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The Experience of Hospital Discharge Planning for Informal Caregivers of Older People with Dementia - An Interpretative Phenomenological Analysis

Thesis Submitted in Partial Fulfilment of the Requirements of London Metropolitan University for the Professional Doctorate in Counselling Psychology

By

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Declaration

I hereby declare that the work submitted in this dissertation is the result of my own investigation, except where otherwise stated.

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Acknowledgements

I would like to thank first and foremost the five individuals who volunteered to partake in this thesis and whom without this study would not be possible. I am also very grateful to the local authorities from which participants were recruited. A special thank you also goes to my supervisor, Dr Catherine Athanasiadou-Lewis for her invaluable feedback and my peers for their friendship and support.

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Glossary

HDPP – Hospital Discharge Planning Process

NHS - National Health Service

IDC - Informal Dementia Caregivers

HDP - Hospital Discharge Planners

BPS - British Psychological Society

DoH - Department of Health

NICE - National Institute for Health and Care Excellence

LMU - London Metropolitan University

IPA - Interpretative Phenomenological Analysis

UK – United Kingdom

TNA – The National Archives

ADASS - Association of Directors of Adult Social Service

FDA - Foucauldian Discourse Analysis

CGT – Constructivist Grounded Theory

Abstract

Background: Whilst involving IDC in the HDPP can reduce patients' length of stay and readmissions, research has shown that their inclusion is scarce. Limiting IDC participation in decisions relating to their needs or the welfare of those they care for can yield adverse repercussions for their mental-health, disrupt continuity of care, extend patients' hospital stay, and increase the likelihood of patients' readmission to hospital. Given these costs it is imperative to comprehend how this particular client-group thinks and feels about the hospital discharge planning phenomenon. Nevertheless, minimal studies have investigated this topic area. In response to this gap in knowledge, the present thesis investigated the experience of the hospital discharge planning process for informal caregivers of individuals with dementia.

Method: Data was harvest from participants via the employment of face-to-face semi-structured interviews which were later verbatim transcribed. Participants idiosyncratic narratives were examined and analysed using Interpretative Phenomenological Analysis. The participants were five informal caregivers of older patients with dementia aged between 52 and 71 who took part in their care-recipient' hospital discharge planning process.

Findings: Three superordinate themes emerged from the IPA analysis: 1) the negative aspects of the discharge planning process 2) focus on relationships and 3) employing coping mechanisms to counteract taxing experiences. It appears that the challenges that participants encountered in their meetings with hospital personnel and the changes they experienced in their interactions with their care-recipients, coupled with the costs they incurred in their daily life, triggered in them a range of negative thoughts and feelings which diminished from their psychological wellbeing. This propelled the participants to employ various coping strategies in an attempt to alleviate their internal turmoil. However, the efficacy of these tactics was questionable.

Conclusions: The experience of the HDPP for IDC comprises of multiple psychological dimensions. Nevertheless, the HDPP does not address IDC mental health needs. Therefore, this thesis suggests that counselling psychologists work as facilitators of psychological wellbeing on hospital wards. Such an initiative could provide caregivers access to mental health interventions in real time which they would struggle to attain in the community due to long waiting lists. Additionally, counselling psychologists and other applied psychologists should share their knowledge of therapy skills with hospital personnel in order to help staff form and maintain a nourishing relationship with IDC. Implications for future investigations and clinical work are also proposed.

1. Reflexive Statement – Part One

This part of the thesis sought to explore how my own views, personal motivations, experiences and dialectical interaction with participants had impacted on this study and how the study affected me as an individual and a researcher. Equally, it sought to examine the measures I employed in an attempt to manage the influence of my biases on this research process. The reflexive statement has been divided into two sections; the first pertains to the period prior to participants' recruitment and the second section reflects on my personal responses to the various stages that followed and to the study as a whole.

I am a 44-year-old white single woman. For the past 20 years I have worked in the capacity of a social-worker with vulnerable adults and their caregivers in various social care and NHS settings. The decision to research the topic at hand was prompted by my experience of working as a hospital social-worker on acute medical wards where I was responsible for planning and facilitating the hospital discharges of adult and elderly patients in collaboration with their unpaid caregivers and hospital staff. During this time, I was struck by the increasing number of IDC who struggled with distress generated by this process. However, to my disappointment the bulk of social care and NHS resources were directed towards meeting patients' outcomes. Where IDC needs were discussed, it was mostly in relation to their concrete requirements in the post discharge period (e.g. receiving help with managing their loved ones' personal hygiene) whilst their mental health state in the pre-discharge period was ignored. Frustrated and disheartened by this phenomenon, I wanted to learn more about IDC lived experience in the context of the HDPP and what can be done to enhance their wellbeing.

Reflecting on the reasons that impelled me to undertake this study has highlighted that I may have held negative attitudes about the HDPP. Specifically, I had entered this study with criticalist and constructivist epistemological views, wanting to give a voice to an unheard group of people who appeared to experience a disempowering phenomenon during a difficult time in their life. However, through the use of personal therapy I have come to recognise that my motivation to conduct this research was more personal than I initially acknowledged. Several years ago, a close relative of mine had an operation to remove a tumour from his brain. This has subsequently left him with cognitive deficits and psychological problems. As a result, my mother had become his informal caregiver. Witnessing the emotional turmoil that my mother experienced in her caregiving role may have contributed to my identification with IDC pain. Thus, it is possible that I inadvertently wished for my own voice to be heard. Additionally, it may be that the difficulties I experienced in my attempts to alleviate my mother's distress, gave rise to an unconscious desire to help other caregivers with their struggles, as a mean to satisfy my own unmet object need.

Using a reflexive diary to reflect on these hidden motivations has helped me to identify that I had aligned myself with the psychodynamic paradigm. Drawing on my past experience and this approach could influence the way I undertake various stages within the research process. For example, having a prior understanding of the emotional and physical difficulties that IDC experience in their caregiving role could facilitate empathic relations in my future interactions with participants. However, it could also guide my comprehension of participants' experience of caregiving in the context of their loved ones' HDPP. To illustrate, I initially designed an interview schedule that could have pulled participants to convey thoughts and feelings that chimed with my own personal and professional experiences. As a trainee counselling psychologist, I adhere to my profession's pluralistic stance which recognises individuals' rich and distinctive way of experiencing. Therefore, I proceeded to adjust my draft questionnaire to mitigate the impact of my subjectivity. Specifically, I used interview questions that were open rather than leading in the direction of my suppositions.

Equally, I was mindful that my subjectivity could unwittingly impact on the manner in which I carry out the literature review. For example, probing for studies and critiquing their data in a manner that would fit in with my social work experience. In an attempt to contain my preconceptions, I used a search strategy that included entering numerous key words into various database engines to identify different research findings pertaining to the topic at hand. Further, I used the reflexive research group meetings at LMU to identify how my personal and professional preunderstandings of the present research subject may have biased my appraisals of existing evidence.

Whilst the practice of reflexivity is aimed at bracketing the impact of the researcher's past experiences on the research process, it is impossible to completely eliminate such influences, particularly in the hermeneutic phenomenological approach (Koch, 1995; Spinelli, 2005) which the present study has employed. This is because in IPA investigations the researcher's interpretations and understandings of her participants' lived experience develop from her own personified perspective (Smith, Flowers & Larkin, 2009).

2. Introduction

2.1 Definition of Hospital Discharge Planning

Hospital Discharge Planning is a process that is carried out in health systems within the UK as well as in many countries across the world (Wong, Yam, Cheung, Leung, Chan, Wong & Yeoh, 2011). It seeks to address patients' after care arrangements prior to discharge through collaborative working between NHS bodies and local councils (Petch, 2009). The process commences with admission and often entails the assessment of patients' medical, physical and social needs. The multidisciplinary teams which are responsible for completing assessments for people with ongoing health and social requirements will normally include doctors, social workers, occupational therapists, physiotherapists and staff nurses (ADASS, 2010; NHS Choices, 2018). When patients are medically fit for discharge, they are encouraged to participate in decisions pertaining to the delivery of their aftercare (Bangsbo, Liden & Duner, 2014). A care plan that stipulates the services they agreed to receive in the community is provided as well as education in the management of their needs (Age UK, 2017). By undertaking this process, hospitals endeavour to reduce patients' length of stay, facilitate their safe and timely discharge and guarantee the continuity of their care in the community (Chenoweth & Luck, 2002; Driscoll, 2000; Rachman, 1993).

2.2 The Political Context of the HDPP in the UK

Governmental policies pertaining to hospital discharge planning in the UK can be traced back to as early as 1963. Over the years these policies have been subjected to constant revisions in an attempt to curtail growing costs associated with delays in patients' transfer from hospital to the community and patients' readmissions (Petch, 2009; Parkes & Shepperd, 2001). The Good Practice Guidance published in 2003 is a case in point, emphasising the activities that health and social-care bodies should be undertaking to facilitate effective discharges. One such activity stressed the need to involve informal caregivers in the HDPP, since caregivers' inclusion was found to enhance patients' recovery and reduce their hospital stay and readmissions (DoH, 2003; Henwood, 1994; Naylor, Brooten, Jones, Lavizzo-Mourey, Mezey & Pauly, 1994; Petch, 2009).

Informal caregivers are blood relations, partners, comrades or neighbours who offer and deliver voluntary care to individuals with physical, cognitive and/or mental health problems (Hancock & Jarvis, 1994). There are 700,000 IDC in the UK and their voluntary work is estimated to be worth 11.6 billion pounds (Alzheimer Society, 2014; Lewis, Karlsberg Schaffer, Sussex, O'Neill & Cockcroft, 2014).

Viewing informal caregivers as a resource has been the historical approach upon which British governmental policy pertaining to Community Care has been based. The chief goal of Community Care was to treat and care for physically and mentally disabled individuals in their own dwelling through the employment of statutory services and the use of informal caregivers. In so doing, it sought to prevent or delay the institutionalization of dependent people following their discharge from hospital and restrain subsequent public expenditures (Bulmer, 2015; Bungay & Alaszewski, 2002).

During the 1980’s informal caregivers’ position started to shift due to policymakers increasing concerns that the burden experienced in the caregiving context might erode informal caregivers’ capacity to continue to provide unpaid care (Baldwin & Parker 1991; Pickard 2001). The government went on to address these concerns in the 1990 NHS and Community Care Act which necessitated local authorities to consider informal caregivers’ practical requirements and later with the Carers Act (1995) which provided specific caregivers with the legal right to be assessed for their requirements (Nolan 2001). However, these Acts were limited in that informal caregivers were not eligible for an assessment unless their care recipient was also assessed. Also, local authorities struggled to meet informal caregivers’ needs as no additional funds accompanied these Acts (Bungay & Alaszewski, 2002; Parker, 1993; Twigg & Atkin, 1994).

In April 2015, the Care Act (2014) came into effect in England and replaced the majority of preceding legislation pertaining to adult service users, giving informal caregivers the same recognition in law as their care-recipients (Anchor, 2018; TNA, 2014). Additionally, the UK government pledged to improve informal caregivers’ quality of life and reduce their psychological burden in the context of dementia (Department of Health & Social Care, 2014).

2.3 Definition of Dementia & Prevalence in the UK

Dementia is a progressive disease which damages increasing parts of the brain resulting in general cognitive impairment. Whilst dementia predominately affects elderly individuals aged 65 and over, it is not a typical aspect of the ageing process (Alzheimer Society, 2017). Over 500,000 individuals in the United Kingdom have been diagnosed with dementia and this number is likely to exceed two million in 2051. This suggests that dementia is becoming an epidemic (Alzheimer Society, 2014; NHS Digital, 2018).

2.4 Rationale

Due to the surge in lifespan expectancy, an aging population and the unremitting rise in the prevalence of dementia, elderly individuals occupy more than half of acute hospital beds and dementia clients form a large proportion of this older inpatient demographic (Mockford, 2015; World Alzheimer Report, 2016). Further, compared with other patients, older individuals with dementia require more support in the post discharge period which increases their discharge planning requirements (Grimmer, Moss, & Falco, 2004; World Alzheimer Report, 2013). For these reasons demand for IDC contribution will rise over time. Still, IDC need to be willing and available to adopt this role given that they are a voluntary workforce. Comprehending and improving their caregiving experience in the context of the HDPP is therefore vital to gaining and retaining their support (Currow, Burns, Agar, Phillips, McCaffrey & Abernethy, 2011).

Despite these findings and the raft in governmental policies, research shows that IDC involvement in their care-recipients' HDPP is limited (Nay, Fetherstonhaugh, Pitcher, Closs, & Koch, 2004; Naylor, Stephens, Bowles & Bixby, 2005). Further, patients are often discharged while they're still recovering from their illness. This renders little time for a comprehensive discharge planning and in turn increases patients' dependence on informal caregivers in the post discharge period (Maramba, Richards & Larrabee, 2004; Victor, Healy, Thomas, & Seargeant, 2000). Limiting individuals' participation in decisions relating to their needs or the welfare of those they care for, can negatively affect their wellbeing and drive to self-actualise their potential in that context (Crethar, Rivera & Nash, 2008). With regards to caregiving, it can also disrupt continuity of care resulting in delays in discharge and hospital readmissions (Atwal, 2002; Douglas-Dunbar &

Gardiner, 2007; Lewis, Lewis, Daniels, & D'Andrea, 2003). Thus, understanding how IDC experience their care recipients' HDPP is imperative.

Nevertheless, very few studies exist in this topic area and none were found within the counselling psychology discourse. This is unfortunate given the profession's commitment to identifying how social contexts affect individuals' wellbeing (BPS, 2005). By exploring IDC subjective lived experience of their care recipients' HDPP, the present investigation endeavours to address this gap in knowledge thereby informing the practice of both counselling psychologists and applied practitioners work with this defined population.

Equally, through the dissemination of subsequent insights amid HDP and policy makers, this study could inform their work with IDC thereby contributing to service delivery. Such undertakings are consistent with the government's call to improve IDC life satisfaction (DoH & Social Care, 2014) and the profession's orientation towards enhancing individuals' wellbeing (Cooper, 2009). Equally, conducting research that benefits people beyond the therapeutic encounter is in keeping with counselling psychology future directions (Milton, 2010).

Moreover, moving away from NHS emphasis on imposing nomothetic suppositions onto individual clients (Cooper, 2009) to treating IDC as unique entities, is consistent with the profession's idiographic value and desire to empower. Finally, the present study could potentially instigate the work of counselling psychologists as facilitators of psychological wellbeing on hospital wards. Such an initiative could provide IDC access to mental health interventions during the HDPP which they would struggle to attain in the community due to long waiting lists. From a counselling psychologist perspective, it could also make clinicians' practice more inclusive thus realising equality.

3. Literature Review

3.1 Outline

The literature review commences with a look at the tasks that IDC undertake over the course of the disease. This is to provide insight into the extent and type of support IDC provide, thereby situating the study and the sample in the wider framework of caregiving for people with dementia. The review will then explore the drives that may propel IDC to provide unpaid care to their care recipient. The goal is to attain greater insight into the possible link between IDC internal processes and their caregiving behaviour. Studies pertaining to the benefits and costs of caregiving for a loved-one with dementia are examined in the succeeding section. This is followed by a critical evaluation of existing investigations pertaining to the HDPP and informal caregivers of older people with chronic illnesses and dementia. Finally, limitations of past research are discussed, highlighting the research gap and rationale for the present investigation.

3.2 Informal Dementia Caregivers' Roles & Tasks

The amount and range of support provided by IDC will depend upon their care recipient needs and the changes that tend to follow as the disease evolves. For example, in the early stages individuals with dementia become forgetful and confused. Therefore, support will often consist of making decisions pertaining to care recipients' abilities, limitations and daily routines as well as assistance with instrumental activities such as finance management, shopping and domestic tasks. People with dementia can also experience low mood (e.g. poor motivation & interest) for which many IDC provide emotional support. In the middle stage, problems with communication worsen and further deterioration in cognition, function and behaviour (e.g. wandering, clinging, repeated questioning) is evident. Consequently, assistance will extend to managing personal hygiene (e.g. bathing, dressing/undressing & toileting) supervising behaviour and coordinating care (Adams, 2006; Alzheimer's Association, 2013; Alzheimer Disease International, 2013). In the late stages of the illness, IDC will tend to provide care around the clock with most adult daily life tasks including help with feeding, drinking, mobility and managing nonverbal agitation (World Health Organisation, 2012).

IDC also play an important role in supporting their loved ones during their hospital admission (Romøren & Blekesaune, 2003). For example, they represent patients &

communicate on their behalf (Bauer, Fitzgerald & Koch, 2011). They also facilitate their participation in decision making processes pertaining to the delivery of their care (Fotaki, 2011) and manage information about their requirements (Hellesø, Eines & Fagermoen, 2012). Whilst the caregiver's role is recognised in the Care Act (2014) hospitals have received little guidance on how to actively engage them in older patients care (NICE, 2013). Current practice suggests that caregivers' involvement is predominately determined by staff primacies (Porter, O'Halloran & Morrow, 2011). However, minimal evidence exists about the extent to which this situation benefits or diminishes from informal caregivers' mental health and their caregiving experience (Bull, Hansen & Gross, 2000).

3.3 What Drives Informal Caregivers to Provide Care?

It has been argued that caregiving is a fundamental element of the attachment system (Kunce & Shaver, 1994) alerting caregivers of loved ones needs and subsequently propelling them to offer care (Reis & Patrick, 1996). Equally, people will often seek support from significant others when feeling vulnerable and this has also been linked to the activation of the attachment system across individuals' life span (Bowlby, 1988; Collins & Feeney, 2000). Thus, informal caregiving takes place in the context of emotional ties that are rooted in personal relationships (Pallett, 1990). Further, it is likely that individuals' beliefs about providing care will be guided by their childhood experiences with their own caregivers (Main, Kaplan & Cassidy, 1985). This suggests that caregiving behaviour will vary amongst individuals with different styles of attachment (Collins & Feeney, 2000). Indeed, research shows that participants with a secure style of attachment provided more support as their marital partners exhibited increasing distress whilst participants with an insecure style offered less support (Simpson, Rholes & Nelligan, 1992).

Caregiving can also be viewed as a process of joint exchanges (Horwitz, Reinhard & Howell-White, 1996). Social exchange theories postulate that individuals engage in a cost benefit analysis to guide their interactions with others. Accordingly, individuals will enter relationships that are likely to be rewarding and sustain such ties as long as they continue to benefit from them (Homans,1961; Thibaut & Kelley, 1959). Further, when people obtain rewards from others they will feel obligated to reciprocate (Sprecher, 1998). Reciprocity is an aspect of caregiving which refers to the normative duties that motivate people to assist individuals who have supported them in the past or are likely to support them in the future (Gouldner 1960; Neufeld & Harrison, 1995).

Research shows that the extent and type of reciprocated support is determined by the amount of aid that people attained or anticipate to attain in return (Finch, 1989; Antonucci 1990). Thus, balance is a primary notion in reciprocity. However, when one party keeps giving whilst the other party is continuously receiving, as in long-term relationships of unpaid caregivers of dependent individuals, the norm of reciprocity may limit informal support and impend prolongation of caregiving (Roberto & Scott, 1986). Still, the expectation of reciprocity might vary in different relationships such as filial ties where exchanges of aid need not comprise equivalent and immediate assistance (Curtis 1986; Mutran & Reitzes 1984).

To illustrate, Neufeld and Harrison (1995) examined whether reciprocity exists in the context of caregiving for cognitively impaired older individuals who struggled to communicate their needs and provide verbal feedback to their adult children who were meeting their needs. Results showed that most caregivers viewed caregiving as a chance to reciprocate for past support and perceived their care recipients' social cues as expressions of gratitude. Further, this constructed reciprocity increased caregivers' sense of satisfaction with themselves and strengthened emotional bonds with their care recipients.

Two small groups of informal caregivers in Neufeld and Harrison (1995) study, mentioned above, did not expect to be reciprocated for their support and attributed their provision of ongoing care to altruism or obligation. According to the empathy-altruism hypothesis, empathic concerns for another person's wellbeing evoke altruistic drives to provide care without expectations of attaining personal benefits (Batson, 1991). Whilst past research seems to support this perspective (e.g. Batson, Duncan, Ackerman, Buckley, & Birch, 1981) the negative-state relief view argues that empathy-related support stems from egoistic rather than selfless reasons. This outlook employs contemporary theories of the self, postulating that individuals see parts of their selves in other people and therefore the desire to help others in distress stems from the motivation to aid that part of the self that is located in the other (Cialdini, Brown, Lewis, Luce, & Neuberg, 1997).

Neufeld and Harrison (1995) associated caregivers' sense of obligation to provide care with early socialization to norms pertaining to filial behavior. Specifically, the general expectation that grownup offspring will offer help to their elderly parents (Cicirelli, 1988). It has been argued that caregiving motivations that are fueled by feelings of duty can have detrimental effects on informal caregivers' wellbeing (Hobfoll, 1986) and are likely to cause greater psychological distress than caregiving motivations that are based on positive drives such as love (Pyke & Bengtson, 1996). Indeed, in Neufeld and Harrison (1995) study caregivers that linked their caregiving to a sense of obligation reported feeling bitter and trapped by their care recipients' illness. This, according to Pearlin, Mullan, Semple and Skaff (1990) can increase caregivers' risk of developing depression.

3.4 The Positive Aspects of Caregiving for People with Dementia

It has been argued that the term caregiving suggests that care-recipients are the sole beneficiaries of aids in the caregiver-care recipient dyad. This is because rewards tend to shift in one-direction i.e. from caregivers to their care-recipients. However, informal caregivers also attain personal gains from caregiving which can manifest in emotional, mental, behavioural and relational experiences (Cheng, Mak, Lau, Ng & Lam, 2015). Understanding these benefits could enhance insights into the processes that underpin IDC adjustment to their caregiving role since the positive and negative dimensions of informal dementia caregiving coexist side by side (Doris, Cheng & Wang, 2018). Further, the mere reduction in levels of anguish does not yield happiness; it simply eliminates one barrier to wellbeing. Therefore, psychologists should seek to widen their attention beyond pathology and its direct relief and focus on increasing IDC wellbeing (Lee Duckworth, Steen & Seligman, 2005). This could be done using positive psychology. Specifically, explore the gains that IDC attain in the context of caregiving, foster pleasurable experiences, promote involvement in caregiving activities that help IDC actualise their potential, and assist IDC achieve meaning in caregiving (Seligman, 2004).

However, minimal studies have researched this topic area (Lloyd, Patterson & Muers, 2015). Among the few investigations that did is Doris et al.'s (2018) systematic review of studies which sought to identify the rewards that IDC procure in the context of caregiving and the determining factors that are associated with this phenomenon. The review found that IDC experienced feelings of triumph and fulfilment when they managed to acquire the competences needed to deal with their care-recipients' needs **(**Ribeiro & Pau'L, 2008), when their own idiosyncratic strategies were helpful to manage their loved ones' dementia (Peacock, Forbes, Markle-Reid, Hawranik, Morgan, Jansen, Leipert & Henderson, 2010), when they enhanced their loved ones physical and emotional wellbeing (Cheng, Mak, Lau, Ng & Lam, 2015), and when they used productive techniques such as problem-solving (Kramer, 1997). Overcoming difficult situations also yielded a sense of personal growth that manifested in IDC outlook on life. For example, they reported feeling more attuned to others needs and prioritised interpersonal relationships over materialistic gains (Netto, Jenny & Philip, 2009). According to Nakamura and Csikszentmihalyi (2014) this finding could be interpreted to mean that caregiving can strengthen IDC belief that they are living a meaningful life.

Interestingly, other studies that examined the rewarding facets of caregiving for people with dementia showed that IDC differed in the quality of gratification gained in the caregiving context. To illustrate, some IDC reported that their sense of pleasure derived from merely trying to do their utmost to meet their caregiving commitments (Murray, Schneider, Banerjee & Mann, 1999) whilst other IDC recounted deeper feelings of fulfilment such as pride (Ribeiro & Paúl, 2008). One possible explanation for these differing results is that IDC who recounted their past interactions with their care-recipients in a negative way offered and delivered care due to a sense of responsibility and therefore gained less pleasure from their role (Shim, Barroso & Davis, 2012).

Further findings from Doris et al.'s (2018) systematic review showed that IDC experienced the rise in mutuality within the caregiver-care recipient duo as a positive outcome. Mutuality referred to care-recipients' presence, company and fine positive reactions which IDC interpreted as gratitude for their labours (Mausbach, Coon, Depp, Rabinowitz, Wilson-Arias, Kraemer, Thompson, Lane & Gallagher-Thompson, 2004; Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry, 2001). Mutuality was also linked to IDC belief that if they were the dependent party, their care recipient would take care of them. In line with McAdam, Diamond, de St. Aubin and Mansfield (1997) findings, this outcome implies that IDC engaged in meaning making to alter their perception of their situation from ill-fated to fortunate which according to Seligman, Rashid and Parks (2006) is important in offsetting the onset of depression.

Moreover, IDC in Doris et al.'s (2018) systematic review viewed caregiving in a positive way if their support was driven by love and if it provided them with the opportunity to maintain closeness and intimacy with their loved ones. Strengthening bonds with other family members by sharing responsibilities for meeting loved ones' needs was also experienced as a rewarding consequence of caregiving (Kinney & Stephens, 1989; Sterritt

& Pokorny, 1998). Likewise, emotional support received from close relatives in the form of reassurance, praise and encouragement strengthened IDC sense of fulfilment in their caregiving role (Lee & Bronstein, 2010). Positive feelings, in turn, have been shown to offset the influences of adverse emotions on physical health as well as strengthen resilience in challenging situations (Fredrickson & Branigan, 2005; Tugade & Fredrickson, 2004).

Finally, Doris et al.'s (2018) systematic review showed that IDC who employed adaptive techniques such as balancing their caregiving responsibilities with their own needs and who used cognitive strategies that involved accepting their caregiving role and their loved ones' diagnosis as well as focusing on pleasing rather than disagreeable experiences and reframing their caregiving experiences to match with their own values, also felt positive in the caregiving milieu (Baker, Robertson & Connelly, 2010; Heo, 2014; Shim, Barroso & Davis 2012; Shyu, Yang, Huang, Kuo, Chen & Hsu 2010). Such psychological factors have been associated with high levels of resilience in IDC (Dias, Santos, Sousa, Nogueira, Torres, Belfort & Dourado, 2015). Resilience in the milieu of dementia caregiving has been defined as a process where distressing experiences interact with caregivers' strengths to help them recuperate from such phenomena, thus enhancing their physical and mental health wellbeing in this context (Cowan, Cowan & Schulz, 1996; Garity, 2006; Hodge & Sun, 2012; Shuter, Beattie & Edwards, 2014; Wilks & Croom, 2008).

The findings discussed above show that IDC can experience uplifts in their caregiving role. However, most of the existing evidence in the milieu of caregiving for people with dementia examined the adverse implications of caregiving for informal caregivers. A brief outline of some of these studies will be presented in the next section.

3.5 The Negative Ramifications of Caregiving for Individuals with Dementia

The Stress Process Model postulates that particular life circumstances can enhance individuals' experience of existing strains and/or generate new stressors. This coupled with loss of self-worth and command over processes people value, could increase the experience of stress (Pearlin, Menaghan, Lieberman & Mullan, 1981). Accordingly, the demands experienced in the milieu of caregiving for dementia patients, can yield significant adversities for their informal caregivers (Pearlin, Mullan, Semple & Skaff, 1990). To illustrate, it can give rise to disagreements between filial members and IDC over the nature of support required to meet their loved ones' needs as well as quarrels regarding less involved relatives' failure to appreciate the strain experienced by the caregivers (Gwyther, 1995). Such conflicts were linked to IDC increasing risk of developing depression (Semple, 1992).

Further, as the illness evolves IDC will need to devote more time to caregiving. This will often require them to give up their leisure activities and invest less time in developing and maintaining interpersonal relationships. Reduced opportunities for recreational undertakings and meeting people can lead to filial relatives' and friends' withdrawal, resulting in caregivers' social isolation (Johnson & Troll, 1994; MacRae, 1999; Wimo, Winblad & Grafstorm, 1999). Informal caregivers may also experience social isolation when they intentionally avoid contact with other people due to feelings of embarrassment pertaining to their care recipients' inappropriate conduct (Tebb & Jivanjee, 2000). Past research suggests that this form of behaviour is driven by IDC fear of being stigmatised due to their affiliation with their care-recipient (Blum, 1991). This is because dementia, like other mental health disorders, is associated with unsocial interactions and taboo behaviours (Mukadam & Livingston, 2012). Stigma by association can evoke feelings of blame and humiliation and increase IDC experience of burden which could lead to a reduction in caregiving (Werner, Goldstein & Heinik, 2011; Werner, Mittelman, Goldstein & Heinik, 2012).

Furthermore, informal caregivers bear the direct and indirect financial costs associated with caregiving for a loved one with dementia. Direct financial costs refer to expenses incurred for the purchase of medication, professional healthcare services, and the time that the caregivers invest in supporting their loved ones. Indirect financial costs refer to the undesirable effects that caregiving has on informal caregivers' work such as missing out on career moves or relinquishing their employment entirely to meet their care recipients' increasing needs (McDaid, 2001; Ory, Hoffman, Yee, Tennstedt & Schulz, 1999). Indeed, Luscombe, Brodaty and Freeth (1998) study showed that 59% of the employed IDC that participated in their study (N=61) decreased their number of working hours or stopped working altogether following their care recipient diagnosis.

Changes in lifestyle due to increasing caregiving demands leaves little time to engage in activities that defined caregivers' identity prior to caregiving. This can propel individuals to espouse the caregiver's identity and forgo past identities. Loss of identity in turn has been linked with poor self-worth and depression in some caregivers as well as emotional detachment from the care-recipient (Eifert, Adams, Dudley & Perko, 2015; Jones & Martinson, 1992; Skaff & Pearlin, 1992).

A number of studies have described the adverse outcomes that informal caregivers' experience in the milieu of caregiving for a person with dementia. Adams (2006) set out to explore adult daughters' and spouses' personal experiences of espousing caregiving duties for a relative with early onset dementia. Information was gathered using semi-structured interviews which consisted of questions pertaining to caregivers' views about their relationship with their care-recipients during this period and the impact of this transitional process on caregivers' lives. Results showed that spouse caregivers adopted new instrumental activities that were previously managed by their husbands or wives and that both partner and daughter caregivers struggled to decide to what extent should they be limiting their loved ones' participation in daily life tasks. These demands evoked mixed emotions in all participants including resentment about their situation and guilt for being angry and impatient with their care-recipients. Family caregivers' guilt has been positively associated with their sense of burden suggesting negative appraisals of their performance (Gonyea, Paris & de Saxe Zerden, 2008).

With regards to changes in interpersonal ties, adult daughters in Adams (2006) study, noted above, expressed sadness and frustration about the loss of a relationship that they previously had with their parents describing role reversal. Spouse caregivers reported that mental and emotional changes in their care recipients meant that they were no longer able to discuss important decisions with them or share the burden of bad news in the same manner as they had. Spouse caregivers' interviews also suggested that they experienced loss of intimacy and had to deal with increasing demands for emotional attention.

Earlier research shows that in marital situations where the wife has dementia, the caregiving husband may also experience loss of social relationships since the wife is often the husband's chief source of companionship as well as his key link to external social ties (Harris, 1993; Kramer, 2000). Changes and decreases in the nature and value of the bond that exists in the caregiver-care recipient dyad, can have adverse ramifications for caregivers' wellbeing (Owens, 2000) and precipitate anticipatory mourning over lost facets of their relationship (Kaprio, Koskenvuo, & Rita, 1987; Light & Lebowitz, 1989). Anticipatory grief can be burdensome if the care recipient's decline persists for a lengthy period of time as in the case of dementia patients (Pattison, 1978).

Further, caregivers may experience loss of shared identity. Shared identity is constructed through caregivers' transactions with their loved-ones as in the case of parent-child dyads and spouses. Since caregiving alters caregivers' relationship dynamics with their care-recipient, their perception of themselves in that interaction will also alter (Eifert et al., 2015). Indeed, wives' caregiving for their husbands in the milieu of dementia recounted changes in the perception of themselves following changes in their spouse personality. Specifically, they espoused a mothering position whilst forgoing their role as wife and lover (Hayes, Boylstein & Zimmerman, 2009).

Papastavrou, Kalokerinou, Papacostas, Tsangari and Sourtzi (2007) study sought to investigate the relationship between dementia clients challenging behaviours and their informal caregivers experience of burden. Further, they sought to identify the impact of dementia caregiving on informal caregivers' mental health and whether placing a loved one in a care home would reduce informal caregivers' experience of burden. Findings showed that care recipients' aggression was strongly associated with caregivers' burden. According to Mahoney (2003) it is dementia caregivers attempts to control their care-recipients' challenging behaviours and the vigilance they employ when faced with such experiences that evokes their sense of burden. Burden in turn has been linked with poor self-care and health problems in IDC (Connell, Janevic & Gallant, 2001; Fuller-Jonap & Haley, 1995; Vitaliano, Zhang & Scanlan, 2003). Further, persistent strain might be perceived by informal caregivers as evidence of their failure to manage difficult situations which in turn could lead to negative self-evaluation (Pearlin, Lieberman, Menaghan & Mullan, 1981).

With regards to Papastavrou et al (2007) second aim, findings showed that almost half of the caregivers were at risk of developing clinical depression which was highly correlated with long-term caregiving careers (ranging from one to thirteen years) and caregivers' burden. Still, informal caregivers' burden did not diminish when their loved ones were transferred to a care facility. Past research demonstrates that whilst caregivers no longer provide hands-on care following their care recipients' placement, they continue to support them by ensuring that their needs are met (Townsend, 1990). This suggests that caregivers' burden in Papastavrou et al (2007) study altered rather than diminished following their care recipients' institutionalisation.

Given that both hospitals and care homes are institutional settings that provide care to vulnerable people, it is conceivable that IDC burden will also linger in the context of their loved ones' HDPP. Equally, IDC may suffer from anxiety about the reasons for which their care recipients were hospitalized (Bradway & Hirschman, 2008) and experience an increase in their level of burden due to their care-recipients' loss of skills following hospitalization (Douglas-Dunbar & Gardiner, 2007). Further, whilst preparing for their care recipients' hospital discharge, IDC may feel pressured to re-establish their everyday routine and experience stress and ambiguity pertaining to their caregiving commitments (Cameron & Gignac, 2008). However, there is a paucity of research exploring IDC experience of their mental health in the milieu of their loved ones' HDPP. Where literature does exist, it is mainly centred on describing informal caregivers' struggles to attain information and participate in decisions pertaining to their loved ones' care. Additionally, majority of studies employed a sample of informal caregivers of older patients who did not have dementia. A brief outline of these investigations will be presented in the next section.

3.6 How do Informal Caregivers Make Sense of their Care-Recipients' HDPP?

Grimmer et al. (2004) undertook a qualitative phenomenological study with twenty-four Australian informal caregivers, describing participants' experience of caregiving for an elderly person with a chronic illness following discharge from hospital. In their interviews, caregivers recapped on their experience of their care recipients' HDPP. Specifically, they said that staff did not provide information pertaining to the management of their care recipients' medical conditions as well as the length and extent of informal support required post discharge. Caregivers also recounted that hospital staff invested minimal efforts in establishing whether they were physically and emotionally willing and capable to undertake caregiving tasks post discharge and that they felt underestimated.

Grimmer et al.'s (2004) study has several limitations. First, minimal verbatim extracts were provided to evidence the authors' analysis. Consequently, it is the authors' rather than caregivers' voices that readers hear. Second, minimal information was divulged regarding care recipients' health problems. Thus, it is unclear whether any of them had dementia. Further, it is possible that patients differed in their level of need due to differing chronic illnesses. Consequently, caregivers' experience of their care recipients' HDPP may have varied. However, this limitation was neither investigated nor acknowledged. Third, the study did not explore caregivers' responses to being excluded from their loved ones' discharge planning process.

In its defence, the study focus was on caregivers’ experience of caregiving in the post-discharge period rather than during admission. The study concluded that to sustain informal caregivers’ support in the community, hospital staff need to adequately prepare them for their caregiving role in the pre-discharge period. Whilst this implies that the authors view informal caregivers as a resource when they should be recognised as having needs and interests in their own right, it does recommend that future research should shift the focus from care-recipients to caregivers. This in turn could empower informal caregivers to identify their idiosyncratic requirements in the context of their loved ones’ HDPP.

A more recent investigation used thematic analysis to explore nineteen Norwegian family caregivers’ attempts to gain influence over their elderly relatives’ HDPP (Bragstad, Kirkevold & Foss, 2014). The measures that caregivers employed in response to being excluded from their loved ones’ HDPP were as follows: One participant informed members of staff that he would be away on the day that his spouse was due to leave the hospital. This was to postpone her discharge whilst she was still unwell. Similarly, a daughter confiscated her mother’s front door keys to stop the HDP from sending her mother home to a vacant dwelling. Another daughter, who advocated for her mother to be placed in a nursing home following a series of admissions, contacted a senior manager to intervene after hospital staff disregarded her views.

Participants’ actions in Bragstad et al.’s (2014) study might be explained using the Reactance theory. It suggests that when individuals observe their liberty to participate in different activities as restricted, they will be motivated to recover their threatened freedom by declining to cooperate with those who constrained their liberty in the first place (Brehm, 1966). This suggests that informal caregivers are central to the success or failure of older individuals’ transfer from hospital to the community. It also highlights that it will be in staff best interest to work collaboratively with informal caregivers, given that hospitals are keen to reduce costs associated with patients prolonged stays (Cox, 1996).

Among the limitations of Bragstad et al.’s (2014) study is that they summarised rather than interpreted participants’ extracts. Consequently, the authors missed an opportunity to attain in depth understanding into of how caregivers thought and felt during their care-recipients’ hospital discharge planning. Likewise, they did not explore how caregivers experienced their life outside the hospital environment whilst the HDPP was taking place. Further, it is unclear whether any of the participants were dementia caregivers, since information pertaining to the care recipients was omitted. Moreover, Bragstad et al. (2014) concluded that informal caregivers must be empowered to partake in discharge planning, explaining that failing to do so could have adverse effects on public healthcare services function over time. This proposition overlooks the possibility that caregivers may also endure adverse effects as a consequence of their exclusion, suggesting that the authors prioritised the system's needs over informal caregivers' outcomes. As with Grimmer et al.'s (2004) study, Bragstad et al.'s (2014) research demonstrates that a decade later, informal caregivers of older people continue to be viewed as a resource and their mental health needs remain unaddressed.

Where informal caregivers' outcomes were investigated, it was in the milieu of the post discharge period. For example, Bull et al. (2000) conducted a quantitative study with 130 American family caregivers of older individuals who were hospitalized due to heart failure. The authors sought to identify whether the level of caregivers' involvement in their loved ones' discharge planning made any difference to their wellbeing, satisfaction with hospital care, readiness to provide care, and acceptance of the caregiving role following discharge. Results showed that caregivers who recounted moderate (21.5% of participants) and high levels (32.3% of participants) of participation in their care recipients' hospital discharge planning scored higher on the above measures than those who reported poor or no involvement (46.2% of participants).

These findings are helpful since they suggest that involving unpaid caregivers of older people in the HDPP contributes to their wellbeing and continuity of care post discharge. However, the study did not explore in depth caregivers' subjective lived experience of the HDPP. This is because the authors employed structured questionnaires to collect their data which did not permit participants to engage in rich exploration or deliver a personal narrative about their experience. As a result, the study's findings impose nomothetic suppositions onto individual caregivers of older people. Further, almost half of the caregivers were not involved in their loved ones' discharge planning, yet the authors did not discuss this finding. Moreover, the study concluded that hospital staff should inform informal caregivers about their care-recipients' needs and care routines in an attempt to increase their care-recipients' independence at home and reduce their hospital readmissions. This suggests that the authors' prime concern was patients' outcomes whilst caregivers' needs were secondary, reinforcing the view that caregivers should be treated as a resource. Finally, Bull et al.'s (2000) investigation is based on a sample of unpaid caregivers of older people with heart failure. Thus, it is uncertain whether its results would generalize to IDC.

Alternatively, Fitzgerald, Bauer, Koch and Kings' (2011) Australian study did explore IDC experience of their relatives' HDPP using thematic analysis. Caregivers' semi-structured interviews yielded three main themes that echoed the findings reported in Grimmer et al.'s (2004) study. Specifically, inadequate communication, poor preparation for discharge, and underestimating caregivers as a resource. Inadequate communication pertained to caregivers' reports that staff neglected to inform them in advance about their relatives' discharge day; some caregivers were notified of their relatives' discharge during patients' transfer to the community and others were unaware that their relatives had already left the hospital. A number of caregivers recounted chasing staff for information about their relatives' discharge destination during their admission but to no avail. Consequently, they resorted to gathering information from whomever was on the ward at the time. Similarly, caregivers struggled to gather information about their relatives' post-discharge requirements for which several resorted to lodging a complaint that would yield their desired information. Further, some caregivers reported that hospital staff did not consult them about transferring their relatives to another care facility and others disagreed with staff decision to discharge their relatives from hospital reporting that they were still unwell.

Poor preparation for discharge referred to caregivers' concerns that the discharge planning seemed to be ad hoc, taking place the day prior to their loved ones' actual discharge. Also, family caregivers of individuals who were discharged home complained that their pre-discharge requests appeared to go unnoticed. This was because community services arranged by hospital staff failed to meet their requirements and their care recipients' level of need. Underestimating caregivers as a resource was predominately about staff ignoring caregivers' knowledge of their loved-ones needs.

Fitzgerald et al.'s (2011) research is useful because it elaborates on the challenges experienced by IDC in the context of their loved ones' hospital discharge planning process. However, the study did not examine whether these challenges had an impact on caregivers' mental health wellbeing. Also, since the study focused on exploring the lack of dialogue between hospital staff and caregivers it did not investigate how participants experienced other aspects of the HDPP such as their relatives' hospitalisation. Good practice mandates that the HDPP commences on the day that patients are admitted to hospital (NHS Choices, 2018) and since hospitalization disrupts both patients’ and caregivers’ daily routine, it may drive caregivers to gain control over their new situation (Lindhardt, Nyberg & Hallberg, 2008). Yet, Fitzgerald et al.’s (2011) study did not investigate how their participants thought and felt about being excluded from their loved ones’ HDPP and whether this experience impacted on their relationship with their care recipients and staff. The only comment made in this context was that participants felt undervalued. Furthermore, individuals with dementia have greater mental and physical limitations than other elderly people. Therefore, they require more nursing care which in turn increases their discharge planning requirements (Erkinjuntti, Wikström, Palo & Autio, 1986). Nevertheless, Fitzgerald et al.’s (2011) study did not examine how care-recipients’ dementia related needs impacted on caregivers’ experience of the discharge process. Equally, there was no discussion about the possible reasons for which hospital staff neglected to fully incorporate family caregivers in their loved ones’ HDPP. Such information could have highlighted areas for improvement in discharge practices for elderly individuals with dementia and their informal caregivers.

In another qualitative study exploring IDC experience of their loved ones’ admission to a UK general hospital, Clissett, Porock, Harwood and Gladman (2013) identified two main themes. First, disruption to IDC established caregiving routine due to their care-recipients’ hospitalisation and due to patents’ increased distress and challenging behaviours associated with the change in their caregiving environment. Caregivers reported that they experienced their care-recipients’ admission via the emergency department as slow, exhausting and uncomfortable as well as insensitive to the needs of their confused care-recipients. A number of caregivers were also worried about their loved ones’ community services being withdrawn following their hospitalization and that their loved ones would need to adjust to new formal carers on their return, causing further disruption to patients’ care.

With regards to Clissett et al.’s (2013) second theme, informal caregivers employed several coping behaviours to regain control over their new caregiving situation. These included engaging healthcare professionals in conversations about their care-recipients’ needs and visiting their care-recipients at different times to find out what was happening with them on the ward. In doing so, caregivers aimed to obtain an accurate picture of the quality of care supplied by members of staff. Caregivers explained that they could not rely on their loved-ones to provide such information due to their poor memory. Caregivers varied in their reactions to perceived poor quality of care; some rationalised it as the government's fault thereby reducing hospital staff accountability. The authors argued that this may have maintained caregivers' trust in the multidisciplinary team thereby helping caregivers feel in control. Other caregivers provided direct support to their loved ones on the ward as a mean to bridge gaps in care or questioned staff about inadequacies in care. A final strategy consisted of protecting care-recipients' rights by advocating on their behalf. This helped caregivers attain a sense of control over their loved ones' experience of the hospital context.

As with the studies described above, Clissett et al. (2013) did not explore in depth how informal caregivers experienced their mental health during the disruption to their normal caregiving routines, in their disagreements with staff over inadequate care, and in their attempts to regain control over the caregiving situation. Further, the authors did not discuss the reasons for which caregivers differed in their coping behaviours. It may be that variations in caregivers' demographics (e.g. relationship to the care recipient, gender, age) account for this divergence. Yet this possibility was not discussed or acknowledged.

Notwithstanding these limitations, the differences between caregivers in the behaviours they employed to deal with the disruption to their normal caregiving routine, suggests that they also differed in other aspects. Specifically, in the way they thought about the HDPP and in their perceived ability to deal with it. This in turn underlines the importance of researching IDC idiosyncratic experiences in the context of their loved ones' hospital admission which, as stated earlier, forms the first stage of discharge planning (NHS Choices, 2018). Equally, the study demonstrates that care-recipients' dementia related difficulties (i.e. poor memory, confusion, distress, challenging behaviours & adjustment difficulties) contributed to caregivers' poor sense of control. This suggests that IDC mental health needs may differ from other unpaid caregivers' needs in the context of the HDPP. Furthermore, the study shows that in the face of disruption, IDC attempted to regain control over their loved ones' caregiving situation using cognitive and behavioural strategies (e.g. rationalisation, questioning staff & visiting patients on the ward at different times) which highlights their resourcefulness and need to be involved in their loved ones' care.

The literature explored in this section consistently illustrates that the mental health needs of IDC have yet to be explored in the milieu of the hospital discharge planning phenomenon. Nevertheless, it has been examined in the context of care homes. For example, Riddick, Cohen-Mansfield, Fleshner and Kraft (1992) found that family dementia caregivers felt sadness, anger and guilt over their loved ones' medical deterioration and subsequent institutionalization as well as anxiety about their own future given their potential genetic predisposition to develop the illness. Moyle, Edwards and Clinton (2002) more recent research in this area showed that IDC experienced feelings of distress, loneliness and loss associated with the transformation in their caregiving role. Specifically, the shift from providing constant care which enabled IDC to show their affection to their loved ones, to caregiving from afar and no longer having control over the caregiving situation. Further, IDC in Moyle et al.'s (2002) study reported that having nursing staff around, observing their communication with loved ones, infringed on their privacy and detracted from their relationship with their care recipient. Moreover, IDC recounted feeling worried about raising complaints with care workers due to fear that conflict may subsequently affect the quality of care provided to their loved ones (Moyle, Edwards & Clinton, 2002). Whilst these studies were conducted in the context care homes and caregiving for persons with dementia, it is possible that IDC will experience similar psychological outcomes during their care recipients' HDPP. This is because both of these phenomena entail a period of transition within an institutional context. Still, it has yet to be demonstrated forming a gap in the literature.

3.7 Summary of Research Findings, Limitations & Gap

The studies examined in this literature review demonstrate that hospital personnel neglected to adequately involve IDC in their loved ones' HDPP. Specifically, they did not provide sufficient information about care-recipients' care requirements nor include informal caregivers in decisions pertaining to patients' discharge date and destination. Likewise, they ignored caregivers' knowledge pertaining to their loved ones' needs and did not consider whether caregivers were able and willing to provide care post discharge (Bragstad et al., 2014; Fitzgerald et al., 2011; Grimmer et al., 2004). It has been argued that limiting individuals' capacity to partake in discussions and decisions pertaining to their needs or the welfare of those they care for, can yield unfavourable outcomes for their wellbeing (Crethar et al., 2008).

Nevertheless, how IDC responded internally to these challenges in terms of their thoughts and feelings has yet to be explored in depth. Where IDC responses were examined, the emphasis was on describing the strategies they employed in their attempt to attain control over aspects of the discharge process (Bragstad et al., 2014; Clissett et al., 2013). Findings from these studies illustrate that IDC varied in the measures they used to gain influence. According to the family adjustment and adaptation response model (Patterson, 1988) this suggests that they also differed in the way they thought and felt about their experience and in their perceived capacity to deal with it. Yet, none of the investigations undertaken to date have examined in depth IDC idiosyncratic experience of their loved ones' HDPP. Further, majority of investigations have focused on the lack of dialogue between HDP and informal caregivers of older people (e.g. Bragstad et al., 2014; Fitzgerald et al., 2011; Grimmer etal., 2004). Consequently, IDC experience of their caregiving role, their relationship with their care recipients and staff and their life outside the hospital environment have been overlooked.

Furthermore, very few studies employed a sample of IDC. Among those that did is Fitzgerald et al.'s (2011) study which omitted to explore the role that dementia played in caregivers' experience of their loved one's discharge planning. Alternatively, Clissett et al.'s (2013) paper highlighted that caregivers' poor sense of control was linked to their care recipient's dementia related requirements. This may suggest that in the context of hospital discharge planning, IDC differ from other unpaid caregivers in their mental health needs. However, as with other studies, the authors did not go on to investigate what those needs may be. In the absence of such information, IDC needs may go unmet which could increase their emotional burden and diminish from their quality of life. This notable gap in research is also becoming more pressing with time given that the demand for IDC support is expected to increase with the rise in the number of dementia patients, and since discharge planning requirements for individuals with dementia are often greater and more complex than other elderly patients (Grimmer et al., 2004; Mockford, 2015).

Moreover, this literature review found that researchers consistently concluded that informal caregivers should be involved in their care recipient HDPP since their exclusion could lead to delays in discharge, hospital readmissions, and patients' placement (Bragstad et al., 2014; Bull et al., 2000; Cox, 1996). However, this conclusion overlooks the possibility that caregivers may also experience adverse outcomes as a result of their exclusion. One possible reason for this omission is that most of these studies were conducted by authors with a background in nursing and were published in academic journals about nursing. Still, by employing the medical model caregivers are viewed as a resource which constitutes a barrier to treating them as individuals who have needs in their own right. Finally, most of the studies pertaining to the HDPP and informal caregivers of older people were conducted outside the UK (e.g. Bragstad et al., 2014; Bull et al., 2000; Fitzgerald et al., 2011; Grimmer et al., 2004) where both the culture and governmental policies pertaining to hospital discharge planning are likely to differ from those in Britain. Therefore, these studies findings are not necessarily generalisable to British caregivers and the NHS.

3.8 Research Questions & Aims

To address these limitations, the current study endeavours to investigate the following research question: How do IDC experience their care-recipients' HDPP. Specifically, how do they think and feel about their experience and how do they make sense of their thoughts, feelings and behaviour? The thesis aims are as follows: to achieve an understanding of how IDC experience their caregiving role, their relationship with members of staff, their relationship with their care-recipients and their everyday life in the context of the HDPP. It is hoped that the present investigation will empower IDC to identify their own unique needs as such insights could inform the practice of applied psychologists working with this particular client group. Likewise, it could inform the work of hospital staff which according to NICE (2013) have received little guidance on how to actively engage informal caregivers in older patients' care.

3.9 Relevance to Counselling Psychology

At the time of writing, no research was found within the counselling psychology discourse regarding IDC experience of their care recipients' HDPP. One likely reason for this omission is that hospital discharge planning and dementia care are processes embedded within the medical system, a context which has traditionally been the terrain of clinical and health psychologists. Despite this lack of engagement, counselling psychology is well placed to research this topic. First, it is committed to employing a phenomenological stance which could facilitate IDC examination of their thoughts and feelings whilst firmly placing their experiences within the milieu of their loved ones' HDPP. By employing this principle in the current thesis, novel insights can be attained about IDC mental health requirements and behaviour in the milieu of the hospital discharge planning phenomenon.

Similarly, the profession is orientated towards empowering participants and engaging in democratic relationships (Kasket, 2012) which could give caregivers a voice in a hierarchically structured environment, namely the NHS. Second, much of the research undertaken to date resides in nursing journals where the authors employed the medical model to impose nomothetic suppositions onto individual caregivers. Alternatively, counselling psychology uses a client-centred approach which will treat IDC as unique entities and could provide an alternate way to conceptualise their experiences. Finally, the dissemination of insights amid hospital staff and clinicians could facilitate a more pluralistic way of working with IDC. Such undertakings are consistent with the government's call to improve IDC life satisfaction (DoH & Social Care, 2014) and the profession's orientation towards enhancing individuals' wellbeing (Cooper, 2009). Equally, conducting research that benefits people beyond the therapeutic encounter is in keeping with counselling psychology future directions (Milton, 2010).

4. Methodology

4.1 Outline

The epistemological and ontological positions of investigators set the context for their study (Ponterotto, 2005). Therefore, this chapter commences with a look at this investigator's research paradigms. This is followed with a discussion pertaining to the reasons for which qualitative rather than quantitative methodology was chosen for this study. The rationale for employing a phenomenological approach and more specifically an IPA method of inquiry is then stipulated. In line with counselling psychology pluralistic attitude, alternative methodologies are also explored namely, Foucauldian discourse analysis (FDA) and grounded theory. The remaining sections describe the participants, recruitment process, data collection, procedure and materials and analysis. Finally, ethical issues and the research validity are considered.

4.2 The Researcher's Epistemological & Ontological Position

This study draws upon a constructivist and criticalist perspective. Constructivists postulate that reality is created within peoples' minds since they experience, process and label it. Therefore, constructivists believe that there are numerous idiosyncratic valid realities rather than one neutral and visible truth (Hansen, 2004). Accordingly, constructivist researchers place emphasis on exploring the personal accounts of their participants' experiences. By assuming that different persons ascribe different and numerous meanings to a particular phenomenon that they experienced, the constructivist paradigm adopts a relativist ontological stance (Schwandt, 1994) which this researcher shares. The view that exploring individuals' subjectivity is important and should not be ignored has also been advanced by counselling psychology (Orlans & Van Scoyoc, 2008) and IPA (Smith, Flowers & Larkin, 2009) which is the method employed in the present investigation. Nevertheless, the constructivist researcher would never be able to fully access her participants' world since her understanding of their accounts stems from her own personified outlook (Smith et al., 2009).

Further, constructivists adopt a hermeneutical approach since they believe that lived experiences might exist outside participants' consciousness (Sciarra, 1999). IPA shares this perspective in that it views the researcher's analysis of the data as an opportunity to offer meaningful insights which may surpass participants' overt claims (Smith et al., 2009). In espousing a hermeneutic position, the researcher accepts that to reveal hidden meanings she and her participants must engage in reflective discussions and interpretations and that the researcher-participant relationship will ultimately affect the study's findings. This is because any yielded knowledge is co-constructed. Moreover, constructivist epistemology posits that reality is formed within a specific framework such as individuals' belief system and social environment (Ponterotto, 2005) which is compatible with counselling psychology core principles namely, that context impacts on the construction of knowledge (Strawbridge 2016).

Like constructivism, the critical-ideological stance also assumes a constructed reality that is moulded by individuals' ethnicity, culture, gender, beliefs and views (Ponterotto, 2005). However, criticalists also contend that reality is mediated by power dynamics that are firmly founded within social structures (Kemmis & McTaggart, 2000). This means that participants' understanding of their lived experiences might be influenced by conceptual mechanisms (such as available language) which work to make the interests of the strongest groups in society appear normal. Hence, the criticalist researcher's goal is to empower participants to gain new insights via dialectical interaction and subsequently work towards change (Tolman & Brydon-Miller, 2001). Similar theoretical underpinnings have been endorsed by the counselling psychology profession. Specifically, to 'work in ways that empower rather than control' (BPS, 2005 p.1) to give clients a voice and increase their awareness, and to give them the tools to advance with social change (Goodman, Liang, Helms, Latta, Sparks & Weintraub, 2004).

4.3 Self-Reflection

It has been postulated that making researchers' views transparent will help them and their readers evaluate how such stimuli may have influenced their rendering of data (Morrow, 2005). In keeping with this argument, I have documented the assumptions that I hold about the HDPP. Specifically, that hierarchical and authoritarian relations exist between IDC and hospital discharge planners and that these processes are formed and perpetuated by the medical model which in my opinion diminishes from IDC wellbeing. Likewise, I believe that local authorities and NHS bodies continue to view IDC as a resource rather than as equal partners who have needs in their own right. Moreover, I think that existing research pertaining to the HDPP and informal caregivers of older people contribute to the preservation of this view. Finally, I presumed that caregiving for individuals with dementia is characterised by negative experiences and implications for family members. These assumptions are based on my past social work experience and familiarity with existing literature, and probably informed my analysis of participants' transcripts. This is due to two primary reasons: First, increase in knowledge pertaining to a particular phenomenon also increases the volume of pertinent information that one perceives when witnessing it. Second, I was cognizant that my subjectivity and grasp of this research topic was required to develop understanding pertaining to IDC experience of the HDPP. However, by engaging in reflective and reflexive practices to evaluate my role in this research process, I attempted to reduce such impositions of meanings on IDC plentiful and idiosyncratic way of experiencing.

On further reflection I have recognised that my assumptions can also be traced back to my criticalist values and orientation towards social justice practice. Specifically, I believe that people do not live their lives in a vacuum. Rather, they exist within a context such as societal systems and their practices as well as interpersonal relations which privilege particular groups over others (Crethar & Ratts, 2008; Kincheloe & McLaren, 1994). Consequently, certain individuals in society are left feeling disempowered which could subsequently lead to their development of psychological problems (Comstock, Hammer, Strentzsch, Cannon, Parsons & Salazar, 2008). Therefore, I endorse the notion that counselling psychologists should recognise and address such issues (Kennedy & Arthur, 2014).

4.4 Why Employ a Qualitative Rather than a Quantitative Approach?

Qualitative research seeks to describe and understand individuals' experiences from their own perspective as they engage with the world rather than substantiate existing findings or theories (Elliott, 1995). The reasons for which a qualitative methodology was employed in this study are as follows: First and foremost because it matched well with the epistemological stance that underpins the research question. Specifically, the present investigation seeks to narrate and interpret IDC idiosyncratic experience of their loved ones' HDPP in order to attain in-depth understanding of how each caregiver makes sense of this particular phenomenon. In doing so, this study endeavours to produce phenomenological knowledge which is inductive and idiographic and therefore could only be harvest using a qualitative approach. Equally, a qualitative approach fits well with the relativist ontological stance that underpins the research question. Explicitly, each of the participants could experience the HDPP in an idiosyncratic and diverse way since their experience of this phenomenon is constructed internally and is influenced by their own unique subjectivity.

Conversely, in quantitative methodology the researcher imposes his own suppositions onto the research process by using predefined variables to predict the study's outcomes, thereby precluding identification of participants' personal experience of the investigated subject matter (Willig, 2013). Further, quantitative methodology assumes that humans are governed by natural principles which dictate their cognition and conduct and it is those laws that this approach seeks to discover and unravel. Alternatively, qualitative methodology views the meaning that individuals ascribe to their experiences as vital to understanding their inner world (Kasket, 2012; Slife & Grantt, 1999) which fits with the researcher's constructivist and criticalist epistemological stance. Moreover, quantitative methodology is guided by empiricistic epistemology which focuses on the study of direct observable phenomena thus only validating knowledge obtained from a narrow array of experiences (Slife & Grantt, 1999). Yet the present investigation aim is to explore the wide range of internal processes experienced by caregivers in the context of their loved ones' hospital discharge planning. Qualitative research can facilitate such endeavours since it is concerned with the discovery of participants' subjective experiences (Nelson & Quintana, 2005).

4.5 Phenomenology

Generally speaking, there are three categories of knowledge which qualitative research can aim to produce namely, realist, social constructionist and phenomenological (Willig, 2013). The present investigation is concerned with the latter since the study's research question seeks to generate data which is phenomenological in nature. That is, to produce insights about, and facilitate understanding of, IDC personal experience of the HDPP irrespective of whether their reports reflect an accurate picture of what has actually happened to them in this context. Thus, phenomenology places emphasis on the study of humans' subjective accounts of their personal experiences rather than the construction of objective and detached explanations of data (Flowers, Hart, & Marriott, 1999). Further, phenomenology seeks to empower participants by giving them a voice and this fits with the researcher's criticalist epistemological stance and counselling psychology values.

Whilst there are numerous phenomenological methods, they are normally characterised as either descriptive or interpretative (Lopez & Willis, 2004). The descriptive stance is linked to Husserl (1970) and has been informed by transcendental phenomenology. It holds that research should focus on the description of a specific phenomenon as it is experienced by the participants. The goal is to produce knowledge of a lived world as it presents to the researcher in her engagement with it and which is free from empirical explanations and interpretations. To achieve this, the researcher must apply three principles namely, bracketing, phenomenological reduction and imaginative variation. In bracketing the researcher contains her preunderstandings of the phenomenon under investigation to be fully aware of the unique characteristics of the investigated experience. Phenomenological reduction aim is to discover these characteristics through the detailed description of participants' experience. Finally, imaginative variation seeks to identify the conditions that facilitated the birth of the researched phenomenon (Giorgi & Giorgi, 2008; Langdridge & Hagger-Johnson, 2009; Willig, 2013).

Alternatively, interpretative phenomenology draws on the hermeneutic theory and is associated with philosophers such as Heidegger and Gadamer. It holds that to make sense of participants' reports, intimate interpretations of the data are required and these are always influenced by the researcher's past conceptions. Therefore, it is impossible to suspend all biases when reflecting on a phenomenon. However, the researcher's initial assumptions are modified through her interaction with the participants and the data (Giorgi & Giorgi, 2008; Smith et al., 2009; Willig, 2013). The present study has elected to employ an interpretative phenomenological method of inquiry and more specifically IPA. The reasons for this are considered below.

4.6 Why Employ an IPA Method of Inquiry?

IPA, like counselling psychology, is idiographic in that it seeks to unravel in detail the underlying subjective meanings that each participant ascribes to a particular life event rather than investigate whether participants' experiences match with external reality (Smith et al., 2009). This is because it assumes that a specific phenomenon within a certain setting can be experienced in different ways by a particular group of people (Smith, 2011). This is consistent with the present research overall goal namely, to understand IDC experiential world in the context of the HDPP from their perspective. Likewise, it chimes with the researcher's and counselling psychology relativist ontological stance. Specifically, that IDC experience of the HDPP is influenced by their subjectivity and hence there are multiple and rich ways in which IDC can observe and construe the hospital discharge planning phenomenon. Further, IPA's aims match with counselling psychology quests to examine how individuals' psychological problems are linked to the context in which they were formed (Higley & Milton, 2008). Moreover, IPA espouses a phenomenological stance and this will help the researcher answer her research question. Specifically, describe and analyse participants' emotional reactions to, and understanding of, their experience of the HDPP as well as explore how IDC render what is occurring with them in this context (Smith, 2011).

Nevertheless, IPA recognises that the researcher's perception of her participants' lived world stems from her own prior embodied conceptions and thus the researcher-participant relationship commences from a position of difference (Merleau-Ponty, 1962). This means that the researcher can never share completely her participants' experiences and can only attempt to gain an insider perspective by being 'experience close' (Smith, 2011, p.10). To achieve this the researcher must engage in interpretative activity which ties IPA to the hermeneutic tradition. Further, IPA engages in double hermeneutic since the investigator is striving to interpret participants' experience, who are trying to interpret their own experience (Brocki & Wearden, 2006). In that, IPA acknowledges the role that the researcher's and her participants' subjectivity and intersubjectivity play in shaping the research findings. This is consistent with the counselling psychology view that prior knowledge and biases cannot be eliminated and forms the first step in reflexive practice, a primary quality in the profession's research process (Kasket, 2012).

Alternatively, descriptive phenomenological approaches seek to produce knowledge that represents the real essence of the phenomenon under investigation (Allen,1995; Natanson,1973) by precluding the researcher's interpretations in the construction of knowledge (LeVasseur, 2003; Lopez & Willis, 2004). They assume that employing techniques such as bracketing will eliminate the researcher's biases (Drew, 1999). However, this belief is incompatible with counselling psychology practice of reflexivity (Kasket, 2012) and hence these methods were deemed unsuitable.

4.7 Alternative Methods of Inquiry Considered in the Research Process

Counselling psychology pluralistic stance recognises that different methods could be appropriate for examining research questions (McAteer, 2010). Therefore, this researcher remained open to exploring other available methodologies namely, FDA and grounded theory. FDA was considered as an alternative method since like the present study it shares an interest in human subjectivity. Specifically, this approach pays particular attention to what participants say and the relationship between the way they talk and the way they think and feel (Willig, 2008). Further, FDA assumes that there are various versions of reality, each of which are created via language (Arribas-Ayllon & Walkerdine, 2008) and thus subscribes to a relativist outlook which chimes with the researcher's ontological stance.

Equally, FDA postulates that discourse facilitates power dynamics that privilege knowledge which is socially constituted. Hence, it seeks to investigate the manner in which knowledge is employed to influence peoples' behaviour through the use of available language (Burman & Parker, 1993; Langdridge & Hagger-Johnson, 2009) which chimes with the researcher's criticalist epistemological position. Moreover, FDA seeks to analyse how participants' immediate and wider social and political contexts are implicated in their experience of the investigated phenomenon (Smith et al., 2009). This is consistent with the present research question in its pursuit to identify whether the context of hospital discharge planning makes any difference to IDC experience of caregiving. Nevertheless, FDA was deemed unsuitable for the present study since its chief concern is the role that dialect plays in the creation of peoples societal and psychological experiences. As such, it aims to recount and analyse the discursive contexts individuals occupy to gain insight into how they construct their internal processes (Gavey, 1989; Willig, 2013) whilst the present study seeks to make sense of how individuals' personal experiences shape the way they think and feel.

Grounded theory was also considered as a potential method of inquiry for the present investigation despite its preoccupation with unravelling social processes. This is due to the increasing attention it pays to the study of lived experience. Specifically, the approach has shown interest in the structure of participants' inner processes such as their cognitions and emotions. Equally, it allows such data to be analysed for the purpose of representing participants' experience of an investigated phenomenon (Dey, 2012; Willig, 2013). Whilst this resembles the phenomenological orientation of the present research question, grounded theory researchers adopt a realist and a positivist epistemological approach to knowledge production. Specifically, they aim to harvest insights that reflect a precise picture of what is actually happening in reality by positioning themselves and participants in the role of a witness, by viewing transcripts as factual accounts, and by taking care not to import their own suppositions into their interpretations (Pidgeon & Henwood, 1997; Willing, 2013).

This outlook contrasts with the researcher's constructivist position namely, that there is no one single objective truth. It also contrasts with the epistemological stance that underpins the present research methodology which places participants in the expert role with regards to their experiences and views their transcript as expressions of their subjective inner processes. Moreover, grounded theory does not match with counselling psychology stance on reflexive practice (Kasket, 2012) because it overlooks the researcher's influence on the research process and the construction of knowledge. Indeed, grounded theory was criticised for not addressing issues pertaining to reflexivity adequately (Stanley & Wise, 1983).

Nevertheless, a constructivist version of this method also exists which was submitted by Charmaz (2003). A primary goal of CGT, which chimes with counselling psychology humanistic desire to empower, is to give participants a voice by producing an interpretive description of their internal experiences (Charmaz, 2000**;** Kasket, 2012**)**. The CGT approach diverges from other grounded theory traditions (e.g. Glaser 1978; Strauss & Corbin, 1998) by espousing an epistemological stance that contests the idea that there is only one unbiassed outward reality that lies dormant within research data, waiting to be measured. Rather, it postulates that there are many and various idiosyncratic realities that are influenced by context thereby espousing a relativist position. This is because CGT believes that reality is created in peoples' minds through their contact with the world (Appleton & King 2002; Crotty 1998) which is congruent with the researcher's ontological stance.

Further, CGT is critical of classic grounded theory for the detached and commanding role that their researchers adopt in their relationship with participants and for precluding researchers' perceptions from the analysis, by requiring them to adopt an impartial outlook to their study. This is because CGT believes that researchers cannot maintain an objective view since they are part of the world they are investigating. Accordingly, knowledge develops through the collaborative interpretation of meaning that takes place in the researcher-participant encounter and via the investigator's engagement with data (Charmaz, 1990; Charmaz, 2000; Charmaz, 2006). Similar views have also been postulated by counselling psychology namely, that any research output is inexorably influenced by the researcher's subjectivity and intersubjectivity (Kasket, 2012; Orlans & Van Scoyoc, 2008).

Equally, the profession's orientation towards facilitating democratic relationships between researchers and participants is consistent with Mills, Bonner and Francis (2006) call within the CGT framework to reduce power imbalance in this context. To facilitate such endeavours, Mills et al. (2006) argue that CGT investigators need to adopt a reflexive attitude, an important characteristic of the counselling psychology discipline (Orlans & Van Scoyoc, 2008). This is to help researchers identify situations within the research process that might disempower participants and to bring both parties to a more equal plane of power. For example, by enabling participants to assume greater control over the direction of their interviews. Moreover, CGT researchers use memos as an instrument to record and think deeply about the impact of their biases on the joint creation of knowledge. This, in turn, provides readers with the opportunity to examine the sway of the researcher's subjectivity on the rendering of data (Mills et al., 2006).

Despite the matches between CGT, counselling psychology philosophy, and the researcher's beliefs, this method was deemed less suitable for the present study than IPA. This is because CGT seeks to understand participants' experiences in order to investigate interactions between individuals and subsequently harvest a theory that would explain social processes within a particular context (Charmaz 2006). Alternatively, the present thesis is purely concerned with IDC personal experiences in the milieu of the HDPP rather than the co-construction of a model that would explicate an under-theorised field in human phenomenon.

4.8 Participants

To obtain a homogeneous sample as advanced by the IPA approach (Smith & Osborn, 2008) the preliminary inclusion criteria consisted of White British primary informal caregivers of older people with dementia and more specifically daughters who were caregiving for their mothers. This was due to the increasing likelihood of daughters espousing the caregiver's role in the milieu of social expectations and the unique mother-daughter relationship, and since more females than males are affected by dementia (Hebert, Scherr, McCann, Beckett & Evans, 2001; Lawton, Silverstein, & Bengtson, 1994; Ward-Griffin, Oudshoorn, Clark & Bol, 2007). However, the potential participants identified (by the local authorities from which they were recruited) consisted of male and female family caregivers who differed by the type of connection that existed between them and their care recipient. For this reason, the inclusion criteria were extended to include informal caregivers of older people with dementia irrespective of their gender and relationship to the individual with dementia.

Further, since the local authorities encountered difficulties in identifying potential participants, five informal dementia caregivers were recruited. This was considered consistent with IPA's purposive sampling principle and compatible with its idiographic theoretical underpinning. Specifically, a small sample size allows the researcher to examine in detail each of the participants' accounts (Smith et al., 2009). Caregivers were excluded if they did not take part in their care recipients' hospital discharge planning and if their care recipients were admitted to a hospital outside the UK where governmental policies pertaining to discharge planning are likely to differ from those in Britain. Information pertaining to participants' demographics can be found in Table 1. All participants were given pseudonym names to preserve their anonymity. Likewise, names of places such as hospitals were omitted.

Table 1. Participants Demographics

Participant Pseudonym	Gender	Age	Marital Status	Employment	Relationship to Care Recipient	Reason for Admission	Patients' Discharge Destination
Brian	Male	52	Divorced with Adult Children	Unemployed	Son	Urine Infection	Own Home
Robert	Male	59	Divorced with Adult Children	Self Employed	Son	Fall Resulting in a Fractured Hip	Own Home
Richard	Male	60	Married with Adult Children	Full time	Son	Fall	Care Home
Jacquie	Female	69	Divorced with Adult Children	Part time	Daughter	Fall Resulting in a Fractured Hip	Rehab Centre & then Own Home
Debi	Female	71	Divorced with Adult Children	Retired	Ex-Wife	Collapse	Own Home

4.9 Recruitment

The participants were recruited from a number of adult social services departments which at the time of writing were part of a London tri-borough. The researcher contacted the tri-borough Research Governance Framework Panel (RGF) to obtain consent for the recruitment of participants. This involved emailing the RGF Panel a copy of the research proposal and the ethical approval attained from London Metropolitan University (LMU) departmental ethics committee. Once the RGF panel approved the study, the researcher contacted the adult social services departments team managers and negotiated a date to attend one of their forthcoming team meetings where she discussed the justification and objectives of the thesis and specified the participants' inclusion/exclusion criteria. During this time, it was also decided that social workers would approach potential participants, on the researcher's behalf, to enquire whether they would like to take part in the study and provide those who showed interest with a briefing sheet (Appendix A). The contact details of IDC who consented to participate were then passed on to the researcher who proceeded to call them and arrange for an interview.

4.10 Data Collection

Face-to-face semi-structured interviews were employed to collect information from caregivers. This method was chosen because it facilitates rapport in the researcher-participant encounter which in turn provides participants with the space to convey their personal narrative and reflect on their thoughts and feelings. Hence, semi-structured interviews afford researchers the opportunity to harvest rich and comprehensive narratives of participants' lived experience. This is compatible with IPA and counselling psychology phenomenological and idiographic approach (Eatough & Smith, 2017; Kasket, 2012; Reid, Flowers & Larkin, 2005; Smith et al., 2009; Willig, 2013) and the researcher's constructivist epistemological stance. Equally, in employing interview questions as a guide rather than rigidly, and in treating participants as the experiential experts on the investigated phenomenon, this method affords the researcher and her participants the opportunity to explore topics that arise in the interview which may not be on the schedule yet are pertinent to the research question (Smith & Osborn, 2003; Smith & Osborn, 2015). Moreover, face-to-face semi-structured interviews are designed to minimise data reduction at collection point and enables participants to correct the researcher's assumptions (Willig, 2003).

4.11 Procedure & Materials

All participants were interviewed in the first month following their care recipient discharge from hospital. The decision not to interview participants during their care recipients' hospital discharge planning was due to the following reasons: First, it was felt that participants' preoccupation with the discharge process will render them emotionally, cognitively and physically unavailable. Second, the researcher thought that conducting interviews in the first moth post discharge will give participants enough time to reflect on their experience whilst preserving the accuracy of their recollections pertaining to the investigated phenomenon.

Caregivers were interviewed on their own and their interviews were conducted in a venue of their own choice. Thus, whilst three were interviewed in their own home, the other two caregivers were interviewed in a private room within the grounds of London Metropolitan University. Before the beginning of each interview, the researcher recapped on the objectives of the thesis and what participation would involve. The researcher also inquired whether participants had any questions about the study and/or the interview. Following this, written consent to be interviewed (Appendix B) and for the interview to be tape recorded (Appendix C) were discussed and obtained from all participants. The researcher also asked participants to complete a demographic questionnaire (Appendix D) to contextualize the sample. A digital voice recorder was employed to record participants' interviews and each interview lasted approximately 60 minutes.

Further, an interview schedule (Appendix E) was used to facilitate rapport and induce rich data. The schedule was developed using the researcher's past social work experience with IDC in the context of hospital discharge planning, her familiarity with the current literature, and the gaps in research that she sought to examine. The questions were rewritten following reflections with the researcher's reflexive research group, and after consulting Smith (1995) guidelines for creating a schedule for semi-structured interviews. This was manifested in using open rather than closed questions that were neutral rather than leading in nature, to encourage participants to talk in length about their experience and to avoid bias answers. It also manifested in revising the structure of the schedule. Specifically, the revised interview commenced with questions that allowed participants to recount a descriptive account of their experience, in order to facilitate rapport, whereas the following questions invited participants to engage in analysis, after rapport has already been established.

The researcher considered giving all caregivers a replica of the interview schedule ahead of the interviews. However, on reflection with the research supervisor it was decided that this may bias their answers. For example, participants may feel the need to answer questions in line with what is expected instead of feeling free to explore new avenues that could provide new insights. Therefore, it was decided that should participants request a schedule then a copy would be provided five minutes before the interview was due to commence.

Following the conclusion of the interviews, all caregivers were debriefed and provided with a debriefing form (Appendix F). This was to verify that no harm came to them as a consequence of their participation in this thesis, and to enable participants to discuss their interview experience. Finally, to manage the possibility that a participant may become distressed during or after their interview, a distress protocol (Appendix G) was developed.

4.12 Analysis

Smith et al.'s (2009) principles for undertaking analysis in IPA research were employed to analyse the research data. The analytic process consisted of the following stages: Verbatim transcripts were produced for all interviews and wide margins were left on both the right and left side of each text to enable the researcher to record her comments. Following this, the researcher read the first transcription numerous times, using the right side of the margin to record her initial thoughts, feelings, and interpretations. With subsequent reading of the transcript and the preliminary notes made in the right-hand margin, emergent themes were developed and documented in the left side of the margin. These emergent themes reflected the synergistic process of participants' words and thoughts and the researcher's different levels of interpretations and ways of thinking about the transcript.

The next stage consisted of grouping together emergent themes based on the links between them and labelling each developed constellation with a super-ordinate theme. Subsequently, a table of super-ordinate themes and their associated emergent themes was developed, and each emergent theme was annotated with information pertaining to its source. These new clusters were then checked against the transcription to confirm that they reflected participants' accounts. Emergent themes that were deemed irrelevant were discarded. This process was then completed for each of the research participants. By examining in depth each transcript before moving on to the next one, the researcher adopted an idiographic approach to analysing participants' accounts. Further, the researcher attempted to bracket ideas that had been developed in the preceding transcripts, to facilitate the emergence of new themes with each text.

The final stage of the analysis involved looking for connections across participants' tables. Like in previous stages, some of the themes were merged or discarded whilst others were relabelled. This process yielded sub-themes which were then grouped into superordinate themes. A master table of super-ordinate themes and their associated sub-themes for the group was developed. These themes were evidenced with citations taken from participants' transcripts to ground the researcher's interpretations in participants' accounts. All interviews were transcribed using a transcription notation key (Appendix N).

4.13 Ethical Considerations

This strudy was carried out in accordance with LMU Code of Good Research Practice (2005) and the BPS code of ethics and conduct (2009). Before the study commenced, the researcher obtained both an ethical certificate from LMU departmental ethics committee (Appendix H) and authorisation from the tri-borough RGF panel to recruit participants (Appendix M). All participants were briefed about the study and what participation would involve ahead of each interview. This included recapping on caregivers right to withdraw from this research throughout the interview and within the three-week period post interview, at which time the researcher would be embarking on their data analysis. Informed consent to be interviewed and for the interview to be tape recorded were also discussed with, and obtained from, all participants before each interview. Copies of these forms were given to the participants whilst the originals were retained by this researcher. Furthermore, caregivers were made aware that their recorded interviews would not be used for any purpose other than this study and that anonymous excerpts from various segments of their transcript would be employed in the published thesis and possibly future articles.

Anonymity was guaranteed by designating a pseudonym to every caregiver and by disguising or removing all other identifiable information pertaining to the participants as well as the people and places they talked about. Aural recordings of caregivers' interviews were kept on an encrypted USB flash drive which was stored in a locked draw within the researcher's dwelling. Participants' written transcripts were saved under an encrypted file on the researcher's password protected computer. All other confidential papers were placed in a locked dresser within the researcher's dwelling. The reason for keeping sensitive information separately from each other was to ensure that no name could be linked to its recording. Audio recordings of interviews were deleted upon completion of their data analysis.

The likelihood that participants would be vulnerable individuals was small. Nevertheless, the subject of this thesis was almost certainly to be private and sensitive to all IDC. Hence, the fundamental principles of the humanistic paradigm were employed to offer a safe psychological environment. Further, the effects of the interview on caregivers' wellbeing was monitored and caregivers' preparedness to persist was verified throughout. All participants were debriefed following the conclusion of their interviews to confirm that no harm came to them following their involvement in the present research. Since none of the participants reported or showed distress, the distress protocol was not employed. A debriefing form (Appendix F) that contained information pertaining to helpful organisations that could offer support should participants feel distress after their interview, was provided. This form also included the researcher's and her supervisor's contact details should any of the participants want to make a complaint about the study.

4.14 Research Quality

In this section, the researcher examined the quality of the present research using Yardley's (2000) criteria which consists of four dimensions namely, sensitivity to context, commitment and rigour, transparency and coherence and finally impact and importance. Sensitivity to context was met in several ways as follows: First, by negotiating the researcher-participant encounter using a person-centred paradigm to form rapport and enable the emergence of participants' idiographic experiences. Second, through the provision of several verbatim extracts to support the researcher's rendering of the data. This, in turn, enables readers to check the accuracy of the researcher's analysis. Further, it gives participants a voice which brings the reader closer to the human experience. Third, by conducting a literature review on the investigated phenomenon. This enabled the researcher to contextualise the study within the British socio-political milieu and identify the scope of existing evidence. Likewise, awareness of IPA's principles and how these helped to construct the study's data and findings (which is discussed throughout the study with regards to reflexivity) also illustrates the researcher's sensitivity to context. Finally, by using open-ended questions in her interviews, to empower participants to reflect on their lived experience, the researcher showed sensitivity to the study's constructivist philosophical orientation.

Yardley's (2000) commitment principle has been met by paying close attention to participants' accounts and by verifying that caregivers feel safe and at ease (which also illustrates the researcher's sensitivity to context). Rigour was evidenced in the researcher's choice of a purposive and homogeneous sample that matched the actual population that the research question sought to study. Specifically, informal caregivers of older people with dementia who experienced their loved ones' hospital discharge planning. Equally, it was illustrated in the manner in which the researcher conducted her interviews. For example, by facilitating in-depth reflections via the utilisation of prompts, probing, and by attending to participants' cues. Further, rigour was evidenced in the researcher's idiographic engagement with the data. Specifically, in conducting a detailed analysis of participants' accounts using a hermeneutic approach. This, in turn, allowed the researcher to move beyond the descriptive realm to generating meaning for each case, and for the group as a whole, which also showed rigour.

Transparency was demonstrated in recounting participants' inclusion and exclusion criteria, in describing the construction of the interview-schedule, and in detailing the stages of gathering and rendering the data. Transparency was also illustrated via the researcher's reflexive practice in each stage of this investigation. Coherence was assured through the investigator's judicious examination of the fit between the research question, the researcher's epistemological and ontological outlook and IPA underpinnings. Similarly, in employing an inductive and idiographic approach to engage with participants and their transcripts, and by using iterative and hermeneutic methods to make sense of participants' personal stories, the researcher demonstrated coherence with IPA underpinnings in the write-up of this study.

Impact and importance refer to the study's validity. Yin (1989) suggested that validity can be verified by filing the research data in a way that would enable readers to check the trail of evidence. In the present study, this is manifested in the inclusion of Jacquie's (Pseudonym) annotated verbatim transcript (Appendix I) together with her table of emergent themes (Appendix J) and her table of emergent themes enveloped within super-ordinate themes (Appendix K). Additionally, a master table of sub-themes enclosed within super-ordinate themes for the group as a whole (Appendix L) was provided. Validity could also be verified through the employment of an independent auditor whose responsibility would be to ensure that the data are credible and presented in a comprehensible sequence (Smith et al., 2009). Therefore, the researcher employed a fellow qualified counselling psychologist, who was familiar with the IPA approach and who played no part in this study, to check that her yielded emergent and superordinate themes were grounded in participants' anonymous transcripts. Similarly, the researcher's supervisor conducted a mini audit of the data. This involved checking that the interpretations of the first interview transcript had validity in relation to participants' accounts and IPA principles.

5. Analysis

5.1 Overview

Three superordinate themes emerged from the IPA analysis of the five interviews: First, the negative aspects of the discharge planning process which examines' communication problems between IDC and HDP, participants' responses to their care-recipients' needs going unmet and caregivers' experience of their everyday life in the context of the HDPP. Second, focus on relationships which explores reconstructed relations in the caregiver-care recipient dyad, the power dynamics in the IDC-HDP partnership and caregivers' experience of the co-worker role. Third, employing coping mechanisms to counteract taxing experiences which discusses the strategies that caregivers employed in their attempt to deal with their internal responses to the HDPP. Table 2, the master table of themes for the group, is a schematic representation of these super-ordinate themes, their sub-themes and relevant excerpts.

Table 2. Master Table of Themes for the Group

Super-Ordinate Themes	**Sub-Themes**	**Relevant Excerpts**
The Negative Aspects of the Discharge Planning Process	Communication with Discharge Planners as Problematic	*"No one wanted to sit down and talk to us exactly what was wrong with my mum" (Brian 1:17-20)*
	"We Need the Bed"	*"Being told that there is nothing that they can do for your mum and they are sending your mum home"* *(Brian 4:224-227)*
	"I Had Nothing I Had No Life"	*"I did spinning and went to the gym…but I haven't been able to do anything"* *(Jacquie 13:502-507)*
Focus on Relationships	Reconstructed Relations in the Caregiver-Care Recipient Dyad	*"I've gone from somebody who just…got his shopping for him to suddenly being in control of him"* (Debbie *13:739-744)*
	"They Seemed to Be in Control": A Power Imbalance in the IDC-HDP Partnership	*"I am the consultant I make the decisions"* *(Brian 2:105-106)*
	Caregivers as Co-Workers	*"Everybody said you are one of us working"* *(Jacquie 9:364-365)*
Employing Coping Mechanisms to Counteract Taxing Experiences	Cognitive Strategies	*"Some of their organisational skills…were a bit lacking...but hey…nurses are not administration people"* *(Debbie 8:429-432)*
	Behavioural Strategies	*"As a carer you don't automatically get, you only get it if you scream and shout" (Robert 6:337-340)*
	Mobilising Social Support Systems	*"I rang up my ex-wife…I did break down and she went to me don't worry"* *(Brian 6:320-325)*

5.2 Super-Ordinate Theme One: The Negative Aspects of the HDPP

This superordinate theme consists of three sub-themes as follows: 1) communication with discharge planners as problematic 2) "we need the bed" and 3) "I had nothing I had no life".

5.2.1 Subtheme One: Communication with Discharge Planners as Problematic

All participants experienced communication difficulties in their encounters with the HDP and whilst this yielded negative implications for their psychological wellbeing, none of the participants revealed how they felt to the HDP with whom they were communicating. This is highlighted by the absence of such information from participants' accounts. See the following passage from Brian:

> *"No one wanted to sit down and talk to us exactly what was wrong with my mum, all we were told was that she's got an infection….and it's just a lot of miscommunication....when your told that your mum is going to be in hospital for a long time and then a week later they let her out after being on her death bed so they say… and…it was a shock to find out a week later that my mum got the worst case of dementia so you can see my feelings towards the hospital" (Brian 1:16-45).*

It seems that Brian held expectations about the style of communication between HDP and patients' relations: his phrase "sit down and talk to us" suggests that he turned to staff for information about his mother's condition since he did not know what was "wrong" with her. However, instead of being treated with respect he felt dismissed which may well have perpetuated his sense of uncertainty and worry and left him feeling insignificant. His words "no one wanted" is indicative of this, conveying the impression that he thought there was something unpleasant in him and his family for which they were ignored. Brian's evident need for "exact" information illustrates that he did not understand the feedback he received about his mother from his brief encounter with the HDP. His reference to "all we were told" suggests that this was because of inadequate sharing of information by members of staff. It also indicates that he was being critical of hospital personnel for withholding information which implies that he was angry with them. Indeed, he goes onto say "you can see my feelings towards the hospital" which is telling of his internal turmoil. The miscommunication he experienced in addition appeared to have yielded frustration and confusion as emphasised by his use of "it's just". Perhaps because he wasn't prepared for discharge since he was told that his mother was on her "death bed". If so, this implies that he was not included in the decision to discharge his mother "a week later" and that his own needs went unmet. This may well have generated in him anxiety about his ability to manage his mother's needs in the community given the "shocking" news that he received just before discharge about his mother having the "worst case of dementia". Finally, it seems that despite his "feelings towards the hospital" Brian did not disclose how he felt to the HDP. Clearly, his extract in superordinate theme three, sub-theme two 'behavioural strategies', is indicative of this.

Similarly, Jacquie recounts lack of communication in her encounters with members of staff:

> *"I was very much puzzled…because one of the doctors said ohh she is going to be moved to […] rehab centre and then nothing happened for like three four days after, so I had no idea if she was going to be discharged or if she was going to rehab. All of a sudden in the morning at around 11 o'clock one of the nurses came and she said ohh you're going to go to […] rehab centre and I did not know what to do because I I wasn't prepared" (Jacquie 3-4:107-126).*

Jacquie's reference to "puzzled" implies that she was both confused and anxious as a result of the dissonance she experienced in her communication with the HDP regarding her mother's discharge plans. Jacquie's phrase "doctors said ohh she is going" suggests that she was neither aware of, nor included in the decision-making process to discharge her mother to another facility. Jacquie's exclusion is also manifested in her mother's ad-hoc discharge from hospital: her use of "all of a sudden" implies that she was startled by the news. It also implies that she expected to be given sufficient notice to prepare for discharge. Further, Jacquie's reference to "you're going" conveys the impression that she felt as though she had no choice but to comply with discharge, and one wonders whether this left her feeling disempowered. Jacquie goes onto say "I did not know what to do" which suggests that she struggled to problem-solve on the day and this may have generated in her feeling of being stuck and inept.

The HDP insensitive style of communication also contributed to Jacquie's anxiety:

> *"I felt very rushed, I felt very anxious, very anxious....I felt very much that they wanted to get rid of us now you know (laughs) of course it is time to move on, it's not that it is a luxurious place" (Jacquie 7:266-275).*

Jacquie's reference to "get rid of us" suggests that she felt like rubbish that was about to be cleared out and therefore inconsequential. Further, Jacquie's laughter implies that she felt angry and embarrassed about her ordeal and her words "it's not…a luxurious place" suggests that she was being defensive, perhaps in an attempt to protect herself from feeling worthless. When asked whether she conveyed how she felt to the HDP, Jacquie reported the following:

> *"No…I am very very cautious because they are doing their job and ahh and because I was always present there" (Jacquie 9:359-363).*

Jacquie's extract suggests that she wanted to maintain a positive relationship with staff since she spent most of her time in hospital and therefore in their presence. Her reference to "very very cautious" suggests that she was fearful of the HDP reaction to any complaints she might raise, highlighting the power imbalance in their relationship. To reduce the risk of conflict, she concealed her negative views and emotions, and to deal with her internal turmoil she seemed to rationalise professionals' behaviour.

Whilst Jacquie and Brian relied on staff to handover information to them, Debbie was chasing "people" for information:

> "*The problem was that I had to get all these bits of information from different people" (Debbie 7:369-372).*

Debbie was trying to obtain a picture of her ex-husband's discharge plans. Her words "I had to get" imply that information was not offered. Rather, she had to pursue "different people" to attain it. Chasing after one individual in itself can be exhausting. Thus, one wonders how she felt in her pursuit of many members of staff. Her use of the word "problem' suggests that she found this experience to be time consuming, wearing and stressful. It also suggests that she expected staff to offer information rather than having her trailing them for it. Interestingly, Debbie didn't articulate whether she disclosed her feelings to the HDP and this could be interpreted to mean that she obscured her emotional responses from them. If so, it maybe because she felt in a disadvantaged position given her reliance on their competence and good will to share information. Despite Debbie's efforts she was only able to attain "bits of information" which may have triggered in her feelings of uncertainty that left her feeling unprepared for discharge. Her extract below is telling of this:

> *"I have to have that control in the knowing, in the knowledge, it's the knowledge really......I suppose it's the feeling that the buck stops with me" (Debbie 7:390-397).*

Debbie's reference to the "the buck stops with me" suggests that by espousing the caregiving role she had accepted the ultimate responsibility for her ex-husband's care. This overwhelming sense of accountability may have triggered anxiety in her about failing to meet his needs. If so, Debbie's pursuit of "knowledge" can be seen as her attempt to counteract her feelings of anxiety and attain a sense of "control" in the caregiving role. Of interest is Debbie's use of the words "I have to have" which imply that she struggled to function in her caregiving role when her need for information and thereby control went unmet.

Alternatively, Robert's quest to be heard was his main challenge:

> *"The most distressing thing was trying to get through to doctors and nurses and pharmacists a lot of the time they will dismiss you until they actually talk to you for a period of time and understand that what your saying is correct" (Robert 4:195-204).*

Robert equates his experience of not being listen too, to being treated as unworthy of serious consideration. His words "trying to get through" imply that he was often excluded from decision making processes. Whilst these negative experiences did not deter Robert from pursuing staff, his strategy was probably time consuming and "distressing" for both parties. Further, latent power dynamics appear to emerge from Robert's account, portraying an image of a tug war: on one side there's team Robert and on the other side lies the hospital team. Robert is constantly trying to pull towards him the hospital team in a test of strength to prove that he is "correct" whilst the hospital team continues to resist. Of interest is Robert's need to show that he is right in what he says. Perhaps he felt angry with the HDP for "dismissing" him because he felt that he was the expert on his mother's needs and because they triggered in him feelings of worthlessness and powerlessness. However, rather than conveying how he felt, he attempted to counteract his adverse feelings by chasing staff "until they" agreed with his concerns which inadvertently validated his self-worth. Robert's distress may also stem from concerns about his mother's needs going unmet since members of staff did not access information that he espoused about his mother.

5.2.2 Sub-Theme Two: "We Need the Bed"

In this sub-theme participants draw attention to the fact that their loved ones' dementia related needs went unmet and to the emotional responses that this experience generated in them. See Brian's extract below:

> *"Being told that there is nothing that they can do for your mum and they are sending your mum home not very nice….it made me feel that they didn't give a shit...that's like him saying we need the bed so we're going to send your mum home and if she dies at home she dies at home that's not our problem" (Brian 5:224-270).*

For Brian, the HDP had given up on his mother when they told him "that there's nothing" else they could do for her. However, in his mind this was not for lack of remedy but because they "needed the bed". It seems that for Brian the hospital requirements were prioritised over his mother's needs, conveying a sense of unfairness. Further, his phrase "we're going to send your mum home…. not our problem" suggests that he felt the HDP attributed to him their own responsibility for his mother's care. It is also possible that this additional responsibility made Brian anxious about his ability to manage increasing caregiving tasks at home. Moreover, when Brian says "they didn't give a shit" it suggests that he was feeling insignificant and angry about the doctors' indifferent attitude. Alternatively, it may be that Brian struggled to accept the doctors' inability to cure his mother as this would have required him to face her mortality. Indeed, Brian's phrase "if she dies at home" suggests that he was anxious about losing her.

A similar account has been relayed by Robert:

> *"I do get the feeling that they sort of say to you well we can't do anything, there's the toilet seat off you go and get on with it and that's (laughs) sort of how I feel" (Robert 7:396-401).*

Robert's use of the words "we can't do anything" is similar to Brian's phrase "being told that there is nothing…they can do" and suggests that like Brian he felt that the medical team had forsaken his mother. Robert's reference to "off you go and get on with it" implies that he and his mother were being discarded since the hospital needed the bed and that the HDP were shifting responsibility for care back to Robert which also echoes Brian's experience. Further, from both accounts emerges a sense of caregivers being cast aside by staff. Robert's words "off you go" sound as though he was treated like a child which may have left him feeling belittled. Indeed, his laugh is indicative of the embarrassment he endured. Similarly, Robert's reference to "get on with it" conveys the impression that he was being instructed to hurry up and leave the hospital. Perhaps Robert protested against his mother's discharge, prompting staff to respond in an assertive manner. If so, this may well have left him feeling angry and powerless.

This sub-theme is elaborated by Richard's description of the HDP poor understanding of his father's dementia related needs:

> *"When you disrupt dementia patients it's not very good, they need uniform they need consistency, and that is something that with dementia that should be learnt……you can't take them out of their environment and put them in another environment and then another environment within quick succession they get not aggressive but they get more and more confused and it's very difficult" (Richard 4-5:183-214).*

Richard's account suggests that the HDP were keen to transfer his father from hospital to a temporary care home, perhaps since they needed the bed. His reference to "disruption" and "it's not very good" implies that he opposed their plans due to the negative implications for his father's wellbeing, namely increased "confusion". Equally, his phrase "it's very difficult" implies that he also opposed this plan due to the potential impact of his father's challenging needs on his own mental health. Furthermore, Richard seems to differentiate between dementia and other elderly patients when he says "they need…consistency", perhaps to highlight individuals' with dementia idiosyncratic requirements but also to emphasise that with regards to his father, these needs were overlooked. One wonders whether Richard also perceived IDC as a unique group with distinctive needs given that IDC need to negotiate needs such as consistency, uniformity, aggression & confusion in their care-recipients. His reference to "it's very difficult" suggests that this may be the case. Richard goes on to say "that…should be learnt" which suggests that he is being critical of the HDP for their poor understanding of his father's dementia related needs which may have left him feeling angry and stressed.

Like Richard, Jacquie was worried about discharge since it necessitated further disruption to her mother's caregiving routine, which is telling of her need for prior preparation:

> *"Another novelty, another new atmosphere for her, new nurses, new place for her. I was very worried…because of her reaction, how is she going to be you know in a new environment" (Jacquie 5:173-185).*

Whilst Jacquie's use of the words "for her" highlights that she was "very worried" about her mother's response to the changes in her caregiving environment following discharge from hospital to the rehab centre, one wonders whether she was also anxious about her own need to adjust to a new setting and the implications of the potential changes in her mother's behaviour for her own wellbeing. Further, Jacquie's worry and sense of ambiguity imply that her concerns were not addressed by staff and that the potential adverse implications for her mother's dementia related needs were ignored, which echoes Richard's account.

5.2.3 Sub-Theme Three: "I Had Nothing I Had No Life"

Most participants discussed the negative implications of partaking in the HDPP for their everyday life. See Jacquie's extract below:

> *"I had nothing I had no life, my life was to come here, by 8:30 I was in hospital, all my friends I wanted to see ahh they came to the hospital to see me basically, and amm clients I cancelled a lot of them in advance or on the day because I just couldn't….I am quite an athletic person and I did sculling once a week, I did spinning and went to the gym, golf at least once a week you know" (Jacquie 12-13:486-507).*

Jacquie aptly encapsulates the negative impact of the discharge planning process on her every-day life when she says "I had nothing", conveying a sense of bitterness and loss of the activities that she valued. Indeed, when Jacquie says "I....went to the gym" she employs the past tense to highlight that she was unable to participate in these recreational activities. This suggests that she felt deprived of her own needs which may have dampened her mood and left her feeling frustrated. Equally, these activities seemed to have contributed to the construction of her “athletic” identity and by losing them one wonders whether she also lost facets of her sense of self. Jacquie goes on to say “by 8:30 I was in hospital” which suggests that she was feeling anxious given the time of her visits. Perhaps she was worried about the quality of care that her mother received in hospital, since she no longer commanded her caregiving environment. If so, it may be that she was trying to attain control over her mother’s new caregiving situation by being present and keeping a watchful eye. This may further explain Jacquie’s experience of “no life”. Furthermore, the discharge process may have diminished from Jacquie’s sense of control over her own life by disrupting her daily routine and compelling her to adapt to the hospital regime. However, Jacquie’s account also portrays an image of a committed daughter, suggesting that her own internal need to support her mother propelled her to put her life on hold.

A similar experience is expressed by Robert:

> *“I didn’t have the time to A) to go to work and B) to have relationships or C) to have hobbies that was none existent to a large degree. I mean I still tried to do a little bit of everything but it was only a small amount which then created more pressure because your trying to do everything in a small amount of time” (Robert 12-13:713-723).*

Robert’s reference to “I didn’t have the time…none existent” suggests that he was angry about giving up his needs and valued activities to partake in this process. Further, the lack of time to “work” and engage in “relationships” may have also generated financial and emotional strain and giving up his “hobbies” may have left him feeling isolated. Indeed, he goes on to say that he “tried to do a little bit of everything” indicating that he attempted to improve his wellbeing. However, this only “created more pressure” for him since he tried “to do everything in a small amount of time”, depicting a self-perpetuating cycle of distress.

Like Jacquie and Robert, Brian conveys a sense of loss though for him it appears to be linked to anticipatory grief:

> *“At home it was like…she……passed away, it was an empty…part of my life when she wasn’t here, even though I was seeing her in hospital seeing her every day, it was a different atmosphere….and that’s what it was like every day. Going up there and looking at people in hospital and then knowing your mum is one of them people and then coming*

> *home realising as if that person ain't alive anymore, there's no smell of her, there no noise of her amm its horrible and that's…what it felt to me when I left the hospital" (Brian 8:425-447).*

For Brian everyday life in the milieu of the hospital discharge planning process was a "horrible" experience. However, his words "at home…passed away" suggests that his devastating feelings of grief and loneliness were restricted to the context of his dwelling whilst in hospital he felt differently. Possibly because "there's no smell of her" and "no noise of her" at home and therefore he missed his mother. Equally, the images of patients coupled with the realisation that his mother "is one of them" may have triggered anxiety in him about her mortality, which most likely increased when he went back home where the "atmosphere" was "different" since he was away from his mother.

Debbie goes onto discuss the undesirable consequences of partaking in the HDPP for her interpersonal relationships:

> *"I have got a partner…. I was juggling that, I was juggling him [ex-husband] I didn't want him [partner] to see my ex-husband taking up too much of my time…. and of course my son was living at home which was very stressful because his wife died...so I was trying to care for him and my [ex-husband] so it was a bit of a juggling amm a psychological juggling match trying to keep everybody happy so I did suffer" (Debbie 9:490-516).*

Debbie's account suggests that caregiving had consumed much of her time, triggering worries about her partner finding out. Perhaps she felt that this would put their relationship at risk. Her use of the word "juggling" to describe her attempts to simultaneously sustain both relationships implies that she was feeling exhausted and frustrated about the negative impact this had on her wellbeing. Debbie goes on to describe a "very stressful" situation at home, and of interest would be to consider whether caregiving for her ex-husband left little resources for supporting her son. Indeed, her reference to a "psychological juggling match" suggests that her son and ex-husband were both competing for her support, draining her mentally and emotionally. Further, prioritising others needs at the expense of her own needs seemed to deplete her resource pool.

5.3 Super-Ordinate Theme Two: Focus on Relationships

This superordinate theme consists of three sub-themes: 1) reconstructed relations in the caregiver-care recipient dyad 2) “they seemed to be in control”: a power imbalance in the IDC-HDP partnership and 3) caregivers as co-workers.

5.3.1 Sub-Theme One: Reconstructed Relations in Caregiver-Care Recipient Dyad

The participants explored their relationship with their care-recipients in the context of the HDPP. See Brian’s extract below:

> *“At home I am doing a job but at the hospital I am a visitor even though I am her son but with me once I walk into that hospital my job title mum’s carer don’t exist, its Brian not mum’s carer, so going up there it’s like talking to my mum as mum” (Brian 9:487-495).*

Brian’s phrase “at home I am doing a job” conveys the impression that he was emotionally detached from his mother when he espoused the caregiver’s role. Perhaps the caregiving responsibilities he adopted at home were mechanical in nature which left him little time to bond with his mother. During discharge planning Brian’s identity seemed to shift from caregiver to “visitor”, perhaps as a result of surrendering hands-on care to hospital staff. The word “visitor” conveys the impression of a person who comes and goes and therefore bears few caregiving responsibilities. Perhaps Brian decided to take a break from caregiving. Clearly his words “my job title mum’s carer don’t exist” suggest that this was the case. It is also possible that Brian did not want to be viewed as a caregiver since he felt invisible to others when espousing this role. Indeed, he goes onto say “it’s Brian, not mum’s carer” suggesting that in the caregiver’s role he lost his sense of self. Further, Brian’s transformation may have precipitated changes in the way he related to his mother: when he says “talking to my mum as mum” he depicts a move from the caregiver-care recipient relationship to the mother-son affiliation. This suggest that by adopting the role of a “visitor” he was no longer distracted by the caregiving tasks he espoused prior to admission and therefore was free to pay more attention and show more affection to his mother.

Whilst Brian was able take a break from the role reversal he experienced at home, Debbie felt compelled to engage in such a process during discharge:

> *"I've gone from somebody who just…got his shopping for him to suddenly being in control of him…because he was ten years older than me…so when we were married it was always a case of he was the one I sort of I looked up to, so a real role reversal really quite difficult" (Debbie 13:739-751).*

Debbie's use of "just" highlights the extreme change she experienced in her relationship with her ex-husband: whilst prior to admission she had little say in the governing of his needs, following admission she was in "control" of his life. Her reference to "suddenly" implies that this shift was unexpected, leaving her little time to adjust to her new caregiving duties, which she seemed to perceive as all-encompassing. Indeed, when she says "being in control of him" it suggests that she felt responsible for meeting all of her ex-husband's needs which may have left her feeling overwhelmed and anxious. Debbie's phrase also highlights her new omnipotent feelings, though her reference to "role reversal…quite difficult" suggests that she struggled with this emotional response, perhaps because it triggered in her worry and guilt about the power disparities in their relationship. Furthermore, when Debbie says that her ex-husband was "ten years older" and that she "looked up to" him, she indicates that she used to perceive and relate to her ex-husband as an authority figure whom she admired as opposed to the vulnerable individual she perceived him to be during admission. This loss seemed to alter her own sense of self in their relationship. Specifically, she was now the commanding party.

Similarly, Jacquie's account depicts multiple losses linked to the changes she experienced in her relationship with her mother:

> *"She…was very much independent you know like walking by herself, putting her clothes on and we had a good quality of life, like we went to the casino…we went out for lunch, I took her to the park…because I thought to myself she has been such a wonderful mum…that she needs to have a nice time…but this has happened and it's just downhill from then on" (Jacquie 2-3:60-77).*

Jacquie's account illustrates that her view of her mother as "independent" refers to the pre-admission period, implying that following admission she regarded her as a dependent individual. It is possible that consequently she adopted new caregiving responsibilities which increased her identification with the caregiver's role. Reconciling past perceptions with new ones may have been painful for Jacquie since she lost the independent identity she ascribed to her mother as well as meaningful aspects of their relationship. Indeed, when Jacquie says "we went to the casino...we went out for lunch" she uses the past tense to highlight that in her mind they were no longer able to share the experiences they jointly enjoyed. This decrease in the quality of their relationship appeared to impede Jacquie's wish for her mother "to have a nice time" in her old age, which seemed to stem from her need to reciprocate for the "wonderful" times they shared. One wonders whether Jacquie's inability to continue to reciprocate in the manner she hoped was also experienced as loss and whether these changes left Jacquie feeling frustrated and inept. Similarly, when Jacquie says "I thought to myself…but this has happened" it suggests that she lost the imagined future she had envisaged for them both.

This sub-theme is elaborated by Richard's apparent struggle to accept the negative ramifications of dementia for his father's personality:

> *"They found him to be aggressive and ahh ohh well ya well basically aggressive and wouldn't conform but he has just been in a fall (shouting)……..he didn't know what was going on he didn't know where he was…. Ohh I was annoyed because when I got that information from the care home I said your joking (shouting) and they said we love him here because he is an absolute wonder, his just a beautiful person, he is a lovely caring person" (Richard 6:252-280).*

Richard's account refers to a hospital assessment which found his father to be aggressive. Richard's reference to "but he has just" illustrate that he was defending his father's reputation, perhaps since he regarded him as vulnerable and therefore in need of protection. This is telling of role reversal in their relationship. It also seems that Richard felt that his father was being labelled unfairly, thereby placing the blame for his father's aggressive behaviour elsewhere. Indeed, his repeated use of the words "he didn't know" implies that he blamed the dementia. If so, he may have viewed this disorder as an entity that is separate from his father's personality since he didn't want to accept the changes in his father's character. Perhaps it would have required him to surrender the image of a "beautiful person" that he ascribed to his father and the pride that he clearly felt about having a "lovely caring" father. It is also possible that in his struggle to preserve his father's identity he also attempted to delay engagement with feelings of loss of a meaningful relationship. This proposition is further supported by Richard's attempts to distance his father from the label "aggressive".

5.3.2 Sub-Theme Two: "They Seemed to Be in Control": A Power Imbalance in the Informal Dementia Caregivers – Hospital Discharge Planners Partnership

Participants described the power disparities that they experienced in their relationship with members of staff and the subsequent responses it generated in them. See Brian's extract below:

> *"They might have all of these and that letters between their names but no one knows the patients better than their own family…when we spoke to the consultant, me and my daughter both told him that my mum is not right and his exact words were I am the consultant I make the decisions and your mum is coming home on Monday" (Brian 2-3:96-108).*

Brian highlights the consultant's use of his authority to override his knowledge of his mother's needs. It is possible that Brian felt angry, dismissed, belittled and powerless as a result. Clearly, his words "they might have all of these and that letters between their names" is indicative of this. Brian's defensive and challenging response "no one knows the patients better than their own family" could be interpreted as his efforts to recover the power and dignity he had lost.

Like Brian, Robert also recounts power dynamics in his encounters with members of staff. However, whilst Brian conceded to the consultant's assertiveness, Robert refused to surrender control over his mother's discharge plans:

> *"There is a bit of a battle of wills, yes, she's ready to go home…or actually I say she's not really because she needs this done and that needs to be done ahh so then we continue for a few weeks until she is ready to come home" (Robert 5:282-290).*

Robert's reference to "a battle of wills" portrays an image of a contest between two teams who are trying to defeat each other by refusing to withdraw their demands, hoping that the other team will compromise first. This, in turn, conveys the impression of a waiting game. Indeed, Robert goes on to say "we continue for a few weeks" which is indicative of this. Robert's use of the word "battle" and the words "I say she's not" suggests that this contest was dominated by confrontation. Perhaps Robert felt that his views were ignored and the show of force was his desperate attempt to attain control over his mother's discharge plans. Moreover, Robert's words "until she is ready" could be interpreted to mean that he perceived himself as the ultimate arbitrator in deciding when should his mother be discharged home. This is interesting as it suggests that his efforts paid off though one wonders at what cost to his wellbeing.

The battle for control is also manifested in Debbie's extract:

> *"She [the social worker] said he [ex-husband] wanted someone to go to the bank with him. I said no...he didn't want that...he said my ex-wife is going to come to the bank with me, so she said ohhh will cross that off, but they seemed to be…in control and she has given me the care company's phone number so I feel I've got a bit of control back"* **(***Debbie 5:267-283).*

When Debbie says "no…he didn't want that" she seems to be challenging the social worker's understanding of what her ex-husband requested. This may have generated tension in their interaction, leaving Debbie feeling uncomfortable. Further, Debbie's reference to "he said" sounds as though she is being defensive to strengthen her argument against the social-worker's claims. Perhaps she felt threatened by the social-worker since she commanded the conversation and this diminished from her sense of control over the caregiving situation. Indeed, Debbie's phrase "she said ohhh will cross that off" is telling of this. Furthermore, when Debbie says "they seemed to be…in control" it implies that she felt as though she was facing a system rather than an individual. This may also have contributed to the power imbalance that Debbie experienced. Her words "I've got a bit of control back" is indicative of this.

In contrast to the other participants, Jacquie's account suggests that she did not challenge her mother's discharge plans:

> *"Unfortunately, when we were…done with [the hospital] after 14 days they said she can go to […] which is a rehab centre, so we went there but I was really really frightened you know about going" (Jacquie 3:78-85)*

Jacquie's reference to "unfortunately" and "frightened" implies that she did not want her mother to be discharged to a rehab facility. Yet, her words "so we went there" illustrate that she complied with the HDP decision. Of interest is what stopped her from contesting against her mother's discharge plans. The answer may lie in her phrase "they said" which implies that in her dealings with hospital personnel, she felt as though she was facing an entire system rather than a particular member of staff which echoes Debbie's account. This may have tipped the balance of power in favour of the HDP for Jacquie. If so, this experience could have left her feeling threatened and disempowered.

5.3.3 Sub-Theme Three: Caregivers as Co-Workers

Most of the participants depicted situations where they immersed themselves in hospital work, helping staff meet their care-recipients' needs. This relationship appeared to trigger conflicting feelings in them. See Robert's extract below:

> *"I had to show a nurse how an inhaler works, how it was dispensed and administered…the hospital is under pressure they are short of staff" (Robert 11:605-611).*

Whilst Robert appears critical of the nurse's incompetence, he also seems empowered by his ability to assume control and help the nurse as indicated by the medical terminology he used to highlight his knowledge in managing inhalers. Further, Robert's reference to "I had to show" implies that there was no one else to help the nurse. Therefore, he felt compelled or pressured to take-action. Indeed, he goes onto say that the "hospital is…short of staff", rationalising his intervention. Perhaps he was ambivalent about helping since he was angry about the inadequate quality of care on the ward and because he found himself in a situation where he felt he had no choice.

Like Robert, Jacquie assisted members of staff to meet her loved one's needs:

> *"Everybody said you are one of us (laughs) working…I did all the nursing stuff myself...because they are too busy" (Jacquie 9:364-381).*

When Jacquie says "everybody said" she is generalising which implies that she is engaging in self-praise for the contributions she made in helping the nurses meet her mother's needs. Jacquie's reference to "one of us working" suggests that she also felt recognised, accepted and validated by staff for her input. Furthermore, it maybe that by espousing responsibility for “all” the nursing tasks, Jacquie gained control over her mother’s caregiving situation which empowered her. Alternatively, Jacquie’s extract implies that she was subjected to friendly banter by the nurses who viewed her as a worker. This may have triggered anger in her, as indicated by her laugh, because she was undertaking tasks that the nurses were responsible for. Indeed, she goes on to rationalise her assistance stating that the nurses were “too busy”, suggesting that she wouldn’t have chipped-in if they were available.

Richard also attempted to espouse control over his care-recipient’s care plans:

> *“We agreed on a date as soon as I knew from the care home when they would accept him” (Richard 13:599-601).*

Richard’s extract illustrates that he acted as a link worker between the hospital and the care-home he chose for his father. Richard’s reference to “I knew” implies that the hospital was dependent on him to provide information that would facilitate his father’s discharge. This may have empowered Richard by increasing his sense of control over aspects of the discharge process, which could be the reason for which he adopted this role in the first place. However, Richard’s words “as soon as” suggest that he felt pressured, perhaps because the hospital was waiting for his response and relying on him to perform well. Equally, he may have been anxious for his father to leave the hospital and any delays on his part would have prolonged his father’s admission.

Whilst Robert, Jacquie and Richard seemed to attain some positive gains from espousing the role of co-worker, Debbie appeared to experience negative outcomes:

> *“I had three bacterial rushes…from trying to clean it and I thought no (laughs) I am going a step too far so I said I really can’t do this so the social worker arranged for a cleaning company to come in” (Debbie 3:158-165).*

Debbie’s ex-husband’s flat had to be cleaned before he could be sent back home. To help the HDP facilitate a speedy discharge, Debbie offered to clean his flat. Debbie’s assertive reference to “no…step too far” and laugh implies that she was irritated with the social-worker, perhaps because the social worker let her undertake work that she was responsible for. Equally, it sounds as though Debbie was setting boundaries both to herself and the social worker which suggests that she felt carried away with her desire to chip in. Debbie's desire may have been driven by her need to gain control over aspects of the discharge process. However, the difficulties Debbie encountered propelled her to withdraw and in doing so she also relinquished the control she was seeking to the social-worker. This could have left her feeling inept.

5.4 Super-Ordinate Theme Three: Employing Coping Mechanisms to Counteract Taxing Experiences

All participants used cognitive and behavioural tactics to deal with the emotional responses that they experienced during their care-recipients' HDPP and most caregivers also resorted to employing social support in the form of family and friends.

5.4.1 Sub-Theme One: Cognitive Strategies

Different participants appeared to engage in different cognitive strategies. Debbie's extract suggests that she used reasoning as well as other coping mechanisms to manage negative feelings triggered in her by members of staff:

> *"Some of their organisational skills, because I was a personal assistant…were a bit lacking…but hey the nurses are not administration people so that's not what they do so there were somethings that were a bit haphazard…trying to find the key I wanted….but you know to find the key ohhh it's in a safe, in a safe somewhere and I went through about three people about half an hour" (Debbie 8:426-445).*

Debbie is highlighting her past experience as a "personal assistant" to strengthen her argument that nurses' lack "organisational skills". In doing so she positioned herself in the expert role and this could have served to validate her self-worth and empower her in a context where she lacked control over the management of her care-recipient's affairs. Further, when Debbie says "ohhh...in a safe somewhere" she seems to be criticising the nurses which is indicative of the frustration and confusion they triggered in her. However, her account also suggests that she rationalised her experience: when she says "hey...nurses are not administration people" she indicates that she assigned the nurses "haphazard" behaviour to their job description rather than making it personal, perhaps in an attempt to dampen her negative feelings towards the nurses and circumvent her drive to challenge them. This in turn preserved their partnership.

Richard also seemed to rationalise his experiences in an attempt to modify how he felt:

> *“They [care home] rejected him saying that his needs were not great enough for what they were supplying, in other words they didn’t think my dad was let’s say amm ahh needy as for what they provide so that was ok, that’s fair enough” (Richard 4:158-165).*

Richard’s use of the word “rejected” is interesting as it holds negative connotations. Perhaps he interpreted the care home’s response to mean that his father was not good enough for them. If so, he could have felt shame for thinking there was something unpleasant in his father for which he was declined. In his attempt to attain relief from his emotional turmoil, he rationalised the feedback he received from the care-home as suggested by his words “that was ok, that’s fair enough”.

Jacquie demonstrates the power of denial in distancing herself and her mother from the dementia “label”:

> *“I don’t really believe in dementia because I think that people at each age they have…their own world…all these labels that are given are basically for the doctors and it’s not very good for the patients because they label them and then they identify.....they become that, anybody, even a sane person, would become, if labelled, become like that so I don’t look at my mum as she has dementia….because she is elderly” (Jacquie 6-7:222-252).*

Jacquie’s account suggests that she used denial to refute her mother’s diagnosis and illness. Perhaps she perceived dementia as a sign of insanity and therefore attempted to distance herself and her mother from it. Indeed, her words “anybody even a sane person…if labelled become like that” is indicative of this, since she clearly differentiates between a rational person and an individual who has dementia. By rejecting the existence of this disorder, she refrains from engaging with feelings of anxiety about losing her own identity. Finally, the doctors’ power to label her mother seems to impose on Jacquie’s freedom to construct her own reality about her mother’s identity. By rejecting their diagnosis, Jacquie is challenging the doctors’ authority and reclaiming control over the manner in which she interprets the changes in her mother.

5.4.2 Sub-Theme Two: Behavioural Strategies

All participants engaged in behavioural strategies though it appears that for some these tactics yield undesirable outcomes, as demonstrated in Brian's extract below:

> *"No, because I would have said or done something that I would have regretted" (Brian 4:222-224).*

Brian's extract suggests that he was anxious about expressing his feelings to the HDP regarding their decision to discharge his mother for fear of losing his temper with them. His reference to "I would have regretted" implies that his desire to express his anger conflicted with his wish to maintain a collaborative relationship with members of staff. Alternatively, it may be that he was fearful of being criticised and punished for his undesirable behaviour as well as worried about the embarrassment he could have experienced as a result. If so, this suggests that he felt threatened in his interaction with the HDP. In his attempt to cope with his internal turmoil, he refrained from revealing how he felt. However, one wonders whether the need to kerb his anger left him feeling disempowered and resentful. If so, this may have fuelled his anger, thereby perpetuating his distress.

Whilst Brian avoided confrontation by concealing his anger, Robert employed confrontation to express his anger. Perhaps Robert was more informed of his and his mother's rights which increased his sense of confidence in his course of action:

> *"Whatever my mother is entitled to or what I am entitled to as a carer you don't automatically get, you only get it if you scream and shout and even then, you don't always get it and that is stressful" (Robert 6:336-342).*

Robert's reference to "entitled" and "don't automatically get" imply that he was angry since his and his mother's rights were overlooked. This could have propelled him to use the desperate behaviours he recounts in his extract in an attempt to attain the services he was seeking. Indeed, his words "you only get" indicate that he believes the show of force is the sole strategy that yields results. He also sounds as though he was driven to act in this way because he had no choice. If so, this suggests that he does not take responsibility for his destructive behaviour and blames members of staff instead, perhaps in his attempt to avoid engagement with feelings of shame and guilt. Nevertheless, his words "scream and shout" create a sense of conflict which most likely diminished from his wellbeing and his relationship with members of staff. Indeed, he goes onto say "even then, you don't always get" which left him feeling distressed.

Richard resorted to bridging gaps in healthcare in an attempt to cope with his anxiety:

> *"But where do we go from there…I am thinking well he is too bad to be in a flat on his own you know, you can't put anybody else in the flat with him….they won't put him in to the extra care place because it was still not enough, so he was in between an extra care place and a care home, so I offered to find another care home that would accept him" (Richard 4:165-176).*

Richard's account implies that he experienced uncertainty surrounding his father's discharge plans and this may have generated in him feelings of anxiety. Richard's reference to "thinking" suggests that he diverted his attention to and engaged with the ambiguity he experienced perhaps in his attempt to make sense of it. However, by doing so he seemed to experience further distress: his quote "where do we go from there" indicates that he felt stuck and confused. Further, Richard phrase "they won't put him in…extra care" sounds as though he is blaming the HDP for complicating the process. This may have triggered in him feelings of frustration and distrust about their capacity to facilitate discharge and ultimately increased his distress. In his attempt to regain a sense of control over his father's discharge plans and move forward with this process, Richard offered to help the hospital find a suitable care home.

5.4.3 Sub-Theme Three: Mobilising Social Support Systems

Most participants sought emotional support from people with whom they had a close relationship as seen in Brian's extract below:

> *"I actually thought they've asked that question because they know something that I don't, so I rang up my ex-wife I told her what the doctor said...I did break down and she went to me don't worry" (Brian 6:317-333).*

Brian thought the doctors were concealing from him information pertaining to his mother's condition. This may have triggered in him feelings of uncertainty and fear. Equally, he may have felt in a disadvantaged position relative to the doctors given that they held information that he did not have access to, and since they espoused the power to decide whether to share this information with him. This in turn may have left him feeling disempowered and angry. Interestingly, Brian did not confront the doctors about his misgivings. Perhaps he lacked the confidence to do so due to the power imbalance that he experienced in their encounter. If so, this may have also generated feelings that he is not coping. These stressors could have depleted Brian's resource pool to deal with his internal turmoil. Clearly, his reference to "break down" is indicative of this. In his attempt to cope with his emotional responses, he "rang up" his "ex-wife" for reassurance.

In contrast to Brian, Robert did not find his social network as helpful as he hoped, perhaps since he felt misunderstood:

> *"People that know me but don't really know the situation will say ohh your mum is in hospital that will give you a break and you can go out and go to work, they don't understand, they really don't understand because when my mother is in hospital I constantly have to chase things" (Robert 10-11: 592-601).*

Robert words "constantly have to chase things" highlight the distress he experienced during the discharge process. His words "they don't understand" suggest that he was seeking validation for his ordeal but instead was faced with criticism as reflected in his words "ohh…go to work". Consequently, he may have felt pressure to resume work which could have triggered in him feelings of resentment, resulting in conflict and loss of social support. Equally, it may have triggered in him feelings of guilt and inadequacy for struggling to work whilst partaking in this process. If so, these emotional responses could have increased his distress. Further, Robert's phrase "don't really know the situation" implies that he felt unfairly judged and his words "they really don't understand" convey the impression that he was disappointed and frustrated with his social network. Consequently, he may have felt isolated and lonely.

Jacquie's experience of the social support she received from her friends was tainted by the context in which it took place:

> *"Awful you know but what to do it was nice for my mum to have company and also for me to see my friends who were very very supportive but it's not a nice place to see people" (Jacquie 13:518-526).*

Jacquie's words "it was nice…see my friends" suggest that she experienced her friends visits as rewarding. Specifically, they may have reduced hers and her mother's sense of isolation and provided an opportunity for both of them to ventilate their feelings. Indeed, she goes onto say that they were "very supportive" which is indicative of this. However, Jacquie's reference to "awful" implies that she was embarrassed about having to ask her friends to meet her in hospital, since it wasn't "a nice place to see people". Perhaps she viewed the hospital setting as lacking in hygiene, privacy and tranquillity. Equally, it maybe that she didn't want them to see her and her mother when they were feeling low. If so, this may have impeded her experience of support.

6. Discussion

This chapter examines the present thesis results with respect to current literature and the implications of these results for research and clinical practice. This is followed by the study's limitations before concluding this section with the second part of the researcher's reflexive statement.

6.1 Super-Ordinate Theme One: The Negative Aspects of the HDPP

Participants reported that hospital personnel excluded them from decision-making processes and provided inaccurate and inadequate information pertaining to their care-recipients' discharge plans. Some participants pursued members of staff to either gather information since it wasn't readily offered or to voice their concerns since they were repeatedly ignored. These findings mirror the results from previous studies which suggest that IDC participation in their care-recipients HDPP is incumbered by staff and therefore limited (Douglas-Dunbar & Gardiner, 2007; Fitzgerald et al, 2011; Nay et al, 2004). Further, like the caregivers in Grimmer's et al.'s (2004) investigation, participants' accounts suggest that they felt unprepared for discharge. Also, none of the participants reported being asked whether they were ready and capable to support their care-recipient in the post-discharge period, suggesting that their own needs were overlooked.

These findings are concerning since limiting individuals' participation in discussions and decisions relating to their needs or the welfare of those they care for, can affect their mental health wellbeing in a negative way (Bull et al., 2000; Crethar, Rivera & Nash, 2008). Indeed, participants in this thesis seemed very anxious due to the ambiguity they experienced in relation to their care-recipients' discharge plans. Anxiety, in turn, has been shown to impede individuals' understanding of information (Goold & Lipkin, 1999) which may well have increased participants' distress and make communication with the HDP more difficult. Nevertheless, participants' transcripts suggest that their emotional turmoil was not addressed by members of staff.

The communication problems that participants experienced in their interaction with hospital staff could be explained in the context of existing literature which suggests that the culture on acute medical wards labels individuals with dementia as disruptive and challenging (Alzheimer Society, 2009; Eriksson & Saveman, 2002) and that these negative attitudes maybe extended to those around them namely their informal caregivers due to stigma by association (World Alzheimer Report, 2012). Stigma by association can evoke feelings of guilt and shame as well as increase IDC experience of burden which could lead to a reduction in caregiving (Werner et al., 2011; Werner et al., 2012) and imped the discharge process. This coupled with the medical terminology used on hospital wards and the pressures that HDP face namely, to release hospital beds and reduce readmissions (Brothwick et al., 2009; Efraimsson et al., 2003) could explain the difficulties that participants encountered in their communication with members of staff.

Participants also reported that they were overlooked, discarded, disempowered and dismissed by members of staff and this seemed to diminish from their self-worth. Poor self-esteem in turn has been found to be a determining factor in the development of mental health problems such as depression, substance misuse and violence (Mann, Hosman, Schaalma & De Vries, 2004). Interestingly, participants' accounts indicate that they obscured their emotional responses and in doing so they may have inadvertently contributed to the obstruction of open communication with hospital personnel. This new insight is significant since the disinclination to speak up and the withholding of information that follows, can undermine decision making processes undertaken by organisations which could affect the trust and mood of individuals within such organisations (Morrison & Milliken, 2000; Tamuz, 2001). Equally, keeping silent may have prolonged participants' preoccupation with unresolved feelings, thereby perpetuating their distress.

Participants' concealment might be explained using the social rank theory (Gilbert, 1997). Accordingly, participants perceived themselves to be in a lower status relative to members of staff (who held information about their care-recipients' hospital discharge plans and who espoused the power to make decisions about their loved ones' care). This may have triggered in them feelings of lowliness and humiliation. It may also have left them feeling powerless and fearful of being scorned. In an attempt to avoid further rejection and disapproval, they masked their feelings. Indeed, Gilbert's (2000) study showed that low social rank was highly associated with feelings of inferiority, non-assertive behaviours and shame. Shame, in turn, has been linked to depression and poor problem solving (Harder, Cutler & Rockart, 1992). Participants' concealment could also be explained in the context of Saunders, Shepard, Knight and Roth's (1992) study which showed that the inclination to voice one's feelings to those who espouse a higher rank within a particular organisation, was dependent on the extent to which one perceived other people as open and responsive. Accordingly, participants in this study concealed their feelings from hospital of staff due to the lack of empathy and disrespect they endured in their meetings.

Taken together, it can be argued that participants' experience of poor communication and restricted participation in the HDPP was also influenced by their own responses (e.g. concealment of their internal turmoil) the characteristics of the IDC - HDP relationship (e.g. IDC were dependent on staff for information & inclusion in the HDPP) the organisational context namely NHS (e.g. hierarchical & non-democratic) and the negative content they concealed (e.g. feeling angry, anxious, dismissed). This new insight adds to findings from past investigations which suggest that HDP bear the sole responsibility for IDC exclusion. It also provides an opportunity for future research to increase understanding into the range of factors that affect IDC involvement in their care-recipients HDPP.

With regards to the second sub-theme, participants' accounts suggest that the HDP prioritised the hospital's requirements over their loved ones' dementia related needs and that they and their care-recipients were written off as a result. This new insight is concerning because perceived disparities are stressors that can yield cognitive and health problems (Krieger 1999) as well as diminish from individuals' self-concept (Anderson, 1991). Likewise, it suggests that individuals with dementia and their unpaid caregivers are treated like second class citizens in the context of the HDPP. One possible explanation for these disparities is that individuals with dementia are viewed as utilising much of the nursing capacity on hospital wards (Cowdell's, 2009) and therefore discharged swiftly. This, in turn, renders little time for comprehensive discharge planning processes, thereby increasing individuals with dementia dependency on their unpaid caregivers (Maramba et al., 2004; Victor et al., 2000) which could intensify caregivers' sense of burden.

Further, participants seemed angry with hospital personnel for ignoring the potential negative ramifications of their discharge plans for their care-recipients wellbeing. This is an important finding since forming and maintaining a collaborative partnership has been identified as a crucial factor that could influence the successfulness or breakdown of alliances in the milieu of therapy and the doctor-patient relationship (Norcross & Wampold, 2011: Tessler & Mechanic, 1975). By the same token it can be argued that the nature and characteristics of the IDC - HDP alliance could determine the execution of timely discharges and the likelihood of patients' readmissions as suggested by Naylor et al.'s (1994) findings.

Moreover, participants seemed anxious about potential changes in their care-recipients' cognition, behaviour, and health following discharge and how this would impact on their own wellbeing. Perhaps because dementia patients' challenging behaviours increase caregivers' sense of burden (Papastavrou et al, 2007). Burden in turn has been linked with poor self-care and health problems in IDC (Connell et al., 2001; Fuller-Jonap & Haley, 1995; Vitaliano et al., 2003). Further, persistent strain might be perceived by caregivers as evidence of their failure to manage difficult situations which in turn could lead to negative self-evaluation (Pearlin et al., 1981). Nevertheless, IDC anxieties were overlooked by the HDP which contrasts with the government's call to enhance IDC life satisfaction (DoH & Social Care, 2014).

In the third sub-theme, participants reported that partaking in their care-recipient HDPP came at a cost. For most participants this was manifested in sacrificing aspects of their daily routine that they valued such as work, interpersonal bonds and recreational interests. This finding highlights that participants continued to provide substantial support to their care-recipients in spite of relinquishing hands-on care to hospital personnel. Some participants also described their engulfment in the caregiving role. Abandoning other social roles in favour of the caregiver's role has been associated with poor self-worth and mastery and depressive symptoms in IDC (Skaff & Pearlin, 1992). It can also lead to financial pressures and caregivers' isolation (Johnson & Troll, 1994; Luscombe, 1998; MacRae, 1999; Wimo et al., 1999). Further, engulfment in the caregiving role has been linked with loss of self. Specifically, as caregiving responsibilities increase so does the identification with the caregiver's role. Consequently, former identities become less pertinent and diminish (Eifert et al., 2015).

Finally, participants reported that the HDPP deprived them of the time to meet their own needs which seemed to generate in them a range of emotional responses including stress, frustration and bitterness. However, participants' interviews also illustrate that it was their own choice to invest their resources in their care-recipients' HDPP, and their feelings of obligation to offer support appear to have propelled them to do so. Neufeld and Harrison (1995) associated filial caregivers' feelings of obligation to deliver care with early socialization to norms pertaining to filial behavior whilst Sprecher (1998) stated that individuals' sense of obligation stems from their own need to reciprocate for the rewards they obtained from others. Notwithstanding these arguments, it seems that the participants' sense of duty yielded adverse ramifications for their wellbeing. This result is consistent with existing literature which argues that caregiving motivations fueled by feelings of duty can have detrimental effects on caregivers' wellbeing and are likely to cause greater psychological distress than caregiving motivations that are based on positive drives (Hobfoll, 1986; Pyke & Bengtson, 1996).

The implications of this thesis findings for clinical practice are as follows: Applied psychologists who work with IDC in the milieu of the HDPP would need to consider and address the negative impact that the IDC - HDP relationship has on their clients' emotional wellbeing and behaviour. They may want to employ assertive skills training to increase IDC array of coping tactics (Robinson, Ramsey & Partridge, 1996). This could empower caregivers to voice their thoughts and feelings in this hierarchically structured environment. Therapists also need to be aware of the far-reaching influence of the HDPP on IDC lives. It may be useful to teach caregivers self-care practices to promote their physical and emotional wellbeing during this time (Myers, Sweeney, Popick, Wesley, Bordfeld & Fingerhut, 2012). Further, good practice would normalise caregivers' feelings of shame and anxiety as this could boost their confidence and improve their coping (Dudley & Turkington, 2011).

Moreover, counselling psychologists could use the context of training to educate HDP about the negative ramifications of the discharge process for IDC psychological wellbeing. They could also share with hospital personnel their knowledge of therapy skills (Gilbert and Leahy, 2007) to help members of staff form and maintain a nourishing relationship with caregivers. Likewise, counselling psychologists could offer their services as facilitators of psychological wellbeing on hospital wards. Such an initiative would provide IDC access to mental health support during the HDPP which they would struggle to attain in the community in real time due to long waiting lists. Finally, policy makers may wish to espouse the opportunity to address the behaviours that would strengthen the alliance between HDP and IDC in hospital guidelines.

6.2 Super-Ordinate Theme Two: Focus on Relationships

Consistent with the commentary that caregiving can generate a shift in the manner in which caregivers regard their care-recipients (Sherrell, Buckwalter & Morhardt, 2001) most of the interviews in this study suggest that the increase in patients' needs and the caregiving responsibilities that followed, instigated change in IDC perception of their care-recipients. These changes were experienced as loss of an identity that participants attributed to their loved ones. Interestingly, Brian's account suggests that the shift in his interaction with his care-recipient (e.g. "talking to mum as mum") and the shift in his self-perception (e.g. "it's Brian not mum's carer") seemed to yield positive outcomes for both parties as it enabled them to reconnect. Brian's decision to put on hold the caregiver's role, which left him little time to bond with his mother at home, may account for his differing experience.

Transformation in self-perception and role reversal were also recounted by other participants. However, participants varied in the changes they experienced, perhaps due to the differences in their filial ties to their care-recipients. For example, Richard recounted how he defended his father's reputation. This suggests that he no longer viewed him as a protector but rather as needing protection, thereby espousing the parent role. Similarly, Debbie talked about a shift from the follower-leader relationship she experienced in her interactions with her ex-husband whilst they were married, to commanding his needs during discharge planning. Further, Jacquie's account portrays her mother as a vulnerable and dependent individual as opposed to the relatively strong figure she perceived her to be prior to admission. The increase in her caregiving responsibilities may have strengthened her identification with the caregiver's role. These findings chime with Hayes et al (2009) study which showed that changes in established patterns of interactions between IDC and their care-recipients generated change in the way the IDC perceived themselves in the caregiver-care recipient dyad.

Most participants experienced the changes in their interactions with their care-recipients as a decline in the quality of their bond. According to existing literature such shifts can evoke mixed emotions in IDC including sadness and frustration about the losses they incurred as well as resentment about their situation and guilt for being angry with their care-recipient. Caregivers' guilt, in turn, has been associated with their sense of burden, suggesting negative appraisals of their performance (Adams, 2006; Gonyea et al., 2008). Further, such shifts could precipitate anticipatory mourning and feel burdensome if the care recipient's decline persists over a lengthy period of time as in the case of dementia patients (Kaprio et al., 1987; Light & Lebowitz, 1989; Pattison, 1978).

Whilst the UK government pledged to reduce IDC psychological burden (Department of Health & Social Care, 2014) and the Care Act (2014) sought to give them greater control and influence over their needs (Anchor, 2018; TNA, 2014) the present study shows that in the context of the HDPP, this particular client group continues to be subjected to staff's primacies. Specifically, participants spoke of the power imbalance that they experienced in their encounters with members of staff, recounting situations where professionals used their status to enforce decisions pertaining to their loved ones' discharge plans that they opposed. Such power disparities can diminish from individuals' sense of control and trigger feelings of helplessness (Crethar et al., 2008). It can also constitute a barrier in attaining a collaborative relationship between consumers and health providers (Scholz, Bocking & Happell, 2017) which could impede patients' timely discharge. Indeed, Robert's account shows that the HDP attempt to impose discharge was met with his resistance which in turn prolonged his mother's admission. Similar experiences were also reported by family caregivers of elderly patients in Bragstad et al.'s (2014) study.

The power imbalance that participants depicted could be explained in the context of existing literature. Accordingly, hospital personnel endeavor to gain power over the demands of their work and this includes dealing with IDC who seek to gain power over the factors that influence their experience of the HDPP. Consequently, both parties find themselves in a battle for control (Rosenthal, Marshall, Macpherson & French ,1980). However, the power that staff possess may propel them to gain further influence over caregivers' actions, to appreciate them less, and to use stereotypes to maintain their control (Fiske, 1993; Kipnis, 1976) thereby constraining IDC outcomes.

Further, governmental policies pertaining to hospital discharge planning in the UK emphasise the importance of working in partnership with informal caregivers (Department of Health, 2003). However, the present thesis illustrates that in some cases participants' knowledge of their care-recipients' needs was overlooked or discounted by members of staff. Perhaps hospital personnel consider their expertise as more valuable than caregivers' experience of their loved ones' requirements (Lewis, 2014). This, in turn, limits the benefits that a partnership with caregivers could yield (Scholz et al., 2017). It also diminished from participants' sense of control and left them feeling angry, belittled and anxious. Poor sense of control has been linked with psychological and medical problems (Jimmieson, 2002).

Moreover, in line with the approach/inhibition theory of power (Keltner, Gruenfeld & Anderson, 2003) it can be argued that the sway of these power disparities on caregivers' wellbeing were mediated by their perceptions of their own power and that held by hospital personnel. For example, it appeared that most participants felt as though they were dealing with a system rather than a particular member of staff which seemed to have tipped the balance of power for them in favour of the individual with whom they were communicating. One participant also perceived himself to be in a disadvantage position compared to the HDP due to the power accorded to them by virtue of their skills and status. This could mean that despite feeling low in power relative to the HDP, participants were still influential.

Indeed, in response to their views and wishes being overridden, most of the participants challenged the HDP discharge plans though they differed in the way they went about it. A few participants were defensive and protective whilst another employed confrontation and rationalisation. Participants' behaviours could be explained using the Reactance theory (Brehm, 1966). Accordingly, they perceived their freedom to control their loved ones' discharge plans as restricted and this propelled them to regain their jeopardized freedom by refusing to cooperate with the HDP who constrained their sense of choice and autonomy in the first place. Interestingly, Jacquie's account illustrates that she refrained from debating her mother's discharge plans. Perhaps Jacquie's poor sense of control inhibited her due to fear of losing favour with those higher in power namely the HDP. This proposition is consistent with Henley's (1973) research findings.

In the third sub-theme, participants depicted situations where they immersed themselves in hospital work. Like the family caregivers of hospice residents in Stajduhar, Nickel, Martin and Funk (2008) study, most caregivers in this thesis indicated that constraints within the system propelled them to do so. This generated positive and negative emotions in them. On one hand, they appeared empowered by their participation, perhaps because they were able to attain control over certain aspects of the discharge process. This finding chimes with existing literature (Lord & Hutchison, 1993; Nelson, Lord & Ochocka, 2001). On the other hand, most seemed angry for undertaking work that they viewed as the responsibility of hospital personnel. This finding highlights that IDC should be offered the choice to espouse a co-worker's position rather than being compelled into such roles.

Another interesting point pertaining to the third sub-theme is that on first inspection it seems to diverge from caregivers’ narratives regarding their exclusion from the HDPP. This is because it indicates that in certain circumstances IDC were incorporated in their care-recipients’ HDPP, in the capacity of a co-worker. However, a close examination of IDC transcripts suggests that they were the driving force that facilitated their participation rather than members of staff. Specifically, it was the participants who identified the particular conditions that would allow them to partake in this phenomenon and who seized control, rather than offered command, over aspects of their loved ones’ HDPP. Thus, participants’ inclusion could not be credited or attributed to hospital personnel initiatives; it was the shortcomings within the system coupled with caregivers’ resourcefulness and desire to participate in this process that enabled their involvement.

Still, it seems that most participants felt empowered by their actions and by attaining their goals within the co-worker context. In line with Bandura’s social cognitive theory (1986) this may well have strengthened IDC sense of self-efficacy and mastery. Equally, the co-worker role enabled IDC the occasional opportunity to transition from their marginalized status to a higher rank where they were helping staff fill in gaps in care. This tension between periods when IDC involvement was welcomed owing to the system’s needs, versus times when it was rejected and hampered due to no need, placed IDC in an ambiguous stance relative to hospital personnel. In common with past research findings (e.g. Rosenthal et al.,1980; Twigg & Atkin,1994) it is possible that on one hand caregivers’ labour was viewed by the HDP as an opportunity to cut costs in care but on the other hand was interpreted as caregivers attempt to attain control over staff’s working environment. However, by allowing IDC to adopt the co-worker role, the HDP were able to restrict IDC pursuit of power and subject them to their authority. Indeed, IDC extracts suggest that their input was not recognised or valued by members of staff, indicating that they were treated as a resource rather than as experts and clients with needs in their own right. This appeared to have left participants feeling unappreciated and may account for their short-lived experience of control. According to past research, professionals’ neglect to appreciate informal-caregivers’ contribution to care, triggered clashes between the two parties (Bowers, 1988; Duncan, & Morgan, 1994; Powell-Cope, 1994) which in this thesis seemed to have hampered their working relationship.

Finally, the tension encompassed within the co-worker sub-theme echoes the convergence and divergence that emerges from the analysis of IDC idiosyncratic voices in each shared theme which according to Smith and Osborn (2008) is indicative of a good IPA study. Equally, this tension adds new insights that are congruent with other themes, showing that the co-worker role may have been used by members of staff as a strategy to govern IDC behaviour which perpetuates their demoted status.

The implications of the findings examined in this section for research and clinical practice are as follows: First, practitioners could employ individual therapy to help caregivers recognise and make sense of the losses they incurred due to the changes they experienced in their relationship with their care-recipients. Further, practitioners should facilitate support groups where IDC can share their stories as this could alleviate their social isolation and help them deal with unresolved grief. Moreover, practitioners should help IDC explore their identity within the caregiver-care recipient dyad as this will increase their clients' insight into the losses they endured. Notwithstanding these interventions, therapists must be mindful of the social context of dementia and the diverse losses experienced by different caregivers. Therefore, therapy must be tailored to meet the idiosyncratic grief requirements of IDC.

Second, the differences between participants in the strategies they employed to deal with the power imbalance that they endured suggest that they also varied in other aspects. Specifically, in the way they interpreted their experience of disparities and in their perceived capacity to deal with them. This underlines the importance of conducting further research into the processes through which caregivers negotiate (or battel) for control over the HDPP. Such insights could help practitioners working with IDC in this context, match their therapeutic treatments to caregivers coping style.

Third, by engaging in democratic relationships and using a person-centred approach (Kasket, 2012) counselling psychologists could empower IDC to explore their internal processes in the milieu of the medical model. Likewise, they could provide an alternate way to conceptualise caregivers' experiences of power dynamics. This in turn could enhance caregivers' sense of control in their interactions with members of staff. Similarly, applied psychologists may wish to employ cognitive behavioural interventions to raise caregivers' awareness of how their own perceptions of power imbalance mediate the effect of the disparities they experienced on their mental health outcomes.

Finally, to address the power imbalance in the caregiver-HDP relationship, hospital personnel could undergo training to enhance their understanding of the negative ramifications of such disparities for caregivers' wellbeing and for their partnership. They could also identify and modify aspects of their clinical practice that trigger and perpetuate feelings of powerlessness amid caregivers. Equally, policymakers may wish to reflect on the ethical implications involved when IDC feel compelled to espouse the co-worker's role.

6.3 Super-Ordinate Theme Three: Employing Coping Mechanisms to Counteract Taxing Experiences

As with other research (Clissett et al., 2013) participants in this study invested cognitive efforts to reduce internal demands that were triggered in them during the discharge process. What this study adds is that it showed that IDC differ in the mental tactics they employ. Some utilised rationalisation to justify the behaviour of the professionals with whom they interacted. This was to offset the adverse emotional responses triggered in them by the actions of those professionals. Whilst it is unclear how helpful this strategy was for participants, past research suggests that in the case of filial members coping with a loved one's brain death diagnosis, rationalisation appeared to be helpful both immediately and over time (Long, Sque & Addington-Hall, 2008). Another participant in this study used denial to refute her mother's diagnosis of dementia since she viewed the disorder as a sign of insanity. Perhaps like the caregivers in Blum's (1991) study, this participant was worried about being stigmatised by the virtue of her relationship with her care recipient. Nevertheless, the literature pertaining to denial is equivocal: Wilson (1981) argued that it can reduce distress and thus facilitate coping whilst Sun, Kosberg, Kaufman and Leeper (2010) study showed that it was not helpful in reducing undesirable emotions in dementia caregivers. This underscores the need for further investigations into the efficacy of denial as a coping mechanism since such insights could shed light on the strengths and limitations of this strategy for this particular client group.

Further, Fitzgerald et al.'s (2011) research illustrates that IDC employed behavioural strategies to deal with external challenges that arose during their care-recipient admission. This thesis extends their findings by showing that IDC also employ behavioural strategies to deal with their internal turmoil and that they differed in the tactics they used. For example, Brian seemed anxious about articulating his feelings to members of staff for fear of losing his temper which subsequently led him to restrict his communication with them. According to Operario and Fiske (2001) interpersonal conflict can undermine relationships and subsequently lead to reprisals which may explain Brian's fear of losing his temper. Indeed, Moyle's et al (2002) study shows that IDC refrained from raising complaints with care-home staff due to fear that conflict may subsequently affect quality of care. However, inhibiting negative feelings could lead to psychological distress (Levy, 1990) and communication problems (Spezzano, 1993) which raises questions about the efficacy of Brian's coping strategy.

In contrast to Brian, Robert utilised confrontation as a coping strategy to propel staff to provide the services that he and his care-recipient were entitled to. His desperate behaviour seemed to be driven by feelings of unfairness and anger. This suggest that he also used this tactic to deal with or express his internal turmoil, generated by the HDP actions. Interestingly, Robert's account suggests that he was ambivalent about using confrontation as a coping strategy due to limited successes in attaining his goals and the negative implications for his wellbeing. Existing evidence pertaining to the usefulness of confrontation coping is equivocal (Noh, Beiser, Kaspar, Hou & Rummens, 1999; Noh and Kaspar, 2013) highlighting the need for further investigations in this area of research.

Another strategy used was filling in the gaps in care which Richard employed to resolve his sense of uncertainty, and to gain control over his father's discharge planning process. Since control is exercised via action such as making choices, realising intensions and influencing the behaviour of others (Botelho, 1992) it is possible that Richard was successful in counteracting his negative feelings using this strategy. No research has been found pertaining to the efficacy of this tactic which provides an opportunity for future studies to explore amid IDC.

Moreover, most of the participants recounted how they sought social support from relatives and friends though they differed in the emotional needs that they were seeking to meet through this medium. For example, Jacquie's sense of isolation was alleviated by her friends' visits to the hospital, whilst Brian's ex-wife enabled him to ventilate his overwhelming feelings of anxiety and attain a sense of reassurance in the face of ambiguity. These findings are consistent with Finch and Vega's (2003) commentary which postulates that greater socialising could buffer the adverse influence of stressors on individuals' wellbeing. Interestingly, Robert's account suggests that his need for empathy and validation was met with criticism which appeared to have left him feeling frustrated and disappointed. Dissatisfaction with social support, in turn, could propel individuals to employ maladaptive coping strategies that could yield adverse outcomes for their welfare (O'Brien, 2000) and Robert's account is a case in point.

Taken together, these findings show that participants' choice of strategy (e.g. cognitive, behavioural or social support) varied depending on the negative emotional responses that were triggered in them by the different challenges they faced in the discharge process. This finding chimes with Thompson, Kent and Smith's (2002) study which showed that coping is not a linear and discrete process. Rather, it is governed and shaped by several factors such as the unique appraisals individuals employ to assess the level of risk in a specific context and their resources to deal with it (Lazarus, 1966). This may also explain why participants differed in the cognitive and behavioural strategies they employed.

The implications of the findings examined in this section for research and clinical practice are as follows: First, future research could examine the processes that underpin IDC decisions to utilise one coping tactic over another in the context of the HDPP. Such insights could strengthen practitioners' understanding of the negative ramifications that this phenomenon has for IDC mental health wellbeing. Second, applied psychologists may wish to identify situations in the discharge planning process that trigger negative thoughts and feelings in IDC. Such insights could enhance their clients' capacity to convey their difficulties and help them utilise more adaptive strategies to coping. Third, counselling psychologists should provide psycho-education to caregivers about dementia, anxiety and coping mechanisms as this could increase their sense of control and empower them.

6.4 Evaluation of the Current Study

A primary strength of the present thesis lies in its contribution of new evidence to this research topic, showing that IDC experience of the HDPP does not comprise of a single layer of meaning. Rather, it consists of multiple psychological dimensions including identity, attachment, loss, coping and emotional disturbance. This overall finding aligns itself well with and extends Pearlin et al.'s (1990) stress process model. Specifically, it illustrates that indicators of primary stressors do not have to emanate from dementia patients' condition (e.g. memory loss & challenging behaviour) or the caregiver-care recipient relationship, as suggested by the above paradigm. Indeed, in the milieu of the HDPP, they could also stem from the HDP actions and their communication with IDC.

For example, excluding caregivers from decision making processes, providing inaccurate and inadequate information regarding care-recipients' discharge plans, prioritising the system's requirements over care-recipients' needs, overlooking IDC concerns regarding the potential negative ramifications of discharge plans for care-recipients' wellbeing, using their status to enforce decisions that caregivers opposed, dismissing IDC expertise regarding their care-recipients' needs and asking caregivers to fill in gaps in care. IDC response to these challenging situations, in an attempt to meet their care-recipients' needs, constituted tremendous stressor.

Further, consistent with Pearlin et al.'s (1990) theory, this study shows that indicators of primary strains yielded secondary stressors. For instance, IDC experienced constrictions in multiple areas of life including work and interpersonal relationships, since caregiving in the context of the HDPP consumed much of their time and energy. Another example includes IDC diminished sense of control over their care-recipients' HDPP and feeling humiliated due to staff primacies. Moreover, this link between primary and secondary stressors highlights to readers the negative implications of organisational practices within the NHS for IDC mental health. In response to these strains, caregivers used two types of mediators namely, coping and social support. According to Pearlin et al. (1990) these strategies aim to reduce the severity of primary stressors and subsequently bound the expansion of secondary strains. However, these authors do not discuss the possibility that such resources could have the opposite effect on individuals' state of mind and behaviour as suggested by the present thesis.

To illustrate, Robert's transcript indicates that he felt criticised, frustrated and isolated by the people in his network from which he sought empathy and validation. As noted earlier in this study, this could propel people to employ maladaptive strategies to offset taxing experiences, resulting in adverse consequences for their well-being (O'Brien, 2000). Indeed, Robert's interview implies that he used confrontation as a defence mechanism which in turn perpetuated his cycle of distress. This finding informs the stress process model by offering an alternative perspective to the role that mediators may play in governing the impact of stressors. Finally, the present thesis findings show the complex interlinks between different stressors, mediators and IDC outcomes in the context of the HDPP. This could constitute as an adaptation to Pearlin et al.'s (1990) stress process model and used as a conceptual framework for learning about IDC experience of the HDPP.

The present thesis also has several limitations. First, it could be argued that the sample is not sufficiently homogeneous because participants differed in some of their demographic characteristics (e.g. gender and relationship to their care-recipient). However, this thesis findings show that psychological variability within the sample was investigated comprehensively by parsing how each participant's experience diverged from and converged with his fellow group members unique experiences across themes. Equally, the present thesis produced a list of themes that were common among participants. This, in turn, provided important insights into the idiosyncratic thoughts and feelings that each caregiver experienced in the context of the HDPP as well insights into participants shared experiences, which suggest that the sample was reasonably homogeneous. Another limitation pertains to recruitment which was difficult and accounts for this thesis small sample size. If the sample size was larger it would have been appropriate to pilot the interview schedule with an IDC who met the inclusion criteria. This could have allowed the researcher to make any necessary revisions to the interview schedule (Leon, Davis & Kraemer, 2011) in addition to those that were made following self-reflection. Still, a small sample size enabled this researcher to conduct a thorough exploration of the experience of the HDPP phenomenon with each caregiver which is congruent with IPA's underpinnings and guidance for doctoral training (Smith et al., 2009). Further, given the study's small sample size and the use of IPA, which employs an idiographic rather than a nomothetic approach, the results from the present study cannot be generalised to the broader community of IDC. However, caregivers spoke similarly and therefore readers could assess the ubiquity of this thesis findings in the context of their own practice. Likewise, readers can make links between the results from this study and prevailing evidence within the discipline of psychology, thus shedding light on existing knowledge (Smith et al., 2009). Finally, participants' accounts indicate that they were anxious about expressing their negative thoughts and feelings to members of staff. Given that members of staff namely, care-recipients' social-workers, played a role in this research process (e.g. facilitated IDC recruitment) it is possible that participants were also anxious about discussing their internal processes in the milieu of this study. Retrospectively, the researcher could have used alternative means of recruitment such as charities and social media.

6.5 Conclusions

This thesis set out to explore the experience of the HDPP for IDC of older patients. Data analysis revealed that participants felt dismissed in their interactions with members of staff and this seemed to diminish from their self-esteem. The poor communication they experienced in addition increased participants sense of ambiguity and anxiety about their care-recipients' discharge plans. Participants also thought that hospital requirements were prioritised over their care-recipients' needs, perhaps due to negative attitudes about dementia patients. Furthermore, caregivers' lives were significantly disrupted by this process which added to their frustration and distress. These multiple stressors coupled with the loss of valued facets of their relationship with their care-recipients appeared to deplete IDC resource pool and diminish from their sense of control and psychological wellbeing. However, participants avoided discussing their internal experiences with members of staff due to power disparities and lack of empathy, respect and emotional support that they experienced in their interactions with staff. To cope, participants employed various strategies though it was unclear how useful these were in alleviating their distress. Taken together, these findings offer applied psychologists and other professionals working with IDC in the context of the HDPP new insights into IDC internal experiences, the drives that underline their responses to hospital personnel and their care-recipients, and the role that their responses play in creating their experiences within the context of these transactions. It is hoped that these contributions will inform both practitioners and HDP work with this particular client group.

7. Reflexive Statement - Part Two

This second part of the reflexive statement discusses how I identified and addressed my subjectivity with regards to participants' recruitment and interviews, data analysis and thesis findings.

The local authorities from which I recruited participants were inherently positive about my study though I noticed that the social workers were hesitant about discussing my research with their service users. There appeared to be multiple reasons for this: a few social workers reported that they had a poor rapport with their clients and therefore were reluctant to speak to them about the study. Other social workers implied that they were short of time due to work commitments and therefore were unable to assist with recruitment. However, the majority of social workers regarded their clients as inappropriate for the study. In response I reiterated the inclusion and exclusion criteria which resolved this problem. Nevertheless, the recruitment difficulties I experienced triggered feelings of frustration and anxiety in me about finding participants. Further, I recognised that my decision to rely on the local authorities to produce participants diminished from my sense of control over the research process and left me feeling as though they espoused the power in our relationship. These emotional responses impacted on the way I communicated with the social workers. For example, I recognised that I was constantly thanking them for their support, overly apologetic for the time they invested in identifying potential participants, and exceedingly flexible in conceding my needs to meet their schedule. Through the employment of a reflexive journal I realised that my behaviour only perpetuated my distress. To alleviate my internal turmoil, I discussed my thoughts and feelings with fellow researchers who also encountered problems with recruitment. This helped to normalise my experience and provided a space to give and receive support which felt empowering.

During the interviews stage I recall empathising and identifying with participants who felt that they "had nothing" that they "had no life" during their care-recipients' hospital discharge planning. I recognised that this theme resonated with me because like my participants I also felt that I had no life in the milieu of this study: my thesis consumed much of my day, leaving me with very little time to engage in paid work, socialising and recreational activities. However, on further reflection I also realised that I experienced similar feelings several years ago when a close relative of mine was hospitalised for an elective operation to save his life. It felt as though I was trapped on another plant whilst life in the outside world continued without me. Identifying with participants' narratives may have inadvertently conveyed to them the impression that I was aware of and familiar with their internal processes. This in turn could have hindered their exploration of this theme. Alternatively, I wonder whether my identification enabled me to relate to participants on an emotional level thereby facilitating rapport and further discussion. Participants texts suggest that the latter maybe the case.

Moreover, it is possible that my past social work experience and criticalist epistemological positions (e.g. that social structures such as the medical model privilege professionals over consumers, thereby facilitating authoritarian relations between these parties) have guided my understanding of IDC experience when analysing their transcripts. To illustrate, I linked Robert's anguish (e.g. "the most distressing thing was trying to get through to doctors, nurses and pharmacists, a lot of the time they will dismiss you…." p4:195-204) to the underlying power dynamics in his interaction with HDP. I also suggested that this experience may have subsequently triggered in him feelings of powerlessness and worthlessness. However, it is equally possible that Robert's distress also emanated from his concern for his mother's wellbeing and fear that her needs would go unmet.

Another example where my subjectivity, and more specifically my familiarity with relevant literature, may have impacted on the rendering of data involves Richard's extract: "they found him to be aggressive and ahh ohhh well ya well basically aggressive…but he has just been in a fall…ohh I was annoyed…" p6:252-280). Specifically, I suggested that Richard felt the urge to defend his father's behaviour since he no longer viewed him as a protector but as one who needs protection, suggesting role reversal. However, it is also possible that Richard's defensive behaviour and anger also stemmed from feelings of shame, since aggression is frowned upon in our society and Richard didn't want to be stigmatised as aggressive by his association to his father. In an attempt to manage such biases, I proceeded to explore my interpretations of the data with fellow researchers to confirm that they were grounded in caregivers' narratives. I also used the hermeneutic cycle (Smith et al., 2009) interpreting participants' excerpts in the context and collective meanings of their transcripts.

Undertaking this thesis has been an interesting learning experience, particularly in my understanding of IDC experience of their mental health in the milieu of the HDPP. Participants' interviews portrayed a complex picture of their psychological wellbeing which differed from what I expected to find at the outset of the present study: I thought that participants would disclose a straightforward and simple description of their internal processes that encompassed a single layer of meaning. Looking back, I recognised that my past practice as a hospital social-worker biased my outlook, which underlined for me how important it was to conduct research in this topic area, since without it my suppositions (and potentially other practitioners' suppositions) could have gone unchallenged. This realisation has also triggered reflections in me about the possibility that I had overlooked the different layers of meaning contained within my mother's experience of caregiving, which was painful to acknowledge yet helpful in strengthening our bond. Moreover, this study taught me to pay close attention to my subjectivity and inter-subjectivity in my clinical work as a counselling psychologist and in my interpersonal relationships with family and friends. Similarly, it helped me adopt a more open and curious stance to individuals' idiosyncratic life events.

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Appendices

Appendix A: Briefing Sheet

Dear Sir, Madam

My name is Natalie and I am a student at London Metropolitan University, where I am studying counselling psychology at a doctorate level. I am writing to ask whether you might be interested in participating in a study that I am undertaking for my degree. The study has received ethical approval and its purpose is to explore the experience of hospital discharge planning for informal caregivers of older people with dementia. The study seeks to increase insight into how caregivers experience their wellbeing in this context.

Participation will involve an informal conversation that will last about one hour in a venue that suits you. Often people involved in these types of studies choose to have the researcher visit them in their own home. Our conversation will revolve around your thoughts and feelings as well as your experience of your everyday life in the context of your care recipient hospital discharge planning.

I would like to record our conversation on a digital recorder which will be used to make a word-for-word transcription of the interview, so I can analyse the information you provided. Anonymous quotes from different parts of your transcription may be used in the writing of my study. I will need to obtain your written consent for taking part in this study and another to record our conversation.

Participation in this study will be entirely confidential; this means that your name and any other identifying information you provide will be changed. Once I completed the process of examining the information you provided, I will delete your interview recording.

If you wish to withdraw from the study during or after our interview you can do so by contacting me or my supervisor. Our contact details are listed below. Withdrawal from the study after our meeting can be facilitated up to the point of which I will start to analyse your transcript. This will be within three weeks from the date of our meeting. Withdrawing from the study will not affect any of your current or future services.

I hope that you will be able to participate in this study and if you wish we could have an initial meeting or a phone conversation should you have any questions. My contact details are noted below.

Yours sincerely
Natalie O'Hana
TEL: 07427359935
Email: n_ohana@hotmail.com

This study is supervised by Dr Catherine Athanasiadou-Lewis. If you wish to contact the supervisor, her contact details are as follows: The School of Psychology, Faculty of Life Sciences and Computing, London Metropolitan University, 166-220 Holloway Road, London N7 8DB, Tel: 0207 133 2669, Email: c.athanasiadoulewis@londonmet.ac.uk

Appendix B: Consent Form

I understand that I will be participating in a study that examines the experience hospital discharge planning for informal caregivers of older people with dementia. This study is conducted by Natalie O’Hana, a counselling psychologist in training at the Department of Psychology in London Metropolitan University.

The purpose of the study and the part that I shall undertake has been fully explained to me. I have been able to ask questions about the procedure which were answered to my satisfaction and I understand that:

The research will be carried out in line with the British Psychological Society Code of Ethics and Conduct

The study will be supervised by Dr Catherine Athanasiadou-Lewis at the School of Psychology, Faculty of Life Sciences and Computing, London Metropolitan University, 166-220 Holloway Road, London N7 8DB, Tel: 0207 133 2669, Email: c.athanasiadoulewis@londonmet.ac.uk.

My participation in this study will involve an informal conversation with Natalie O’Hana which will take about an hour.

The information gathered in my interview will be used solely for the purpose of this study and my private details will remain confidential throughout the study and in any subsequent reports concerning the outcomes of the study.

Results from this study may be published in psychological journals or scientific reports but I will not be identified in any publication or report.

I have the right to ask for the audio recording to be turned off at any time during the interview and refuse to answer any questions.

My participation in this study is voluntary and I may withdraw my consent to take part in this study up to the point that the researcher, Natalie O'Hana, begins to analyse my transcript which will be within three weeks from the date of our interview. I understand that any current or future services provided by the council will not be affected by my withdrawal.

If I withdraw my consent to participate in this study then my audio recording and other data I provided will be deleted.

If I have any further questions or wish to withdraw from this study then I can contact the researcher, Natalie O'Hana, using the following contact details: n_ohana@hotmail.com TEL: 07427359935.

I agree for the researcher to audio record the interview
I can confirm that I am over 18 years of age
I willingly agree to participate in this study

Name of Participant………….Signature…………………...Date………………………...

Name of Researcher…………Signature………………….…..Date……………….…….…

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Appendix C: Informed Consent Form for Audio Taping

The purpose of this agreement is to stipulate the conditions for the use of audio recordings made by the researcher, Natalie O'Hana, for the sole purpose of this study.

I……………………(Participant's Name) give permission for my interview to be audio recorded permitted that:

- Only the researcher, Natalie O'Hana, will have access to the audio recording of my interview
- The audio recording will be kept under secure conditions and will be destroyed once the analysis of my transcript has been completed

I have read, understood and agree to the conditions noted above

Signed (Participant)…………..……………Date ………………………..………………

Signed (Researcher)……………….………Date…………………..…………………….

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Appendix D: Demographic Questionnaire

- Age……………………………………………………………………
- Ethnicity………………………………………………………………
- Religion……………………………………………………………….
- Marital status………………………………………………………….
- Employment…………………………………………………………..
- Where was your care recipient living prior to his/her hospital admission?...
- When was your care recipient diagnosed with dementia?..
- How long have you been caregiving for your care recipient?...
- What was your care recipient discharge destination?...

Appendix E: Interview Schedule

Dear Sir, Madam, the researcher would like to ask you about your thoughts and feelings regarding your experience of your care recipient’s hospital discharge planning. The following questions are for guidance purposes only:

1) Could you briefly describe for me the reasons that led to your care-recipient hospital admission?
Prompt: What was it like for you when your care recipient was admitted to hospital?
Prompt: What went through your mind at the time?

2) Could you please describe your involvement in your care recipient hospital discharge planning?
Prompt: How did you find out about your care recipient’s discharge destination, medication, package of care, medical state?
Prompt: How did you go about negotiating day of discharge, package of care?
Prompt: Were there any aspects of the process that you found helpful/unhelpful? If yes/no, what were they?

3) How did you experience your interaction with the hospital discharge planners?
Prompt: To what extent were you able to convey your views about your care recipient’s discharge plans?
Prompt: To what extent were you able to convey your views about your own needs?

4) How did you experience your caregiving role during the discharge planning process?
Prompt: What did your caregiving involve?
Prompt: What was is like for you to communicate with your care-recipient in the context of the HDPP?

5) What was your daily life routine like during this process?
Prompt: With regards to personal relationships, work commitments, family life, recreational activities

6) What impact did this experience have on your care-giving role post discharge?
Prompt: Can you tell me a bit more about that?

Appendix F: Debriefing Form

Thank you for taking part in this study. Your help is much appreciated.

The purpose of this study is to explore the experience of hospital discharge planning for informal caregivers of older people with dementia, and how they experienced their psychological wellbeing in this context. It is hoped that this study will increase insight into the psychological needs of informal caregivers of older people with dementia in the context of hospital discharge planning.

If you have any further questions regarding this study or would like to withdraw your consent to participate (within three weeks from the date of this interview) then you can contact the researcher directly by email: n_ohana@hotmail.com or by phone 07427359935.

You can also contact the researcher's supervisor, should you want to discuss any issues concerning the study or the conduct of the interview. The supervisor is Dr Catherine Athanasiadou-Lewis at the School of Psychology, Faculty of Life Sciences and Computing, London Metropolitan University, 166-220 Holloway Road, London N7 8DB, Tel: 0207 133 2669, Email: c.athanasiadoulewis@londonmet.ac.uk.

When the interview concluded I asked how you felt during and after the interview. If you experienced any form of distress as a consequence of your participation in this interview then you may wish to consider contacting one of the support services I have detailed below:

- Samaritans: provide 24-hour emotional support for those experiencing distress. TEL
  08457 90 90 90. Website: www.samaritanes.org.uk
- Mind: a mental health charity, information line 0300 123 3393 and email: info@mind.org.uk

- Relate: a charity that provides relationship support. Their website address is: www.relate.org.uk
- Carers UK: a charity that provides help and advice to caregivers. TEL 0808 808 7777. Website: www.carersuk.org
- Dementia Carers: a charity that provides advice to carers on practical care support. TEL: 0191 217 1323 Website: www.dementiacare.org.uk
- IAPT (improving access to psychological therapies). General Website: http://www.iapt.nhs.uk
- You could contact your local Community Mental Health Team. General number for advice: 0300 5000 927 Monday – Friday 10am-2pm.
- You could contact your GP for support

Appendix G: Distress Protocol

This protocol was constructed to handle the likelihood that a participant might experience distress during or after their interview. If a participant reports that they are feeling distressed or their behaviour suggests that they are distressed (e.g. tearfulness, difficulty speaking, shaking or restlessness) then the researcher will carry out the following procedure:

Stage-1

- Stop the interview
- Offer assistance
- Ask if they would like to take a break to compose themselves
- Appraise their mental-state using the following prompts:

Can you please tell me what you are thinking right now?
How are you feeling at this moment?
Do you think you can continue with your plans for the day?

- Ask participants if they would like to continue with or stop the interview

Review

- If the participants feel that they can continue then resume interview
- If unable to continue with the interview, go to stage 2.

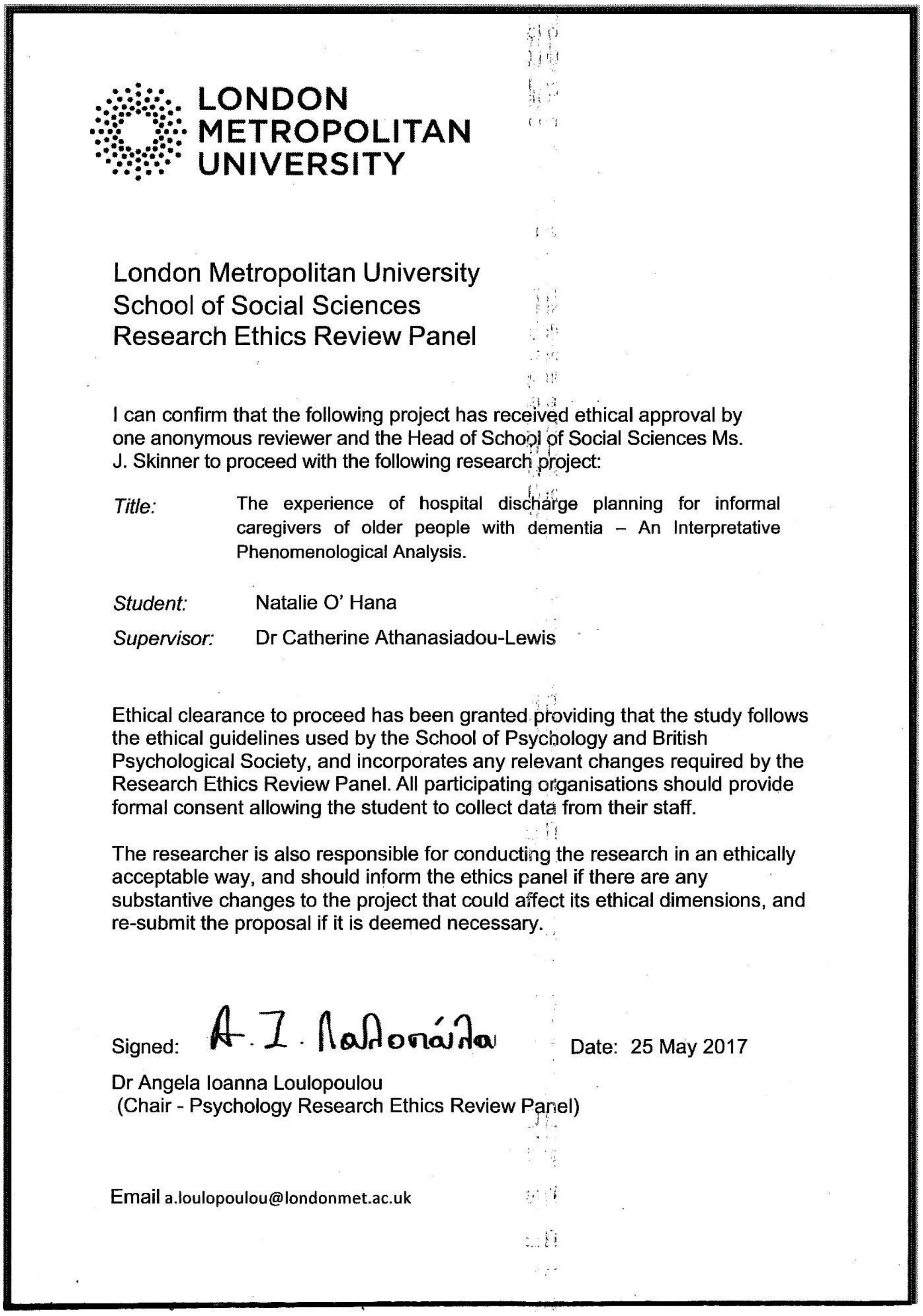
Stage-2

- Discontinue the interview
- Encourage them to call their general practitioner or one of the support services detailed in the briefing sheet
- With participants consent offer to call their GP
- With participants consent offer to call a member of their family or friend for support

Follow up

- Make a courtesy call (if they consent)
- Encourage participants to call if their distress intensifies following the interview

Appendix H: Ethical Certificate from LMU



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London Metropolitan University
School of Social Sciences
Research Ethics Review Panel

I can confirm that the following project has received ethical approval by one anonymous reviewer and the Head of School of Social Sciences Ms. J. Skinner to proceed with the following research project:

Title:	The experience of hospital discharge planning for informal caregivers of older people with dementia – An Interpretative Phenomenological Analysis.
Student:	Natalie O' Hana
Supervisor:	Dr Catherine Athanasiadou-Lewis

Ethical clearance to proceed has been granted providing that the study follows the ethical guidelines used by the School of Psychology and British Psychological Society, and incorporates any relevant changes required by the Research Ethics Review Panel. All participating organisations should provide formal consent allowing the student to collect data from their staff.

The researcher is also responsible for conducting the research in an ethically acceptable way, and should inform the ethics panel if there are any substantive changes to the project that could affect its ethical dimensions, and re-submit the proposal if it is deemed necessary.

Signed: A. I. Λουλοπούλου Date: 25 May 2017

Dr Angela Ioanna Loulopoulou
(Chair - Psychology Research Ethics Review Panel)

Email a.loulopoulou@londonmet.ac.uk

Appendix I: Jacquie’s (Pseudonym) Annotated Verbatim Transcript

This is a segment from a participant’s (Jacquie) annotated transcript.

Exploratory comments were noted on the right-hand side of the transcript.

Transcript Notation Key

[...] Omitted information to preserve confidentiality

[ ] Explanatory information added by the interviewer

Emergent Themes	Original Transcript	Exploratory Comments
	Interviewer: Can you please tell me the reason for which your mother was admitted to hospital **Jacquie:** She fell, she fell in the middle of the night on her way to the toilet and she fractured her hip	Contextualising?
	Interviewer: And how did you respond to your mother’s fall? **Jacquie:** It was one o’clock in the morning and I didn’t know what was going on. I just woke up from the impact of her falling and ahhhh she couldn’t move and I didn’t know whether to move her so I called 999 but they took about ahhh I think they came around four o’clock and ahh so we went to the to the emergency and she was operated on. I mean it’s just amazing, the next day ten o’clock in the morning, I went with her to do	Notes the time to highlight the sense of uncertainty, ambiguity, confusion she experienced? Startled. ‘Impact’ creates a sense of loud noise, potentially anxiety provoking. Mum as stuck, immobile Not knowing as anxiety provoking? Worry and fear about making things worse by moving mum? Use of ‘but’ to emphasise dissatisfaction Notes the time to indicate she was irritated and frustrated with LAS for taking their time? ‘We’ – they went together, shared ordeal Mum as a passive recipient Amazing? referring to the speed in which things happened? it was overwhelming? Accompanying mum to her operation, change from ‘we’ to ‘I’ – maybe in relation to anaesthesia, mum faced this

	anaesthetic to operate on and she was there for one hour and I was just observing her and they did epidural and she was about one and a half hours in there in the operation. At that time the doctor said you better go home because I was still from one o'clock in the morning, I quickly changed before the ambulance came but I was still so ya I came home and then went back [to hospital] and then they took her to intensive care unit	experience alone. Sense of role reversal like a mother accompanying her child. 'One hour' - a period of time which she experienced as distressing? Use of 'just' to highlight her sense of helplessness? Shift in caregiving mode from active to passive? Repeat of duration of operation Did she feel guilty about leaving mum alone in H and therefore highlights that it was the doctor's idea to return home? She was feeling fatigued and dishevelled Refreshed self and went immediately back to H since she was very worried about her mum? Contextualising her experience?
	Interviewer: What went through your mind when your mum was admitted to hospital? Do you remember what you were thinking at the time? **Jacquie:** I was very very very very much overwhelmed because ahh it was a horrible experience for me you know to see my mum like that and I had no idea if if she had broken something and what was happening, I was in a panic state you know because amm she is quite elderly and quite fragile but was very much independent you know like walking by herself, putting her clothes on and we had a good quality of life, like we went to the casino, she likes to go there, we went out for lunch, I took her to the park you know, because I thought to myself she has been such a wonderful mum and	Repetition to emphasize the magnitude of her shock, fear, anxiety, sense of helplessness? Horrible experience to see mum in a vulnerable, dependent, dishevelled state? this contrasts with how she perceived her mum so far i.e. independent Not knowing as anxiety provoking Poor sense of control? Panic Uses present tense and then moves on to past tense – suggests that she was fragile prior to admission but this did not affect her ability to function independently. use of 'very much' to contrast with how mum appeared to her following fall: mum's autonomous self was replaced by a dependent self? Loss of quality of relationship. Loss of the ability to reciprocate? Repetition of 'we' suggests loss of the ability to share experiences they jointly enjoyed. Role reversal She had a plan where she was going to help her mum have a nice time and now she is no longer able to follow up on this plan - loss of imagined future The roles mum espoused in family life Recognition of mum's contribution to the family. Own need to reciprocate

	grandmother and wife that she needs to have a nice time especially after my father's death so ya so but this has happened and it's just downhill from then on Unfortunately when we were amm when we were done with [the hospital] ahhh after 14 days they said she can go to […] which is a rehab centre so we went there but I was really really frightened you know about going to […] because I had no experience of you know what it is, what's a rehab centre, and I didn't want her to go to one of these, like if its dirty or like very old so I was very upset because I had no idea where we were going	A sense of loss triggers memories of past loss? 'This' - a life changing experience Downhill - loss of control, no stopping the deterioration, how has that affected her mood? 'Unfortunately'- unhappy with mum's discharge to rehab 'Done' - done and dusted. Suggests that H experience was a negative one, wanted to go back home? 'We' – shared experience, ordeal 'They said' – discharge planners make the decisions, they have the power, she didn't participate in this decision-making process? Jacquie vs the system rather than a member of staff? 'We went' – sharing this experience with mum. Accompanying mum to rehab, complying with H decision to discharge due to no choice? Repetition of 'really' to highlight that this was an anxiety provoking experience. Wasn't provided with sufficient information about discharge destination? Reluctant to go to rehab but didn't protest against it? 'I didn't want her' – she didn't want mum to go due to her own fear 'Very upset' - angry, stressed? Lack of clarifications about discharge destination, in the dark
	Interviewer: Can you please describe for me your involvement in your mother's hospital discharge planning. For example, how did you find out about your mother's discharge date and medication? **Jacquie:** There was no date, there was no date, they were looking for ahh I was a little bit ahh because this is my first experience being in the hospital amm I was very much puzzled to tell you the truth, because one of the doctors said ohh she is going to be moved to […] [rehab centre] and ahh then nothing happened for like three four days after so I had no idea if she was	Repetition suggesting anger/frustration with lack of planning or for not being informed in advance? Difficulty articulating criticism? Wasn't aware of the decision to discharge mum to rehab until the last minute, was not included in the decision-making process? Confused? Poor sense of control, anxiety provoking, ambiguous situation, in the dark about discharge plans? what stopped her from asking what's happening?

	116 going to be discharged or if 117 she was going to rehab all 118 of a sudden in the morning 119 at around 11 o’clock or 120 maybe earlier one of the 121 ahh nurses came and she 122 said ohh you’re going to go 123 to […] [rehab centre] you 124 know and I did not know 125 what to do because I I 126 wasn’t prepared you know 127 and ahh so I said ok let me 128 go get some clothes for my 129 mum but I didn’t have time 130 to go get some clothes for 131 my mum and then I had to 132 pack all the things that I 133 brought for her and left it in 134 my own car which was 135 parked near the hospital 136 and I left my car and then 137 they said around one 138 o’clock ambulance is 139 coming to take you to […] 140 of course they didn’t come 141 on time they were like 142 about three four so we sat 143 together and then they kind 144 of put her on a stretcher and 145 took her to, we went to [...] 146 One of my girlfriends she 147 was supposed to come and 148 see us in […] hospital to see 149 my mum. I told her listen, 150 we are going to be at this 151 place [referring to the rehab 152 centre] so instead of 153 coming to the hospital go to 154 […] I was in the ambulance 155 she called me and she said 156 well I am here [referring to 157 the rehab centre] this is 158 such a lovely place, my 159 heart was going you know, 160 where are we going, where	Unexpected news, startled? Contextualising her experience Imposed discharge, ad hoc discharge, lack of planning, being evicted Poor sense of control, confused, overwhelmed, incapacitated by stress, feeling stuck? Caught unprepared Requesting permission – indicative of poor sense of control over caregiving situation? Sense of being rushed, pressure to exit the H Lack of planning hindering caregiving Role reversal Feeling rushed Feeling rushed ‘They said’ – they hold the power since they have the information about what is going to happen and they make the decisions about discharge. ‘They’ are dictating the process. Critical, complaining, dissatisfaction, irritated, left to wait for a few hours ‘We’ – a shared ordeal, they are in this together. Mum as a passive recipient – treated as if she was an object No time to have a lengthy conversation and thus alerts friend to listen Change in plans as a result of imposed and unexpected discharge Reassuring Palpitations Fear of the unknown

	are we going, so in any case we went to ahh she called me and she said ohh she has a private room and its really clean and lovely here, where are you, are you coming, I said yes, we are on our way we will be there in a, so it was a very nice, a very welcoming place, they were quite attentive and she had her own room and of course another novelty, another new atmosphere for her, new nurses, new place for her	Reassuring Rehab as a welcoming place vs H which was not? Worry about change in mum's caregiving environment as it affects her dementia related needs? 'For her' – suggests that the worry is about mum's adjustment difficulties to a new setting and not caregiver's adjustment, though mum's needs may impact on caregiver's wellbeing.
	Interviewer: And how did you experience these differences? **Jacquie:** I was very worried and I was puzzled because you know of her reaction, how is she going to be you know in a new environment, there [referring to the hospital] she was with three other patients and here [referring to the rehab centre] she is all alone and ahh you know, so I felt even more obliged to be with her coming earlier and leaving later so that she can feel at home and ya so the thing is that I believe that rehab is very good but really to get her home is the best atmosphere for her and for people	Worried and anxious – suggests rumination about mum's future presentation in rehab. Dementia related needs as a cause for concern when changing caregiving Environments. The worry is about mum but the caregiver is experiencing it. Making comparisons between the H and the rehab environments. Hospital as a crowded place Worry about mum feeling lonely, isolated? Caregiver's own need to reciprocate and protect as a primary drive for caregiving Keeping mum company = shift in caregiving mode. Trying to gain control over mum's experience/protect her from isolation by extending duration of visits? Does caregiver represent home? What is the difference between the atmosphere at home and the atmosphere in rehab? No place like home Home affords caregiver control over caregiving situation? 'People' – including self

Appendix J: Jacquie's (Pseudonym) Table of Developing Emergent Themes

This is a segment from Jacquie's Table of developing emergent themes.

Emergent themes were noted on the left-hand side of the transcript.

Emergent Themes	Original Transcript	Exploratory Comments
	Interviewer: Can you please tell me the reason for which your mother was admitted to hospital **Jacquie:** She fell, she fell in the middle of the night on her way to the toilet and she fractured her hip	Contextualising?
Confused Startled Mum as immobile Uncertainty/Worry Frustration Escorting Mum as a passive recipient Escorting Keeping a watchful eye	**Interviewer:** And how did you respond to your mother's fall? **Jacquie:** It was one o'clock in the morning and I didn't know what was going on. I just woke up from the impact of her falling and ahhhh she couldn't move and I didn't know whether to move her so I called 999 but they took about ahhh I think they came around four o'clock and ahh so we went to the to the emergency and she was operated on. I mean it's just amazing, the next day ten o'clock in the morning, I went with her to do anaesthetic to operate on and she was there for one hour and I was just observing her and they did epidural and she was about one and a half	Notes the time to highlight the sense of uncertainty, ambiguity, confusion she experienced? Startled. 'Impact' creates a sense of loud noise, potentially anxiety provoking. Mum as stuck, immobile Not knowing as anxiety provoking? Worry and fear about making things worse by moving mum? Use of 'but' to emphasise dissatisfaction Notes the time to indicate she was irritated and frustrated with LAS for taking their time? 'We' – they went together, shared ordeal Mum as a passive recipient Amazing? referring to the speed in which things happened? it was overwhelming? Accompanying mum to her operation, change from 'we' to 'I' – maybe in relation to anaesthesia, mum faced this experience alone. Sense of role reversal like a mother accompanying her child. 'One hour' - a period of time which she experienced as distressing? Use of 'just' to highlight her sense of helplessness?

Fatigued & dishevelled Mum as a passive recipient	hours in there in the operation. At that time the doctor said you better go home because I was still from one o'clock in the morning, I quickly changed before the ambulance came but I was still so ya I came home and then went back [to hospital] and then they took her to intensive care unit	Shift in caregiving mode from active to passive? Repeat of duration of operation Did she feel guilty about leaving mum alone in H and therefore highlights that it was the doctor's idea to return home? She was feeling fatigued and dishevelled Refreshed self and went immediately back to H since she was very worried about her mum? Contextualising her experience?
Overwhelmed Altered perception of mum Uncertainty/Worry Panic Self-justifying Change in perception of mum Loss of quality of life Loss of quality of relationship Role reversal Loss of imagined future Desire to reciprocate A life changing experience Desolation	**Interviewer:** What went through your mind when your mum was admitted to hospital? Do you remember what you were thinking at the time? **Jacquie:** I was very very very very much overwhelmed because ahh it was a horrible experience for me you know to see my mum like that and I had no idea if if she had broken something and what was happening, I was in a panic state you know because amm she is quite elderly and quite fragile but was very much independent you know like walking by herself, putting her clothes on and we had a good quality of life, like we went to the casino, she likes to go there, we went out for lunch, I took her to the park you know, because I thought to myself she has been such a wonderful mum and grandmother and wife that she needs to have a nice time especially after my father's death so ya so but this has happened and it's just	Repetition to emphasize the magnitude of her shock, fear, anxiety, sense of helplessness? Horrible experience to see mum in a vulnerable, dependent, dishevelled state? this contrasts with how she perceived her mum so far i.e. independent Not knowing as anxiety provoking Poor sense of control? Panic Uses present tense and then moves on to past tense – suggests that she was fragile prior to admission but this did not affect her ability to function independently. use of 'very much' to contrast with how mum appeared to her following fall: mum's autonomous self was replaced by a dependent self? Loss of quality of relationship. Loss of the ability to reciprocate? Repetition of 'we' suggests loss of the ability to share experiences they jointly enjoyed. Role reversal She had a plan where she was going to help her mum have a nice time and now she is no longer able to follow up on this plan - loss of imagined future The roles mum espoused in family life Recognition of mum's contribution to the family. Own need to reciprocate A sense of loss triggers memories of past loss? 'This' - a life changing experience Downhill - loss of control, no stopping the deterioration, how has that affected her mood? 'Unfortunately'- unhappy with mum's discharge to rehab

Unhappy Done and dusted Imposed discharge destination Complying Anxious Lack of clarification about discharge destination Worry Distressed Lack of communication about discharge destination	77 downhill from then on 78 Unfortunately when we were 79 amm when we were done 80 with [the hospital] ahhh after 81 14 days they said she can go 82 to […] which is a rehab 83 centre so we went there but I 84 was really really frightened 85 you know about going to 86 […] because I had no 87 experience of you know 88 what it is, what's a rehab 89 centre, and I didn't want her 90 to go to one of these, like if 91 its dirty or like very old so I 92 was very upset because I had 93 no idea where we were going	'Done' - done and dusted. Suggests that H experience was a negative one, wanted to go back home? 'We' – shared experience, ordeal 'They said' – discharge planners make the decisions, they have the power, she didn't participate in this decision-making process? Jacquie vs the system rather than a member of staff? 'We went' – sharing this experience with mum. Accompanying mum to rehab, complying with H decision to discharge due to no choice? Repetition of 'really' to highlight that this was an anxiety provoking experience. Wasn't provided with sufficient information about discharge destination? Reluctant to go to rehab but didn't protest against it? 'I didn't want her' – she didn't want mum to go due to her own fear 'Very upset' - angry, stressed? Lack of clarifications about discharge destination, in the dark
Inadequate sharing of information Lack of experience with the discharge process Confused Excluded from decision making processes Miscommunication Confusion Shock	94 **Interviewer:** Can you 95 please describe for me your 96 involvement in your 97 mother's hospital discharge 98 planning. For example, how 99 did you find out about your 100 mother's discharge date 101 and medication? 102 **Jacquie:** There was no 103 date, there was no date, 104 they were looking for ahh I 105 was a little bit ahh because 106 this is my first experience 107 being in the hospital amm I 108 was very much puzzled to 109 tell you the truth, because 110 one of the doctors said ohh 111 she is going to be moved to 112 […] [rehab centre] and ahh 113 then nothing happened for 114 like three four days after so 115 I had no idea if she was 116 going to be discharged or if 117 she was going to rehab all 118 of a sudden in the morning 119 at around 11 o'clock or	Repetition suggesting anger/frustration with lack of planning or for not being informed in advance? Difficulty articulating criticism? Wasn't aware of the decision to discharge mum to rehab until the last minute, was not included in the decision-making process? Confused? Poor sense of control, anxiety provoking, ambiguous situation, in the dark about discharge plans? what stopped her from asking what's happening? Unexpected news, startled? Contextualising her experience

	120 maybe earlier one of the	Imposed discharge, ad hoc discharge, lack of planning, being evicted
	121 ahh nurses came and she	
Ad-hoc discharge	122 said ohh you're going to go	Poor sense of control, confused, overwhelmed, incapacitated by stress, feeling stuck?
	123 to […] [rehab centre] you	Caught unprepared
	124 know and I did not know	Requesting permission – indicative of poor sense of control over caregiving situation?
Distress as incapacitating	125 what to do because I I	
	126 wasn't prepared you know	Sense of being rushed, pressure to exit the H
Poor sense of control	127 and ahh so I said ok let me	Lack of planning hindering caregiving
	128 go get some clothes for my	
	129 mum but I didn't have time	Role reversal
	130 to go get some clothes for	Feeling rushed
Feeling rushed	131 my mum and then I had to	
	132 pack all the things that I	Feeling rushed
Role reversal	133 brought for her and left it in	
	134 my own car which was	'They said' – they hold the power since they have the information about what is going to happen and they make the decisions about discharge. 'They' are dictating the process.
Feeling rushed	135 parked near the hospital	
	136 and I left my car and then	
	137 they said around one	Critical, complaining, dissatisfaction, irritated, left to wait for a few hours
	138 o'clock ambulance is	
	139 coming to take you to […]	
	140 of course they didn't come	'We' – a shared ordeal, they are in this together.
	141 on time they were like	Mum as a passive recipient – treated as if she was an object
Anger	142 about three four so we sat	
	143 together and then they kind	
	144 of put her on a stretcher and	
Keeping mum company	145 took her to, we went to [...]	No time to have a lengthy conversation and thus alerts friend to listen
	146 One of my girlfriends she	
Mum as a passive recipient	147 was supposed to come and	Change in plans as a result of imposed and unexpected discharge
	148 see us in […] hospital to see	
	149 my mum. I told her listen,	
	150 we are going to be at this	
	151 place [referring to the rehab	
	152 centre] so instead of	
Feeling rushed	153 coming to the hospital go to	Reassuring
	154 […] I was in the ambulance	
	155 she called me and she said	Palpitations
	156 well I am here [referring to	Fear of the unknown
	157 the rehab centre] this is	
	158 such a lovely place, my	Reassuring
	159 heart was going you know,	
	160 where are we going, where	
Supportive friend	161 are we going, so in any case	
Anxiety	162 we went to ahh she called	
	163 me and she said ohh she has	

Supportive friend Worry	a private room and its really clean and lovely here, where are you, are you coming, I said yes, we are on our way we will be there in a, so it was a very nice, a very welcoming place, they were quite attentive and she had her own room and of course another novelty, another new atmosphere for her, new nurses, new place for her	Rehab as a welcoming place vs H which was not? Worry about change in mum's caregiving environment as it affects her dementia related needs? 'For her' – suggests that the worry is about mum's adjustment difficulties to a new setting and not caregiver's adjustment, though mum's needs may impact on caregiver's wellbeing.
Worried & anxious Dementia related needs as unpredictable Hospital vs rehab Worry An urge to reciprocate / protect Extending duration of visits as gaining control over mum's experience Rehab vs home	**Interviewer:** And how did you experience these differences? **Jacquie:** I was very worried and I was puzzled because you know of her reaction, how is she going to be you know in a new environment, there [referring to the hospital] she was with three other patients and here [referring to the rehab centre] she is all alone and ahh you know, so I felt even more obliged to be with her coming earlier and leaving later so that she can feel at home and ya so the thing is that I believe that rehab is very good but really to get her home is the best atmosphere for her and for people	Worried and anxious – suggests rumination about mum's future presentation in rehab. Dementia related needs as a cause for concern when changing caregiving Environments. The worry is about mum but the caregiver is experiencing it. Making comparisons between the H and the rehab environments. Hospital as a crowded place Worry about mum feeling lonely, isolated? Caregiver's own need to reciprocate and protect as a primary drive for caregiving Keeping mum company = shift in caregiving mode. Trying to gain control over mum's experience/protect her from isolation by extending duration of visits? Does caregiver represent home? What is the difference between the atmosphere at home and the atmosphere in rehab? No place like home Home affords caregiver control over caregiving situation? 'People' – including self

Appendix K

Jacquie's (Pseudonym) Table of Emergent Themes Nested Within Super-Ordinate Themes

Super-Ordinate Themes	**Emergent Themes**	**Page/Line**	**Key Words**
Psychological State on Admission			
	Confused	1/13-14	I didn't know what was going on
	Startled	1/14-16	I just woke up from the impact
	Uncertainty/Worry	1/16-18	I didn't know whether to move her
	Frustration	1/19-21	Called 999 but they took about
	Overwhelmed	2/50-52	Very much overwhelmed
	Uncertainty/Worry	2/55-58	I had no idea if she had broken something
	Panic	2/58-59	I was in a panic state
Psychological State During Discharge Planning			
	Desolation	3/76-77	It's just downhill from then
	Unhappy	3/78-79	Unfortunately, when we were…done
	Anxious	3/84-85	I was really really frightened you know
	Worry	3/89-91	If its dirty or like very old
	Distressed	3/91-92	I was very upset
	Confused	3/107-108	I was very much puzzled
	Confusion	4/115-117	I had no idea if she was going to be discharged
	Shock	4/117-118	All of a sudden
	Distress as incapacitating	4/124-126	I didn't know what to do
	Poor sense of control	4/127-129	I said ok let me go get some clothes
	Feeling rushed	4/129-131	I didn't have time to go get some clothes
	Feeling rushed	4/132-136	And left it in my own car…and I left my car
	Anger/Frustration	4/140-143	Of course they didn't come on time
	Feeling rushed	4/149-151	I told her listen
	Anxiety	5/158-161	My heart was going…where are we going
	Worry	5/172-176	Another new atmosphere for her…new nurses
	Worried & anxious	5/180-181	I was very worried and I was puzzled
	Worry	5/188-190	Here…she is all alone
	Worry	206-212	She is in a totally new environment
	Feeling pressured	7/265	I felt very rushed
	Very anxious	7/266-267	I felt very anxious
	Poor sense of control	7/268-269	What was happening
	Humiliated	7/271-272	They wanted to get rid of us now
	Worry	11/453-454	I am not going to be there at night
	Anxiety	12/473-474	Trying for me also to be calm
	Feeling constrained	13/518-519	But what to do

Impact on Everyday Life			
	Life on hold	12/486-489	I had nothing, I had no life
	Socialising restricted to the hospital environment	12/489-492	Friends I wanted to see…came to the hospital
	Cancelled work	12/492-495	Clients I cancelled
	Giving up valued activities	12/499-507	I did sculling…I did spinning
	Caregiving at the cost of filial relationships	13/532-536	My grandson…I only seen him three times
	Caregiving at the cost of filial relationships	13/536-538	I haven't seen my daughter
Hospital Care: A Dehumanising Experience			
	Lack of personal control	10/392-394	She doesn't want to have her breakfast now
	Patients treated like numbers	10/389-390	It's like you're a number
	Lack of humanity	10/398-402	Unfortunately…humanity…goes for a lot
	Mechanical treatment of patients	10/402-403	It becomes very mechanical
A Critical Focus on Nurses			
	Sanitation as lacking	7/292-293	I don't think the nurses are cautious enough
	Requests go unnoticed	10/390-391	A lot of time I was there…I said please
	Needs go unmet	10/404-406	A lot of them don't want to do
	Nurses lack tolerance & patience	11/432-436	Job that needs a lot of tolerance
	Needs go unmet	11/439-442	Don't want to wash somebody's bottom
	Needs go unmet	11/445-448	You are not doing your job
Communication with Discharge Planners as Problematic			
	Lack of clarification about discharge destination	3/86-89	I had no experience of…what's a rehab cantre
	Lack of communication about discharge destination	3/92-93	I had no idea where we were going
	Inadequate sharing of information	3/102-103	There was no date, there was no date
	Excluded from the decision-making process	3/110-111	Ohh she is going to be moved
	Miscommunication	3/110-114	Doctors said ohh she is going to be moved…then nothing happened
	Ad-hoc discharge	4/120-123	Ohh you're going
	Lack of communication about discharge destination	7/267-270	I didn't know where we were going
	Imposed discharge	7/271-272	They wanted to get rid of us now
	Hindering caregiving	7/280-282	Like saying…your leaving tomorrow bring clothes
	Insensitive style of communication	8/305-308	If for example your mum goes into a comma
	Anxiety provoking questions	8/309-310	It's just the last thing I wanted to hear
	The doctor's question inflicting pain	8/310-311	It was very very panful
	Lack of clarification	8/314-317	I wasn't aware of this process
	Ambiguous communication	8/320-322	I mean are they asking this
	Not understanding as anxiety provoking	8/326-330	When you don't understand…accompanied with anxiety
	Ambiguous communication	8/330-331	Is she going to die tomorrow
	Insensitive style of communication	8/332-334	Need to be very cautiously introduced

	Insensitive & ambiguous style of communication	8/335-336	You need to be asked to sit and get an explanation
	Unclear communication hinders understanding	9/338-339	Doesn't really mean anything
	Lack of information	9/399-341	What are the options about resuscitation
	Lack of clarifications	9/341-345	What does it really mean
	Unclear communication hindering decision-making	9/345-348	So you can make an informed decision
	Insensitive style of communication	9/348-351	It isn't just pass on, you don't call
	Communication with nurses as a mixed bag	9/368-373	Some…attentive and some…not at all
Negative Aspects of the Hospital Environment			
	Hospital routine insensitive to dementia patients	6/209-214	She has no understanding why she needs to wake up at six
	Lack of personal control	6/214	She wants to sleep
	Different environments different presentations	6/220-221	She is like, she is vey very different
	Crowded	7/286-287	There are so many patients there
	Hospital as a difficult place	7/287-288	Such a difficult place to
	A dangerous place	7/289	A dangerous place
	Full of germs	7/290	It's full of germs
	Risk of contracting infections	7/291	You can catch anything
	Hospital as a difficult place	10/384-385	It's a difficult place to be for everyone
	Isolating	13/520-523	It was nice…to have company
	Anxiety provoking	14/558-564	It's really frightening…a new environment
	Crowded & hectic	14/565-566	Being among so many other people
	Home vs hospital	14/566-570	I think it's much more calm
	Home vs hospital	14/569-570	I think she is happier at home
	Home vs hospital	14/571-574	She can sleep when she wants
	Home vs hospital	14/574-576	There is always someone here to take her to the toilet
Caregiver-Staff Relationship Dynamics			
	Imposed discharge destination	3/81-83	They said she can go to […] which is a rehab centre
	Complying	3/83	So we went
	Lack of control over caregiving situation	5-6/209-214	Why she needs to wake up at six
	Vigilant style of communication	10/373-377	I was very very cautious not to anger them
	Power imbalance	11/428-430	They have a lot of power…how to treat the patients
	Lack of openness	10/414-416	How can you say, to who do you say, that what you stupid shit
	Power imbalance	10/419-420	You can't, they have a lot of power
	Nurses as powerful	10/419-421	They have a lot of power to do anything
	Vigilant communication with nurses	11/443-445	Have to be very very gentle with the nurses
	Holding back complaints for fear of reprisal	11/445-446	Can't really say you are not doing your job
	Lack of openness for fear of reprisal	11/449-453	If they get upset what they do to your mum
	Lack of control over caregiving situation	11/453-454	I am not going to be there at night
	Vigilant style of communication with staff	11/455-456	Have to be very like please please

Caregiver-Care Recipient Relationship Dynamics			
	Altered perception of mum	2/52-55	A horrible experience…to see my mum like that
	Change in perception of mum	2/60-64	Was very much independent…like walking
	Loss of quality of life	2/64-65	We had a good quality of life
	Loss of quality of relationship	2/65-68	We went out for lunch, I took her to the park
	Role reversal	2/68	I took her to the park
	Loss of imagined future	2/69-70	I thought to myself
	Desire to reciprocate	3/73	Needs to have a nice time
	Life changing experience	3/75-77	This has happened and it's just downhill
	Role reversal	4/131-133	I had to pack all the things that I brought for her
	Dementia related needs as unpredictable	5/182-185	how is she going to be…in a new environment
	An urge to reciprocate/protect	5/191-192	I felt even more obliged to be with her
	Communication as problematic	6/229-230	She might not make much sense to me
	Communication as problematic	6/249-251	Sometimes she makes…sense
	Caregiving as an honourable deed	6-7/254-256	Honourable place…to be assistance to her
	Communication with mum as problematic	12/469-470	Trying to ahh just explain things to her
	Soothing mum as a struggle	12/470-473	Trying to calm her
Behavioural Strategies			
	Extending duration of visits as gaining control over mum's experience	5/192-194	To be with her coming earlier and leaving later so that she can feel at home
	Keeping tabs on mum's needs	9/365-368	To catch the night nurse to see
	Filling in the gaps in care	9/376-378	I did all the nursing stuff myself
	Relaying information about mum's needs	11/457-459	She is not incontinent
	Advocating on mum's behalf	10/391-397	I said please let her sleep she doesn't want
	Advocating on mum's behalf	11/459-461	Say if she has to go to the toilet
Cognitive Strategies			
	Denial/Rejection of dementia diagnosis	6/222-224	I don't really believe in dementia
	Rationalising	6/224-227	Because…each age…have…own world
	Denial as pacifying self	6/224-228	Her world makes very much sense for her
	Rationalising/Dementia labelling benefits doctors	6/233-235	Labels that are given…for the doctors
	Rationalising/Dementia labelling detrimental to patients	6/235-236	It's not very good for the patients
	Rationalising/Dementia labelling as transforming identity	6/237-238	Label them and then they identify
	Rationalising/Dementia labelling as transforming the self	6/243-245	Anybody…would become if labelled…that

	Rationalising/Dementia diagnosis as a sign of insanity	6/243-245	Even a sane person would become…that
	Denial/Rejection of dementia diagnosis	6/246-247	I don't look at my mum as she has dementia
	Denial as pacifying self	6/247-248	She is in her own world
	Rationalising	6/249-252	Sometimes…she doesn't make sense because she is elderly
	Rationalising poor discharge planning	7/285-287	Hospital, I can understand there are so many patients there
	Rationalising poor quality of care	10/380-384	Because ahh they are too busy
Social Support in Discharge			
	Supportive friend	4-5/155-158	This is such a lovely place
	Supportive friend	5/162-165	She has a private room and its really clean
	Friends elevate mood	13/520-523	Nice…to have company
	Supportive friends	13/523-524	Friends…were very very supportive
Focus on Self			
	Self-justifying	2/59-61	Because she is quite elderly and quite fragile
	Defensive	7/274-275	It's not that it is a luxurious place
	Self-protective	6/314-315	I didn't know, I wasn't aware
Life Post Discharge			
	Life on hold	12/497	I don't have a life now
	Engulfed by the caregiving role	12/498-499	I don't do anything, nothing
	Trapped in the caregiver's role	13/507-509	When I get to go out
	Own needs go unmet	13/507-509	Its only to do chores
	Life on hold	13/511-512	There is no life
	Life is difficult	13/528-529	It is very difficult
	Increase in caregiving burden	14/576-577	I don't leave her alone now…difficult
Discarded Themes			
	Mum as immobile	1/16-17	She couldn't move
	Escorting	1/22	We went to the emergency
	Mum as a passive	1/23-24	She was operated on
	Escorting	1/26-28	Went with her to do anaesthetic
	Keeping a watchful eye	2/30	I was just observing her
	Fatigued & dishevelled	2/36-40	I was still from one o'clock in the morning
	Mum as a passive recipient	2/42-43	Then they took her
	Done and dusted	3/79-81	When we were done with [the hospital] ahh after 14 days
	Lack of experience with the discharge process	3/105-107	This is my first experience being in the hospital
	Mum as a passive recipient	3/110-111	She is going to be moved
	Keeping mum company	4/142-143	We sat together
	Mum as a passive recipient	4/144-145	Put her on a stretcher and took her
	Hospital vs rehab	5/185-190	There…she was with three other patients and here
	Rehab vs home	5/196-199	Rehab is very good but really to get her home
	Mum as a passive recipient	6/213-214	Give her the pills
	Home affords personal control	6/215-216	She can sleep until ten o'clock
	Home affords privacy	6/216-217	She is in her own room

	Home affords personal control	6/218-219	Watching the programme that she wants
	Rehab vs hospital	7/282-285	Rehab and hospital are totally different
	Mum as a vulnerable patient	11/459-461	Say if she has to go to the toilet
	Keeping company	12/466-467	I was just sitting by her side
	Explaining	12/467-469	Telling her that your' going somewhere
	Keeping company	12/466-467	I was just sitting by her side
	Explaining	12/467-469	Telling her that your' going

Appendix L: Master Table of Themes for the Group

Super-Ordinate Themes	Sub-Themes	Relevant Excerpts
The Negative Aspects of the Discharge Planning Process	Communication with Discharge Planners as Problematic	*"No one wanted to sit down and talk to us exactly what was wrong with my mum" (Brian 1:17-20)*
	"We Need the Bed"	*"Being told that there is nothing that they can do for your mum and they are sending your mum home" (Brian 4:224-227)*
	"I Had Nothing I Had No Life"	*"I did spinning and went to the gym…but I haven't been able to do anything" (Jacquie 13:502-507)*
Focus on Relationships	Reconstructed Relations in the Caregiver-Care Recipient Dyad	*"I've gone from somebody who just…got his shopping for him to suddenly being in control of him"* (Debbie *13:739-744)*
	"They Seemed to Be in Control": A Power Imbalance in the IDC-HDP Partnership	*"I am the consultant I make the decisions" (Brian 2:105-106)*
	Caregivers as Co-Workers	*"Everybody said you are one of us working" (Jacquie 9:364-365)*
Employing Coping Mechanisms to Counteract Taxing Experiences	Cognitive Strategies	*"Some of their organisational skills…were a bit lacking...but hey…nurses are not administration people" (Debbie 8:429-432)*
	Behavioural Strategies	*"As a carer you don't automatically get, you only get it if you scream and shout" (Robert 6:337-340)*
	Mobilising Social Support Systems	*"I rang up my ex-wife…I did break down and she went to me don't worry" (Brian 6:320-325)*

Appendix M: Tri-Borough RGF Panel Authorisation to Recruit Participants

From: Lambkin, Christopher: WCC <clambkin@westminster.gov.uk>
Sent: Tuesday, November 29, 2016 6:08 PM
To: natalie ohana
Subject: Thesis

Hi Natalie

There are no problems from the research ethics point of view, so it's really a case of waiting to hear back from the hospital teams.

Kind regards

Chris

Appendix N: Transcription Notation Key

[...] Omitted information to preserve confidentiality

[ ] Explanatory information added by the interviewer