher, but only to request a copy of the final dissertation.

Analysis
From the analysis of the seven scripts gained, the subsequent themes were identified as reoccurring throughout the majority. A number of examples have been selected to reflect an understanding into each area.

The themes depicted are: loss, which consists of a number of subcategories; denial; stigma and stereotypes and; blame and responsibility.

Loss
Loss of Identity or Self
‘Her life has just been turned upside down’ (Stacey, line 61)
‘I think she’s losing herself’ (Aunt, line 52)
‘The guilt she feels because she cannot be a proper mum’ (Emily, line 48)

Chronic pain is known to cause an interruption in a person’s behaviour, interfere with their functioning and may go as far as to compromise their identity: ‘their sense of who they are and what they might become’ (Harris, Morley & Barton, 2003, p.365). Considerable losses are experienced as a result of the multiple impacts upon a person’s life (Roy, 2008). Loss, in this case, refers to life events/changes that result in a person being or feeling deprived of something they once valued (Miller and Omarzu, 1998). Walker (2006) identified a catalogue of socio-economic and other material losses including loss of: abilities; role; employment; finances; identity; and ultimately hope. Roy (2004) compared such losses to a form of grief, whilst Blackburn-Munro and Blackburn-Munro( 2002). Compared them to the symptoms of depression, it is therefore implied that during the loss of these once valued assets, the individual must undergo a grieving process of the old life and adapt to the new. Here the battle begins to reconstruct their personal life histories (Werner, Isaksen & Malterud, 2004). Central to the sociological approaches, coming to terms with disrupted identities is a main issue to consider in terms of illness experience (Bury, 1991).

Aujoulat et al (2008) carried out a qualitative study on 40 chronically ill patients in Europe where personal transformation was achieved through a two stage model: (i) ‘holding on’ to prior self-representations to differentiate one’s self from the illness; and; (ii) ‘letting go’ by accepting and integrating one’s self within the limits of illness-driven boundaries. This model states that the ‘process of relinquishing control is central to empowerment’ (p.1229), and in this case could be linked to acceptance over denial when a person comes to terms with their compromised identity. Their main finding from the interviews was for participants to describe a reconciled identity; they were aware their disease was part of them, however, it was distinct from their selves. Using this model, Lola is still very much in the stage of ‘holding on’, Her family system though seems to be more realistic in terms of how the illness has affected her: ‘She’s more distant now, I don’t think she’s herself with anybody and I don’t think she’s the bright bubbly person that she used to be’ (Aunt, line 50-52).
According to her partner, Adam, ‘she is unhappy about most things in her life right now’ (line, 33). Such a statement can be linked to life satisfaction (Diener et al, 1999), which is as a person’s overall evaluation of their QoL. This is an important indicator of the person’s subjective perception of well-being. Life dissatisfaction has been recognised as a risk-factor for ‘all-cause mortality, suicide and work disability’ (Koivumaa-Honkanen et al, 2004). ‘I think the only parts of her life she is happy with is being a mummy and in our relationship’ (Adam, line 53). This said, it is clear that there is some loss associated with the maternal bond Lola has with her daughter, as Adam also stated ‘as she’s getting older she started to notice that her mummy isn’t well… now she is getting older she is asking questions like “why do you take tablets and why can’t you pick me up?”’ (line 24 & 26) This loss is shown in Emily’s narrative: ‘Lola has struggled physically to be a mum and I know that mentally this torments her. She has told me how guilty she feels because she cannot be a proper mum’ (lines 47-49).

![Figure 5](image.jpg)

**Figure 5.** Dibb & Yardley’s (2006) hypothesised effects of the variables believed to influence adjustment to illness.

**Loss of Confidence and Self-Esteem**

‘I wouldn’t have the confidence to go out socialising anyway’ (Lola, line 224)

‘Putting on 3 stone, I’d rather stay in’ (Lola, line 212)

‘I know she’s not happy with her weight at the moment’ (Adam, line 56)

Weight management has become a major issue in Lola’s life, which has led to an extensive loss of confidence in her appearance: ‘I know she is not happy with her weight at the moment… is affecting her confidence’ (Adam, lines 56-58). Today feminine beauty is young, tall, thin and full breasted (Levine & Smolak, 2002) with thinness being synonymous with beauty, attractiveness and reputation (Tiggermann, 2002) and mass-media promoting dieting and exercise to endorse this idealised, perfect female figure. This pressure, along with the pressure of illness has results in
low self-esteem (Symister & Friend, 2003). Huang et al (2007) similarly correlated negative body image with lack of self-esteem and self-confidence, decreased exercise behaviours, sexual experiences and emotional stability and perhaps because of this, Lola stated that ‘putting on 3 stone has massively affected my confidence… I would rather stay in’ (Lola, line 211-212). This along with the stigma attached to disability has caused Lola to become somewhat of a ‘hermit’ (Aunt, line 107): ‘she hides in the house now’ (line 78).

Loss of Physical Ability, Independence and Employment

‘I needed help with all aspects of daily living’ (Lola, line 131)
‘She wouldn’t be as withdrawn as she maybe is now’ (Stacey, line 71)
‘She’s definitely more reliant on me’ (Mother, line 43)

Sudden onset chronic physical illness is commonly expected to lead to a loss in physical dependence and in turn an increased dependence on others. Gignac and Cott (1998) presented a conceptual model of physical independence and dependence as determined by ‘domains of disability, the role of subjective perceptions, demographics, the physical and social/political environments, personal resources, attitudes and coping resources, illness and efficacy appraisals, and the nature of the assistive relationship’ (p.739). Within their findings, they describe a concept ‘Not Independent’, which they described as occurring when individuals are unable or experience difficulties performing certain tasks, they may not receive help as they prefer to not seek or ask for it. This links in significantly with the further theme, denial.

Together with mental well-being, physical ability is also impacted through living with pain (Basler, Jakle & Kroner-Herwig, 1997). Loss and adjustment was a significant theme found in Harris et al’s (2003) study. They reported work as the most affected by this, with the family domain being less impacted. It is suggested that this could be due to the family sustaining the self-esteem of the individual by allowing an increase in dependence. Patients, however, consider pain related illness as a burden on their families (Morley et al, 2002): ‘I also do a lot more around the house than I used to’ (Adam, line 21); ‘She’s definitely more reliant on me, definitely. Well for herself and her daughter’ (Mother, line 37). Restrictions on life have been suggested to impact subjective well-being and quality of life (Lame et al, 2005) as loss of previously valued activities and roles can result in inner turmoil (Roy, 2004).

Within this subsection comes employment. Pain-related disability has forced Lola to be on permanent sick leave from work and it can be assumed that it will eventually lead to her being unemployed if no progress is made with her condition. Following this is the unavoidable lack of financial stability. Physical limitations places restrictions on activities and as a direct result can cause people to have to give up work due to chronic pain (Volinn, Fargo & Fine, 2009). Loss of employment has impacted upon Lola highly as it was of high importance in her life: ‘Currently being off work and doubting I’ll be returning’ (Lola, line 137). Quite clearly, this is a shared thought throughout the family system: ‘I think it would be best if she could go back to work…just keep her mind occupied’ (Mother, line 39); ‘I know she’s definitely happier and more focused when she is working’ (Adam, line 35); ‘She’d be a lot happier if she could get back to work even part time’ (Stacey, line 85); ‘She is no longer able to
work and this has had a massive impact on her confidence and also financially’ (Emily, line 45). Employment is crucial in defining identity, ranking people in social positions and providing them with an individual role (Roy, 2004). Loss of work also impacts on social interactions and friends: ‘Start meeting new people again and getting out of the world of just her, Adam and their daughter cos that’s why things get on top of her as much’ (Mother, line 44).

Lacking physical ability or capacity to carry out an activity, does in no way hinder the desire to do so: ‘I was finding it hard to make arrangements or most of the time having to cancel as no day is the same’ (Lola, line 220). Lola wants to continue on living her previous life, however it is purely the physical limitations that are preventing this, leading to her exasperation: ‘I don’t think she realises how she talks to Adam…it’s just a frustration’ (Mother, line 145).

Relationship Losses

‘She started to notice that her mummy isn’t well’ (Adam, line 24)
‘My relationship with the majority of my friends has now broken down’ (Lola, line 218)
‘I think she’d have a better relationship if she was able to do more things’ (Aunt, line 89)

‘Keeping up appearances’ is a rather appropriate term to be explored in this subsection as Lola revealed that she restricts what she tells others: ‘I don’t tell them everything that is wrong with me as I don’t with all my family’ (line 228). Perhaps this is a way of protecting others from the truth (Haraldseid, Dysvik & Furnes, 2012) and most importantly protecting herself from what she may perceive as sympathy or judgement.

Throughout previous literature, qualitative methods have been utilised to report the personal experiences of those suffering with chronic illness or pain. Reoccurring themes involved loss of interpersonal contacts and the breakdown of their social interactions. Schibbye (2009) believes that the person we are relies on who the people around us allow us to be. Our identity is founded within a context of our social network which enables us to differ in roles appropriately to fit the people around us. Henare (2003) suggests that when chronic pain prevents participation in something previously taken for granted, roles and identity shift. This is most evident in Adam’s transcript where he states ‘we no longer go out or do things as a couple like we used to’ (line 15). Lyons and Sullivan (1998) state that illness and disability are not simple a weight on the individual, but instead a vacuum for their familial social relationships, making interpersonal losses and the breakdown of social networks somewhat inevitable (Haraldseid, Dysvik & Furnes, 2012): ‘I feel the need to isolate herself makes socialising together difficult’ (Emily, line 17). Lola’s life at this moment in time involves much uncertainty and day-to-day inconsistencies in terms of ability which disrupts any chance of planning ahead.

Pain and disability are linked to psychological distress in the individual and also their spouses (Cremeans-Smith et al, 2003). Research has shown that couples often report that marital and sexual satisfaction often decline after the onset of chronic pain (Flor, Turk & Scholz, 1987): ‘physically/sexually is no doubt most affected…medication has an effect on your sex drive’ (Lola, line 215). Although this
is a crucial aspect of any relationship Lola said that their relationship has changed ‘some ways for the better’ (line 206). Emotionally, it seems to have made them stronger as a couple: ‘I really don’t know how I would get through life without him by my side’ (Lola, line 213).

Relationship losses and loss of employment both result in a reduction in social contact and in turn a reduction in contact with those involved in a person’s microsystem. The microsystem directly influences a person’s development, not only as a child but throughout the lifespan, so declines in contact could hinder development in a person’s adult life (Objective 1 & 3.).

Denial
‘I hope every day that there will be a miracle cure’ (Adam, line 36)
‘She doesn’t want to acknowledge it at this age’ (Aunt, line 71)
‘She does suffer but she tries to make herself do things’ (Mother, line 59)

Common defence mechanisms for coping with the anxiety associated with illness are as follows; regression, intellectualisation, projection, displacement introjection and finally denial (Abram, 1972). In previous literature, denial is a term usually used when describing a person’s psychological response to physical illness as an unconscious coping strategy. In this case, denial does not refer to a refusal to accept the illness, but rather a refusal to accept that the illness does in fact have an impact upon her life. Historically, Freudian psychoanalytical theory describes the purpose of a defence mechanism is ‘to abolish objective, neurotic or moralistic anxiety by denying or falsifying the existence of the external or internal threat to the ego’s safety’ (Hall, 1954, p.86).

Lola’s defence mechanism involves an ideology of eventually getting better. This naivety spans to her partner and cousin respectively: ‘I hope that every day that there will be a miracle cure…and she will be happy and healthy like she used to be’; ‘I do hope one day by way of a miracle that her health will improve’. It is worth noting that this idea is not shared by all, as her Mother and Aunt seem much more realistic in terms of the illness progression: ‘She’s never going to get any better’; ‘I’d like to think that she could start to get better but I know it would never happen which is upsetting’. This is likened to the research conducted by Ridley (1989) on family response to head injury whereby relatives seemed to cling to unrealistic fantasies that the person will all of a sudden wake up one day in their formerly healthy state. Lola and Adam also present with the idea of one day expanding their family: ‘hopefully my health will improve to have more children’; ‘it would also be nice if her medication and level of pain was reduced so we could have more children’. Again, her Mother appears to have a more pragmatic view of the situation as this would severely further her health deterioration: ‘I don’t know how she’d ever go on with a baby, I don’t know how she ever managed with her daughter’.

Ridley goes on to express that denial can become the foremost problem if there is a refusal on the families part to make essential changes to the home. This encompasses the family’s overview entirely: ‘it’s not like she’ll have anything adapted in the house, she doesn’t want it to look like a disabled persons’ (Mother). Adam was asked if more could be done to help now and he simply said ‘no not now, maybe
at the time when she first came out of hospital...we are used to everything as it is now’ (line 42).

This coping mechanism (Objective 1 & 4.), although suitable for the family in current circumstances, cannot continue indefinitely. The task-model theory (Samson et al, 2008) places emphasis upon the restructuring of the individual’s life to adapt their routine to a more manageable framework. This may involve a move from Lola’s current three floor home to ‘somewhere more suitable for her like a bungalow’ (Stacey, line 37).

**Stigma and Stereotypes**

‘Registered disabled at her age’ (Mother, line 171)
‘I’m very conscious of when I’m limping’ (Lola, line 210)
‘Applying for DLA and getting a car on disability’ (Lola, line 177)

Pierret (2003) found that illness narratives revealed concepts which centred on stigma and other people’s perceptions. Stereotyped individuals differ in how self-conscious they are of their status, which is labelled by Pinel (1999) as stigma consciousness. As a previously healthy 27 year old, it has caused Lola much grievance to accept her status since as a disabled young woman. In 2005, the World Health Organisation estimated that there were 600,000,000 people worldwide with a disability (cited in Kiani, 2009, p.517). The stereotype attached to chronic illness and disability is usually associated with ‘healthcare use increase with aging, escalating healthcare costs and other negative societal effects’ (Ory et al, 2003) along with one of old age, decline and loss (Minkler, 1990). Linking to the theme denial, Lola will not accept help in the form of aids within the house. It is evident that a critical issue as to why was the stigma attached to being ‘disabled person’. ‘She doesn’t want the house adapted to look like a disabled persons’ (Mother, line 86).

Osborne and Smith (1998) stated that downward comparisons aid people in promoting their own positive well-being. Social comparison is utilised in events of fear and uncertainty to allow a person to evaluate themselves and their identity in terms of its differing to another (Aspinwall, Hill & Leaf, 2002). Willis (1999) found that downward comparisons in fact produce a positive effect upon self-esteem. Stigma is largely based on this and involves assuming one’s own superiority over another person or group. Due to this sense of judgement, Lola sees it as vital to present herself as ‘normal’ to the outside world; ‘I just don’t like them seeing me struggle’ (Lola, line 228). Davis (1995) contends this social inequality arguing the need for a reassessment of the construct disability;

> ‘The first task at hand is...to see that the object of disability studies is not the person using the wheelchair or the Deaf person but the set of social, historical, economic and cultural processes that regulate and control the way we think about and think through the body.’ (Davis, 1995, p.2)

This stigma relates back hugely to Lola’s micro, meso and exosystems due to the fact that they are all to some degree external to her and the Illness and therefore may label her. Lola’s well-being will be impacted by this perception as she may avoid socialising even when she is having a good day (Objective 2.).
Blame and Responsibility

‘Waiting made the operation become harder and more complicated’ (Adam, line 11)
‘A lot of it is a knock on effect’ (Aunt, line 25)
‘I have no faith since what happened’ (Emily, line 37)

Eccleston, Williams and Rogers (1997) concluded that in all accounts of chronic pain, blame and responsibility is placed away from the sufferer and removing individual ownership. In this case, the family as a collective blame the health care system for Lola’s current ailments; ‘I’m sure if I would have has the surgery sooner it could have been prevented’ (Lola, line 182); ‘I believe she was left too long and it was really negligent on the hospitals behalf’ (Aunt, line 22). Baring this in mind, there has been consideration of legal action, however, this has not been possible due to Lola’s deterioration. Through extensive research, it became clear that during lumbar surgery, ‘incidental tear of the dural sac and subsequent cerebrospinal fluid leak is possibly the most frequently occurring complication’ (Tafazal & Sell, 2005). This attribution of blame is therefore partially unjustified in terms of credibility as Tafazal et al also state there is an increased awareness of this risk and subsequently the need to inform patients of the possible complications during spinal procedures. Blame could be inferred as a further coping mechanism utilised by Lola and her family in order to come to terms with the illness and differentiate it from herself.

This attribution of blame seems to have had a negative impact upon Lola and her family’s faith in the healthcare system: ‘let me down as a partner and the family down as a whole’ (Adam, line 49). In terms of Bronfenbrenner’s systems theory, the relationship between microsystem and exosystem could be compromised. The mesosystem encompasses the relationship between these two systems and without trust in healthcare then this interconnection is somewhat disrupted across the family (Objective 1 & 4).

Critical Evaluation

The findings throughout this study are considerably supported by previously published literature based on chronic illness and chronic pain. It is clear that chronic illness does have a vacuum effect upon, not only the individual but the whole family system and social network (Haraldseid, Dysvik & Furnes, 2012). Overall it is believed that the aims and objectives of the research were successfully met, in that all of the data gained points to a systems theory of illness, with the event becoming a disruptive event to the family, friends and employability. Thus support is gained for an adult illness model of Bronfenbrenner’s ecological systems theory.

It is accepted that with any study there are limitations. In this case, time became a restraint on the process of interviewing which in turn restricted the researcher in gaining data. Furthermore, illness of Lola during the interview process called for a slight change in methodology which allowed for a narrative account to be gained. In hindsight, this was beneficial as it gave Lola time to consider her answers and provide detail, rather than being under the constraints of an interview procedure. Also, this gave the study more ethical grounds as it reflects an understanding researcher as interviewing under the circumstances would have caused unnecessary distress.
Overall, the qualitative techniques used were essential as quantitative methods would simply not have gained substantial detail of the subjective viewpoint of Lola and her family. Chronic illness experience is a concept that cannot be quantified and reduced down to numerical data and it is for this reason that qualitative perspectives were employed.

Further research in this area would allow for additional families to be interviewed and therefore provide a comparison to ensure the findings are generalisable across all diagnosed with chronic illness. However, there is an inevitable subjectivity for each family, in terms of the chronic illness they are diagnosed with and in turn their individual related restrictions and coping strategies. Supplementary research would further this piece by way of comparison across these differences.

Reflexivity
It is accepted that my own personal beliefs, experiences and social status will all in some way influence the research, whether it be in the form of questions asked or during the process of analysis. I had prior contact with Lola and knowledge of her and her experience with chronic illness which suggests there will be some subjectivity throughout. This pre-established knowledge and involvement with the family is, in my opinion, an advantage as an unknown contact may have not gained the personal information that I did. Also, the rapport required for interviews was already established prior to the study starting.

Nevertheless, I was still an inexperienced interviewer when I started this study, and I recognise that I may not yet have all the interview skills that others may possess. I may not have enabled the interviews to uncover all that there was to discuss as I might possibly have missed certain cues may not have been picked up on. Therefore, this may have restricted data and consequently the findings established from the research.

At the beginning of the study, I was enthusiastic in pursuing the case study and uncovering the extent to which Lola’s family was affected by her illness. To a certain extent, I was fairly naïve in the initial period and, although I was aware there would be mass alterations to their lives, I assumed there would be little differences to the interpersonal relationships within the family. Through the narrative accounts and interviews it seems this was not the case and relationships have changed immeasurably, especially in regards to Lola, Adam and their daughter.

It was difficult and uncomfortable when reading about the physical and sexual differences within their spousal relationship. This discovery was not expected, purely to the personal nature of it and with there being a further stigma attached to lack of sexual contact within a relationship. Women are thought to have many motivations and reasons for participating in sex, with the main being a desire for emotional closeness with their partner (Basson, 2006). Suggesting a lack of sexual contact may result in a decrease in emotional closeness within a relationship. Furthering this, the effect the illness has had upon Lola’s relationship with her daughter was incredibly distressing to expose. I myself am extremely close with my mother and so I found this especially difficult to explore. The bond between mother
and child is one of extreme value and the fact that Lola cannot pick up her four year old little girl must be indescribably hard for her each and every day.

Due to the sensitive subject matter, I was considerably affected during analysis of the transcripts and even more so, the personal narrative of Lola. Even with prior knowledge there was still a ‘shock factor’ when reading the transcripts, as seeing how this illness has affected such a close knit family was rather saddening. I believe this hit me whilst reading, as seeing how the illness has affected so many lives collectively was more obvious when faced with piles of transcripts to analyse, compared to one-to-one interviews. The family are still undergoing a transition into the illness and I was left in admiration at the vast amount of support they received from another.

Concerning the NHS, I believe Lola will to some extent always blame them for what has happened over the last three years. Personally, I don’t see them as directly responsible, purely due to the research I conducted into the risk factors in revision spinal surgery (Baker et al, 2012). I hope that one day in the future, and possibly with the help of this thesis, Lola and her family will come to terms with what happened and slowly begin to trust healthcare services again.

On the whole, I feel the entire process of writing this dissertation has been physically and emotionally exhausting. Even though I have known Lola and her family for some time, it was still upsetting for me. I felt powerless when I uncovered the magnitude of the difficulties that Lola now has and the problems that she encounters daily. I have much empathy all concerned and I hope I have done them proud in reflecting an accurate account of their lives since the illness and given them a voice to express their own experiences and emotions.
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