

Using real stories to capture
informal carers' perceptions of
effective interprofessional
working

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USING REAL STORIES TO CAPTURE
INFORMAL CARERS' PERCEPTIONS OF
EFFECTIVE INTERPROFESSIONAL WORKING.

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Abstract

The aim of the study is to capture informal carers' perceptions of effective interprofessional working.

The theoretical background of this research is founded in the existing knowledge base of interprofessional working and the experiences of informal carers in their role of caring.

A naturalistic approach is used in this exploratory study which involves informal carers in the North of England. Stories are developed from two carers' experiences. These stories are subsequently used in interviews with eleven other carers. The interviews are audio-recorded and transcripts are produced.

Three subjective meanings of caring emerged from the analysis: 'It's all a battle', 'That's how it is' and 'I know how it should be'. Three main themes were identified, namely individual attributes, shared philosophy of care and information communication. A synergistic relationship exists between these three themes.

Implications from the findings are that professionals need to understand the realities of caring and actively listen to the patient and their families in order to communicate effectively with other professionals. Professionals need to be aware of the impact of their attitudes and behaviours on effective collaboration with other professionals.

The routinisation of care, whilst being an important component of efficiency, can override decisions based on need. There needs to be an awareness of how some rules and routines, whether local or organisational, can prevent the achievement of successful care outcomes.

There needs to be a cultural shift away from the notion of team to an increased focus on working with others to deliver effective care. To achieve the policy directive of providing person centred care, professionals need to be willing to open up their minds to others' perspectives. This may require a change in mind set and a change in practice

This study provides an alternative perspective of effective interprofessional working.

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1 Introduction

This study focuses on the experiences of care of a group of informal carers' and their perceptions of effective interprofessional working. The study was carried out in two stages. The first stage involved the development of two stories with two carers, Grace and Crystal. In the second stage, their stories were used in subsequent interviews with other carers.

1.1 Research Aim

To explore informal carers' perceptions of effective interprofessional working through their own experiences of caring.

1.2 Research questions

- How and to what extent does the interaction between professionals impact on the experience of caring for someone?
- What makes interprofessional working effective from the perspective of the carer?
- What are the implications of the findings for professional practice?

1.3 Outline of the chapter

In this chapter I provide the context and background to this study in relation to me as the researcher, my reason for the study and the context of interprofessional working in health and social care practice. The chapter also outlines the structure and focus of the rest of my thesis.

1.4 About the researcher

It is important to introduce myself and to identify the influencing factors that have shaped my approach to this study. The researcher as a person and the stance they take is important in any qualitative research (Finlay, 2006). To acknowledge and understand my position in this study, it helps me to see myself as having three 'selves'.

Self 1: As an experienced educator of health professionals of many years, I have introduced my undergraduate students to the complexities of health care delivery and explored the theories of teamwork on many occasions. I have facilitated my postgraduate students to reflect on their own clinical practice and to question the evidence around teamwork.

Self 2: I am also a Chartered Physiotherapist and as a registered health professional, have experience of clinical practice in both hospital and community settings. On reflection, my interactions with other professionals tended to happen more in hospitals and mainly occurred on specific occasions such as ward rounds, discharge planning meetings and written or telephone referrals. In the hospital settings I seemed to work less with families of patients than when I worked in the community setting.

Self 3: As a community physiotherapist I tended to work in isolation and rely on the patient and the family to inform me of other professional involvement. At that time, my records of the patients were stored in the physiotherapy department and were not accessed by other professionals. It was mainly for reasons of referral or discharge of the patient that I communicated with other professionals; this tended to be mostly the general practitioner (GP).

Two years prior to the start of my doctoral studies, my father became very ill and my mother who was the main carer for my father had a minor stroke which dramatically affected her balance and coordination and the ability to walk any great distance. From that point, as their only child, I became their main carer; my third 'self'. It was from then I attended GP and hospital appointments with one or both of them. It was during this period of time I noticed the behaviour of my fellow professionals. For the first time I was seeing my fellow professionals from a different perspective. I noticed the way they worked with other professionals was varied and inconsistent. There were times when the care received by my parents could not be faulted and our encounters with all the professionals involved were positive and there was excellent continuity of care. However there were occasions during consultations with me and my parents, when professionals made defamatory remarks regarding other professionals.

At this time, I was undertaking a review of one of my teaching modules on a Masters programme. My experiences of caring was making me question my preconceptions around the reality of interprofessional working. During a session, I asked my students

to reflect on the way they worked with other professionals. I shared my experiences of caring for my parents with the students and this led on to an interesting discussion around working with others. On reflection, this was probably the moment when I first started to develop my research questions. My doctoral journey had begun. Later on in Chapter 5, I discuss my experiences during my research with the assistance of Lewis Carroll's Alice (Carroll, 1993).

I had already had a discussion with a colleague about starting doctoral study around the topic of interprofessional working, however my ideas lacked focus. From that point, I began to explore the literature and talk to other colleagues and my research idea started to become more focussed. Becoming a carer and having experience of caring for someone else was probably most influential in developing my research questions.

My previous research has taken a more positivist approach and I have not had extensive past experience in qualitative research. I was experienced in teaching statistics and my thinking was constrained by a positivist standpoint. Yet my experiences of caring and the frustrations with the inconsistencies of care provided, alongside the lack of willingness on the part of some professionals to work collaboratively on occasions and my own feelings as a carer of disempowerment, gave me the desire to explore other carers' experiences.

From my then comfortable and positivist standpoint, I was aware this background and my experiences as a carer may inhibit discovery and undermine credibility of my research. However I soon came to understand the importance of acknowledging my position in the research and the nature of my intended research. The purpose of my research was to explore others' views; my experiences of caring provide an insider's viewpoint of this and will have had an influence on the outcomes (Bold, 2012). How I dealt with my subjective experiential viewpoint is discussed in further chapters.

1.5 Context and background

There is clear support in the literature for the importance of health and social professionals working effectively together. Organisational websites provide rhetoric of

their staff working together to provide quality care for the patients and their families. Policy suggests that effective collaboration between professionals is essential for optimum health and social care delivery (Department of Health (DH), 2000a, 2004a, 2005, 2010a).

Whilst there is a clear drive for interprofessional working, this is not happening consistently in practice from my own experiences of caring and the experiences of the carers in my study. For many reasons, professionals are not working together effectively, whether it is through their own volition or whether other factors prevent this from happening. Whatever the reasons, it is necessary to explore this further as literature around the experiences of service users and their carers' suggests links exist between effective interprofessional working and the quality of care provided.

In the past twenty years, competencies and capabilities for interprofessional teamworking have been identified in the literature (Kvarnström, 2008; Walsh et al., 2005; Schmitt, 2001; Barr, 1998). These studies have considered interprofessional working from the perspectives of professionals and from the analysis of policy and regulatory frameworks. Few have focussed on the reality of these competencies and capabilities in practice. Whilst Xyrichis and Ream (2007) argue a lack of conceptual clarity regarding a definition of effective interprofessional teamwork, the focus is around the team. Research has investigated interprofessional working in specific areas such as palliative care, mental health, stroke rehabilitation, and critical care.

Following their realist synthesis of interprofessional teamworking evidence, Sims et al. (2015b) concluded there is a lack of evidence of the outcome of interprofessional teamworking. Where research identified outcomes, these focused on the impact on professionals or the team as a whole. Sims et al. (2015b) found few studies considered outcomes from the perspectives of patients or their families.

The notion of team and teamworking is apparent in most literature around interprofessional collaboration and research has focussed on factors contributing to the effectiveness of teams. Interestingly in reality, many health and social care professionals do not see themselves as members of interprofessional teams. They work with other professionals on different occasions in different types of professional activity; an activity termed knotworking by Reeves and Lewin (2004).

The question of the visibility of interprofessional teamwork has challenged researchers and more recent studies highlight this in their findings (Hewitt et al., 2015; Goodman et al., 2011a). The majority of research has focussed on factors and processes influencing teamwork and I suggest there is a need to rethink the research questions. Studies investigating the experiences of those in receipt of care and the impact of those experiences on care outcomes have limited coverage. Even fewer studies have investigated the perceptions of informal carers on care outcomes.

My study provides insight into the experiences of caring of a group of informal carers. Their stories capture their encounters with a range of health and social care professionals. A conceptual framework for effective interprofessional working was then developed from the carers' perspective.

Ethical approval for my study was granted from Manchester Metropolitan University.

1.6 Methods of inquiry used

In this study, I focussed on the experiences of caring and the encounters of carers with health and social care professionals. Interpretations of those experiences were used to develop a conceptual framework for interprofessional working from the carers' perspective.

I chose an interpretative paradigm as I was exploring carers' perceptions through their experiences. I chose to use a narrative approach (Bold, 2012). Instead of carrying out interviews using the standard format, I used stories in the interviews to elicit the carers own narratives (Gubrium and Holstein, 2009).

In the first stage of my fieldwork, two stories, Grace and Crystal, were developed by two carers, prior to the interview stage. The detail of how I developed these stories with carers and used of them in the interviews can be found in (Wright et al., 2014).

Eleven volunteer carers were recruited to take part and were interviewed in the second stage of my field work. There were ten female carers and one male carer. The male carer was interviewed alongside his wife. Recruitment of participants and the profile of each carer is covered later in Chapter 3.

1.7 The Structure of my thesis

Whilst I fully acknowledge the subjective position of myself in my research, I have not found it easy to present myself within the text and engage more explicitly with the literature and findings. Initially from my comfortable positivist research background, I was completely hidden. Whilst initially content with my formal and academic writing style, I realised with gentle prompting from my supervisors, my writing was dry and flat. I have attempted to present my own thinking within the text throughout the thesis and for parts of this thesis I have adopted a more narrative style and written in a personal voice.

Chapter 2 presents a review of literature pertinent to the research questions and to the stories of the carers. It is divided into two main sections. As my main overall focus is to have a better understanding of interprofessional working, I chose to start with this topic in my review. The first section focusses on the literature around interprofessional working and explores influencing factors, such as policy drivers, professional practice in health and social care, the role and influence of education and evaluation of interprofessional working. The second section focusses on informal carers, and their role as expressed by policy, their experiences of caring and their perspectives of effective interprofessional working.

In Chapter 3, I provide the theoretical perspective of the methodology and the rationale behind the chosen design of the research process. I explore the use of stories and describe the method of inquiry developed to capture the stories of other carers more effectively than using a standard interview format using the work of Gubrium and Holstein (2009) and other authors. Chapter 4 presents my findings and the discussion in relation to my findings, supporting theories and current research. The strengths and limitations of my study are explored in this chapter. The extent to which my research aim has been achieved is also considered. Chapter 5 provides a critical reflection of my research journey using the analogy of Lewis Carroll's Alice's adventures in wonderland (1993). Chapter 6 concludes my thesis and provides a summary of my findings and the implications and new contributions to the existing body of knowledge.

1.8 Summary.

This study aims to gain a clearer understanding of effective interprofessional working through carers' experiences and based on their perceptions. Much previous research has utilised the perspectives of professionals and policy frameworks.

A naturalistic qualitative research design was chosen. To capture the views of informal carers, a group of eleven carers were interviewed. As Sir Robert Francis outlined in his report from the first inquiry at the Mid Staffordshire NHS Foundation Trust, it is the experiences of individuals that lie behind organisational statistics and action plans that matter and must not be forgotten when policies are being implemented (The Mid Staffordshire NHS Foundation Trust , 2010).

In the next chapter, I present a review of the pertinent literature surrounding interprofessional working and the increasing need to involve informal carers in policy making, service design and the evaluation of service provision.

2 Literature Review

Introduction

In this chapter, I aim to review the literature which is relevant to this study and to explore key themes and arguments through the literature. Throughout this review I have used the thoughts and conclusions of other authors to clarify my own thinking. The literature review is presented in two main sections. The first section concentrates on the literature surrounding interprofessional working and the second section focuses on the literature around informal carers and their experiences and perceptions of interprofessional working. The rationale for this sequencing of the literature is because my study is predominantly about effective interprofessional working through the experiences of informal carers.

The literature search I used included the use of relevant internet databases such as CINAHL, OVID, Scopus, Cochrane library and the use of journal alert mechanisms such as Zetoc. I used a range of search terms, separately and in combination, such as health; social care; interprofessional; multiprofessional; interdisciplinary; multidisciplinary; collaborative; integrated; working; teamwork; informal carers; caregiving; family caregivers; effective care; person centred care; stories; narrative; voice; vignette; patient experience; education; professionalism. I found Google Scholar a useful resource when literature was limited or difficult to access (Dochartaigh, 2012), particularly in the case of interdisciplinary studies (Haigh and Hardy, 2011).

There is a plethora of literature regarding interprofessional working and I have selected pertinent literature to support my understanding of a conceptual framework of interprofessional working. Informal carers provide an alternative perspective to this conceptual framework and the literature regarding informal carers and their role within caring is explored with this in mind.

Firstly the literature around interprofessional working is explored by highlighting political and professional drivers for interprofessional working. The complexity in defining interprofessional working and its many forms are then discussed. Key features of professional practice are discussed and an exploration of how professional practice

impacts on collaborative working across teams and across professional and organisational boundaries is provided. The influence of leadership and the role of interprofessional education are discussed next. Finally the notion of patient centred care and the difficulties posed in the evaluation of the effectiveness of interprofessional working are presented.

In the second part of the chapter, the literature around informal carers and their experiences of caring is explored. Informal caring as expressed by policy and the lack of carer perceptions of interprofessional working is explored.

Finally, a summary of the review is provided and the resulting implications for a conceptual framework for interprofessional working is discussed.

2.1 Interprofessional working

Over the past twenty years, interprofessional working has been seen as a vehicle for improving communication between professionals, increasing knowledge and respect for other professional roles which ultimately should improve service delivery (CIPW, 2007; D'Amour and Oandasan, 2005; Schmitt, 2001). There appears to be a consensus in policy documents and in reports following major failings in care such as the Mid Staffordshire Foundation NHS Trust public inquiry (2013) that the quality of health and social care services is dependent upon how effectively health and social care professionals work together. However despite this claim, there is limited evidence of the effectiveness of interprofessional working, particularly in terms of outcomes for service–users and their families.

Since the inception of the National Health Service (NHS), government policies have emphasised the need for professionals to work together more effectively (Kharicha et al., 2004). Yet despite these many policies, the need for interprofessional working is still a priority for health and social care provision. Before we explore the responses made by the professionals to these policies, a more detailed analysis of the different policies is required to explore the difference in rhetoric and reality.

2.1.1 Political drivers for interprofessional working

For forty years after the inception of the NHS, the funding for health and social care services was provided centrally and professionals, mainly the medical profession, had a high level of control in the delivery of care. Services were configured mainly at uni-professional levels with minimum interprofessional working (Pollard et al., 2005). For a long period of time, health professionals had autonomy in their clinical practice and in developing ways of working. Medicine was generally considered to be the dominant profession and to hold power over other professions (Miers, 2010).

However, this professional power was challenged in the 1980s when the Conservative government under the leadership of Margaret Thatcher, brought about large scale changes to the way all public services were funded and managed, under the auspices of the White Paper, 'Working for Patients' (DH, 1989a). The rationale to drive down costs and move to more efficient ways of working led to the introduction of the internal market. This competitive climate between different providers, alongside the purchaser-provider split, led to a move away from the professionals to greater managerial control of service delivery. It encouraged competitive rather than collaborative working. Some providers of services, such as general practitioners (GPs) found themselves as purchasers whilst NHS Trusts became self-governing organisations. Not all general practices became fund holders and this led to a two tier system and inequalities in service provision. Interestingly, the NHS and Community Care Act 1990 promised better working between the health and social services to improve the care for older people and promoted joint working (Pollard et al., 2005). Yet as a result of this new direction for health and social care, the changes in service delivery led to increased fragmentation of services which constrained the potential and opportunity for interprofessional working.

A change to a Labour government and a commitment to remove the internal market for health led to the publication of the White Paper, 'the New NHS: Modern, Dependable' (DH, 1997). This paper continued to emphasise patient centred care, however with the emphasis on patient need and equity across provision. It also indicated the need to break down organisational barriers created by the internal market. The concept of clinical governance was introduced and the expectation for

every NHS Trust to have quality at the core of its business. All professionals were expected to accept responsibility for delivering high standards of care in line with national clinical guidelines and evidence based practice advocated by the National Institute for Health and Clinical Excellence (NICE) (DH, 1998). It could be argued whilst ensuring patients receive the best care through professional adherence to clinical guidelines, professionals lost autonomy to make their own clinical decisions in certain clinical situations and their professional power ultimately decreased.

Since 2000, there has been an increasing emphasis in policy on the importance of interprofessional working. Effective collaboration was deemed as essential for optimum health and social care delivery (DH, 2012; 2010; 2005; 2004a; 2004b; 2000a; 2000b). Despite this political drive to improve quality and accountability, the situation was different in reality. In order to prevent further tragedies, the recommendations in the Kennedy Report of the Bristol Royal Infirmary inquiry in 2001 and the Victoria Climbié inquiry report by Lord Laming in 2003 created an urgency for more effective interprofessional working and the involvement of service users in developing health and social care policies (Lord Laming, 2003; Bristol Royal Infirmary Inquiry, 2001). These two inquiries highlighted major failings in communication between professionals and between organisations. Issues around confidentiality of patient and client information was raised as reasons for not sharing relevant information. The covering up of errors, failure in the duty of candour and a reluctance to challenge the practice of other professionals were all highlighted as underlying causes of the problems. Both these inquiries indicate the uni-professional focus by professionals and the lack of perceived need to work collaboratively. However, organisational management and leadership was found to be critical and the failure of senior managers to take responsibility for their front line staff were uncovered in both reports. These inquiries led to The Children's Act 2004 which advocated effective joint working between agencies and professionals in order to safeguard children.

The restriction by professional and organisational boundaries to effective joint working had been identified previously in the NHS Plan (DH, 2000a) and the White Paper outlined new roles for professionals and an agenda for the redesign of services; the modernisation agenda. One of the solutions in the NHS Plan towards the provision of

seamless care was the enhanced focus on interprofessional education. I explore the promotion of interprofessional education in detail further on in this chapter.

Four years later, the NHS Improvement Plan changed its emphasis from professionals working more collaboratively to professionals working differently (DH, 2004a). The introduction of more flexible roles such as advanced practitioners and specialist GPs was seen as the key to the improvements needed. The emergence of advanced practitioners roles and extended scope of practice for other health professionals presents a challenge to the position of power held by doctors as others were taking on roles traditionally believed to belong to doctors (Miers, 2010). The response of the different professionals to these changes varies depending on whether professional status has been increased such as advanced nurse practitioner roles or their professional boundary has been encroached, such as doctors. Further exploration is required of how this challenge to professional boundaries manifests into the willingness of professionals to work collaboratively and how this impacts on care delivery. This is pertinent to this study as the experiences of carers highlight differences in the behaviours and attitudes of the professionals they came into contact with.

To address the variation in the levels of quality of service provision, financial incentives were put in place and awarded for achieving quality performance targets. These indicators were initially focussed around quantitative measures such as numbers of patients seen, waiting times in emergency departments and waiting times for treatment and procedures such as elective surgery. Another year on and the White paper, 'Creating a Patient-led NHS', acknowledged the failings of past policy to improve collaborative working and called for a joined up health service to provide continuity of care and the need to identify barriers that prevent this (DH, 2005). As part of the quality clinical governance agenda, the achievement of performance targets remained, although the number of targets to be achieved had reduced. The impact of the achievement of targets on the level of collaborative and joined up working is not reported in the literature.

Lord Darzi, in 'the NHS Next Stage Review', emphasised the need for frontline staff to be empowered to be innovative and improve the provision of services (DH, 2008b). He challenged the power of managers and stressed the importance of professionals taking

responsibility for their professional practice. Darzi advocated leadership at all levels and collective responsibility of all professionals in order to provide quality care, partnership working and providing information and choice for patients and the public (DH, 2008b).

This was reaffirmed five years later by the newly elected coalition government in the White Paper 'Equity and Excellence: Liberating the NHS' (DH, 2010a). Again, policy promised to put patients first, 'no decision about me without me' (DH, 2010a:13). This paper proposed a change in focus from achieving targets to the importance of outcomes and the move to less fragmented work across boundaries; however the emphasis was on increased efficiency with the assumption this would lead to effectiveness. The focus of these policies remained on process and procedures and the focus of professional practice was on achieving targets with the resulting expectation of increased quality of care.

Despite this emphasis on performance targets to improve the quality of care provision, the Mid Staffordshire NHS Trust Inquiry in 2009 and the subsequent more comprehensive public inquiry's final report in 2013, highlighted major failings in the delivery of care provided by Mid Staffordshire Hospital (The Mid Staffordshire NHS Foundation Trust, 2010; The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013). These public inquiries prompted speculation of other failings elsewhere in NHS organisations (Reeves et al., 2014).

The Health and Social Care Act 2012 sets out clear requirements for services across the NHS, public health and social care to be integrated. Whilst these services were expected to be person-centred to reduce inequalities in health and to improve health outcomes, the independent and public inquiries and their subsequent findings highlighted the failing Mid Staffordshire NHS Foundation Trust was process and system driven rather than person-centred. A culture of blame and failure of communication were also highlighted as contributory factors (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013). Despite the various mechanisms for regulatory oversight and quality assurance requirements of the Care Quality Commission (CQC) and Monitor, there was a significant lapse in the quality of care provided. As indicated by Andrew Lansley, the first Secretary of State for Health of the Coalition Government, it was not a statutory organisation or the hospital itself which exposed the failings; it was

a group of families who fought tirelessly to get their voices heard (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

The provision of quality and effective care is the responsibility of the whole health and social care workforce. This requires professionals and those who manage them to prioritise the needs of patients. For this to happen, there needs to be a clear governance framework that is embedded in a culture of patient and person centred care and not solely focussed on the achievement of performance targets.

The voices of service users and carers were more apparent in 'Caring for our future: reforming care and support' (DH, 2012e). Lack of integrated and joined up care in the health and social care sectors was again highlighted as one of the major frustrations for patients and their families. These frustrations extended to housing and support. Whilst the Health and Social Care Act 2012 prioritised integration, concern existed regarding the strength of powers given to Health and Wellbeing Boards and the lack of duty on GP consortia to promote integration (Goodwin et al., 2012).

The NHS Five Year Forward View purports to provide a way forward to address the growing gaps in the areas of care and quality; health and well-being; and in funding and efficiency (NHS, 2014a). The White Paper suggests this will be done by enabling new models of care to be developed such as multi-speciality community providers (MCP), new primary and acute care systems (PACS) and redesigned urgent and emergency care services; by empowering patients and their carers; by investing in health informatics and technologies and by commissioning research and innovation. These new models of care present potential challenges for health and social care professionals. They will present challenges to professional boundaries and may require the blurring of some boundaries (Miers, 2010). Staff will need to have the time to support the development of these capabilities.

While the vision and strategy created by the NHS Five Year Forward View has been generally welcomed, it could fail to deliver. Ham and Murray (2015:28) provide strong recommendations,

...that transformational changes of the kind set out in the Forward View are almost invariably emergent in nature, requiring adaptability and flexibility as they are implemented. National leadership of the highest order is therefore needed to align policies with the plan.

In February 2015, an agreement was signed between 37 NHS organisations and local authorities in Greater Manchester. This historic agreement outlined the devolution of health and social care with the bringing together of both budgets for the whole of Greater Manchester. The Greater Manchester Combined Authority (GMCA) claim their focus for the arrangements is on people and place and not organisations. Integration of services will extend beyond health and social care to include other services such as fire and rescue service and the police service (McKenna and Dunn, 2015). The plan is ambitious and GMCA have consulted with health and social care staff, patient and carer group and the general public in developing the plan (GMCA, 2015). The final plan was published in March 2016 and includes details of proposed changes for the next five years with the aim of designing ways for more effective integration and collaborative working.

Cornwall reached a similar agreement in July 2015, however there are differences to the Greater Manchester Combined Authorities plan. Whilst Greater Manchester will focus on public health and integration of services beyond health and social care, Cornwall's plan is to combine health, social care and welfare budgets and more focus on its voluntary and community sectors (McKenna and Dunn, 2015).

The Cities and Local Government Devolution Act 2016 provides legislation to devolve power and budgets to local areas. Over 19 applications have been submitted to the government proposing integration of health and social care (Local Government Association, no date). Whilst the potential benefits of these proposals have been welcomed, they raise further questions with regards to sustainability, long term fiscal responsibility and accountability. These changes will take time and requires support for all the leaders and for the different staff groups to implement them effectively. How this will impact on the effectiveness of collaborative working between the different groups of professionals and the resulting provision of care remains to be seen.

In summary, over the last 25 years, government policy has emphasised the importance of interprofessional working and integrated services. Each policy has led to many changes in service provision; some have led to fragmentation whilst others have emphasised more integration. There has been various methods employed to evaluate services. Efficiency savings and performance targets formed a major part in the drive

to improve quality; however the historic failings highlighted in the various reports and public inquiries indicate problems remain with clinical governance, organisational culture and the effectiveness of collaborative professional working to deliver quality care.

Despite this emphasis on collaborative and joined up working, the responses of individual professionals to the introduction of new roles, the continual changes to service design and organisational structure will have influenced the way in which professionals collaborate with others. How this is enacted in practice will be explored in my study; from the perspectives of carers through their experiences of caring.

To be able to ascertain the effectiveness of interprofessional working on service outcomes, there is a need to understand the complexities of interprofessional working. As there are many definitions of interprofessional working reported in the literature, this will be explored further in the following section.

2.1.2 Definition of interprofessional working

Interprofessional working is complex, highly variable and dependant on contextual factors (Cameron et al., 2014; Reeves et al., 2010; Zwarenstein et al., 2009; Mikan and Roger, 2005). As stated previously, there is a lack of conceptual clarity regarding a definition of effective interprofessional working.

The definition of teamwork as representative of interprofessional working is frequently reported in the literature. A commonly cited model for effective teamwork in the literature is that identified by Molyneux (2001). Molyneux (2001) in her study of one interprofessional health care team identified personal qualities of the staff, communication within the team and the opportunity to develop creative working practices contributed to the team's effectiveness. The limitations of the study need to be acknowledged. The assumption of the effectiveness of the team in question was made by the author, herself a member of the team and external verification of effectiveness was not provided. Whilst her findings are supported in subsequent research, the nature of the team described in the study is not representative of the majority of other health care teams.

Xyrichis and Ream (2007:238) provide a definition for teamwork in health care derived from a concept analysis of the literature:

...a dynamic process involving two or more health professionals with complementary background and skills, sharing common health goals and exercising concerted physical and mental effort in assessing, planning or evaluating patient care. This is accomplished through interdependent collaboration, open communication and shared decision making. This in turn generates value-added patient, organizational and staff outcomes.

The literature reviewed in their concept analysis was predominantly from healthcare and nursing literature from 1966 up to 2006 as literature outside of health care was deemed by the authors to have limited use. The interpretation of the concept is dependent on the different settings and health contexts, a point noted by the authors. Whilst the authors postulate the adoption of this model should lead to better patient, organisational and staff outcomes, this conceptual model takes no account of external factors such as organisational culture and processes, financial resources and staffing levels.

Zwarenstein et al. (2009) provide a more simplistic definition. They use the term interprofessional collaboration rather than interprofessional teamwork to define,

...the process in which different professional groups work together to positively impact health care (Zwarenstein et al., 2009:2).

There are various typologies of team working such as multidisciplinary, interdisciplinary and transdisciplinary (Jelphs and Dickinson, 2008). The interpretation of these terms is not uniform and can be used to describe the collaboration between different specialities within one profession such as medicine or nursing. Different organisations tend to use a particular term: 'integrated working' is favoured by NHS organisations, 'partnership working' is favoured more by social care and third sector organisations, whilst service users and professionals tend to use 'joined up working' and 'integrated and collaborative working' (Goodman et al., 2011a). The use of these different terms in the literature and in practice adds further complexity to the

conceptual and theoretical understanding of interprofessional working (Zwarenstein et al., 2009).

Miller (1997) provides an alternative model of collaborative practice, representing a continuum of practice along two dimensions of organisational structure and philosophical commitment. She identified one distinctive practice which she labelled 'synergistic supercollaboration' (Miller, 1997: 306). She found that the practitioners who worked within one of these practices, were confident and competent, interacting well with other professionals and with clients, providing a positive and enabling environment. Trust and mutual respect between professionals led to successful outcomes, such as good patient care, financial rewards and high patient satisfaction (Miller, 1997). This model was derived from collaborative practice between nurse-midwives and physicians and may not be represented in collaborations between other professionals. The study also did not consider the patient or family perspective of successful collaborative practice. Despite this limitation, this model supports service user and carer's perceptions of effective collaborations discussed later in this chapter.

The existence of a definition for interprofessional working on its own does not provide the contextual reality in practice. Research has provided broader definitions of interprofessional working which take into account issues which exist due to different groups of professionals working together, such as dynamics of power, communication strategies, role understanding and conflict (Nancarrow et al., 2013; Reeves et al., 2010; Mickan and Roger, 2005).

Mickan and Rodger (2005) developed the healthy team model which consisted of six key characteristics of effective teamwork in health care environments: purpose, goals, communication, leadership, cohesion and mutual respect. These six characteristics link across four themes; environment, structure, process and individual contribution of the team. Their model was constructed from the subjective perspectives and experiences of teamwork of a range of health care practitioners and managers in Australia. Their definition of teamwork focused around a small number of members working together to achieve a specific task who are held collectively responsible. This type of team can be seen across health care and can consist of members from the same profession or from another profession. Whilst the participants in their study were from a range of

health care professionals and positions, the nature of the teams they had experienced was not explicitly described by the authors.

Rather than providing a definition, Reeves et al. (2010) provide a theoretical framework for the factors which influence interprofessional teamwork. They argue that there are four categories of influential factors; these are processual, relational, organisational and contextual. These categories were determined from a wide range of evidence, including expert opinion. The authors suggest the four categories are not mutually exclusive and are interconnected in various ways (Reeves et al., 2010).

Mickan et al. (2010) found effective collaborative practice was facilitated by shared governance in primary health settings in developed and developing countries. Leadership, management, interprofessional education and shared patient records were identified as influencing factors. The authors used a multiple case study design and whilst it could be argued the findings are limited, they are similar to other studies carried out in both developing and developed countries.

Nancarrow et al.(2013) provide a guide on the attributes and characteristics of good interdisciplinary team practice from their study drawn from two sources of knowledge; a published systematic review on interdisciplinary team work and the perceptions of 253 community rehabilitation and intermediate care professionals from across the UK. They identified ten principles for good interdisciplinary teams in intermediate care and community rehabilitation:

...positive leadership and management attributes; communication strategies and structures; personal rewards, training and development; appropriate resources and procedures; appropriate skill mix; supportive team climate; individual characteristics; clarity of vision; quality and outcomes of care; respecting and understanding roles (Nancarrow et al., 2013: 9).

A strength of this review is they included qualitative evidence (Zwarenstein et al., 2009) and interestingly, the authors acknowledge this as a limitation; however they argue the approach is strengthened by the triangulation of their systematic review with the primary data gathered from their fieldwork. This predominance of the positivist approach in the literature to demonstrating effectiveness with the aim of

drawing generalizable inferences is limiting and does not acknowledge the multiple dimensions and realities of practice. Teamworking varies in nature and is context dependant. What is successful in one situation may not be successful in another situation.

To address this issue and to identify the context, mechanisms involved and subsequent outcomes, Sims et al. (2015a) carried out a realist synthesis of the existing evidence as part of a larger study into the impact of interprofessional working on carer and patient experience and outcomes after stroke. In the same series of four articles, Hewitt et al., (2014: 503) identified 13 mechanisms for interprofessional teamworking,

...collaboration and coordination; pooling of resources; individual learning; role blurring; support and value; efficient, open and equitable communication; team behavioural norms; shared responsibility and influence; critically reviewing performance and decisions; generating and implementing new ideas; leadership; shared sense of purpose; and tactical communication.

The aim of the realist synthesis was to conceptualise and understand the processes of teamwork; however the research team acknowledged the majority of the literature used in the review was from the perceptions of health care professions and not those of patients and their families (Sims et al., 2015a). The studies reviewed predominantly considered clinical outcomes from the perspective of the professionals or used measures such as length of stay and re-admission to hospital. There remains a dearth of information regarding the impact in terms of experiences of patients and their families.

To summarise, there are many definitions of interprofessional working in the literature with some research focusing on the notion of the team. More recent research has highlighted the importance of context and the multiple realities of professional practice. There is a distinct dearth of research involving patients and their families in terms of their perceptions of effective interprofessional working. My study aims to provide further evidence of this.

The next section aims to provide a further exploration of the mechanisms and influencing factors identified in the literature. A large proportion of the literature has

emphasised the importance of the awareness of others' roles on the team (MacDonald et al., 2010; Reeves et al., 2010; Mackintosh et al., 2009; Suter et al., 2009). The roles of others in other teams or other organisations are not always clearly articulated and understood. In the current climate of health and social care reform, current roles are changing and new roles are emerging. Unless these are clearly acknowledged and understood by other professionals in the future, awareness of others' roles will inhibit collaboration.

Another influential factor on interprofessional working highlighted in the literature is the location of professional groups. Co-location has been identified as an important factor contributing to effective working. A shared physical base potentially provides more opportunities for collaborative working than if professionals do not share a common base (Reeves et al., 2010; Xyrichis and Lowton, 2008; Hudson, 2007; Molyneux, 2001). However this is not always the case; the findings of Kharicha et al. (2005) do not support co-location and their findings indicated co-location can sometimes lead to increased informality which potentially undermines professional practice. Whilst co-location provides easier opportunity for collaboration when compared to groups of professionals based in different locations, it does not always ensure better collaboration.

There are circumstances where groups of professionals do not regularly work with other professionals. Many health and social care teams are not static. The combination of staff working in a particular area or with a particular client group can vary on a daily, weekly or monthly basis. Some staff work shift patterns and others work fixed-term rotational patterns. Many professionals work across a number of teams and locations such as social workers, physiotherapists, occupational therapists and speech and language therapists both in the hospital and community based settings. Some of these professionals do not see themselves as part of an interprofessional team; they see themselves as working with other professionals as required. This variability in the interaction between professionals has been termed knotworking (Reeves et al., 2010). In an earlier study, Reeves and Lewin (2004) in their study of professionals working on a general and emergency directorate in a large inner city teaching hospital in the UK, applied Engestrom's activity theory to the activities they observed in the medical settings. Interprofessional interactions rather than teamworking was observed with

professionals working together to tie and then untie these interactive threads of professional activity.

The type of care and the nature of the service will also influence the effectiveness of interprofessional working. In acute settings such as accident and emergency and emergency theatres, there is an unpredictability in the nature of the work which could affect interprofessional working. In emergency situations, it is crucial for key professionals to work together efficiently and effectively to ensure a positive outcome for the patient. In these particular circumstances the contribution of all key professionals or team members is necessary for success.

Critical and intensive care settings provide a similar environment to emergency departments; whilst the length of stay is obviously considerably longer than the emergency department, the pace of work is similar with similar fluctuations in levels of clinical activity. There is limited evidence of the collaborative practice occurring within these settings (Paradis et al., 2013). They emphasise the fragility of the interprofessional relationships and the need to better understand these by carrying out qualitative research that provides rich data. Reeves et al. (2015) present preliminary findings of their ethnographic study carried out on four intensive care units in the US to explore the culture of interprofessional collaboration and the nature of family member involvement. Discussions of teamwork tended to be profession specific rather than interprofessional due to the parallel nature of the different professional areas of clinical work. As discussed previously this knotworking appears to be the dominant mode of working on the units (Reeves et al., 2010). However when a critical medical event occurred, such as the patient requiring intubation, both the researchers and family members observed the professionals coming together and working in a highly collaborative way.

The way professionals work together can be dictated by external factors such as organisational policies and procedures (Reeves et al., 2010). All organisations have policies and procedures in place to ensure efficient and effective use of resources. Professionals are expected to follow these policies and procedures in their daily practice. As highlighted earlier in this chapter, the introduction of clinical guidelines and professional standards potentially influences the way professionals choose to work. Routinisation of clinical practice is a key component of efficient working and the

existence of care pathways offer both efficient and evidence informed professional practice.

Literature around policies and procedures is limited in terms of the impact on the way professionals work together. Studies have identified policies and procedures as influential factors but mainly implicitly rather than explicitly (Sims et al., 2015a; Nancarrow et al., 2013).

A Dutch study by Elissen et al. (2011) into multidisciplinary cooperation in primary care, highlighted the negative effects of organisational rules in terms of providers competing for scarce resources. They carried out twelve semi structured interviews with professionals from six professions working in one region of the Netherlands and examined documentary evidence from the respondents' practices. Organisational rules seemed to promote uni-professional rather than interprofessional working. They found one of the main barriers to multidisciplinary collaboration across services and organisations was their current system of fee-for-service reimbursement. Elissen et al. (2011) tended to focus their discussions around formal rules. Most health care settings have informal working cultures and informal rules which will influence the way professionals work together. The extent to which professionals are facilitated or inhibited by formal and informal rules to work collaboratively needs further exploration. Patients and their families will experience the outcomes of this in terms of their overall experience of care.

In summary, organisational structures and cross boundary working can impact on effective interactions between professionals. Different organisational structures, policies and procedures can inhibit communications and different funding streams can impact on referrals for specific professional input. The preoccupation and continued emphasis on teamwork in the literature does not reflect all the various groups of professionals who work together with the aim of providing effective and seamless health and social care. This care can be delivered across teams and across the different sectors, for example community rehabilitation teams for older people (Enderby, 2002).

There exists an overemphasis on how members of particular teams work effectively together and not on the resulting impact this has on the overall care provided. There is a preponderance of assumption that teamworking is a holistic way of providing cost

effective care (MacDonald et al., 2010). The emphasis has been focussed around the characteristics of effective teams, rather than the factors influencing and inhibiting effective interprofessional working in different settings across different boundaries.

A more detailed exploration of professional practice is required. How this then impacts on collaborative working across teams and across professional and organisational boundaries is discussed in the next section.

2.1.3 Professional Practice

The traditional definition of professional practice is characterised by a high level of expertise, the autonomy to carry out particular tasks, practice within an ethical framework and professional standards, self-regulation and autonomy and dominance over other groups of workers (Baxter and Brumfitt, 2008).

Values, attitudes and beliefs of a chosen profession are believed to be learned by individuals through their professional education and subsequent professional career (Molleman and Broekhuis, 2012; Richardson et al., 2002). This is learned through a process of professional socialisation. This socialisation occurs through a variety of social networks both in the universities and in the workplace settings (Baxter and Brumfitt, 2008; Hall, 2005; Richardson et al., 2002). Attitudes are reinforced through education and clinical practice and individuals take on the governing values that are based on expectations and social consensus of certain behaviours.

For the health professions this may be more straightforward than in professions such as social work. Oliver (2013) emphasises that due to the diversity of social work practice, it has become difficult for the profession to build on a coherent knowledge base and identity. This is particularly pertinent for social work practice in interprofessional settings, with many new social work graduates working within these teams. Oliver (2013:776) argues a need for social workers to perceive themselves as 'boundary spanners', working in complex situations and across organisational settings. The concept needs to be closely associated with the core values of social work practice, namely social justice and human rights; however the concept of boundary

spanning is not exclusive to social work and is in fact a quality required of all professionals who work in complex health and social care settings.

For one of the larger allied health professions and my own profession, physiotherapy, professional practice is also complex (Bithell, 2005). She suggests there is no coherent theoretical framework or epistemology of physiotherapy practice which adequately describes current practice. Historically to increase the perceived status of the profession, physiotherapy aimed to position itself alongside the medical profession by adopting a biomedical approach to professional practice. This approach fails to acknowledge the subjective psychosocial paradigm of physiotherapy practice. Edwards and Richardson (2008) highlight this limitation and advocate physiotherapists use both deductive and inductive forms of clinical reasoning in their clinical practice in order to acknowledge the subjectivity of illness and experience of disability.

Using three case studies of physiotherapy practice in international settings, the authors concluded that physiotherapy practice could be defined as,

...a deployment of diverse professional practice knowledge, skills, and techniques (i.e. clinical expertise) that are truly linked to patient values in implementing and integrating best evidence toward health strategies for individuals in the context of communities' (Edwards and Richardson, 2008:191).

Shaw and Deforge (2012) support this definition and suggest a multiple epistemological perspective should be given to the definition of physiotherapy practice. They suggest physiotherapists should be seen as bricoleurs and embrace new ways of knowing to provide a more holistic approach to their practice.

Similarly, in mental health nursing, Warne and McAndrew (2007) suggest mental health nursing practice is underpinned by theoretical knowledge and ritualised practice. They suggest there was an overreliance on using interventions based on medical precepts. They highlight the drive for evidence based practice may have paradoxically compromised mental health nurse practice and similar to physiotherapy, this reliance on the medical framework is used as a way of reinforcing their sense of professional identity and status.

Professionals use their unique and distinctive knowledge to carry out complex activities and to make effective decisions (Molleman and Broekhuis, 2012; Hall, 2005). With this level of autonomy to make certain decisions, comes status and certain professional privileges. An interesting perspective of professionals was provided by Ivan Illich, who suggested professionals seek to mystify their expertise in order to gain power and control (Hall, 2005). Cameron (2011) supports this perspective and argues professionals maintain their position and status by protecting their knowledge base. They accumulate rather than share knowledge in the interests of themselves and the profession. Their uni-professional education and resulting professional socialisation has provided affirmation of their professional boundaries (Cameron, 2011). These boundaries are socially constructed and can become areas of conflict as changes in practice occur and professional groups compete against each other to protect their claims of expertise (Edwards et al., 2010).

Sims (2011), an advocate of joint training programmes, argues that if boundaries are socially constructed, there is scope for professional roles to be redefined and specific tasks to be reallocated to meet the changing needs of health and social care. It could be argued this will only be considered by the different professionals if there is no decrease in perceived professional status.

A longstanding history of differences in class, gender and status exists between the professions. Medicine is the longest established and the most dominant profession in health and social care. Only medicine was traditionally seen as a profession; other professionals such as nurses, allied health professionals and social workers were seen to belong to semi-professions (Pollard et al., 2005). Medicine was traditionally dominated by men; however over time the proportion of females has grown significantly in certain disciplines within medicine. In areas such as general practice the ratio of female to male GPs is 50.8 to 49.2 respectively (General Medical Council, 2015). This picture is different in the nursing and in most allied health professions, where females tend to dominate.

The medical profession predominantly reflects the values of the upper and middle classes (Hall, 2005). Traditionally, undergraduate medical students were from these social classes. However, over recent decades, whilst this is predominantly the case, as part of the widening participation agenda, there is an increase of students from the

lower social classes undertaking a medical education. An influential factor of professional status lies with pay differentials that play an important part in the status of health and social care professions. Medical and dental professions consistently receive higher pay than the rest of the professional groups. In the NHS, the introduction of the Knowledge and Skills Framework under the Agenda for Change framework facilitated transparency and equity across professional roles, as it focussed on the knowledge and skills required for certain roles and not for a specific profession (DH, 2004c). Medicine and dentistry were not included in this process change and had a separate pay review body. This continues to reinforce the difference in pay and subsequent perceived status between professional groups.

In regard to the influence of status and power, an interesting finding of the diminishing dominance of the position of medicine as care moved from the acute to the community setting was identified in a study by Baxter and Brumfitt (2008). In their qualitative study with a range of health professionals, Baxter and Brumfitt (2008) explored the nature of joint working practices at three sites providing care and services to stroke patients. They carried out interviews and fieldwork observations across the three sites. The professionals reported a sense of equal status in the community settings compared to acute settings. As care became less acute and the philosophy of care moved from a medical to a more holistic approach, staff perceived there was a difference in the ways professionals worked together (Baxter and Brumfitt, 2008). The professionals identified differences between those professionals whose roles were primarily medical and those whose roles were related to rehabilitation.

Gender and social class issues have contributed to the friction and conflict that has continued to be seen between professions up until the present day. Both of these issues influence basic values and world-views of all the professions (Hall, 2005; Richardson et al., 2002). The influence of passive power is difficult to quantify and should not be underestimated. It can be evidenced as apathy towards another professional group or particular team or as a reluctance or even refusal to engage with collaborative activities such as team meetings (Reeves et al., 2010). This type of behaviour and attitudes can have detrimental effects on joint decision making and on the referral to other professionals, preventing access to the required resources or services. It can also inhibit communication between professional groups and the voice

of some staff are seen as not important or relevant, as was the case in the Mid Staffordshire NHS Foundation Trust, when nurses reported concerns with level of care and staffing levels and was ignored by senior managers (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

Much of the literature around interprofessional working focuses on inhibitors and barriers to effective collaborative practice. Hudson (2007) presents two models for understanding the complexities of professional practice and in particular, interprofessional working; the pessimistic and the optimistic models. The evaluation of the Sedgefield integrated team was offered as an example of the optimistic model (Hudson, 2007). Findings from interviews with staff, service users and carers indicated satisfaction with the service and a sense of wholeness and the team working efficiently and effectively. A sense of shared culture was found to exist in the team which extended beyond professional boundaries (Hudson, 2007).

Culture refers to values, beliefs, attitudes, behaviours and customs and can be applied from an individual level to society in general. It has been established and accepted in the literature that each health care profession has a different culture (Hall, 2005). In response to policy and organisational change, professional roles have expanded over time and a shift to more autonomous practice has occurred for some professionals. This has resulted in the challenge of perceptions of certain professions and created rivalry between professions for particular roles. This can lead to difficulties in the definition of professional boundaries and the acceptance of these by other professionals. Whilst Sellman (2010) argues there are more similarities than differences in the ethics and values guiding professional practice in health and social care, in reality they are likely to be interpreted and enacted in different ways by the various professional groups.

Differences in interpretation and enactment of the professional ethics and values suggests there exists a way of thinking which is specific to a particular professional group. This has been developed through experience of professional education and reinforced by professional practice (Pecukonis et al., 2008). Pecukonis et al. (2008: 420) term this 'profession-centrism'; for example, doctors are trained to assume the lead role in care and in taking responsibility for decisions.

Reeves et al. (2009) found Canadian doctors working in general internal medicine settings tended to dominate the more formal interactions such as ward rounds, where the other professionals felt there was not a mutual exchange of opinions. The interactions between the nursing staff, therapists and other staff were observed to be richer and more meaningful, consisting of negotiations related to clinical and social issues. These findings are similar to Baxter and Brumfitt (2008) from the acute ward setting of their study. These studies explored the nature of interactions between professionals and not the outcome of these interactions. For patients and their families, the nature of the interactions may not be perceived as relevant. It is the outcome of the interactions they experience, which is relevant and more visible to the carers and the person they care for.

As the different professionals gain experience and expertise, they develop different cognitive maps (Baxter and Brumfitt; 2008). Hall (2005) describes these cognitive maps as different ways of seeing and highlights these as a major challenge for interprofessional working as professionals need to be aware and understand others' cognitive maps if they are to work effectively together. Similarly, Hubbard and Themessl-Huber (2005) emphasise the need to create shared models of thinking as the majority of health and social care professionals continue to be socialised into their respective professions, yet are expected to practice in a changing environment where their professional identities are being challenged (Sims, 2011).

The influence of professional identity on effective collaboration with other professionals has limited coverage in the literature. As highlighted earlier, Baxter and Brumfitt (2008) found variation in the staff perceptions of professional identity and team identity; some staff saw themselves primarily as members of a particular team whilst others had a strong allegiance to their own profession.

Sims (2011) advocates the adoption of this within pre-registration curricula of future health and social care professionals in order to prepare them for the new roles emerging across the health and social care sectors. However, there needs to be further exploration of the influence of professional identity on collaborative practice and care outcomes before recommendations are made for a required change in practice

Specific individual qualities and characteristics of professionals are essential for collaborative practice to be successful or not. Sellman (2010) proposes three

conditions: willingness, trust and leadership, which he believes are essential for effective interprofessional working. As one professional cannot meet all the health and social care needs in isolation, there is a moral obligation of all health and social care professionals to be willing to work in collaboration. Trust in another professional's competence and expertise is identified by MacDonald et al. (2010) in their study to identify key competencies for collaborative practice.

Commonly, health and social care professionals are required to work across and outside of their usual boundaries as different models of service provision are developed. Rather than being seen as a dilution of skills and expertise, this could be acknowledged as an additional layer of expertise. Edwards et al. (2011:31) identified the concept of 'relational agency', which they describe as the capacity to work with others to address complex problems and situations more effectively. Whilst their study was carried out in secondary schools and aimed to identify how school-based welfare managers were collaborating with other services in relation to the social exclusion of their students, it is pertinent to the health and social care context. They identified the development of new roles and some blurring of existing roles to enable education professionals to work across and outside their usual boundaries. Whilst this blurring of roles and boundaries appears to be a necessary component for effective interprofessional working, if there is reluctance of acceptance by professionals this will ultimately impact on the effectiveness of the care or service delivered.

However, caution is needed with decisions around the introduction of new roles or the expectation that another professional will adopt part of another's role. Unless the professional has a strong knowledge base and experience of interpreting and acting in specific situations, then they may find themselves in a vulnerable position. Provision of effective staff development is necessary to ensure the professional has the relevant expertise to carry out the role. Edwards et al. (2011) found this to be lacking in their study, where the school-based welfare managers were expected to take on an additional role without necessarily having the relevant expertise to carry it out.

Kharicha et al. (2004:139) highlight concerns with merging the knowledge and skills of professionals resulting in an 'interprofessional porridge'. In such a porridge the individual ingredients, the skill sets of the different professionals, are blended into a single homogenous product; easy to digest but with individual contributions lost to the

whole. This could arguably be a positive move in terms of a common philosophy of care and standardised care; however the resulting 'porridge' could lead to a potential loss of creativity, negatively affecting the availability of alternative choices for service users and their families. There needs to be a balance between service-user and carer outcomes and economic analysis in the development of any new role. Other food-based metaphors are discussed in Tamura et al. (2005).

In summary, professional socialisation has been identified as an important component of an individual professional's development. Professional identity can provide a distinctiveness to represent the knowledge base, values, and expertise of a particular profession. Whilst this has important implications for working collaboratively and interprofessionally, as discussed earlier, this can present barriers to interprofessional working. Professional status and power will impact on the way professionals are perceived and how they work with others.

This diversity and expertise between the different professionals can also provide opportunities for professionals to work collaboratively to ensure the delivery of effective care and services. A balance needs to be drawn in acknowledging both the similarities and differences of professional practice and a willingness on behalf of the professionals to develop new skills to enable effective collaboration.

How visible professional practice is to patients and their carers is questionable. Individual or group behaviour will be more noticeable. The impact of individual professional values, beliefs and attitudes on professional practice is felt directly by carers. How professionals work with carers and how carers are perceived as partners in care is questionable and is explored later on in the chapter.

2.1.4 Leadership and interprofessional working

As highlighted earlier, effective interprofessional working requires effective leadership (Sellman, 2010). A person may have the official title and role of leader or a team may function with no named team leader. In this case the most senior person or member of a perceived high status profession normally takes the lead. The leadership role in teams is commonly assumed by the medical profession. Doctors are trained to assume

responsibility for decision making (Sellman, 2010; Baxter and Brumfitt, 2008; Hall, 2005). In many cases leadership will be part of a particular professional role; however there are situations where hierarchical status of a particular profession does not dominate, commonly in the areas of rehabilitation or community services (Baxter and Brumfitt, 2008; Molyneux, 2001).

Medical dominance is reflected in the findings of Goldsmith et al. (2010), who carried out semi-structured interviews with members of an interdisciplinary geriatric and palliative care team in the USA. They analysed the interviews using a functional narrative approach. Whilst all members of the team valued an interdisciplinary approach to care, there was a lack of agency with the physician on the team resulting from the latter dominating the decision making of the team (Goldsmith et al., 2010).

As part of the research to support the Creating an Interprofessional Workforce project in 2007, Meads et al. (2009) carried out interviews with eight Deans from medical schools in England and follow up interviews with directors of interprofessional health and social care education programmes. They found existence of a level of resistance amongst the Medical Deans and inertia to interprofessional education and working, which the authors argued impeded progress. Their findings were supported by international evidence prevalent at that time. Unless this perceived lack of engagement is addressed, medicine will continue to dominate and will impede the progress of collaborative working which aims to achieve outcomes which are beneficial for patients and their families and that go beyond any personal or professional agenda.

Shared or distributed leadership spans professional groups and requires professionals to work together to deliver high quality and patient centred care (NHS Leadership Academy, 2011; DH, 2008). Prescott and Rowe (2015) provide an alternative view of the required leadership in the current complex health and social care systems. They advocate leaders should be seen as 'revitalising entrepreneurs' (Prescott and Rowe, 2015:103). They describe these leaders as those individuals who make the most of difficult situations to drive through the change that is required. They are innovative, work through organisational barriers, and are solution driven not problem focussed. This is not always easy for individual health and social care professionals to accomplish as organisational rules and structures and professional hierarchical barriers need to be overcome.

Dixon-Woods et al. (2013) carried out a large mixed-methods study examining culture and behaviour in the NHS in England. It involved seven separate sub-studies involving interviews with NHS staff, patients and carers; ethnographic observations in hospitals and in primary care practices; analysis of Trust board minutes from 71 NHS Trusts; data from national surveys of patients and carers and team performance data from a range of clinical teams.

They identified six key elements that were necessary to ensure delivery of high quality, compassionate care; four of these elements were related to leadership. They concluded leadership was required that involved a clear, shared vision operationalised across all levels. They described different approaches of leaders to intelligence gathering of quality data. These were 'problem-sensing' and comfort-seeking' behaviours (Dixon-Woods et al., 2013:6). The leaders who adopted a problem sensing approach were found to be more insightful and used additional qualitative data gathered from observations, discussions with staff and patients. The comfort-seeking behaviours adopted by other leaders tended to focus on external impressions and on quantitative data sources for quality. Some staff in the study felt this style of leadership resulted in a culture of blame (Dixon-Woods et al., 2013). From their survey of 621 clinical teams, they found there was lack of clarity regarding team leaders, team members and team goals. In teams where clarity existed, this was positively associated with team performance and provision of quality care.

This type of shared leadership is described in the literature as collective leadership (West and West, 2015). Collective leadership requires all staff to accept recognition of their leadership role and to take responsibility for that role by working with other professionals. It assumes hierarchy exists between certain groups; however, power to make decisions is based on the relevant expertise required at a particular time or in a particular situation (West and West, 2015).

Leadership at a local level can vary depending on shift patterns and the teams of staff on duty. The individual style of leadership will have an impact on how groups of professionals work together. In certain settings, a particular clinical or practice area may have different staff who take on the role of leader depending on shift patterns of work. This is particularly evident in the nursing profession. The preferred style of leadership of each person will influence the nature of working within and beyond their

team. Differences between individuals or teams can develop tribal cultures that impact on patient care and should not be underestimated (Prescott and Rowe, 2015; Sims et al., 2015b).

This presents a challenge for interprofessional teams as the leadership role may be assumed by themselves or by other members of the team. The assumed dominance by one profession is not always appropriate in certain situations and settings. To add to the complexity of effective leadership, organisational factors play a significant role in influencing working practice across health and social care. The White Paper 'Creating a Patient led NHS' acknowledged this and clearly advocated organisational support and incentives which would improve patient outcomes (DH, 2005). However, the incentives were around particular achievement of targets and mainly benefitted the organisations and senior management rather than professionals directly. As discussed earlier, these incentives did not necessarily reflect improved patient outcomes from the perspectives of the patient and their families.

When individual professionals or teams do not receive support to implement change or are not rewarded, the professionals are likely to feel discouraged and powerless and as Cashman et al. (2004) found, will tend to drift back to previous patterns of working. Xyrichis and Lowton (2008) also identified that organisational support and leadership that encouraged innovation and implementation of change, play an important role in team function.

It can be assumed professionals require the appropriate support and resources to perform effectively. Kvarnström (2008) conducted a critical incident study with Swedish health professionals working in established health care teams found that the professionals in the study did not perceive themselves as being supported by their organisations due to insufficient resources and they felt they did not perform as effectively as they could do with optimal resources. Staff in managerial positions in the organisations in this study were not included in the data collection. The findings are solely based on the perceptions of the professionals and not based on additional information collected from the different health care organisations. Service user and carer perspectives could also provide valuable insight into the effectiveness of the teams; however, the authors did not acknowledge this.

In summary, leadership at all levels is required to effectively facilitate change and innovation. Leaders need to be willing to drive change and be solution focussed, not problem driven. All professionals need to recognise a collective responsibility to work with relevant others. There is a need for the recognition of the influence of the different qualities and leadership styles of leaders at a local level. This can have a direct impact on the quality of care provided and the experiences of both the patients and their carers. The realities of health and social care provision is complex and professionals may not have the skills or capabilities to work collaboratively. They most likely will have experienced uni-professional pre-qualifying education. Whether the experience of interprofessional education facilitates interprofessional working remains open for debate. This is explored in the next section.

2.1.5 Interprofessional Education

Educational experiences and the resulting professional socialisation of future health and social care professionals immerse each professional group in the norms and values of their individual professions. It is the nature of the pre-registration experience that influences future collaborative working (Suter et al., 2009; Hall, 2005; Walsh et al., 2005; Barr, 2001).

The NHS Plan suggested interprofessional education should occur in both pre- and post-qualifying professional education (DH, 2000). Interprofessional education is where two or more professionals learn with, from and about each other to improve the quality of health and social care (Centre for the Advancement of Interprofessional Education, 1997).

For over twenty years, the centre for the advancement of interprofessional education (CAIPE) has actively promoted interprofessional research and initiatives in the UK. Interprofessional education should be 'collaborative, egalitarian, group directed, experiential, reflective and applied' (Barr et al., 2005:32). CAIPE advocates the use of a range of learning and teaching methods, alongside a patient centred approach with meaningful engagement with service users in the learning opportunities for students. Its focus has been on interprofessional education with the espoused assumption that this will lead to effective interprofessional working. This assumption has been widely

accepted by researchers, yet the evidence to demonstrate this is limited. Despite this, much of the research has focused on how best to prepare students for collaborative working and has highlighted specific skills and competencies required for interprofessional working (Reeves et al., 2008; Barr et al., 2005).

Whether interprofessional education at prequalification stage is effective in changing attitudes and behaviours in professionals, is explored in a longitudinal study conducted by Pollard et al. (2004). The initial findings from their study of students entering onto 10 pre-registration programmes identified some students entered onto the programmes with pre-existing negative attitudes and opinions of interprofessional working in health and social care. These pre-existing attitudes and beliefs of students will have implications for any future interprofessional education initiatives. In the final report of the study in 2008, they found the nine months to one year post-qualified professionals who had experience of interprofessional learning in their pre-registration education, were more positive about their interprofessional relationships than were those professionals who had experience of uni-professional education (Pollard and Miers; 2008). This does not address whether they work effectively with other professionals and cannot be necessarily assumed.

Competencies for interprofessional working have been identified by different studies for students to achieve through their pre-qualifying education (MacDonald et al., 2010; Suter et al., 2009; Walsh et al., 2005).

For practice-based learning, Walsh et al. (2005) argue capability rather than competence is the goal for interprofessional practice as this encompasses the ability to apply, adapt and synthesise experiential learning. Walsh et al. (2005), from the Combined Universities Interprofessional Learning Unit (CUILU), Sheffield, proposed an interprofessional capability framework defining capabilities which would facilitate effective collaborative working; ethical practice; knowledge in practice; interprofessional working; and reflection. The framework was designed to be used in the practice context and it guides students from a range of health and social care professions to the achievement of common placement learning objectives. Whilst these capabilities can be achieved in practice by the students, the influence of the existing practice of other professionals in their placement area will affect the interpretation of these capabilities in the students. The professional socialisation of

the students into particular ways of working whilst on placement may influence their perceptions and interpretations of the capabilities. The students need to be confident in their own governing values and not automatically conform to any social consensus of inappropriate behaviour of other professionals.

In order to provide a clearer framework of competencies to inform the development of health professional education, Suter et al. (2009) carried out a Health Canada funded study to identify the competencies required for collaborative practice. They interviewed 60 staff from a range of health and social care professions, including administrators and identified two core competencies: understanding and appreciating others roles and responsibilities; effective communication. The authors acknowledge the complexities of both these competencies, however they assert these two competencies are linked to positive patient outcomes and supported by the literature. They suggest that by focussing on these two competencies in interprofessional educational activities, this would facilitate stronger connections between practice and patient outcomes.

Another Canadian study by MacDonald et al. (2010) identified a further four competencies to Suter et al.'s two, which are required for successful interprofessional practice: leadership; team function; strength in one's professional role; and negotiation for conflict resolution. The data was obtained from semi-structured interviews with 24 participants; undergraduates, recent graduates, university lecturers and practitioners from different health professions. They also identified behavioural indicators emerging from analysis of the data. The authors claim these competencies and behavioural indicators will shape relevant teaching strategies to prepare students for interprofessional practice and secondly to provide a tool for the assessment of the students in the classroom and on clinical placement. Both the above studies could be seen to be oversimplifying the complexity of interprofessional working. They fail to acknowledge sufficiently the influence of professional hierarchy, power and culture on these competencies identified for effective working.

Post qualifying education presents different challenges to interprofessional education for prequalifying students. Professionals have established ways of working and their governing values are more likely to be established. These professionals may be less willing to change their practice and less open to develop different ways of thinking.

Whilst all professionals are expected to engage in continual professional development, the extent to which they engage in critical reflection of practice is variable.

Blickem and Priyadharshini (2007) aimed to provide suitable patient-centred education for the professionals who worked on a stroke rehabilitation ward. The training was focussed around constructed patient narratives. Data obtained from interviews with and observations of patients and carers were used in the development of the narratives to ensure an element of plausibility. The researchers found that once they shared the narrative, the professionals were more open to reflecting on their own perceptions and exploring new ways of thinking. The professionals identified the need to work more closely with other professionals and to communicate more effectively with each other; however, their need to understand the patient and family context appeared to override the former.

A strength of this approach is that it enables professionals to see themselves from the perspective of patients and carers. It also provides professionals with a window into the realities of being a patient and a carer. This powerful use of patient and carer narratives is reflected in this study. The use of stories facilitates the exchange of experiences.

'Creating an Interprofessional Workforce' (CIPW) programme was set up in 2004 with three years funding with the aim of embedding interprofessional learning and development into health and social practice (Meads et al., 2009). The programme through a wide range of consultation events, the programme team developed a framework for interprofessional education and training (CIPW, 2007). The programme placed an emphasis on the need for a sustained collaborative culture focused on delivering patient and family centred care (CIPW, 2007).

Baron (2009) carried out an action research study, examining a patient journey model to improve patient centred care. Baron's study focused on the journey of vascular patients in a hospital in the south of England. The project team comprised of different groups of professionals and other groups of hospital staff who were all involved in working with patients who had undergone surgery for a femoral bypass graft (Baron, 2009). The project team commented how listening to the patients' and carers' experiences had made them think differently and their thinking had been broadened as a result. Whether this resulted in an actual change in their practice was not

reported, however changes to practice that were reported were mainly procedural changes such as improved patient information leaflets and a revised short notice admissions procedure to the surgical unit.

Goodrich (2012) highlights the introduction of Schwartz rounds, piloted in two NHS Trusts in the UK. She argues that the introduction of this model for interprofessional staff development, has the potential to impact positively on all staff. The findings from staff surveys carried out following the Schwartz rounds, indicated improvements in teamworking, staff having more empathy and a perception of a supportive working environment.

Despite this increasing trend for interprofessional education, there is a lack of evidence to support the benefits of this to improved patient outcomes. This is partly due to methodological difficulties in demonstrating cause and effect between interprofessional education and patient outcomes. Much is assumed in the literature and tenuous links are made between educational initiatives and its impact on patient care. Many assumptions have been made in the educational literature on positive outcomes and many failed to involve the perspectives of patients and their families. Sustainability of educational initiatives has not been prominent in the literature and more studies are required to demonstrate this. Where education initiatives have been successful, it is where they have involved the patient or carer perspectives (Goodrich, 2012; Haigh and Hardy, 2011; Baron, 2009; Blickem and Priyadharshini, 2007).

2.1.6 Interprofessional Working and Person-centred care

Problems arising from poor interprofessional working can have negative effects on health care (Reeves et al., 2010; Kvarnström, 2008). Professional and regulatory bodies, such as the General Medical Council (GMC), the Nursing and Midwifery Council (NMC) and the Health and Care Professions Council (HCPC), advocate that patients and clients should be at the centre of decision-making and service provision (GMC, 2013; NMC, 2015; HCPC, 2008).

There are different definitions of patient or person-centred care and this terminology changes over time (Collins, 2014; Goodrich and Cornwell, 2008). Most definitions

include seeing the person in their individual context, the provision of care which takes into account the person's needs and preferences and partnership working between the person and the health and social care practitioners. (DH, 2015a; 2008a; NICE, 2011). More recent definitions, such as the NHS Constitution, include the consideration of the needs of the person's family and carer (DH, 2015a). Principles underpinning person-centred care therefore include the provision of care, which affords compassion, dignity and respect; is personalised; offers informed choices; and is enabling through involving the person and their family in decision-making.

Recommendations from the second Francis report emphasise the importance of establishing the right culture and of making patient care as a strategic priority throughout the health sector (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013). This culture needs to be established at every level within an organisation.

At an organisational level, Shaller (2007) identified success factors for patient-centred organisations in the United States (US). From the semi-structured interviews with leaders from organisations across the US, seven factors were identified. These were leadership; clear strategic vision; involvement of patients and families; supportive work environments; continuous monitoring and evaluation with feedback; quality buildings and supportive technology (Shaller, 2007). The leaders who participated in the study were considered to be leaders of successful organisations. Whilst they felt progress had been made in their organisations, progress was therefore in a small proportion of the health care organisations. They felt the majority of hospitals and medical practices in the US were not achieving high standards of patient-centred care (Shaller, 2007). The US health system is different from that in the United Kingdom (UK), however there is resonance with this situation in the UK.

The report from the public inquiry into the Mid Staffordshire NHS Foundation Trust, Sir Robert Francis identified a need for a cultural shift and a shared culture to be embraced across the health service.

The common culture of caring requires a displacement of a culture of fear with a culture of openness, honesty and transparency, where the only fear is the

failure to uphold the fundamental standards and the caring culture (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013:48).

Following this report, responses were made from the various stakeholder groups and they all agreed that a combined approach to addressing the issues was needed (Reeves et al., 2015). Whilst this solution was addressed at all the professions, government policy focussed specifically on the nursing profession. By focussing on a single profession, such as nursing, there was a missed opportunity to strengthen the need for an interprofessional response to develop a culture of shared patient-centred care (Reeves et al., 2015).

A shift in the balance of power from the professional to the patient is required for health and social care professionals to work together with the patients at the centre. This presents challenges to the existing theoretical knowledge base of professionals. It requires professionals to ensure their use of critical reflection considers each individual patient or therapeutic encounter. Warne and McAndrew (2007) identified this challenge for mental health nurses. Mental health nurses need to relinquish their preconceptions of professional knowledge and allow for a deconstruction and reconstruction of that knowledge which takes into account the patient experience (Warne and McAndrew, 2007).

Collins (2014) proposes a conceptual model, the 'House of Care', which outlines different stakeholder responsibilities for a person-centred system of high quality collaborative support and care (Coalition for Collaborative Care, no date). The emphasis of people being involved in the design of services is at the heart of this model.

How person-centred care is enacted in reality is not clear in the literature, however the majority of people surveyed who were inpatients in 2013-14, felt they were treated with dignity and respect (NHS England, 2015a). Despite this overall positive finding, 20% of the respondents felt they could have been better informed; they were dissatisfied with the amount information provided about their hospital treatment or condition. The relationship between person-centred care and effective interprofessional working is not explicit in any of the literature. The most recent publication, the NHS Constitution, highlights 'working across organisational

boundaries' (NHS England, 2015a:4) and 'working together for patients' (NHS England, 2015a:5), but does not present explicit guidance for professionals.

Along with this vision for person-centred care, the evaluation of the outcomes of care requires specific person-centric measures being used in surveys and service evaluations. This drive for person-centred care also requires more exploration to identify how professionals work together to achieve this.

2.1.7 Evaluation of interprofessional working

As discussed previously, a large proportion of the literature focuses on the qualities, skills and attributes for effective interprofessional teamworking (Nancarrow et al., 2013). Factors have been identified in the literature, which contribute to effective teamworking. Focus on the reality of these competencies and capabilities in practice or the impact of teamworking on the quality of care delivered is limited in the literature.

The quality agenda aims to reduce patient complaints, increase patient satisfaction and decrease stress among professionals. Measuring effectiveness of interprofessional teamwork is complex; it can be measured at many different levels, team, organisational and systems level (Cameron et al., 2014; Reeves et al., 2010). Different methodologies have been used to evaluate effectiveness of the numerous interprofessional teamworking interventions from randomised controlled trials to mixed methodology approaches to capture experiences of those involved. Despite this, there remains limited literature in terms of quantity and rigour (Cameron et al., 2014; Reeves et al., 2010; Rummery, 2009; Zwarenstein et al., 2009).

Zwarenstein et al. (2009) carried out a systematic review of randomised controlled trials on practice based interprofessional collaboration interventions in health and/or social care settings. This review included other health and care professionals such as social workers, speech and language therapists and physiotherapists, which previous reviews had excluded. Only five studies met the inclusion criteria and were included in the review. The five studies evaluated the effects of three interprofessional activities, namely interprofessional ward rounds, interprofessional meetings and externally driven interprofessional audit. Only three of these studies demonstrated

improvements in patient care in terms of drug use, length of hospital stay and hospital charges. The limitations of this review, acknowledged by the authors, and discussed earlier, is the nature of the positivist approach adopted by systematic reviews. By excluding qualitative studies, the opportunity to gain a clearer understanding of the complexities of the effectiveness of interprofessional working is lost.

Cameron et al. (2014) conducted a review of the research published after 2000 relating to joint and integrated working between health and social care services. Instead of carrying out a systematic review, the authors adopted a review methodology advocated by the Social Care Institute for Excellence (SCIE). The studies reviewed included those with primary data and those with an explicit evaluation of a model of care. Whilst they conclude that the evidence suggests joint working can lead to improvements in health, reduce inappropriate admissions and reduce costs, they acknowledge that the evidence remains weak (Cameron et al., 2014). Few of the studies reviewed were comparative in design and therefore it is difficult to ascertain the effectiveness of integrated or joint working across services.

Studies have investigated interprofessional working in a range of specific areas such as critical and intensive care, intermediate care, stroke rehabilitation, palliative care, mental health, and primary care (Reeves et al., 2015; Nancarrow et al., 2013; Harris et al., 2013; King et al., 2004).

Harris et al. (2013) conducted a mixed methodology NIHR funded project to investigate the impact and effectiveness of teamwork across stroke care pathways. They obtained staff data from interviews and staff questionnaires and observed interprofessional team meetings using an ethnographic approach. The findings suggest that the quality of relationships between team members was an important determinant of team working. These relationships were facilitated by face-to-face contact at meetings, shared workspace and social activities.

Most of the literature evaluate the effectiveness of interprofessional working from the perspective of the professionals and focus on the process of teamwork. Hewitt et al. (2015) provide alternative findings of the patient outcome data and patient and carer interviews carried out as part of the study reported by Harris et al. (2013).

They found that patients and carers valued communication with team members provided; it matched their needs and relevant information was shared. Whilst the authors reported patient and carer perceptions separately, they were combined on occasions. They failed to acknowledge the complexity of the relationship between patients and their carers and the potential impact this has on their perceptions.

An interesting and relevant finding from this study highlighted that whilst interprofessional teamworking was considered important to the patients and carers interviewed, interprofessional teamworking was largely invisible to them. This is an important factor to consider when exploring carers' perceptions of effective interprofessional working. As collaborative working may not be always visible to carers, carers may find it easier to recount experiences of caring, rather than attempt to answer questions specifically focussed on interprofessional working.

In summary, three main assumptions exist in the literature about interprofessional working. Firstly, there is a common tendency to accept teamwork as the solution to the provision of effective care and services. As highlighted earlier, not all professionals are perceived or perceive themselves as belonging to a specific team. They may be based in a different setting within a different organisation, but they are still involved in the care pathway of a particular group of patients or service users. Professionals work together in different ways and varying service configurations will influence how professionals work together. The literature describes different ways of interprofessional working (Reeves et al., 2010). They can work as part of a team; in collaboration with others; networking or knotworking as originally described by Reeves and Lewin (2004). The focus needs to be on how professionals work together to deliver effective care and not on the effectiveness of the processes involved in a particular way of working.

Secondly, there is an assumption that there is a single model for effective teamwork, which encompasses all the various modes of interprofessional working. The literature clearly indicates the complexities of interprofessional working. The literature suggests these complexities may be better understood across four areas of individual, process, structure, environment (Reeves et al., 2010; Mikan and Roger, 2005) and the outcomes of interprofessional working can be experienced at three levels: patient or service user, professional and organisational (Xyrichis and Ream, 2007). In order to

address the difficulties and limitations in previous studies, my study aims to take an alternative approach to address the difficulties of determining the outcomes of effective interprofessional working. It explores the perceptions of informal carers of effective interprofessional working through the stories of their experiences of caring.

Thirdly, it cannot be presumed that effective interprofessional working will lead to effective health outcomes. Effectiveness can be measured in many different ways and it depends on the purpose of the study and the outcome measure chosen to determine this. A large proportion of the evidence on the outcomes of the effectiveness of interprofessional working focusses on process and generally rests on the perceptions of the professionals involved rather than on the perceptions of those in receipt of the care, namely the service user and their carer(s) (Sims et al., 2015b; Nancarrow et al., 2013). My study aims to address an exploration of the latter.

2.2 Informal Carers.

In the following sections, the term 'informal carer' will be explored in terms of definition, numbers and policy implications for those in the carer role and the resulting implications for interprofessional working. Literature on the involvement of the perspective of carers on research into interprofessional working will be explored and the implications discussed. Throughout this section, the term 'informal carer' and 'carer' will be used interchangeably. The terms 'patient', 'service user' and 'care recipient' will be used to represent the cared for person.

2.2.1 Informal carer: definition and statistics.

Informal carers are vital to the wellbeing and independence of thousands of people (DH, 2015a). An informal carer is someone who provides unpaid assistance and care for another person, usually a relative, partner or friend. The caring role can occur at any time, is not always predictable and is usually unplanned (Carers UK).

There are almost seven million carers in the UK. Out of the UK's carers, 58% are female and 42% of male. The number of people over 85 in the UK, the age group most likely to

need care, is expected to increase by over 50% to 1.9 million over the next decade (Carers Trust, 2015). The 2011 Census included a question on carers for the first time. It identified that working age carers are the largest group of carers in England and Wales; 4.3 million are aged between 19 and 64. One in four women aged between 50 and 64 (Carers UK, 2013b) and approximately 225,000 young carers and the 110,000 carers aged over 85 were caring for someone in England (NHS England, 2014a).

The number of people providing 50 or more hours of informal care a week has increased by 25% in the past 10 years. They provide a significant contribution to the UK economy. The economic value of the contribution made by carers in the UK is £132 billion per year, which is nearly equivalent to the total annual health spend (Yeandle and Buckner, 2015). This is set to rise with changes in demographics of people living longer, better survival rates from cancer and better survival and longevity rates of those born with congenital disabilities.

A survey by Carers UK (2015) highlights the increase in the total number of carers and the growing number of carers providing care between 50-100 hours a week. This is in response to the growing costs of paid care and in the cuts to the social services budgets (Carers UK, 2015).

2.2.2 The nature and characteristics of carers.

There are different ways policy and research has categorised carers: in terms of themselves, such as gender, age and ethnicity; in terms of the relationship with the person they care for, such as parent, spouse, partner, friend; and in terms of the medical condition of the person they care for, such as stroke carer, learning disabilities, cerebral palsy, acquired brain injury, dementia (Stalker, 2003; Twigg and Atkin, 1994).

The growth in the carers' movement in the early 1990s was followed by a change in direction towards a more generic view (Stalker, 2003). There are advantages to viewing carers as one, in providing a focus for policy changes and for service developments. Whilst it may also be helpful to look across the different groups of

carers, differences will exist and may not be dependent on the patient or client group they care for (Twigg and Atkin, 1994; Bond, 1992).

From their study involving 90 carers in the UK, Twigg and Atkin (1994:122) identified three typologies of the responses of carers to their role: 'engulfment, balancing/boundary setting and symbiotic'. Engulfment occurs when caring becomes the centre of the carer's life. These carers tended not to seek help and accepting help for themselves was difficult. The balancing/boundary setting approach was adopted by carers, who were able to separate the caring role and the need to have a life outside of caring. They were more likely to accept help. Some carers adopted this approach after involvement with carer support groups, while others felt or developed a less emotional connection with the person they cared for. The authors commented on the transition between these approaches, some carers starting in the engulfment mode and then with support from others, adopting the more pragmatic balancing/boundary setting approach (Twigg and Atkin, 1994). The symbiotic mode was observed in carers who saw a positive benefit from caring and did not want the caring relationship to end. Twigg and Atkin suggest this was commonly seen in carers who were parents of an adult child. Since 1994, changes will have occurred such as policy and the nature of caring. These typologies as representations of the caring role may not be exhaustive.

However, not all carers recognise themselves as a carer; they do not associate the title of carer with the role they undertake. This is commonly seen with parents and with partners or spouses (Stalker, 2013; Heaton, 1999).

Another perspective to the characteristics of carers is that provided by health and social care practitioners. Twigg and Atkin identified four typologies or models of carers as perceived by professionals and agencies: carers as resources; carers as co-workers; carers as clients and superseded carers (1994: 13). With the first, carers are seen as resources to provide free care for the cared for person and the carer role is expected by the professionals to be adopted by the carers and the wider informal support network. As co-workers, carers are seen as joint providers of care and their contributions recognised. There is some acknowledgement of the impact of caring on the carer. The primary aim of this model is to provide high quality care for the cared for person. As co-clients, carers are seen as clients in their own right with their own needs. The carers needs can be seen to override those of the cared for person, for

example in situations where respite care is provided. Finally, in the superseded carer model, the carer is seen as independent from the cared for person and are called family or relative rather than carer (Stalker, 2003; Heaton, 1999; Twigg and Atkin, 1994). In reality, these models are variable in practice, as not all professionals will share the same views as others. A more recent study is required to determine if these models of carers represent current health and social care professionals' perceptions.

The notion of co-worker has been identified more recently by James (2014) and Rand and Malley (2013). Carers' experiences with health and social care professionals varies between the different professional disciplines and the individual professionals. In particular, some carers interviewed by Rand and Malley (2013) felt they were consulted fully by professionals and were involved in decisions as co-workers; whilst others reported they were not perceived as co-workers and in fact were ignored by professionals on occasions. People, who care for relatives with learning disabilities, want to work collaboratively with professionals as co-workers (James, 2014). The group of carers, who are perceived by professionals as co-workers, tend to have a better quality of life than those who are not (James, 2014).

Each relationship between the carer and the cared for person is unique and the circumstances will vary in terms of context and dynamics. By categorising carers and the cared for person or service users as separate, this fails to acknowledge the relationship that exists between them (Lloyd, 2003).

Many carers provide perspectives of the needs of their relatives by proxy, namely those carers of children, adults with cognitive impairment such as following an acquired brain injury or adults with a learning disability or dementia. Robertson (2015) found carers who perceived dementia as an erosion of the person's identity, represented the quality of life of the care recipient less positively than those carers who saw dementia as a loss of skills and abilities. Further exploration is required to determine how effectively these carers' perspectives represent the real needs of the patient or the cared for person.

Caring occurs in a complex and unique relationship between the cared for person and the carer. The evidence argues for a more integrated approach, taking into account the complexity of the needs of the whole family unit (James, 2014; Stalker, 2003). In establishing the perceptions of carers of how professionals work together effectively,

the complex and unique relationships need to be taken into consideration when interpreting the findings from any study.

There is an increasing requirement for the contribution made by carers and the resulting needs of carers to be acknowledged genuinely by local and national government, health and social care professionals and employers (Rand and Malley, 2014; Roulstone and Hudson, 2007; DH, 1995).

The next section explores the development in legislation and policy around the role of caring.

2.2.3 Policy and informal carers

Over the last 20 years, there has been an increasing significance in legislative and policy developments placed upon the role of carers. The term carer first appeared in the literature around the 1980s (Stalker, 2003). The Invalid Care Allowance was introduced in 1975. Carers were recognised in various health and social care policies in the 80s and 90s, Caring for people (DH, 1989b) and the NHS and Community Care Act (DH, 1990). In 1995, the Carers Act gave carers the right to request an assessment (DH, 1995).

The White Paper, *Our health, our care, our say: a new direction for community services*, published in 2006 claimed to provide a new deal for carers (DH, 2006). It acknowledged the impact of caring on the carers' own health and called for 'a fundamental culture and shift in focus' (DH, 2006:192). It recognised the future demographic challenges and emphasised the need for a shift towards prevention and community based care. It advocated more joint commissioning between primary care trusts and local authorities and the requirement to acknowledge carers' needs in their own right and to provide support for carers.

The National Strategy for Carers was first published in 1999 and revised in 2010 (DH, 2010d; 1999). These publications acknowledged the growing numbers of carers and valued carers' contributions, recognising carers as experts and partners in care (Rand and Malley, 2014). In 2012, the White Paper, *Caring for our Future: reforming care and support* was published (DH, 2012a). This White Paper went further than the

National Carers Strategy and had three main objectives: firstly the identification and support of carers to provide them with the relevant information to carry out their role; secondly, the carers' ability to maintain their own quality of life and thirdly, the entitlement of carers to an assessment of their own needs.

Whilst the Care Act 2014 and NHS five year forward view (NHS, 2014a) build new rights for carers and promise to find new ways to support carers, nothing substantially different has been identified from past policy. Recognition and identification of someone in a caring role remains an issue, alongside the role of GP practices and the support of carers in general. The vision of a cultural shift promised in 2006 may have been acknowledged in policy, whether this has happened in reality is still questionable. Whilst the NHS GP survey carried out in 2014/2015 will have included carers as they are also patients in their own right, there is only one question directly referring to caring responsibilities. There is no follow up question asking about the quality of support and information given to carers (NHS England, 2015b). The question is simply used as part of the demographic section of the survey.

The expectation that family members will become carers, identified by Heaton in 1999, remains. Whilst the policy agenda has aimed to improve carer outcomes, limited consideration has been given to whether carers or care recipients want to adopt the role or receive informal care (Rand and Malley, 2014; Heaton, 1999). Discharge from hospital to home is an important transition for both the care recipient and carer. Both health and social care professionals need to work together to ensure carers are willing to take up the role and that they have sufficient support and information to take on the caring role (Glasby, 2004; Smith et al. 2004).

Despite the changes in legislation for carers to be provided with easier access to assessment and support, carers remain concerned over the amount of support they will get. In a survey of 4,500 carers carried out by Carers UK (2015), 55% of carers surveyed are worried about the cuts to social services budgets and the implications for the resulting support they will receive. Forty-two percent of the carers reported a reduction in the care and support provided by social services; this was due to either rising costs of the services or the services was closed and no replacements offered (Carers UK, 2015).

Stalker (2003) recommended a refocus on the complexities behind the actual experiences of caring. Despite new policy and legislation and the recognition of carers' contribution to the UK economy and the wider society, as promised in 2006 new ways of thinking and a cultural shift need to happen to more effectively support carers across the UK. The voice of carers needs to be heard to better inform health and social care policy and service delivery in the future.

2.2.4 Carers as 'expert partners in care'

As stated earlier, policy acknowledges carers should be perceived as expert partners in the provision of care (Rand and Malley, 2014). The rise in the carers' movement is well documented (Roulstone and Hudson, 2007; Stalker, 2003). Carers UK is the only national membership charity for carers in the UK. For over 50 years, it claims to have been at the forefront of the carers' movement for change. Alongside the Carers Trust (formerly Crossroads care and Princess Royal Trust for carers), Carers UK provide a collective voice for carers and they campaign for the rights of carers at local, regional and national levels.

The Carers UK national survey carried out in 2013, recommended all health and care professionals need to recognise carers as expert partners in care (Carers UK, 2013a). Only approximately 50% of the respondents reported they were involved with and consulted about decisions made. Carers have reported to be seen as a resource by professionals, such as providing transport to and from hospital appointment rather than being perceived as a co-worker or as an expert partner (Rand and Malley, 2014).

The concept of carers as partners needs to consider the relationship between the people involved in the caring partnership. Where the balance of knowledge, information, power and responsibility falls is under explored in the literature (Rummery, 2009). The call for the perception of carers as experts can be misleading for both carers and professionals. Carers' expertise comes from knowledge gained from the lived experience of caring for someone; this may involve in-depth knowledge regarding service provision or detailed knowledge of a particular medical condition.

This expertise is distinctive to the relationships between carer and cared for and to the context of the relationships.

Carers may have been given information following diagnosis or early on in their role as carers. This information is not always sufficient to answer all the carers' questions. They may want the opportunity to discuss their concerns with professionals who they perceive as the experts. The Parkinson's Disease Society (2008) reported on their findings of a survey of 13,000 people with Parkinson's and carers. Just over 3,000 respondents were carers. The majority (86%) of carers identified the importance of getting expert professional advice on the available health and social care services, but only 20% had actually received this.

Assumptions on the level of carer knowledge and expertise are made by professionals. Stigmatised views held by NHS professionals of people with schizophrenia has been reported by both carers and the service users (Jenkins, 2008). As Chief Executive of Rethink, Jenkins advocates NHS professionals become more aware of the condition to dispel these stigmatised views and to recognise the expertise held by this group of carers.

Whilst the different patient and carer organisations advocate carers are experts, not all carers view themselves as such. Carers can find themselves in the caring role unexpectedly and suddenly due to an unexpected event of a relative, such as a stroke or sudden mental illness (Nalder et al., 2012; Pereira and Botelho, 2011; Simon and Kumar, 2002). The person is expected suddenly to take up the role of carer and in these circumstances cannot be seen as experts (Kerr and Smith, 2001). They are new to the role and they may not even want to take on the role. This particular group of carers could be said to be in a situational transition (Pereira and Botelho, 2011). Pereira and Botelho (2011:2451) found the carers they interviewed experienced episodes of 'focussing and de-focussing' on giving care.

Despite being given information, which at times can be overwhelming, new carers report feeling isolated and are not always made to feel part of the care team (Nalder et al., 2012; Pereira and Botelho, 2011; Simon and Kumar, 2002). In these situations, new carers learn through the experience of caring and whilst they may have received information from professionals, the carers can at times become more anxious and not more informed on receipt of this information (Nalder et al. 2012). Whilst this group

may not be seen as experts, they want to be involved in decisions and be consulted by professionals. Nalder et al. (2012:2448) emphasise carers want to have another identity outside that of carer, namely they are 'also a caregiver'.

One of the issues facing professionals is how to involve carers in decision-making. Professionals may find it difficult to find time to talk to carers when resources are scarce and staffing levels low, whilst others may use this as an excuse to avoid the interaction. This was identified in by Walker and Dewar (2001), who carried out a qualitative study with the staff and 20 carers from an assessment ward for older people within a psychiatric unit. The carers identified missed opportunities for collaborative decision making, such as admission procedures, family meetings and discharge meetings. The carers also reported staff did not ask their opinions and in some cases decisions had already been made on their behalf by the staff. The extent of the involvement of carers in decision-making was dependant on individual staff members. There did not appear to be any consensus by staff to the commitment of involving carers in decision-making (Walker and Dewar, 2001). A paternalistic attitude was adopted by the staff towards the carers and they did not display any indication of valuing them as partners. Where these cultural barriers exist, genuine involvement of carers in decision-making will not be realised and carers will not be recognised as partners in care.

A particular area of concern highlighted by carers is around discharge planning (Carers UK, 2013a). The Association of Directors of Adult Social Services (ADASS) (2010) recommended a need to change attitudes and cultures of all health and social care professionals and agencies to treat carers as genuine partners in the discharge process from hospital. Glasby (2004) highlighted this as an issue years earlier and structural as well as cultural barriers were identified. This picture remains as the issues of poor discharge planning are still being reported (Rand and Malley, 2014; Pereira and Botelho, 2011). Further exploration of the factors underlying these individual, organisational and structural barriers is required.

The independent living movement suggests the concepts of care and caring reinforces the dependence rather than independence of disabled people (Stalker, 2003). It argues independence is about the ability to choose and have control over one's life. By using direct payments and personal budgets, the person requiring support is in control of

their own care. It cannot be assumed all people requiring support will want to use this model or this will have a positive impact on their carers. There is a need to recognise and respect these individual preferences in both policy and in the way, professionals work with carers and disabled people.

The Adult Social Care Outcomes Framework (ASCOS) 2015-2016 includes outcomes for carers and care recipients, however they are analysed separately (DH, 2014). Rand and Malley (2014) recommend exploring ways to capture this complex relationship in carer and care recipient outcomes by combining these together to establish any trade-offs or efficiencies.

Policy and carer organisations advocate carers as expert partners in care. This is not always realised in practice for the many reasons highlighted above. The role of carer is complex and the experiences of caring will depend on many factors.

2.2.5 The experience of caring and interprofessional working

The impact and experiences of informally caring for someone has been widely reported in the literature (Carers UK, 2015, 2013a; James, 2014; Rand and Malley, 2014; Nalder et al., 2012; Goodman et al., 2011a; Pereira and Botelho, 2011; Parkinson Disease Society, 2008; Sawatzky and Fowler-Kerry, 2003). Studies have explored the role of caring for specific groups of people such as people following stroke, older people with complex needs, adults with learning disabilities and children and adults following a traumatic brain injury.

Studies have explored the lived experiences of being a carer. This caregiving experience has been described as a transition process or life course (Nalder et al., 2012; Pereira and Botelho, 2011; Sawatzky and Fowler-Kerry, 2003). Carers are at different stages in this caring continuum and they may have experiences common to others or they may have different experiences. Each experience will be unique to each individual carer; however, studies have found commonalities within the carers' experiences.

For carers suddenly finding themselves in the role, feelings of loss of control over time and feeling alone were common themes identified in the early stages of caring (Pereira

and Botelho, 2011; Smith et al., 2004; Kerr and Smith, 2001). Sawatzky and Fowler-Kerry (2003) described these early days as life changing and consuming. Carers have identified failing expectations, particularly around the differences in their own perception of their needs and that made by professionals (Pereira and Botelho, 2011; Kerr and Smith, 2001). These noted differences varied from perceptions about the ability of the carer to adopt the role, to identifying suitable resources that address their needs.

In their study with 22 carers to explore the experiences of caring for people following stroke, Kerr and Smith (2001) found limited evidence of a seamless transition on discharge from hospital to home. A similar finding was identified by Simon and Kumar (2002). In their study, the eight carers of people following stroke identified holistic care seemed to cease at point of discharge home from hospital. The carers reported professionals had discussed discharge from hospital and any requirements for equipment or adaptations for their home; however, the provision of the equipment and follow up services appeared arbitrary and required a lot of effort and time on the part of the carers (Simon and Kumar, 2002).

The Care Quality Commission surveyed 59,083 patients' experience of their stay in hospital, with the majority of respondents being satisfied with the information given regarding period following discharge (NHS England, 2015a). Carers' experiences of this process were not captured in the survey, however the patients reported 50% of their families were given information regarding the period following discharge. Whilst there is a certain level of satisfaction with the information provided, the survey does not capture the extent of the provision of support and/or adaptations. Smith et al. (2004) found most of the carers in their study had to find out for themselves how to access certain services; the support they received was limited and some felt abandoned by the system. For those carers who accessed the voluntary organisations, the carers reported these agencies were the most important sources of information and support, rather than the health and social care professionals, particularly immediately following discharge from hospital (Carers UK, 2013a; Parkinson' Disease Society, 2008).

From the perspective of carers of older people in their study, Goodman et al. (2011a) identified continuity of care was important to them. Carers need to have a sense of security and knowledge of someone taking responsibility for the care of the older

person. The carers in Goodman et al. (2011a) reported this could be done by someone keeping in contact with the carer and older person. They wanted to have someone or a place where links could be made to professionals or other services in times of changing circumstances or times of crisis.

Another group of carers are those caring for someone who has been diagnosed as terminally ill. King et al (2004) explored bereaved carers' experiences of out-of-hours community palliative care and support services. The study ran alongside the evaluation of a protocol for handover from in-hours to out-of-hours services. The bereaved carers particularly valued personal relationships established with professionals. The researchers advocate an anticipatory approach for this type of service to ensure effective continuity of care with up to date information available for all professionals and agencies involved (King et al., 2004). It could be argued this approach is relevant for most services providing care for people in their own homes, such as community mental health services (Wynaden et al., 2006).

A group of carers not commonly researched are those who have relatives on intensive care units (ICUs) or acute medical wards. Reeves et al. (2015) present emerging findings from an ethnographic study of family carer involvement on ICUs in North America. Unsurprisingly, most carers acted as the proxy voice for their relatives when the relatives were not able to communicate for themselves. The carers in the ICUs found themselves to be the conduit for information between professionals and the nature of interprofessional working was observed to be more on a uni-professional level. The authors related this way of working as similar to knotworking (Reeves et al., 2010). The importance of relationships between the family carers and the professionals working on the units was highlighted as a central theme within the main preliminary findings.

The involvement of carers in the planning and care delivery for their relatives is facilitated if positive relationships exist with the professionals providing the care (James, 2014). Lindahl et al. (2009:462) go as far as to say that in care provided at home, 'professional friendships' should be developed as part of the professional relationship. This is supported by a carer in the study by Goodman et al. (2011a:78), who described a social worker who responded to the changing needs of her situation as like 'a friend holding your hand'. Carers want their role to be valued and listened to

by professionals and be involved with decision-making (James, 2014; Rand and Malley, 2014; Carers UK, 2013a; Sawatzky and Fowler-Kerry, 2003; Simon and Kumar, 2002).

The place of care is an important factor to consider when exploring the experiences of carers. Care provided in the home is different from care provided in hospitals as the role of guest and host is reversed. This will influence the dynamic relationships between carer, professional and cared for person. Lindahl et al. (2009) identified a need for professionals to alter the meaning of home. They argue the interaction between carer, the cared for person and the professional needs to take into account home as place and space.

As highlighted earlier, interprofessional working is not always visible to carers and the people they care for (Hewitt et al., 2015; Goodman et al., 2011a). The focus of both the patients' and the carers' reported experiences was around the actual care received and not on any observed teamworking process.

The carers of older people interviewed in the study by Goodman et al. (2011a) found it difficult to say what an indicator of effective interprofessional working would be. They highlighted continuity of care, timely information and follow up between different services, and respectful care delivery as important indicators for positive outcomes. The experiences they reported were focussed around periods of change such as discharge from hospital or an increase in need of care for the older person: periods of transition and crisis.

The carers interviewed in Hewitt et al. (2015) reported their observations of interprofessional teamwork were limited by physical constraints such as hospital visiting times or therapy sessions with the older person when the carer was not in the hospital. Teamwork was not regarded as a priority for both the service users and carers; however one of the carers reported that it was the outcome that was important and not the process of teamworking behind it (Hewitt et al., 2015).

Hewitt et al. (2015) found communication to be the most frequently reported observed indicator of teamwork; however, this communication was with the carer and the patient rather than between the professionals. The carers' and patients' priority was to have timely and adequate information.

The above two studies indicate a need for studies to refocus on the intended outcomes for collaborative working rather than the processes involved.

2.3 Summary

As stated earlier, the evidence of the effectiveness of interprofessional working is mainly measured from the perspective of those involved in the formal delivery rather than those in receipt of care (Sims et al., 2015b; Nancarrow et al., 2013).

The need for effective interprofessional working is seen in the many policies surrounding health and social care. The complexities in defining interprofessional working and the many influential factors on its effectiveness are well documented (Reeves et al. 2010); however many questions still remain, such as conflicting opinions on what works well, when, where, how and by whom (Zwarenstein et al., 2009). Many of the methodologies used in the literature to demonstrate effectiveness lack rigour and are not comparative in design (Cameron et al., 2014); however many fail to consider the perceptions from all the relevant stakeholders and in most studies perceptions are predominantly captured from the professionals' perspectives.

The impact of interprofessional working on service users and carers is not easily identified and the literature tends to focus around the experiences of service users and carers with respect to particular services. There is a tendency in the literature to group together service user and carer outcomes and not acknowledge the differences between the two groups. The acknowledgement of the complex relationships between service users and carers is limited.

From the lived experiences of carers of older people reported in the literature, the impact of transition and episodes of crisis are commonly reported by carers (Goodman et al., 2011a). On these occasions, carers reported requiring support or information from professionals and it was in these circumstances that interprofessional working or lack of it became visible to them.

The focus on teamwork is not always useful, as is the question of whether teamwork is visible or not to carers and patients. It can be questioned whether process outcomes and the nature of the different relationships are just as significant or important as the

end product. What is required are other ways of capturing carers' and patients' perceptions. Further exploration of carers' perceptions of effective interprofessional working is needed.

The next chapter outlines the methodology and the method I used to explore carers' perceptions of interprofessional working through their experiences of caring.

3 Methodology

The previous chapter outlined the background to and the focus of the study. It explored relevant issues surrounding interprofessional working, the influence of policy and the experiences of informal carers. This chapter outlines the theoretical perspective of the methodology and discusses the rationale behind the chosen research design and the way it was operationalised. It describes in detail the method of collection and analysis of the research data and explores the ethical issues pertaining to this study.

The study aims to gain a clearer understanding of effective interprofessional working utilising carer experiences and perceptions as opposed to using professional perspectives and policy frameworks. The study investigated the following research questions:

- How and to what extent does the interaction between professionals impact on the experience of caring for someone?
- What makes interprofessional working effective from the perspective of the carer?
- What are the implications of the findings for professional practice?

3.1 Research philosophy and theoretical framework

Researchers are guided by principles based on a paradigm which is based on epistemological and ontological premises (Denzin and Lincoln, 2003). This section discusses the research philosophy and theoretical framework, which underpinned the design of the study. These have been influential in the choices and decisions I have made throughout the research process.

Ontology is concerned with the nature of the world and what we know about it; whether there is a common shared reality or multiple realities, which are context specific. The aim of this study is to provide a clearer understanding of effective interprofessional working from the carers' perspective by capturing and portraying the multiple realities of caring through their lived experiences as carers. The reality of caring is complex and exists across a variety of relationships (Twigg and Atkin, 1994).

The cared for person as well as the carer has needs and interests and this will influence the experience of caring. I believe there are multiple realities of caring and that reality is socially constructed through the carers' individual interpretations of their lived experiences of caring. I am of the belief that my role is to understand these multiple constructions of meaning and knowledge and take a relativist ontological stance (Denzin and Lincoln, 2003).

Epistemology is concerned with ways of knowing and learning about the social world (Ritchie and Lewis, 2003). In scientific research, phenomena or findings are seen as independent and unaffected by the behaviour of the researcher; consequently, the researcher remains objective in their approach and the research framework can be seen as value free. This positivist or objectivist paradigm is not held by all researchers. In the social world, there is a held belief that the researched are affected by the process of being studied and the relationship between the researcher and those being studied can be said to be interactive. Findings are therefore not value free and can be seen as value laden (Denzin and Lincoln, 2003; Ritchie and Lewis, 2003).

As stated earlier, my study aims to gain further insight into the views of informal carers on effective interprofessional working and adopts a subjectivist paradigm. Carers' views are gained from their personal and unique experiences of caring. This study gave them a voice so that their own views could be captured and not those views constructed by others namely professionals. The study allowed them to tell their stories, however their choice of story or experiences will be affected by time and context. My study therefore takes on an interpretivist epistemology where understandings gained from the research are entirely dependent on context (Finlay, 2006).

A quantitative approach to the design of this study is not relevant as it assumes an epistemological framework of objectivity, that one reality exists and it measures a causal relationship within a value free framework. A qualitative approach is more relevant to this study as it assumes a subjective epistemological framework and that reality is socially constructed. It is more interpretive and inductive in nature and explores meanings and interpretations (Finlay, 2006).

I chose a subjectivist paradigm for my study as it is concerned with capturing the views and perceptions of carers of effective interprofessional working, informed by their

lived experiences of caring. The reality of caring is shaped and constructed by the carers through these experiences. Their views of effective interprofessional working are captured through their stories or narratives of caring. The study also aims to give the carers a voice (Kvale, 2006) to tell of their experiences of caring, their perceptions and beliefs of how effective care should be delivered. Denzin and Lincoln (2003:4) describe qualitative research as a 'situated activity that locates the observer in the world'.

Finally, the study adopts a participatory approach in its design with the involvement of two carers in the development of stories for use in subsequent interviews. Other carers were involved in the data analysis phase of the study.

3.2 My position in the research

It is widely accepted that in qualitative research the researcher is influential in the collection, selection and interpretation of data (Runswick-Cole, 2011; Finlay, 2006). My position as researcher in this study takes neither a totally objective and neutral approach to any assumptions or interpretations nor do I take the view that I play a completely active role in the construction of the findings; my position as a researcher is to produce a co-construction of the subjectivity of the carers' experiences.

Richardson (2006), in her ethnographic study of the culture of physiotherapy practice, discussed the choices made in the design of her study. She needed to gain her participants' confidence while they needed to be reassured of the credibility and legitimacy of the study. Whilst she could not remove her influence on proceedings, she could design the study to minimize this. This is a dilemma I faced; the need to understand my position as insider or outsider.

In considering my position in the research, I describe myself as having three 'selves'. As highlighted in the introduction, I am a Chartered Physiotherapist and as such, have a wealth of experience as a practitioner. Secondly, I am an experienced educator of health professionals, introducing them to the complexities of health care delivery and exploring the theories of effective working in my teaching. Finally, at the start of my

doctoral studies, I was the sole carer for both of my elderly parents. This was probably the most influential in developing my research questions.

As a carer, I experienced the consequences of the effectiveness or not of interprofessional working. This enabled me to empathise with the carers during the interviews. I also found it gave me an element of credibility with the carers. Finch (1993) in her study with vicars' wives suggested this is useful in establishing non-hierarchical relationships. Ritchie and Lewis (2003) who advocate a more realist ontological stance to social science research, suggest that the researcher should not divulge personal information and should remain neutral and objective throughout. This was a position I was familiar with in my past research. However, my study takes a more relativist assumption to the reality of caring and so I divulged my carer 'self' at the start of each interview (Finch, 1993). I also referred to it when I was asked direct questions by the carers.

As a health professional, I have experienced working with other professionals but I had not fully appreciated the impact of certain behaviours and actions on the experiences of others. This posed a challenge during the interviews as carers described situations where professionals had let them down and in some cases were very critical of health and social care professionals. It was challenging and presented a dilemma for me as a professional; however, I attempted to remain non-judgmental and genuinely acknowledge their concerns. I found my experience in professional practice enabled me to establish a rapport easily with the carers and put them readily at ease.

As an experienced university lecturer, I have explored ways of interprofessional working with my students and have discussed the evidence base. Whilst this level of understanding could have increased credibility with the carers, I attempted at all times to encourage the carers to share their thoughts rather than impart my own. In every interview, I attempted to retain an element of humility during the interview process (Legard et al., 2003).

These dimensions to my past experiences shaped my research questions and I wanted to explore effective interprofessional working from the carers' perspectives. One of the ethical dilemmas faced by a researcher who claims to be an insider is the credibility of the authenticity of the relationship. A researcher could make claims simply to obtain data from the participant. As a health professional, I could be at risk of mixing my role

as researcher and capitalizing on my skills as a health professional to obtain information from participants which they may later regret (Kvale, 2006).

To avoid this and guided by my ontological and epistemological standpoint, I took the position as a health professional researcher and carer exploring carers' perceptions of interprofessional working. I shared this with the carers so that my position in the research was transparent, to potentially put them at ease and for the carers to feel sufficiently confident to disclose their opinions and beliefs (Hayman et al., 2012). By doing so, I was attempting to balance the power dynamics in the interviews, acknowledging that absolute symmetry in the power distribution of researcher and participant may not be always possible (Runswick-Cole, 2011).

In their study with lesbian mothers, the first author in the study by Hayman et al. (2012) shared some of her own stories of motherhood with her participants in interviews. The authors suggest this story sharing promoted non-hierarchical relationships between the researcher and the mothers, as the researcher was herself a lesbian mother. Humorous stories were selected to break down barriers and the power imbalance. Feminist researchers have advocated reciprocity and some self-disclosure by the researcher; however, caution is needed if researchers truly believe they can have equal balance of power in the researcher and researched relationship (Runswick-Cole, 2011).

I believe there was not an equal position of power with the carers I interviewed. Kvale (2006) warns of the wolf in sheep's clothing. He argues as the researcher has the primary aim of collecting data, they are more likely to be in a more powerful position than those being interviewed. Whilst I shared my role as carer with my participants at the start of the interview, at no point did I fully disclose my experiences. Instead of adopting the approach used by Hayman et al. (2012) and using my own story of caring in the interviews, I chose to share two real stories, Grace and Crystal, in my interviews with the carers.

In order to capture my immediate thoughts and any potential influences on the research process, I made notes in my research diary following each interview and throughout the study.

3.3 Developing the method

The main decision in selecting an appropriate method is that it addresses the research questions of the study. From my ontological and epistemological position, my research was not setting out to establish facts based on one truth. It was not adopting a positivist paradigm. I was interested in capturing the views of carers of effective interprofessional working through their lived experiences of caring and as a researcher, how I could make sense of this.

There is a variety of methods of qualitative data collection available for selection. I could have used questionnaires however these would not have generated the depth and richness of data I wanted. A major limitation of questionnaires is they do not allow for detailed exploration of issues raised by the participants nor do they allow for clarification of questions (Robson, 2002). This would only be possible if an interview survey or structured interview was used. I discounted these in terms of the limitations in the depth and type of the data that would be generated.

Focus group interviews were explored as another method of data collection. Carers would be encouraged to share their thoughts in their own words, while being stimulated by comments from other carers. The carers may provide mutual support for each other, particularly in discussing difficult or emotive issues (Bold, 2012; Finch and Lewis, 2003). On a practical point, focus group interviews are an efficient way of qualitative data collection and are relatively inexpensive and can be set up in a short period of time (Robson, 2002).

The choice of focus group interviews presented me with a number of potential problems of using this method. My study aims to capture individual perceptions of effective interprofessional working through the experiences of caring. Focus groups may not provide each participant the opportunity to express their individual thoughts as extreme views of others may dominate the discussion. I was also interested in capturing individual stories and focus groups would have made this more difficult as I was not experienced with this method of data collection. Whilst it has been presented as a potential advantage, focus groups could be disadvantageous as participants may be less willing to divulge sensitive information to the group through fear of breach of confidentiality.

Focus groups require a common location for the data collection; this then limits the geographical area of the sample population of carers. Carers have limited spare time as the demand on their time for caring is high. Attending and travelling to a particular location may prevent their participation in the study or it may lead to their feeling obliged to attend and would present an ethical dilemma. This was one of the main reasons I chose not to conduct focus groups, as the main data collection method.

In order to capture the carers' experiences, in depth semi-structured interviews were used in this study. The interviews took place in a convenient venue for the carers, for example at the carers' centre they attended or in their own home. This addressed my concerns raised previously when considering focus group interviews. Interviews allow complex and personal experiences to be discussed and explored in depth and provide opportunity for clarification. The interview provides opportunity for the exploration of the experiences of each carer's personal perspective and allows the carers to tell their stories of caring in their own words (Runswick-Cole, 2011).

The semi-structured interview allows the researcher to follow a planned set of questions or prompts, whilst providing flexibility for a particular line of action to be followed if required. This allows new ideas and insights to emerge (Bold, 2012). The approach used and the expertise of the interviewer researcher impacts on the responses given by the participants. Too many direct closed questions can limit the responses and too many open questions can become uncomfortable for the participants if they are not sure how to respond. The nature of the language used by the researcher can be either facilitatory or inhibitory. This was not an issue for me as from my experience as a health professional, I was used to switching between everyday language and medical terminology as appropriate when working with my patients and their families.

The way in which the interview data is recorded can influence the interview process. Note taking, whether written or electronically captured can be distracting for both the participants and the interviewer, the latter potentially missing important data. Audio recording has more advantages and the recording device can be positioned unobtrusively, but within a suitable distance to capture the participant's voice. Digital recordings can be stored electronically and revisited, however transcription is time consuming. I found the latter to be very time consuming, however I felt it was time

well spent. It was in the transcription phase, my analysis of the carers stories began. Going backwards and forwards between listening to the audio recording and typing the transcripts, enabled me to become immersed in the carers' stories. I found this time valuable.

One disadvantage of using audio recorders is they do not capture gestures, body language and facial expressions (Bold, 2012). I did consider using video recording, however I felt it would be distracting for the carers. I was also not experienced in handling video recording equipment.

Even though the interview was selected as the main data collection method, I favoured the idea of enabling the carers to feel empowered to share their experiences. In his study with nursing home residents, Gubrium found that his respondents were biographically active as they may never have been asked to tell their story or been asked to consider their experiences in a particular way (Gubrium, 1993). The carers in this study can be considered similarly biographically active, in that they had stories to tell. This was confirmed by carers' comments at the end of some interviews and reflected in my diary. This will be discussed in detail later. The carers were asked to share their stories of caring. I wanted their story telling to be prompted by listening to others' stories of caring.

Eliciting stories or narratives from participants can pose problems and is not always straightforward. The use of trigger questions or prompts and examples of experiences can be helpful (Gubrium and Holstein, 2009). As a lecturer in higher education, I have used vignettes as part of my teaching to undergraduate and postgraduate health professionals. I found vignettes useful to provide exploration of issues and a useful contextual reference for further discussion. I also found the vignettes provided a powerful trigger to generate discussion of the students' own attitudes and beliefs. The use of vignettes or narratives in professional education is not new and can be a useful educational tool to promote critical reflection in the students (Bold, 2012; Blickem and Priyadharshini, 2007; Chambers, 2003).

Following discussion with my supervisors and exploration of the evidence on the use of vignettes, it was initially proposed to use vignettes in my interviews with the carers to trigger participants' thoughts and views on care. This initial proposal to use vignettes

and the final decision to use real stories in the interviews with my carers is covered in detail in my published article (Wright et al., 2014).

3.4 Use of vignettes in research

Vignettes have been used for a long time in research in the fields of social sciences and health. They are commonly hypothetical and are created by researchers using knowledge drawn from their own experience and scholarly work or from research findings. A vignette is a short piece of text, which simulates real life experiences (Schoenberg and Ravdal, 2000). Most of the literature suggests that the vignette is short or compact; however, the actual length of the vignette is not discussed widely (Spalding and Phillips, 2007; Brechin et al., 2003; Richman and Mercer, 2002). Hughes and Huby (2002) argue that short vignettes should be used with people with cognitive impairment; however, they give no indication of a suggested length. They also suggest vignettes are created and then commonly pre-tested to ascertain clarity, accuracy and relevance. Vignettes do not need to be in the written form; they can also be in other forms such as images, audio or video tape recordings (Jenkins et al., 2010; Johnson, 2000; McKinstry, 2000; Hughes, 1998).

Vignettes have been used across the health and social care disciplines in the form of surveys, interviews and action research to explore attitudes, perceptions, beliefs and awareness (Goodman et al., 2011a; Jenkins et al., 2010; Spalding and Phillips, 2007; Taylor, 2006; Hughes and Huby, 2002; Richman and Mercer, 2002; Barter and Renold, 2000; Schoenberg and Ravdal, 2000; Hughes, 1998; Finch, 1987). They have been mainly used in studies, which look at normative measures rather than experiences and have been used in both the qualitative and quantitative paradigms.

Within the quantitative paradigm, they have been used in large-scale studies (MacIntyre et al., 2011; Taylor, 2006; Johnson, 2000). Typically, participants are presented with a set of standardised scenarios as vignettes and then asked a set of questions with predetermined responses or categories. The participants in these studies include health or social care professionals, recipients of care and undergraduate students on professional programmes. A large proportion of the studies using vignettes are investigating decision-making, predetermining future

behaviour or evaluating strength of opinion using rating scales (Jenkins et al., 2010). This type of use of vignettes provides the ability to investigate complex issues with a large sample and generating data, allowing for comparisons and generalisations within a given population.

Spalding and Phillips (2007) explored the use of three different types of vignettes, snapshots, portraits and composites in an action research case study aiming to improve preoperative education for patients awaiting a hip replacement. The snapshots were based on observations from interview data and were mainly descriptions of events; the portraits were constructed from what was said in the interviews and included the researcher's interpretations of patients' experiences and the composites were constructed to convey a particular purpose. All the vignettes were constructed from primary interview data and then used for secondary data collection.

Similarly, Goodman et al. (2011a) utilised four vignettes in a consensus event to establish benchmarks for effective interprofessional working in services for older people. The vignettes were developed in previous interviews with service users and carers, however it is not clear how the vignettes were constructed and could have been either portraits or composites.

In contrast, Taylor (2006) used vignettes as decision aids in a factorial survey to determine the professional decision making process of social workers. He constructed vignettes and used them as a tool for data collection. The vignettes had a series of sentences that contained relevant factors to the decision making process. The sentences were in a fixed order; however, the factors varied randomly in terms of presence and level. Multiple regression was used to analyse the findings. Taylor argues that the use of vignettes in a factorial survey provides a rigorous method to investigate decision making in professionals. He goes on to suggest that the factorial survey uses both the strengths of an experimental design in terms of randomisation of factors and the validity of the survey, which simulates real life practice. He does not fully address the impact of the relationship between client and professional in the decision making process; this use of the vignette cannot replicate real life practice (Taylor, 2006).

Whilst vignettes can be used to generate large amounts of data from a larger group of participants, they can also provide a focus for discussion in individual interviews

(Goodman et al., 2011a; Hughes and Huby, 2002). Using vignettes can potentially improve the quality of data by reducing the influence of socially desirable responses that may occur in focus group interviews or one to one interviews (Hughes and Huby, 2002). Vignettes can also be powerful in stimulating reflections and discussion in participants (Goodman et al., 2011a; Spalding and Phillips, 2007). In my study with the carers I was planning to use vignettes to stimulate reflection and to facilitate sharing their experiences.

Another advantage of using vignettes is highlighted by Brechin et al. (2003). They used vignettes with carers to identify sensitive issues surrounding elder abuse. Individuals can be reluctant to disclose candid and personal feelings through fear of reprisal and the researchers felt that the vignettes took the focus away from the carers themselves and the carers referred to them to discuss their own experiences. Schoenberg and Ravidal (2000) echo this de-personalisation and suggest it encourages respondents to think beyond their own circumstances. The use of vignettes in this way can be less threatening to respondents and can distance the intimate and therefore threatening issues (Finch, 1987).

Using vignettes in interviews can provide a safe space for disclosure of information. Barter and Renold (2000) carried out research into violence amongst children and young people in residential children's homes and suggested the use of vignettes in the interviews allowed the young people to retain a high level of control over the research process. They found that once the participants had been given space and time to freely explore their responses to the vignettes, they more readily shared their own experiences.

Flexibility in the use of vignettes in qualitative research can be seen as an advantage. Vignettes can be used as a precursor to other methods such as an ice-breaker (Gubrium and Holstein, 2009); to close an interview or to be self-contained and generate data which can be compared across different groups. The choice of how to use the vignette should depend on the methodological and theoretical framework and the aims of the research. Schoenberg and Ravidal (2000) suggest the storytelling aspect of the vignette approach is relaxing, pleasant, interesting and may reduce the overwhelming feelings of being interviewed.

As stated previously, there are different uses and types of vignettes; for example, they can be videotaped rather than text based. Videotaped vignettes may be more readily retained and remembered than text based ones by interview participants (Hughes and Huby, 2002).

Limitations have been acknowledged by researchers, specifically that vignettes cannot exactly replicate real lived experiences and a large proportion of vignettes used in research are predominantly hypothetical in nature (Wright et al., 2014). Finch (1987) discusses issues around credibility when she initially developed vignettes containing eccentric fictitious characters that experienced disastrous events. The vignettes she developed later described events, which were more commonplace.

Barter and Renold (2000) found that the young people in their study were more enthusiastic about taking part when they were told that the vignettes were based on actual situations. However, they add caution in the total acceptance of this as they found that in one instance some of their young people appeared shocked to hear of incidents of peer violence when they had not experienced this type of violence themselves.

The use of vignettes can raise questions of truth and uncertainty. Some authors argue vignettes as representations, stimulate reflexivity and action planning and the pursuit of truth is for positivist not qualitative research (Bold, 2012; Spalding and Phillips, 2007).

It could be said that the voice of the individual is not reflected in the constructed vignette; however, this is dependent on how the vignette is developed (Wright et al., 2014). The aim of the research, the nature of the participants and the level of sensitivity of the area under investigation should be taken into account when considering using vignettes in research (Richman and Mercer, 2002).

3.5 From Vignettes to Stories

In contemporary society today, we are surrounded by stories of one kind or another. There appears to be a desire to tell one's own story to as wide an audience as possible and to also hear others' stories. This is demonstrated clearly through the increased use

of social networking sites, the many postings of videos on websites and the growing demand for appearances on television tabloid talk shows. Telling and hearing stories is not new; in fact, stories have been used for thousands of years to teach, inform and inspire from one generation to the next.

Generally stories have a beginning, middle, and end and are told around a main set of characters (Frank, 2010). A story commonly involves these characters passing through various events and encounters with others over a specific period. Bruner (2002) suggests that commonly there is a feature of stories, which sometimes is overlooked or not acknowledged. He identifies this as 'the coda'; that is, an evaluation of what it might all mean (Bruner, 2002:20). It could be included as a message or moral at the end of the story; sometimes it is left to the listener or reader to work out for himself or herself. He suggests 'great narrative is about problem finding and not problem solving' (Bruner (2002:20).

Autobiographical stories are created by people through their lived experiences or by their interpretation of those experiences. They may or may not accurately represent what actually happened. Smith and Watson (2001) agree and argue that the autobiographical story should not be interpreted as factual truth but an acknowledgement that the story lies outside 'any logical or juridical model of truth or falsehood; it lies within an intersubjective mode' (cited by Charon, 2006: 102).

Frank (2010) argues that stories pull patterns out of chaos and they reflect and symbolically represent people's experiences. He goes on to say that, stories provide templates for people to make sense of their experiences. When someone tells their story, it could be said they select episodes or snapshots of their experiences, that is, their own created vignettes. They select, whether consciously or unconsciously, what to include and what to leave out. To capture the stories of caring from the carers in my study, I needed my carers to be able to make sense out of their experiences and to reflect on their interactions with professionals.

Terry Pratchett in his novel 'Witches Abroad' suggests people are shaped by stories and not the other way round (Pratchett, 1991). He argues stories are parasitical life forms. Frank (2010) suggests that stories are symbiotic, in that they provide companionship, provide instructions on how to behave and they empower people by giving them the courage to act. In Corrie ten Boom's powerful testimony of her

experiences of her family providing shelter to persecuted Jews in occupied Holland, the co-authors John and Elizabeth Sherrill suggest the story does not just look at the past but also into the future (ten Boom with Sherrill and Sherrill, 1971). Corrie ten Boom's story spoke to them about the world that lay ahead of them. Memory and imagination are powerful influences in the construction of stories. The stories can permit the person to look back selectively to the past whilst shaping oneself for an imagined future. The stories can be constructed and reconstructed by the cultures that nurture the person (Bruner, 2002).

Charon and Montello (2002: xi) in their work on narrative ethics, highlight the 'unexpected utility and transformative power' of stories when using narrative methods in their clinical work with their patients. Bruner (2002) suggests stories tell people about the expected and about the surprises that upset the expected. He goes on to say that people are like a library, full of stories. Stories can be used to communicate important needs and offer a means of exploring these issues from multiple perspectives. They can be powerful in stimulating debate and promoting valuable reflection and dialogue (Hardy, 2007). Stories acknowledge the person's own area of expertise that is their own unique experience.

The emergence of narrative medicine is increasing and it is acknowledged through professional standards and regulation, through government policy and through global health issues (Wright et al., 2014). The failings in care reported by the recent public inquiry at Mid Staffordshire NHS Foundation Trust emphasised the need for organisations, senior managers and health professionals to listen to and act upon the experiences of patients and their families (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

Stories about oneself grow over time. Memories can be affected by these self-making stories. The story of what happened ten years ago may not be the original story that is told today. Rather it would be the new story about the person told in a way that has been shaped by ten years of experiences. Frank (2010) suggests stories provide an ontological dilemma; whether they are real or imagined. As stated earlier the experience and reality of caring is complex and the interpretation of what happened by the carers in this study some years previous may be interpreted differently some time later, but it is not imagined; it is perceived real for the carer involved.

In the health care setting, telling a story does not necessarily come easy for a patient or informal carer as the person may not know what needs to be told. The stories told can sometimes become the stories others expect them to be. Frank (1995), in exploring errors made in medical decisions, claims that some mistakes are made when there is a breakdown in the listening process on the part of the professional. He suggests that people, who are ill, tell their stories to make sense of their lives at a particular point of time. They do not tell stories in order to assist health professionals make decisions. Julia Connelly picks this up in her presentation of a case study in primary care. She stresses the absence of narrative results in unethical failure of medical care (Connelly, 2002).

The listener shapes the story and each person can bring a different interpretation. Telling a story will have an impact on the storyteller; it will also have an impact on the listener. The listener can empathise with the storyteller and can relate or not to the experiences recounted. This can be thought provoking and provide insight into ways of dealing with certain issues. It can trigger previous experience that may have been forgotten and provide insight which can lead to a change in future practice.

Experiences through stories provide a powerful resource for health professionals (Charon, 2006). All health professionals need to listen effectively to their patients and carers.

A medicine practiced with narrative competence will more ably recognize patients and diseases, convey knowledge and regard, join humbly with colleagues, and accompany patients and their families through ordeals of illness. These capabilities will lead to more humane, more ethical and perhaps more effective care (Charon, 2006: vii).

Charon argues this approach comes with a warning. She highlights a potential danger of streamlining the story. Professionals need to be aware that too much streamlining or fitting the story to preconceived ideas, can result in the loss of the most important information. Similarly, it can be argued that a researcher offers himself or herself as a sympathetic listener. The researcher then packs up these stories and uses them. The researcher has a moral and ethical duty to use them appropriately (Bold, 2012). I attempted to adopt this approach throughout my study so that my interpretation of

each story did them justice and reflected that of the carers and their voices were heard throughout the research process (Peled and Leichtentritt, 2002).

Carer involvement occurred in the data analysis phase of my study. They were involved in the verification of transcripts, the refinement of themes following thematic analysis, the development of the representative constructions and in the final production of the conceptual framework for effective interprofessional working.

People live by stories and their stories give a sense of meaning to their lives (Bruner, 2002). A person's expertise of their own life experiences is acknowledged through their stories. In regard to informal carers, stories are not just about the person they care for but about the experiences told through the people they care for (Frank, 1995). Hewitt et al. (2015) found that the patients and carers found it difficult to talk in detail about interprofessional teamwork. The authors found the use of the critical incident technique in their study did not effectively elicit accounts of teamworking. They concluded refinement of the questions and the approach used in the interviews may have facilitated more productive responses to the questions. As teamworking is largely invisible to patients and carers, I chose to use stories to elicit my participants' experiences. I used two real stories, 'Grace' and 'Crystal', in my interviews with the carers. These stories were obtained from, and developed with the two carers and shared with other carers in subsequent interviews.

In summary, the use of vignettes has been discussed and the power of stories explored. I have outlined and justified my rationale for using real stories instead of vignettes in interviews. The next section provides detail of the two-staged procedure I carried out.

3.6 Procedure

The study was carried out in two stages. Initially, the first stage consisted of the researcher working with a group of carers to develop a case scenario or vignette based on their experiences. This constructed vignette would then be used as a trigger in the interviews in the second stage. During this first stage, I made the decision with Grace and Crystal to use their stories rather than constructed vignettes in the second stage.

In the second stage, I carried out in depth interviews using the two stories from stage one to trigger participants' thoughts and views on their experiences of caring.

3.6.1 Recruitment of participants.

The study population for my research is informal carers who care for a relative or friend. Their caring role is not part of paid employment. This study is not confined to a particular group or category of informal carer. Instead, it is concerned with a more generic approach to the experiences of caring as an activity. Twigg and Atkin (1994) suggest that this generic approach has been influential in the activities of the carer lobbyists and that policies have been advanced by adopting this approach.

The inclusion criteria used for each stage of the study were that the participant: was in the carer role and had been for more than one year; was the main carer for more than 30 hours a week and was committed to engage with the study.

3.6.1.1 Recruitment for Stage one

In order to recruit carers for stage one, a letter was sent to all members of the researcher's Faculty service user and carer forum, explaining the purpose of the study and inviting them to participate. Copies of the recruitment leaflet and consent form can be found in Appendices I and II. Two carers from the group volunteered to participate in stage one.

3.6.1.2 Recruitment for Stage Two

The use of gatekeepers was chosen to assist in the recruitment of participants for this stage of the study (Wiles, 2013; Yeowell, 2010). The gatekeepers used in this study were either managers of carer centres or university groups. Their permission was obtained before any recruitment activity took place (Appendix III). Letters, along with a permission form, were sent to the managers of five carers centres in the north west of England. Only one of these centres replied with permission to recruit from its members. Reminder letters were sent to the other centres; however, there were no further responses.

A meeting was organised to discuss the study with the manager of the participating centre. Following the meeting, recruitment posters were then displayed around the centre (Appendix IV). The manager also invited me to attend the next meeting of the female carer group. I attended the group and presented an overview of the study to a group of female carers. In total six female carers expressed an interest to take part and the manager passed on their details to me.

In addition, I was invited to speak to a group for Pakistani female carers who also met at the centre. Following a similar format and with the help of a translator at the centre, I presented my study. Following the presentation, one carer expressed an interest to take part in my study. The coordinator of the group passed her details to me.

All seven carers who agreed to take part were sent a participant information sheet and consent form (Appendices V and VI). The female carer from the Pakistani carer group was happy to receive all information in English and felt she did not require a translator at the interview. She also requested her husband would like to attend the interview. All the carers replied with suggested dates and times for an interview. Two carers wanted to be interviewed at the centre, whilst the remainder requested to be interviewed in their own homes.

During this time, the manager of a service user and carer group at a university in the north of England contacted me. She had heard me present at an international conference and had discussed the study with her group. Several of her members were interested in taking part. The manager invited me to attend their next service user and carer group meeting. Three members of this group agreed to take part and an information sheet and a consent form was sent to them. Dates, times and venue were agreed with each carer. All three carers chose to be interviewed on their university campus. This particular group of carers all lived near the campus and preferred not to be interviewed in their own homes. The group manager organised rooms on the university campus for each of the interviews.

In summary, eleven carers in total were interviewed in stage two of the study. The focus of my study was to capture the experience-centred narratives or stories of caring and the interactions with health and social care professionals. Bold (2012) suggests that for this type of focus, the sample of interviewees will usually be small. The

recruitment of my carers was opportunistic, and relied on the carers being interested and willing to participate in the interviews (Bold, 2012).

3.6.2 Fieldwork procedure.

3.6.2.1 Stage One

Prior to the first meeting, both carers were briefed about the aim of the study and about their specific input in the meetings. Two meetings were planned to produce the vignette.

3.6.2.2 Meeting One

The first meeting was planned for two hours. For the venue, I used a meeting room in an office complex, which was within five miles of where both carers lived and which offered free parking. I was aiming to provide a more relaxed and informal setting than my university campus to facilitate discussion around a sensitive topic. The informality and neutrality of the chosen setting also aimed to reduce any notions of power. I arranged for refreshments and snacks to be provided for the meeting.

At the start, I explained in detail my study and the purpose of the two meetings. Following this, I obtained their signed consent forms. The carers, who were both female, were then asked to each choose a pseudonym. They chose 'Grace' and 'Crystal'. In order to establish a non-hierarchical relationship, I wanted to invest some of my own identity (Hayman et al, 2012; Wibberley and Kenny, 1994; Finch, 1993). I shared my three 'selves' by giving an overview of my background as an experienced academic lecturer, a health professional and as an informal carer. I then encouraged them to tell their stories and facilitated where necessary when they needed guidance, such as expanding on certain areas to gain more depth and expression of feelings, rather than to simply state facts. We discussed different approaches we could use to produce vignettes constructed from their experiences. We agreed that I would transcribe the discussions and then email the typed transcription to Grace and Crystal

before the second meeting. In preparation for the next meeting, I asked them to consider areas that they felt needed to be included in the proposed vignettes.

In the period between the two meetings, I had been reading the works of Charon (2006) and Frank (1995). Their work stimulated me to rethink the use of constructed vignettes and to explore the use of real stories in my interviews. A subsequent discussion with a colleague regarding her own use of narratives in research reinforced this decision.

3.6.2.3 Meeting Two

I allowed two hours for the second meeting and this was held at the same venue as before. I shared my thoughts of using the stories as they were told rather than creating shorter vignettes, which simulated some of the experiences of Grace and Crystal. Both Grace and Crystal were in agreement that they would rather hear a 'real' story than one that had been manufactured. The transcripts were edited to remove areas of repetition and changes were made to the chronological order of the text to improve the flow of their stories. Both stories were finalised in this meeting (Appendices VII and VIII).

3.6.2.4 Trial Interviews

At the start of the second stage of my study and in order to increase the rigour of my chosen method, two trial interviews were carried out using 'Grace' and 'Crystal'. I approached two people who I knew personally and were informal carers for their elderly parents. Both carers agreed to take part in the trial interviews. These trial interviews gave me an opportunity to practice my interview technique and to observe how best to use 'Grace' and 'Crystal' in subsequent interviews. They provided practice with the recording equipment and how best to position the recorder in different settings to avoid picking up external noise. The trials enabled me to appreciate my skills in interviewing. As an experienced health professional, this should have been expected; however, it gave me confidence in the preparation for research interviewing rather than therapeutic interviewing. The trials were useful as they picked up a

distracting habit of mine in that, in some circumstances, I attempted to finish sentences of the participants. This insight enabled me to be more careful to avoid this in the subsequent interviews.

Review of these trial interviews led to the following changes. Firstly, each story was digitally recorded so that in the interview the carer's chosen story could be listened to, rather than read out by the interviewer as originally planned. Secondly, more time was allowed for the interview session; namely two hours.

During this period of my research, I presented the first stage of my study at an international service user and carer conference. Following the presentation in discussion with the audience of service users and carers, academics and researchers, constructive feedback was obtained. This led to the following change for the second stage: typed copies of both stories would be sent to the participants prior to interview. Participants would then be asked to select one of the stories to listen to in the interview. My rationale for this was to give the carers more time to think about their own story before their interview.

Whilst some might argue these trial interviews should be considered as an additional stage of my research, I believe they form an important and integral part of the interview process as a whole; and I have chosen to present them as an essential component of the second stage of my study.

3.6.2.5 Interviews

In total, ten semi-structured interviews were carried out with the eleven informal carers; five interviews in the carers' homes, two in a room at the respective carer centre and three in a room on campus for the university service user and carer group. I carried out all the interviews and all interviews used the stories of 'Grace' and 'Crystal'.

If the interview took place in the carer's home, I contacted a colleague at the start of the interview and at the end of the interview. This enabled the ethical issues of the safety of lone working of the researcher to be considered and the risk reduced (ESRC, 2015). In order to ensure smooth running of the interview and consistency across interviews, I developed and used an interview preparatory checklist (Appendix IX).

Before the interview date, each carer was sent a typed copy of both 'Grace' and 'Crystal'. At the start of the interview, the carers were asked to select the story they wanted to listen to. After the carers had listened to their chosen story, they were asked how they related to the experiences of 'Grace' or 'Crystal'. During each interview, I had sight of an interview schedule with useful prompts and probes if required (Appendix X). I attempted to intervene little except where I felt the carer needed a prompt. I tried not to come in too quickly with these prompts so as not to affect the flow of the story and to allow the carer time to think. I tended to use prompts for clarification or for further detail on a particular point raised.

Two hours were allocated for each interview. The interviews varied in length from an hour and a half to two hours. I ensured that the interviews did not run over the two hours, in recognition of the carers' limitations in time due to their caring responsibilities.

3.6.2.6 Research Diary

I recorded fieldwork notes in a diary. Observations throughout the stages of the study and my reflections following each interview were captured in the diary. These varied from specific observations about the reaction and behaviour of the carers to procedural issues and particular practicalities. At times I was caught up in the interview process I forgot to make timely notes, however I made sure I captured my thoughts at a later date.

3.6.3 Ethical considerations.

Ethical issues arise regularly in the field of qualitative research (Denzin and Lincoln, 2003). Wiles (2013) indicates that there are conflicting views amongst academics on the need and appropriateness of ethical regulation in qualitative social research as they argue that the risks posed are minimal. Despite this, Wiles advocates the enhancement of 'ethical literacy' by qualitative researchers to understand ethical issues throughout the process and not simply to gain ethical approval by a research committee in order to proceed with the research (Wiles, 2013:1).

In the UK, there are established ethical frameworks developed by research funding bodies and professional and regulatory bodies, such as the Economic and Social Research Council (ESRC) and the British Psychological Society (BPS) (ESRC, 2015; BPS, 2009). My own regulatory body, the Health and Care Professions Council (HCPC) and my professional body, the Chartered Society of Physiotherapy (CSP), have a set of ethical guidelines for practice, which have influenced and shaped my behaviour (HCPC, 2012; CSP, 2011). Alongside these, my own moral beliefs and experiences will have influenced decisions made throughout the research process.

Ethics commonly refers to a set of principles or codes of conduct and the way the research conforms to that code. This set of principles can influence choices and actions taken throughout the research process (Wiles, 2013; Fouka and Mantzorou, 2011). Autonomy, beneficence, non-maleficence and justice are four common principles used in making ethical decisions in research (Wiles, 2013).

Respect for autonomy relates to non-coercion, informed consent, confidentiality and anonymity. Beneficence relates to the responsibility to do good, and non-maleficence is concerned with avoiding harm. Justice relates to the impact of the research being equitably distributed (Wiles, 2013; Ritchie and Lewis, 2003). This framework and guiding principles have been used throughout this study.

Ethics approval was gained for both stages of the study by the faculty research ethics committee. However, there were initial concerns raised by the reviewer of my ethics application over whether additional ethics approval would be required by the carers' centres approached to take part in the study. This was not the case and all managers of the carers' centres and of the university service-user and carer group gave permission to approach their members. No additional ethics approval was needed. Appendix XII contains the emails from the chair of my faculty ethics committee regarding this.

There are four main areas of ethical principles discussed for this study: informed consent; anonymity and confidentiality; protection of participants from harm and protection of the researcher from harm.

3.6.3.1 Informed consent

This involves providing clear information to participants about what participation in the study means for them, giving them the opportunity to decide whether to participate in the study. This needs to occur at all stages of the study so that participants have the right to withdraw at any stage of the study if they so decide. In studies, which involve recruiting participants from organisations, consent should be gained from the managers or directors of the organization before approaching group members (Ritchie and Lewis, 2003). I used gatekeepers for the different groups of carers. The gatekeepers were either managers or lead coordinators for the particular carer group or centre. These gatekeepers gave permission to approach their group of carers and it was the choice of each carer to go through the respective gatekeeper in order to volunteer for the study. I ensured individual consent was gained from each carer prior to any data collection. This was also to ensure the carers were free from any potential influence from the gatekeepers.

Written consent forms were produced for stage one and stage two and for the trial interviews prior to the interviews in stage two (Appendices II and XI). The consent forms were distributed to all carers participating in the study and to the managers of the various groups from which the carers were recruited. Participant information sheets were given to all participants and managers to ensure that they would understand what their participation would entail.

I made sure that the content in these participant information sheets was clear and was of sufficient detail to be clear but not too detailed as to be confusing. I considered how the information was presented, in terms of user-friendly terminology, language, layout, and font size. An example of the participant information sheet for stage 2 can be found in Appendix V.

The participant information sheet included how the data collected would be written up and how dissemination in the public domain was envisaged. This was an important issue for me as I had planned to share the carers' stories not only in journal articles and conference presentations but also in teaching sessions with health professional students. The participant consent forms included a statement regarding this issue.

3.6.3.2 Anonymity and confidentiality

Every effort was made to ensure that this study complied with the Data Protection Act 1998. The management of anonymity and confidentiality is closely related to issues around informed consent. To prevent the identification of the participants from the data, that is to ensure anonymity, each interviewee was given a pseudonym chosen by the participant. This information was only known to the carer and me, therefore complete anonymity did not occur however the identity of each carer was only known to me and remained confidential (Wiles, 2013). If a gatekeeper was used to approach a particular group of carers, the gatekeeper did not know the names of the carers, who finally agreed to take part in the study.

All the data collected during the study was therefore coded and all identifiable information was removed such as names of people, hospitals and towns. This included transcripts and field notes from the interviews. The codes were kept separate from the original data. I am the only person who has access to the codes.

All paper data was stored in my home in a locked filing cabinet. All electronic data was stored on two of my computers; one based at the university and the other at my home. Access to any data was password protected. It is planned that this data will be retained for seven years. A difficulty I faced regarding participant data was the information written in my research diary. I made sure I used the names chosen by each carer, rather than their real names, when I reflected on the interview process. My diary is stored alongside my paper data in a locked filing cabinet.

Digital recordings from the interviews were copied to digital files for transcription. The files have been stored on my computers as stated earlier and have been password protected. As one of the aims of my research is to give voice to the carers and to use their stories as a teaching resource, I included a statement to this effect on the consent form. All carers gave consent for this and when I use the recordings, I will ensure that the digital recordings used do not contain any identifiable information, thus preventing indirect identification of the participant. I have already used excerpts from their stories in the form of written text in teaching sessions and all identifiable information has been removed.

3.6.3.3 Risk factors: protecting participants from harm

The assessment of risk involves consideration of the potential for harm in terms of physical, psychological and practical terms such as cost, time and inconvenience. A number of potential risks to the carers were considered and procedures were put in place to address these. There would inevitably be an element of inconvenience for each carer with regards time; however, the benefit of expressing their views could outweigh this disadvantage. This risk was deemed therefore to be of a low level. In stage one of the study, the carers' travel costs for attendance at the two meetings were reimbursed. The time taken to travel to the venue was kept to a minimum as I agreed a mutually convenient location with both the carers involved in this stage of the study. In the second stage of the study where the carers were involved in individual interviews, I ensured that each carer was interviewed at a time and place convenient for them.

In terms of psychological issues, sharing their stories could potentially stir up sensitive issues for the carers and I ensured that if a carer appeared upset, I paused the interview with the option of terminating the interview depending on the desire of the carer. During the interview the participant may be freely disclosing information; however, it may become apparent that at the end of the interview they are left with feelings and emotions stirred up by the interview (Wiles, 2013; Ritchie and Lewis, 2003). I made it clear to all carers following the interview that if they did experience this and they wanted to discuss their feelings further, they were advised to seek counselling arranged through their local carers' centre or university group.

A particularly difficult ethical dilemma to deal with is that of the identification of a potential harmful risk to the participant. (Wiles, 2013; Ritchie and Lewis, 2003). I followed my professional codes of conduct at all times (HCPC, 2012; CSP, 2011). This was made clear in the information given to each carer prior to gaining consent.

3.6.3.4 Protecting researchers from harm

Any research involving fieldwork places the researcher at risk. Whilst this risk is usually small, a risk assessment should be undertaken prior to any fieldwork (Ritchie and Lewis, 2003). There are two types of potential risk to the researcher, physical and

emotional risks. In this study, I identified a potential physical risk if I was undertaking the interviewing in a carer's house. To address the risks posed by this, I had my mobile phone with me at all times and also had the option of taking a colleague along if I perceived any risk to myself. In addition, I had informed a named person of the location of the interview and of the time of arrival. I informed them when the interview has finished and had safely arrived back at work or home. The time of day and the location of the carer's house were assessed prior to any visit. Various recommendations and guidelines exist for managing the safety of researchers (CSP, 2005; Social Research Association, 2001). I made sure I followed these guidelines during the fieldwork.

One of the greatest risks to researchers has been identified as their emotional well-being (Wiles, 2013). Bloor et al. (2007) suggest this is a widespread concern amongst qualitative researchers. I built in formal debriefing time with my supervisor to discuss my feelings following each interview. I also utilised an action learning set with other colleagues undertaking qualitative doctoral research. This gave me time to reflect and discuss my feelings and to offload any anxieties raised following the interviews if the need arose.

3.7 Data Analysis

My study utilised a naturalistic qualitative research design and aimed to explore informal carers' perceptions of effective interprofessional working. The method of analysis used needed to be inductive and data driven. Thematic analysis was chosen as it aims to identify, analyse and report patterns or themes within textual data (Braun and Clarke, 2006; Attride-Stirling, 2001). Braun and Clarke (2006) propose thematic analysis captures experiences, meanings and the reality of participants. I was guided by a combination of the method outlined in Braun and Clarke (2006) and the analytic hierarchy advocated by Spencer et al. (2003).

I transcribed all the interviews. Whilst this took a considerable amount of my research study time, I felt it was a necessary evil. My study time was precious to me and difficult to plan for, as I was balancing full time work with doctoral study. However, by transcribing the interviews myself, it allowed me to be immersed in my data; a concept

my supervisors talked about but one I had never fully appreciated. This allowed me to stay close to the original data and I found this facilitated the extraction of meaning of my data at an early stage; a process advocated by Braun and Clarke (2006), who highlighted transcription as an interpretative act.

Once each transcript was completed, I sent a copy to each carer. I did this for several reasons. Firstly, I promised them at interview I would send them a copy. Secondly, in line with my ethical and moral approach outlined earlier, to provide verification and agreement with the way I had transcribed it and to offer an opportunity for feedback. I waited for a response from the carer before analysis of the transcript commenced. A copy of a completed transcript can be found in Appendix XI.

Each transcript was read and re-read and initial codes were identified for each interview (Braun and Clarke, 2006; Spencer et al., 2003). At the same time as reading the transcripts, I listened to the recorded interviews to refine the initial codes. This allowed me to familiarise myself with the data to a much greater extent than just reading the transcript. It also triggered memories of the actual interviews and the way in which the words were spoken by the carers. This allowed me to make better sense of the data by moving backwards and forwards between the interview data and the initial codes.

Figure 1 is an example of the initial coding I derived from one extract of data. Following this, initial codes were identified for each carer’s interview and were tabulated for ease of reference.

FIGURE 1 DATA EXTRACT WITH INITIAL CODE APPLIED

Code	Place	Data extract
Reluctance to complain/fear of reprisal	Page 1 Line 53-56	That’s when we realised if we said anything it came back on you, because my sister had just thought when she said have you any concerns, you know, if they just said something it would save you saying it. So we never had anything to do with them after that, the Stroke Association, but maybe we should have had; it wasn’t her fault. But it sparked a thing off.
	Page 1 Line 58-59	When we do say things it seems to get twisted and come back so we try to keep quiet about a lot of it, really.

The next phase of the analysis involved identifying initial themes. A thematic map was created using large flip chart paper and many post-it notes. Each post-it note represented an initial code. I discussed these with my supervisors and with colleagues experienced in qualitative research methods. Relationships between codes and themes and sub-themes were explored. A set of initial themes was derived.

At this point in the analysis of my data, I felt I had not entirely answered my research questions. I felt there was another layer of meaning I had not captured or explored sufficiently at this stage. As I had not had a lot of previous experience in using narrative approaches in research, I arranged to meet with my supervisors to discuss this. When I met with them and presented my findings, I found I was talking about the carers as different types. I distinctly remember talking about the fighters, the dutiful and the carers who were knowledgeable and how their experiences were similar yet their responses were different.

I provided the carers opportunity to tell their stories of caring in the interviews, I wanted to capture these narratives in my findings and not allow their contribution to be lost in a more homogenous account of the findings (Gubrium, 1993). I grouped these care narratives into similar typologies or orientation groupings (Gubrium, 1993). I constructed the carers' stories into care narratives, to represent the whole story rather than fragmented parts as represented in the themes. Bold (2012:145) uses created stories in her research; she refers to these as 'representative constructions'. She emphasises the challenge for the researcher is to retell the participants' stories so that their voices are captured in a way that meaningfully represents their experiences (Bold, 2012).

The aim of my study is to explore the perceptions of effective interprofessional working through informal carers experiences of caring. I chose to use the care narratives as part of the analytical process to provide insight into the realities of caring. I believe this will enable health and social care professionals to have a better understanding of the realities of caring and subsequently deliver person centred collaborative care; a belief which is highlighted by Blickem and Priyadharshani (2007).

As part of the refining process, I chose to share this stage of my analysis with the Faculty Service user and Carer group, from where Grace and Crystal had been recruited. Grace and Crystal no longer attended the group and I presented my initial themes and the care narratives to the rest of the group, which consisted of service users, carers and academic staff from the faculty. I did this partly to gain external verification and partly to provide me with further stimulus for my continuing refinement of the themes.

The majority of the group supported my findings and said it reflected their experiences whilst one carer recommended I change the wording of one of my themes. The group was unanimously supportive of the use of the care narratives. They felt they provided more depth and insight into the carers' experiences of interprofessional working than just the themes alone. They also provided me with some words of caution; I needed to acknowledge the orientations and groupings identified could change over time. This whole experience provided me with an opportunity to vocalise my findings to an audience who have had similar experiences and to provide a level of trustworthiness to my data (Bold, 2012). It also served to boost my confidence at a time when it was waning.

As Grace and Crystal no longer attend the Faculty Service group for various reasons, I contacted them individually to see if they would be able to assist in the final stages of the analysis. Grace responded and she agreed to meet up. The analysis was shared with Grace prior to the meeting and during the meeting. Grace shared her initial thoughts regarding the narratives, the initial coding from the interview transcripts and the identified themes at that stage in the analysis. I explained the process used to identify the themes and subthemes. The sub themes were reframed and the main themes reworded to capture the overall findings.

Following this meeting with Grace, the themes were finalised, defined and named. It is important to acknowledge the influence of my three selves on the analysis of the data and identification of themes; it was primarily through this theoretical lens that I identified the main themes and representative constructions.

4 Findings and Discussion.

Introduction.

This chapter presents the findings from my research and includes discussion of these findings in relation to the existing evidence.

The implications of the findings for individual professionals, the provider organisations, pre-registration and post-registration education and policy makers are explored.

Strengths and limitations of the study are included in this chapter.

4.1 Findings

My study utilised a naturalistic qualitative research design and aimed to explore informal carers' perceptions of effective interprofessional working. My method of analysis was guided by a combination of the methods outlined in Bold (2012), Braun and Clarke (2006) and Gubrium (1993) and the analytic hierarchy advocated by Ritchie and Lewis (2003) to enable the analysis to be inductive and data driven, but to also capture the stories of the carers' experiences. My three 'selves', identified in previous chapters, played an influential role in the lens used to view the data and in the development of my findings.

My findings are presented as follows:

- Each carer is introduced with a summary of their experiences, as 'representative constructions' (Bold, 2012:145). The relevant demographic information of the carers is included within these constructions. Specific ages, ethnicity, gender orientation, social class are implicit, rather than explicitly stated.
- Three orientation groupings are explored (Gubrium, 1993).
- The key broad themes are presented, illustrated with quotations from the carers.

- A final synthesis and discussion of the findings includes reference to literature and relevant theoretical concepts.

4.1.1 Introduction to the carers- representative constructions

I have chosen to present my carers in terms of their stories rather than in terms of demographic data. Goodrich and Cornwell (2008) in their point of care review acknowledge the effectiveness of stories of providing a different perspective on care from those held by professionals and managers.

Patients' stories have a unique power to engage and move listeners and provide invaluable insights into the relationship between the care process and the patient's world. They provide material from which it is possible to generate hypotheses about relationships between events and causes and are the source par excellence for evidence of the reliability and consistency of standards of service over time and in different settings. (Goodrich and Cornwell, 2008:10).

Bold (2012) believes stories as a type of narrative assist in constructing and understanding social events and settings. I have constructed a story for each carer using the data obtained from the interview with each carer. The stories can be said to be based on facts, however they are fictions as I have constructed them from my own interpretation. Bold prefers to call these fictions 'representative constructions' as the story is a form of analysis and reporting of the data collected (Bold, 2012:145).

Whilst the demographic data of the carers is implicit within their representative constructions, it is worth noting the diversity of the carers in my study. Eleven carers were interviewed: ten female and one male. All the carers were adults with the age range spanning 40 years, with Karan in her early thirties up to Hilda at 75 years old. The ethnicity of the carers included white British, mixed ethnicity (white and black Caribbean) and Pakistani British. The relationship between the carers and the cared for included carer of a child, a parent, a partner and one carer Judy, was a volunteer carer on behalf of a local authority.

4.1.1.1 Ava

Ava has cared for her elderly mother Helen for six years since Helen had a stroke resulting in left sided hemiplegia. Ava and her second husband live with Helen in the family home. Ava moved back to the family home years previously, following the breakup of her first marriage. Ava's father was alive at the time but then became ill and needed to be cared for. Ava helped Helen to care for her father. When her father died and she married her second husband and they continued to live with Helen. At that time Helen was leading a very active life until she had a stroke.

Ava has a supportive family, three sisters and one brother who live near. Her sisters help her when they can. Helen has additional support from paid carers. Ava's husband works full time and Ava is in part-time self-employment.

I interviewed Ava in their home. Helen was sitting in the same room as us, but fell asleep at intervals throughout the interview. When I spoke to Ava initially to arrange the interview, she needed reassurance that what she said would not be used against Helen and the family. Once she was reassured all names would change in the transcripts and she would receive a draft of the interview transcript to check and approve before I could use it, she agreed to be interviewed. It became apparent during the interview Ava and her family had experienced defensiveness from health professionals when she and her family had challenged poor care.

When Helen was first in hospital following her stroke, the family were approached by the Stroke Association and asked if they had any concerns about Helen's care. Ava's sister responded:

She said about these tablets and she said they keep giving her the tablets on a spoon at once. So she said she'd go and see them about it and the sister of the ward came flying down the corridor and said, "What have you involved them for" and she was quite nasty to my sister. That's when we realised if we said anything it came back on you.

Ava found the professionals' opinion of Helen's progress lacked clarity, especially regarding their recommendations for the future. They were inconsistent with the information regarding her discharge plan.

The OT they had at the time didn't do much and then we had a meeting with everybody, the family and all the professionals and the nurses said to us don't worry. They said all what they thought to us, but when we went into the room, they changed what they'd said, they sort of lied. They told us she was doing well and we'll get her going. But when we went into the room, they said "oh no she'll never do anything." They just said she had to go in a home and that was that.

Ava was transferred into a nursing home, but she was extremely unhappy and the family wanted to have her at home. They called a meeting with social services. On this occasion, Ava felt the professionals seemed to be listening to the family rather than deciding between themselves what was needed for Helen.

So we had more meetings with physios, the community ones, social workers and we got it set up. We had a brilliant OT and physio community and they came and looked at the house and they said what we could do and they said they'd get the equipment and we'd try it. She's been home six years now.

A new social worker was involved with Helen's care and he made a referral to the re-ablement service, which Ava believed to be highly inappropriate with respect to her mother's physical abilities and needs.

Maybe that's part of the thing that people don't read back; even GPs don't read back.

She was also unclear where the information regarding Helen's ability and needs was recorded and who had access to it.

I assume they have a big file somewhere. I always think it's on computer and they've got access. I don't know.

Ava and her family remain concerned about the information in Helen's notes. They wonder if there are statements about the family complaining. They remain concerned

that professionals will be negatively influenced by another professional's opinion. They remain reluctant at times to challenge and raise concerns.

We have trouble because my sister saying my mum's notes are following her around and if someone wrote something like it did in the hospital at the beginning, is that why it keeps coming back on you. Has it followed round? You don't know. If you have trouble with one professional it doesn't mean you're going to have trouble with another. But these are all the questions. You don't sit down and think about it. You just deal with the thing at the time and move on and you're surprised when it happens again.

Ava recommends that future professionals must not try to cover up their own and others mistakes and should be open and transparent regarding the care or treatment they have given. They should not be defensive when challenged.

4.1.1.2 Hilda

Hilda is seventy-six years old and has been married to eighty-year-old Arthur for fifty-six years. Arthur had a severe stroke eighteen months previously and Hilda is now his main carer. She currently pays for additional help through a care package. Hilda had previously cared for her one hundred year old mother for six years until her mother died. There was only five months between her mother dying and Arthur's stroke. Hilda and Arthur had only one holiday together before Arthur had his stroke.

I first met Hilda at a carers' resource centre when she had responded to my advert for volunteers. She told me she found support from talking to other carers. Hilda chose to be interviewed in her home as it was costly to bring in additional care for Arthur. I interviewed Hilda in her sun lounge whilst Arthur slept in his chair in the adjacent room.

Hilda's role as carer for Arthur happened suddenly and occurred five months after she had cared for her mother. It was a natural assumption for Hilda to care for Arthur.

You do it willingly; you have to do it, there's no two ways about it. We've been married for fifty-six years so I'd hope he'd look after me as I look after him.

Hilda was uncertain whether the professionals talked to one another as she experienced both lack of support and lack of equipment needed to care for Arthur. When Arthur was discharged from hospital, there was a lack of a coordinated approach to the supply of equipment for home. Hilda and Arthur lived in one locality and the hospital fell under another locality. Whilst Hilda challenged the lack of support and lack of equipment she needed to care for Arthur, she accepted that it was both stressful and inevitable.

Well I just felt it was politics between the two councils to be quite truthful but it was very stressful. Anyway, this was new to me, Arthur with a stroke.

Despite home visits and assessments from a range of professionals, Hilda had to wait a long time for the required adaptations and the apparent lack of collaboration between them.

We got the social services, she was the OT. She came to the house and assessed everything what Arthur would need and it took thirteen months before anything started. We lived in the living room with the hospital bed downstairs. I sat in a deck chair for thirteen months in the living room. The carpet was absolutely horrendous. Erm... he couldn't have a bath. Oh that's good to put down I suppose. He never had a bath or a shower for thirteen to fourteen months.

Her main frustration was the need to repeat information to professionals and she suggests a central database of information to facilitate better working between professionals.

Have one central computer that's not just for one but for everyone: care, social, doctors, all homecare, the OTs, district nurses that come here. If it was all together in one place so they could see what was going on. If I rung one of them people they could look and see if anyone else had been involved.

Despite a range of professionals being involved with Arthur's care, Hilda still felt alone.

4.1.1.3 Karan

I interviewed Karan in the carers' resource centre from where I recruited some of the carers. Karan worked part-time in the centre and told me she wanted to participate in my research so the voice of the carer could be heard.

Karan started caring at the age of 20 years and left school with no qualifications. She looked after her mother who had chronic respiratory disease. At the start of her carer role, she did not recognise herself as a carer. She accepted it was her role as a daughter.

Well I'm the daughter you see. I get this from my dad. You're the daughter and it's your job to do. Even though I'm working full time.

She also found herself caring for other members of the family and soon felt the impact of this role on her self-esteem and confidence.

Karan recalled the time her partner was in hospital and how the professionals failed to recognise her as the main carer despite it being recorded in his records. She was reluctant at that time to challenge the professionals. She also found that some professionals share a negative perception of the carers' role.

I felt like I was begging for something and I was actually stating I will be caring for him and he actually pooh poohed it. "He's got his doctor here and the district nurse will come out and do his wounds. You don't need to do anything. There's no need to have a title love". That's how I felt.

Over time, she started to attend the carers' resource centre and gained numerous qualifications. Her self-confidence grew and she began paid employment at the resource centre. Karan has gained confidence through her experiences as a carer and

in her journey from novice to expert carer. She feels the professionals should take a more active role in listening to the carers and working together to identify and meet the needs of the carer and the person they care for.

I think what's got worse is that there are more people needing help. I think, you know, low needs, medium needs and high needs. I think there are more people or services needed to intervene at the low needs so that it doesn't get any further. Maybe it's that that's getting missed. It could have been stopped at the low needs and stopped from getting to crisis. I think if that carers' issues are identified early on it could stop this getting to the higher level if you start talking about funding, we could reduce...

In addition, they fail to communicate with each other regarding the needs of the family unit. She strongly advocates that this should be identified and communicated to the relevant professional or professionals for action.

It's not rocket science that if you go into the GPs or even for me it could start at the chemist. 'I've bathed my dad and I've noticed he's got a bed sore or he's not making it to the toilet'. Someone must go somewhere and discuss this, whether it's the GP, as soon as there is a link to being a carer. Whether that's through carer awareness which is what I do.

She continues to be an advocate for other carers in her work at the carers' resource centre.

But I like to be the voice of carers where I can, because carers have a hard enough time and they haven't got the capacity to speak and have a voice and they get pushed to one side and pushed in the gutter. I think it's our job to make a difference.

4.1.1.4 Parveen and Hussain

I met Parveen at a meeting for female Asian carers. Parveen and her husband Hussain had recently moved to the area and were struggling to access services for their son Kenny who has cerebral palsy. Parveen volunteered to take part in the study and she

wanted her husband Hussain to be part of the interview, work permitting. I agreed to interview them in their home.

The family came to live in the UK from Pakistan when Kenny was thirteen. They first lived in Scotland and then relocated a year later to the North of England due to a change in Hussain's employment. Parveen was a secondary school physics teacher in Pakistan; she has not been able to work in the UK. In Pakistan, Parveen taught Kenny at home and provided physiotherapy and speech and language therapy herself. Her family encouraged her to have another baby when Kenny was seven. Parveen reported Amir as being 'quite normal'. From this time, Parveen no longer had time to provide physiotherapy and speech and language therapy for Kenny. They experienced different levels of care between Scotland and England. Parveen found support through her faith, but she worried about the future for Kenny.

When I interviewed Parveen and Hussain, Kenny and Amir were at school. Hussain was only able to stay for half of the interview due to work commitments. When they lived in Scotland, Kenny had received physiotherapy and speech therapy through his school. Both parents agreed it was effective and all the professionals worked well together. Since moving to England, Parveen and Hussain have been told they had to start again to organise Kenny's care. Hussain was particularly frustrated about the situation, whilst Parveen appeared to be resigned.

Both Parveen and Hussain questioned why the organisation of Kenny's care should be different from Scotland. It did not appear to be simply a lack of resources as they had friends who lived in other areas of England and they received appropriate care. Kenny was waiting for an initial physiotherapy assessment seven months after the move to England. Parveen had been told by her GP that Kenny was on the waiting list for physiotherapy; she felt,

They are not working actually. The service is not good. They are not serious about this special people.

Parveen was having to cope alone and provide therapy herself for Kenny. His unmet needs were not being addressed by the relevant professionals. She accepted this, as

she had to manage on her own in Pakistan; however, she felt she could not cope for much longer as Kenny was growing and becoming too heavy for Parveen to manage.

Whilst they were in Scotland, Kenny was referred to a paediatric neurologist who diagnosed a type of epilepsy and recommended Kenny wear a monitoring device to enable a detailed diagnosis to be made. At this time, the family moved to England and they took a letter from the neurologist in Scotland to their new GP. This GP said he would have to refer to a local neurologist before a monitoring device could be supplied. Kenny was referred to a neurologist but unfortunately, the GP did not send the relevant medical records. The neurologist said he would need time to access the information and the family were given another appointment for 6 months' time.

Both Parveen and Hussain found the GP practice staff unhelpful and obstructive. They believed that they should be more flexible in their approach to the needs of their patients when making appointments. Parveen had a routine appointment with the GP and Kenny had developed a high temperature. She was told that she could not have an appointment on the same day and,

...we are not childcare centre. This is your problem.

Parveen and Hussain do not hold their GP solely responsible, they believe the bureaucratic procedures are to blame.

GP is sitting in second and third layers and it is very difficult to get in.

Parveen experienced effective care in Scotland and she has clear views on what effective interprofessional working looks like.

It is again the connection between each other. If a letter comes, it must go to everyone. It is not difficult in this time of fast media links. Cc names and copy will be sent. Even the GPs can send us the reports on our email addresses and these are our reports. He has staff. One can do this; one can answer email or send reports to everyone. There must be some staffs for families with special

children to link with schools or other agencies. It doesn't have to be the GP; somebody needs to be doing it. I don't know if it will be possible in the future.

4.1.1.5 Bailey

I first met Bailey when I presented my research at a University service user and carer group. As soon as I had finished my presentation, she rushed over and said she wanted to be involved with my research. I arranged to interview Bailey at the university, as this was the most convenient venue for her. From first meeting her, I recognised her to be a passionate and determined woman who would not give up easily.

Bailey is a single mother to her son Lenny, who is now 22 years old. Lenny has attention deficit hyperactivity disorder (ADHD) and other associated co-morbidities. She has been Lenny's carer for most of his life until recently when this has become more difficult. She has another daughter Ebony, who is 12 years old. Bailey is the eldest sibling and has helped in raising all the other children in the family. She also used to work with children. She found professionals were reluctant to listen to her and dismissive of her opinions, especially when Lenny was young.

I'd obviously got the health visitors coming in and then when they stopped coming when he was two or three years old, he was really hyper. The GP wasn't really saying much apart from, 'he's healthy, he's fine, he's not underweight or anything. He's a bit active and he's very bright. You get this with bright children.

As Bailey gained more insight and knowledge, there was an increase in media coverage into behavioural problems. As she was getting no support from her GP, she approached the health visitors she knew previously and they recognised there was a problem with Lenny. Bailey managed to speak to the doctor at the local clinic with support from the health visitors.

So when I went to clinic and spoke to this doctor, they listened more. It wasn't 100% about ADD and he should be medicated for it but they did listen more, more sympathetic and because they worked in the clinic where the health visitors, they knew there were problems there. And what happened was this

doctor gave me a referral. I had to go above my GP's head to get to the consultant at the hospital because I asked if she could help me. They did that. He was 7 years old by then and I'd struggled for 7 years.

Despite her increase in knowledge and acceptance by more professionals, there remained professionals who were reluctant to recognise her expertise.

They didn't want to accept it. And because most of them had never heard of it, come across it, had any training in it or anything like that. They just saw these children as naughty and the parents as bad parents or something. For some reason they didn't want to listen. It could be something else, some medical condition.

She also felt this was due to the fact she was just a mother, not a professional or a teacher. Bailey recounted the reaction from the teaching staff at Lenny's school,

Some people didn't want to listen; some teachers said, "I know all about children with behaviour problems, I've been teaching for 20 years and I know what I'm doing."

Bailey found when professionals were willing to listen, it resulted in a positive outcome.

As Lenny got older, he was often influenced by his peers, which led to him being involved with the police and in some instances appearing in court. Bailey found this frustrating as the legal professionals and the police officers did not fully understand Lenny's condition.

He doesn't know his rights. He doesn't know what they are saying to him. If they say have you done this, he'll just say yes. He might not have done it. It's really difficult. Sometimes he might not understand what they are saying. He'll sign things without reading things, and that's happened a lot. "Well he's signed this". But it doesn't mean he's understood it. He's old enough to sign things especially once he's 18. I found that from when he was 16 that was happening. There didn't seem to be anywhere I could go for advice or help. Even solicitors haven't listened to me. I've given them information, I've given them case studies, people they can contact, professionals and it's all been ignored.

She reflected on the number of professionals she has come in contact with and the different agencies who offer different services. She questioned how much the professionals work together for the benefit of the clients.

They all do their own thing instead of working together. What I've found is that you need to use a multi model approach where everyone is working together and singing from the same hymn sheet. It doesn't happen and that is what needs to happen really for people to get the help and support they need.

Lenny received the care he needed because of the determination and drive of Bailey and not necessarily through effective interprofessional working. This has had enormous implications on Bailey's own health. Despite this, Bailey continues to give lectures and seminars to undergraduate doctors and other health professionals. She has been recently invited to talk to undergraduate social work students; a prospect she will relish.

4.1.1.6 Britney

Britney was one of the first to volunteer for my research after I had attended a meeting at a carers' resource centre. She told me she felt that the professionals were very quick to judge and accept others' opinions about her and her son and she wanted a chance to give her perspective.

Britney cares for her son Mark, now 22 years old. Mark has been diagnosed with severe autism, severe epilepsy and ADHD. She has three other children and has been married twice with periods as a single mother. Britney felt that from the start of her encounters with her doctor and the staff at the hospital, she had been labelled as a poor mother.

He was also a sickly baby; constantly vomiting and diarrhoea. He was constantly back at hospital under Consultant called Dr [name] who was very, very old. Basically they put him in the isolation unit, starve him off his baby milk and then he'd be weaned onto water and then once diarrhoea stopped 'cause the

water had flushed it out, he was put straight back on the milk and sent home. A few days later he was back again. That went on for a long time actually. In that process, I was classed as an unfit mother. I was told it was because I was young.

She knew this was not the case as she had an older son and he was developing as expected. This was supported by her health visitor, who recognised Mark's needs and seemed to understand Britney's situation.

I'd had another baby by then and split up with the dad again, so I'm left as a single mother with three kids. Because I was a single mum so then I'm pinpointed again as a bad mum. The health visitor got Mark into a nursery, knowing he would be picked up and an assessment done. That basically got the ball rolling, people were listening.

When Mark was young, Britney seemed to accept what the professionals were saying and whilst not accepting the label of unfit mother, she did not challenge it at this point. Her priority was clearly her son and finding out what was wrong with him. However, when she wanted more information on her son's condition, she felt that explanations from the professionals were poor or she was being told that Mark's condition would improve as he got older.

By the time Mark was five years old, Britney and Mark were regular visitors to the children's ward at the local hospital. The staff knew them. On one occasion, Mark was admitted as an emergency. The attitude of the doctor who saw Mark in the unit surprised Britney. She was not sure if he had made a judgement from speaking to the ward staff, from reading the notes or based on his own perceptions.

Anyway this New Zealand doctor came and said, "we're not here as baby sitters, there's nothing wrong with him." I said, "He's unconscious and I'm not taking him home." I'd not met this doctor before and I just looked at him and said, "You or any member of your staff have never ever baby sat for my son. When he's been in here, he's been in because he needed it and I have slept on the floor at the side of him." Then all of a sudden, in the corner of my eye I saw Mark rise up off the bed and his full body was completely going into a proper fit. I'm shouting he's having a fit, and this poor nurse turned round and said "I'll get the doctor now." As this doctor comes back in, he's slowly coming out of

this fit and so he put his arm on Mark and said, “See he’s acting because he’s autistic.”

It was only when she had to move to a different area to avoid an abusive partner, she realised that she and Mark had not been receiving all the support to which they were entitled. When Britney moved back, she struggled to find a school to accept Mark and for the local authority to fund one-to-one support. Mark did not receive any education for 6 months and out of frustration, Britney approached the local newspaper. Within two days, a school was found for Mark, with funded one-to-one support.

Through the experience of Mark’s many admissions to hospital and to specialised units, she witnessed episodes of staff working well together and overriding local policy to provide patient centred care.

It was the first time Mark had been in hospital on his own for the night. But they put his nursing staff on two-to-one and they only allow his nurses to be with him for one hour on their own and then they’d have to swap over. He’s always had an obsession with cars and water. The cars has completely taken over his life. The nursing staff, if they couldn’t control him, they’d take him down to their car and sit with him and he’d be as happy as Larry then.

She also witnessed instances where staff accepted poor standards of care or were reluctant to challenge inappropriate behaviour of a colleague.

This old gentleman is going “hello, hello” as we’re being transferred to this bed. I heard, “Right you shout that again I’m going to shove you in that room and you can shout as much as you want”. I didn’t want to see who this nurse was or I’d have ripped her head off ‘cause I knew this patient wasn’t going to be telling his family. None of the other nursing staff was interested or said “hang on, don’t talk like that”.

Britney no longer accepts all that she is told by the professionals and is not afraid to challenge. Her sister, paid for by a personal budget, now cares for Mark part-time. She is prepared to do whatever it takes to get the best care for her son. She regularly attends the carers’ resource centre and supports other parents of children with autism and other learning disabilities.

4.1.1.7 Judy

Judy was different from all the other carers I interviewed. She had been a volunteer carer for over 30 years and an advocate for many people over that time. When I first met Judy at the carers' resource centre, she told me she had a terrible experience when she was younger and lived in Africa. A stranger had helped her on a train and she wanted to repay that kindness by helping others.

In the interview, she told me stories of caring for Mary, Alice and Ann. Judy has her own family, a son with a young family and a sister who lives nearby. At the time of the interview, Judy was living on her own in her local authority bungalow.

Judy started visiting Mary on a psychiatric ward over 30 years ago. When social services were looking to rehouse Mary, but could not find anywhere suitable, Judy agreed to temporarily look after Mary.

And I said, "Alright, let her come and live with me till you find somewhere.... And try to get her back to work." So she came to me and she was alright and she was thrilled. I had a little dog and err..., she was very hesitant about the dog at first, but alright eventually. I got her back to work. Then every time the social services offered her anything, a flat or a house and took her to see them, she refused. But in those days, I didn't push it because I thought, well, poor soul, she'll find something somewhere.

In that time, Judy helped her with shopping, cooking and personal hygiene. When Mary retired at 60, she became more demanding of Judy. She did not like Mary's grandchildren; particularly her granddaughter and Judy had to rethink her situation. Social services found her alternative accommodation close to Judy, but Mary refused it. Judy was determined to find a solution and moved Mary into the bungalow next door to her when her neighbour died.

Both her GP and the social services team recognised the huge demands on Judy and the impact on her health. They advised her many times to put Mary in a home, but she insisted she could not do it. When Mary had to be admitted to hospital for an above knee amputation, Judy recounted good communication between her and the consultant who kept her informed of Mary's progress through his secretary. However,

following Mary's discharge to a care home, Judy received no further communication from the hospital. Judy realised Mary had missed a hospital appointment.

So I rang his secretary and I won't stand any nonsense from anybody about someone I'm caring for. She said, "I'm very sorry but she's missed two appointments". So I told her then and said I knew something was wrong because he'd never seen her. Mary needs to see the doctor and for him to say that her leg is alright because they didn't go below, they had to take it above. I've got to ring in the morning to see if she can fit her in with an earlier appointment. I said could she write to me and she said no, as Mary's address was the home.

Judy was devastated and felt she had let Mary down. Judy also cared for Alice who she had been asked to visit in hospital. Alice had terminal cancer and the hospital team wanted to discharge her home. Judy was concerned because Alice lived in squalid conditions and she was at risk of falls particularly when trying to feed her two cats. The team refused to refer her to a nursing home. Judy would not give in, became Alice's advocate, and met with a team from the hospital. Funding was found for Alice to go into a nursing home. The sister and the doctor from the ward told Judy,

We wish there were more people like you that will stand up. This is terrible to think we're here as a hospital and we're supposed to nurse and we can't give this lady what she wants, sending her home to die.

When I asked Judy why she thought professionals listened to her, she felt that unlike her, staff were reluctant to speak out or to challenge poor practice. In the case of the care homes, she felt the reason was fear of reprisal. Judy was not a relative of the people she cared for but she felt she was their advocate. I asked her if that made a difference to the way professionals dealt with her.

Oh, yes. I think so. Well... I don't know. I suppose it was better I wasn't related because I could stand to one side and see things. Well, I must be fair, the majority of professionals once I tackled them I was alright. Yes. I don't go blaring and shouting.

Judy continues to visit Mary every day in the care home and makes sure she is well cared for. She takes her smoked mackerel, tripe and a piece of salmon once a week; all the things Mary likes.

4.1.1.8 Chris

Chris was recommended to take part in my research by her husband who was a service user member of a university service user and carer forum. I found her interview to be the most challenging on two accounts. Firstly, Chris spoke very quietly due to a speech impairment and secondly on occasions, I felt she was trying to give me what I wanted to hear rather than her experiences of caring.

Chris had been a carer for her two daughters and she currently cares for her husband, a retired doctor who has mental illness. She had been a member of her local Community Health Council and is currently involved in research into head and neck cancer. She highlighted findings from her research regarding difficulties with access to funding, the burden of caring and the inequity in service provision between localities.

Once I had facilitated Chris to share her own experiences of caring, she relaxed and talked about her experiences with her two daughters. When her eldest daughter was six months old, she had inflammation of the intestinal diverticulum which led to further problems such as eczema and asthma. Chris described her strong family and social network, which she believed helped her to access particular services and support for her daughter at that time.

Her youngest daughter developed infantile epilepsy at the age of two. Just before her daughter was due to start school, her paediatrician prescribed a ketogenic diet. Chris met with the school meal preparation staff, the teachers and the dinnerladies and she recalled acceptance by the school but felt it was because the paediatrician had suggested it.

She wondered how other carers coped who were not in her position.

But for others it could be more of a problem. Caring for two young daughters but I was able to help. I had a cleaner and work part time in the practice and

have a car for business. But what about those who couldn't. But when I was very ill in hospital again family members could care for my daughters. But I could see the problems others could have without that. I do remember a doctor had come to visit me at home with my younger daughter with epilepsy before she started school. The doctor came. I'd just driven up in my car. It was obviously a nice house; middle class professionals. She went through it and said, "You're obviously providing excellent care".

She recognised her privileged social position and wondered if professionals listened to her because of this.

I was able to absorb information and pass it on to other professionals so I found that I could transliterate between medical and other professionals.

Then Chris's marriage broke up and she found herself a single parent. She had completed a degree in English prior to her husband leaving and so she undertook teaching training and taught at the local prison. The breakdown of her marriage had negatively affected both daughters. Despite being a single parent, Chris felt her strong social network supported her through this time. Chris met her second husband who was a doctor, recently retired due to ill health. She knew of his mental illness and history of marital violence when she married him.

For the first time in her interactions with professionals, she experienced her General Practitioner (GP) ignoring her concerns regarding her husband. She felt her GP had preconceptions of the severity of her husband's condition. She believed her husband, a fellow doctor, had convinced his professional colleague there was nothing of concern.

Her husband finally agreed to go into cognitive behaviour therapy. Chris attended most appointments with her husband, who insisted she accompany him. She felt he wanted her there so he could blame her if he was not satisfied with the consultations. It was at this point Chris felt she had nowhere to go to support her with coping with her husband's behaviour. She eventually joined a mental health charity and encouraged her husband to join a doctors' support network. Both of them found these useful areas of support.

Through her teaching and research work, she feels she has a sound understanding of the issues facing carers and the burden felt by carers. She feels it is important that professionals understand these issues to be able to deliver effective care.

It's about opening their eyes to the different perspectives.

4.1.1.9 Kylie

I first met Kylie at a carers' resource centre and she chose to be interviewed in her own home. Kylie became a carer suddenly when Susan, her partner of 20 years, was diagnosed with terminal cancer. Kylie is a registered nurse and currently works in a hospice. Previously she had worked as a specialist urology nurse at a large teaching hospital.

Kylie struggled with the conflicting roles of being a nurse and of being a carer and discussed her vulnerability. She questioned her own actions as to why she had not identified Susan had a problem earlier. She felt that some professionals treated her differently because she was a nurse and altered their approach to her as a carer. There were times Kylie did not know if Susan had not been given adequate information because the professionals expected her to have prior knowledge or if they simply did not provide adequate information to all patients and carers.

Whilst Kylie had developed a good relationship with the district nurses who came to see Susan, there were times when Kylie felt uneasy with her conflicting roles. She wanted the nurses to treat her as a carer and not a nurse, even though she had said she wanted to be involved when they asked her. She wondered if the reason she had not challenged this was her appreciation of the pressures on the district nurse service.

Kylie experienced effective working between the Macmillan nurses, the district nurses and the GP practice. They worked closely together to ensure Susan's medication for pain control was effective. Communication between the different teams was enhanced by Kylie's diary comments on the front of the district nursing notes. This proved particularly effective when Susan was admitted to the emergency department and into

the hospice for respite care. Kylie was clear to point out the diary was instigated by her and not by the district nursing team.

The district nursing team had a high turnover of staff and Kylie noticed a difference in their approach to caring. She particularly highlighted one district nurse who 'went over and above', compared to others who 'you could tell it was just a job; they were in and out.'

She felt that all professionals listened to what Susan wanted, but felt that they relied heavily on Kylie's nursing skills. She felt that the professionals involved with Susan's care were extremely busy and knew that she would be able to pick up anything they had missed.

Through her experience of caring for Susan, Kylie believes communication is the most important factor for effective interprofessional working; particularly communication with the patient and their family.

As long as you tell them what's going on. It's important to tell them the truth. Sometimes having time to sit and talk to someone, you can learn such a lot from them. Professionals tend to concentrate on the patient but very rarely ask the carer how they are.

Kylie started bereavement counselling which she has found helpful. She still attends the carers' resource meetings once a week. At the time of the interview, she was planning to return to work in the near future.

4.1.1.10 Sarah

Sarah is married with two children. At the time of the interview, she was the manager of a University service user and carer group. I first met Sarah at an international service user and carer conference, where I was presenting the first stage of my PhD. Sarah heard my presentation and asked if she and her group at a university in the North of England could be involved in my research. She invited me to attend a meeting to discuss my research. Following the meeting, Sarah and two other members volunteered to be interviewed.

At the time of interview, Sarah had been an advocate for her parents for the past seven years due to the failing health of her father. She attended many hospital appointments with them, 'helping them through the NHS system'.

More recently, her mother was diagnosed with cancer and underwent a hysterectomy. Sarah found herself in the caring role for both her mother and father.

Throughout her treatment, Sarah's mother was admitted to a number of different hospitals. Sarah recounted a difference in the standards of care provided by staff at these hospitals. She also noted a difference within the same hospital. She felt the hospital staff at times hid behind policies and procedures and did not challenge certain procedures. Sarah noticed differences in the continuity of care and communication between professionals and the family. She felt whilst her mother was under the care of the consultant, they knew what was happening and professionals tended to work well together. However once her mother was discharged home under the care of her GP, many decisions were made, with minimal information given to the family.

They did get together and talk about it, but it was this feeling of nobody seemed to know my mum's case properly. He knew her medication, the district nurse knew her care plans but it wasn't quite talking together. It felt very abandoned; it felt very patchy in that period.

Eventually, Sarah's mother was admitted to the local hospice. Sarah immediately saw a difference in the philosophy of care between the hospitals and the hospice. She felt, 'people seemed to care for her' and 'because in the hospital it was very easy to get ignored, particularly if you were in a side room. No-one seemed to notice that you were there.' Sarah commented on the different attitudes and behaviours of the staff in the hospice and the hospital settings.

So nurses who are interested in caring seem to be in that environment. That was very obvious, a lot of the others were more policies and procedure driven ...I'm not saying all the nurses in hospitals are dreadful. That's not at all, but I've seen a real mixed bag.

She acknowledged care in the primary health setting was difficult in terms of continuity but she believed effective care was down to individual professionals delivering a basic standard of care and taking responsibility to ensure it happened. She felt there was a certain reluctance by some professionals to challenge poor care and the governing values of the leader set the culture of the working environment.

She went on the gynae ward and it was well run, the staff were lovely, it was spotlessly clean, you were well attended to and she went on the chemo ward where you were abandoned. Yet there was probably not a great deal of difference in terms of staffing.

When I asked Sarah about her opinions of how professionals could work together more effectively, she highlighted several areas such as strong leadership of the team from someone who knows the full case history. She felt it did not always need to be the doctor.

Her mother died in the hospice and now Sarah shares the caring for her father with her sister. She also needs time and space to grieve for the loss of her mother.

4.1.2 Three orientation groupings.

Gubrium, in his study on nursing home residents, talks of the residents as biographically active (Gubrium, 1993). Gubrium used orientations or horizons of meaning to represent the varied linkage of experiences of the residents. He used these to reveal the subjective meanings of their experiences. I have used this concept in the next stage of my analysis of the interviews.

One of the aims of my research is to capture the experiences of carers through their own stories of caring. In the previous section, I presented the carers stories as representative constructions. In this section, I have grouped the stories into three narrative orientations; 'It's all a battle', 'That's how it is' and 'I know how it should be'. It is hoped that this approach will reveal a further layer of meaning to the realities of the experiences of caring and the perceptions of effective interprofessional working, that would have been obscured by either an overall thematic analysis or a purely

individual perspective. This will provide greater insight for health and social care professionals into the experience of providing care (Wynaden et al., 2006). This will facilitate more effective interprofessional working to achieve better outcome for the whole family unit.

4.1.2.1 'It's all a battle'

The stories of some of the carers I interviewed highlight the constant battles they had with professionals and different agencies to get the care needed for the person they care for. The quality of care provided appears to be the driving force for their determination to persevere. Two of the carers, Bailey and Britney, are caring for their own child, whilst Judy cares for others who have no family of their own.

As mothers, Bailey and Britney found themselves driven into corners by professionals' reluctance to listen to them or to other professionals. At times, an individual professional's attitude or prejudice prevented access to the right care for their child. Whereas Judy, not being directly related to the people she cared for, would not give up and continued to pursue the professionals with dogged determination until her voice was heard. It appeared more difficult for the professionals to close ranks on Judy, perhaps because she was not a relative. This pursuit of justice to have access to quality services is central to all these narratives. These carers not only wanted the best care for those they cared for but also for other children and families in similar situations. Britney, Bailey and Judy are aggrieved by the apparent reluctance of some professionals to challenge poor practice and to accept policies and procedures that do not deliver effective care.

Yet at times, the systems overwhelmed them all: Britney and Bailey through the labelling by professionals as a bad parent or having a badly behaved child and Judy through her own health failing. It was at these times they found support from an individual professional, who recognised their position: a person who listened and respected their views. These professionals, working alongside the carers, supported them and signposted or facilitated access to the care or service they needed at that time. Some of these professionals experienced the same frustration as the carers when other professionals chose not to listen to them or to respect their views.

All three carers felt it was important to support other people in similar situations and remain involved in support groups. Bailey, for example, is currently involved in the education and development of current and future professionals.

These stories highlight the effect of professional attitudes on the willingness to acknowledge the needs of the carers and the cared for person. From these carers' experiences, it can be seen professional attitudes influence the way in which professionals choose to work with other professionals or other agencies.

The experiences of Bailey and Britney are reflected in the findings from the review of literature on caring for someone with a learning disability by James (2014).

Stereotyping by professionals and the notion of having to fight to be heard is supported by Wilson and Mansell (2010). Bailey, Britney and Judy were all prepared to 'fight for' better care and to be listened to by professionals, however not all carers respond to their role in this way.

4.1.2.2 'That's how it is'

The stories of five of the carers I interviewed depict the acceptance of the role as carer as inevitable. Hilda is the wife of Arthur; Parveen and Hussain are the parents of Kenny; Ava is the daughter of Helen and Karan cares for both her parents and for her partner John. This sense of duty and inevitability influenced the way they responded to issues arising from the care provided for the people they care for. They are different from the fighters, in that whilst they were not satisfied with the care provided or the attitudes of professionals, they were more ready to accept the situation.

Hilda and Parveen accepted their role as natural and yet wanted the best for Arthur and Kenny respectively. Hilda, whilst having cared for her mother for a period of time and perceiving herself as experienced, remained reluctant to challenge professionals and accepted long delays in the provision of equipment or services. Parveen and Hussain, whilst frustrated at the time delay in services for Kenny when the family relocated from Scotland, failed to challenge the time taken for an initial therapy assessment for Kenny.

Whilst Ava accepted her role dutifully, she was reluctant to challenge the quality of the care provided through fear of reprisal from the professionals. Karan in the early stages of her caring role was also reluctant to challenge. She started to care for her mother when she was still at school. It was expected of her, as she was the female in the family. Her low self-esteem and lack of confidence were her main reasons for not challenging the professionals. She extended the role of carer to her partner who had long-term medical conditions and to her father when he became ill following the death of her mother.

These stories highlight examples of professionals prioritising the support of other team members to the detriment of the service user and their family. When things went well, the carers felt it was usually down to the influence of an individual professional who recognised the need for intervention and facilitated access to the relevant services or referral to a particular professional.

All five carers felt the same as the 'it's all a battle' carers, in that they were aggrieved by the reluctance of professionals to challenge poor care and willing to cover up episodes of poor care. Yet, through lack of self-esteem, fear of reprisal or not feeling empowered, they chose to accept the situation they found themselves in, such as the lack of access to resources or delay in service delivery. These findings are supported by carers involved in other studies (Goodman et al., 2011a; Wilson and Mansell, 2010).

All five carers felt the professionals should be more aware of the needs of the whole family and they wanted to see more open, transparent and non-judgemental communication between professionals and services in order to work more effectively together.

4.1.2.3 'I know how it should be'.

The stories of Sarah, Kylie and Chris depict the experiences of three carers who are professionals. All three are in professional roles or have knowledge of health and social care outside their caring role. All of them are knowledgeable in different ways and 'know how it should be'. Sarah is a manager of a university service user and carer

group; Kylie is a registered nurse and Chris is a lecturer and researcher in the health and social care field.

Sarah is one of two daughters caring for elderly parents; Kylie cared for her partner Susan and Chris cares for her two daughters and her husband. As they are each in professional roles, they found this conflicted at times with their roles as carer. It also affected the relationship with professionals they came into contact with whilst in their caring role.

Sarah saw her role initially as an advocate for her parents, guiding her parents through the health and social care system. Kylie, as a registered nurse, found professionals treated her differently; she felt professionals expected her to have prior knowledge. This led to altered communication between Kylie and the professionals involved with her partner Susan's care. Chris felt her standing in the local community and supportive family network, was recognised by most professionals and she felt she was fortunate compared to other carers.

These knowledgeable carers expect a high standard of care as they have experience and knowledge of how it should be. Whilst committed to the necessity of policies and procedures, they repeatedly question professionals' focus on the completion of tasks rather than on meeting the needs of the patients and their families through more effective communication with other professionals and agencies.

The three carers felt that when professionals recognised their knowledge they received better care than other families; however, they also experienced defensiveness by some professionals and they perceived these professionals felt threatened by their knowledge. Each of these carer's story highlighted individual professionals who delivered effective care and ensured care plans were acted upon by other professionals.

Sarah, Kylie and Chris, whilst their stories were filled with examples of how care could have been better, still tended to accept the circumstances. There is a sense in their stories, of not wanting to challenge the behaviour of fellow professionals. These carers presented a dilemma for the various professionals. How much they recognised their expertise and resulting involvement in decision-making was variable and did not always match the needs of Sarah, Kylie or Chris. In Kylie's case, whilst she wanted to be

involved in some of the nursing care, she also wanted to be recognised as a carer who was new to her role and who needed guidance and support.

In summary, these three orientations, 'It's all a battle', 'That's how it is' and 'I know how it should be' provide subjective meanings of the carers' experiences of caring (Gubrium, 1993). Whilst they represent the varied linkages of their experiences and as in Gubrium's study, I acknowledge they are not exhaustive of the horizons of meaning of caring. The carers' stories emphasise the need for all health and social care professionals to consider the different subjective meanings of caring to better understand the complexities of caring. In doing so, professionals should be better informed to implement strategies to provide better outcomes for the whole family.

4.1.3 Findings from Thematic Analysis.

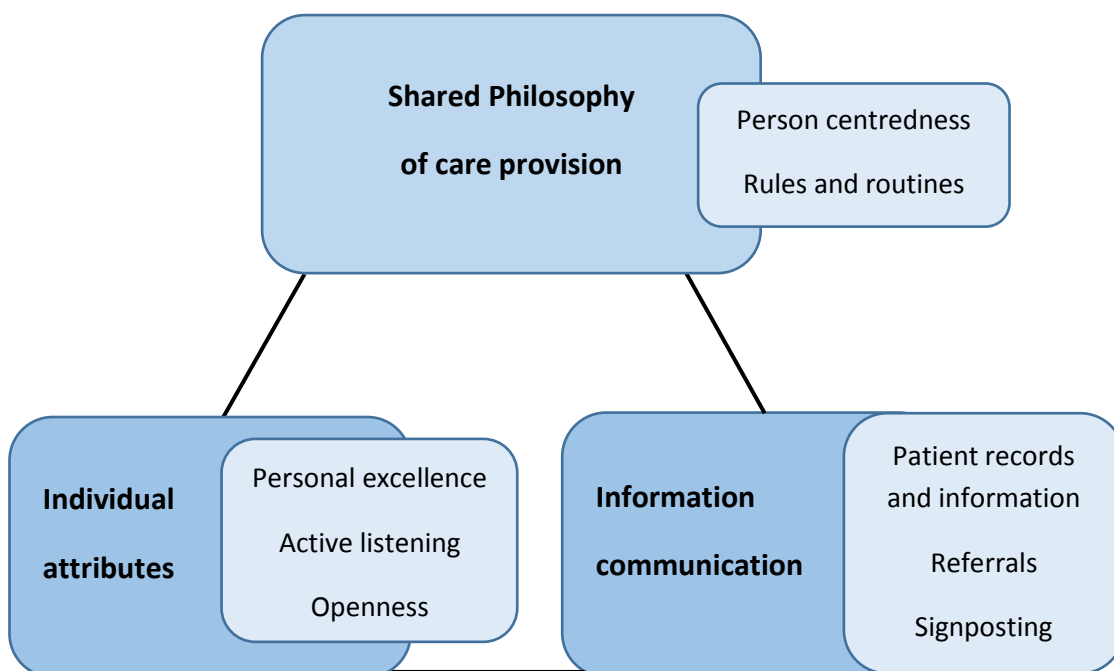
In the two previous sections, I introduced the carers in terms of their own stories and in terms of the three orientations of meanings. Carers are normally categorised by professionals and researchers in terms of their roles, and in terms of the diagnosis of those they care for (Stalker, 2003). The aim of my study focuses on exploring carer perceptions of effective interprofessional working through their experiences. Carers are not a homogenous group and each of their biographical particulars should be considered in light of the overall findings (Gubrium, 1993).

In this third section of analysis, key themes of effective interprofessional working were identified using thematic analysis (Braun and Clarke, 2006; Ritchie and Lewis, 2003). Three main themes emerged from the analysis, each with sub themes. The themes are not mutually exclusive and there is a synergistic relationship between the themes.

The carers' stories revealed a complex interplay of factors that contributed to the effectiveness of interprofessional working. The findings suggest a synergistic relationship between the themes; that is the outcome, namely effective interprofessional working, is accomplished through the interaction of these components. Various factors work together to produce an enhanced result; the sum being greater than the individual parts.

Figure 2 provides a conceptual framework in the form of a diagrammatic representation of the synergistic relationship between the three main themes. This representation is not advocating individualistic working; instead, it represents groups of individual professionals working together with common attributes, shared goals and a shared philosophy of care.

FIGURE 2 SYNERGY OF EFFECTIVE INTERPROFESSIONAL WORKING



The three main themes and sub themes are listed and discussed below.

Shared philosophy of care provision

With sub themes:

- person centredness
- rules and routines

Individual attributes

With sub themes:

- personal excellence
- active listening
- openness

Information communication

With sub themes:

- patient records and information systems
- referrals
- signposting

4.1.3.1 Shared philosophy of care provision

A common emergent theme from all the carers interviewed was regarding the overall philosophy of the provision of the quality of care delivered across organisational and professional boundaries. As Parveen and Hussain experienced effective care with professionals working well together in Scotland they were surprised when they moved to England and found this was not the case. They expected all the services their son Kenny received in Scotland to be resumed; this did not happen. They became frustrated with the approach of professionals and the systems in place to deliver services. When I asked what the solution was, the answer was simple, 'work together; work under one umbrella'.

Sarah noticed a difference in the philosophy of care between the hospitals and the hospice where her mother had spent time.

So there were times when you were well looked after and there were times when you might as well have been at home in your bedroom. Whereas at the hospice there seemed to be a lot more people checking but in a very unobtrusive way.

These findings are supported by those of Cowley et al. (2002), who utilised a multiple case study design to explore models of palliative care provision. Similar to Sarah's experiences, Cowley et al. (2002) identified a lack of clarity in the organisational philosophies regarding the application of policy of interagency and partnership working in some areas. The authors concluded where professionals and organisations embrace the difference in professional cultures and philosophies, an effective model of palliative care can be found.

A shared philosophy of care has many components and the carers in my study talked about the consideration of meeting the needs of both the patient and their family. They also questioned the behaviour of some professionals in the delivery of care.

4.1.3.1.1 Person centredness.

A sub theme of person centredness was identified as important to the carers. A common experience highlighted by the carers was, that the focus of care provided did not always seem to be driven by the needs of the patient or family, but instead by the needs of the organisations or the individual professionals.

Following her stroke Helen, Ava's mother, was being cared for at home. Initially care progressed well, with the therapists providing a joint assessment and management plan.

We had a brilliant OT and physio community and they came and looked at the house and they said what we could do and they said they'd get the equipment and we'd try it. She's been home six years now.

When the physiotherapist stopped the regular visits, she taught the agency carers how to stand Helen. Unfortunately, this did not happen for long.

What it was, was the physio had got my mum standing up; twelve months getting her standing up. They were absolutely brilliant. So she was doing that and then one carer didn't want to do it so...They used to have the choice of either standing her up or hoisting her because one carer didn't want to do it and some didn't know how to. They said she can't stand up anymore. They just take it away without asking you.

The care agency decided to withdraw the option of standing Helen without any consultation with Helen or Ava, or the community physiotherapy team. This decision by the agency and the lack of consultation with the community physiotherapists culminated in an increase in difficulty with Helen's transfers. In addition, it created more difficulties for Ava and the agency staff, when assisting Helen in everyday functional activities.

When Sarah's mother was in the hospice and under heavy sedation, she became restless and wanted to get up and walk. Sarah praised the staff for their support in enabling her mother to be moved out of bed to another room. Sarah's mother was not

able to walk. Rather than the staff saying this was not possible, they identified an easy solution. The hospice staff recognised the positive impact of moving Sarah's mother to another area of the hospice.

They said if she wanted to get up there was a wheelchair and they'd help me get her in it. We did that and I took her round the hospice and I thought at this point she was blind because of her eyes and she couldn't acknowledge me, I thought she couldn't see me. I was taking her round and showing her the hospice. She saw this water fountain and said she wanted one of those. I got her a drink then thought, 'she can see'. We moved her to the lounge and one of the nurses said she could sit in one of the armchairs. We put her in this chair and then my sister came and couldn't believe she was in the lounge. So that was really nice the way they did everything they could to give people their wishes.

Whilst Sarah witnessed this philosophy of care in the hospice, she acknowledged different philosophies of care existed between different units within the same organisation. I asked her to expand on this reflection.

...a friend of mine who is an NHS manager says it can be like that. You can have two sister wards, exactly the same funding, same staffing, one of them is fantastic, the other... it's different attitudes of staff who work on the ward and their approach to patient and customer care. That just shows that one place is absolutely dreadful, she couldn't wait to leave and the other place was lovely.

Whilst an organisation may have a mission statement outlining a particular philosophy for service provision, this can be enacted differently between units within the organisation. It is influenced primarily by the attitudes of the professionals working within that unit.

When her son Mark was admitted into a specialised assessment unit for children with epilepsy, Britney identified effective working in specialist centre with Mark's needs at the centre of their practice. Britney questioned why this could not happen in a more local setting.

But what they did in that centre could have been done in [TOWN]. They wasted £30,000. All they had was a neurologist, support working staff, 24 hour EG, video monitoring, psychologist in site, speech therapist on site, teachers onsite.

I'm sure there is a service that could accommodate all these people in one building for assessment.

When I encouraged Britney to expand on how she felt the professionals had worked together and why this was effective, she could not give specific reasons other than Mark was calmer and the family finally had a comprehensive diagnosis and prescription for the appropriate medication. All the professionals worked together in one specialist unit in one building and Britney felt this was a reason for the successful outcome; this supports findings by Xyrichis and Lowton (2008) and Hudson (2007). However Sarah's experiences, highlighted previously, suggest a shared location does not guarantee a shared philosophy of care (Kharicha et al.; 2005).

There are many definitions of person-centred or patient-centred care. The terms patient and person are used synonymously in the literature. Goodrich and Cornwell (2008) recommend the use of the Institute of Medicine definition, which is multi-dimensional and comprises the following constituents: compassion, empathy and responsiveness to needs; coordination and integration; information, communication and education; physical comfort; emotional support and involvement of family and friends. A similar definition is described by Collins (2014). He describes the Health Foundation's principles of person centred care: providing care that affords dignity, respect and compassion and care that is personalised, coordinated and enabling (Collins, 2014). The Health and Social Care Act (2012) indicates the need for individual patients and their carers to be involved in decisions about their treatment and care.

Whilst these definitions exist, the term could be said to be interpreted and enacted differently by professionals, service managers and commissioners (Goodrich and Cornwell, 2008). Collins (2014) argues the outcomes measures used by professionals, service providers and commissioners do not necessarily capture person centredness. He suggests care delivered does not always address what matters to the patient or to their carer. Sawatzky and Fowler-Kerry's (2003) study of the impact of caring on a sample of female carers supports Collins. The carers in their Canadian study felt professionals did not listen to their perspectives of the patient's needs and their views of how care should be provided in the patient's best interests. Professionals who embrace a person centred philosophy of care and take into consideration the needs of the whole family unit when making their professional assessments are more likely to

understand the complexities of the caring relationship (Wynaden et al., 2006). It could be concluded therefore that professionals who share a common person centred philosophy, rather than a common location, are more likely to work more effectively together as their goal is to deliver an outcome which has considered the needs of both the person and their family.

4.1.3.1.2 Rules and routines.

A second subtheme is rules and routines. Routines can be defined as patterns of learned behaviour. These routines are shaped by the rules set out in legal and organisational policy (Elissen et al., 2011). In most of the stories of caring, the carers did not explicitly talk about when things went smoothly; they focussed more on when things did not go to plan or were unexpected. They talked about experiences of crisis and of transitions between services or agencies. This is similar to the carers in Goodman et al. (2011a).

During their interviews, the carers identified occasions when the professionals carried out their normal activities and were reluctant to deviate from these routines. The carers felt some professionals used the routines and policies as an excuse, resulting in the disregard of the implications for the patient and carer experience.

Professionals can easily become socialised into ways of doing that may conflict with their professional education and their reasons for becoming a professional. These ways of working become normal routines and if not challenged, can potentially depersonalise and dehumanise the care provided. Custom and practice can, over time override the formal organisational policies and procedures. Protocols are developed by organisations to address resource issues, efficiency and effectiveness of the service provided; however, the implications of these for patients and their families are not always fully appreciated.

On one of the occasions her mother was admitted to hospital, Sarah felt hospital staff were hiding behind routines and rules; in this instance citing health and safety policy.

It was things like not adjusting my mum's bed for health and safety so the ill patient should adjust their own bed, which is ridiculous. Other health and safety rules; not being allowed to wheel the table over her bed. They couldn't move those for health and safety reasons. I was talking to my uncle who is a miner and his best friend got killed at work and yes there is a need for health and safety but you look at some health and safety and you think that's absolute rubbish. A common sense approach says a table on wheels is not hard to move. Stand properly with a sensible pair of shoes and push it. {Laughs} So I thought it was used as an excuse for poor care.

There may have been a health and safety reason in this case, but the staff had not explained their reasons effectively to Sarah and so she assumed they were using it as an excuse for not carrying out the task.

When Karan arrived late to visit her partner in hospital following cardiac surgery, she wanted to discuss his progress with the nurses as his main carer and next of kin. Karan felt the nurses on the ward assumed they had communicated with the patient's family and so followed due process. She felt the nurses did not appreciate her circumstances.

They discussed things with his ex-wife. I got there late one day, and they discussed his medication with her and his daughters and when I walked in she actually said, "She's here you can discuss it with her" and they [the staff] said, "Do you want to pass it on 'cause we've got to go." So she had to pass that to me. There was no point shouting and balling. And he said, "I'll sort it out when we get home". That's really bad that. They should have waited for me.

When I asked if on reflection she would do anything different, she said she would try to be more assertive and insist the nurses inform her of progress. She continued to reflect.

You've got the pressure of... it's like you've got him in hospital; you've got to get there; you don't drive yourself; you've no money; you're on benefits anyway so how do you get there. You've got to wait for the buses and hang around. You've got mum and dad back at home to see to first. These hadn't. They'd just gone to take him some grapes. I hadn't, I'd gone through a whole day of rubbish and had to get there to be told I'm not worth waiting for anyway. It makes you feel inadequate. It makes you feel you've been late for some major thing; they don't know what you've gone through at home, do they. And there's no point in bleating because they just think...they are not interested anyway. Why bother.

The staff in this case believed they had followed due process and informed the family, despite Karan being the official next of kin recorded in the patient notes. No one recognised the impact of their decision on Karan and her partner and no one appeared prepared to offer time to talk to Karan.

Britney had a similar experience when her son Mark was admitted to hospital as an emergency. It was the first time Britney could not stay overnight with him and she wanted to speak to the doctors before they made any decision about discharge.

One o'clock I rings the hospital. "You better be here for seven in the morning". I said "I can't" ... Anyway, I'm arguing with this nurse at one o'clock that I can't get there. "Well the doctors are here at seven".

I said, "Well tell the doctors not to see my son till I get there. I will be over there at eight as soon as I've got the baby sorted." "Well I can't guarantee they will bother to wait around for you." "Well I'm telling you, don't let him discharge him until I've spoken to him. That's why he's in your hospital cause [name of hospital] has just done it."

The doctors normally performed their rounds at 7am and the nursing staff seemed reluctant to ask the doctors to come back later to meet Britney before they made any decisions about discharge. This latest hospital admission of Mark's was due to problems with a previous admission, when Britney had not been consulted and Mark was discharged home too early. In this last case, the nurses were reluctant to challenge the routine of the ward round to enable Britney to be consulted as part of the decision making process for discharge.

Professionals across most areas of care routinely carry out their roles following particular policies and procedures; policies and procedures that are mainly driven by external demands (Dixon-Woods et al., 2013). There is a tendency of professionals to use automatically these procedures to inform clinical practice for all patients and service users, especially when time is limited (Huby et al., 2007). Dixon-Woods et al. (2013) in their large multimethod study found a tendency of care to be task-focussed and not person centred. Sometimes it is custom and practice rather than particular procedures that dictate the practice of staff. Staff have become conditioned to certain ways of working (Prescott and Rowe, 2015).

Policies and procedures should enhance quality as well as achieving efficiencies (San Martin-Rodriguez et al., 2005). Tutton (2005) following the introduction of a framework to enhance quality and patient participation on an elderly care ward, found a small change in nursing practice led to improved outcomes in terms of patient satisfaction and involvement in care.

Parveen and her husband Hussain found the appointment system frustrating at their GP practice. They felt the rules were in place for the benefit of the practice staff and did not always result in a positive patient experience.

(Hussain) Last time Kenny had severe flu, doctor said, 'I can't do anything. Just wait for seven days.

(Parveen) After seven days, we've got a high fever at the night. And I was not feeling well either myself. I called the doctor for an appointment. The same day I had an appointment with my gynaecologist. I said my appointment with them is at 10am and my two children have flu and high fever and also, I need an appointment for them the same day. She said, "I can't do this. You are better to come at two-thirty for your appointment and I can't arrange for your children." I said, "How can I leave them at home because the younger one is eight years old with fever and the other one is in wheelchair. It is not possible for me to come again and again." She said, "We are not child care centre. This is your problem."

The inflexible approach adopted by the receptionist may have been due to practice procedures or policy; however, for whatever reason, it did not take into account of the family situation.

Organisational protocols, evidenced based practice and published clinical guidelines exist to assist professionals in their decision-making. Through her different roles, Sarah questioned why some professionals were reluctant to challenge areas of professional practice, which are guided by these protocols or clinical guidelines.

I find NHS best practice a really strange term. In manufacturing, we had terms like world-class manufacturing or whatever, but what they meant was you'd start off with something and you'd think it was good. But every day you would refine it. But best practice in the NHS is finding somebody who has done it before, who describes it as best practice and everyone copies it whether it makes sense or not. So I have a real problem with anything in medicine which is

described as best practice because I don't really believe it is. It might well be researched but it isn't refined and that's what I don't like about it. This is the model for us, this is best practice and you'll do that because that's what the guidelines say. That isn't what best practice is about.

Sarah's experience of working in manufacturing and alongside health professionals, has given her insight into the theories of best practice. Her experiences as a carer reinforces her views of its use by health professionals; guidelines are for guidance. Each situation will vary and professionals should use their knowledge of the evidence, their clinical reasoning skills, and the patient and family situation to inform their decision-making (Prescott and Rowe, 2015; Warne and McAndrew, 2007).

Bailey highlighted another issue, which was common across the carers' experiences of caring for a child. The rules and procedures are different once the child reaches the age of sixteen. She found professionals generally did not, or were unwilling to, consult with carers when interacting with these young people with learning disabilities.

So when he was 16, they were saying to him it's your choice. He's never taken it [medication] since. So obviously he's got worse. It's just a case of he's an adult now and I can advise him but he doesn't have to listen to me. He just seems to bumble through life, doing his own thing and getting into lots of problems and I'd never hear until it's too late and I try to do what I can but it's quite often too late. Whatever has happened has happened. Whatever the situation, that's it usually. People never listen really; they are not interested in listening. People with ADD because a lot of them are quite bright and you can have a conversation with them, people think there is nowt wrong with them, you know, it's just not the case.

Bailey offers a solution for professionals,

.....speak to the parents even when the kids are classed as an adult. They're the experts to me; they are the ones who know the child best; they know what works best with them; they know what makes them kick off. I can't cope that no one wants to speak to the parents once they're adults; it's confidential and they won't speak to you.

In cases such as Bailey's, there are ways in which professionals can engage with the family if they want to gain a better understanding of the situation; however from

Bailey's experience of working with other carers and families, there is a tendency not to do so (James, 2014; Wilson and Mansell, 2010).

Many of the carers experienced difficulties accessing the necessary equipment or appropriate service due to issues related to cross boundary collaboration. Sarah found that organisational policies hampered and delayed her mother accessing oxygen therapy, to the detriment of her health.

Then there are all the problems of GP services because mum and dad moved to [County1] but always lived in [County 2], it's only the next village. So they were having [County 2] GP and Macmillan nurses but [County 1] hospitals. So things like when mum needed a breathing machine who would pay was it [County 1] or the [County 2] GP? So all silly bureaucracy. GPs had to get very involved in and that seemed a waste of their resources.

Hilda was frustrated that Arthur's place of residency had not been highlighted previously as this could have facilitated equipment being ordered and delivered prior to discharge from hospital.

We sat through an hour's talk with Arthur and I, asking us about how we felt and then all of sudden they found out we lived in [LOCALITY] and we come under [TOWN 2]. We'd been in hospital three months and our address was in the [TOWN 2] area and this first get together was squashed and we had to wait for a social worker to come from [TOWN 2]. So we did all the same things again; went through all the same rigmarole and then they started the ball rolling for Arthur to come home. Well, [TOWN 1] council said it was nothing to do with them it was [TOWN 2] council. [TOWN 2] council said it was nothing to do with them it was [TOWN 1] to get the proper equipment set up in our house for Arthur. So I was absolutely devastated, screaming down the phone and crying.

Sarah and Hilda's experiences are not uncommon. This lack of joined up planning for discharge and lack of collaborative requisition of necessary equipment is having a negative impact on the quality of the service provided. Many patients and their families report problems accessing equipment following discharge from hospital (Goodman et al., 2011a). A major reconsideration is required regarding effective management of resources across boundaries and the different sectors within health

and social care. Only if this is achieved, can professionals work effectively together to deliver quality services.

From her work at the carers' resource centre and as a carer, Karan felt that professionals were protective of their service for fear of losing funding.

I think that's also services working together, not being so protective about the work they do. We're all a bit, this is mine and you're not having it. You've got to drag it out of them. Erm, some services they put on an activity. They will tell the service user about the activity but what about all the other services that if they know about the activity, they could be telling all these people they work with. But they don't, it's got to be direct to the client and I think that's petty. "It's our service and if we tell everyone else they might copy it and they won't come to us for it."

This particular barrier in cross boundary collaboration and resulting impact on continuity of care needs to be addressed to ensure a positive experience for the patients and their families. Elissen et al. (2011) in their study exploring multidisciplinary cooperation in primary care highlighted the negative effects of organisational rules in terms of providers competing for scarce resources. They found the current system of reimbursement for services was one of the main barriers to multidisciplinary collaboration. Whilst this reflects the situation in the Netherlands, the same claim was highlighted in the carers' stories.

In 2010, the newly formed coalition government released its vision for adult social care with emphasis on its intention to remove barriers preventing the sharing of budgets alongside its vision for the NHS (DH, 2010a; 2010b). Cameron et al. (2014) concluded whilst there was evidence of more integration of services, most of the studies they reviewed were evaluations of local initiatives and were descriptive in nature. There is a need for more large-scale studies investigating cost effectiveness of integration of health and social care and the resulting impact on patients and their carers and families (Goodwin et al., 2012).

In 2013 following the second Francis report recommendation for the need for better collaboration across professionals and for person centred care, there has been an acknowledgement of this by policy makers. This was evidenced in the call for research proposals by the NIHR (HS&DR) Programme; the call was for research to strengthen

organisational capacity to deliver compassionate care in the NHS (NIHR, 2013). The call was focussed on three specific areas highlighted in both the Francis reports; strengthening the patient voice, improving frontline care and changing culture through leadership.

4.1.3.2 Individual attributes

Individual attributes is the second main theme identified. Whilst the carers identified examples of professionals working together, this was largely not directly observable. What the carers noticed more was individual attitudes and behaviours that seemed to influence the nature of the collaboration with others.

4.1.3.2.1 Personal excellence.

All of the carers identified individual attributes that influenced the overall effectiveness of care. I have summed these up as 'personal excellence' (Brophy, 2006): qualities such as perceiving their position as a professional as a vocation and not simply as a means to earn money; being non-judgemental of patients' and families' circumstances; empathetic to the realities of caring and the individual situations of the patients and their families; valuing the role of the carer and others and taking responsibility for effective care.

In their stories, the carers spoke of individual professionals who stood out from the rest of the professionals. They seemed to go beyond delivering tasks and were more intuitive to the needs of the circumstances. They would find time for the family. The carers felt it was more than a job for these individuals; they had a clear professional vocation.

Kylie recognised and appreciated the demands placed on the district nurses who visited Susan. She spoke about one in particular.

During the time Susan was poorly, the district nurses, the team were for ever changing people. There was one of the district nurses, [name], she was like really took a shine to Susan. She was what I would be if I was on the district,

she went over and above. But some of them, you could tell it was just a job; they were in and out.

Sarah identified an oncology nurse who was extremely helpful to her mum, to Sarah and worked closely with other professionals.

For instance, there was a very good cancer nurse, a specialist oncology nurse, who my mum saw when she first had her gynae op and whilst she was in [CITY] hospital, that was the person mum got advice from and then she came more involved in the GP phase and that mixed phase. It wasn't actually her job but she was one of those who let it become her job.

Hilda and Arthur had many visits from a range of health professionals and Hilda was generally satisfied with the care they provided. Despite this contact with physiotherapists, occupational therapists and district nurses, she felt alone. She never received a call to ask how she was.

Once the physio's been, once the nurses have been, nobody rings. You can't expect them to ring and ask how Arthur is getting on because I mean there are too many people to look after. You think there's only you but you're not individual that's what I say, there are so many other people worse off than us.

In Hilda's case, the professionals delivered their part of the care package but did not follow up on progress. To Hilda, it appeared there was a lack of collaboration between the professionals involved. This may not have been the case in reality, but Hilda felt she had been abandoned.

Britney experienced a difference in the professionals she came into contact with. She experienced professionals making judgements about her as a person and a mother and about the way in which she cared for her son Mark. She also found professionals who remained open and non-critical of her. She felt they understood her situation and they liaised effectively with other professionals because of this.

At the time, I had a really good health visitor and she knew I wasn't a pathetic mum. Our GP at the time really listened; he was really good. The health visitor

got... I'd had another baby by then and split up with the dad again, so I'm left as a single mother with three kids because I was a single mum so then I'm pinpointed again as a bad mum. The health visitor got Mark into a nursery, knowing he would be picked up and an assessment done. That basically got the ball rolling, people were listening.

In Bailey's case, it was the health visitors, who recognised a problem with her son Lenny and put the relevant support in place.

The health visitors were well aware of the situation and felt sorry for me because he was such a demanding baby and he continued to be demanding and bright but still wasn't sleeping as he got older. Although I'd stick to bedtimes; I was quite firm with that, it still wasn't working. So they recognised there was a problem; the GP wasn't listening to what I'd said.

Empathy is a quality identified as necessary by the carers in this study. It can be defined as an understanding of another person's condition from their perspective by placing oneself in their position. Whilst not explicitly stated, it is implicit in professional and regulatory standards and codes of practice (NMC, 2015; GMC, 2013; HCPC, 2008) and implicit in the NHS Constitution (DH, 2015a). Professionals may perceive they adopt this approach and feedback from patients and carers through the many surveys reflect this, there are other significant reports which present a different reality such as the Francis report and the Winterbourne View Hospital review (The Mid Staffordshire NHS Foundation Trust Public Inquiry (2013); DH, 2012d).

Kylie, a registered nurse herself, questioned the level of empathy professionals have and how perceptive professionals are about the realities of caring.

I don't think it's picked up how tired you are as a carer. It was after Susan died I realised how tired I was. You go on automatic pilot. It took me six or seven weeks before I got a full night sleep because I was so used to not sleeping. If somebody just said, 'how are you?' I think carers are undervalued and it's things like you go from having a wage to forty to sixty pounds a week. I couldn't get carer's allowance because Susan was on disability living allowance and it's the finances, but a lot aren't as fortunate as us.

Karan began caring at the age of twenty. She highlighted the impact of caring on her self-esteem. Despite coming into contact with many different professionals, the professionals involved with her family members did not pick up that she was the main carer and the impact this was having on her own health and confidence:

It's things you don't realise at that age, how many responsibilities, so I did know there was some sort of restraint but I didn't know the name carer. It gradually got worse because my sister in law passed away and there's been that role because my brother was a man's man and didn't do a lot round the house so it was left to me. I was looking after mum, dad, partner, going up seeing to his two girls and I think it got a point where I could no longer hold a conversation outside my caring family. I couldn't hold a conversation about everyday things because my whole day surrounded round having to be this piece of glue for so many people. I couldn't think about me and I got really inwards and really angry and lost a lot of confidence. I think it came to the point where I had to go to the bank and I couldn't face it. I avoided doing things where I had to talk to other people. I was fine in my own group 'cause I was the person holding that together but I think my confidence had been so suffocated I forgot to be able to speak to other people. I think I went inwardly and I started talking to the computer more. I don't mean having a conversation with the computer, but I think I threw myself into it because it didn't question me on anything.

Sarah found in her experience it was the smaller things that make the greatest difference to patients and their carers, such as terminology used by professionals and the way in which they introduced themselves to patients and their families. She felt it came down to appreciating the vulnerability of the patient and their families when receiving health care. This also has links with a previous theme of a shared philosophy of care between professionals.

I've just been watching a video from a Trust. Somebody introduced themselves on the lines of, "I'm Joan Smith and I'm your specialist oncology nurse from so and so Trust" rather than say "Hello, I'm June and I'm your cancer nurse." You know they've got these long NHS titles and are just incomprehensible. It's about proper introduction so, "hello I'm so and so. I'm a doctor or nurse", is almost good enough so that people know who you are and what you've come for. "Today I've come to do an assessment to see how you are and to discuss what we are going to do next" or "I've come now to top up your medication and what that will involve is I'm going to ...this might be a little uncomfortable", you know, so prepare for whatever.

Sarah's view supports that of Dr Kate Granger. She tells her story as a patient through the eyes of a doctor (Granger, 2012). When she was diagnosed with a rare tumour, she went through the transition from doctor to patient and experienced the patient journey through cancer care at first hand. Many professionals failed to introduce themselves to her and frequently made assumptions about her feelings and her knowledge about her condition. Her lived experiences of receiving care illustrate how the behaviours of professionals can individually and collectively impact on the people they look after.

Another important individual attribute identified by the carers is the need for recognition by professionals of the contribution carers make to overall care provision. Karan, from her experiences and from the years of working at the carers' resource centre, advocates professionals valuing carers and the role they play in care provision. She wants to see the carer viewed by professionals as part of the wider care team and their expertise and the contribution they make in the overall package of care valued.

Communication is the key. Listening to the carers, not thinking you know best. You're in this profession and you've got a badge that says so. It's not about that. Actually, treating everyone as an individual not giving the carer the label. We are all individual with individual needs and it's about treating them as an individual. Communication is massive between carer and professional and between services.

Judy was not a direct relative of the people she cared for but social services turned to Judy many times to voluntarily support people with no families. Judy felt her input was valued by social services, but at times, she found she still had to argue with them to get what she wanted. She remembered a time when she had Mary rehoused in the bungalow next door to her. Once she had made her case and they listened and supported her, the result had a positive impact on the overall care of Mary.

I had this wall knocked out and an adjoining door done to it. The council knocked me back the first time, but I appealed against them and said, "Look I've looked after this lady for all these years. Shouldn't I be entitled to

something? I am getting old as well as her". To cut a long story short, they did it for us. And that was ok.

An interesting finding was highlighted when I interviewed Ava. When I asked her if she felt valued, she was not sure how to answer the question. She deliberated for a while and then replied.

I don't know about that. They'd probably prefer me out of the way [laughs]. I can't answer that. It's not something I've ever thought of. To be honest, all I do is keep my mum home and happy. I knew that if she went into a nursing home, I've not found a good one yet. As long as we can keep things ticking over. Whether my husband will that's another question. He's been very good. But I can't answer that... valued... I don't know.

Carers are most satisfied when they are valued and respected by professionals (James, 2014; Goodman et al., 2011a). In his review of the literature of people who care for someone with an intellectual disability, James (2014) highlighted similar qualities carers want professionals to have, such as being honest, reliable and non-judgemental. Carers want professionals to be aware of, and responsive to, the changing needs of the whole family (James, 2014).

Another individual attribute the carers identified as being influential on interprofessional working, was that of leadership and taking responsibility. Whilst a professional may not be the designated team leader, the carers felt they should take responsibility to ensure high standards and continuity of care occurs. The carers frequently experienced professionals working in their own professional silos and completing the required tasks specific to their professional role. In addition, the carers perceived a lack of willingness on the part of some professionals to provide continuity of care. There was a reluctance in ensuring other professionals were updated on progress. They felt they should have taken the lead to ensure the patient and family received timely and appropriate care. In many cases, this happened when the patient moved from one setting to another.

Sarah became frustrated in identifying who was in charge of her mother's care and who she and her family could go to for information regarding progress.

...one of the disadvantages of multidisciplinary care is that there isn't a lead professional so no one coordinates my mum's care or knew my mum's history and what's going on with her. I found that when she was going through the cancer treatment the registrar who understood mum's case could answer all the questions.

Goodrich and Cornwell (2008) identified this similar question of 'who is in charge' from the interviews they carried out with patients and carers. They found from their interviews with patients and carers examples of a lack of clarity regarding the person in charge of care for the patient. Individual professionals were not willing to discuss the patient's circumstances as they were not the lead professional or named nurse in one example. When the patients and families found a professional who was willing to talk to them, they found they concentrated on their own professional input and not the total care package of the patient.

West and West (2015) suggested a change to the way health and social care organisations consider leadership. They recommend all staff take responsibility for the success of the organisation as a whole, rather than concentrating on their own area of work. This is supported by Prescott and Rowe (2015:103), who advocate leaders as 'revitalising entrepreneurs' to drive forward change.

Sarah summarised in her reflections on the reasons why the effectiveness of care is inconsistent between teams and between different units. She identified the crucial role and influence the person in charge has on the wider team and the way they work together to deliver care.

Another thing is, I think the thing is that nurses find most difficult is if they are working with a colleague who isn't very competent, to challenge them is the biggest issue. That is why you have exemplar wards and bad wards depending on the leader. That's not necessarily matron, it is who really is in charge. It's the nurse who sets the... It not who you think is really in charge. So it's like having the courage to say no this isn't good patient care. I don't believe I am going to do this but I think fitting in and whatever is quite a thing. That you don't see in other areas very much. It's the down side of nursing.

The King's Fund report 'Patient-centred Leadership', suggested caring and compassion should not be limited to the interactions with patients, but also to those interactions with other professionals (The King's Fund, 2013).

The question of effectiveness relates to the whole team and not individuals. It could be argued that this assumes all team members are providing effective care. The impact of one member of the team not performing their role effectively can be detrimental to the overall performance of the team and ultimately to the patient and carer experience. Shaun Brophy discussed his personal experiences as a patient over seven episodes of hospital care and integrated his experiences with personal construct psychology (Brophy, 2006). Brophy discussed the difference between professionals doing their job in terms of completion of tasks and professionals who are carrying out their roles with a sense of achieving personal excellence. He described this as an individual doing their best in every circumstance and,

...being guided by their humanity rather than just doing a job defined by the task dimensions of their occupational role. The latter people just do their job and serve a system that relies on them to do so. The former people have a calling that transcends the limits of system requirements and leads them to be their best in every circumstance. This calling is most in evidence in their relationships with patients. (Brophy, 2006:375).

This is not advocating individualistic working, instead groups of individual professionals working together to deliver effective care; that is effective interprofessional working.

4.1.3.2.2 Active listening

Another subtheme identified is the importance of the carers being listened to and of being heard by the professionals. The majority of the carers identified the need for professionals to appreciate the reality of the carer's situation and be aware of their particular context.

Karan experienced professionals making assumptions and not asking the right questions. They assumed her father was the main carer for her mother, whilst it was Karan who had taken on this role.

I mean, I'm going back a long time and my mum had a lot of appointments with her chest and diabetes and glaucoma and because dad was there with her as her husband, even though he wasn't doing the caring role, they didn't ask anything. Looking back, they saw a good family network but wouldn't question or ask if she was ok when she got home. The same with dad, cause mum would be there and I'd be there and my partner would be there. No-one questioned that. Mum's condition wasn't necessary for services to come in. It was for me to give me a break but mum didn't need help with personal hygiene although she did need help with getting into the shower. I don't think they picked up on that because I did it. They probably thought dad would do it, I don't know.

Karan went on to emphasise the importance of professionals listening and recognising and valuing cues from the patients and their families.

I would like to break this confidence thing because they are ignored so many times as a carer. That's what batters the confidence so they feel they can't speak up. They've got a right. It's their family and they have a right to voice it and I just think...That's people's inability to listen, they just don't listen. I think if carers really talk from the heart and they show they are not listening to them, you'll never get that carer to open up. If you look at your watch and forget what they've said. I know it all goes back to your listening skills and you're supposed to be taught that as a professional. It's common human decency. Talking to someone's who struggling, you don't look at your watch or say "sorry what did you say I wasn't listening". You'll never get that person to open up. It's so personal you've got to trust them.

The Macmillan nurse noticed that Kylie was struggling to care for Susan effectively, despite other professionals visiting Susan more frequently. Assumptions had been made by other professionals about her ability to cope, as Kylie is a registered nurse. It was this particular professional, who picked up on cues of Kylie's struggle to care and acted accordingly. A similar finding from the lived experience of Dr Kate Granger in relation to her husband (Granger, 2012).

Professionals tend to concentrate on the patient but very rarely ask the carer how they are. When Susan went in the hospice it was when the Macmillan nurse looked at me and said, "You can't go on like this you look dreadful, you need to have some respite". She said to Susan, "Will you go into the hospice?"

Hilda had experienced professionals working in their professional silos and not picking up she had to sit in an uncomfortable deckchair for thirteen months because Arthur's bed had to be moved downstairs in their living room. She had started to develop shoulder problems and received out-patient physiotherapy; however her problems at home were not picked up in that time. When I asked Hilda what message she would like to give to future health professionals, she responded.

Well, they need to look at the person who is ill and the person who is caring. They should be able to pick up to see if they are coping. I might sound stressed out sometimes but they have to remember that every house they go to is going to be different. Mostly, it's the women, who are doing the looking after. The men aren't. Nobody can put themselves in the place you are in at the time but you need a lot of compassion and patience in your job.

Most of the stories highlight the carer journey: the journey from novice to expert carer. Even Kylie, whilst she was a registered nurse, the role of carer was new to her. All carers wanted professionals to recognise the journey and in particular, where each carer was on this journey. Many professionals saw the carers as a homogenous group and made assumptions as to their position on the novice to expert continuum. Carers who are new to the role can often feel isolated and anxious (Nalder et al., 2012; Pereira and Botelho, 2011).

In the cases of Britney, Parveen and Bailey who were more experienced in their role, professionals refused to acknowledge the expertise they brought to the decision making process regarding the most effective care provision. All three carers are carers for a child. James (2014) highlighted evidence in his review of the literature that reported mothers feeling they have to prove to professionals that they have the specific skills and expertise. Professionals can be reluctant to recognise carer expertise gained through their experience of caring.

As discussed previously, Charon (2006) is a powerful advocate for active listening. She emphasises that not only should professionals listen to their patients and families, they should listen for stories in each encounter. 'Listening with the third ear' requires a certain level of skill and experience and medical professionals can spoil the patients' story by forcing it into a preferred style (Charon, 2006:66). As experienced by the

carers in my study, professionals made their own judgements based on their own clinical reasoning or professional and clinical guidelines. This was not always appropriate to the carer or patient circumstances. Charon advocates the need for professionals to undertake a much deeper analysis of the situation presented to them to ensure the whole story has been heard.

Evidence of this can be seen in the action research study by Baron (2009), who used stories of patients who had undergone surgery for a femoral bypass graft. Following the interviews with patients, the professionals on the project team commented on the impact of hearing the patients and carers' experiences at first hand, how it had 'broadened their thinking' and how this would positively influence their future working practices (Baron, 2009:23). The extent and nature of this change in practice was not made explicit in the findings of the study. It does however reinforce the view that unless professionals actively listen to patients and their carers during their interactions, preconceptions will not be challenged and practices will not change.

Active listening presents a challenge for professionals. It challenges preconceptions of existing knowledge and established patterns of thinking. Warne and McAndrew (2007) in their discussion paper on an approach to enhance patient centred care in mental health nursing practice, advocated mental health nurses to become 'knowingly knowledgeable' (Warne and McAndrew, 2007:227). To achieve this, the authors suggest mental health nurses acknowledge 'patient expertise', a term they used to describe the patient being the expert in their own experience (Warne and McAndrew, 2007: 225). This argument extends to other professionals and their interactions with carers.

Both reflection on and in action are commonly recognised models of reflection in health professional education and practice (Schön, 1983). Reflection does not imply making an assessment on what is being reflected upon, whereas critical reflection does. Mezirow (1998) described action critical reflection of assumptions (Action CRA) as a method for improving performance. It involves the person examining critically his or her own assumptions defining a problem, in order to take more effective action to solve it. In reality, the high demands on health and social professionals to do this effectively is limited. Where time pressure is high, reflection in action for the busy health professional becomes limited (Clouder, 2000). In these conditions, professionals

learn to use routinised practices, devoid of genuine critical reflection and clinical reasoning.

Judy summarised how future professionals should question their own and others' practice.

You must ask questions. You mustn't just take what is in the records. If you query anything or are doubtful in any way. If you are not sure, you know... like that doesn't look right to me.

Professionals need to feel comfortable challenging their own and other professionals' views if they are to work effectively together. This is not always easy for a variety of reasons such as the influence of power relationships, professional status (Nancarrow et al., 2013; Reeves et al., 2010) and an unwillingness to listen to others.

4.1.3.2.3 Openness

The third subtheme is the need for professionals to be open: open to challenges; ability to demonstrate candour; a willingness to learn from others and an openness to changing their preconceptions. The codes from each regulatory body are clear about the expected behaviour of every professional, the reality from patient and carer experience is different (NMC, 2015; GMC, 2013; HCPC, 2008). The carers described experiences of staff being defensive when challenged.

From the first day, Helen was admitted following her stroke, her daughter Ava felt the ward staff were very defensive towards her family as they had complained about Helen's care from that first day. The air mattress on Helen's bed had not been inflated and Helen had slept the night on an uninflated mattress and was crying for help in the morning when the family attended. Once the staff became aware of the situation, the mattress was immediately inflated. Ava's family were not happy with the general care given to their mother. When they responded to a request for feedback regarding Helen's care, Ava felt that the attitude of most staff changed towards the family. Ava and her family were made to feel uncomfortable and they chose not to provide any further feedback as they were concerned about reprisals surrounding Helen's care.

Ava and her family are not alone in this. According to a Patients Association survey, 50% of surveyed patients had concerns if they made a complaint, this would have negative implications on the quality of care provided following the complaint (Patients Association, 2014). Walker and Dewar (2001) in their study of staff and carers on a psychiatric ward for older people found similar findings to Ava. They found the nursing staff regarded problems raised by carers as personal criticisms, rather than providing opportunities for service improvement.

Sir Robert Francis, in his summary of findings from the public inquiry into the Mid Staffordshire NHS Foundation Trust, identified a need for a cultural shift and a shared culture to be embraced across the health service.

The common culture of caring requires a displacement of a culture of fear with a culture of openness, honesty and transparency, where the only fear is the failure to uphold the fundamental standards and the caring culture. (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013:48).

Openness to learning from others was another theme identified through the carers' experiences. They identified a need for professionals to be more willing to learn from others. Bailey found that once her son had a diagnosis of attention deficit disorder (ADD), some teachers and other professionals were willing to listen and work with the family. She also found not all professionals were willing to change their preconceptions and somewhat prejudiced views.

...the head teacher at the junior school, I went and spoke to him and said, "my son's got this condition, he's been diagnosed". I'd actually been part of... at that point, I'd got a support group together and I'd got all sorts of professionals on board and we'd help put together a booklet that went to all the local schools on how to deal with children with ADD. The problem was none of them seemed to adhere to it really and so I did mention this booklet and if they wanted any more information, or if they wanted to speak to other professionals, I could do that. The headmaster just looked at me and said, "Well it's only people who come from certain backgrounds that have children like this; they come from council estates and backgrounds like that."

Even when Bailey had established herself as an expert and had presented to different teams of professionals, there were some whose opinions remained fixed.

I went to social services disabilities team ; I've spoken to people in children and families; I've spoke to people at university that teach social work courses; and for whatever reason they've not... , you know. I'm actually now ... What happened was I had to give up work to look after my son. I've always done voluntary work, twenty odd years of voluntary work and I'm classed as an expert now in the field, but these people still don't want to listen and they don't want to be educated and I just think they need to listen more and open their minds.

The carers' experiences emphasise the importance of these individual attributes and the powerful influence they have on the relationship with other professionals and with the patients and their families. If professionals do not possess these attributes, it will impact on the effectiveness of interprofessional collaborations in a variety of ways. Professionals may be less willing to cooperate with other professionals if they do not value others' contribution or professional opinion (Cameron, 2011; Hall, 2005). They may not recognise or value the important role of the carer and fail to work with other professionals or agencies to meet the needs of the person and their family. There may be a sense of tribalism and protectionism leading to lack of candour regarding the standard of care delivered. They may concentrate on their own professional or clinical specialities and not take collective responsibility for the delivery of quality services.

My findings demonstrate individual attributes of professionals are an important dimension of effective interprofessional working from the carers' perspective.

4.1.3.3 Information Communication

The third and final main theme is information communication. All of the carers highlighted the provision of relevant information as an important factor influencing effective care. Three subthemes are identified: patient records and information systems; referrals and signposting.

4.1.3.3.1 Patient records and information systems

This subtheme is around the documentation, storage and sharing of information regarding service users or patients and their families. Many carers perceived a lack of efficacy of the patient record systems that contained information about the person they cared for. One common area was the lack of perceived communication across different systems.

Sarah found medical information about her mother was stored in different places and professionals did not have easy access to this information, especially in the community setting. One time when her mother was discharged home from a short stay in hospital to have her lung drained, she felt that there was no one coordinating care or that fully understood her mother's current condition.

He was a lovely empathetic GP but then he was on call one week and not another so when we called for the on call doctor, another GP came. He was the one who decided she should go into the hospital to get her lung drained and I didn't think she was well enough. He didn't have the history and the knowledge and so it was another GP... They did get together and talk about it, but it was this feeling of nobody seemed to know my mum's case properly. He knew her medication, the district nurse knew her care plans but it wasn't quite talking together. It felt very abandoned; it felt very patchy in that period.

Ava's experience of caring for her mother Helen has led to an overwhelming sense of fear of reprisal from the professionals. She was suspicious of what was written in the notes and neither she nor Helen had been offered access to see the notes.

When I asked her about the support from her GP and the rest of the primary care team, Ava believed she was the only person who had the most up to date information on Helen's progress and the input of other professional services. She did not feel this was captured sufficiently in the records.

[Researcher]: How much do you think the GP knows about what's happened with your mum?

[Ava]: Well he knows all her medical side.

[Researcher]: How much does he know about the social side?

[Ava]: Very little actually. It's not come up really.

Helen received care provided by a private care agency. Ava felt she could not fully trust the agency carers to deliver the agreed documented care plan, as it frequently changed and contained inadequate information about Helen. Ava had to be in the house to ensure effective delivery of the documented plan.

Well there's the care plan and we used to have a full detailed plan but the girl who did that left and they took that out and put another in that's just a few lines. So it doesn't tell them anything really. So if there is a new one ...

When we have a new one, I make sure I'm around a bit because they obviously don't know it. Because my mum's quite gentle, if she asks for something, they ignore her so if they're washing her and the waters not hot enough, they'll make her be washed in it. Whereas if I'm around I'll hot it up or say she doesn't like it cold.

Whilst Ava could view Helen's care plan, Britney was unsure what was written in her son Mark's hospital notes when he was admitted to hospital as an emergency. The doctor who she had never met before assumed Mark's admission was not necessary and told Britney quite clearly he was not providing a baby-sitting service. Britney assumed there was something written in the notes to suggest this was the case as the doctor could not have made that assumption within seconds of seeing Mark.

Kylie found the district nursing team looking after her partner Susan were extremely busy and often did not update Susan's notes adequately. Kylie devised a diary for the front of the notes, which she kept updated. When Susan was admitted to the emergency department in the local hospital, this provided useful and timely information regarding current medication.

[Kylie]: In the district nursing notes I kept a diary at the front so if when we went to A and E everything was there. When she was in the hospice, Susan used to say it's all there in the front.

[Researcher]: Was this something you'd devised on your own?

[Kylie]: Yes. I thought there was so many different nursing coming in. It was all there for them. I used to use it to request things as well if I wasn't there, dressings and things.

[Researcher]: Did they look at it?

[Kylie]: Oh yes. But it was only because I was organised. You could refer back to it as well.

Without Kylie's intervention of the additional information on Susan's notes, Susan's records would have been inadequate for effective continuity of care between the different professionals. Fortunately, Kylie was a registered nurse and knew the contraindications of common drugs. When Susan started her chemotherapy treatment, Kylie was prepared for the side effects; however, she noted she was in a fortunate position compared to most carers. The information provided by the professionals when they prescribed the drugs was limited and they relied heavily on the manufacturer's leaflets to provide information to patients and families.

[Kylie]: It got to the fifth cycle of chemotherapy and I tried to tell her to try to look after her mouth. She had a horrendous mouth. We tried all sorts. Even when she was drinking water it hurt and I eventually got her mouth right.

[Researcher]: Did the hospital not tell her?

[Kylie]: No. I think they relied on the leaflets. How many patients read them. They stick them in a drawer.

The 2014 National Cancer patient experience survey reported similar findings. Whilst 89% of the respondents were satisfied with their overall care, 44% of patients reported they were not informed of the side effects of the treatment that might affect the patient in the future (NHS England, 2014b).

Parveen and her husband Hussain had experienced effective care for their son Kenny when they lived in Scotland. They were surprised to find a different experience when they moved to the North of England. Kenny had been waiting eighteen months for an assessment by a neurologist. The delay was due to poor communication of medical information between the two countries and between the GP and the hospital. Whilst Parveen did not explicitly suggest a centralised database, she queried how communication could take so long. Parveen and Hussain were frustrated with the delay and could not understand why this had taken so long in an era of high speed telecommunications.

Hilda thought the care for Arthur and her experience of caring for him would have been improved if professionals had access to a centralised system that contained all the relevant information. She felt she had to repeat a lot of information for the professionals or for reception staff. She believed it was information they should have had.

Have one central computer that's not just for one but for everyone: care, social, doctors, all homecare, the OTs, district nurses that come here. If it was all together in one place so they could see what was going on. If I rung one of them people they could look and see if anyone else had been involved. It's too much, I don't know.

Belling et al. (2011) explored the perceptions of 113 health and social care professionals working in community mental health teams in Greater London. Their aim was to identify facilitators and barriers perceived to influence continuity of care. Participants who were interviewed described the challenges presented when two separate electronic record systems needed to be combined to allow use by newly formed integrated health and social care teams. Incompatibilities in existing record system software, difficulties encountered in using new systems, and limited quality and quantity of IT equipment were barriers identified for recording information and for communication among and beyond the teams.

Despite the move towards improved patient records and sharing of information, Cameron et al. (2014) concluded from their review of the literature, there remain issues concerning the sharing of information between professionals across teams, despite the many reforms to increase integration and more effective collaborative working. They suggest national protocols for the sharing of information; however this may become increasingly difficult in the future with the move to devolution and more locally commissioned and delivered services.

4.1.3.3.2 Referrals

The carers' stories contained examples of poor referral and follow up following discharge from hospital. Few stories contained positive experiences of effective and

efficient discharge; however, this does not necessarily represent more negative experiences. It could be argued the negative experiences were more memorable to the carers.

Following Mark's many hospital in-patient episodes, Britney felt the professionals were relieved to discharge him as Mark had challenging behaviour that was difficult to manage. They rarely referred Mark for any support nor discussed the options available for him. Frequently, Britney was left to pick this up. She felt some professionals did not appreciate the reality of her situation and were relieved at times to discharge a difficult patient.

We was back at [CHILDREN'S HOSPITAL], this doctor said to me, "we're going to let him go home. But I don't know how you live with him 'cause I wouldn't let him in my car." I laughed. "It's alright for you to say but I've got to live with it. I'm the one that's got to clean the **** off the walls at three and four in the morning; in his eyes and in his hair and in his ears. I just want some help and I want some answers.

Hilda had a similar experience when the doctors decided to discharge Arthur.

[Hilda]: The doctors discharged him and there was nothing in the house for him. He was in for Christmas and the New Year. I suppose they didn't want to be mithered but I wanted him home for Christmas. But there was nothing in place. They were all going out; the ward that Arthur was in. All the men who'd had strokes walked out even though they stumbled. Everyone walked out except Arthur. They told me he would never walk and they were saying like they'd had showers put in and they were doing this and that and they did nothing for Arthur at all.

[Researcher]: Did you ask for anything?

[Hilda]: Yes I kept saying I got nothing in the house. I got a bed then and a commode and that's all we got.

In Hilda and Arthur's case, there did not seem to be a coordinated and streamlined transition from hospital to home. The hospital appeared satisfied with the way Arthur was discharged, but there was lack of follow up once he was at home. Hilda and Arthur had to wait thirteen months before all the necessary equipment and adaptations were

in place. In the meantime, Hilda was expected to cope with caring for Arthur's complex needs with only a commode and his bed downstairs in their living room.

Similar to Hilda and Arthur, 82% of respondents to the NHS Inpatient Survey 2014 had discussions with hospital staff about relevant equipment and home adaptations after leaving hospital (NHS England, 2015a). The survey also found 85% of patients reported having discussions with hospital staff about referrals to other community services including physiotherapy, GP services or community nursing. Whilst a large majority of respondents said provision of equipment was discussed with them in hospital, whether this arrived in a timely manner was not followed up in the survey. This was also not addressed in the separate National GP survey (NHS England, 2015b).

These national surveys suggest that patients and their families to a lesser extent, are satisfied with their care overall; however it does not reflect the number of complaints the NHS receive. The surveys capture overall satisfaction and not individual experiences, which can provide a better view of the reality of care and of the overall experience.

Baron (2009) in her action research study examining the vascular patient journey identified an initial overall satisfaction rate was expressed by the patients and carers in her study. When this was explored further through interviews and focus groups, more insightful and more disturbing information was revealed about their experiences.

The carers in my study who required equipment, experienced long delays or the equipment did not arrive and alternatives had to be found, usually at the expense of the family themselves. Nalder et al. (2012) carried out a qualitative study in Queensland, Australia of ten carers of adults following traumatic brain injury and explored their experiences of the transition from hospital to home. From the carers' experiences, there was a gap in the perceived service by professionals and actual provision for the families. The authors acknowledged the study was carried out at one time point and the sample size was small, however Borthwick et al. (2009) highlighted similar findings from their review of the UK literature. More longitudinal research is needed regarding the realities of transition from hospital to home as there is a tendency to measure effectiveness on the grounds of information given prior to discharge rather than ensuring resources and support are in place once the person is at home.

In Hilda and Arthur's case, as highlighted previously, several different professionals came into their home and observed Hilda struggling to cope with Arthur without the necessary aids and adaptations, yet not one of them queried the length of time or tried to expedite the provision of the equipment. It appeared to Hilda that they believed it to be someone else's role.

On other occasions, the carers' stories revealed some professionals were reluctant to refer to other professionals or other services. Bailey found that her GP was unwilling to change his views on Lenny's condition despite a clear diagnosis being made. This reluctance to change an opinion resulted in a delay of referral to the services Lenny needed. Bailey had to find other professionals to support her when she needed referrals to specific services:

The GP still did nothing even after diagnosis. My GP is one of these who doesn't really believe in this disorder, certain people, he's got his own view on it and I don't think he's willing to change on that.

Highlighted earlier, Parveen and Hussain, in waiting eighteen months for a referral to a neurologist for their son Kenny, remained unclear of the reasons for this delay. They felt it was a combination of policy and procedures and their own GP's lack of willingness to assist in expediting a referral. Goodman et al. (2011a) found similar findings with certain professionals precluding effective working between services and other professionals.

4.1.3.3.3 [Signposting for information](#)

When Mark was young, Britney was given a diagnosis for Mark's condition and the consultant she saw provided her with minimal information about the diagnosed condition or explained where she could find out more. It is worth noting this incident was prior to the availability of the internet.

[Britney]: He was attending nursery, while he was there we were given an educational psychologist and this doctor used to come in do little tests. The nursing staff was picking up issues. I didn't have a clue what could have been

wrong or why he never slept, why his speech stopped. All his little words he did know completely stopped, no concentration; very aggressive; he never slept; screamed all the time. I had to keep pulling him up like Pinocchio on a string 'cause he'd thrown himself on the floor. At this time, this psychologist got involved and decided to do this education assessment. A consultant had said he'd got global development delay, I didn't have a clue what it meant. It was complete jargon. I remember he was two and a half and I went to see this other doctor, and he said to me "I think your son's got ADHD". Like I say, these words I didn't know.

[Researcher]: Did he explain?

[Britney]: He said something like, "well, it's an American term for hyperactivity. Go home and get on with it." I went "right". He said, "he'll probably grow out of it; it's a behaviour thing." I still wasn't none the wiser as a mum.

Whilst this occurred a while ago, similar findings exist in more recent literature. In 2008, an independent inquiry into access to services for adults and children with learning disabilities highlighted issues remained regarding limited information provision by professionals to carers (Michael, 2008). Wilson and Mansell (2010) reported problems accessing information about specific services such as physiotherapy, speech and language therapy and counselling. This could be for a number of reasons. GPs or other primary care professionals may not be referring to these professionals because of personal bias or a lack of awareness of the benefit of these services; there may be financial reasons for the non-referral and signposting or access is limited due to lack of adequate resources for these services. Professionals are reluctant therefore to refer due to lengthy referral times. Whatever the reason, services provided by relevant professionals are not being offered to those in need.

It has become the norm to provide information for patients when visiting a hospital or clinic or being admitted to hospital for treatment. There is limited information provided however for their carers or relatives. When she reflected on her experiences in the hospice, Sarah made a suggestion for an information booklet for carers and families. As there was a booklet for patients, she recommended a similar one for carers, which would assist in the orientation of the building and provide useful information such as car parking and visiting times.

All simple housekeeping things that would help you. So it needn't be a big leaflet, just to help. "If you are struggling with the fact your mum or whatever is dying there are people in the hospice who can help you or ask to speak to a member of nursing staff." It might well open the floodgates to a continuous stream but those people are there and anxious anyway, it would probably be more useful doing some of that.

Professionals need to be aware of services available for patients and their families.

Karan in her work at the carers resource centre recognised the importance of signposting of information for carers to resources that would directly support them in their role. She suggested the failure of this by professionals could potentially lead to serious consequences.

To inform people, it shouldn't come down to funding because that information saves lives and I don't mean that in a dramatic way but it does. That advice stops carers walking away from the caring role but it gives them the advice they can have a life and carry on with the caring role.....to get that awareness, to know exactly what is out there. It saves a lot of carers going under and hitting crisis point. To see a carer at crisis point is the most horrible thing ever from a carer's side and from a professional's side. That's quite sad really and quite hard. Saving the government billions of pounds a year doing this job looking after somebody, their loved ones and taking that on board and becoming ill themselves. It's tragic really.

Chris found from the research studies she had been involved in, carers who are new to their role may require signposting to information to assist them in their role and to access various types of support networks.

It backs up what I know already. Trying to get hold of any out of hours care whether it's for a young patient, help for elderly disabled parents or for crisis of any kind including patients with physical problems and carers; funding issues; lack of information about what benefit applies to which situation; lack of seamless care; trying to facilitate arrangements for patient; lack of information agencies and funding available and perhaps lack of support for filling in forms. My father is a citizen's advice bureau worker now. He's had his own problems with redundancy so I know where to go for advice. A lot of people can't.

If professionals are aware of available services, signposting to these services could potentially prevent unwanted hospital admissions or the breakdown in health of an informal carer. In addition, the needs of the person being cared for are met.

Sarah felt professionals should be more sensitive to the needs of the patient and their family. They need to be sensitive to how the public perceive them; some people like her father would never challenge a doctor.

I think as a carer you go on a journey: you wait for the doctors to tell you. Then you go and find the doctor and find out what's going on. So I think you become a more knowledgeable carer and don't wait for the doctor to arrive and ask them, you go and find them and ask them. And normally people are quite happy with that if you ask. But it is about asking. My dad would never ask and those that don't ask won't know anything.

The findings from my study suggest there tends to be a standard of providing information in terms of was it provided or not, rather than the quality and relevance of the information. This is evidenced in the questions asked in the NHS patient experience surveys (NHS England, 2015a; 2015b; 2013). It is the responsibility of health and social care professionals to adequately signpost people and their carers to relevant and timely information. It is also the responsibility of the commissioners of these services to ensure families have access to sufficient resources, such as speech and language therapists and physiotherapists.

4.2 Implications of the findings

The main themes identified a shared philosophy of care, individual attributes and information communication as important dimensions of effective interprofessional working, from the lived experiences of the carers. These dimensions have a synergistic relationship and elements from each dimension are interlinked with others. As stated earlier, the carers' stories and the three orientations provide a further layer of

meaning of the multiple realities of caring and the varied linkage between their experiences.

In this study, teamworking between professionals was largely invisible to most of the carers, a finding supported by Hewitt et al. (2015). The carers in my study experienced the outcome of care delivery and only on a few occasions, such as case conferences or joint home visits, did they directly observe interactions between professionals. Many of the carers highlighted instances where attitudes and behaviours of individuals or groups of professionals inhibited access to other professionals or services. When things went well, the carers highlighted a sense of a shared philosophy of care between the professionals and services which seemed to transcend structural and organisational boundaries. From the carers' perspective, the ultimate outcome of effective interprofessional working is the delivery of effective care.

As highlighted previously, other studies have identified factors for effective interprofessional working (Simms et al., 2015b; D'Amour et al., 2005); however outcomes of effective interprofessional working tended to be from the professionals' perspective and evidence of the impact on the patient and carer outcomes remains weak.

My study provides the perspectives of a group of carers of the impact of interprofessional working on both patient and carer outcomes. From the carers' lived experiences of caring, the study identified influential factors which contribute to the understanding of effective interprofessional working and collaboration.

4.2.1 Implications of the findings for individual professionals.

As discussed earlier, individual attributes of professionals have an impact on the overall effectiveness of care and how they work with other professionals. The carers identified qualities such as empathy, governing values that embrace the vocational aspect of the professional role, valuing others' opinions and expertise and taking individual and collective responsibility. Suter et al. (2009) identified two core competencies for collaborative practice: role understanding and effective communication. MacDonald et al. (2010) identified four further competencies: leadership; team function; strength in one's professional role; and negotiation for conflict resolution. They also identified behavioural indicators for each competency.

Whilst most professionals recognise the value of collaborative practice, in reality barriers exist which inhibit collaborative working in some way (Elissen et al., 2011; Suter et al., 2009). This study identified factors such as rules and routines, task driven protocols, organisational targets, system driven rather than patient centred philosophies of care; the carers reported these impacted on the overall care provided and on the effectiveness of the collaboration between professionals.

Whilst not directly visible to the carers in my study, professional identity is in conflict with person centredness. The reported reluctance to refer to others and the defensiveness of staff when their practice was challenged could be seen as an indicator of this. Professionals tend to be protective of their own identity to keep hold of the power that professional status affords (Hall, 2005; San Martin-Rodrigues et al., 2005). Elissen et al. (2011) found that multi-disciplinary cooperation between primary health care professionals was viewed as a supplement to individual practice and played a subsidiary role in professional routines.

The carers identified a need for professionals to value the contribution of others in identifying the needs of the patient. As stated earlier, effective models of collaboration can be found when individual professionals embrace the differences in professional cultures and value the information provided from the patient or their carer when making professional decisions. The carers in my research were frustrated at professionals making assumptions and not actively listening to them or to the people they cared for. This is reflected in the findings of McPherson et al. (2014). My findings highlight the need for individual professionals to recognise the impact this has on the overall outcomes of care and how their individual practice can inhibit or promote effective care through their interactions with others.

The carers' stories highlighted issues regarding the measurement of successful outcomes by professionals. Hilda's experience of discharge from hospital epitomises the problems with systems perspectives of success rather than person centred perspectives. Arthur, Hilda's husband was discharged home from hospital with appropriate equipment ordered and referrals for therapy at home organised. This discharge is successful in terms of the systems perspective. However, Hilda and Arthur waited thirteen months for the right equipment and adaptations to be installed. A failing if measured from the person centred perspective. Collins (2014) offers an interesting

thought paper on outcome measurement systems for person centred care. A hypothetical patient Dorothy is referred by her general practitioner (GP) for a knee replacement. Consequently she undergoes a knee replacement, which is considered successful. This would be viewed differently if success was measured from Dorothy's perspective. At the very first encounter with her GP, Dorothy was not asked if she had been taking her pain medication. The reasons for not taking the medication was not explored and other alternatives of pain relief were not identified. Whilst the outcome of Dorothy's surgery was considered successful, it may not have been the best option for her.

Rarely is feedback from the person and their family gained by professionals during routine practice. In reality, this would be time consuming for every encounter. However to fully appreciate the needs of the person and the carer, professionals should adopt a more critical dialogue with their patients and their families and as Charon (2006:66) advocates, professionals need to 'listen with the third ear'. Time required for this should be taken into account by managers in expectations of workloads of their staff and should be acknowledged as a valuable activity.

As discussed earlier, the implications for individual professionals is they need to be aware of their own practice and the impact of their actions on others. They need to embrace reflective practice in a more critical way and not just as a way of evidencing competency (Warne and McAndrew, 2007; Clouder, 2000; Schön, 1983). They need to take responsibility for their own actions and not hide behind rules and routines, policies and procedures (Prescott and Rowe, 2015). Lord Darzi called for distributed leadership or leadership at all levels with the patient at the heart of all decision making (DH, 2008a). The carers in my study suggest every professional needs to understand their role in this.

4.2.2 Implications of findings across professions and teams

Many health and social care professionals belong to more than one team and work across health and social care organisations (Reeves et al., 2010; Goodrich and Cornwell, 2008). My study identified information communication as a main theme and in particular, patient records were seen as crucial in providing relevant information for

other professionals. The carers identified the following essential criteria for information to be effective: information needs to be accessible, timely, accurate, non-judgemental and shared.

With the increasing reliance on electronic records, it is important patient records contain relevant information to enable other professionals to continue the treatment and management of the patient effectively. Notes should contain information regarding the context of the service user or patient situation, including carer perspectives. Professional voice is given to the patient or carer voice in the medical records or care plans. As this information gets passed between professionals, teams and organisations, it needs to remain true to the voice from the original notes. Professionals need to engage in critical reading and look for the story beneath the written notes or the spoken report. Professionals should reflect upon the 'worldviews' of the person who has written the notes (Poirier, 2002:54). This was reflected in Judy's story who identified the need of professionals to question; that is, question what is written in the patient records and verify the notes with the patient or carer or other professionals if necessary. This could be perceived by professionals and by service managers as unnecessary and time intensive, however this could be argued as time invested well to prevent future problems.

The evidence suggests that patient records and other recording processes can be seen as unproductive and takes nursing staff away from direct patient contact (Nolan, 2007). There has also been an increase in the amount of recording processes health professionals need to complete to evidence they are achieving strategic and operational targets. In response to this, there is a growth in different interventions to increase efficiency such as the Productive Ward Releasing Time to Care (Morrow et al., 2014; Wilson, 2009). Streamlining patient records and reducing the time spent on completing patient records can be viewed as improving efficiency.

The above is in conflict with my findings in which the carers emphasised the need to ensure the content of patient records reflects the true patient voice to ensure effective continuity of care. This requires health professionals to value the time spent on the construction of the content of their notes and for managers to ensure sufficient time is incorporated in their workloads. Balancing efficiency and effectiveness is required. If

this is not recognised by professionals and managers, it will likely compromise continuity of care and hence, effective interprofessional working.

The findings from my study highlight the importance of professionals considering the way they are communicating information in the records about the person concerned. The information to be shared should be unbiased and reflect the contextual reality of the person concerned. Professionals may not be aware of the presence of any bias and prejudiced view and are usually too busy to spend time re-reading notes and undertaking critical appraisal of the content. However, by taking time to reflect critically on their practice, these biases may be uncovered and the individual professional is able to consider the consequences (Charon, 2006; Clouder, 2000; Schön, 1983). The time spent on producing and reviewing critically the information in patient records will then be valued.

4.2.3 Implications of the findings for organisational culture and systems.

A common theme identified from the findings was the need for a shared philosophy of person centred care. Organisations need to create a person centred culture throughout their organisation. They need to recruit and develop individuals and teams who are able to work collaboratively with a shared common purpose of delivering high quality care (Collins, 2014; Reeves et al., 2014; Goodrich and Cornwell, 2008; CIPW, 2007).

Not only was a shared philosophy important to the carers, they also identified a sense of collective responsibility and leadership was required to deliver the quality of care every individual deserves. This collective responsibility includes administrative staff, and other groups of professionals. The carers identified unnecessary barriers created by different groups of staff, such as general practice managers, head teachers and local housing officers.

Belling et al. (2011) in their study of community mental health teams, did not include the views of administrative staff and they acknowledged this was a limitation in their study. Administrative staff should be viewed as powerful gatekeepers to the access of health and social care professionals and to the information required for effective care

delivery. They should be seen as important links between the different professionals and services ensuring continuity of care (Parker et al., 2011).

Collective responsibility should be seen as an aim for effective integration of health and social care and for partnership working with the third sector (Goodwin et al., 2012). The carers' stories in my study identified occasions when rules and routines created barriers to effective care provision and prevented effective interprofessional working. As discussed earlier, protocols and care pathways can have a tendency to focus more on efficiency and resources rather than effectiveness from the perspective of the patients and carers. Parker et al. (2011) suggest service users and carers are more interested in a positive experience of continuity of care delivery than one model of care delivery. It is the nature of the experiences of care which dictates whether the outcome is positive or negative from the perspective of the carers.

Organisational policies and procedures such as discharge from hospital; referrals to other professionals or services; access to specialist equipment and sharing of patient information were all recognised by the carers as problematic and have the potential to prevent professionals working effectively together. Health and social care organisations need to consider the impact on the patient and their families in the review of current policy or in the development of a new policy regarding referrals, discharge, access to specialist equipment and systems for sharing patient records. This impact, however measured, should be done over a period of time as the needs of the person and their family are likely to change (Goodman et al., 2011a).

4.2.4 Implications of findings for pre and post registration education and staff development

The carers highlighted the need to be involved with decision making and for their voices to be heard by professionals. Several of the carers in my study were involved in the education of pre-registration health and social work students; however, most of their involvement was working with one professional group of students in their pre-qualifying stage. Opportunities for interprofessional learning should include the patient and carer voice wherever possible.

Frenk et al. (2010) advocate a global redesign of the professional health education systems to enable a positive effect on health outcomes that is centred on the interests of service users and populations. They suggest one outcome of this redesign is transformative learning and the development of shared competencies around social accountability. As McPherson et al. (2014) identified in their study, knowledge exchange between patient and carer and professionals and between professionals is important. Whilst the engagement with patients and carers in higher education can be problematic, the benefits outweigh the challenges (Farrell et al., 2006).

My findings suggest future health professionals should value the expertise and contribution made by other professionals whilst maintaining their own professional identity. Khalili et al. (2014:95) suggest to enable this, future health professionals need to develop 'a sense of belonging to the interprofessional community'.

Reeves et al. (2014) in their editorial on the final report of the Mid Staffordshire NHS Foundation Trust Public Inquiry in 2013 advocate more interprofessional learning opportunities for all pre-registration students with learning outcomes focussing on collaborative decision making, coordination of care and planning of services in order to gain a better understanding of quality care.

Interprofessional learning should not just be promoted in pre-registration education. Over the past ten years, many health and social care professionals have graduated with experience of some interprofessional education. Organisational cultures, existing attitudes and behaviours of qualified professionals influence behaviours of these newly qualified professionals (Dixon-Woods et al., 2013). Post-registration education needs to promote attitudes and behaviours which promote collaborative working and person centred care. Whilst the focus of current funded post-registration education is predominantly on clinical leadership and advanced clinical skills, the learning outcomes of any education offered should clearly articulate the benefits to service users and carers.

Goodrich and Cornwell (2008) highlight the success of Schwartz rounds, which have been adopted in the UK. Schwartz Centre Rounds consist of a multi-professional forum for staff to meet monthly to discuss and reflect on the emotional and challenging aspects of their roles. Goodrich (2012) carried out a pilot study of the use of the 'Rounds' in two hospitals in the UK. Her research explored the views of senior leaders

and the key players involved in the establishment of Rounds via face to face or telephone interviews at beginning and end stages of the pilot. Goodrich (2012) found the staff involved in the rounds were mostly positive about the experience and felt they gave them support, increased awareness of other professionals' contribution to patient care and anecdotally staff reported they believed they were more compassionate to their patients. The short duration of the pilot meant it was too early to make claims about any positive changes in policy or practice (Goodrich, 2012).

Since then, the Point of Care Foundation, an independent charity, has supported 65 NHS organisations in the UK to provide Schwartz Rounds for their staff (The Point of Care Foundation, 2014). The evidence of the impact on the patient and carer experience has yet to be published, but has been commissioned by the NIHR Health Service & Delivery Research (HS&DR) Programme (NIHR, 2013).

To increase a family inclusive culture, Stanbridge et al. (2013) describe a 3-day training package for professional and non-professional staff working on two inpatient wards for older people within an NHS foundation trust providing mental health services in the UK. The training was specifically designed to primarily address staff attitudes and included a family member or carer on the training team. The authors claim the training has led to staff having more direct involvement with families and carers and developing a greater appreciation of their needs. In addition to this, the authors acknowledge that whole team staff development has led to a more family inclusive team culture. Increased partnership working has been observed due to a combination of the training alongside the development of a trust-wide family liaison service (Stanbridge et al., 2009).

The Francis report of the public inquiry provided the opportunity for conversations to take place between different groups (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013). Reeves et al. (2014) argue that instead of focussing on one profession, namely nursing, it is a combined response by all professional groups, policy makers and commissioners of services that is required to achieve solutions to issues raised. Post registration education and staff development should be focusing on these issues to drive the quality agenda.

As highlighted earlier, my findings suggest a shift in culture is required regarding patient records. This should be incorporated into the curricula for both the pre-

registration professional education and the continuing staff development post-registration. The latter will be the most difficult as this potentially requires a change in mind set, and the challenge of established beliefs and practices regarding patient documentation. Curriculum content for patient documentation should be evident in interprofessional learning sessions as well as in those sessions that are uni-professional. The voice of the patient and the carer should also feature in these sessions to facilitate an awareness of the impact of poor patient information on the patient and their carer and family.

4.2.5 Implications of findings for Policy

The Government White paper, the Five Year Forward View, suggests a change in the number and nature of providers for health and social care (NHS England, 2014a). This means a range of employers for health and social care professionals will be working within various models of care. One obvious benefit of this is the potential for local services to meet the needs of the local population. However it poses a challenge for effective interprofessional working as new roles emerge and new patterns of working evolve within the different organisations. This will potentially impact on the effectiveness of the communication of information between the different service providers.

Information communication was highlighted by the carers as an important factor in determining effective interprofessional working. They aired their frustrations over information not being shared between services and gave examples of having to recount information repeatedly to different professionals.

Better patient information communication is highlighted as a priority in the White paper, advocating electronic patient records and other IT systems which are operable between different organisations (NHS England, 2014a). The Health and Social Care Information Centre (HSCIC) was established in April 2013. It is the national provider of information, data and IT systems for the health and social care sectors (HSCIC, 2015) and has set an ambitious five year strategy to improve the information systems for health and social care in England. The main challenge over the next five years is to ensure all health and social care professionals, commissioners of services and all care

providers are fully committed to this strategy and have the necessary resources in place to enable this to happen.

A note of caution is highlighted in the Norwegian study by Christenson and Grimsmo (2008). In their study of the use of electronic patient records by Norwegian GPs, they found that whilst systems had improved in providing individual electronic records for patients, the availability of relevant information in the records was lacking. This was found to be for numerous reasons such as the GPs only reading certain sections of the records and limitations in the functionality of the systems affecting access to previous notes and progress summaries.

Any new information system requires effective communication for full implementation. In a recent survey of patient satisfaction of GP practices in England, 52.6% of patients were unsure if any online services were available at their practice, whilst only 2.4% patients knew they could access their own records (NHS England, 2015b). The response rate for this survey was low, 32.5%, so caution is needed in generalisation of these results.

A multi-country survey carried out by Accenture investigated information technology and patient and doctor engagement. Six countries were included in the survey: Australia, Brazil, England, Norway, Singapore, and the United States of America (Accenture, 2015). Five hundred and two doctors working in England responded to the survey with a 50:50 split between the settings of primary care and secondary care. 68% reported using electronic health records and 86% perceived they were proficient in using the systems. Only 41% of the doctors used electronic referrals to health professionals in other organisations. The majority of the electronic communication with patients was regarding patient appointments and repeat prescriptions. Whilst 78% of the doctors felt electronic records impacted positively on health outcomes, 45% of the doctors felt that accuracy of the records would be compromised if patients were involved in updating the records. Less than 10% of the surveyed doctors' patients were able to update their records.

The findings from my study indicate a lack of compatibility of information systems was a barrier. The carers also highlighted the importance of accuracy and relevance of the content of the information in the patient records in facilitating continuity of care.

Unless this is the case, the value of the any electronic or paper-based patient record system will not be felt by the individual patients and their carers.

Greater Manchester sees the devolution of health and social care in April 2016, overseen by a Health and Social Care Partnership Board (Greater Manchester Combined Authority (GMCA), 2015). It claims the focus is on people and place and not organisations. Services will be designed collaboratively and services integrated around local communities. There will be shared budgets to ensure streamlining of the purchase of health and social care services (GMCA, 2015).

Rummery (2009) conducted a purposive literature review of the international evidence base regarding improved service user or patient outcomes resulting from health and social care partnership working. She concluded evidence of service user involvement and improved user outcomes was limited, particularly in services provided as a result of government and policy directives; whereas in more locally driven and incrementally developed services, evidence of improved outcomes for service users appeared more robust (Rummery, 2009).

There needs to be equal weighting given to the community health and social care services to that given to the acute sector if integration is to be truly successful (Cameron, 2011). The findings from this study highlight problems with fragmented services and professionals knowing to whom and to where they refer their patients. With the potential of more fragmentation of services and the emergence of new roles of workers, collaboration between professionals could be negatively affected.

Only time will tell if devolution in Greater Manchester is successful; however caution is required regarding from whose perspective success is measured.

4.3 Discussion of strengths and limitations of the study

A strength of this study is the chosen participatory approach with the involvement of two informal carers, Grace and Crystal. They took an active part in the development of the stories which were then used in the subsequent interviews carried out in the second stage of the study. The advantages of the use of these stories instead of vignettes in the interviews is covered in Wright et al. (2014).

Grace also contributed to the analysis of the findings to the selection of the final themes. An important output from the study is the development of real stories which I have already used for educational purposes with groups of pre-registration students. All the carers in the study gave informed consent for their stories to be used for this purpose.

This study was a small scale qualitative study aiming to capture informal carers' perceptions of effective interprofessional working through their lived experience of caring. All carers volunteered to participate in the study and all but one of the carers who volunteered were female. Only one male carer was involved in the study and he shared his story alongside his wife; he had to leave the interview early due to work commitments.

The majority of the male carers when they attended the carers resource centre participated in day trips and I was not able to meet with them personally to explain my study. Despite posters being displayed in the centre, no male carer volunteered. More involvement of the managers at the centre could have facilitated more male involvement, however I was concerned with the issue of coercion and chose not to pursue this further. The members of the service user and carer group at the university in the north of England who were carers, were all female; the male members were all service users.

As all participants self-selected in taking part, the sample is not representative in terms of age, gender, or ethnic origin and no generalisation claims can be made. I attempted to address this by meeting with three different groups of carers, one group being female carers from a particular ethnic background. I did not have access to a carers group for young carers, so this group of carers were not included in my study.

During the interviews, all the carers freely told their stories and the stories are specific to each one of them. Other carers may tell a different story of their experiences; however the carers' stories in my study are their experiences of caring. The carers encountered different professionals through these experiences. Their stories are valid and their voices should be heard. This study has provided opportunity for this.

The use of Grace's and Crystal's stories in the interviews may have influenced the way the other carers' stories were told; however I felt they acted as prompts and triggers

for the carers to tell their stories in a way they had not been asked to do before (Wright et al, 2014). Bailey found listening to Crystal's story particularly useful,

I could have talked because I'm used to talking, but for someone else it's really, really good this, because it triggered quite a lot of things for me. Like she said she had a son with Asperger's sitting at home doing nothing. That reminded me of something because we can't get him to college. Her health was obviously affected and I was in a similar position.

Despite these limitations, the key aim of the study has been achieved; to allow carers voices to be heard through their experiences of caring and their perceptions of effective interprofessional working explored.

4.4 Summary

This chapter presented the findings of my research through the voice of the carers. I presented the stories as representative constructions; explored three orientation groupings 'It's all a battle', 'That's how it is' and 'I know how it should be'; and identified three core themes of shared philosophy of care, information communication and individual attributes, emphasising the synergistic relationship between these three themes. A final synthesis and discussion of findings included reference to the existing literature.

In the next chapter, I will reflect upon my personal development and progression through this piece of research. I will do so with the help of a young girl called Alice and all the colourful characters to be found in a place called Wonderland.

5 A critical reflection of the research journey OR My adventures through research wonderland



The aim of this chapter is to reflect critically on key points through my doctoral journey and to elicit a self-awareness of the relationship between myself and those involved in the research process; the carers, my supervisors and academic colleagues. I have done this with reference to excerpts from Lewis Carroll's text and other literature.

According to Pillow (2003), reflexivity involves continuous practice of self-awareness during the research process which provides visibility to the construction of knowledge within research studies. By doing this, the analysis of research studies will be more accurate (Pillow, 2003). Doyle (2013) provides a note of caution for researchers in the practice of reflection and reflexivity. She cautions the dangers of an overemphasis on narcissism and she advocates the need for 'thinking about' rather than 'simply revealing aspects of self' (Doyle 2013:6).

5.1 An adventure begins...

When I contemplate reflecting on my doctoral journey I am constantly reminded of the process being more than a journey. I knew once I had made the decision to proceed with my doctoral studies, I would change; however I had not appreciated how or by how much, my thinking state of mind would evolve.

Early on in my studies, I remember talking to a colleague who was asking me how I was progressing with my PhD. I distinctly remember replying that I felt like I was falling down a hole and I was not certain when I would reach the end. Prior to this I had made a note in my diary that I should purchase an Alice headband to wear. I felt like a small girl at the start of a quest in search of answers to my research questions. In fact, I asked him in the future to call me Alice. My situation reminded me of one of my

favourite childhood stories, Alice's adventures in Wonderland by Lewis Carroll (Carroll, 1993).

At the beginning of Alice's adventures, Alice was sitting with her sister who was reading a book without pictures or conversations. Alice contemplated the uselessness of a book of just words. Her curiosity was roused when she noticed a white rabbit with pink eyes, which seemed quite natural at the time. The rabbit took out a watch from his waistcoat pocket, announced 'Oh dear! Oh dear! I shall be too late' and ran off (Carroll, 1993:38). Burning with curiosity, Alice ran after the rabbit. The adventure had begun. I recall a teaching session with my postgraduate students. I asked them to reflect on the ways they worked with other professionals in their daily practice. During the discussion with the students, I shared my experiences of caring for my parents. This I believe was my white rabbit moment as my research questions started to develop from this point in time.

5.2 My burning curiosity

My background as a physiotherapist, an academic and a carer to my elderly parents has been discussed in earlier chapters. As an academic with over twenty years of working in a department within a faculty of health, I faced the challenge of how best to prepare future health professionals to work effectively with other professionals. As highlighted earlier, evidence exists recommending that professionals should learn from and with each other in order to work together effectively in practice in the future. For many years, the students in my department have learned with other students and with other professionals in the classroom and through their clinical placement experiences. They have heard the stories of patients and carers throughout their years of study and at times have been assessed by patients and carers. Whilst they achieved the educational learning outcomes which included awareness of other professionals' roles and the need to work collaboratively, I am uncertain if these were enacted in their clinical practice and if, in fact, they worked effectively with other professionals.

As a registered health professional, I had experienced effective and ineffective interprofessional working and I had my own preconceptions of what should happen in

practice from my experiences of delivering health care; however, as an informal carer for my elderly parents, I experienced the consequences of both effective and ineffective working on care delivery. I had experienced similar situations to the carers in this study and found the systems and processes frustrating and despite being a fellow professional, encountered episodes of defensiveness from other professionals.

As I started to explore the literature to a much greater extent and depth than I had done previously, I found the reality was more complex than some of the literature suggested. It raised more questions. Many studies focussed on teamwork and competencies for team working. There appeared to be a suggestion that if teams work effectively, effective care and services would be provided; that is, a causal relationship exists between effective teamwork and effective health outcomes. This relationship was often based on tenuous assumptions and mostly from the perspectives of professionals.

As covered in earlier chapters, there is limited evidence evaluating the impact of interprofessional working on health outcomes. Less exists on the outcomes for carers. More recent studies explored service user and carer perceptions of effective teamwork. From the start of my doctoral study, I knew I wanted to capture informal carer's views of effective interprofessional working through their experiences of caring.

5.3 Writing the research proposal OR 'Down the rabbit hole'.

In Carroll (1993), Alice follows the rabbit down a hole, and suddenly she finds herself falling down a very deep well. The initial six months of my doctoral study felt like falling down Carroll's rabbit hole: a slow descent, having time to look around but with the feeling of a lack of control. Alice found time to ask questions and to contemplate answers. Whilst the aim of my study was clear to me initially, as I explored the literature, it raised more questions than answers. At the time I found this was a period of discomfort for me, not knowing what I did not know and raising many questions and not finding the answers I expected.

Whilst the university webpages contained information for doctoral students and other resources such as self-help guides for doctoral students exist, I did not feel in control. I generally like to be organised and it seemed I had lost my locus of control. I felt vulnerable and in the early years of part time study, I still felt as if I was falling down that hole.

Alice soon found herself at the bottom of the hole, faced with a small door in the wall she needed to go through. Through trial and error and by drinking and eating various substances, Alice finally escaped the tunnel with the assistance of a mouse.

During the early stages and following the submission of my research proposal, the RD1 form, I realised that through further reading, through questioning research findings, through talking to informal carers and listening to their stories, I recognised the importance of understanding my philosophical and theoretical frameworks; a process not encouraged in my previous positivist research experience. Like Alice, through trial and error, and reflecting on my experiences, I gradually started to develop confidence in my research and how I planned to carry it out. However during this time, I experienced times of lack of self-confidence, self-doubt, well reported in the literature (Thomson and Walker, 2010). I too, like Alice, found myself on occasions sitting in a puddle of tears.

From the very start, I battled with the 'ologies' such as ontology and epistemology and the 'isms' such as post-positivism; constructivism; and relativism. I wrestled with my positivist research background and had many early conversations with colleagues to enable me to understand the philosophical position of my research. A colleague directed me to the doctoral work of Christopher Jenkins which helped me to see the concept of truth differently (Jenkins, 2006). A story from Jewish folklore told by Kossoff (1997) and cited by Jenkins. This enabled me to understand the value of story and its relationship with truth.

One day Story is coming down the road, dressed in bright colours. Behind the village inn, shivering, cold and naked, he finds Truth.

Story asks Truth what he is doing out here in the cold.

They won't let me in, Truth answers. I'm too much for them.

Story lends Truth a spare set of clothes.

Now try, Story says.

And Truth, dressed as Story, was welcomed everywhere (Kossoff, 1997 cited by Jenkins 2006).

I retell this story to my current students and I've included it in presentations to fellow doctoral students. As I am nearing the end of my doctoral journey, I have come to view myself as a storyteller and by retelling their stories I am giving voice to the informal carers. The stories are a vehicle through which their experiences can be shared and through which a better understanding of interprofessional working can be gained.

An image which regularly came to mind in the early stages of my study and also during the analysis of my data, was Carroll's famous Cheshire Cat. Alice meets him as she walks through a wood. Alice asks the Cat for directions: he first asks her where she is headed. Alice says that she doesn't care where. To which the Cat responds:

"Then it doesn't matter which way you go..."

"--so long as I get somewhere," Alice added as an explanation.

"Oh, you're sure to do that," said the Cat "if you only walk long enough"

(Carroll, 1993: 87).

In the initial stages, the direction of my study was not entirely clear to me. My past research experience in public health and epidemiology was mainly from a positivist standpoint, where the direction and research process was more clearly defined and laid out to follow. My doctoral study was different and the direction uncertain. The choice of using carers' stories in my study developed. I chose to present my findings as stories that represent a 'realistic version of events' of the carers' experiences (Chambers, 2003: 408). My role as the writer of their stories is that of cypher, opening up a 'window on reality' (Chambers, 2003:411).

In his book, 'the Annotated Alice', Gardner cites Kemeny (1959). Kemeny's text 'A Philosopher Looks at Science' relates the conversation between the Cheshire cat and Alice when he highlights the 'eternal cleavage' between science and ethics (Gardner, 2001: 68). Kemeny argues whilst science cannot tell us where to go, it can tell us the best way to get there.

5.4 Learning with and through others OR 'The Mad Tea Party'.

There were times when I found myself in what appeared very strange situations and at these times I wasn't sure if or what I was learning. Following her encounter with the Cheshire cat, Alice visited the March Hare's house and she joined a very strange tea party.

"Why is a raven like a writing desk?" said the Hatter.

"I believe I can guess that," Alice replied.

"Do you mean you think you can find out the answer to it?" said the March Hare.

"I do," Alice hastily replied; "at least- at least I mean what I say- that's the same thing, you know."

"Not the same thing a bit!" said the Hatter. "You might just as well say that "I see what I eat" is the same thing as "I eat what I see."

"You might just as well say, that I like what I get is the same thing as I get what I like," added the March Hare.

...the party sat silent... Alice thought over all she could remember about ravens and writing desks, which wasn't much" (Carroll, 1993: 91).

This mad tea party reminds me of an action learning set early on in my PhD. Everyone talked about their work and the progress made so far.

Alice felt dreadfully puzzled. The Hatter's remark seemed to have no meaning in it, and yet it was certainly English...

"Have you guessed the riddle yet?" the Hatter said, turning to Alice again.

"No, I give up," Alice replied: "what's the answer?"

"I haven't the slightest idea," said the Hatter (Carroll, 1993:92).

I certainly wasn't getting any answers as such or so I believed at the time. On occasions it seemed like another language. In fact it was: the next day I ordered a sociology dictionary to assist me at the next meeting.

When I look back on those early days of the learning set, I now appreciate the support and encouragement I received from my fellow members. They challenged me to look differently at the world, to not accept what I see at face value and to question, question, question... I needed to be reflexive and not simply reflect; I needed to understand the complexity of the researcher's role in relation to others (Bolton, 2010). This is highlighted by Yarwood et al. (2015). Yarwood et al. (2015), all full time lecturers and fellow doctoral students, found support from each other by providing safe, yet critical learning opportunities, enabling consideration of circumstances and relationships through reflexivity.

Another important consideration for me and a point noted in my diary, was whilst completion seemed a long way off for me, others in the group were completing. It was achievable to work in a full time post and be a part time student. I found this to be a powerful source of motivation to keep going despite the demands of my full time academic role.

Throughout my doctoral study, I received guidance and feedback from a variety of others. From my doctoral supervisors, colleagues in my action learning set and from my informal carers involved in the development of the stories for the interviews, I also received useful feedback from unexpected sources. For example, at the end of the first stage of my study and the development of the two stories 'Grace' and 'Crystal', I gave a platform presentation at an international conference. The audience consisted of a variety of stakeholders including academics, patients and informal carers. I fielded audience questions regarding methodology and also received some useful recommendations for the second stage of my study. When I looked back at my presentation notes made at that particular conference, I found many exclamation and question marks on the notes and next to the list of questions asked and the advice offered. These notes allowed me to revisit assumptions previously made and to rethink future actions. I discussed this with my supervisor at our next supervisory meeting and clarified the next steps of my study.

Similarly, when I was in the midst of analysing my interview data, I presented my preliminary findings to the faculty service user and carer group. As I was the chair-person of this group, my emotional response to the activity caught me unawares and I became uncomfortable and felt vulnerable again; however the constructive feedback I

received was both useful and supportive. I acknowledged from that point that any criticism is a prompt for the researcher to be reflexive and accept the questioning of one's knowledge. This will provide opportunity for a greater depth of critical analysis (Pillow, 2003). I learned to accept criticism with confidence and to view it as an opportunity to strengthen my research.

Burman and Whelan (2011) emphasise that reflexivity is not just exploring what went wrong, but also exploring why things went well. The development of the two carers' stories and the interview stage went well on the whole. By attending the group, it became apparent that this was not the norm. Colleagues discussed problems with planning the interviews and carrying them out. As stated earlier, I am by nature a pragmatist and like to be organised. I had spent a great deal of time planning these stages prior to developing the stories and conducting the interviews.

As an experienced health professional, I was used to arranging visits to clients in their homes and spending time listening to them and their families as part of the clinical assessment. My Masters dissertation involved interviews, albeit semi-structured in nature, and so this method was not new to me. Colleagues in the action learning group gave me positive feedback on how I had approached my fieldwork and in particular the use of the carers' stories in the interviews. This prompted me into submitting an article for publication on the use of stories in interviews (Wright et al., 2014). My confidence grew and like Alice when she appeared in the court of the King and Queen of Hearts to give evidence,

Alice felt a very curious sensation, which puzzled her a good deal until she made out what it was: she was beginning to grow large again (Carroll, 1993:130).

I felt empowered to keep going and continued to attend the group meetings.

5.5 Supervision meetings OR 'The Mock Turtle's Story'.

Alice and the Gryphon went to meet the Mock Turtle.

“When we were little we went to school in the sea. The master was an old Turtle- we used to call him tortoise...

“Why did you call him tortoise, if he wasn’t one?” Alice asked.

“We called him Tortoise because he taught us! ... really you are very dull!”
(Carroll, 1993:115).

When I look back on the early days of my supervision meetings, I remember wanting to provide an answer which was deemed to be correct. As my research progressed and I commenced my interviews with the carers, I began to feel more confident with my research. I also found whilst I was not looking to my supervisors for direction, I was still seeking affirmation and validation of what I had found. Whilst my supervisors never displayed the same dismay as the Mock Turtle at my occasional ignorance, there were times when I felt despondent.

The Mock Turtle goes on,

“I only took the regular course...

Reeling and Writhing, of course, to begin with and then different branches of Arithmetic - Ambition, Distraction, Uglification and Derision.”

“I’ve never heard of ‘Uglification’” Alice ventured to say. “What is it?”

The Gryphon lifted up both its paws in surprise: “What! Never heard of uglifying!” it exclaimed. The Gryphon went on, “if you don’t know what to uglify is, you must be a simpleton.”

Alice did not feel encouraged to ask any more questions about it.

(Carroll, 1993:116).

All doctoral students need to feel safe and do not always feel encouraged to ask further questions from their supervisors. They need to be allowed to make mistakes and be encouraged to continue to ask questions and not to feel vulnerable (Thomson and Walker, 2010). For me, as a senior academic member of staff, this added a further dimension of role conflict and power inequality between me as doctoral student and my supervisory team. There have been occasions when I have needed to raise an issue and I had to carefully consider how I raised it with my team. This is an area for further investigation as the evidence around this topic is limited.

Throughout the research, I realise that I was constantly battling with my past experiences and positivist view of research. Looking back I am aware I had a constant need for affirmation from my supervisors of being right and repeatedly asked if my work was correct. The action learning set played an important part in moving my thinking on. I started to appreciate the subjective epistemological standpoint. I did not realise the benefits of these discussions at the time and my learning was not always directly observable to me. Bold (2012) describes this process as amorphous and ambiguous which allows the researcher to develop and justify their own research approach. On reflection the conversations with my peers made me think about my research in ways I had not previously done. It enabled me to be more reflexive; a similar finding to Yarwood et al. (2015).

Throughout my period of study, I was having to contend with a heavy workload from my current position in senior management and the increasing demands from my now widowed mother with a diagnosis of early stage dementia. There were periods of time when my research had to be put to one side. Vekkaila et al (2013) found a quarter of their doctoral student participants highlighted this as a trigger for disengagement with their studies. I was fortunate as I had a strong network of support from my peers and supervisory team, who kept me on track.

These times were not easy, however I found the periods of low or non-engagement in my study enabled me to return to the research at a later time and view it with a fresher pair of eyes. The ongoing work with the faculty service user and carer group, the development of person-centred curricula in the programmes in my department, the various platform presentations at conferences and meeting service users and their families and hearing their stories, enabled me to stay focussed on my research area whilst I was unable to study. In addition to this, the increasing caring responsibility for my mother gave me greater insight into the caring role. As Doyle (2013) suggests, a sensitivity to experiences of both self and others, the capacity to tolerate uncertainty and an open mind all contribute to sustaining a thinking state of mind, needed for reflexivity; however she acknowledges this is not sufficient.

As my research progressed and I was given some protected time to study, I became more aware of the importance of accepting my position in my study. I found I was no longer attempting to neutralise my influence on the research and on my participants.

The realisation that I was slowly letting go of my positivist baggage and beginning to genuinely embrace the relativist paradigm of my research was confirmed during the analysis phase of my study.

At the end of Alice's journey in wonderland, she found herself lying on the ground waking up from a long sleep. She then recounted her journey in wonderland to her sister. When she had finished, Alice reflected on what a wonderful dream it had been. Like Alice, through my journey I have met and worked with some colourful characters; in particular the carers in my study who shared such powerful stories with me. I hope through this thesis I have enabled their stories to create a reaction in others which provides a better understanding of the factors contributing to effective interprofessional working from the carers' perspective.

I make no apologies for the somewhat self-indulgent approach at times in this chapter. I have attempted to balance this self-reflection with how this has enabled me to engage in more effective critical reflection and reflexivity on the research process and the journey I have taken (Doyle, 2013).

Finally, nearing the end of my journey, my thinking has changed and has been shaped by the many experiences and people I have met along the way. I empathise with Alice, when she first met the Caterpillar and he asked her who she was. Alice replied,

“I - I hardly know, sir, just at present - at least I know who I was when I got up this morning, but I think I must have changed several times since then” (Carroll, 1993:69).

In the next chapter I present the conclusion to my thesis. I highlight my main findings, discuss implications for practice and suggest areas for further research.

6 Conclusions

The previous chapter presented my critical reflections of the research process with the assistance of Carroll's 'Alice's Adventures in Wonderland' (1993) where I reflected upon the journey I have taken through my doctoral study. This final chapter provides a summary of the main findings of my study, makes recommendations for future practice and areas for further research.

In this study I have developed a conceptual framework for effective interprofessional working from the perspectives of a group of informal carers. I chose an interpretative paradigm as the purpose of the study was to explore the carers' perceptions through their own experiences of caring.

The study was carried out in two stages. The first stage involved the development of two stories with Grace and Crystal, two carers and in the second stage, their stories were used in subsequent interviews with eleven other carers.

One of the strengths of this study is the participatory and narrative approach chosen to address the research questions; from the development and co-production of the stories with the carers, to the sharing of the stories in the interviews with carers and finally the development of a conceptual framework for effective interprofessional working informed from the carers' perspectives. The choice to use real stories instead of vignettes in the interviews contributes to alternative approaches to data collection (Wright et al., 2014).

Some recent studies on interprofessional working such as Hewitt et al. (2014) and Goodman et al. (2011a) have considered the views of carers of older people in terms of interprofessional working. Other studies included only the views of service users or considered the views of service users and carers as representing the same voice. My study contributes further to this body of evidence and in particular captures the stories of caring of a range of carers and their different encounters with a variety of professionals. From these encounters, I present their subjective meanings of caring and their perceptions of effective interprofessional working.

6.1 Summary of main findings

Three subjective meanings of caring emerged from the carers' stories: 'It's all a battle', 'That's how it is' and 'I know how it should be'.

Some of the carers recounted constant battles with professionals and services to get the care needed for their child or the person they cared for; 'it's all a battle'. A dominant feature in their stories was the attitudes of individual professionals which hindered or facilitated information communication to other professionals or affected care provision. The carers recounted occasions when they felt they were being judged by professionals and these prejudices were being communicated to other professionals. Some professionals felt threatened by this group of carers and affirmed their position of professional dominance in decision making around care. Whilst these carers were determined and appeared to be coming from a position of strength, this determination and constant fighting had a negative impact on their own wellbeing; an outcome of care which needs to be recognised and considered by professionals when referring to others.

Another group of carers was more ready to accept the situation they found themselves in; despite dissatisfaction with the attitudes of professionals or with the quality of care provided. Their stories portrayed an overwhelming sense of duty and inevitability of their caring role; 'that's how it is'. Their stories contained examples of defensiveness and aggression from professionals when challenged. The carers expressed a sense of a fear of reprisal if they chose to challenge the professionals. Professionals need to have insight into the effect of the power they have over patients and their carers and also other professionals. To work effectively with others, they need to value the contribution each person brings when they are making any decision on care provision.

The third group of carers were either in professional roles or had an additional knowledge of health and social care beyond their role as carer. These carers understood the complexities of health and social care and the roles of the different professionals; 'I know how it should be'. These carers felt they received better care than other families on the occasions when professionals acknowledged and recognised their additional knowledge; however this was not always the case. Some of the carers experienced defensiveness by some professionals which the carers perceived was due

to feelings of threat. In these stories the perceived status of the carer influenced the professionals' behaviour. This affected referrals to other professionals, the care provision offered and the nature of the shared information communicated to other professionals and services.

Whilst the carers' stories provided their subjective meanings of caring, common themes were identified in all their stories. Following a thematic analysis of the interview data, three main themes were identified that represented a synergistic relationship of factors required for effective interprofessional working: a shared philosophy of care; individual attributes and information communication.

The carers reported when a culture existed where professionals understood the needs of the person and their family, the latter were more likely to experience a more positive care outcome. Whilst an organisation may have a clear vision and mission statement, differences in the attitudes and behaviours of staff were found between units or departments; even within the same unit. The findings suggest the differences in culture and resulting attitudes and behaviours of staff were partly dependant on the leadership of the unit or department. This concurs with Prescott and Rowe (2015) who identified many cultures and micro climates within an organisation.

The routinisation of care, whilst being an important component of efficiency, can also override decisions based on need. Rules and routines can act as barriers to interprofessional working. If certain practices are not challenged by other professionals, particular behaviours will become the norm and accepted as normal practice. The carers identified a reluctance of some professionals to challenge certain behaviours of others and on occasions protect their colleagues when challenged, rather than demonstrate candour.

Many of the carers identified points of transition and in particular discharge from hospital as particularly stressful and problematic. They highlighted how organisational structures, policies and procedures restricted continuity of care and the effective transition to their home or to another service. The study highlights an over-reliance on the part of professionals to achieve tasks and targets rather than on person centred outcomes. A positive experience of continuity of care is important to carers and is a measure of effectiveness (Parker et al., 2011). There is a need for professionals to look beyond working as a team to achieve local or organisational targets. They need to

work with others in a more collaborative way and consider the impact on the patient and their carers and families.

Similar to other studies, interprofessional working was largely invisible to the carers in my study. What was noticeable was individual professional attitudes, a characteristic also identified by Nancarrow et al. (2013). These attitudes influenced professional behaviour and the nature of the collaboration with others; including the person being cared for, the carers, other professionals and staff in other services. Carers in my study valued professionals who were non-judgemental, empathetic to the realities of caring and saw their role as more than earning a living; similar findings to those of James (2014). These professionals valued the roles of others and took responsibility for effective care, following up on referrals to other professionals and services. These professionals were perceived to be more intuitive to the needs of the person and their family; they were person centred rather than task focussed.

The carers called for professionals to listen to them in a meaningful way; that is, to listen for stories and be prepared to learn from the carer and accept they may be the expert in certain situations. The findings also suggest professionals should avoid making assumptions about the family situation and be non-judgemental in their referrals to other professionals or services.

The final main theme is information communication. Similar to other studies, the carers identified the existence of different record systems between organisations and even across services within the same organisation and the resulting problems they encountered (Cameron et al., 2014; Belling et al., 2011). However, a finding not reported in other studies is the importance of the content of the information in the records. The content should be accurate, non-judgemental and capture the reality of the situation.

My findings suggest carers want to experience a certain level of collective responsibility when referrals are made to other professionals or services. They expect referrals to be followed up by someone to ensure continuity of care; their stories suggested this was not common practice. Referrals and signposting to other services should be made to address the needs of the patient and their family and not be dependent upon individual professional bias.

In conclusion, my findings highlight the multi-dimensional nature of interprofessional working and suggest effective interprofessional working from the perspectives of informal carers is dependent on the complex and synergistic relationship between three main themes: a shared philosophy of care; individual attributes and information communication.

6.2 Recommendations for future practice

To achieve the policy directive of providing person centred care, professionals need to be willing to open up their minds to others' perspectives. This may require a change in mind set and a change in the way they practice. As stated earlier, there requires a shift away from the notion of 'team work' to considering working effectively with others in order to deliver effective care. Professionals need to value working with other professionals is part of their professional practice and not a subsidiary activity.

Organisations need to create a culture at all levels, which encompasses a person centred philosophy and values the contribution made by a range of stakeholders in the complex provision of health and social care. This may require organisations to provide relevant staff development or to support professionals to pursue more formal post-registration education.

Despite the existence of standards for interprofessional learning within the different standards for education and training of the professional and regulatory bodies, pre-registration education needs to review current curricula design to ensure professionals of the future are aware of the realities of caring and the complexities of interprofessional working from the different perspectives of those involved.

Appropriate attitudes and behaviours need to be encouraged and inappropriate attitudes challenged. Health and social care students should be encouraged to challenge critically the practice of themselves and others and be supported not to conform to unhelpful uni-professional attitudes which do not promote collaborative practice.

This is not necessarily advocating widespread curriculum reform with only interprofessional pre-registration professional programmes being provided and approved. Opportunities for both campus and placement learning with other professional groups of students should be evident in all health and social care

professional programmes. This interprofessional learning needs to involve patients and their carers to ensure appreciation of the different perspectives of all involved. In a similar way to health and social care organisations, Higher Education Institutions need to create a culture of collaborative learning and facilitate teaching and research which are truly interprofessional.

Commissioners of services need to ensure genuine involvement of carers, alongside service users in the design, development and evaluation of current or new services.

6.3 Areas for further research

Studies into perceptions of interprofessional working, including this study, have predominantly involved female carers and carers who are adults. Further research to explore male carers and the group of carers known collectively as 'young carers' would add further dimensions to the findings of this study.

As health and social care becomes increasingly integrated, longitudinal research is required to evaluate the realities of the transition from hospital to home and to identify effective methods of information communication between professionals to ensure continuity of care.

There is a need for longitudinal studies exploring the collaborative practice of those professionals who experience interprofessional education as an undergraduate. This would need to include the perceptions of the professionals themselves, other professionals they work with and the perceptions of service users and carers. This would provide a different dimension to my findings, yet provide further insight into the concept of interprofessional working gained from this study.

6.4 Summary.

Many professionals do not see themselves as working on one team and there is an overemphasis on the process of teamwork in the discourse surrounding interprofessional collaboration. This has been influenced by the perceptions of professionals and not the perspectives of service users and their families. My findings

suggest there needs to be a cultural shift away from the notion of team to an increased focus on working with others to deliver effective care; that is, to look beyond teamwork and to focus more on the factors which facilitate effective interprofessional working. My study identified a synergistic relationship between individual attributes, shared philosophy of care and information communication is required for effective interprofessional working.

My study achieved its aim by exploring carers' perceptions of effective interprofessional working through their experiences of caring. What matters most to service users and their carers should be prioritised in future research and in any developments involving changes to service delivery.

Working alongside carers in the process of this research, hearing their stories and sharing mine, has enabled me to value them as genuine partners. If I am truthful, I do not think I did this previously. My undergraduate teaching, though limited in my current role, has been enhanced. I now receive a round of applause at the end of my lectures on policy instead of students rushing to get out of the lecture theatre! I have engaged them with national campaigns on social media and shared my enthusiasm for stories with them. I have even converted a few students to undertake qualitative research, something they would never have considered before. I am currently working with academic colleagues to facilitate more effective collaborative working to deliver more opportunities for interprofessional learning; this is work in progress.

Whilst I have limited time for my own professional clinical practice, I am able to influence the practice of others when I teach my post graduate Masters students. As with my undergraduate teaching, I have shared my carers' stories, explored the notion of collaborative working, the impact of organisational culture on delivery of care and the philosophy of person centred care. I have challenged them to think differently and this is evidenced in their assessments.

As part of the dissemination of my findings and as a way of exploring my findings further, I have accepted an invitation from the manager of the carers centre involved in my study to present my research to a group of professionals which includes commissioners; a prospect which excites me.

My final thoughts and comments relate to the notion of the power of stories. Professionals need to think with stories not about them (Frank, 1995). They need to consider what they are gaining by being a listener. Health and social care professional education, whether pre-registration or post-registration, should provide opportunities to develop skills in critical reflection alongside other professionals. It should facilitate the understanding of the impact of listening for stories. Carers are asking professionals to see the author behind their stories and to value their opinions and include them in decision making. When communicating verbally or in the written format with other professionals, professionals need to understand how they are retelling others' stories. Finally, I would like my carers to have the last words. When I asked the carers what message they would like to give to future health professionals, two of the carers provided the following:

You must ask questions. You mustn't just take what is in the records. If you query anything or are doubtful in any way. If you are not sure, you know... like, that doesn't look right to me. You must treat patients and carers as if they were your own. You must have patience (Judy)

and

Work together; work under one umbrella (Parveen).

7 References

- Accenture (2015) *Doctors Survey 2015. Six-Country Report*. [Online] [Accessed on 31st March 2017] <https://www.accenture.com/gb-en/insight-accenture-doctors-survey-2015-healthcare-it-pain-progress>
- ADASS (2010) *Carers as partners in hospital discharge: a review*. [Online] [Accessed on 29th April 2016] <http://www.adass.org.uk/Content/Article.aspx?id=850>
- Attride-Stirling, J. (2001) 'Thematic networks: an analytical tool for qualitative research.' *Qualitative Research*. 1(3): 385-405.
- Atwal, A., Caldwell, K. (2006) 'Nurses' perceptions of multidisciplinary teamwork in acute health-care.' *International Journal of Nursing Practice*. 12: 359-365.
- Banister, P., Bunn, G., Burman, E., Daniels, J., Duckett, P., Goodley, D., Lawthom, R., Parker, I., Runswick-Cole, K., Sixsmith, J., Smailes, S., Tindall, C., Whelan, P. (2011) *Qualitative methods in Psychology. A research guide*. 2nd ed., Maidenhead: Open University Press. McGraw Hill Education.
- Baron, S. (2009) 'Evaluating the patient journey approach to ensure health care is centred on patients.' *Nursing Times*. 105(22): 20–23.
- Barr, H. (2000) 'Working together to learn together: Learning together to work together.' *Journal of Interprofessional Care*. 14:177-179.
- Barr, H. (2001) *Interprofessional Education: Today, Yesterday and Tomorrow*. London: LTSN.
- Barr, H., Koppel, I., Reeves, S., Hammick, M., Freeth, D. (2005) *Effective Interprofessional Education*. London: CAIPE, Blackwell Publishing.
- Barter C, Renold, E. (2000) '“I wanna tell you a story”: exploring the application of vignettes in qualitative research with children and young people.' *International Journal of Social Research Methodology*. 3(4):307-323.
- Baxter, S.K., Brumfitt, S. M. (2008) 'Professional differences in interprofessional working.' *Journal of Interprofessional Care*. 22(3): 239-251.
- Belling, R., Whittock, M., McLaren, S., Burns, T., Catty, J., Rees Jones, I., Rose, D., Wykes, T. (2011) 'Achieving Continuity of Care: Facilitators and Barriers in Community Mental Health Teams'. *Implementation Science*. [Online] [Accessed on 29th April 2016] <http://www.implementationscience.com/content/6/1/23>
- Bevan G., Janus K. (2011) 'Why hasn't integrated health care developed widely in the United States and not at all in England?' *Journal of Health Politics, Policy and Law*. 36 (1): 141–164.

- Bishop, N., Haslam, D. (2014) *The Francis report and the role of professions*. Care Quality Commission. [Online] [Accessed on 7th November 2014] <http://www.cqc.org.uk/content/francis-report-and-role-professions>
- Bithell, C. (2005) 'Developing theory in a practice profession' [Editorial]. *Physiotherapy Research International*. 10: iii–v.
- Blickem, C., Priyadharshini, E. (2007) 'Patient narratives: the potential for "patient-centred" interprofessional learning?' *Journal of Interprofessional Care*. 21(6):619-632.
- Bloor, M., Fincham, B., Sampson, H. (2007) *Qualiti (NCRM) Commissioned inquiry into the risk to well-being of researchers in qualitative research*. [Online] [Accessed on 29th April 2016] <http://www.cardiff.ac.uk/socsi/qualiti/publications.html>
- Bold, C. (2012) *Using Narrative in Research*. Thousand Oaks: Sage Publications Ltd.
- Bolton, G. (2010) *Reflective practice writing and professional development*. 3rd ed. London: Sage.
- Bond, J. (1992) 'The Politics of Caregiving: The Professionalisation of Informal Care.' *Ageing and Society*. 12: 5-21.
- Borrill, C., West, M., Shapiro, D., Rees, A. (2000) 'Team working and effectiveness in health care.' *British Journal of Healthcare Management*. 6(8): 364-371.
- Borthwick, R., Newbronner, L., Stuttard, L. (2009) "Out of Hospital": a scoping study of services for carers of people being discharged from hospital.' *Health and Social Care in the Community*. 17(4), 335–349.
- Braun, V., Clarke, V. (2006) 'Using thematic analysis in psychology.' *Qualitative Research in Psychology*. 3(2):77-101.
- Brechin, A., Barton, R., Stein, J. (2003) 'Getting to grips with poor care.' In Stalker, K (ed.) *Reconceptualising Work with 'Carers'*. London: Jessica Kingsley Publishers, 160-176.
- Brindle, I. (2014) *Ingrid Brindle: a patient perspective on shared electronic health records*. The King's Fund. [Online] [Accessed on 29th April 2016] <http://www.kingsfund.org.uk/audio-video/ingrid-brindle-patient-perspective-shared-electronic-health-records>
- Bristol Royal Infirmary Inquiry (Chairman: Professor Ian Kennedy) (2001). *The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: learning from Bristol*. Cm 5207. London: HMSO.
- British Psychological Society (2009) *Code of Ethics and Conduct: Guidance published by the Ethics Committee of the British Psychological Society*. Leicester: British Psychological Society.

- Brophy, S. (2006) "Personal excellence" as a value for health professionals: a patient's perspective.' *International Journal of Health Care Quality Assurance*. 19(5): 373-383.
- Brown, J., Lewis, L., Ellis, K., Stewart, M., Freeman, T.R., Kasperski, M.J. (2011) 'Conflict on interprofessional primary health care teams- can it be resolved?' *Journal of Interprofessional Care*. 25:4-10.
- Bruner, J. (2002) *Making Stories: Law, Literature, Life*. New York: Farrar, Straus and Giroux.
- Buckner, L., Yeandle, S. (2011) *Valuing Carers*. London: Carers UK.
- Burman, E., Whelan, P. (2011) 'Problems in/of qualitative research' In Banister, P., Bunn, G., Burman, E., Daniels, J., Duckett, P., Goodley, D., Lawthom, R., Parker, I., Runswick-Cole, K., Sixsmith, J., Smailes, S., Tindall, C., Whelan, P. (2011) *Qualitative methods in Psychology. A research guide*. 2nd ed., Maidenhead: Open University Press. McGraw Hill Education, 208-222.
- Burns, C.M., Dixon, T., Smith, W.T., Craft, P.S. (2004) 'Patients with advanced cancer and family caregivers' knowledge of health and community services: a longitudinal study.' *Health and Social Care in the Community*. 12(6): 488-503.
- Burton, M. (2008) 'Grounding Constructions of Carers: Exploring the Experiences of Carers through a Grounded Approach.' *British Journal of Social Work*. 38:493-506.
- Cameron, A. (2011) 'Impermeable boundaries? Developments in professional and interprofessional practice.' *Journal of Interprofessional Care*. 25:53-58.
- Cameron, A., Lart, R., Bostock, L. and Coomber, C. (2014) 'Factors that promote and hinder joint and integrated working between health and social care services: a review of research literature.' *Health and Social Care in the Community*. 22(3):225-233.
- Campbell, S., Watson, B., Gibson, A., Husband, G., Bremner, K. (2004) 'Comprehensive service and practice development: City Hospitals Sunderland's experience of patient journeys.' *Practice Development in Health Care*. 3(1):15-26.
- Care Act 2014 (c.23.) [Online] [Accessed on 29th April 2016]
<http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>
- Carers Trust (2015) *What is a carer*. [Online] [Accessed on 29th April 2016]
<https://www.carers.org/whats-a-carer>
- Carers UK (2007) *Carers' priorities for a new National Strategy for Carers. February 2007*. [Online] [Accessed on 10th October 2009] <http://www.carersuk.org>
- Carers UK (2013a) *The State of Caring 2013*. [Online] [Accessed on 29th April 2016]
<http://www.carersuk.org/for-professionals/policy/policy-library/the-state-of-caring-2013>

- Carers UK (2013b) *Evidence to Labour Party Commission on Older Women* [Online] [Accessed on 29th April 2016] <http://www.carersuk.org/for-professionals/policy/policy-library/evidence-to-labour-party-commission-on-older-women>
- Carers UK (2015) *The State of Caring 2015*. [Online] [Accessed on 29th April 2016] <http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015>
- Carroll, L. (1993) *Alice's Adventures in Wonderland and Through the Looking Glass*. Hertfordshire: Wordsworth Editions Limited.
- Cashman, S.B., Reidy, P., Cody, K., Lemay, C. A. (2004) 'Developing and measuring progress toward collaborative, integrated, interdisciplinary health care teams.' *Journal of Interprofessional Care*. 18(2):183-196.
- Chambers, P. (2003) 'Narrative and reflective practice: recording and understanding experience.' *Educational Action Research*. 11(3):403-414.
- Charon, R. (2006) *Narrative Medicine. Honoring the Stories of Illness*. Oxford: Oxford University Press.
- Charon, R., Montello, M. (eds.) (2002) *Stories Matter: The Role of Narrative in Medical Ethics*. New York: Routledge.
- Christenson, T., Grimsmo, A. (2008) 'Instant availability of patient records, but diminished availability of patient information: a multi-method study of GP's use of electronic patient records.' *BMC Medical Informatics and Decision Making*. 8:12. [Online] [Accessed on 29th April 2016] <http://www.biomedcentral.com/1472-6947/8/12>
- CIPW (2007) *Creating an Interprofessional Workforce: An education and training framework for health and social care. Executive summary*. [Online] [Accessed on 29th April 2016] <http://www.caipe.org.uk>
- Clark, D. (1999) 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967.' *Social Science & Medicine*. 49(6):727-736.
- Clark, P.G. (2011) 'Examining the interface between interprofessional practice and education: lessons learned from Norway for promoting teamwork.' *Journal of Interprofessional Care*. 25: 26-32.
- Clarke, D. J. (2010) 'Achieving teamwork in stroke units: the contribution of opportunistic dialogue.' *Journal of Interprofessional Care*. 24: 285-297.
- Clouder, L. (2000) 'Reflective Practice in Physiotherapy Education: A critical conversation.' *Studies in Higher Education*. 25(2): 211-223.
- Coalition for Collaborative Care (no date) *House of Care*. [Online] [Accessed on 29th April 2016] <http://coalitionforcollaborativecare.org.uk/aboutus/house-of-care/>

- Collins, A. (2014) *Measuring what really matters: towards a coherent measurement system to support person-centred care*. London: The Health Foundation.
- Connelly, J.E. (2002) 'In the absence of narrative' In Charon, R., Montello, M. (eds.) *Stories Matter: the Role of Narrative in Medical Ethics*. New York: Routledge, 138-146.
- Cooper, H., Carlisle, C., Gibbs, T., Watkins, C. (2001) 'Developing an evidence base for interdisciplinary learning: a systematic review.' *Journal of Advanced Nursing*. 35(2):228-237.
- Cowley, S., Bliss, J., Mathew, A., McVey, G. (2002) 'Effective interagency and interprofessional working: facilitators and barriers.' *International Journal of Palliative Nursing*. 8(1):30-39.
- Creswell, J. W., Plano Clark, V.L. (2007). *Designing and Conducting Mixed Methods Research*. Thousand Oaks: Sage Publications.
- D'Amour, D., Ferrada-Videla, M., San Martin Rodriguez, L., Beaulieu, M-D. (2005) 'The conceptual basis for interprofessional collaboration: core concepts and theoretical frameworks.' *Journal of Interprofessional Care*. 19 (Supplement 1):116-131.
- D'Amour, D., Oandasan, I. (2005) 'Interprofessionality as the field of interprofessional practice and interprofessional education: an emerging concept.' *Journal of Interprofessional Care*. 19 (Supplement 1):8-20.
- Dawson, S. (2007) 'Interprofessional working: communication, collaboration...perspiration!' *International Journal of Palliative Care Nursing*. 13(10):502-505.
- Denzin, N.K., Lincoln, Y.S. (eds.) (2003) *Strategies of Qualitative Enquiry*. 2nd ed., Thousand Oaks: Sage Publications.
- Department of Health (1989a) *Working for Patients*. London: HMSO.
- Department of Health (1989b) *Caring for people*. London: HMSO.
- Department of Health (1990) *The NHS and Community Care Act*. London: HMSO.
- Department of Health (1995) *Carers (Recognition and Services) Act*. London: HMSO.
- Department of Health (1997) *The New NHS: Modern, Dependable*. London: HMSO.
- Department of Health (1998) *A first class service: Quality in the new NHS*. London: HMSO.
- Department of Health (1999) *Caring about carers: a national strategy for carers*. London: HMSO
- Department of Health (2000a) *The NHS Plan: A Plan for Investment. A Plan for Reform*. London: HMSO.

Department of Health (2000b) *Meeting the Challenge: A strategy for the allied health professions*. London: HMSO.

Department of Health (2004a) *The NHS Improvement Plan. Putting people at the heart of public services*. London: HMSO.

Department of Health (2004b) *Choosing Health: Making healthier choices easier*. London: HMSO.

Department of Health (2004c) *The NHS Knowledge and Skills Framework and the Development Review Process*. London: HMSO.

Department of Health (2005) *Creating a patient-led NHS. Delivering the NHS Improvement Plan*. London: HMSO.

Department of Health (2006) *Our health, our care, our say: A new direction for community services*. London: HMSO.

Department of Health (2008a) *High Quality Care for All*. London: HMSO.

Department of Health (2008b) *NHS Next Stage Review: A High Quality Workforce*. London: HMSO.

Department of Health (2010a) *Equity and Excellence: Liberating the NHS*. London: HMSO.

Department of Health (2010b) *A Vision for Adult Social Care: Capable Communities and Active Citizens*. London: HMSO.

Department of Health (2010c) *Carers and personalisation: improving outcomes. Social care*. [Online] [Accessed on 29th April 2016]
<https://www.gov.uk/government/publications/personalising-services-and-support-for-carers>

Department of Health (2010d) *Recognised, Valued and Supported: Next steps for the Carers Strategy*. London: HMSO.

Department of Health (2012a) *Caring for our Future: Reforming care and support*. London: HMSO.

Department of Health (2012b) *Liberating the NHS: Developing the healthcare workforce*. London: HMSO

Department of Health (2012c) *Response to NHS Future Forum's second report*. [Online] [Accessed on 29th April 2016] <http://www.dh.gov.uk/health/2012/01/forum-response>

Department of Health (2012d) *Transforming care: a national response to Winterbourne View Hospital. Department of Health review final report*. [Online] [Accessed on 29th

April 2016] <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

Department of Health (2014) *Adult social care outcomes framework 2015-2016*. [Online] [Accessed on 29th April 2016] <https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-ascof-2015-to-2016>

Department of Health (2015a) *NHS Constitution for England*. [Online] [Accessed on 29th April 2016] <https://www.gov.uk/government/publications/the-nhs-constitution-for-england>

Department of Health (2015b) *2010 to 2015 government policy: carers' health*. [Online] [Accessed on 29th April 2016] <https://www.gov.uk/government/publications/2010-to-2015-government-policy-carers-health/2010-to-2015-government-policy-carers-health>

De Silva, D. (2014) *Helping measure person-centred care: a review of evidence about commonly used approaches and tools used to help measure person-centred care*. London: The Health Foundation.

Dixon-Woods, M., Baker, R., Charles, K., Dawson, J., Jerzembek, G., Martin, G., McCarthy, I., McKee, L., Minion, J., Ozieranski, P., Willars, J., Wilkie, P., West, M. (2013) 'Culture and behaviour in the English National Health Service: overview of lessons from a large multimethod study.' *BMJ Quality and Safety*. [Online] [Accessed on 29th April 2016] DOI: 10.1136/bmjqs-2013-001947

Dochartaigh, N.Ó. (2012) *Internet research skills*. London: Sage Publications Ltd.

Doron, N., Harrop, A. (2012) *For the Public Good. How people want their public services to change*. London: Fabian Society. [Online] [Accessed on 29th April 2016] <http://www.fabians.org.uk/publications/for-the-public-good/>

Doughty, M., Gilbert, D. (2013) 'The missing link in engagement.' *Health Service Journal*. 16 August: 26-27.

Doyle, S. (2013) 'Reflexivity and the capacity to think.' *Qualitative Health Research*. 23(2):248-255.

Economic and Social Research Council (2015) *ESRC Framework for Research Ethics 2015*. [Online] [Accessed on 29th April 2016] <http://www.esrc.ac.uk/>

Edwards, A., Lunt, I., Stamou, E. (2010) 'Interprofessional work and expertise: New roles at the boundaries of schools.' *British Educational Research Journal*. 36(1): 27-45.

Edwards, I., Richardson, B. (2008) 'Clinical reasoning and population health: Decision making for an emerging paradigm of health care.' *Physiotherapy Theory and Practice*. 24(3):183-193.

- Elissen, A.M.J., van Raak, A.J.A., Paulus, A.T.G. (2011) 'Can we make sense of multidisciplinary co-operation in primary care by considering routines and rules?' *Health and Social care in the Community*. 19(1): 33-42.
- Enderby, P. (2002) 'Teamworking in community rehabilitation.' *Journal of Clinical Nursing*. 11:409-411.
- Farrell, C., Towle, A., Godolphin, W. (2006) *Where's the Patient Voice in Health Professional Education*. [Online] [Accessed on 29th April 2016]
http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=1&ved=0ahUKEwivk4KGrbbMAhUhKMAKHSNaC0AQFggcMAA&url=http%3A%2F%2Fwww.dhcc.chd.ubc.ca%2Fsites%2Fdefault%2Ffiles%2Fdocuments%2FPtsVoiceReportbook.pdf&usg=AFQjCNFU6EXjwBj5mlQGtouM1fu_fBqbAw
- Feldman, M.S., Rafaeli, A. (2002) 'Organizational routines as sources of connections and understandings.' *Journal of Management Studies*. 39(3):309-331.
- Finch, J. (1987) 'The vignette technique in survey research.' *Sociology*. 21(1):105-114.
- Finch, J. (1993) 'It's great to have someone to talk to: ethics and politics of interviewing women.' In Hammersley, M. (ed.) *Social Research: philosophy, politics and practice*. London: Sage, 166-180.
- Finch, H., Lewis, J. (2003) 'Focus Groups.' In Ritchie, J., Lewis, J. (eds.) *Qualitative Research Practice. A guide for social science students and researchers*. London: Sage Publications Ltd, 170-198.
- Finkelstein, J., Knight, A., Marinopoulos, S., Gibbons, M.C., Berger, Z., Aboumatar, H., Wilson, R.F., Lau, B.D., Sharma, R., Bass, E.B. (2012) *Enabling Patient-Centered Care through Health Information Technology. Evidence Report/Technology Assessment No. 206*. (Prepared by Johns Hopkins University Evidence-based Practice Center under Contract No. 290- 2007-10061-I.) AHRQ Publication No. 12-E005-EF. Rockville, MD: Agency for Healthcare Research and Quality. [Online] [Accessed on 29th April 2016]
<https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=1158>
- Finlay, L. (2006) 'Mapping methodology' In Finlay, L., Ballinger, C. (eds.) *Qualitative Research for Allied Health Professionals: Challenging Choices*. Chichester: Wiley, 9-29.
- Finn, R., Learmonth, M., Reedy, P. (2010) 'Some unintended effects of teamwork in healthcare.' *Social Science and Medicine*. 70:1148-1154.
- Fouka, G., Mantzorou, M. (2011) 'What are the major ethical issues in conducting research? Is there conflict between the research ethics and the nature of nursing?' *Health Science Journal*. 5 (1): 3-14.

- Frank, A. W. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: The University of Chicago Press.
- Frank, A. W. (2010) *Letting stories breathe. A socio-narratology*. Chicago: The University of Chicago Press.
- Freeth, D. (2001) 'Sustaining interprofessional collaboration'. *Journal of Interprofessional Care*. 15:37-46.
- Frenk, J., Chen, L., Bhutta, Z.A., Cohen, J., Crisp, N., Evans, T., Zurayk, H. (2010). 'Lancet Commission Report on health professionals for a new century: Transforming education to strengthen health systems in an interdependent world.' *The Lancet*. 376: 1923–1958.
- Gardner, M. (ed.) (2001) *The Annotated Alice: The Definitive Edition*. London: Penguin Books.
- Gardner, S.K. (2010) 'Contrasting the Socialization Experiences of Doctoral Students in High- and Low-Completing Departments: A Qualitative Analysis of Disciplinary Contexts at One Institution.' *The Journal of Higher Education*. 81(1): 61-81
- General Medical Council (2013) *Good Medical Practice*. Manchester: GMC.
- General Medical Council (2015) *List of registered medical practitioners-statistics*. [Online] [Accessed on 29th April 2016] http://www.gmc-uk.org/doctors/register/search_stats.asp
- Giddens, A. (2001) *Sociology*. 4th ed., Cambridge: Polity Press.
- Glasby, J. (2004) 'Discharging Responsibilities? Delayed Hospital Discharges and the Health and Social Care Divide.' *Journal of Social Policy*. 33(4):593-604.
- Glasby, J., Beresford, P. (2006) 'Who knows best? Evidence-based practice and the service user contribution.' *Critical Social Policy*. 26(1):268-284.
- Glasby, J., Littlechild, R., Pryce, K. (2004) 'Show me the way to go home: a narrative review of the literature on delayed hospital discharges and older people.' *British Journal of Social Work*. 34:1189-1197.
- Goldsmith, J., Wittenberg-Lyles, E., Rodriguez, D., Sanchez-Reilly, S. (2010) 'Interdisciplinary Geriatric and Palliative Care Team Narratives: Collaboration Practices and Barriers.' *Qualitative Health Research*. 20(1): 93 –104.
- Goodman, C., Drennan, V., Manthorpe, J., Gage, H., Triveldi, D., Shah, D., Scheibl, F., Poltawski, L., Handley, M., Nash, A., Iliffe, S. (2011a) *A study of the effectiveness of interprofessional working for community-dwelling older people. Final report*. NIHR Service Delivery and Organisational programme.

- Goodman, C., Drennan, V., Scheibl, F., Shah, D., Manthorpe, J., Gage, H., Iliffe, S. (2011b) 'Models of inter professional working for older people living at home: a survey and review of the local strategies of English health and social care statutory organisations.' *BMC Health Services Research*. 11:337.
- Goodrich, J. (2012) 'Supporting hospital staff to provide compassionate care: do Schwartz Center Rounds work in English hospitals?' *Journal of the Royal Society of Medicine*. 105:117-122.
- Goodrich, J., Cornwell, J. (2008) *Seeing the person in the patient: the Point of Care review paper*. London: The King's Fund. [Online] [Accessed on 29th April 2016] <http://www.kingsfund.org.uk/publications/seeing-person-patient>
- Goodwin, N., Smith, J., Davies, A., Perry, C., Rosen, R., Dixon, A., Dixon, J., Ham, C. (2012) *Integrated care for patients and populations: Improving outcomes by working together. A report to the Department of Health and the NHS Future Forum*. London: The King's Fund, The Nuffield Trust. [Online] [Accessed on 29th April 2016] <http://www.nuffieldtrust.org.uk/publications/integrated-care-patients-populations-improving-outcomes>
- Graham, C., Killpack, C., Raleigh, V., Redding, D., Thorlby, R., Walsh, J. (2013) *Options appraisal on the measurement of people's experiences of integrated care*. The Picker Institute Europe. [Online] [Accessed on 29th April 2016] <http://www.pickereurope.org/research-policy/>
- Granger, K. (2012) *The Other Side*. Kate Granger.
- Greater Manchester Combined Authority (2015) *Taking charge of our Health and Social care in Greater Manchester. The Plan*. [Online] [Accessed on 29th April 2016] <http://www.gmhsc.org.uk/resources/>
- Green, M.C. (2006) 'Narratives and cancer communication.' *Journal of Communication*. 56: s163-183.
- Greenwood, N., Mackenzie, A., Cloud, G.C., Wilson, N. (2008) 'Informal carers of stroke survivors- factors influencing carers: a systematic review of quantitative studies.' *Disability and Rehabilitation*. 30(18): 1329-1349.
- Gubrium, J.F. (1993) *Horizons of Meaning for Nursing Home Residents*. New York: Aldine de Gruyter.
- Gubrium, J.F., Holstein, J.A. (2009) *Analysing Narrative Reality*. London: Sage.
- Haigh, C., Hardy, P. (2011) 'Tell me a story - a conceptual exploration of storytelling in healthcare education.' *Nurse Education Today*. 31(4):408-411.
- Hall, P. (2005) 'Interprofessional teamwork: professional cultures as barriers.' *Journal of Interprofessional Care*. 19 (Supplement 1):188-196.

- Ham, C., Murray, R. (2015) *Implementing the NHS five year forward view: aligning policies with the plan*. London: The King's Fund. [Online] [Accessed on 29th April 2016] <http://www.kingsfund.org.uk/publications/implementing-nhs-five-year-forward-view>
- Hannan, A. (2014) *Amir Hannan- representing patients and their families in the transformation of primary care*. [Online] [Accessed on 29th April 2016] <http://www.kingsfund.org.uk/audio-video/amir-hannan-representing-patients-and-their-families-transformation-primary-care>
- Hardy, P. (2005) *Patient Voices: an investigation into improving the quality of healthcare using digital patient stories*. [Online] [Accessed on 29th April 2016] <http://www.pilgrimprojects.co.uk/papers/pvpreview.pdf>
- Hardy, P., Sumner, T. (eds.) (2014) *Cultivating Compassion: how digital storytelling is transforming healthcare*. Chichester: Kingsham Press.
- Hardy, S., Gregory, S., Ramjeet, J. (2009) 'An exploration of intent for narrative methods of inquiry.' *Nurse Researcher*. 16(4):7-19.
- Harris, R., Sims, S., Hewitt, G., Joy, M., Brearley, S.T., Cloud, G.C., Drennan, V., Greenwood, N. Jones, F., Kalra, L., Mackenzie, A., Ross, F. (2013) *Interprofessional teamwork across stroke care pathways: outcomes and patient and carer experience. Final Report*. London: NIHR Service Delivery and Organisation programme.
- Hayman, B., Wilkes, L., Jackson, D., Halcomb, E. (2012). 'Exchange and equality during data collection: relationships through story sharing with lesbian mothers.' *Nurse Researcher*. 19(4):6–10.
- Health and Care Professions Council (2008) *Standards of Conduct, Performance and Ethics*. London: HCPC.
- Health and Social Care Information Centre (2015) *Information and technology for better care: HSCIC Strategy 2015-2020*. [Online] [Accessed on 29th April 2016] <https://www.gov.uk/government/publications/hscic-strategy-2015-20>
- Health Professions Network Nursing and Midwifery Office (2010) *Framework for Action on Interprofessional Education & Collaborative Practice*. Geneva: World Health Organization Department of Human Resources for Health. [Online] [Accessed on 29th April 2016] http://whqlibdoc.who.int/hq/2010/WHO_HRH_HP_N_10.3_eng.pdf
- Heaton, J. (1999) 'The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care.' *Sociology of Health and Illness*. 21(6): 759-777.
- Herbert, C.P. (2005) 'Changing the culture: interprofessional education for collaborative patient-centred practice in Canada.' *Journal of Interprofessional Care*. 19 (Supplement 1): 1-4.

- Hervey, N., Ramsey, R. (2004) 'Carers as partners in care.' [Editorial] *Advances in Psychiatric Treatment*. 10:81-84.
- Hewitt, G., Sims, S., Greenwood, N., Jones, F., Ross, F., Harris, R. (2015) 'Interprofessional teamwork in stroke care: Is it visible or important to patients and carers?' *Journal of Interprofessional Care*. 29:4, 331-339.
- Hewitt, G., Sims, S., Harris, R. (2014). 'Using realist synthesis to understand the mechanisms of interprofessional teamwork in health and social care.' *Journal of Interprofessional Care*. 28: 501–506.
- Howe, A. (2006) 'Can the patient be on our team? An operational approach to patient involvement in interprofessional approaches to self-care.' *Journal of Interprofessional Care*. 20 (5): 527-534.
- Hubbard, G., Themessl-Huber, M. (2005) 'Professional perceptions of joint working in primary care and social care services for older people in Scotland.' *Journal of Interprofessional Care*. 19(4):371-385.
- Huby, G., Brook, J.H., Thompson, A., Tierney, A. (2007) 'Capturing the concealed: Interprofessional practice and older patients' participation in decision-making about discharge after acute hospitalisation.' *Journal of Interprofessional Care*. 21(1):55-67.
- Hudson, B. (2007) 'Pessimism and optimism in inter-professional working: The Sedgefield Integrated Team.' *Journal of Interprofessional Care*. 21(1): 3-15.
- Hughes, R. (1998) 'Considering the vignette technique and its application to a study of drug injecting and HIV risk and safer behaviour.' *Sociology of Health and Illness*. 20 (3): 381-400.
- Hughes, R., Huby, M. (2002) 'The application of vignettes in social and nursing research.' *Journal of Advanced Nursing*. 37(4):382-386.
- James, N. (2014) 'Importance of good relationships between carers and professionals.' *Learning Disability Practice*. 17(8):25-37.
- Jelphs, K., Dickinson, H. (2008). *Working in Teams. Better Partnership Working Series. Community Care*. Bristol: Policy Press.
- Jenkins, C. (2006) *A voice denied: clients' experience of the exclusion of spirituality in counselling and psychotherapy*. Ph.D. University of Manchester.
- Jenkins, P. (2008) 'Receiving care for schizophrenia: a users' and carer's perspective.' *Psychiatry*. 7(11): 451-453.
- Jenkins, N., Bloor, M., Fischer, J., Berney, L., Neale, J. (2010) 'Putting it in context: the use of vignettes in qualitative interviewing.' *Qualitative Research*. 10 (2): 175-198.

- Johnson, B. (2000) 'Using Video Vignettes to Evaluate Children's Personal Safety Knowledge: Methodological and Ethical Issues'. *Child Abuse & Neglect*. 24(6): 811–27.
- Jones, I. (2007) 'The theory of boundaries: impact on interprofessional working.' *Journal of Interprofessional Care*. 21(3): 355-357.
- Kerr, S.M., Smith, L.N. (2001) 'Stroke: an exploration of the experience of informal caregiving.' *Clinical Rehabilitation*. 15:428-436.
- Khalili, H., Hall, J., DeLuca, S. (2014) 'Historical analysis of professionalism in western societies: implications for interprofessional education and collaborative practice.' *Journal of Interprofessional Care*. 28(2): 92-97.
- Kharicha, K., Levin, E., Iliffe, S., Davey, B. (2004) 'Social work, general practice and evidence-based policy in the collaborative care of older people: current problems and future possibilities.' *Health and Social Care in the Community*. 12(2): 134-141.
- King, N., Bell, D., Thomas, K. (2004) 'Family carers' experiences of out-of-hours community palliative care: a qualitative study.' *International Journal of Palliative Nursing*. 10(2):76-83.
- Kvale, S. (2006) 'Dominance through interviews and dialogues.' *Qualitative Inquiry*. 12:480-500.
- Kvarnström, S. (2008) 'Difficulties in collaboration: a critical incident study of interprofessional healthcare teamwork.' *Journal of Interprofessional Care*. 22(2):191-203.
- Legard, R., Keegan, J., Ward, K. (2003) 'In-depth Interviews.' In Ritchie, J., Lewis, J. (eds.) (2003) *Qualitative Research Practice. A guide for social science students and researchers*. London: Sage Publications Ltd., 138-169.
- Lindahl, B., Lidén, E., Lindblad, B. (2009) 'A meta-synthesis describing the relationships between patients, informal caregivers and health professionals in home-care settings.' *Journal of Clinical Nursing*. 20:454-463.
- Lloyd, L. (2003) 'Caring relationships: Beyond 'Carers' and 'Service Users'.' In Stalker, K. (ed.) *Reconceptualising Work with 'Carers': New Directions for Policy and Practice*. London: Jessica Kingsley Publishers, 37-55.
- Local Government Association (no date). Summary analysis of devolution bids. [Online] [Accessed on 29th April 2016]
http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwjztXe_ljLAhWFzRQKHUbtAmAQFggcMAA&url=http%3A%2F%2Fwww.local.gov.uk%2Fdocuments%2F10180%2F6917361%2FSummary%2Banalysis%2Bof%2Bdevolution%2Bbids%2F4241e0cb-b513-41e1-a1c6-

21d5e1d65aa2&usg=AFQjCNHfDiJnGYjLrWSpWzPyAGMWNS0eoA&bvm=bv.114733917,d.ZWU

Lord Laming (2003) *The Victoria Climbié Inquiry*. London: HMSO.

MacDonald, M.B., Bally, J.M., Ferguson, L.M., Murray, B.L., Fowler-Kerry, S.E., Anonson, J.M.S. (2010) 'Knowledge of the professional role of others: a key interprofessional competency.' *Nurse Education in Practice*. 10(): 238-242.

MacIntyre, G., Green Lister, P., Orme, J., Crisp, B.R., Manthorpe, J., Hussein, S., Moriarty, J., Stevens, M., Sharpe, E. (2011) 'Using Vignettes to Evaluate the Outcomes of Student Learning: Data From the Evaluation of the New Social Work Degree in England.' *Social Work Education*. 30(2): 207–222.

Mackintosh, N., Berridge, E-J, Freeth, D. (2009) 'Supporting structures for team situation awareness and decision making: insights from four delivery suites.' *Journal of Evaluation in Clinical Practice*. 15:46-54.

Mayhew, L. (2012) *The UK Care Economy. Improving outcomes for carers*. London: Carers UK.

McAdams, D.P. (2001) 'The psychology of life stories.' *Review of General Psychology*. 5(20): 100-122.

McGee, H.M., Molloy, G., O'Hanlon, A., Layte, R., Hickey, A. (2008) 'Older people-recipients but also providers of informal care: an analysis among community samples in the Republic of Ireland and Northern Ireland.' *Health and Social Care in the Community*. 16(5):548-553.

McKenna, H., Dunn, P. (2015) *Devolution: what it means for health and social care in England*. London: The King's Fund. [Online] [Accessed on 29th April 2016] <http://www.kingsfund.org.uk/publications/devolution>

McKinstry, B. (2000) 'Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes.' *BMJ*. 321: 867-871.

McPherson, K., Headrick, L., Moss, F. (2001) 'Working and learning together: good quality care depends on it, but how can we achieve it?' *Quality in Health Care*. 10 (Supplement II):ii46-ii53.

McPherson, K.M., Kayes, N.K., Moloczij, N., Cummins, C. (2014) 'Improving the interface between informal carers and formal health and social services : a qualitative study.' *International Journal of Nursing Studies*. 51:418-429.

Meads, G. (2007) *Walk the Talk- sustainable change in post 2000 interprofessional learning and development. Third supplement to Creating an Interprofessional Workforce: an education and Training framework for Health and Social care in England*.

London: CAIPE. [Online] [Accessed on 29th April 2016]
<http://www.caipe.org.uk/silo/files/cipw-walk-the-talk.pdf>

Meads, G., Jones, I., Harrison, R., Forman, D., Turner, W. (2009) 'How to sustain interprofessional learning and practice: messages for higher education and health and social care management.' *Journal of Education and Work*. 22 (1): 67-79.

Mezirow, J. (1998) 'On Critical reflection.' *Adult Education Quarterly*. 48(3):185-198.

Michael, J. (2008) *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Department of Health.

Mickan, S., Hoffman, S.J., Nasmith, L. & on behalf of the World Health Organization Study Group on Interprofessional Education and Collaborative Practice (2010) 'Collaborative practice in a global health context: Common themes from developed and developing countries.' *Journal of Interprofessional Care*. 24 (5): 492-502,

Mickan, S.M., Rodger, S.A. (2005) 'Effective health care teams: a model of six characteristics developed from shared perceptions.' *Journal of interprofessional Care*. 19 (4): 358-370.

Miers, M. (2010) 'Professional Boundaries and Interprofessional Working.' In Pollard, K.C., Thomas, J., Miers, M. (eds.) (2010) *Understanding Interprofessional Working in health and social care*. Basingstoke: Palgrave Macmillan, 105-120.

Miller, S. (1997) 'Midwives' and Physicians' Experiences in Collaborative Practice: A Qualitative Study.' *Women's Health Issues*. 7(5):301-308.

Miller, K.L., Reeves, S., Zwarenstein, M., Beales, J.D., Kenaszchuk, C., Gotlib Conn, L. (2008) 'Nursing emotion work and interprofessional collaboration in general internal medicine wards: a qualitative study.' *Journal of Advanced Nursing*. 64(4): 332-343.

Molleman, E., Broekhuis, M. (2012) 'How working in cross-functional teams relates to core attributes of professional occupations and moderating role of personality.' *Group Dynamics: Theory, Research and Practice*. 16(1):50-67.

Molyneux, J. (2001) 'Interprofessional teamworking: what makes teams work well?' *Journal of Interprofessional Care*. 15 (1): 29-35.

Morrow, E., Robert, G., Maben, J. (2014) 'Exploring the nature and impact of leadership on the local implementation of the Productive Ward Releasing Time to Care.' *Journal of Health Organization and Management*. 28(2):154-176.

Moustakas, C. (1994) *Phenomenological research methods*. Thousand Oaks, CA: Sage.

Nalder, E., Fleming, J., Cornwell, P., Foster, M. (2012) 'Linked Lives: The experiences of family caregivers during the transition from hospital to home following traumatic brain injury.' *Brain Impairment*. 13(1): 108-122.

Nancarrow, S.A., Booth, A., Ariss, S., Smith, T., Enderby, P., Roots, A. (2013) 'Ten principles of good interdisciplinary team work.' *Human Resources for Health*. 11:19

National Institute for Health and Care Excellence (2011) *Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services. NICE guidelines CG136*. [Online] [Accessed on 29th April 2016] <https://www.nice.org.uk/guidance/cg136/chapter/personcentred-care>

National Institute for Health and Care Excellence (2012) *Quality standard for patient experience in adult NHS services*. [Online] [Accessed on 29th April 2016] <http://www.nice.org.uk/guidance/qs15>

National Institute for Health and Clinical Excellence (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. London: NICE.

National Institute for Health Research (2013) *Commissioning Brief. After Francis: Research to strengthen organisational capacity to deliver compassionate care in the NHS*. [Online] [Accessed on 29th April 2016] <http://www.nets.nihr.ac.uk/projects/hsdr/130749>

NHS Employers (2015) *2015-16 General Medical Services (GMS) contract - Quality and Outcomes Framework Guidance*. [Online] [Accessed on 29th April 2016] <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/quality-and-outcomes-framework>

NHS England (2013) *Cancer patient experience survey*. [Online] [Accessed on 29th April 2016] <http://www.england.nhs.uk/2013/08/30/cancer-patients-positive/>

NHS England (2014a) *Five Year Forward View*. [Online] [Accessed on 29th April 2016] <https://www.england.nhs.uk/ourwork/futurenhs/>

NHS England (2014b) *National Cancer Patient Experience Survey 2014 National Report*. [Online] [Accessed on 31st March 2017] <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-national-reports>

NHS England (2015a) *National results from the 2014 inpatient survey*. [Online] [Accessed on 29th April 2016] <https://www.england.nhs.uk/statistics/2015/05/21/overall-patient-experience-scores-2014-adult-inpatient-survey-update/>

NHS England (2015b) *GP Patient survey: National Summary Report*. [Online] [Accessed on 29th April 2016] <https://gp-patient.co.uk/surveys-and-reports#july-2015>

NHS Institute for Innovation and Improvement (2013) *The productive leader programme: Improving efficiency through LEAN management*. [Online] [Accessed on

29th April 2016]

<https://www.nice.org.uk/search?q=The+productive+leader+programme%3A+Improving+efficiency+through+LEAN+management>

NHS Leadership Academy (2011) *Clinical Leadership Competency Framework*.

[Online][Accessed on 29th April 2016] <https://www.leadershipacademy.nhs.uk/wp-content/uploads/2012/11/NHSLeadership-Leadership-Framework-Clinical-Leadership-Competency-Framework-CLCF.pdf>

Nicol, E.D. (2012) 'Improving clinical leadership and management in the NHS.' *Journal of Healthcare Leadership*. 4:59-69.

Nolan, A. (2007) 'Productive ward: releasing time to care.' *Health Service Journal*. 117 (6052):51-59

Nursing and Midwifery Council (2015) *The Code: Professional standards of practice and behaviour for nurses and midwives*. London: NMC.

O'Callaghan, A.M., McAllister, L., Wilson, L. (2011). 'Experiences of care: Perspectives of carers of adults with traumatic brain injury.' *International Journal of Speech-Language Pathology*. 13(3):218–226.

Oliver, C. (2013) 'Social Workers as Boundary Spanners: Reframing our Professional Identity for Interprofessional Practice.' *Social Work Education*. 32(6): 773-784.

Parab, C.S., Cooper, C., Woolfenden, S., Piper, S.M. (2013) 'Specialist home-based nursing services for children with acute and chronic illnesses.' *Cochrane Database of Systematic Reviews*. Issue 6. Art. No.: CD004383.
DOI:10.1002/14651858.CD004383.pub3.

Paradis, E., Myles, L., Gropper, M.A., Aboumatar, H.J., Kitto, S., Reeves, S. (2013) 'Interprofessional care in intensive care settings and the factors that impact it: results from a scoping review of ethnographic studies.' *Journal of Critical Care* [Online] [Accessed on 29th April 2016] <http://dx.doi.org/10.1016/j.jcrc.2013.05.015>.

Paradis, E., Reeves, S., Leslie, M., Aboumatar, H., Chesluk, B., Clark, P., Courtenay, M., Franck, L., Lamb, G., Lyndon, A., Mesman, J., Puntillo, K., Schmitt, M., van Soeren, M., Pearson, M., Hunt, H., Cooper, C., Shepperd, S., Pawson, R., Anderson, R. (2015) 'Providing effective and preferred care closer to home: a realist review of intermediate care.' *Health and Social Care in the Community*. 23(6): 577-593.

Parker, G., Corden, A., Heaton, J. (2011) 'Experiences of and influences on continuity of care for service users and carers: synthesis of evidence from a research programme.' *Health and Social Care in the Community*. 19(6):576-601.

Parkinson's Disease Society (2008) *Life with Parkinson's today- room for improvement*. [Online] [Accessed on 29th April 2016] <http://www.parkinsons.org.uk/content/life-parkinsons-today-room-improvement>

Patients Association (2014) *Handling Complaints with a Compassionate Human Touch*. [Online] [Accessed on 29th April 2016] <http://www.patients-association.org.uk/press-release/complaints-report/>

Pecukonis, E., Doyle, O., Bliss, D.L. (2008) 'Reducing barriers to interprofessional training: Promoting interprofessional cultural competence.' *Journal of Interprofessional Care*. 22:4, 417-428.

Peled, E., Leichtentritt, R. (2002) 'The Ethics of Qualitative Social Work Research.' *Qualitative Social Work*. 1(2): 145-169.

Pereira, H. (2012) 'Rigour in phenomenological research: reflections of a novice nurse researcher.' *Nurse Researcher*. 19(3): 16-19.

Pereira, H.R., Botelho, M.A.R. (2011) 'Sudden informal caregivers: the lived experience of informal caregivers after an unexpected event.' *Journal of Clinical Nursing*. 20: 2448-2457.

Pillow, W. (2003) 'Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research.' *International Journal of Qualitative Studies in Education*. 16(2):175-196.

Poirier, S. (2002) 'Voice in the medical narrative' In Charon, R., Montello, M. (eds.) *Stories Matter: The Role of Narrative in Medical Ethics*. New York: Routledge, 48-58.

Pollard, K. (2009) 'Student engagement in interprofessional working in practice placement settings.' *Journal of Clinical Nursing*. 18: 2846-2856.

Pollard, K.C., Miers, M.E. (2008) 'From students to professionals: results of a longitudinal study of attitudes to pre-qualifying collaborative learning and working in health and social care in the United Kingdom.' *Journal of Interprofessional Care*. 22(4):399-416.

Pollard, K.C., Miers, M.E., Gilchrist, M. (2004) 'Collaborative learning for collaborative working? Initial findings from a longitudinal study of health and social care students.' *Health and Social care in the Community*. 12(4):346-358.

Pollard, K., Sellman, D., Senior, B. (2005) 'The Need for Interprofessional Working.' In Barrett, G., Sellman, D., Thomas, J. (eds.) *Interprofessional Working in Health and Social Care. Professional Perspectives*. Basingstoke: Palgrave Macmillan, 7-17.

Pollard, K.C., Thomas, J., Miers, M. (eds.) (2010) *Understanding Interprofessional Working in health and social care*. Basingstoke: Palgrave Macmillan.

- Potkins, D., Bradley, S., Shrimanker, J., O'Brien, J., Swann, A., Ballard, C. (2000) 'End of life treatment decisions in people with dementia: carers' views and the factors which influence them.' *International Journal of Geriatric Psychiatry*. 15:1005-1008.
- Prescott, D., Rowe, M. (2015) 'Leadership in systems, organisations and cultures.' *British Journal of Hospital Management*. 76(2):101-103.
- Pullon, S. (2008) 'Competence, respect and trust: key features of successful interprofessional nurse doctor relationships.' *Journal of Interprofessional Care*. 22 (2):133-147.
- Pyper, C., Amery, J., Watson, M., Crook, C. (2004) 'Patients' experiences when accessing their on-line electronic patient records in primary care.' *British Journal of General Practice*. 54:38-43.
- Rand, S., Malley, J. (2014) 'Carers' quality of life and experiences of adult social care support in England.' *Health and Social Care in the Community*. 22(4): 375–385.
- Rapaport, J., Stevens, M., Manthorpe, J., Hussein, S., Harris, J. & Martineau, S. (2008) 'Weighing the evidence: a case for using vignettes to elicit public and practitioner views of the workings of the POVA vetting and barring scheme.' *Journal of Adult Protection*. 10(2): 6–17.
- Redfern, S., Norman, I. (1999) 'Quality of nursing care perceived by patients and their nurses: an application of the critical incident technique. Part 1.' *Journal of Clinical Nursing*. 8(4): 407-421.
- Reeves, S., Lewin, S. (2004) 'Hospital-based interprofessional collaboration: strategies and meanings.' *Journal of Health Services Research and Policy*. 9: 218-225.
- Reeves, S., Lewin, S., Espin, S., Zwarenstein, M. (2010) *Interprofessional teamwork for health and social care*. Oxford: Wiley-Blackwell.
- Reeves, S., McMillan, S.E., Kachan, N., Paradis, E., Leslie, M., Kitto, S. (2015) 'Interprofessional collaboration and family member involvement in intensive care units: emerging themes from a multi-sited ethnography.' *Journal of Interprofessional Care*. 29(3): 230-237.
- Reeves, S., Rice, K., Gotlib, L., Lee-Miller, K., Kenaszchuk, C., Zwarenstein, M. (2009) 'Interprofessional interaction, negotiation and non-negotiation on general internal medicine wards: An ethnographic study.' *Journal of Interprofessional Care*. 23:1–13.
- Reeves, S., Ross, F., Harris, R. (2014) 'Fostering a "common culture"? Responses to the Francis Inquiry demonstrate the need for an interprofessional response.' *Journal of Interprofessional Care*. 28(5): 387-389
- Reeves, S., Zwarenstein, M., Goldman, J., Barr, H., Freeth, D., Hammick, M., Koppel, I. (2008) 'Interprofessional education: effects on professional practice and health care

outcomes.' *Cochrane Database of Systematic Reviews 2008*, Issue 1. Art. No.: CD002213. DOI: 10.1002/14651858.CD002213.pub2.

Rice, K., Zwarenstein, M., Gotlib Conn, L., Kenaszchuk, C., Russell, A., Reeves, S. (2010) 'An intervention to improve interprofessional collaboration and communications: A comparative qualitative study.' *Journal of Interprofessional Care*. 24(4): 350-361.

Richardson, B., Lindquist, I., Engardt, M., Aitman, C. (2002) 'Professional socialization: students' expectations of being a physiotherapist'. *Medical Teacher*. 24(6):622-627.

Richman, J., Mercer, D. (2002) 'The vignette revisited: evil and the forensic nurse.' *Nurse Researcher*. 9(4): 70-82.

Ritchie, J., Lewis, J. (eds.) (2003) *Qualitative Research Practice. A guide for social science students and researchers*. London: Sage Publications Ltd.

Robertson, J.M. (2015) 'Using carer biographical narratives to explore factors involved in proxy reporting of quality of life in people with dementia.' *Aging and Mental Health*. [Online] [Accessed on 29th April 2016]
<http://www.tandfonline.com/doi/full/10.1080/13607863.2015.1109056>

Robson, C. (2002) *Real World Research*. 2nd ed., Malden: Blackwell Publishing.

Robson, M., Kitchen, S.S. (2007) 'Exploring physiotherapy students' experiences of interprofessional collaboration in the clinical setting: a critical incident study.' *Journal of Interprofessional Care*. 21(1): 95-109.

Ross, F. (2010) 'Learning from older people: shifting the balance in research.' *Generations Review*. 20(4). [Online] [Accessed on 29th April 2016]
<http://www.britishgerontology.org/DB/gr-editions-2/generations-review/learning-from-older-people-shifting-the-balance-in.html>

Roulstone, A., Hudson, V. (2007) 'Carer participation in England, Wales and Northern Ireland: a challenge for interprofessional working.' *Journal of Interprofessional Care*. 21(3):303-317.

Rummery, K. (2006). 'Partnerships and Collaborative Governance in Welfare: The Citizenship Challenge.' *Social Policy and Society*. 5:293-303.

Rummery K. (2009) 'Healthy partnerships, healthy citizens? An international review of partnerships in health and social care and patient/user outcomes.' *Social Science & Medicine*. 69:1797-1804.

Runswick-Cole, K. (2011) 'Interviewing.' In Banister, P., Bunn, G., Burman, E., Daniels, J., Duckett, P., Goodley, D., Lawthom, R., Parker, I., Runswick-Cole, K., Sixsmith, J., Smailes, S., Tindall, C., Whelan, P. *Qualitative methods in Psychology. A research guide*. 2nd ed., Maidenhead: Open University Press. McGraw Hill Education, 88-99.

- Saha, S., Beach, M.C. (2011) 'The impact of patient-centred communication on patients' decision making and evaluations of physicians: a randomised study using video vignettes.' *Patient Education and Counseling*. 84:386-392.
- Salas, E., Weaver, S. J., DiazGranados, D., Lyons, R., King, H. (2009) 'Sounding the Call for Team Training in Health Care: Some Insights and Warnings. Invited address 2008.' *Academic Medicine*. 84 (10):S128-S131.
- Salhani, D., Coulter, I. (2009) 'The politics of interprofessional working and the struggle for professional autonomy in nursing.' *Social Science and Medicine*. 68: 1221-1228.
- San Martin-Rodriguez, L., Beaulieu, M.D. and Ferrada-Videla, M. (2005) 'The determinants of successful collaboration: a review of theoretical and empirical studies.' *Journal of Interprofessional Care*. 19 (Supplement 1): 132-147.
- Sandercock, L. (2003) 'Out of the closet: the importance of stories and storytelling in planning practice.' *Planning Theory and Practice*. 4 (1): 11-28.
- Sawatzky, J.E., Fowler-Kerry, S. (2003) 'Impact of caregiving: listening to the voice of informal caregivers.' *Journal of Psychiatric and Mental Health Nursing*. 10: 277-286.
- Schmitt, M.H. (2001) 'Collaboration improves the quality of care: methodological challenges and evidence from US health care research.' *Journal of Interprofessional Care*. 15(1): 47-66.
- Schoenberg, N.E., Ravdal, H. (2000) 'Using vignettes in awareness and attitudinal research.' *International Journal of Social Research Methodology*. 3(1): 63-74.
- Schön, D.A. (1983) *The Reflective Practitioner: how professionals think in action*. London: Basic Books.
- Sellman, D. (2010) 'Values and Ethics in Interprofessional Working' In Pollard, K.C., Thomas, J., Miers, M. (eds.) *Understanding Interprofessional Working in health and social care*. Basingstoke: Palgrave Macmillan, 156-170.
- Selman, L., Beynon, T., Higginson, I.J., Harding, R. (2007) 'Psychological, social and spiritual distress at the end of life in heart failure patients.' *Current Opinion in Supportive and Palliative Care*. 1:260-266.
- Shaller, D. (2007) *Patient-Centered Care: What Does It Take?* [Online] [Accessed on 29th April 2016] <http://www.commonwealthfund.org/publications/fund-reports/2007/oct/patient-centered-care--what-does-it-take>
- Shaw, A., de Lusignan, S., Rowlands, G. (2005) 'Do Primary care professionals work as a team: a qualitative study.' *Journal of Interprofessional Care*. 19 (4): 396-405.
- Shaw, J.A., DeForge, R.T. (2012) 'Physiotherapy as bricolage: Theorizing expert practice.' *Physiotherapy Theory and Practice*. 28(6): 420-427.

- Simon, C., Kumar, S. (2002) 'Stroke patients' carers' views of formal community support.' *British Journal of Community Nursing*. 7(3):158-163.
- Sims, D. (2011) 'Reconstructing professional identity for professional and interprofessional practice: A mixed methods study of joint training programmes in learning disability nursing and social work.' *Journal of Interprofessional Care*. 25(4): 265-271.
- Sims, S., Hewitt G., Harris, R. (2015a) 'Evidence of collaboration, pooling of resources, learning and role blurring in interprofessional healthcare teams: a realist synthesis.' *Journal of Interprofessional Care*. 29(1): 20-25
- Sims, S., Hewitt G., Harris, R. (2015b) 'Evidence of a shared purpose, critical reflection, innovation and leadership in interprofessional healthcare teams: a realist synthesis.' *Journal of Interprofessional Care*. 29(3): 209-215
- Smith, L.N., Lawrence, M., Kerr, S.M., Langhorne, P., Lees, K.R. (2004) 'Informal carers' experience of caring for stroke survivors.' *Journal of Advanced Nursing*. 46(3): 235–244.
- Social Research Association (2001) *A Code of Practice for the Safety of Social Researchers*. [Online] [Accessed on 29th April 2016] http://the-sra.org.uk/sra_resources/safety-code/
- Somekh, B., Lewin, C. (2005) *Research Methods in the Social Sciences*. London: Sage.
- Spalding, N.J., Phillips, T. (2007) 'Exploring the use of vignettes: from validity to trustworthiness.' *Qualitative Health Research*. 17 (7): 954-962.
- Spencer, L., Ritchie, J., O'Connor, W. (2003) 'Analysis: Practices, Principles and Processes' In Ritchie, J., Lewis, J. (eds.) *Qualitative Research Practice. A guide for social science students and researchers*. London: Sage Publications Ltd, 199-218.
- Stalker, K. (ed.) (2003) *Reconceptualising Work with 'Carers': New Directions for Policy and Practice*. London: Jessica Kingsley Publishers.
- Stanbridge, R.I., Burbach, F.R., Leftwich, S. H. (2009) 'Establishing family inclusive acute inpatient mental health services: a staff training programme in Somerset.' *Journal of Family Therapy*. 31: 233–249.
- Stanbridge, R.I., Burbach, F.R., Rapsey, E.H.S., Leftwich, S.H., McIvere, C.C. (2013) 'Improving partnerships with families and carers in in-patient mental health services for older people: a staff training programme and family liaison service.' *Journal of Family Therapy*. 35:176–197.
- Stewart, M. (2001) 'Towards a global definition of patient centred care' [Editorial] *BMJ*. 322: 444.

Strauss, A., Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd ed., Thousand Oaks: Sage Publications.

Suter, E., Arndt, J., Arthur, N., Parboosingh, J., Taylor, E., Deutschlander, S. (2009) 'Role understanding and effective communication as core competencies for collaborative practice.' *Journal of Interprofessional Care*. 23(1): 41-51.

Tamura, Y., Bontje, P., Nakata, Y., Ishikawa, Y., Tsuda, N. (2005) 'Can one eat collaboration? Menus as metaphors of interprofessional collaboration.' *Journal of Interprofessional Care*. 19(3): 215-222.

Taplin, S.H., Foster, M.K., Shortell, S.M. (2013) 'Organizational leadership for building effective health care teams.' *Annals of Family Medicine*. 11 (3): 279-281.

Taylor, B.J. (2006) 'Factorial Surveys: Using Vignettes to Study Professional Judgement' *British Journal of Social Work*. 36: 1187–1207.

Ten Boom, C., with Sherrill, J., Sherrill, E. (1971) *The Hiding Place*. London: Hodder and Stoughton.

The Chartered Society of Physiotherapy (2005) *Personal Safety for Loneworkers*. London: CSP.

The Chartered Society of Physiotherapy (2011) *Code of Members' Professional Values and Behaviour*. London: CSP.

The King's Fund (2010) *How to deliver high quality patient-centred cost effective care*. [Online] [Accessed on 29th April 2016]
<http://www.kingsfund.org.uk/publications/articles/how-deliver-high-quality-patient-centred-cost-effective-care>

The King's Fund (2013) *Patient centred leadership. Rediscovering our purpose*. [Online] [Accessed on 29th April 2016]
https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/patient-centred-leadership-rediscovering-our-purpose-may13.pdf

The Mid Staffordshire NHS Foundation Trust (2010). *The Mid Staffordshire NHS Foundation Trust Inquiry. January 2005 – March 2009 Chaired by Robert Francis QC*. [Online] [Accessed on 29th April 2016] <http://www.midstaffspublicinquiry.com>

The Mid Staffordshire NHS Foundation Trust Public Inquiry (2013) *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. Chaired by Robert Francis QC. Executive Summary*. [Online] [Accessed on 29th April 2016]
<http://www.midstaffspublicinquiry.com>

The Point of Care Foundation (2014) *Annual Report 2014*. [Online] [Accessed on 29th April 2016] <http://www.pointofcarefoundation.org.uk/What-We-Do/#Publications>

- Thomas, J. (2010) 'Service Users, Carers and Issues for Collaborative Practice.' In Pollard, K.C., Thomas, J., Miers, M. (eds.) *Understanding Interprofessional Working in health and social care*. Basingstoke: Palgrave Macmillan, 171-185.
- Thomas, C., Morris, S.M. (2002) 'Informal carers in cancer contexts.' *European Journal of Cancer Care*. 11:178-182.
- Thomson, P., Walker, M. (eds.) (2010) *The Routledge Doctoral Supervisor's Companion: Getting to Grips with Research in Education and the Social Sciences*. London: Routledge.
- Turner, P., Sheldon, F., Coles, C., Mountford, B., Hillier, R., Radway, P., Wee, B. (2000) 'Listening to and learning from the family carer's story: an innovative approach in interprofessional education.' *Journal of Interprofessional Care*. 14(4):387-395.
- Tutton, E.M.M. (2005) 'Issues and innovations in nursing practice: patient participation on a ward for frail older people.' *Journal of Advanced Nursing*. 50:143.
- Twigg, J., Atkin, K. (1994) *Carers Perceived: Policy and practice in informal care*. Maidenhead: Open University Press.
- Ussher, J.M., Sandoval, M. (2008) 'Gender differences in the construction and experience of cancer care: the consequences of the gendered positioning of carers.' *Psychology and Health*. 23(8): 945-963.
- Vekkaila, J., Pyhältö, K. and Lonka, K. (2013) 'Experiences of disengagement: a study of doctoral students in behavioural sciences.' *International Journal of Doctoral Studies*. 8:61-80. [Online] [Accessed on 29th April 2016]
<http://www.ijds.org/Volume1/IJDSv1p021-033Ali13.pdf>
- Wachter, B., Zwarenstein, M., Gropper, M., Kitto, S. (2014) 'Exploring the nature of interprofessional collaboration and family member involvement in an intensive care context.' *Journal of Interprofessional Care*. 28 (1): 74-75.
- Waddie, N. (2007) 'Interprofessional Working' In Wilkinson, C. (ed.) *Professional Perspectives in Health Care*. Basingstoke: Palgrave Macmillan, 61-82.
- Walker, E., Dewar, B. (2001) 'How do we facilitate carers' involvement in decision making?' *Journal of Advanced Nursing*. 34(3): 329-337.
- Walsh, C.L., Gordon, M.F., Marshall, M., Wilson, F., Hunt, T. (2005) 'Interprofessional capability: a developing framework for interprofessional education.' *Nurse Education in Practice*. 5:230-237.
- Warne, T., McAndrew, S. (2007) 'Passive patient or engaged expert? Using a Ptolemaic approach to enhance mental health nurse education and practice.' *International Journal of Mental Health Nursing*. 16(4): 224-229.

- Warne, T., Stark, S. (2004) 'Service users, metaphors and team working in mental health.' *Journal of Psychiatric and Mental Health Nursing*. 11(6): 654-661.
- West, M., West, T. (2015) 'Leadership in healthcare: a review of the evidence.' *Management Matrix*. 15(2) [Online] [Accessed on 29th April 2016] <https://healthmanagement.org/c/healthmanagement/issuearticle/leadership-in-healthcare-a-review-of-the-evidence>
- Wibberley, C., Kenny, C. (1994) 'The case for interactive interviewing.' *Nurse Researcher*. 1 (3): 57-64.
- Wiles, R. (2013) *What are qualitative research ethics?* London: Bloomsbury Academic.
- Wilson, G. (2009) 'Implementation of releasing time to care—the productive ward.' *Journal of Nursing Management*. 17: 647–54.
- Wilson, C., Mansell, I. (2010) 'Access to health and social care services and information.' *Learning Disability in Practice*. 13(5): 32-38.
- Wright, J.M., Heathcote, K., Wibberley, C. (2014) 'Fact or fiction: exploring the use of real stories in place of vignettes in interviews with informal carers.' *Nurse Researcher*. 21(4): 39-43.
- Wright, S., McSherry, W. (2013) 'A systematic literature review of Releasing Time to Care: the Productive Ward.' *Journal of Clinical Nursing*. 22: 1361–1371.
- Wynaden, D., Ladzinski, U., Lapsley, J., Landsborough, I., Butt, J., Hewitt, V. (2006) 'The caregiving experience: How much do health professionals understand?' *Collegian*. 13(3):6-10.
- Xyrichis, A., Lowton, K. (2008) 'What fosters or prevents interprofessional teamworking in primary and community care? A literature review.' *International Journal of Nursing Studies*. 45:140-153.
- Xyrichis, A., Ream, E. (2007) 'Teamwork: a concept analysis.' *Journal of Advanced Nursing*. 61(2): 232-241.
- Yarwood, G.A., Ogilvie, H., Yianni, C. (2015) 'Working in collaboration: three PhD students trouble reflexivity.' *Journal of Perspectives in Applied Academic Practice*. 3(2):72-81.
- Yeandle, S., Buckner, L. (2015) *Valuing carers 2015 - the rising value of carers support*. London: Carers UK.
- Yeowell, G. (2010) 'What are the perceived needs of Pakistani women in the North West of England in relation to physiotherapy, and to what extent do they feel their needs are being met?' *Physiotherapy*. 96 (3): 257-263.

Young, A. J., Rogers, A., Addington-Hall, J.M. (2008) 'The quality and adequacy of care received at home in the last 3 months of life by people who died following a stroke: a retrospective survey of surviving family and friends using the Views of Informal Carers Evaluation of Services questionnaire.' *Health and Social Care in the Community*. 16(4):419-428.

Zwarenstein, M., Goldman, J., Reeves, S. (2009) 'Interprofessional collaboration: effects of practice-based interventions on professional practice and healthcare outcomes.' *Cochrane Database of Systematic Reviews 2009*, Issue 3, Art: CD000072 . DOI: 10.1002/14651858.CD000072.pub2.

8 Appendix I

Faculty of Health, Psychology and Social Care

Date: **/**/****



Dear Member of Faculty HPSC Service User and Carers Forum,

Are you a carer? If so, your voice as a carer is needed .

I am looking for volunteers to participate in the first stage of a research study looking at the views of carers on how professionals should work effectively together to improve the lives of carers and the people they care for.

In the first stage of the study, I would like to work with a couple of carers to help me to develop a case scenario which I will use in the next stage of my study.

If you are interested in taking part, please return the slip at the bottom of this leaflet or contact me at :

Mrs Julie Wright

Principal Lecturer

Faculty of Health, Psychology and Social Care

Manchester Metropolitan University

Elizabeth Gaskell Campus

Hathersage Road,

Manchester M13 0JA

0161-247-****

j.m.wright@mmu.ac.uk

Please find a study information sheet (stage 1) attached.

If you require any further information with regards to the study or your involvement, please contact me.

Thank you,

Julie M Wright



I am willing to help you in your study. I can be contacted by:

Name: _____

Address: _____

Telephone: _____

Email (if you have one): _____

9 Appendix II

CONSENT FORM for Stage 1 of Study



Study Title: Using real stories to capture informal carers' views of effective interprofessional working

Name of Researcher:

Julie M Wright,
Faculty of Health, Psychology and Social Care,
Elizabeth Gaskell Site,
Manchester Metropolitan University.

j.m.wright@mmu.ac.uk

0161-247-****

Please put your initials in the box.

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my rights being affected.

Having had more than a week to consider my decision, I agree to take part in the above study.

Name of Participant -----

Signature -----

Date -----

Name of Researcher -----

Signature -----

Date -----

(Copies: 1 for participant; 1 for researcher)



Faculty of Health, Psychology and Social Care,
Hathersage Road,
Manchester
M13 0JA

Tel: 0161 247 ****

e-mail: j.m.wright@mmu.ac.uk

Dear [],

Date

I should like to request your permission to approach carers from NAME OF GROUP for volunteers to participate in Stage 2 of my PhD titled, "Using real stories to capture informal carer views of effective interprofessional working".

My study proposes to provide a clearer understanding of interprofessional working which is critically informed by carer experiences and perceptions and not wholly constructed from professional perspectives and policies.

This would assist those involved in the planning and provision of services, those delivering care and those educating present and future professionals.

Each carer will receive a Participant Information Sheet and will be asked to complete a consent form. Ethical approval from the MMU Faculty Ethics Committee has already been granted for Stage 1 of my research and full approval for Stage 2 is dependent on permission from organisations/groups such as yours.

For your information I enclose a summary of my research and a copy of the Participant Information Sheet to be given to all volunteers. If you require any further information or have any questions, please do not hesitate in contacting me.

If you grant permission to approach the group, I should be grateful if you would complete the enclosed Permission Form.

Thank you in anticipation,

Mrs Julie M Wright,

Principal Lecturer/Senior Learning and Teaching Fellow.



Stage 2 Permission Form

I grant permission for Julie M Wright

to approach carers for volunteers to participate in Stage 2 of her
PhD.

Name: _____

Position: _____

Signature: _____

Name of Organisation: _____

Date: _____

Your voice as a carer is needed.

I am looking for volunteers to participate in interviews for a research study looking at the views of carers on how professionals should work effectively together to improve the lives of carers and the people they care for.

The interview with the researcher will take no longer than an hour and a half and will be carried out at a convenient location.

If you are willing to volunteer, please contact:

(insert Name)

(insert organisation)

(insert address)

(insert contact information).

If you require any further information with regards to the study or your involvement, please contact me as researcher:

Mrs Julie Wright

Principal Lecturer

Faculty of Health, Psychology and Social care

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Hathersage Road,

Manchester M13 0JA

j.m.wright@mmu.ac.uk ***** (mobile)

0161-247-**** (office)

12 Appendix V

Stage 2 : Participant Information Sheet



Study Title: Using real stories to capture informal carers' views of effective interprofessional working.

You are being invited to take part in an interview, which forms part of a research study. Before you decide it is important for you to understand why the interview is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Julie M Wright

Background: In a survey of over 3,000 carers, carers themselves identified that they wanted better recognition by professionals of their role and views on care (Carers UK, 2007). Currently, there are no studies that investigated the views of carers on delivery of care and of how professionals in health and social care should work together to deliver effective care.

This study aims to provide evidence from your viewpoint as a carer on how professionals should work together effectively to improve the lives of yourselves and the people you care for.

Purpose of Interview: The purpose of the interview is to obtain the views of informal carers, through their experiences as carers, on how professionals could work together more effectively to provide a high standard of care.

Why have I been chosen?

You have been chosen to be included in the study because you are an informal carer for more than 30 hours a week and have been in that role for more than 1 year.

Do I have to take part?

It is up to you to decide whether to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw yourself and your data at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the support you are already receiving as a carer.

What will happen to me if I take part?

Your whole involvement should take no more than one and a half hours.

You will be provided with an information sheet to read and typed copies of two carers' stories of their experiences of caring. You will be given at least a week to make your decision whether to take part in the study.

If you do not want to participate in the study, I will not contact you again. If you agree to take part, a consent form will need completing before the start of the interview.

At the start of the interview you will listen to a recording of one of the stories you have chosen to hear. During the interview I will guide the discussion by asking certain questions and asking you to give your views of your chosen story. I will ask you to share your experiences of your interactions with health and social care professionals.

A tape recording of the interview will be carried out. Notes will also be taken regarding what is actually said. This will help with the analysis at a later stage.

Will my taking part in this study be kept confidential?

All information, which is collected, about you during the course of this study will be kept strictly confidential. Direct quotes from the interviews may be presented in the final research study, but under no circumstances will your name be included in the study.

I will keep all tapes and transcripts of the interview. These will be coded and no names will appear on the transcripts so that you cannot be recognised from it. I alone will have access to the codes.

What are the possible disadvantages and risks of taking part?

There are no foreseen risks of your taking part in the study.

Some disadvantages may be the inconvenience of your time to be interviewed and that you may get tired during the interview. There is a risk of upset from the topics discussed during the interview. Breaks will be offered to you if you feel you need them. The interview will be stopped at any point if you do not wish to continue at any stage. The interview may evoke emotions or distress. You will be encouraged to seek counselling through your local carers centre/ organisation.

In the interview, you may disclose an experience of unprofessional practice on the part of a professional. I will be guided by her professional codes of conduct (the Health Professions Council and the Chartered Society of Physiotherapy) in dealing with the situation if it arises.

What are the possible benefits of taking part?

The information obtained from you during this study will help inform the current understanding we have of effective working between professionals. It will provide useful information for current and future health professional education and training so that effective care is provided to those in need. With your consent, excerpts from the tape recording of the interview will be used in teaching sessions in the future. Your views will be heard by current and future health and social care professionals.

What will happen to the results of the research study?

The information obtained from the interview will form part of a PhD study. The information will also be used at a later date in the form of a published research article or as part of a presentation at a research conference.

If you need further information, please do not hesitate to contact me:

Mrs Julie M Wright

Principal Lecturer- Practice Placement and Learning

Faculty of Health, Psychology and Social care.

Manchester Metropolitan University

Elizabeth Gaskell Campus,

Hathersage Road,

Manchester M13 OJA

j.m.wright@mmu.ac.uk

Tel: *** *(mobile) /0161 247 *****(office)**

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you,

Julie Wright.

Date: **/**/****

13 Appendix VI

CONSENT FORM for Stage 2 of Study



Study Title: Using real stories to capture informal carers' views of effective interprofessional working

Name of Researcher:

Julie M Wright,
Faculty of Health, Psychology and Social Care,
Elizabeth Gaskell Site,
Manchester Metropolitan University.

j.m.wright@mmu.ac.uk

0161-247-****

Please put your initials in the box.

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw myself and my data at any time, without giving any reason, without my rights being affected.

Having had more than a week to consider my decision, I agree to take part in the above study.

I give permission for the taped recording of the
interview to be used for future teaching purposes.



Name of Participant -----

Signature -----

Date -----

Name of Researcher -----

Signature -----

Date -----

(Copies: 1 for participant; 1 for researcher)

14 Appendix VII

Grace's Story for Interviews

(A recording of this story will be played in the interview session)

My role in caring is for my elderly father. I lost my mum when she was 55, about 24 years ago and dad coped really well. He was only 56 when mum died. And he coped really well and he got a lady friend and they are still together. They never wanted to get married they just wanted to be companions. My boys have been the life and soul for him. We took my dad away with us we used to go up to Scotland, up to St Andrews or wherever and it did help my dad. Basically dad was there for the children so I do owe him something, he does love us. So when dad starting being ill, there was only me.

He's had a series of, what shall I say, off and ons. He's had 3 knee replacements and the last one was a revision which is a replacement of one knee. Before that he'd had to have a lot of medication because this knee had just failed. He was on Tramadol and Tramadol was historically used as an anti-depressant but it was found to be a very good anti-inflammatory. But that, for want of a better word, sent him 'doolally'. We thought he'd had a stroke. He was on list for his revision but it was cancelled twice – because he just wasn't fit enough. And then his knee failed completely and we had to put him in a home through intermediate care while he waited for his op. He went in because his knee was in that bad a state; it had collapsed inside and he couldn't cope. I could have brought him to our house but he wouldn't be able to climb stairs. At our house, he has his own bedroom with an on suite bathroom. The house he lives in... his toilet is upstairs. I'd already got disabled gadgets in for him but then he went downhill with the Tramadol effect and he'd been on this for 3 years. Far too long, far too long. He really didn't know what he was doing. It was at that stage when I realised I needed to get help. I called the doctor out and he came and had a look, said 'he's got to go into hospital and get his knee sorted'. He was on the waiting list but because of the condition of his mind, they weren't prepared to do the knee.

Anyway events superseded this. He couldn't cope at all. He started with waterworks and bowel problems. I was going every day. This was the reason I got social services involved. When he was at his worse, he had been in hospital with a compacted bowel and they thought he had a stroke in hospital because he started hallucinating. They kicked him out and sent him home with a, 'You are on your own again. If you need social services give us a ring'. Anyway, things went on and we had to ring rapid response team who didn't want to know. They said it's social services. It kept getting batted about between rapid response and social services. Eventually the doctor took this on and fortunately we got a social worker who came on in the evening and was prepared to take on dad's case. It had been going on for 12 hours. The GP was fantastic; in his surgery at 8:30 at night arguing and trying to rationalise with social

services and rapid response. The hospital didn't want him as he was already on the waiting list. It was a nightmare. Fortunately this social worker came on duty and managed to take him on. They came to see us that night and found a home he could go in until he had his operation. I think at 1:30 in the morning we finally got him into this home. We waited 5 hours for an ambulance – it was just horrendous. I'm feeling guilty sticking him in a home. There was no other way out really. He had 3 weeks in that home. This was getting on the phone to consultants, secretaries to chase up his position on the list. Finally they got him into hospital and I even had to take him in hospital. They wouldn't send an ambulance because it was a Sunday and ambulances don't run on a Sunday. But whilst he was in that home and intermediate care they were still arguing who should look after him. Rapid response and social services. They were very reluctant to take responsibility. My faith in the NHS plummeted.

It was at that stage when I thought is he really ever going to recover enough to have this operation. He hated it in that home, he just didn't fit in at all. He wasn't his own person because he was with dementia patients, patients with incontinence; the place stunk. He felt he shouldn't have been there in intermediate care. He knew exactly what was happening.

It was me then who he relied on for his after care. He went in for his op and then had rehab care for 6 weeks, which he would have stayed all the time; he'd still be there now. He loved it. It was brilliant. Physio, group sessions, good food, nice room. It was absolutely wonderful. Completely different from the intermediate care home. The food for one. The rehab unit didn't smell. You wouldn't have known it was a home.

The staff were just lovely and it made such a difference. Pleasant, talked to him, they had these exercise sessions where all rehab patients got together. They had communal lounges where my dad used to go and watch tv on his own not because he wanted to watch tv but the room was so pleasant he felt at home in this place. A nice big lounge – I could go whenever; talk, watch tv. There was a nail bar where the staff did old aged pensioners nails, games room, everything.

The staff gave me regular updates. If they felt he needed the doctor they would ring the GP. He had dry skin on his legs from his op and the GP looked at that. Checked his knee, but it was really good. Dad said it was the best 6 weeks of his life he'd ever had. I think the patients are more relaxed and do want to get better. They are there for rehab. Some of them were hard work. But after the experience he'd had in intermediate care, and then hospital he was grateful to be his own person again and to get on with recovering. All he needed was the seafront at Blackpool. It was just wonderful. And that was in the space of a few weeks. It all changed round.

He got better in himself. He still wasn't driving at this stage and this meant I was doing everything for him. Social services came in and he got a bath lift, disabled rails and stuff and slowly but surely, I got him to go in the car and got him driving again and

now, touch wood, he is virtually independent. I'm still there to do all his banking and his personal stuff and I'm on the end of the phone if he needs me but it's been hard. I've just had to get on with it and it's worked. So although I'm still his carer, I've divorced myself from it and I am able to thankfully. I still see him and still do things but at the moment he's coping very well, so hopefully, fingers crossed. Now he's brilliant. There will come a time when we'll be back to square one. It's got to get worse before it gets better. We'll see."

15 Appendix VIII

Crystal's story for Interviews

(A recording of this story will be played in the interview session)

I've got two sons. Jacki's twenty-two and he's got Asperger's syndrome. Luke is nineteen and he's got autism. Jacki is doing nothing at the moment; he's just stuck at home and Luke, the one with autism is leaving school in July. But I don't really know what he's going to do. He wants a job but...he's not done exams, he's got learning disabilities associated with autism so he's in special school... no exams, no qualifications. He went for work experience and I could tell they didn't want him but you know it's just one of those things...

I've really got three of them. I've got my husband as well with M.E. but I'll talk about my youngest Luke. The one that's nineteen. Everything was alright with him until he was about three and a half and then I gave him the dreaded vaccine MMR and he had a fit after that. Plus at this age I'd also realised some of the things he was doing weren't up to speed for his age. He wasn't really speaking, stuff like that. But I felt really guilty because I'd given him this MMR. I didn't know what was happening and I said to the health visitor 'he doesn't seem to be developing. Do you think there's something wrong with him?' She said, 'Oh no he's just lazy. It isn't a problem. He's got an older brother who talks for him and does things for him'. He was having these epileptic fits, although they said they weren't. But later on they decided they were but never did anything. Then when he was supposed to go to school, I declined because I thought I was more able to teach him at home because he was so far behind that I thought it would be better if I try to bring him forward. Any way it didn't work, so when he was due for school and I went up to school and said, 'I think there is something wrong with my son. I can't get to the bottom of it. No-one seems to know what it is. And he's really way behind and he's just weird'.

So they took him into infant school –eventually I had to get support for him because he wouldn't sit down. I had to carry him to school every morning, he wouldn't walk. When he got into school, he'd walk round all the time. They couldn't get him to concentrate so in the end they decided he should see a speech therapist. So she said he had semantic pragmatic syndrome. She couldn't engage him-it was awful. He'd run out of the room. He still wasn't diagnosed when he went into junior school. They were still saying he had semantic pragmatic syndrome, but they also thought he might have this ADHD.

He went into this other school with a language unit in it. Then when he was about eight, they eventually got a psychiatrist from out of the area and she diagnosed him with autism. But then the school said he hadn't got autism after he'd being diagnosed and they were really horrible with him. When he was doing maths, he had a bad memory he used to be able to do it one day, then the next he'd forgotten it so they

said he was doing it deliberately . He was bullied by other kids and he was still having seizures in school. About nine or ten he started getting problems with his stomach. So we ended up in hospital with his stomach. They couldn't find out why he had constipation all the time. He just used to fill up and then overflow and it was a mess. He had it at school and they were getting annoyed because he'd be filling his pants and it was all over the place. We went to see this doctor at the local hospital and he was really good. He was excellent with him but we couldn't get to the cause of the bowel problem so he was put on medication.

By the time he was getting to secondary school age, school had been absolutely horrendous and he couldn't cope with it. The education offered me a school which was a normal secondary school. I said he wasn't going because he'd never handle it. I wanted him in a special school. So when they declined it and said he had to go, I said 'I'll have to take you to tribunal', which I had to do because they wouldn't back down. He was out of school for a year before he got a place in a special school. He missed a year of school and I had to teach him at home which was awful because they didn't put anyone in to teach him. He used to throw things at you and all sorts of stuff. Then he got into a special school and also his doctor changed. It was also about that time that I found out I'd got coeliac disease so I said to this doctor, do you not think it would be a good idea to check my son for coeliac disease. He said 'no he has not got coeliac disease.' This went on and I kept asking if he would do the tests but he just did blood tests. He wouldn't do the test because of his autism; they knew it would be a struggle. They kept giving him medication and it made his tummy worse. They wouldn't do a camera test and then when he got eighteen, because then they leave the paediatrician and go to a normal consultant and so I asked my consultant if he would see Luke. He told me to go to my GP and ask him to refer him which I did. So Luke eventually had the camera test. Four hours it took but he hasn't got coeliac disease. He has, what was it, hydro pyloric bacteria something. Treated with antibiotics. All them years he must have had it, but they wouldn't do the test. I got no support from the GP.

Luke had a psychiatrist for a while. He helped me get through the tribunal with letters of support. The good paediatrician helped and came to the tribunal – he was really good, the first one. Luke's in this special school now and he's leaving soon. He's tried college; I think they withdrew support too quickly. The college said he had to be independent. They decided that he needed support in the classroom only and not in unstructured time where he needed it. He used to phone me from the college loos and said he wanted to come home. He struggled with that for a year. His teacher changed. I spoke to his new teacher and said he is never going to be able to cope, so they withdrew him from college. Now he's looking for a job. He's dead worried, you know, he's panicking saying I want a job. I don't want to be sat at home. He's so aware now. He can speak and everything but they don't want to know. I don't think he'll ever do college. He wants to do I.T. He's never took exams. He can't spell unless he's on the

computer and has a spell checker. He can write but it's poor. He can do it but not in real writing. But it's poor printing. He can't tell the time, doesn't know what day it is unless we have the calendar ticked off. He never goes out by himself because he can't. He doesn't know traffic speed.

He has a support worker they very rarely do anything. They've got this new thing called In Control. What they do is, they assess the person and then they give you a pot of money. Then you can use it to employ someone to take your person out, ok. You don't know where to employ the people from. The ones you get from the broker come with no CRB checks, they seem to be anybody. I've had a few fail. It's not working at the moment. You are supposed to be able to spend this money on what you want; like going to the pictures with a personal assistant. But there's another pot of money called, Independent Living Fund. Luke is entitled to go for this. Unfortunately, if you get this one it stops you having control of the "in control" fund. You cannot use hours from the ILF for going to the pictures; they must be used on personal assistant hours. I have had this hassle for I don't know how long. I've tried to get expenses. Luke can't get reflexology for his scoliosis of the spine. He couldn't get it because it's not personal assistant hours. I'm fighting a losing battle with that at the moment. Social services haven't got a clue what we're talking about. It's open to abuse; people are cheating with it. I know people are doing it. I've got an agency working for me at the moment – that's a dead loss-they don't turn up. Social services say there is nothing they can do. It's down to ILF which is a trust. I phoned ILF and they said there's nothing they can do as it's policy.

Luke has a care manager. Since he hit eighteen I've had about five social workers - I asked for one to be removed because she was a waste of space, there was a discrepancy with the "in control" she said he had an increase and he hadn't so there was loads of stuff she did that weren't right. So I asked her to be removed. I've got this other lady who knows nothing about "in control" and ILF and she's never met my son. But what's happened is because he wants a job we go to training for employment and we have a meeting once a month and the social worker comes along. I've insisted she comes along to the meeting. I did say to her last time, she was on about claiming for incapacity benefits and all that, I said to her, I'm not being funny but that's your job not mine, . Why should I be doing all this, you should be doing it.

I had a really good community nurse. She used to come out a lot, every month. I could just phone her if I needed anything. And she'd come. She'd come to all the appointments, no questions asked. She'd speak to nurses, doctors and everyone, sometimes the nurses were pains in the neck because they didn't recognise autism. Once Luke went for an x ray and this nurse asked him to get on the bed. It was about twenty to five and we'd waited for 2 hours, which was horrendous for him and he wouldn't get on the bed. So I said to her he won't get on the bed, he's got autism. She went, 'oh yes...' I said 'the thing you need to do is explain what you are going to do

before you want him to do anything. He's scared, he doesn't know what you are going to do. You have to tell him'. She said, 'oh I haven't time to mess about'.

The community nurse who'd come in with me had a word with her and we eventually got him onto the bed with a lot of coaxing. I complained to the NHS and said that people with disabilities can't wait for a long time. Plus he doesn't know what time is, to him it's a long time. So the time after that he did get seen quicker. I saw a difference. But I can't have blood tests or others at the hospital 'cause they won't do them. It takes too long and plus they can't get the cream and you have to wait an hour for it to work. I've had to go to my local GP surgery nurse who uses this 'magic' cream because he's hypersensitive to needles.

Once they get 18 and get out of the paediatrics and go into the broader hospital bit, you've really had it. It's all new doctors and Luke can't cope with changes, so it's new doctors wherever you go, it's a nightmare. The community nurse doesn't visit now. They wait for me to ring... She does come, but she's not like the other nurse. I don't feel as confident with her. The other was knowledgeable about autism.

When Luke hit eighteen, the doctor asked him if he wanted the coeliac test and my son said he didn't know. The doctor said 'well it's your decision you're eighteen'. You know what we did. I wrote a letter with Luke to the GP and it sort of went, 'I've got autism. You know I'm not aware of certain things and I would prefer it you spoke to my mum and not me' and Luke signed it. So next time I went instead of him doing this [folds arms and turns away] he did this [turns towards] to me.

Then I've had this physiotherapy thing hanging over my head for two years. They found out Luke had a leg length discrepancy so he's had a shoe done. They said he had a scoliosis and he would see a physio. So we had one session and she said 'bye bye'. It was at the hospital out patients. 'There's a list of exercises to do at home'. And that was it. So I phoned up and complained to the community nurse and said it's not acceptable because one, the hospital is not the right environment for him and two, they gave him a list of exercises which I've got to do with him. It's not my job to do them with him as well as everything else I'm doing so they sent another lady out which I presume was from the learning disabilities team physio. She came to the house, and Luke was upstairs in his bedroom. She said to me, 'is it alright if I go up to his room and see him there?' she went up to his room. I didn't go with her. She came back down and said 'I don't think he's going to do his physio.' 'Why?' I said. She said 'I asked him if he would do his physio exercises on his bed'. And I said 'well he's not going to do them on his bed. That's his bedroom. It's private he goes to bed or plays on his computer. Physiotherapy doesn't come in that room'. Then she asked if he goes swimming? So I said yes and she said she would go ten minutes before his lesson and do some exercises in the water. So Luke agreed but that never happened. That was a year and a half ago.

I had a dietician coming out because he's underweight. I was speaking to her about the physio. Because she's in the learning disabilities team she said she'd have word with the physio so the physios came back out. She said I needed a new mattress for his bed, can't afford it like. It's a sprung mattress with a memory foam top. The mattress can't come out of his fund –it's not personal assistance. I've tried occupational therapy and they said, 'you can't have that off us because it isn't orthopaedic. If it was we could probably sort it out.' She's also asked me to look at a special chair because the chairs we have at home are too low. The occupational therapy said they may pay for that. It's unclear. A lot of them are thinking about this "in control" and think I can buy them. This is the failure now. They don't know you can't do it. It's driving me dotty. I've had a stair rail and shower rail, bath lift put in. I've been after that for ten years. I got it last year and in the end what I found out was you are supposed to go to occupational therapy, but no-one told me that. I then had to phone social services and they came out and said we needed a carer's assessment. I've already had one. So I had to do another one to get these things. I only got carers allowance last year because before I thought it would affect my tax credit. I phoned them and they said you can't have carers allowance because it will reduce your tax credits. They've been saying this for five years. I phoned again last year and this person said 'I don't know who told you that'. So I claimed for it.

What I was offered by adult services was he can go into this home, it was for anybody-little flats with a telly in and he can put his play station in. So I said 'what if he wants to go out?' and they said 'go out where?' 'Asda...' They said 'if we've got enough staff we'll take him out.' I said 'I don't think that's appropriate'. Plus the doors weren't locked and he could have got outside so

The only thing that's good that's working for him is the respite he has and that's out of borough. I get it through children's services actually and I don't think he should be having it but it's the "in control" that's buying it. But it's through one of the children's services community nurses. It was a nurse he had when he was young. So she sets it up and Luke goes away. They go on proper holidays, Hosesons. They go from Friday to Sunday, four disabled go with two carers. It's ok. That's the only thing that's really been any good."

16 Appendix IX

Interview Checklist

PRIOR to interview

2 digital tape recorders

consent form (s)

travel claim form(s)

copies of Grace and Crystal

interview schedule

Do not disturb sign

tissues

drink

paper cups

bottle of water

Spare batteries

AT START

Turn phone on silent

Position digital recorders

Have sight of "INTERVIEW SCHEDULE FOR STAGE 2 OF STUDY"

AT END

17 Appendix X

Interview Schedule for Stage 2 of the study.

1. Introductory comments

“Thank you for taking part in this interview. I can first assure you that you will remain completely anonymous and no records of the interview will be kept with your name on them.”

Explain reasons for the use and obtain permission to tape record interview and make notes of the interview.

2. Complete consent form- 2 signed copies

3. Explanation of purpose of the study (including background of researcher and interest in the area of enquiry.

4. Explanation of the way the interview will run

“You will hear one of the stories read out and then I will ask you to respond to what you’ve heard. You are free to interrupt and to ask for clarification of questions at any time.

5. Identify pseudonyms for themselves and the person they care for.

6. Content Mapping Questions/Factual (Ritchie and Lewis 2003)

(Breadth of information to open up issues and identify what are issues for participant.)

Ask :

- *how long have you been a carer?*
- *who do you care for ?*

7. Listen to recording of Grace or Crystal

(Play dictaphone FOLDER B: Grace: file 2 Crystal file 3)

8. Using Grace or Crystal, probe on their opinions of the case and whether it relates to their own experiences i.e. similar, better, different, worse.

9. Use possible probing questions (to obtain depth and to further explore views and thoughts of participants).

Content Mining Questions (amplifying probes; exploratory probes; explanatory probes; clarificatory probes)

e.g.

- *Have you had experience of this?*

- *Can you tell me more about that?*
- *Can you give me a particular example?*
- *What was it exactly about that that you liked/disliked?*

- *How did you respond?*
- *What did you feel?*

- *What makes you say that?*
- *Why do you think that is?*
- *What do you think should have happened ?*

- *Can you give examples of this?*
- *Can you explain what you meant when you said ..?*
- *You said... Why was that?*
- *What would you like to see?*

- *Earlier you said .., but now you are saying.. Taking this on board, what do you think now?*

- *Are there any circumstances/cases when you would think/act differently?*

10. Expanding on what the participant has said , probe in to their opinions on effective interprofessional working.

11. Closing comments for trial interviews

For example :

“ That is the end of the interview, is there anything else you feel is important to say about how professionals should work together which you feel has not been covered in this interview?”

Any feedback:

- *Have you any thoughts comments on the way I have carried out the interviews ?*
- *Were the stories useful?*
- *Did they make you think about your situation?*
- *Is there anything I could do differently which would improve the interview and achieve my aims?*

“Thank you very much for helping me and giving up your time.”

18 Appendix XI

Transcript of interview with "Bailey"

R =Researcher

B= Bailey (name chosen by interviewee)

[Bailey chose to listen to hear Crystal's story during the interview]

R: How long have you been a carer for Lenny your son? How old is he?

B: Lenny is almost 22years

R: You said initially you also care for your daughter as well.

B: Yes. She's 12,13 .

R: Shall we give her a name?

B: Ebony.

R: Can we listen to Crystal first at this point in the interview.

[Tape recording of Crystal played]

R: Quite a long story there. There's a lot to tell. You can approach this however you want. You may want to tell me similarities or differences in your experiences through Lenny's story.

B: There were quite a few similarities because first of all there is similarity with the condition because my son he's got ADHD and co-morbidities, which are other associated conditions you get alongside and he's quite extreme and quite often Asperger's and autism are linked ; similar conditions on the same spectrum. So I identified with a lot of problems like with school.

My first thing would be the diagnosis when I realised when he was really young something wasn't quite right. Looking back I can actually see that even when I was pregnant he was really, really active in the womb. I was telling the midwives I was having movements. I think it was way before 4 months; it was my first baby I wasn't sure when you should feel movements but I'd got a background of working with children and I was saying I was feeling movements and they were looking at me as if I were stupid. 'You shouldn't be feeling anything yet,' sort of thing. I believe it was really early so there were signs there. He was really, really hyperactive and he was about, I'd say...he wasn't a bad baby 'til he was onto his feet. Once he was toddling around. One thing that I've noticed with him. He never crawled. He just got up and walked one day. I just thought, he was coming up to just one and we were trying to stand him up on his own and he just got up one day and kind of took a few steps and me mum and I looked at each other and that was it. He just didn't go through a crawling stage. He used to get, I noticed if I gave him more sugary things or things with lots of e numbers he seemed to get more hyper. So I started looking at more what he was eating and things like that. The health visitors from young knew from speaking to me and the way he was, he was very very bright, really intelligent, really forward for his age. He could have a conversation with an adult from the time he started talking; they recognised that. So he'd never sleep I used to sit up with books and things and try to read to him and I looked really atrocious I was underweight, I had bags under the eyes cause I wasn't getting any rest or support. I was a single parent as well so all these things: he wasn't sleeping, he was really hyper, he started doing naughty things and I explained to him no, he wasn't listening. He'd still repeat behaviour where as I'd brought up lots of children and I'd not seen... I knew right from very young. I'd helped to bring up all the other children in the family. I'm the eldest, brothers and sisters and cousins and I went to work with children, so I thought straight away something's not quite right. I realised he was really bright but the behaviour side something was going on and I'm not really a parent that should have been happening. People were saying to me, 'with you I'm surprised he's like that. He's not like you. It got to where he started getting more aggressive with his behaviour and when he was playing with other children, say you had a toy or car on the floor he was playing with, he didn't really play. If it couldn't do what he wanted it to do, he'd break it, then obviously couldn't fix it together and get really frustrated he' started being funny with what he was eating, he

wouldn't eat lots of things . No matter what I did, he didn't seem to get better. When I mentioned it to the GP something wasn't quite right, he was really unsympathetic. He said, 'oh well he's bright. I used to be like that. You get this with bright children.'

R: How old was Lenny then?

B: The first time I went he must have been... I'd obviously got the health visitors coming in and then when they stopped coming when he was 2 or 3 year old he was really hyper, the GP wasn't really saying much apart from , 'he's healthy, he's fine , he's not underweight or anything. He's a bit active and he's very bright. You get this with bright children.' Then it was... I was looking for some support and I rang up a support group for hyperactive kids. There wasn't one in my town but after speaking to this lady on the phone she said he's definitely hyperactive , she said , 'I agree with you there is something else , his behaviour that's not just down to hyperactivity.'

R: Was this a health or social care professional?

B: This was just a lady who ran a support group. I'd managed to get hold of her number and I found this number of a lady who lived in another town and I didn't know anything about her apart from she ran a hyperactive support group. She verified that he sounds hyperactive and you're right there is something else but she wasn't sure what that was.

It was then a case of going round and round in circles. He started school and there were problems at school. He was aggressive with other children. He couldn't sit and concentrate. He couldn't sit and listen. When the children were sat on the mat at story time, he didn't want to sit down on the mat and things like that. He did like riding on the little bicycles outside but the thing is there were only so many bicycles not enough for all the children and that's all he wanted to do the whole time he was at the nursery. They were trying to teach him to have a go but to let another child to get on. He didn't want to do anything else, I think what it was he didn't want to sit down and listen to a story but the bike was something active and he wanted to be riding it around. They kept calling me and saying, you know, he's done this today and he's done that. I constantly thought everyday what are they going to say today. They was quite shocked when I first took him as I asked what they do with them as well as just playing because he was really bright and by the time he had gone to nursery , he was already

trying to read and write and his speech was really good. He could recognise his name and he was trying to form the letters. They looked at me like as though they didn't really believe that. They didn't expect them to do that at that age. 'We don't really do anything like that with them.' So I said, 'I don't care, that's fine'.

A lot of the time he was bored, things just carried on and escalated. I didn't find out what was wrong with him for a few years and he was actually 7 before he got the diagnosis and we had a psychologist that came into school and did some tests on him and things.

R: What prompted that? Did you prompt that or did the teachers?

B: I just kept saying there is something not quite right but no-one around was listening: my GP wasn't listening, people at school weren't listening, the people who did special needs and things like that. They were saying things like, 'he's bright and he knows right from wrong. There's nothing wrong with him, you know. If he's so bright then he obviously knows what he's doing. 'I was trying to say 'there something not right but I didn't know what it was then.'

Before he was diagnosed I did get hold of some information. My auntie passed me this sheet of paper she'd come across because when her son was young he was not exactly the same but he was a little bit on hyper side, a little bit aggressive but not as bad as my son. She sort of pin pointed additives and sorted that out but there was a problem with him being aggressive. Back in those days, no-one had heard of ADD disorders and they were put down as naughty children or whatever. But in every other way he wasn't a bad child. So any way this piece of paper she gave me it had very little on it but it said, 'Do you think your child could have ADHD?' and it had a couple of the symptoms and then bells went off in my head and I thought sounds like what he's like. I started looking into it more and study it and the more I learnt about it, the more I realised this was what was wrong with him.

All the things at school saying he couldn't concentrate on a task but if the class was working on a piece of work for the whole morning, he could be working on the same piece of work but be easily distracted so instead of getting on with it and staying on task he'd be out of his seat. If someone said something to him he'd be going over to them saying, 'what did you say?' He'd be caught out of his seat. Where the other

children were watching the teacher and doing things behind the teachers back, he didn't have that kind of way of thinking. If someone came and whacked him on the head say, he'd get up and probably go and do the same thing to them, justifying that 'they've just done that to me.' He'd go and confront them but he'd be the one caught by the teacher. He didn't have that sort of social cues that people have to watch what the teachers doing. Where the other kids would be doing it behind the teachers back he didn't do that, he didn't care, he just did whatever. He'd be talking, looking out of the window, but the teacher would say 'he's a very bright child'. He could do the work no problem he found it easy, he could do it in 10 minutes, so what the whole class had taken the whole morning to do, he could sit and do it in 10 minutes. It was just keeping him focused and on task in his seat. So there was that kind of thing going on.

Again when I went to the GP, because I kept going back saying something's not right, He didn't really listen. But there was a local clinic, a baby clinic and there was a doctor there and I went and had a word with the health visitors. The health visitors were well aware of the situation and felt sorry for me because he was such a demanding baby and he continued to be demanding and bright but still wasn't sleeping as he got older. Although I'd stick to bedtimes; I was quite firm with that, it still wasn't working. So they recognised there was a problem; the GP wasn't listening to what I'd said. So when I went to clinic and spoke to this doctor, they listened more; it wasn't 100% about ADD and he should be medicated for it but they did listen more, more sympathetic and because they worked in the clinic where the health visitors they knew there were problems there. And what happened is was this doctor gave me a referral. I had to go above my GP's head to get to the consultant at the hospital because I asked if she could help me. They did that. He was 7 years old by then and I'd struggled for 7 years and by the time I'd gone there I'd researched this at University and found out all sort of information and the same health visitors and people like that started asking me to speak to other parents about this problem but at first all the professionals didn't want to listen because they were saying 'don't say that, we don't know about that, go away, ' they didn't really want to speak about it. These children who have behaviour issues and hyperactivity wasn't a real condition and have anything wrong with them.

R: Why do you think that was?

B: They didn't want to accept it. And because most of them had never heard of it, come across it, had any training in it or anything like that. They just saw these children as naughty and the parents as bad parents or something. For some reason they didn't want to listen it could be something else, some medical condition. But then they sort of started to change their minds. What did it was I did a bit of research into it and then was something out in the media at the same time and it brought it more to their attention and people were talking about it more. There were a few programmes on tv where it showed the children trying to get diagnosis, visiting people and not all the parents were bad parents. There was something going on. I think I went back to those people who were dismissing me and they said you've been going on about this for a long time to us. But once I'd got the diagnosis, I found people did listen more, but when I went to the consultant, I said, 'this is the situation, this is what I've done, I've studied it. I think this is what he's got because I could tick everything on that list, all the symptoms, characteristics, it's quite extreme, he's hyperactive, I still think there's something as well.' In time I found out was he had another condition alongside it one of the co-morbidities of ADD which is ODD and slight Tourette's; the main thing the ADD. The consultant said 'I think you've done your homework and I think you're right and I agree with you. This is definitely what's wrong with him.'

I believe this consultant was the first in my area to diagnose and what I did was set up my own support group to try to help other people, phone line, 24 hour help line. I've been doing this work ever since then. I helped set up services in NHS with children and now I'm helping to set up service with adults as there isn't anything for adults. I just sort of, it was at that age of 7 and I got the diagnosis everything started changing. I found a lot of people still had their own views on it and didn't want to be educated and didn't really want to listen so much but it was getting slightly better.

I didn't get any support with school we had psychologists that came in and they just said... When he was 3 or 4 years I took him to CAMS child and adolescent units. He got tested there and he was supposed to see a psychologist and the top person a psychiatrist as well and I explained he was a bright child, he was hyperactive and I thought he had something else wrong with him, and by then, possibly ADD or something else going on. He just looked at me and said, 'how do you know that?' I wasn't surprised at that as I'd had that from the past with my GP and other doctors. He

said, 'you leave the room and I'll see what he's like.' So he was in there for 20 minutes half an hour or something on his own and when I went back in the consultant had drawn all these little stick men of my son and he gave me them one at a time and went, 'here's Lenny standing on the chair. Here's Lenny standing on the desk; here's Lenny on top of the computer. There were all these stick men swinging from curtains, you know, he gave me all these pictures and said 'you're right; he's definitely hyperactive. But he's very, very intelligent. He did something with him called the Welcher scale intelligence test. He came out in the 98th percentile, in the top 2% of the population of his age. He basically blamed school, it was the school's fault he wasn't learning and he was a really bright child and they couldn't deal with that. He didn't diagnose him with anything else apart from very overactive. He didn't even use the term hyperactive. He said he was an overactive child and very bright. That's all he said. So we didn't get anything more from there.

The GP still did nothing even after diagnosis. My GP is one of these who doesn't really believe in this disorder. Certain people, he's got his own view on it and I don't think he's willing to change on that.

As he got older, things didn't get any better. I tried to contact people with similar problems. I couldn't find anyone. I didn't know anyone with a child like mine. I was having lots of problems; school ringing me every day. As he got older, he was getting scolded a lot. They recognised he had potential but couldn't get him to sit down and concentrate. He was always getting excluded or sent out of class, things like that. If someone said something to him or did something to him, you know, argue with him. There didn't seem to be anyone at school that understood about it. Because even when we'd got the diagnosis I went back to school and said 'this is what's wrong with him and I can get information for you and even information for teachers, things like that,' and they went, 'oh yes fine.' Some people didn't want to listen; some teachers said 'I know all about children with behaviour problems, I've been teaching for 20 years and I know what I'm doing.' They didn't want to know there was a word for this, there was a medical condition, he's not just being a naughty child, I'm a good parent. They never said after all this time that I was a bad parent. School said to me they wished all parents were like me. I was very supportive trying to work with school. They'd tried lots of things but still didn't accept he had a problem and they didn't really

take the advice you get for dealing with ADD in schools. They were doing their own thing.

R: Why do you think that was? Were you giving them the advice?

B: I think because I was just a mum , you know, I wasn't a professional, I wasn't a doctor, I wasn't a teacher and I think they just thought, 'what does she know. I'm the teacher I know how to teach people in school even if they have behaviour problems.' But the teachers that were willing to listen , I gave them information and there was a couple who used that information so when something kicked off in the classroom they used the information I'd given them and it worked and they came back and thanked me and said thank you very much. But it was very, very few. In all these years, it was maybe three teachers who'd listened to me and if you think of the amount of schools he's been to and the teachers he's had. At one point I couldn't get him into a school. I'd moved house and needed to get him into the local junior school ; he wasn't there that long before he moved up to the local high school but the head teacher at the junior school, I went and spoke to him and said, 'my son's got this condition, he's been diagnosed . I'd actually been part of, at that point , I'd got a support group together and I'd got all sorts of professionals on board and we'd help put together a booklet that went to all the local schools on how to deal with children with ADD . The problem was none of them seemed to adhere to it really and so I did mention this booklet and if they wanted any more information, or if they wanted to speak to other professionals, I could do that and the headmaster just looked at me and said, 'well it's only people who come from certain backgrounds, that have children like this; they come from council estates and backgrounds like that.'

I said, 'I don't have time to sit and argue about that but you are totally wrong. It's not that just that class of people who have problems.' I actually have genned up on this subject to help my son. I've actually gone out and helped lots of people, had lots of people ring me for help and support and most of those people do not come from that background. I've had doctors ring me, psychologists, university lecturers, couples that one's a nurse and one's a doctor. Most of those children were coming from two parented working families with other children who didn't have a problem. It shows it's not the parenting skills, it's the child. I didn't have time to say this because again he was one of those people who'd got his idea on what he thought the problem was and

that was it. The educational psychologist we had at that point was really supportive of me and when we moved to the area, he knocked on my door with another colleague and said, 'oh, I hear you are the person to talk about ADHD. Can you fill us in?' That's how I first met them. My son was about 9 then and from that point, he was the one for that area and he was my son's educational psychologist. So he tried to come to meetings with me, and say to teachers or whoever was involved and we'd have these meetings and say to them, 'I really think you should listen to her. She knows quite a lot of what she's talking about. She's got a lot of knowledge in this area. But I think they just kept seeing me as a mum who didn't know anything. He got frustrated and they wouldn't even listen to him really. He knew what he was on about. It was really hard.

He got to where he was excluded from schools and I had to fight to get him into other schools, EBD schools, which were special schools that could deal with children with those kind of behaviours. Some children have problems and they haven't got a disorder; there are various different reasons why. I got him into these schools but things didn't get better. In those schools, although he's really bright he's not reached his true potential academically because they seemed to focus more on behaviour in those schools and not on the education side. Although he eventually passed quite a few exams, he didn't get high grades in anything.

When he came to do work experience when he was at school, I think he was supposed to spend a week in one place and then another time he was supposed to spend a week somewhere else and on both of those jobs they got rid of him on the first day. They didn't really want him there. He was doing silly things and because one thing that people with ADHD, they take risks and do things without thinking and they are impulsive and hyperactive and he was doing that in the workplace which can be really dangerous. So I think in one job, he was supposed to be sorting something out and there was some bags of things piled up in a corner somewhere and he was just diving into them and there could have been anything in them to injure himself and he was laughing and all his friends thought it was funny. He was jumping from one thing to the next like a conveyor belt or machinery, because one thing as well with them is there is up to a 6 year developmental delay. So if you take 6 years off his age, he was very, very immature. He was really up to the full extent of that, you know. When they

were saying it's up to 4 years, I was saying give him more because he's very immature and now more recent studies say it's more like 6 years delay now, which I've always known with him. Take this off his age you're about right with him when you speak to him and his understanding. So there's all that gone on and other people don't understand. School, I found, wasn't relaying that to people in the workplace.

No one listened to me as he grew up they were speaking to him and not checking with me. There were things I didn't know, situations he shouldn't have been put in, things I should have been asked but didn't know anything things happen and you only get to hear things down the line. When they leave school you try to get them in college. I knew he wasn't capable of doing anything. I didn't know what was going to happen and everything gets ruined. I can't explain. What happens is I work with careers say for instance, trying to get him into college, and because there is always more than one person involved from school, or college, these people needing to work together for that to happen. At that age, they no longer want to talk to you as a parent, confidentiality thing, what does he want? At that point he was still like a very young child; he didn't want to go to work or college anyway.

R: How old was he?

B: Well, ready to leave school, 15, 16. He'd done work placements which hadn't worked out same day 'we don't want him back here.' He left school. I tried to work with careers. But they wanted to see and speak to him more than me. I tried to explain his problem and that really to get anything done they'd have to work through me more. He's forgetful; he can't keep appointments. If they said 'come and see me next Wednesday at 2 o'clock, he'd only get if I could remind him and I'll take him. He doesn't like interviews with people. If you've got an appointment with the doctor or anything, even when you see his consultant at the hospital, he didn't want to go in. He'd run off before we got there. If I could get him there, he didn't want to go into the actual office; he'd stay outside and play with things. He just can't sit down and have a conversation with anyone for more than a minute. He doesn't understand what's being said to him but if they say do you understand what is being said to you, he'll say yes and they take that as read and he doesn't. He'll come out and say, 'mum I don't know what they were on about.' I'll say, 'what did they say? Have you got an appointment or what do you have to do?' And he couldn't really tell me. He'd be off.

So this kind of thing was happening a lot. I didn't know what was going on with my son. I wouldn't even say 18 is when they are adult but from when he's 16 he was being treated by these agencies as an adult where confidentiality comes in, 'we can't tell you this or that. Maybe if we've got his permission we can speak to you.' A lot of the time he'd say to talk to me and that was ok but then if he didn't say that they didn't speak to me. I found that most agencies he got involved with would only contact me when it had all gone wrong, for me to sort it out and things. So then they said 'yes we should have listened. You did tell us. 'But it was too late then. There are lots and lots of instances I could talk about.

R: Why do you think they wouldn't listen to you?

B: I think they just... when someone's 16 and leaving school most people at that age are quite able to speak to a careers advisor or anybody, a doctor or consultant or whoever but he couldn't and they didn't seem to understand that. I used to say 'I'm here if you want support', you know. I used to explain the problem he has but it wasn't always listened to. They'd always speak to him, they needed to speak to him and then if I questioned that it was always, 'well, confidentiality laws; we can't really tell you anything.' One thing with these children who have ADHD is they can follow the wrong crowd and get onto trouble. It's quite common for most teenagers to get in trouble with the law. I went through that as well.

Again it would be recognised I was a good parent and my son's got a problem, but again it's not taken on board. There is no laws and things just seem to ... he could get arrested for something and I might not know about it. If he doesn't say, 'ring my mum' or something. He doesn't know his rights. He doesn't know what they saying to him. If they say have you done this, he'll just say yes, He might not have done it. It's really difficult. Sometimes he might not understand what they are saying. He'll sign things without reading things, and that's happened a lot. 'Well he's signed this'. But it doesn't mean he's understood it. He's old enough to sign things especially once he's 18. I found that from when he was 16 that was happening. There didn't seem to be anywhere I could go for advice or help. Even solicitors haven't listened to me. I've given them information, I've given them case studies, people they can contact, professionals and it's all been ignored. In the court room, no one understands why they may have done this or what has led to this. What happened a lot was wrong

place, wrong time. Quite often it wasn't the person who had done anything wrong but he was there and people used him as a scapegoat or he'd play a small part I but he was quite often the only one to get into trouble for it. So that kind of thing happened a lot. Frustrating to explain what had happened and he'd take the wrap for it.

R: You're saying that the support you've had was from where?

B: Everyone said we sympathise we recognise he's hard work but nobody knew what to say to me, nobody knew where to send me, there was nowhere to go. No doctor, no psychologist. No one that could help me. Social services didn't offer me any support either. I tried ringing them when I got to the point I couldn't manage in the home anymore because he was getting more violent. You've got the ADD behaviours, then you've got the hyperactive side you've got the ODD where they are very confrontational and as they get bigger and older they get more in your face and basically entice arguments and you say it's black they say it's white. They get really aggressive and if you've got other children in the house it's not good. Things get broken; they can kick off at the most minor thing. You may not know what sets it off. One minute they are alright the next they're not. You get mood swings they get frustrated easily; they get in a temper and don't understand social cues. For instance, if I'm somewhere in a room and your child is misbehaving and you give them a look and they think 'better behave myself', well they don't pick up on those things. Quite often it'd be silly behaviour especially when younger. People looking at him and thinking he's a big boy why is he behaving like this. For his age, it wasn't appropriate that kind of thing.

R: So you have got similarities to Crystal in her story, because she said when Luke turned 18, things changed. Although you found it at 16

B: Yes I found it earlier. At 16 it got impossible. He couldn't be dealt with in the home anymore we found him a support home, a 24 hour flat he could stay in and I thought he could stay at home but when he was kicking off he could go there to calm down. So I tried to sort that out for him because at this point no family wanted him. They'd [friends] say, 'we love you coming round but don't bring Lenny'. It was really hard. He'd have friends but he'd fall out with them so I thought this would be a good idea. Not totally saying here you go but, you know, he'd have somewhere else to go basically.

At that point I didn't see myself as a carer when I first had him. I had to give up work to look after him. I was just being a mum trying to cope and he was a good age before I could claim anything and call myself a carer.

What happened was when I got him into this place and he was quite happy about it, they messed up all his benefits and my claim, carers allowance ... I was made his appointee; he can't manage money, he wouldn't feed himself. Just the normal bills, food, that kind of thing and they'd come out and said your mum has to do this side of things for you.

So I'd explained to these people I was doing that and I was still classed as his carer even though he wasn't with us for all the time and they messed all that up. They tried to make a claim ... They said they had done this before. They got his birth certificate and personal papers. He didn't have the sense to ask questions and they did a lot of wrong things.

R: Who were they?

B: It was an organisation that houses people with various problems. It could be a young teenager who is pregnant; someone who'd parents had thrown out; someone who had got into trouble.. It wasn't local authority. It was some sort of housing agency. But it was somewhere where they dealt with young people and they had an office and someone there 24 hours so they were never alone. If any of the kids had a problem they could go to them. I think they took from 16-23 and probably were all homeless for various reasons. They helped them to get on their feet. They helped them to deal with the bills, how to look after their own home; claim benefits, help them fill forms. I thought it was quite good 'cause I'd been doing all this and knew he wasn't capable. But I thought they would help him be more independent as well. Take him shopping. I was still there but it was nice to think someone else could be there for him.

None of that really worked because they ended up taking over, telling him, 'you can claim this yourself your mum doesn't have to do this and you can just go and say you are estranged from your mum and you know we'll take you down there. Get this and that like birth certificates... If you do that we'll go down and ...'

They weren't exactly being truthful and my son didn't ask why did they want this and that. Obviously it's my son's paperwork I'd kept in order and I thought he's old enough, 'if you need this, here it is.' But they were being underhand and everything had been sorted out and they messed it up. He lost his benefit and I'd given up work to look after him prior to this and I was on benefits. My benefits got stopped. They was trying to claim at a different job centre outside my town, so obviously it was being questioned and 'we've been dealing with him and his mum for a long time, what's goin on?'

So everything got stopped. He was left without money. I was left without money and I was trying to sort out with them. I arranged to meet with their manager. I had a friend who had a son with the same disorder and she'd also set up a support group in another town and we've been friends for years now. I got her to come with me and it was appalling. There were three guys in there and they were really aggressive and intimidating and the way they were speaking to me was aggressive and I'm glad I had my friend with me but the manager said hang on a minute. He was really just quite, some people would have found him really, really scary and I thought no, I'm saying what I'm saying and I stood my ground with him and he seemed not to like that even more that I stood up to him and said 'excuse me but this has happened. I explained this to you before and you've ignored what I said and now my son is in this position and I'm in this position.' And basically they just fobbed off everything I said.

I had this kind of thing so often when things go wrong and I try to sort it out it still doesn't go my way it still goes wrong and I find I'm always trying to sort out these situations for my son and these people don't want to listen and don't want to be educated. They just storm in and do what they want and don't recognise that I've got things in place for him and you know, even family and friends don't understand what it's like to bring up a child with this disorder and then an adult. It's a bit of a myth because a lot of people think that they grow out of it at 16 and they don't so you are always a carer, always a mum, always dealing with problems.

It's really hard when no one listens to you and these agencies don't seem to communicate and work together. I mean when he was at school they'd bring in someone from different departments whatever, psychologist or they have someone from careers but they don't seem to speak to each other. Some families have social

services involved or other agencies but they all do their own thing instead of working together and what I've found is that you need to use a multi model approach where everyone is working together and singing from the same hymn sheet. It doesn't happen and that is what needs to happen really for people to get the help and support they need.

R: Have you ever experienced that?

B: I've never ever experienced that. I've had people that have been sympathetic. For instance social services across the board don't offer support for a child with behavioural problems. That was what I was told. It was getting to a really bad state kicking off. This was one of the problems I had when he was 16 and it was his choice whether he took medication or not. He'd never liked taking it. I tried not to put him on medication; I'd tried everything before I did that. Because he was so extreme. It did help but it only took the edge off. School was saying they wouldn't teach him without his medication so it was a case of trying to get him to take it. School made an issue of it. He didn't like that. They'd shout out in class, 'oh it's time to take your medication', so he didn't like that. And rebelled against the whole thing. So when he was 16, they were saying to him it's your choice, he's never taken it since. So obviously he's got worse. It's just a case of he's an adult now and I can advise him but he doesn't have to listen to me. He just seems to bumble through life, doing his own thing and getting into lots of problems and I'd never hear until it's too late and I try to do what I can but it's quite often too late. Whatever has happened has happened. Whatever the situation, that's it usually. People never listen really; they are not interested in listening. People with ADD because a lot of them are quite bright and you can have a conversation with them people think there is nowt wrong with them, you know, it's just not the case.

I think the solution for a lot of people would be to speak to the parents even when the kids are classed as an adult. They're the experts to me; they are the ones who know the child best; they know what works best with them; they know what makes them kick off. I can't cope that no one wants to speak to the parents once they're adults; it's confidential and they won't speak to you. Sometimes you have children who will say, 'don't speak to my parent, deal with me.' So if your child says no, you can't do it. Sometimes they will say that especially if it's to do with managing finances or support

in some way or something they don't want to do or something they can't do themselves and you have to let them do it; confidentiality and they're over 18 you've got no rights to be involved in their business. It's seen as confidential. People they are working with don't want to work with you; I've come across it in housing ...

R: Would you say you were Lenny's carer or would you say you are Lenny's mum?

B: Well I always see myself as a mum first to my kids. A lot of my friends' kids come to me and call me auntie. I'm everyone's mum : I'm quite mummsy but with my son I'm very much a carer and I can't step back from that role because there is always something to sort out. You know.

R: Do you say that to the professionals? Lenny is obviously happy for you to be there.

B: What's happened more recently is that I'm not involved with anyone. It's only when there are issues and he comes to me and I say, 'well you have to get this person to contact me. It's your personal... Unless you tell them, I can't do anything.' So then he might forget to tell them or I get a phone call from them 'cause things are in a bad state. They say, 'der, der, der, der' and I'll explain, 'I'm his mum and I've always been his carer and always tried to work with people but if you don't contact me, I can't do anything.' Quite often people contact me when it's too late. He doesn't see that it's not. All the things he couldn't do when he was young he still can't do. He still can't manage money; he can't look after himself properly; trying to find his own housing or flats but he always ends up back home or for whatever reason he loses them because he can't cope. But the people who are doing that; the housing people or anyone that gets involved with him at the time to support him, end up not wanting to support him, because they can't engage with him and he ends up losing his house, flat or benefits. He can't go to college; he can't work; he's managed to find jobs but he loses them the same day; they don't want him back. I've come across people with ADD who can do that but he's an extreme case. I don't know what the future holds. I just continually come across people that don't want to speak to me unless he says to speak to my mum because he knows I'm the one who will sort things out. I still don't know what is going to happen. He's never had a place of his own for too long, he's coming back to me all the time, it's a circle. My health has suffered. I've got a younger child, it affects them as well. I've got her to focus on more now because he's an adult. He does have a girlfriend now and she says all the things I say, so she knows him quite well. I think a

lot of the time she'd like to say bye but she seems to be hanging in there but it's very hard for her.

R: You said social services said they don't have anything to do with Lenny?

B: They've never offered support with anyone who has a child with ADD. I've never had much to do with them myself after I'd phoned them. A lot of times you don't fit agencies' criteria for support for whatever reason. When I tried ringing social services when, with ADD when they get to the teens everything triples, everything is really really bad. You think your normal teenager is bad it's 10 times worse. Quite often that's when they are experimenting with drugs and drinks and getting in trouble with the police and lots of things. They think everyone is treating them like an adult no and they can do what they want. You lose that rein as a parent more and more and with a normal child you can do that but with a child with ADD who has got a 6 year developmental delay , and on medication , you know what they can and cope with. Parents have no control. You don't know what to do. It's difficult.

R: So if I could offer to you the opportunity to say what you would like to see. You did mention agencies working better together.

B: I think if there was a willingness to be educated. My point is that social services for instance is a big one because if you speak to anyone involved with ADD, any professional or parent you can't reach social services because everyone has had a bad time with them , who's been involved with them . as I've said I've got other colleagues that work in the same field as me and they are constantly going to tribunals of people fighting for kids with ADD that have had their children taken off them by social services or threat of that . It's not that there is a real problem there it's just that the child has ADD and they are not recognising that. What the children are doing, it's because they've got ADD and it's not because the parents are doing anything wrong. They constantly... that's their work. They are constantly being asked to help people. Professionals in the ADD area say social services are just not doing what they are supposed to. Those are the people that should be helping people in this situation and they are not willing to be educated at any level. I've offered to educate them to do what I can and it's been refused.

R: Who did you offer this to?

B: I went to social services disabilities team ; I've spoken to people in children and families; I've spoke to people at university that teach social work courses; and for whatever reason they've not , you know. I'm actually now ... What happened was I had to give up work to look after my son. I've always done voluntary work, 20 odd years of voluntary work and I'm classed as an expert now in the field, but these people still don't want to listen and they don't want to be educated and I just think they need to listen more and open their minds. Once people are willing to listen and be educated, they normally realise straight away, this is a real condition and these are the real issues and how it impacts on the family life and outside that as well.

R: So to improve care and to help professionals work together more effectively, they all need to be knowledgeable and willing to listen to mums, dads, carers..?

B: Yes definitely. Whoever the carer is, whether it's the parent. Obviously when they get older as well, it's not just the parents. They may be trying to have relationships and that's quite difficult. Whoever they are involved with really. You've got housing, benefits, or jobs, relationships, you might have children. My son hasn't got children yet but I'm dreading that. He's going to pass that disorder on as it goes mainly through the male genes so I am prepared that when that happens, I'll be going through that all again, because there is a high chance his children are going to have this disorder as well. You've got all the medical people, the child care people, the teachers, doctors. If they get in trouble with the law, you've got the courts, police, lawyers. There are so many people and none of those people are educated, how can they help you. If you are not even willing to listen to parents

R: Why do you think all these professionals aren't willing to listen? In your view, what can we do to make them listen?

B: Training. One of the jobs I do now is the training and if you get in when people are going through training to be a child care worker, doctor, nurse, psychologists, teacher. If you put that into those training that's where you need to get in really and educate from the beginning as part of the training. I think part of the problem is these people were never trained so to them this doesn't exist, And they form their own view and it's classed as an unrecognised condition and although it's come more recognised, it's been recognised by NICE , people still stigma, people have still got their views . Social services is the main people that need educating.

R: Is that where we need to start?

B: Yes.

R: Is there anything else from Crystal's story that you haven't mentioned that relates to your story?

B: I could talk all day. There are so many things. Education, diagnosis, services. It didn't come under mental health so there was nothing available. Now it does but some people don't recognise it as a mental health problem so for instance I've been in touch with social services because they refused to work with us. Even though it comes under mental health, they still won't work with us. I don't understand. I've said to them it does come under mental health but they still ... They said it doesn't come under their criteria and so we need to get it in there somehow. You've got similar conditions, autism, Asperger's, dyspraxia, dyslexia; those are all hidden disabilities and have problems with. But out of all of them ADD is the worse because people don't want to accept it.

In this story, Crystal's, it mentions there have been various care managers, social workers and other people involved. Like I say, I've tried to find him workers, there's lots of organisations to work with but it just doesn't seem to work very well. If he can't turn up for an appointment, they take him off the list and say well he hasn't turned up for 3 appointments, so we can't do any more for him. And then he's left with nothing. When he got to 16, he's not under any service for his medical care, children's services finish at 16. I actually helped to set that up but there's nothing after 16. I've concentrated trying to set up adult services which has now got funding for this area, but again, he's got to go to them and say 'I want your help'. I can't do that so he's out there with no help. I do all this work but it's for him as an adult to say 'can you help me'.

R: But as you were saying it would be more helpful if it was the professionals and other agencies out there recognised those needs?

B: Yes and quite often you may ring any agency, housing say, you may get that one person who off their own back is fantastic but an organisation as a whole don't put this in training; they don't seem to link with other people. Say you've got a child at school, all the agencies involved, LEA, social services, medical people; they are not

talking to each other. They are all doing things with the same child but none is talking to each other. Most are not educated in the disorder. I'm willing to tell them but they don't want to listen. It's really hard. They need to work together, I think it's needs to be somehow built into their training; education is the key. Really listen to carers because they do know what they are talking about. Quite often carers are ignored.

It mentions a dietician in Crystal's story. I went down that route because a lot of people say it's the diet. I've been down that route with the hospital dietician and that didn't make much difference. I've worked with a lot of different professionals and no one's ever really been able to help us. A lot of people sympathise and go 'I really feel sorry for you but there's nothing we can do. We don't offer services for that kind of thing. So throughout his life, I've always done this work to get services out there for people with this condition. It's never come in time for him, maybe helped other people so that now people can get a diagnosis when the child is young. We couldn't get that. The consultant that diagnosed him had never diagnosed anyone before. He was the first one as far as I know as I did ask on the day. So I didn't know any other parents, support groups; I had to go on a mission.

R: Do you think things have changed?

B: Things have changed. Things are getting slowly better but to say I've been doing this for all these years, things haven't changed that much. We've been fighting and fighting and they've been saying 'no, we are not going to do any services'. I managed to get them to listen to us but it seems to be a really really slow process and there are lots of towns that have not got anything and places that do have something, it's normally the carers and parents who have got together, provided that or have gone on at professionals to provide that and I think more still needs to be done. There is no services for adults and lot of adults have turned to self-medicate with drugs and alcohol and you get problems with that. Parents of children with same disorder. We're finding quite often they've been given wrong diagnosis of psychosis, personality disorders. Things like that and it's been ADD and they've struggled with life. There's lots that still need to be done but there are still professionals who need to be educated and listen to carers and then communicate with each other. So the same care package is being delivered to the one person. Everyone is not just coming from their own bit

and that's it, because that doesn't work. You need consistency; everyone doing the same thing.

R: I think we have come to the end of the interview. Is there is anything else you want to add?

B: I could have talked because I'm used to talking, but for someone else it's really, really good this, because it triggered quite a lot of things for me. Like she said she had a son with Asperger's sitting at home doing nothing. That reminded me of something because we can't get him to college. Her health was obviously affected and I was in a similar position, I've got a daughter who's you know, has health problems as well. Totally different from my son. I've got mine. I've got some people with severe problems and do a little bit of caring for them when I can. I've got an Uncle with Parkinson's and another that's had stroke and can't speak. I've got someone else with polymyalgia, my dad almost died last year and I had to fight for him. I'm surrounded by illness and I do a bit for others but my son is my main one. This triggered a lot of pointers, medical, schooling, work, I've got the same problems. People around you generally don't understand. They don't see it.

R: Anything else? Ok? Thank you very much for taking part.

[Tape recorder switched off]

19 Appendix XII

Re: Application for ethical approval

Bill Campbell [W.Campbell@mmu.ac.uk]


Sent: 03 March 2009 11:48

To: Julie M Wright [55071137@sylar.did.aca.mmu.ac.uk]

Julie,

There's no significant problem here. The reviewer of your RD1 identified a potential ethical issue in that the care organisations that you may wish to access as part of your phase 2 could expect you to obtain ethical clearance from them. Since these were not identified in the RD1, you may need to obtain ethical clearance before commencing phase 2. FAEC would like you to inform us in due course of your intentions in this regard. If ethical clearance is obtained from any other organisations, we require written copies of these.

This does not prevent you from commencing the study.

I'm at home tomorrow if you want to discuss-- 

Best Wishes

Bill

Dr. W. Campbell

Head of Department

Continuing Professional Development and Postgraduate Studies

Faculty of Health, Psychology and Social Care

Manchester Metropolitan University

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>>> Julie M Wright 02/03/2009 12:49 >>>

Dear Bill,

Please could I have more specific guidance on the request so I can respond appropriately. I believed I had included all the relevant information in the completed MMU Application for Ethics form and additional /supplementary information supplied.

Many thanks

Julie Wright

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>>> "Deirdre Connor" <D.Connor@mmu.ac.uk> 03/02/09 11:33 AM >>>

Dear Julie

Thank you for your application for ethical approval.

In order to respond to the observations made by Professor Mitchell in his review of your RD1 application, will you please inform the Faculty Academic Ethics Committee of the details of the local carer groups/organisations that you intend to contact as part of

stage 2 of your study.

A description of how you propose to address ethical issues and obtain their support is required.

Many thanks

Dr. W. Campbell

Chair, Faculty Academic Ethics Committee

Deirdre Connor

Faculty Research Administrator

Extension ****

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