Narratives of Identity & the Informal Care Role

Kip Jones
A Thesis submitted to the Faculty of Health & Community Studies,
School of Nursing & Midwifery in Partial Fulfilment of the Requirements for the
Degree of
DOCTOR OF PHILOSOPHY
De Montfort University
Leicester U.K.
September 2001
Abstract

Questions of continual and/or repetitive informal caring and the part childhood, development and personality play in adult caring roles form the background of the research's focuses on why individuals gravitate toward the informal care role and why they continue to care in the face of overwhelming obstacles. The investigation explores how informal carers create meaning in their everyday lives expressed through actions. Biographies are seen as representations close to those actions, therefore, a biographical narrative interpretive method is proposed to address the questions.

The informal care literature is reviewed, exploring the geography and etymology of terms in the British and North American literature. Meaning, well-being, gender and personality are then reviewed. Concepts of care, informal care and carer identity are bridged, leading to personal histories as a method of discovery. An interpretive narrative approach is underpinned by hermeneutics, or interpretive phenomenology. Approaches to personality study are then explored and a constructionist social-psychological framework is argued as the foundation of the thesis. A biographic narrative interview technique is put forth as the key data-gathering event and a reflecting team approach proposed for the interpretation. Ethical considerations are discussed.

Data from seven interviews with informal carers are presented, describing the participants’ lived lives followed by the researcher’s reflections on the interviews and post interview process. Analyses of the data from four of the narrated biographies, by means of a reflecting team process, are considered. Returning to the initial research problems, questions and hypotheses, conclusions and implications are discussed, delineating implications for theory, policy and practice in the informal care sector. It is argued that these carers’ narratives, including their childhood experiences, offer potential for meaning. It is hypothesised that often-unmet childhood needs propelled these particular individuals into demonstrating those needs as adults by assuming informal care roles. These case studies of informal carers’ personally narrated lives extend the social psychological study of identity and contribute to the field of informal care research.
ACKNOWLEDGEMENTS

My deep appreciation to the following people who made this effort possible:

DE MONTFORT UNIVERSITY FACULTY OF HEALTH AND COMMUNITY STUDIES
MIKE SAKS, DEAN
SCHOOL OF NURSING AND MIDWIFERY
MEL CHEVANNES, HEAD OF SCHOOL

EXTERNAL EXAMINER
ROBERT MILLER, DIRECTOR
THE CENTRE FOR SOCIAL RESEARCH
SCHOOL OF SOCIOLOGY AND SOCIAL POLICY
QUEEN’S UNIVERSITY OF BELFAST, NORTHERN IRELAND

SUPERVISORY SUPPORT
DENIS ANTHONY (1st), MARK JOHNSON (2nd), NAOMI WATSON (ADVISOR)

MENTOR AND ADVISORY SUPPORT
BROWN DMU SCHOOL OF ECONOMICS AND SOCIAL SCIENCE, MILTON KEYNES

ADMINISTRATIVE SUPPORT
SIRRON NORRIS-MONAHAN, MARY SEACOLE RESEARCH CENTRE DMU

BIBLIOGRAPHIC SUPPORT
STAFF OF THE CHARLES FREARS CAMPUS LIBRARY DMU

COLLEGIATE SUPPORT
VERONICA BISHOP, PRUE CHAMBERLAYNE, HARRIET CLARKE, MARK FREEMAN, DAWN FRESHWATER, KENNETH GERGEN, GÜNTER MEY, KATJA MRUCK, TINU OKUBADJO, RICHARD OLSEN, TOM WENGRAF

COMMUNITY SUPPORT
HAYLEY POOLE AND CLASP CARERS’ CENTRE, LEICESTER
FIONA GORDON, TRACEY JEFFERS AND THE WEST INDIAN SENIOR CITIZENS’ PROJECT, LEICESTER

PERSONAL SUPPORT
U.K.: ENID IRVING, SCOTT WOODS
U.S.A.: MARY FALLON, MRS. EDWARD JONES

ANALYSES TEAM MEMBERS:
DENIS ANTHONY, MANDY ASHTON, MARK ATKINSON, ROGER BETTLES, GIOTTO BONOMAULLY, NICKY BROOKS, BROWN, JONATHAN CARVER, VIOLET CHIDOMBWE, JIM DOHER, MARK JOHNSON, CHRISTOPHER MAGGS, FRANCES MAGGS-RAPPORT, BELINDA PLACE, HAYLEY POOLE, ALI RASHED, JENNY SMITH, DENIS WALSH, NAOMI WATSON

THE SEVEN ANONYMOUS INFORMAL CARERS WHO SHARED THEIR LIFE STORIES WITH US.
# Table of Contents

**TITLE PAGE**

**ABSTRACT**

**ACKNOWLEDGEMENTS**

**TABLE OF CONTENTS**

**LIST OF FIGURES & TABLES**

**FORWARD**

I. **INTRODUCTION**

II. **LITERATURE REVIEW** 9
   
   A. Introduction 9
   
   B. Mapping the process 9
   
   C. Unpacking informal care
      
      1. The geography and etymology of terms 10
      2. The history of informal care research 13
      3. The choice of terms in the literature 14
      4. Unearthing personality in the literature 20
      5. Exploring meaning and well-being in the literature 26
   
   D. Discussion 27
      
      1. Gender: the touchstone of informal care 28
      2. Conceptualising a genderless approach 29
      3. Towards redefining informal care 31
   
   E. Conclusions 32

III. **METHOD & METHODOLOGY** 35

   A. Introduction 35
   
   B. Justification for the methodology 37
      
      1. Beyond traits and types 38
      2. Theoretical explorations 39
      3. The narrative approach 42
      4. Hermeneutics or interpretive phenomenology 43
   
   C. Research procedures 46
      
      1. Choosing a method 46
      2. Biographic Narrative Interpretive Method 48
      3. Other narrative approaches 49
      4. Sample size 52
      5. The interviews 53
      6. The data analysis 57
      7. The reflecting teams 58
      8. Analogy of the analytical process 61
   
   D. Ethical considerations 63
   
   E. Conclusions 66
IV. PRESENTATION OF DATA & RESEARCHER’S REFLECTIVE WORK 69
   A. Introduction 69
   B. Carvings 69
      1. Polly Humberston 73
      2. Carl Humberston 77
      3. Mahesh Parmar 83
      4. Maureen Andrews 89
      5. Sally Green 95
      6. Sheila Conner 99
      7. Tansy Johnson 105
   C. Conclusions 109

V. REFLECTIVE TEAMS’ ANALYSES OF DATA 111
   A. Introduction 111
   B. Case Analyses 117
      Sheila Conner 117
      Maureen Andrews 131
      Polly Humberston 139
      Carl Humberston 147
   C. Conclusions 156

VI. CONCLUSIONS & RECOMMENDATIONS 163
   A. Introduction 163
   B. Contributions to knowledge 164
   C. Conclusions about the research questions 167
   D. Conclusions about the research problem 172
   E. Implications for theory 173
   F. Key concepts 174
   G. Implications for policy 175
   H. Limitations 177
   I. Implications for further research 178

VII. AFTERWARD, OR LATER 179
VIII. BIBLIOGRAPHY 185
List of Figures and Tables

Figures

Figure 1: British & American Literature on Caring .......................... 11
(Social Science Citation Index)

Figure 2: British & American Literature on Caring ......................... 12
(Medline)

Figure 3: “The Cry” by Edvard Munch ...................................... 29

Figure 4: “Alex II” by Chuck Close ......................................... 62

Figure 5: “Famille de Satimbanques” by Pablo Picasso .................. 75

Tables

Table 1: Rank Order of Frequency of Terms–Keywords .................. 17
British & American Literature

Table 2: Family factors involved in carers’ early lives .................... 170
This is a narrative. It is a story about a journey. On this journey, the landscape of informal care and the stories of a few of the people who inhabit it were explored. The landscape itself was, in many ways an indomitable mountain of information, constructed layer upon layer and over time, confounding understanding and forming seemingly inpenetratable complexity. Still, the journey continued because individuals occupied the landscape.

Initially, the first people observed were the researchers who lived in the landscape of informal care. (In some ways, lived off the land too!) Just behind and beyond the place that researchers occupied, slightly obscured in the initial view, dwelt the carers themselves. The journey’s aim was to ultimately reach the informal carers, bringing into focus valuable yet neglected aspects of their existences. Their everyday lives remembered over time were recorded in detail and how these constructions were experienced was reflected upon. In this process, the possible ways to get to know who the carers remembered themselves to be, how they describe themselves today and who they may become, were explored. Attention was paid to how it is that they say who they are --because time has ultimately changed who they are and how they express it. It seemed convincing somehow that by knowing who they say they are, understanding could be reached about why they do what they do and, by knowing what they do, understand who they are. This was a circle.

This was a beginning. Others might have transported you to this place by entirely divergent methods. They may have used their own unique map. They may have had different expectations of the journey and, therefore, other possibilities to explore. Such is human nature. This effort documented the traces of one person’s way of taking that journey. The possibilities in generating discovery always include the equal potential for missed opportunities, vistas, grand revelations and understandings. These are the risks taken when a researcher sets out to explore a new territory, or the little known. Similar risks are anticipated in setting out to explore more well-known terrain too. Through the process of unpacking the established territory of informal care, unravelling it, redefining it, reorganising it, old territory has metamorphised into a new horizon reconstructed from one particular view. Like a familiar song rediscovered through a fresh rendition, a personal reinterpretation of established territory offered the potential for renewed resonance, uncovering ground inadvertently overlooked through familiarity and the passage of time.
The first time I went to France (by way of winning a small prize) I was teeming with anticipation and a sense of adventure. I had never been away from my native America before and was filled with expectations. If I lived frugally, I surmised at the time, I would be able to stay in Paris for more than three months. I prepared for, consequently, the luxury of exploring Paris in an unhurried way that would allow the city and its occupants to reveal themselves to me in a natural, unfolding way.

Paris unveiled itself to me gradually. I spent a lot of time camped out in cafés, watching and meeting people. It was in observing passers-by that I particularly noticed other Americans on ‘holiday abroad’ charging from place to place, trying desperately to make all the appropriate stops at the necessary high spots of Paris, attempting to take everything in and doing all this within a very short visit. In the throes of this often-frantic process, my countrymen and women would frequently become quite annoyed with the Parisian French. Annoyed because they (the French) did not speak English, annoyed because their ways of doing things – their culture—was not the same as the American way. Surely they (the French Parisians) understood that they (the Americans) had a lot to accomplish in a short time and that they (the French and their culture) were only making the process that much more difficult!

The reality of the experiences of many Americans abroad is subsequently reinvented when they return home. Like art museum visitors who are more comfortable with the reproductions found in the museum shop (they can buy them) than the art in the galleries, the narratives of Americans’ trips abroad are typically reconstructed through photographs stateside. They are, habitually, not assured that their journey was a success until they get the photos back from processing and can reconstruct the story of their journey into a perceived reality. The defining moment, crucial to their reconstruction of reality, is the moment when they are reassured that they visited, in this instance, the right Paris. This is accomplished when family and friends agree that yes, they were at the right places because those were the same places that they too visited or certainly would visit. At last, after a long journey fraught with unexpected inconveniences, language barriers, unfamiliar terrain and food, peppered with what many American tourists misconstrue as the French penchant for rudeness, they can finally sleep restfully in their American beds. Paris was a success.

Paris for me was different from that. Perhaps it was the luxury of the time available to me to slow my pace down to fit the pace of Parisian life. Perhaps it was by finding the timeframe in which to generate discovery and allow Paris to reveal itself to me. I recall that at the end of my stay there, I did rush around to some of the tourist spots that I had never bothered to visit (even the Louvre, I must admit!) and snap photos of myself posed in front of miscellaneous monuments of French culture. I did this, ironically, in order to have photos to show family and friends back home. Yes, they too might wonder if I had ever been to Paris at all, if I had no photos of the places they had attended on their trips.
A few days before my departure from France my lover at the time, whom I had met in a Parisian café, said, “You haven’t even been outside of Paris the whole time you’ve been here! We must take the train to Versailles!” We departed the following morning, arriving at Versailles in a light but steady rain. We walked the crunchy gravel grounds of Versailles for a while, noted the long queues for the palace and made a dash back to the village of Versailles and a small bistro/café. We sat for hours at a table talking, just under a window, the rain beating its steady rhythm on the leaded panes. It was not exactly Madeleines dipped in tea, but it very well might have been. We sipped slowly these last moments, savouring them for memories. We both knew that the palace of Versailles would have to wait for another time; the pain of imminent separation was far more monumental than any French palace could be. I have been glad of that day since, and retell the story often.

When one approaches a journey slowly and with a sense of expectation at every turn, the journey is never really completed. Fortunately, I was able to return to Paris many times after that first visit. I believe today that it was the way I approached my first stay that provided the longing to return, the opportunities to return.

I proffer these Proustifications only to furnish the reader with a sense of the way that I embraced this journey here. In the retelling that ensues, we are travelling together and ours will be a dialogue. Sometimes purposely, sometimes not, I have allowed a metaphorically ‘blank space’ to encourage our dialogue. At other times, you may say, “Look over here!” and I might reply, “No, come see this first.” I have struggled to describe this project much in the way that Shotter (1995) attempted to describe Wittgenstein’s hermeneutic: “It is as if he is imagining us in a great landscape (perhaps with hills and valleys, cities and villages, and so on), but lost in a fog, trying to find landmarks, attempting to get our bearings, thus to continue with our projects – whatever they may be” (1995: 6).

Please know that although I have mapped this journey for us, a fact that may annoy you at times, my expectation is one of adventure and discovery. What has been excluded or ignored is only fodder for another journey or someone else’s map. The overarching conceptualisation of the work here was that it is a ‘story about stories’ and this is ultimately the ‘thesis of the thesis.’

Will the journey fulfil my hopes and expectations? Will it be an adventure and thereby lead to my being able to tell an exciting story at some point in the future? Or will it be mundane and banal, in which case I might still tell the story but feel compelled to dress it up a bit, perhaps for dramatic effect? The truth, again, is that I cannot say: I cannot possibly see in advance the story to which the present experience –later to be an episode—is contributing. In short, I cannot answer any of these questions until I’ve made the trip. This too seems to be so of our lives more generally.

Freeman, 1997, pp. 377-78

It is with a sense of excited expectation that this personal journey now is told.

-- Kip Jones, Leicester, September 2001
CHAPTER 1: Introduction
“Mapping the Journey”

Background
My interest in informal carers began with two previous research projects. In an investigation on HIV+, Aids and older volunteers in London (Jones 1992), I uncovered, quite by accident, that many of the interviewed volunteers had cared for adults in their younger years and that they continued to seek out caring roles throughout their adult lives. Next, in a study of owners of small boarding homes in Philadelphia (Jones 1995), I uncovered, purely by happenstance, that most of these ‘Mom and Pop’ small boarding home operators had also cared for someone in their families as children or teens. A secondary finding in both studies was that these informal carers did not necessary limit their caring activities to one person at a time, and some were participating in several care roles simultaneously, sometimes in two or more environments. Because of these fascinating facts, I wondered about lifelong, repetitive caring experiences and, particularly, what part childhood events played in later, adult caring roles.

Research Problem and Hypotheses
The provocative problems that developed as the base of my interests in informal carers since were:

- “Why do individuals gravitate toward the informal care role and, at times, even voluntarily seek out the role?” and secondly,
- "What makes informal carers continue to care in the face of the seemingly overwhelming obstacles involved?"

These research problems continued to be central to the questions motivating the research throughout a three-year process.

The assumption is often made in research on carers that the role is taken up reluctantly by most, a result of circumstance or by default. The first aim of the research is to look at the validity of this supposition. This research proposes that informal carers often choose to accept a caring role, based upon a complex mix of their personality and the personal, historical construct of their contextual background. To test this hypothesis, both micro and macro influences were examined through the exploration of the self-narrated biographies of informal carers. These influences included personality, self-identity, life histories, cohort effects, shared values and traditions, and family background and caring experiences.

Essentially, it is argued that the stories that carers create, elaborating the meaning of their lives, support their indications that caring episodes are often seen as positive opportunities and, importantly, are somehow identity affirming and self-fulfilling life events. These facts, in turn, illuminate the dichotomy of the hassles and uplifts of everyday caring and, generally, the enigma of fulfilment through a seemingly often-unrewarding role. Secondly, deeper biographic analyses also reveal that informal
Carers are often catapulted into caring roles because of developmental constructs in their earlier lives, particularly in their childhood and/or teen years. It is proposed that, because of needs that were unfulfilled in their young lives, carers continue to attempt to fill these voids by demonstrative behaviours that parallel their own care needs; that is, they often display, by their caring activity, the care that was lacking in their childhood in the first instance. This is the most singular finding of this research and makes a distinct contribution to knowledge in the field of informal care.

Methodology
The exploration of personality through a social psychological framework (Freeman 1984; Shotter & Gergen 1989; Harré 1993; Gergen 1994; McAdams 1995) provides the overarching concept that facilitated discovery and formed the foundation of this work. Rather than seeing personality as a static, stationary and unchanging component in caring, however, personality is considered as a dynamic and evolving influence, socially constructed. There are strong indications that earlier, childhood events in the lives of adult carers contribute to their tendency and need to seek out caring roles in later life. For this reason, I was particularly interested in looking at life narratives using a biographic interpretive method. I decided to take advantage of training in a biographic narrative interpretive method given by Chamberlayne (Chamberlayne et al 2000) and Wengraf (2001), loosely adopted and adapted from earlier work by Schütze (in Chamberlayne et al 2000), Rosenthal (1993) and Bar-On (Bar-On & Rottgardt 1998) in Germany.

A biographic interpretive approach is based on concepts of how people create meaning in their everyday lives and develop their own ideas of their lives. Meaning is thus expressed through actions. Narrative biography is seen as a representation close to those actions. Everyday events become powerful in that they reflect individual meaning of the whole life. Thus, this exploration of the quotidian provided opportunities to reflect upon lived lives that were rich with powerful thematic material. The universality of the drama of the ordinary was revealed using this narrative method.

Justifications for the research
This thesis provides a modest attempt at making a dent in the vast amount of research on informal care that precedes it and that continues to perpetuate commonly held myths about care giving. The research is also justified because its revelations and discovery add to and enrich the profile of informal carers, not only in the research community, but also in the health and social care sectors. Because the deeper profiles of carers’ personal social-psychological needs are uncovered in this research, providers can begin to assist informal carers in continuing with identity work and further psychosocial adjustment to their carer roles.

In addition, the process of seeking meaning within the told stories of the narrators’ lives enriches those who share the stories of their lives, enhancing the tellers’ abilities to provide testimonies with the potential to benefit others in similar circumstances. Equally, the narration of their lives provides them with a beginning, on a personal
level, at exploring their reasons for caring as well as the potential for further psychological biographic and identity work in the future.

**Outline of the thesis**

**Chapter Two: Review of the Literature** follows this Introductory Chapter and reviews the literature on informal care, exploring the geography and etymology of terms. The history of informal care and how a typology developed is examined. This is followed by an analysis of the choice of words in journal paper titles on informal care, culled from 20 years of informal care research from both the U.K. and North America, particularly looking for negative or positive themes in this literature.

The initial research problems and their subset questions are then used to review the literature. Research that looked at positive aspects of caring and the influence of personality is subsequently examined. The literature on meaning and well-being is explored, as well as explanations of carer outcomes. Next, gender is explored as the touchstone of informal care and a case is made for consideration beyond gender. Finally, a tentative bridge is built between the concepts of care, informal care and carer identity. Through this construct, a proposal is made to investigate informal care through the personal histories of carers themselves.

**Chapter Three: Method & Methodology** presents an examination of method and methodology for the research. The exploration of personality through the social-psychological framework of constructionism (Gergen 1991) provides the overarching metatheory that facilitated discovery and formed the foundation of the thesis. By means of an innovative interview method, informal carers were invited into potential exploration of the forgotten, the suppressed, or the other through a dialogical reflexive posture (Gergen & Gergen 1997: 3-4).

Next, the journey to a qualitative method and the narrowing of the road to a biographical narrative approach using case study is justified. This is accomplished, first, by a consideration of quantitative tools that might be used to describe personality ‘types;’ consequently, several personality measures are explored. Next, a review of the more recent literature on personality ultimately suggests that measurement of personality is, at best, one starting point, and not without its inherent flaws and fallacies (McAdams 1995). Accordingly, qualitative constructionist approaches are chosen as a way forward, suggesting better opportunities for exploration and discovery of multiple and “ambiguous personal meanings” (Plummer 1983: 82) of a dialogically constructed self as well as opportunities to unearth individual differences. The tyranny of numbers is thus abandoned for the enigma of words.

Theoretical explorations are made and life-span developmental theory is examined as one possible theoretical foundation for a narrative method.
Explorations include Erikson’s concept of generativity (Erikson 1984) (included because it is the theoretical basis of McAdams’ recent explorations of narrative [McAdams & de St. Aubin 1992]), but this was found to be insufficient for this research’s purposes. Next, the dialectic as a concept of adult personality development is explored, examining Riegel’s theory that the individual develops through a continuous process of thesis, antithesis and synthesis (Riegel 1976b). Considering Riegel’s dialectic concept of the context of the individual’s experienced past and anticipated future makes a possible connection to biographic work. A historical connection is, therefore, made between Riegel’s work (Riegel in Datan & Reese 1977) and the contemporaneous, early foundational work of Gergen and social constructionism (Gergen in Datan & Reese 1977). Shotter’s consideration of directing attention to everyday practices is also taken into account (Shotter 1997).

The narrative approach is put forth, substantiated by the work of Harré 1997), Freeman (1984), Chesla (1995), Miller (2000), and Chamberlayne & King (2000). Hermeneutics, or interpretive phenomenology, is explored and developed as the methodological underpinning of the research’s interpretive work.

A biographical interview technique is seen as the key data gathering event of the method, whilst the reflecting team approach to data analysis, with its inevitable plurality of perspectives, is conceived as a rigorous method of establishing validity through hypotheses building and testing and multiple viewpoints. The interview/case-study approach ultimately selected for this research is based on the training in the method of biographical-narrative interviewing and analysis developed by Chamberlayne (Chamberlayne et al 2000) and Wengraf (2001). Subsequently, an overview of their Biographic Narrative Interpretive Method is presented. Other narrative approaches are also explored, including the work of De Waele (Van Langenhove et al c.1986; Harré 1976); Miller (2000); McAdams (1996); Hermans (2000) and Hollway and Jefferson (2000).

Issues of sample size, interview procedures and data analysis are then discussed. The reflecting teams are explained and described, including adjustments and changes to the method through this process. An explanatory analogy of the inductive analytical process is made. Finally, ethical considerations are discussed, in dialogue with Lincoln’s (1995) standards for ethics based upon proposed and emerging standards for quality in interpretive social science. Conclusions are drawn that lead to the potential possibility of shared comprehension through the use of a biographic narrative approach to uncover meaning in the stories of others.

Chapter Four: Presentation of data & researcher’s reflective work presents the initial findings. Portraits (Hollway & Jefferson 2000) or cameos of
the seven participants who were interviewed for the project are produced using the method’s process of assemblage of a descriptive, chronological picture of the chain of events, people, and so forth, that comprise the remembered life as told by the participant. This is followed by “First Impressions;” it is here that the researcher’s initial reactions to the interviewee and the interview scene are reported, generally based upon debriefing notes made soon after each interview. “First Impressions” are then followed by “Personal reflections” -- individual responses, not only to the interview itself and post-interview debriefing process, but also the researcher’s reflections during and after the transcription process. These sections represent the layers of reflective activity necessary within the concepts of a hermeneutic interpretive methodology. The chapter ultimately establishes the skeletal frameworks upon which the analyses can begin.

Chapter Five: Reflective teams’ analyses of data presents the results of the analyses of four of the cases, resulting from the reflective team approach and each team’s separate consideration of either the lived life or the told story. It is in this chapter that the skeletal framework of the lived life is compared and contrasted with the told story and reconstructed as an assemblage, creating its own narrative.

The analysis of biographic narrative texts using a team approach is the centrepiece of this research’s biographic interpretive narrative method and it is in this chapter that the results of those analyses are presented. The concept of emotional capital is put forth as the fourth column of resources available to support an individual, a structure that is typically envisaged in terms of social, cultural and economic capital. The use of a team approach is strengthened by a case being made for intuitive, instinctual processes, that, in turn, demonstrate a profound expression of human understanding and identification with an ‘other.’

Chapter Six: Conclusions & Implications returns to the initial research problems, questions and hypotheses in regard to the findings, and as a result of this process, delineates implications for theory, policy and practice in the informal care sector based upon that interface. The areas presented for review and consideration are contributions to knowledge, conclusions about the research questions that developed out of the primary research problems, possible implications for theory and policy and, finally, implications for further research.

Chapter 7: Afterward, or later responds to a set of questions around issues of psychonalytical inferences, veracity within the interview setting, the tendency to care as a normal human impulse, and issues of childhood experiences as automatic predictors of adult behaviours.
Definitions

- **Informal care** is defined as care of a physical, psychological and/or social nature that is performed free and outside of a professional status.
- **Carer or caregiver** is defined as a person who provides such care for another individual. (A discussion of the use of the terms ‘carer’ and ‘caregiver’ and the differences between the use of the two terms in the British and North American literature is explored in Chapter Two.)
- **Biographic Narrative Interpretive Method** is defined as an interview and analysis method of discovery that uses a minimalist interview technique and verbatim transcripts to interpret, through the use of reflective teams, the narrated (told) life stories (biography) of research participants. *(The method is explored fully in Chapter Three.)*

Delimitations

Because the biographic-interpretative method chosen for the research required extensive interviews with follow-up sessions as well as intricate and time-consuming analytical teamwork, the sample frame is necessarily small. Richness of data and thorough and meaningful analysis involved the assemblage of groups of peers to hypothesise and explore themes and, therefore, necessitated the limiting of the number of interviews and subsequent analyses sessions. Efforts were made, nonetheless, to insure that the selection of subjects for interview included a diverse range of subjects with varying demographic and family relationship backgrounds. What might be lost in not using a method with the potential for larger numbers of subjects, producing large data sets, is more than compensated for by the method’s capacity for deep and meaningful case studies. These cases are rich in potential for the discovery of new material with the capacity to generate further hypotheses, effect change through social policy and validate and enrich informal carers’ lives.

Informal carers, who remained anonymous in the analysis phase of this project and remain so throughout this report, were contacted through carers’ organisations only. Although this presented the possibility of missing a population of informal carers who never had joined an organisation, interviewing carer organisation users did ensure that there was follow-up professional support for the interviewees. This is particularly crucial in biographic work where unearthing buried memories may have future repercussions and subsequent support may be needed.

Conclusion

This introduction lays the foundations for the thesis. It introduces the research problem, questions and hypotheses. The research is justified, definitions are presented, the methodology is briefly described and justified, the thesis outlined and the limitations are given (Perry 1995). On these foundations, the thesis can proceed with a detailed description of the research, beginning with a thorough exploratory examination of twenty years of literature on informal care, both in Britain and North America in the following Chapter.
CHAPTER 2: Literature Review
Resurrecting the Person from the ‘Informal’ Care Literature
-- a critical review

INTRODUCTION
The literature on ‘informal’ caring is so extensive that its diverse and sometimes contradictory factors, variables and measures put ‘informal’ caring beyond comprehension in practical terms (Gubrium 1995: 267). ‘Meaning,’ particularly as the individuals who do the caring conceive it, has often eluded both researcher and policymaker alike. Instead, the literature on informal care has co-constructed the informal carer, recirculating popular prejudices and linguistic conventions. Broadly, the person who has emerged from much of this literature is an automaton who lifts, toilets, washes, medicates, cleans, shops, feeds, watches over and, most of all, worries.

Further, subsequent literature reviews of the research on informal caring have then perpetuated the ‘known’ or accepted carer profile. Generally, most literature reviews have continued to miss the opportunity to deconstruct the mechanistic myths too often perpetuated by much of the research as well as a chance to unpack the established language. The next cycle of research then has embedded the prevailing, standard assumptions of the literature reviewers, perpetuating an inevitable rehash of previous suppositions through language. In highlighting only the most accessible and homogeneous, many literature reviews have often ignored the smaller studies that explored the very diversity of the person and the caring experience itself. “Reviews identify what is known and remains unknown, which, in turn, produces more of what is or is not known, and so on. What we need now is a critical, deconstructive examination of the taken-for-granted language of caregiving” (1995: 267-8).

MAPPING THE PROCESS
An investigative process was devised in order to forge a new path through the vast amount of literature on informal care and, in the process, redefine the caring act through the prism of identity as a “relational achievement” (Gergen 1999: 7). The goal of this process was ultimately to seek carer identities, not only through involvement in the caregiving role, but also through multiples roles and their interactions and over time. Nonetheless, first the social science literary fiction of the informal carer needed to be deconstructed before the actual identity and personhood of carers could be constructed in situ by actual carers themselves. In order to deconstruct it, the literature and its language and use needed to be uprooted, explored and exposed. Contrary to the version of the carer that emerged in the light of a medical or economic gaze (one who is seen as most likely female, burdened, incapacitated, and so forth), a more complex identity was sought.

First, the geography and etymology of the terms ‘carer’ and ‘caregiver’ were examined. The process considered when the terms began to appear in journal
papers and their increase in usage over a nearly twenty-year time span. Next, the history of informal care research was examined, looking at which issues occupied researchers efforts and when and how a typology was developed. Analysis of the choice of words used in informal care literature titles uncovered major themes. Frequencies of these terms and comparisons between the British and North American literature then led to an exploration of negative and positive connotations of themes developed by the literature’s titles.

The questions that initially sparked interest in study of the individual and informal care were re-examined. The literature was reviewed looking for work reflecting clues that shed light on those questions, particularly questions about the positive aspects of caregiving and the influence of identity in individual choice to care. Additionally, research that included factors such as optimism, religion/spirituality, motivation, empathy, hardiness, personal resourcefulness and identity was reviewed for particular meaning in the context of identity. The literature on meaning itself and well-being was explored, as well as other possible explanations of caregiver outcomes and satisfactions, including positiveness and the ‘act of giving.’

The caring role has been interpreted largely in terms of a gender role and gender inequality with the consequence that gender has become the touchstone of the informal care literature. This conceptualisation of role by gender was re-examined. This resulted in a case being made for looking ‘beyond gender’ to personality and identity for richer description, data and discovery. ‘Care’ itself and its many connotations was explored and a tentative bridge was built between the concepts of care, informal care and individual caring identity. Finally, a proposal was made for studying informal care through the personal stories presented by carers themselves. Creative and uniquely constructed life narratives offered one way forward to better understanding both the concept and process of informal caregiving and to resurrecting the person as the key to the comprehension of this complicated role.

UNPACKING INFORMAL CARE
The geography and etymology of terms
Research available in the English language on informal care presented a geographical division in its use of language. Quite simply, the Atlantic Ocean marked the great divide. North American (U.S. and Canada) literature on informal caring designated people who care as ‘caregivers.’ British literature on informal caring defined them as ‘carers.’ This division, in one way, helped the reader, as one could usually tell where the author was coming from –literally and geographically.

“To treat the meaning of a word as transparent and trans-contextual is to deny its history, to suppress its broad web of interdependencies, and prevent its potentials for creative and variegated usage” (Gergen 1997a: 2). It was useful to look at the origins and subtleties of these two terms, ‘carer’ and ‘caregiver,’ and to reconstruct their meanings through their geography and history in the literature. ‘Carer’ as word is quite old; it was defined as “one who cares” (OED 1933) in the Oxford English Dictionary as early as 1691. Still earlier, in a 1625 reference, ‘caretaker’ was defined
as “one who takes care of a thing, place or person; one put in charge of anything” (OED 1933). Contemporary British dictionaries continued the use of both carer and caretaker as “a person who takes care of a vulnerable person, often a close relative” (Collins 1994). The chief U.S. dictionaries often ignored both the British ‘carer’ as well as the American ‘caregiver’ (Funk & Wagnall’s 1955; Merriam Webster 1986; Random House 1967) with no listing for either term. Webster’s online dictionary (2001; search term: “caregiver”) listed a 1975 definition of caregiver as “a person who provides direct care (as for children or the chronically ill)”. Although ‘carer’ and ‘caretaker’ were used interchangeably in British literature, especially in early research (before 1990), ‘caregiver’ did occasionally slip into the literature in the U.K. (See Goodman [1986] for a British use of ‘carer’ and ‘caregiver,’ interchangeably) On the other hand, it was ‘caretaker’ that was an early (before 1980) choice in the American literature; it was ‘caregiver’, however, that became the commonly used term in the developing American carer research by the mid 1980’s. “The British/American split seems to be very clear cut. Of nearly 2000 citations in the Bank of English for carer only one is from US sources” (Potter 1999, Collins Cobuilt Co., in private correspondence).

**British & American Literature on Caring**

![Diagram showing the number of articles per year for British and American literature on caring.]

**Figure 1 Source: Social Science Citation Index**

It was notable to mark when exactly work on informal care began to appear in the literature. For the year 1980, (Figure 1) the Social Science Citation Index listed no reference to either ‘caregivers’ (U.S.) or ‘carers’ (U.K). Additionally, most early (1980-84) references to ‘caregiver’ in the U.S. literature referred to articles on childcare. In 1984, care of adults evolved as the focus of the U.S. literature and by 1985-87, an upward trend began in the number of American articles. A surge of 168
articles in 1991-92 more than doubled the numbers of the previous two-year period. Interestingly, it was in this same period (1991-92), that the U.K. literature on adult caring reached two figures (15 articles). The U.K. numbers more than doubled the following year. This exponential increase in the numbers of articles continued to increase steadily throughout the decade.

In both the U.S. and the U.K. policy makers were proposing further government reliance on the family as central to concepts such as ‘Care in the Community’ and social medicine constructions (Parker in Twigg 1992: 6-7; Twigg et al 1990:1-3; Baldock & Ungerson in Jones and Millar (eds.) 1996:167-68). “From a Foucauldian perspective, ‘carers’ did not exist as such prior to the development of the discourse on informal care in policy and other discursive domains” (Heaton 1999: 769). The carer research community scurried to make its mark in this sea change.

A similar check of ‘carer’ and ‘caregiver’ references on Medline, a search engine based in the medical literature (Figure 2), revealed a pattern similar to the Social Science Citation Index search. Checking “carer” (U.K.) from 1966 through 1985 found no references in the literature. 1985-90 presented the first 37 articles referring to ‘carers,’ with the majority (28) appearing in 1990. 1990-95 showed an increase to 140 references and 1995-99, 199 citations. Searching Medline for references to ‘caregiver’ (the U.S. literature), the period 1970-1980 produced but a handful. 1980-85 marked the initial regular appearance of the term ‘caregiver’ in the literature with 54 articles over the five-year period. A substantial increase in the number of references to 356 marked the period 1985-90. It is in the period 1990-95, however that the increase to 2,147 references to ‘caregiver’ indicated that the term ‘caregiver’ and its research agenda were well established. 1995-99 continued this upward trend with 2,403 references.
The history of informal care research

By 1991, Lawton had recognised that “the caregiving process and the effect of care on both giver and recipient has probably been the most-researched gerontological topic of the decade” (Lawton et al 1991: 181). Nonetheless, the volume of research into informal care has increased exponentially throughout the 1990’s. It was important to consider exactly what influenced the growth of research on informal care over those two decades. Were there events that precipitated the interest and work on caring for adults? Were there similarities in influences on both sides of the Atlantic?

The research on informal care evolved over time. “Time is not a constant, something to be measured by mechanical means, but experiential, modulating, personal. We create the past . . . .” (Maggs 1996: 160). The earliest research observed caring behaviours and classified by gender, age, economic status, and so forth (see, Horowitz 1985; Orbell 1996; Parker 1985 for overviews). Research then entered a second phase of measurement. What was measured was the seemingly measurable, and, therefore, measurement of stress in caring situations came to the forefront of the literature (Caserta, Lund & Wright 1996; Novak & Guest 1989b). Issues such as the ‘caring identity or personality’ and the complexities and histories of issues such as motivation, resilience and meaningfulness were more or less ignored.

The third phase began with the call for longitudinal studies of informal caring and measurement over time (Miller & McFall 1991; Stoller & Pugliesi 1991 for examples). Supported by an evolving economic dyad between researcher and policy maker, ‘best practise’ in research on informal care became research into burden and stress. Zarit’s (1989) admonition, “The point that caregiving is stressful is now well established” (1989: 147) fell by the wayside. This preoccupation with the measurement of stress and burden continues today (McDonald et al 1999), too often overlooking the more diverse emotional dynamics of caregiving. Based in the budding field of gerontology, research on stress and informal care became a rich soil in which investigators could establish and grow ‘scientific,’ measurable phenomena and mimic more established procedures in adjacent fields, particularly psychology. Typologies of carers and their families also entered the mainstream (see Parker and Lawton, 1994; Pruchno et al, 1997). Politically driven to either support or oppose prevailing governmental policies, particularly when considering the family and women’s traditional Western role within it, research on informal care became theoretically based in second wave feminism (see Ungerson 1987: 2, for carer research based on “commitment to woman-centred issues and to feminism”). Still, the more illusive area of personal stories of caring experiences was mostly ignored in the rush to legitimise the mainstream, empirically based study of informal care.

Thus, the ‘who, what, when, where and why?’ of the research concentrated on the measurable. (For an example, see Parker & Lawton’s [1994] use of “tasks alone” to develop a typology of caring activity) Missing in this approach, however, was the concept that “measurements are internally related to that which is measured, and
hence are not properly empirical at all” (Maraun 1998: 452). In other words, the ‘meanings’ of the terms measured already had meaning in everyday life, governed by grammar. For example, was does ‘burden’ mean and to whom? --The researcher, the “subject,” or the community at large? Whose community? The concepts used in these measurement studies were founded on “common-or-garden” concepts and are, therefore, ultimately community or populist perceptions. These “concepts are simply not organised around finite sets of behaviours” (1998: 458) or fixed meaning, but evolve and change with use and user.

More enriching then, would have been a different set of conclusions to the who-what-when-where-and-why of caring. Who were the people who care and how were they different from each other? What were the people like who care? What motivated this care? When did they choose to care or not to care? Where in the stories of their lives did caring ‘events’ take place? Why did they often reason that caring is affirmative and enriching? “Studies have tended to focus exclusively on the problems encountered in the caregiver role and have too often failed to recognize the more positive aspects of this role” (Stephens et al 1994: 50). The history of informal care research clearly revealed that these aspects continued to be absent in the majority of work. When these questions were addressed, as was in the case of much of the feminist-based research, individual personality or identity was subsumed by the politics of gender (see Ungerson 1987). This resulted in the caring role being interpreted largely in terms of gender role and gender inequality with the consequence that the underlying subtleties and richness of the individual person were too often ignored or lost.

The choice of terms in the literature
A neo-pragmatist, use-based account of language was helpful in that its “emphasis is placed on meaning as embedded with language use, words deriving their meaning from the attempt of people to coordinate their actions within various communities” (Gergen 1997a: 6). The community of researchers’ use of precise terminology in describing their work in the titles of journal papers afforded a rich source of language and co-constructed meaning. In addition, by analysing the choice and use of words in titles, patterns and frequencies were unearthed that began to disclose the history of research on informal care itself. By allowing nearly 20 years of research to be reduced to a limited number of selected keywords from journal titles, a history was (re)constructed with the power to illuminate. Keywords became peaks, indicating the ebb and flow of directions in the research bubbling underneath. These keywords also evolved into symbols over time with the ability to ‘telegraph,’ in concise terminology, assumed knowledge and background information to their informed readership. Keywords became icons with the accumulated power to persuade, to convince, to establish authority and to represent authenticity. “Words . . . are always related to other words or to the objects, events, or qualities that they denote” (Riegel & Riegel 1972: 136). Reviewed papers became indicators of trends in a field, building blocks forming a basis for the next round of work and papers, thus establishing a continuum that moved the field onward in time, but too rarely in any
other direction. Too often, a closed system seldom detected new emergent trends or supported the more innovative work.

Below are a few examples of journal titles (from just a few of the papers cited in this document) that begin to strengthen the argument that language and its use has constructed meaning and identity for the informal care role:


Analysis of the journal titles of a nearly twenty-year period of informal caring research provided opportunities for the literature to begin to 'reveal itself.' The major themes in the past twenty-year's research into informal care were exposed by the carefully chosen and weighted choice of terms in journal titles. (See Table 1) Examining more than 3,155 titles of journal papers, using the Social Science Citation Index and the search terms ‘carer’ (British terminology) and ‘caregiver’ (North American terminology), keywords were culled to give shape and meaning to the research on informal care. Articles on ordinary childcare or ‘formal’ care were eliminated in the process.

The use of the Social Science Citation Index was particularly valuable in that the number of journals actually indexed stays roughly constant over time (Massey, 1999, Ingenta Services, private correspondence). For example, in 1981, 3,244 journals were indexed; in 1998 there were 3,181 journals. Numbers of issues also remain relatively constant. In addition, the number of articles indexed also remains
consistent. There was a slight increase in numbers of articles in 1995 (1994: 11,333; 1995: 12,571 or +1,238) but the numbers remain stable at this higher level thereafter.

The first examination of the titles looked for frequency of terms (Table 1). Overwhelmingly, the words burden and stress were used most frequently in the American literature (Table 1). Burden is defined as “something that is carried” like a “load” or as “a duty or responsibility”; stress in defined as “a state resulting from a stress; especially: one of bodily or mental tension resulting from factors that tend to alter an existent equilibrium” (WWWWebster Dictionary 2001+search terms). Burden (N=97) and stress (N= 64) were used four times as often than even the third most frequently used terms in the American literature, race, ethnicity and culture (N=37). Stress (N=16) was the most frequently used word in British titles (Table 1). Interestingly, research on caring and Aids or HIV+ was second highest (N=9) in the British frequency list; it was equal, however, to the number of times violence or abuse (N=9) in caring was mentioned. In both British (N=8) and American (N=35) research, support (defined as “the act or process of supporting: the condition of being supported” (WWWWebster Dictionary 2001+search term) for carers was the most frequently used term in relation to the words coded as having a positive or affirmative connotation (see following). It must be kept in mind, nonetheless, that the frequency of the use of the term support was equal or almost equal to the frequency of the use of terms such as strain (N=29) (defined as “excessive physical or mental tension” (WWWWebster Dictionary +search term) and depression (N=26) in the American literature and burden (N=7), depression (N=6) and behavioural problems (N=4) in the British. Roles and relationships also occurred frequently in the American literature (N=63), but not so frequently as in British studies (N=4). Interestingly, articles dealing with measurement were highly frequent in the American literature (N=34), while studies using the term assessment (N=4) were slightly more frequent than the use of measurement (N=3) in the British literature. A case can be made that British research was often driven by its more direct influence on national policy, particularly health and social policy, whereas American research sought to influence policy that is often more decentralised and less homogenous in its aims.
### Rank Order of Frequency of Terms – Keywords
(Source: Social Science Citation Index)

**Table 1**

**British Literature**

<table>
<thead>
<tr>
<th>Term</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress</td>
<td>16</td>
</tr>
<tr>
<td>HIV+/AIDS</td>
<td>9</td>
</tr>
<tr>
<td>Violence abuse</td>
<td>9</td>
</tr>
<tr>
<td>Support</td>
<td>8</td>
</tr>
<tr>
<td>Burden</td>
<td>7</td>
</tr>
<tr>
<td>Depression</td>
<td>6</td>
</tr>
<tr>
<td>Behaviour probs</td>
<td>4</td>
</tr>
<tr>
<td>ASSESSMENT</td>
<td>4</td>
</tr>
<tr>
<td>Coping</td>
<td>3</td>
</tr>
<tr>
<td>MEASUREMENT</td>
<td>3</td>
</tr>
<tr>
<td>Race, ethnicity</td>
<td>3</td>
</tr>
<tr>
<td>Strain</td>
<td>2</td>
</tr>
<tr>
<td>Relationships</td>
<td>2</td>
</tr>
<tr>
<td>Roles</td>
<td>2</td>
</tr>
<tr>
<td>Well-being</td>
<td>2</td>
</tr>
<tr>
<td>Education, info</td>
<td>2</td>
</tr>
<tr>
<td>Employment</td>
<td>2</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>2</td>
</tr>
<tr>
<td>Strategies</td>
<td>1</td>
</tr>
<tr>
<td>Meaning</td>
<td>1</td>
</tr>
<tr>
<td>Intervention</td>
<td>0</td>
</tr>
<tr>
<td>Training</td>
<td>0</td>
</tr>
<tr>
<td>PERSONALITY</td>
<td>0</td>
</tr>
<tr>
<td>Positive aspects</td>
<td>0</td>
</tr>
</tbody>
</table>

**American Literature**

<table>
<thead>
<tr>
<th>Term</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burden</td>
<td>97</td>
</tr>
<tr>
<td>Stress</td>
<td>64</td>
</tr>
<tr>
<td>Race, ethnicity</td>
<td>37</td>
</tr>
<tr>
<td>Support</td>
<td>35</td>
</tr>
<tr>
<td>MEASUREMENT</td>
<td>34</td>
</tr>
<tr>
<td>Roles</td>
<td>34</td>
</tr>
<tr>
<td>Strain</td>
<td>29</td>
</tr>
<tr>
<td>Relationships</td>
<td>29</td>
</tr>
<tr>
<td>HIV+/AIDS</td>
<td>28</td>
</tr>
<tr>
<td>Depression</td>
<td>26</td>
</tr>
<tr>
<td>Education, info</td>
<td>17</td>
</tr>
<tr>
<td>Employment</td>
<td>16</td>
</tr>
<tr>
<td>ASSESSMENT</td>
<td>15</td>
</tr>
<tr>
<td>Coping</td>
<td>14</td>
</tr>
<tr>
<td>well-being</td>
<td>14</td>
</tr>
<tr>
<td>Intervention</td>
<td>11</td>
</tr>
<tr>
<td>Behaviour probs</td>
<td>10</td>
</tr>
<tr>
<td>Violence abuse</td>
<td>9</td>
</tr>
<tr>
<td>PERSONALITY</td>
<td>8</td>
</tr>
<tr>
<td>Strategies</td>
<td>5</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>5</td>
</tr>
<tr>
<td>Training</td>
<td>4</td>
</tr>
<tr>
<td>Positive aspects</td>
<td>4</td>
</tr>
<tr>
<td>Meaning</td>
<td>3</td>
</tr>
</tbody>
</table>
The literature titles were then analysed for the specific positive or negative connotations of frequently occurring words or themes (Table 1). For example, the most frequently used words, burden, stress, violence, abuse, strain, depression and behavioural problems were coded as having negative connotations. In addition, the terms Aids, coping and employment were also given negative value for the following reasons. Articles on HIV+ and Aids covered the gamut of caring experiences and in so doing often reflected the general literature on caring and its majority’s emphasis on the larger negative issues of burden, stress and coping. Research dealing with employment and caring almost universally discussed the negative impact on the employment of caregivers in coping with their caring role. (See Stull, Bowman & Smerglia 1994, for evidence to the contrary.) More recently, however, literature has begun to point to positive outcomes of connecting caring and some types of paid employment (Rhoades & McFarland 1999).

“Coping is the process through which the individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions they generate” (Lazarus & Folkman 1984: 19). Coping research itself was generally concerned with a situation, circumstance or problem within which an individual’s coping skills were or were not employed. In the late 1970s, Lazarus and Folkman amongst others abandoned the hierarchical view of coping, with its trait or style emphasis in favour of treating coping as a process that changes over time and in accordance with situational contexts (Lazarus 1993: 235).

Nonetheless, if we emphasize coping consistency over time and across encounters, we are dealing with the trait concept; if we emphasize contextual influences and coping inconsistency over time and across encounters, we are dealing with the state concept or process. They are two sides of the same coin, and both sides are usually relevant. The more consistency, the more the trait side stands out; the more inconsistency, the more the state or process side stands out. (1993: 236)

Lazarus had found repeatedly that “a coping strategy that produces positive outcomes in one context, or in one person, may not in another” (1993: 240; emphasis mine). Important to this study, Lazarus added that “coping process measures would be far more meaningful and useful if we knew more about the persons whose coping thoughts and actions in specific contexts are being studied” (1993: 242). Lazarus’ Transactional Theory posited, “stress is neither in the environmental input nor in the person, but reflects the conjunction of a person with certain motives and beliefs (personal agendas, as it were) with an environment whose characteristics pose harm, threats, or challenges depending on these person characteristics” (Lazarus 1990: 3). Lazarus ultimately concluded, “we would be wiser to move away from stress toward the measurement of emotion” (1990: 12) and that cognitive, motivational and coping processes underlie each emotion.

“Although the experience of stress is an undeniable part of caregiving for almost everyone, it only represents one of the relevant dimensions; . . . therefore, the
concomitants or determinants of the rewarding aspects of caregiving still warrant further study” (Grant, Ramcharan, McGrath, Nolan & Keady 1998: 59).

The more positive and affirmative aspects of caring appeared infrequently in both American and British literature. Some of the more positive terms such as relationships, roles and support remained mostly descriptive terms and in a certain sense answered only the “Who?” question. Whilst it has been a move in a positive direction (since the 1990’s) to see papers considering race, ethnicity and cultural differences in caring experiences, these still, for the most part, only compared and contrasted with the by-now standard concerns of burden and stress in the largely western culturally-based (and predominantly white middle class) majority of research on informal care. “Much of the work . . . is by white researchers and about white people” (Perring, Twigg & Atkin 1990: 49). Because feminist researchers have done most of the work on informal care, it is gender based as well (see Ungerson 1987).

Research on training for caregivers was prominent in the American literature, but virtually non-existent in the British. Information and education for carers was more frequently discussed in the American literature as well. Perhaps because of the built-in diversity of the American system of health and social care delivery, considerations such as training and education for caregivers became more pressing in America. In the British centralised system, policy-driven research may have pressed for changes more directly through the centralised national healthcare system. Policymakers may not, therefore, have placed as much emphasis on research aimed directly at the consumer of services or the regional statutory and voluntary organisations that delivered services (see Stacey in Lewin & Oleson 1985). Recent central government strategy for carers, however, has begun to support information for carers that “takes account of their particular circumstances and their main needs” (DOH 1999: 37). Education for carers and training needs are, however, still not on the agenda. Still, the mood of recent government policy documents indicates a sea change in policy development, relying on models developed by local as well as national voluntary organisations, local health trusts, and so forth, to drive national strategy (1999: 40). This sort of ground up policy development more closely mirrors the North American model uncovered in the literature search.

“Because of the emphasis on the burdens or difficulties of caring, the potential for satisfactions or uplifts has been relatively neglected . . . As yet we know little about the sources, types and frequency of caregiver satisfaction” (Nolan, Grant & Keady 1996: 3). In terms of why a carer cares, this review of keywords left us with a mostly blank canvass. A few journal papers dealt with well-being and caring. Several researched the satisfactions of caring (Grant & Nolan 1993; Walker, Shin & Bird 1990, for examples). Even fewer journal papers, however, were focussed on the positive aspects and meaning of caring (Cohen, Gold, Shulman & Zucchero 1994; Farran, Keane-Hagerty, Salloway, Kupferer & Wilken 1991, for examples). More positively, it was noted that the quantity of research on the affirmative response to the caring experience that began in the early 1990’s did, for the most part, remain consistent, and in some years even
slightly increased. In comparing the British and American literature, the latter began this positive trend.

In the context of this study, it was important to consider existing research on identity or personality and caring, and how it stood in comparison to other informal care research. Unfortunately, in this analysis of terms in the titles of papers in the British literature on carers from 1989 through 1999, the word personality did not occur once in a title. Ignored until 1992, the American literature did produce one or two references to personality in the caring literature titles yearly since 1992. This meagreness of research into personality and informal care begged for the expansion of work in areas such as well being, satisfaction, meaning and motivation and, more generally, in the arena of personality itself.

**Unearthing personality in the literature**
The massive number of journal papers combined with the now firmly established and immense amount of literature on informal care in book format combined to present a daunting task in making sense of the role of personality in informal care. Because of the tensions of person and identity in the process of care, the literature was reviewed with these concepts in mind. The major works on informal care were read with a view to teasing out personality in its broadest sense.

Secondly, books and papers that veered from the mainstream literature but indicated in their premise a possibility of information on personality were uncovered. Sometimes these small and elegant studies, usually qualitative in approach, offered alternatives, the neglected point-of-view and, occasionally, the substance of the actual caring experience and the motivation and ‘personology’ of the carer. These feminist studies of the 1980s and early 1990s insisted on the subjective dimensions of caring activities and relationships using boundary-breaking qualitative methods (Chamberlayne & King 2000: 10.)

Because of the vastness of the field of informal care research, it was easy to become overwhelmed by the breadth and power of the substantial work accomplished in this area of research and loose sight on the questions that raised interest in the person in the first place. With this in mind the following questions—ones that formed the initial interest and speculation on carer personality—were used as guides to tease out ‘the person’ and personality from the literature:

1. Are there personality ‘types’ that assume caring roles?
2. What enables carers to maintain their psychological integrity?
3. What are they “actually doing and telling themselves in an effort to cope?” (Lazarus 1993: 244)
4. What else are they, other than carers? Who else are they are the ‘rest of the time’?
5. Have they cared for a family member as a child or teenager? (Jones 1992; Jones 1995)
6. What part does the configuration of the particular family play in early family caring experience and/or in later life development of caring roles?
7. What personality factors and roles influence one family member to assume the caring role and other members not to?
8. What are the stories of their lives and in relation to caring activities over the lifespan? Have traumatic or difficult illnesses and/or deaths occurred in their past?
9. What background differences and/or personality differences, if any, exist between family carers and volunteer (non-related) carers?
10. What are the social factors that influence carers in assuming caring roles?
11. What values, traditions, economic forces and other social forces come into play in forming and contributing to personality development and adjustment to a caring role?
12. What part does the community itself play in personality development and influencing carers’ roles?
13. In what social activities and outlets do ‘carer types’ involve themselves over the lifespan?
14. Are they involved in voluntary or religious activities?
15. Have they participated in or had a desire to participate in ‘caring’ professions?
16. How do carers define themselves and their caring role in relation to available health, social and voluntary services?
17. What formal and informal supports are available in the community towards which some carers may gravitate and some do not?
18. How do these support systems help or fail to help the carer define his or her role in relation to the definition of ‘self’?

Clearly, the answers to these questions were not laid out in the literature in succinct form or conveniently in any one source, nor will any attempt be made to answer them in this review. Rather, the questions were used as a guidepost to survey the literature on informal care and tease out as much about what is not known as what is known about personality and caring. The questions were used to form more questions. The value of what was not known helped to shift the paradigm and lead this study to the hidden, the unexplored. At each turn of page, then, the questions were asked: “What did this tell me about the person; what did this tell me about her/his personality?”

What did the vast amount of literature tell us about personality and those carers who are the exceptions to the assumption that caring is burdensome, stressful and depressing? These issues were most often touched upon with but a fleeting mention in the majority of the literature. “I have been struck by two quite different kinds of carer, particularly among the women: those for whom caring was truly grim, and those for whom it seemed to bestow a certain satisfaction, even, in one or two cases, an extraordinary kind of joy. I could not make sense of this at all …” (Ungerson 1987: 144). When personality was raised directly in the literature, it was most often as an afterthought or an enigma for future consideration. Cohen et al (1994) noted the fact that much less
had been written about the positive aspects of caregiving and how they influence outcome (1994: 379) in caring trajectories. In conclusion, they discussed the possibility that “intrapsychic factors” and “personality traits” might provide insight into differences amongst carers, including traits such as extroversion (1994: 389). Finally, they posed the question, “How do positive outcomes relate to different personality traits of the caregivers” (1994: 389)? McKee, Whittick, Gilhooly, Gordon, Mutch & Philp (1997) proposed that one potential influence on coping strategies is personality. “It is entirely consistent with the present study’s findings that a supporter’s dominant way of coping may not be related to the caregiving situation at all, but rather exists as a behavioural disposition used across situations. Such a find supports a ‘trait’ model of coping” (1997: 338).

Perhaps, then, there were personality ‘types’ that gravitated towards a caring role, regardless of gender? Trait characteristics were, however, yet another descriptive tool, a mere window through which we could begin to get a picture of the person underneath. “One of the problems with stopping at trait descriptions is that they are derived from the assumption that a person is a single entity that can be brought to mind and described. … This results in a static picture of the individual, a decontextualized statue permanently fixed by stable traits” (Ogilvie & Rose 1995: 646).

The few existing investigations into personality and caring have, expectedly, looked at personality and coping style. Coping, often simply the reverse of the coin of stress and burden remained, for the most part, the raison d’être of the more recent investigations into personality and caring. Two research teams stand out in this arena, if for no other reason than the scarcity of efforts in this field – the work of Hooker, Monahan, et al (Hooker, Monahan, Shifren & Hutchinson 1992; Hooker, Frazier & Monahan 1994; Monahan & Hooker 1995; Hooker, Monahan, Bowman, Frazier & Shifren 1998) and that of Reis, Markiewicz, Gold et al (Reis, Andres, Gold, Markiewicz, Gauthier 1994; Markiewicz, Reis, & Gold 1997).

Hooker, Monahan et al (1992) saw great individual differences in carers’ coping skills and proposed that meaning is assigned to situations through an “interactive, constructive process in which personality plays a key role” (1992: 367). They viewed personality as one antecedent of social support and used a trait approach to personality. They stated,

Although personality of caregivers has not, to our knowledge, been systematically examined, results from existing caregiving studies suggest that personality is indeed a construct worthy of further study in relationship to caregiving (1992: 368). To fully understand the process by which the strains of caregiving may evolve into health problems, the personality of the caregiver must be taken into consideration . . . It is unlikely that the selection into the caregiver role is a random process with the family. Personality characteristics may determine who takes on such a role (1992: 372).
Additionally, personality characteristics may predict who is willing to utilise available services and resources (Hooker, Monahan et al 1994: 391). Hooker, Monahan et al employed the NEO Five Factor Index (NEO-FFI) (Costa & McCrae 1989a), a measure of the traits of Neuroticism, Extroversion, and Openness to Experience, Agreeableness and Conscientiousness. Hooker, Monahan et al (1995) used a short version of the NEO Personality Inventory, to support their claim, “perceived social support may describe an important organizing principle of self-attributes that mediate an individual’s ego distortions” (1995: 311).

The work of Reis, Gold, Markiewicz et al (1994) examined caregivers’ attachment styles and personality traits over time. They hypothesised that extroverted caregivers may experience more positive affect. “More extroverted caregivers may feel more positive about their own caregiving efforts, may find more aspects of caregiving more enjoyable and be more satisfied with social support they receive from family and friends” (1994: 258). They found considerable stability across a long period of caregiving for some carers and that personality traits demonstrated significant continuity in spite of the pitfalls of caring itself (1994: 264). Also using the NEO Big Five scale, the researchers found that neuroticism was the single largest predictor of health complaints (1994: 267). Surprisingly, they found that extroverted carers “did not derive more satisfaction from their social support network, engage in more recreational activities, or appraise the patient or their efforts more favourably. Nor did they find great enjoyment in caregiving. The responses given to the enjoyment query appear to tap a variety of sources of satisfaction, including underlying motives for caregiving” (1994: 268).

In later work Markiewicz, Reis and Gold (1997) theorised “attachment style as a general trait based on internal models of self and self in relation to others” contributed to the carers’ appraisals of the social support they received and was important during stressful situations (1997: 126-127). Their findings complimented earlier attachment theory work (Sarason et al 1986) “indicating that individual difference variables play a significant role in people’s experience of social support, and that their generalized expectancies about others’ availability for support are based partly on early relationships, such as those with attachment figures” (Markiewicz, Reis & Gold 1997: 128). Prigerson, Shear, Bierhais, Zonarich and Reynolds (1996) looked at childhood adversity, attachment and personality styles as predictors of anxiety among elderly caregivers and found that these factors affect the likelihood of having anxiety disorder. They found “childhood adversity and paranoid, histrionic and self-defeating personality styles all directly increase the risk for experiencing an anxiety disorder, primarily panic, among aged caregivers for terminally ill spouses” (1996: 240).

Suis and David (1996) supported the hypothesis that individual differences in personality play an important role in the coping process (1996: 993). They saw “habitual coping behaviors as part of personality and, unlike coping strategies which are intentional, habitual behaviors may involve little conscious awareness or control. … Different strategies may be enacted as a stressful episode unfolds, but people with similar personality profiles may be more likely to adopt the same strategies during certain phases of the problem situation” (1996: 999).
In their 1997 study McKee, Whittick, Gilhooly, Gordon, Mutch & Philp found that “although the research literature might emphasise the negative aspects of caring in relation to the caregivers’ health and well-being, most supporters in the present study’s sample felt that they were coping well with the stress of caregiving” (1997: 335). They found that “optimism” in the present was highest among supporters who had been caring between two and five years (1997: 337).

In a paper looking at the role of religion/spirituality in coping with caregiving for disabled elders, Chang, Noonan and Tennstedt (1998) supported their hypothesis that religious/spiritual coping affected distress indirectly through quality of relationship (1998: 467). “Caregivers who reported using religious or spiritual beliefs to help them handle the caregiving experience had a better quality of relationship with the care recipients, which was then associated with lower levels of depression and role submersion” (1998: 468).

Park and Folkman, (1997), in a study looking at psychosocial resources during caregiving and bereavement of partners of men with Aids, found that support for the personality hypothesis predominated (1997: 421). Optimism, conceptualised as a personality trait and generally found to be stable across time and circumstances, was an individual psychosocial resource that Park and Folkman found to be robust (1997: 440). Their data indicated, “perceptions of social support do not lessen during long periods of chronic stress” (1997: 441) and “people’s resources may be more robust than is commonly assumed” (1997: 442).

Beyond a coping thesis that includes personality as one factor in the caring process, the literature has yet to explore in-depth the intricacies of personality and the caregiving experience. Looking at the literature on volunteer carers offered an opportunity to begin, at least, to investigate the question of people who transparently choose to care and the personal motivations behind these choices. Volunteer carers’ experiences, their choice of the role and their rewards and satisfactions offered some potential clues to positive aspects of caregiving in general. Still, little work on personality and choice in relation to the caring role has been accomplished, even in the area of volunteer carers.

Davis, Mitchell, Hall, Lothert, Snap and Meyer (1999) conceptualised that empathetic concern and personal distress as personality traits (1999: 471) and that dispositional empathy was associated with a willingness to encounter needy targets (1999: 495). “The decision to enter helping situations is at least to some degree a strategic choice based on a rational consideration of the affect likely to result” (1999: 496). “Dispositional empathy has an important role to play well before an individual finds himself or herself faced with an appeal for help from someone in need” (1999: 497).

In a study of hospice volunteers, Paradis and Usui (1989) found that nine of 38 volunteers were doing work for another organisation as well as the hospice. Among the traits they identified as essential for volunteers are empathy and low tendency toward anxiety (Paradis & Usui 1987: 6). They found, in contrast, that “personality measures
are not a useful predictor of hospice volunteer work performance" (1987: 22). “Empathy, responsiveness, low anxiety, caring, and so forth, are all important human characteristics. However, whether one volunteer is more compassionate or empathic than another does not necessarily mean she or he will be a better volunteer. In fact, other traits such as volunteer's past experience with death, interest in hospice, motivation, availability, and involvement with other community organizations might be better indicators" (1987: 25).

Okun and Eisenberg (1992) posited that the ways that people think about their own identity in relationship to helping are salient: people volunteer because helping others is part of their identity (how they define themselves) or part of their social identity (how others view them) (1992: 221).

In a longitudinal study of MS volunteers helping others with the same chronic disease, Schwartz and Sendor (1999) investigated positive traits such as optimism and hardiness and their protective effects. They proposed that helping others might be beneficial to the helper, generating enhanced feelings of personal control and lower levels of depressive symptomatology. Participants reported a sense of dramatic change in their lives as a result of being a peer supporter, including self-transcendence, improved listening skills, stronger awareness of a higher power, increased self-acceptance and enhanced self-confidence (1999: 1568). The individual's social support network may also be strengthened by this developing outer-directedness (1999: 1572).

In an American study on caregiver meaning amongst individuals paid to provide care in their homes, Rhoades and McFarland (1999) found that caregivers most often referred to altruistic themes, with the most common one being “helping others” (1999: 291). Themes that were prominent in caregivers’ stories included helping people, making a difference, and, crucial to this study, “fostering a sense of family” (1999: 295). Caregivers often mentioned past caring experiences such as raising their own children or ministry work and their present caring activities in terms of self-fulfilment and self-actualisation.

**Exploring meaning and well-being**

“Meaning is not something that can be added to the system after it has been analyzed; rather it is the first and most fundamental topic. It should be studied from the outset” (Riegel 1976a: 690). The concept of “caregiver meaning” has emerged from the coping and adaptation literature with the potential to explain some of the variation in caregiver outcomes (Noonan, Tennstedt & Rebelsky 1996: 314). The findings of Noonan et al confirmed, “despite any negative impacts of providing care to an elderly relative or friend, there are indeed, positive aspects of caregiving (1996: 324). Farran et al (1991) found that meaning was primarily an individual process as opposed to a process linked to one’s race, gender, or relatedness to the care receiver (1991: 485). Carers in their study reported that they valued positive aspects of relationships and of caregiving (1991: 487). Their model suggested “critical antecedents in caregiving, caregiving
stages, caregivers’ response, and phase of suffering assist caregivers to grow and find meaning through caregiving” (1991: 488-89).

In a longitudinal study Townsend, Noeker, Deimling and Bass (1989) found that the length of time that care had been provided bore little relation to subjective stress, effectiveness, or mental health. “The ability of some family members to provide extended community care without significant distress has been largely overlooked by gerontology’s emphasis on caregivers experiencing strain” (1989: 399). They stated that care giving affects the entire family and “caregiving research is often guilty of the ecological fallacy of interpreting family-level processes as individual ones” (1989: 400).

In further work, Noonan and Tennstedt (1997) concluded, “the ability to find meaning and positive value in certain stressful experiences, such as caregiving, may be something that people come into caregiving equipped with and may reflect a more global tendency to find meaning and value in life. Noonan et al could not, however, determine “whether finding meaning is a relatively stable personality trait, a coping strategy called up in stressful situations, or strategy that, over time, becomes a trait” (1997: 793).

Grant and Nolan (1993), in a study of carers’ rewards and satisfactions, found that the largest single source of satisfaction for carers was through the “act of giving” (1993: 151). They too found that informal carers’ rewards and satisfactions could co-exist with very high levels of stress and strain. Sources of satisfaction could be rooted in the intrapsychic and intrapersonal lives of the individual, reflecting particular value positions and closely held personal convictions (1993: 156). Grant and Nolan stated that satisfaction is not significantly associated with the gender of the carer (1993: 154). While the influence of feminist ideology within the informal care literature has highlighted how carers can be marginalized and exploited, “it has perhaps been allowed to overshadow discussion about love and attachment as a basis for informal care” (1993: 157). In a meta-analysis of 14 descriptive studies of gender differences in caregiving, Miller and Cafasso (1992) found that most of the research “examines how the components of caregiving vary by gender but pay little attention to the structural or cultural context. ... What is needed may be less documentation of specific gender differences in isolated components of caregiving and more attention to the role that gender-role explanations play in assigning meaning to the caregiving experience” (1992: 506).

**DISCUSSION**

As earlier reported, research on HIV+ or Aids and informal care, particularly in the British literature, came into the mainstream of informal care literature in the late 1980’s and early 1990’s. It was care for the elderly, particularly informal care for the elderly in the community, that first informed Aids service planners and providers of care possibilities, forming the basis for new structures of informal community care for people living with HIV+ or Aids (Jones 1992). In the early scramble to provide care systems for those affected by the disease, many innovative and groundbreaking approaches to
informal care were developed by medical, social and voluntary agencies. To ignore these efforts in the mainstream of carer research would be unfortunate. Much has been learned from Aids service provision about people's ability to meet the challenges of care, particularly in the face of negativity and prejudice. Amongst Aids voluntary and informal care schemes, in fact, there is great diversity in the people who are attracted to volunteer work within these organisations (Shuff, Horne, Westberg, Mooney & Mitchell 1991). This was true from the very onset of the pandemic (Jones 1992). Typically, the continuum of informal care for persons living with HIV+ or Aids often first included a reliance on friends and partners in the early stages of the disease for minimal care and support (Folkman, Chesney & Christopher-Richards 1994: 50). This was often followed by an expansion of the care network to include volunteers and health professionals as complications increased and, finally, concluded with a late and often painful decision to involve and rely upon family members for belated emotional support and terminal care provision (Jones 1992: 15). This mix of informal care resources, frequent reliance on non-family care (volunteers and friends) and the diversity of background and age of both carer and cared for all offered lessons for ‘mainstream’ informal care planning and policy. In addition, the more recent ‘rediscovery’ of male voices in caring was directly related to the research spawned during the initial years of the pandemic. The demographic diversity of informal carers of people living with HIV+ or Aids within family, friends and volunteers continues to provide a rich proving ground for further investigation of personality and the diversity of persons who gravitate towards the caring role.

**Gender: the touchstone of informal care**

Gender has been the touchstone of the informal care literature for most of the past two decades. Caring has been theorised within feminist research and typically defined as “the unpaid work of kin within the private domain of their family. Gender is seen as the dominant system of social relations which shapes the organisation of such care . . . Most feminist research on caring has been restricted to one form of care (unpaid care by relatives) and one structural division (gender)” (Graham 1991: 61). Based in feminist ideology, “born out of feminist writing on the domestic labour of women . . . the focus (is) on carers as women . . . (and) seen as another instance of women’s unpaid domestic labour” (Arber & Ginn 1990: 431). The case has been consistently made to consider the role of carer a female one and the consequences of that role (Langan & Day 1992). Stated with passion and purpose, early (see Graham in Finch & Groves 1983) and middle (see Ungerson 1987) feminist literature on ‘women as caregivers by default’ made its way into the mainstream informal care literature. As early as the late 1980’s, however, researchers such as Wenger (1987) made a case for a more comprehensive, less politised view. Wenger argued for research to look at reciprocity and long-term relationships and the fact that many carers value their caring role and find it rewarding. Later (1990) Wenger stated, “The assumption continues to be made that caring for elderly people at home is done primarily by adult daughters or daughters-in-law. . . . Such has been the impact of feminist writing, however, that it will be difficult to dispel the image of the stereotypic carer as a middle-aged woman caught between the generations. . . . It is the image of the middle-aged woman carer on which services have been based” (1990: 211). With evidence that supported Wenger’s conclusions,
Stull et al (1994) showed that when women care for parents, they and their parents tend to be older; only a small proportion also have dependent children (1994: 319).

Thus, the more subtle aspects of the caring role needed study and a broader approach to issues of gender was required. Nonetheless, “differences within gender are not debated. The category ‘gender’ is itself represented as unified and closed, and emotional reactions are analyzed on the basis of sexual difference and kinship categories” (Opie 1994: 37). Looking to the individual, however, and her or his unique experience in informal caregiving, gender became the raison d’être for exploration of personality and the end-point and theoretical basis for an exploration of informal care. By researching personality irrespective of gender, for example through individual life stories, the potential for revealing the subtle, the exceptional, the motivational and the inspirational became possible. “Unless this actual diversity is foregrounded, research into caregiving can too easily reaffirm existing gender stereotypes and fail to develop a more detailed awareness of the individual subjectivity operating within, and challenging gender boundaries”(1994: 37).

**Conceptualising an approach beyond gender**

![Figure 3](image)

*The Scream by Edvard Munch*

A lateral glance at the methodology of a discipline quite removed from one’s own can often give clues to a next step forward, an avenue of exploration perhaps ignored or overlooked in one’s own and a chance to “expand vitally our spectrum of methods.”
(Gergen 1998: 102) The History of Art affords such an opportunity. Art History is often divided into two camps: the descriptive and the interpretative. In many ways, the latter develops out of the former historically. For example, one might describe the well-known painting, “The Cry” (or “The Scream”) by Edvard Munch, (1863-1944) as a smallish, casein/waxed crayon and tempera work on paper consisting of a centrally located figure standing on a bridge with a railing, a river beneath and mountains in the distance with two figures approaching from the distance on the bridge. One can say it makes use of bold, flat, simplified forms and primary colours with flowing and agitated brushwork, and so forth.

Interpretatively, much more can be said. The picture contains a “deeply, brooding, melancholy spirit, an almost existential portrayal of isolation” (Cole & Gealt 1989: 264). The central figure, amorphous and genderless, is seen holding its hands to its face, mouth agape, signalling the utterance of some sort of distress sound that is mirrored in the brushwork and swirling motion of the water below and the blood-streaked sky above, echoing the cry. The approaching figures, a man and a woman, seem to be strolling casually, unaware of the anguished emotional state of the figure and its expression of “alienation, danger, fear and despair” (1989: 264). Clearly, judging by its universal recognition, the image of “The Scream,” has become a pop icon. It reflects a dark and vulnerable state of mind that most people recognise and with which they identify. Part of its universality is the genderless nature of the main figure; a viewer, whether male or female, recognises him or herself within the genderless image, distinguishes the emotional state, empathises and understands.

It is this sense of ‘beyond gender’ and ‘interpretative’ consideration that research about the persons who provide informal care to others deserves. Resorting to regurgitating the holy trinity of race/gender/class as the end-all of social science investigation seems a shop-worn and habitual practice. Gender, even race and class, in many ways reveal only the outer layer, the skin of identity, transfixing the person underneath. They are structural variables that often obscure equally important building blocks to understanding which include time effects such as age and the life course, cohort effects and generational differences, and historical trends and period effects (Miller 2000: 24). All of these ascriptions are more rigorously employed when these descriptive attributes are used as keys that unlock the doors to intra-psychic phenomena and co-constructed identities, producing richer use of description of the person as a whole ecology and as a socially constructed individual.

“A social psychological approach acknowledges the individual’s own mental life and the part it plays in governing individual behaviour. Such processes may mediate the effects of social structural position, such as gender, and provide an account of the proximal determinants of caregiving involvement” (Orbell 1996: 162). “Research concerned with self-identity indicated that some people may be more highly motivated to provide care because of their self-involvement in social relationships or because of internalised moral obligations” (1996: 175). In other words, how do carers make sense of what they do (Grant et al 1998) and in what innovative ways can it be interpreted?
Towards redefining informal care

‘Care’ itself (and its many connotations) is a loaded word that abounds universally with shared cultural meanings. It is a warm and nebulous word that wends its way into divergent contexts from commerce (‘gentle care laundry soaps’) to potentially life saving interventions (‘intensive care units’). The term ‘informal care’ has become --in the last 20 years-- just as overworked and pedestrian as its root noun, ‘care’. As a result, ‘informal care’ begs a shift in meaning – a glissement, in order to have meaning about and for the individuals who participate in helping, aiding, watching over, taking responsibility for, supporting and loving another individual in need of such ‘care’. Meaning itself is viewed as embedded within these relational scenarios, dialogically unfolding, so that meaning is formed and transformed by the interlocutors (Gergen 1999: 6).

A more encompassing meaning of informal care needs to be (re)constructed, built not just upon lists of tasks, activities and outcomes --burden, stress, depression, and so forth (Bowers 1987; Nolan, Grant, and Keady 1996), but localised to individuals. Individuals care. They care about things, animals, people, and so forth, and they care for them as well. They often care without reward, financial or material. It is common in the literature on ‘informal’ care, therefore, to say that because they do not care professionally (‘formal’ care) that they provide ‘informal’ care. This is caring reduced to a provider in a health care continuum (medical model). Because they are not paid and because they are not (necessarily) trained to care, the literature designates them as ‘informal’ carers. This is caring reduced to an economic model. Informal care investigations, often a product of gerontological research, rely too frequently on a medical and economic grid “arbitrarily placed over the discussion” (Buchignani & Armstrong-Ester 1999: 23) to establish their validity as a fledgling field of empirical research. Research is needed that looks at evidence from carers which suggests that these models signal devaluation of their caring role and miss the point entirely that informal care is part of a process of human socialisation and interaction, defined by the dialogic telling and retelling of caring stories.

This unfortunate compartmentalisation of informal care belies the fact that many often care when others will not, would not. Many care in the face of drudgery, repetitive tasks and personal loss in income, social supports and psychological well-being. In spite of these as well as other difficulties and limitations, many continue to care for years. After years of caring for a family member, some seek out additional ‘opportunities’ to care as volunteers, neighbours, and friends. Scores of carers report positive affect and rewards from caring. These are just some of the results from redefining ‘informal care’ as individual and unique responses and interactions over time by a person, communicating with the needs of another in his or her environment.

Informal care, then, is about co-constructed personal stories, motivations, expectations and characteristics. As important, informal care is about commitment and relationships, past and present. Care is “the widening concern for what has been generated by love, necessity or accident” (Erikson 1964:131). Informal care is concerned with the
differences in an individual’s responses to need and his/her unique patterns of care over time. ‘Informal care’ is a cloth woven from these divergent strands and more.

Research on informal care can no longer rely solely on studies of caregivers’ reactions to sets of circumstances presented by informal care needs. To understand the role informal care presents, informal care research requires understanding of the whole person engaged in a dialogic of care. Informal care is, therefore, ultimately about the constituted individual, preceded by the culture and rooted in social relationships wherein understanding rests (Gergen 1997b: 1). Care is motivational and self-defining, relating that self to others and to the world around it (Van Hoft 1995: 4).

“People function as organized wholes, and it is in the light of such organization that we must understand them” (Pervin 1993: 2). Thus, the puzzlement of informal care exists in the chiaroscuro of the self, the light and shade of individuality. This bas-relief of individual personality is made visible within an ecology of a perceived past co-constructed in the present. This imagined past transfigures and crystallises ideas of care to illuminate a more complex picture of the whole (caring) person, and, therefore, truths about human (caring) nature itself. It is within the context of this caring nature that it is possible to transform investigations into the self (in relation to and co-created by interface with others) beyond the tyranny and materialism of cataloguing, boxing and labelling human endeavours.
CONCLUSIONS

A new history of informal care has been constructed by journeying through the literature, locating the peaks and valleys, the well-worn footpaths and the nooks and crannies of language in the previous research. Reconstructing the territory itself has set a new map for further exploration. As breath taking as any vista can be, it is the people, nonetheless, who inhabit the terrain who compel one to look more closely, more clearly and learn. Searching the landscape and language of informal care literature, there has been one purpose in mind: to resurrect the complex person who cares and to see her or him as the reason for research on informal care. By doing so, the literature on informal care can present a richer picture, illuminated by the carers themselves who do the caring.

To really know and understand those who give willingly to help others in need of care, more than just a snapshot in time and in one landscape is required. What is essential is in-depth knowledge of the people themselves, their stories, motivations and dreams – their selves, in fact, as co-constructed from a reflected lifetime and remembered in the present. A Verismo is called for that investigates the portrayals of everyday life in the words and thoughts of informal carers themselves. These creative cinematic reflections on lives, as described in the life narratives caregivers construct, can then be co-constructed into ‘patterns of consequence,’ expanding and enriching our concepts of what it is to be human and to care for one another.

“We have to pay serious attention to the application of biographical inquiries by which the individual does not only continue to reconstruct his own past but by which he also constructs his future in ever changing forms and with never ceasing hope” (Riegel 1976a: 698). By looking at life narratives of informal carers, the opportunity to unravel present activity from a personally constructed past seems manifest as the one way forward toward a more complete understanding and a depth of knowledge into this often puzzling and provocative giving of ‘self’ to others. ‘The ‘why it is’ (or ‘what makes it tick’) often translates into ‘how it came to be,’ urging the psychologist to discern the causes, origins, roots, determinants, and reasons for the ‘what is,’ be those reasons nature or nurture, be they internal or external, be they biological, social, cultural, economic or whatever” (Mc Adams 1995: 369). “By its analysis of personal meaning and sense of self in a social context, biographical-interpretive methods offer a research instrument for exploring personal responses in social care situations” (Chamberlayne & King 1997: 618).

The question then remains: what is it within the construct of these ever-so solid ‘selves’ that propels them into such seemingly ‘selfless’ activity and dedication? The resurrection of the self is in the past. Only by understanding the personalities of informal carers, within their own (re)creative stories, can we finally begin to understand this phenomenon we call ‘informal care.’
CHAPTER 3: Methodology & Method

The Verismo of the quotidian:
giving voice to the subjectivity of everyday living

INTRODUCTION
There has been an unexamined assumption over the past several decades of informal care research that there exists a generic, normative informal carer, “that individual differences can be understood as variation around these norms, and that this variation can be explained in terms of insoluble factors such as race, gender, and social class” (Meachum 1999:141). Equally, the assumption has also been made in research on informal carers that the role is taken up reluctantly by most, a result of circumstance or by default (see previous chapter). The aim of this study was to explore the validity of these assumptions and discover alternative explanations. Thus, the research explored another possibility: informal carers often choose to accept a caring role, based upon a complex mix of their personality and contextual background. To test this hypothesis, both micro and macro influences were examined through the exploration of carers’ narrated biographies. These influences included the constructed mix of personality, identity, life stories, cohort effects and family background with its shared values and traditions as well as caring experiences themselves. The concern was with ambiguity, process, meaning, totality and history (Plummer 1983: 122).

The exploration of personality through the social psychological framework of constructionism provided the overarching metatheory that facilitated discovery and formed the foundation of this work. “The chief locus of understanding is not in ‘the psyche’ but in social relationships” (Gergen 1997c: 1). Rather than seeing personality as a static, stationary and unchanging component of the person, it was considered as an indicator of “a changing individual in a changing world” (Riegel in Datan & Reese 1977: 15), a dynamic and evolving process. “Constructionism’s particular emphasis is in meaningful action embedded not within individual minds but within more extended patterns of interchange” (Gergen 1997b: 8). Because there were strong indications that earlier interactive events in the lives of adult carers contributed to their tendency to seek out caring roles in later life (Jones1992; Jones 1995), the study explored life stories. “Personality and one’s present circumstances clearly play a role in the reconstruction of memories of the past” (Meacham 1976: 305). Following this concept, the research found the stories that carers created to elaborate the meanings of their lives revealed constructions supporting their indications that caring opportunities were often compelling and defining life events. This in turn, illuminated the dichotomy of hassles and uplifts of everyday caring and, generally, the enigma of fulfilment through a role too often described as unrewarding.

To really know and understand those who give willingly to help others in need of care, more than just a snapshot in one time and in one landscape was required. What was essential was in-depth knowledge of the people, their stories, motivations and dreams –
their selves, in fact, as (re)constructed from a imaginary, remembered lifetime and (re)assembled in the present as a life story. A Verismo was called for that portrayed the drama of everyday life in the words and thoughts of informal carers.

Verismo (from the Latin for 'truth') was a movement that took place in Italian opera and literature toward the end of the 19th century. Examples of opera in the Verismo style include Mascagni’s Cavalleria Rusticana and Leoncavallo’s Pagliacci. Verismo was a reaction to grand themes and narratives in mainstream arts that were dishing out a steady diet of stories and operas about the nobility, great historical events, and so forth, on a grand scale. Verismo made a case for artistic use of contemporary everyday material in preference to the heroic or legendary. The movement also championed realism, simplicity and strict accuracy. Using the drama of everyday life, stories about ordinary people were raised to extraordinary heights. This challenge to mainstream Grand Opera can be compared to current challenges to grand scientistic theories and the shift to the interpretive postmodern ethnography that makes explicit use of the socio-cultural constructs of narrated reality and the scientist as translator, mediator and communicator (Huber 2001: [1]).

The forecasted outcomes of the present research effort were threefold. First, through their life stories, (re)created in the present, caregivers would construct reflections that drew upon ‘patterns of consequence’ as (re)told and (re)assembled from their remembered past, thus grounding and expanding the part that the antecedents to their informal care roles played in their imaginative narrated lives. Secondly, as importantly, on a micro level, the process of seeking meaning within the narrated story (Plummer 1983: 68) of these individual lives had potential to enrich those lives and enhanced the narrators’ capability to provide testimonies with the potential to benefit themselves as well as others in similar circumstances. Finally, the revelations and discovery of this research would provide opportunity to contribute to and expand the concept of informal care previously held by service providers in the health, social and voluntary care sectors through continuing discourse. Case studies, with their dual capacity for description and interpretation, ability to establish theoretical linkages between case studies and their richness of detail, have the potential to be a viable force in public policy settings (MacPherson, Brooker & Ainsworth 2000: 52).

By means of an innovative interview method, informal carers were invited into potential exploration of the forgotten, the suppressed, or the other through a dialogical reflexive posture (Gergen & Gergen 1997:4). This study’s methodological approach was based on concepts of how informal carers negotiated meaning with others in their everyday lives and, through reflexive (re)construction, developed their own ideas of their lives. Sampson (cited in Gergen 1997a: 11) argued, “All meaning, including the meaning of one’s self, is rooted in the social process and must be seen as an ongoing accomplishment of that process.” Meaning was thus expressed through remembered interactions. Narrative biography was seen as a representation close to those actions and interchanges and a means of sharing authority by enabling those researched to speak for themselves –to tell their own story (Gergen & Gergen 1997: 5-6). Remembered everyday events became powerful in that they reflected a present-day
meaning of the whole life. Thus, this Verismo approach to the quotidian provided opportunity to reflect a lived life rich with powerful thematic material. The universality of the drama of the ordinary was mediated through use of a biographic narrative method. The study’s concern was with needs, as opposed to drives, and those social psychological aspects that converge to make each individual’s story unique and different. “Autobiographical memory is an excellent tool for understanding the individual’s unique way of constructing self, others, and the external world” (Bruhn 1990: 102).
JUSTIFICATION FOR THE METHODOLOGY

The journey to a qualitative method and the narrowing of the road to a biographical narrative approach using case study was not a simple one. Arriving at this destination was the result of a personal journey, beginning naïvely in mainstream empirical thinking, progressing to a period of critical self-reflection spurred on by the work of Kenneth Gergen and others and finally, arriving at a commitment to a constructionist social psychology and the use of a narrative method. The following outlines that journey and its dialogical underpinnings.

Initially, quantitative tools that might describe personality ‘types’ were considered; several personality measures were explored including the Myers-Briggs Type Indicator (MBTI), a forced-choice, self-reporting inventory measuring stable personality traits. The MBTI is the most popular and widely researched of the instruments designed to measure the personality typology developed by Jung (Girelli & Stake 1993: 290). The MBTI is widely used in management (Bayne 1990, for example), but also has been used in such diverse research areas as exploration of nurses’ personality types (Allen 1994; Jain & Lall 1996) and even in to reconstruct Florence Nightingale’s personality type, based upon biographies and letters, to construe her typology (Dossey 1998). It has also been employed to determine physician personality types (Silwa & Shade-Zeldow 1994) and to elicit personality characteristics of hospice volunteers (Mitchell & Shuff 1995).

Next, the ‘Big Five’ or NEO Personality Inventory (NEO PI), a concise measure of the five major domains of personality, as well as the six traits or facets that define each domain, was considered. It is described as a measure that provides “a clear and concise description summarizing an individual's emotional, interpersonal, experiential, attitudinal, and motivational styles” (Costa & McCrae 1999: 1). Costa, McCrea and Zonderman’s work demonstrated considerable stability in responses to well-being measures over long intervals using the Big Five. “We can predict future happiness far more accurately from measures of past happiness than from such significant life circumstances as marital status, sex, race, age; . . . Stability thus appeared to be attributable to enduring dispositions in the individual rather than to continuities in these life circumstances” (1987: 304). In the view expressed by Costa et al, environment played a smaller role in subjective well being than had been commonly thought. Well-being appeared to be temperamental rather than temporal or environmental (1987: 299).

Beyond traits and types

At this stage of methodological possibilities, it was thought that perhaps personality measures held the key to unlocking the door of understanding personality within the informal care phenomenon. A review of the more recent literature on personality (Bruhn 1990; Diener 1996; Gergen & Gergen 1988; Lamiel 1981; McAdams 1994; Sarbin 1986), however, seemed to suggest that measurement of personality is, at best, one starting point, and not without its inherent flaws and fallacies (see Hogan, DeSoto & Solano 1977, for a balanced overview). Ultimately however, because the research problem involved “people’s constructions of meanings which have not been previously
explored” (Perry 1995: 1), the use of personality scales seemed hopelessly limited. For instance, Diener suggested that traits could be overused and limit understanding of a phenomenon (1996: 389) and that “traits are decontextualised and thus do not take into account interactions with specific cultural and social contexts” (1996: 396). It seemed necessary then to “set aside positivist assumptions and to replace them with other ways of conceptualising the human condition” (Sarbin 1986: vii). Further, McAdams argued:

The two most valuable features of trait information –its comparative and nonconditional qualities—double as its two greatest limitations as well. As persons come to know one another better, they seek and obtain information that is both noncomparative and highly conditional, contingent, and contextualized. They move beyond traits to construct a more detailed and nuanced portrait of personality, so that the stranger can now become fully ‘known.’
(1994: 146)

McAdams continued that traits say nothing about human lives being situated in time and, therefore, that to know a person well is to understand a life in time. “Even more richly contextualized in time are such constructs as life scripts and life stories, for they articulate a person’s internalized and evolving sense of who he or she was in the past, is in the present, and will become in the future. . . . A personality psychology that refuses to go beyond traits provides nothing more than a psychology of the stranger” (1994: 147).

According to Gergen & Gergen, the traditional concept of individual selves is fundamentally flawed (1988: 18). They explained, “one’s present identity is . . . not a sudden and mysterious event, but a sensible result of a life story” (1988: 19). The meanings of events are negotiated with others (1988: 38) and the actions of others contribute vitally to the events linked in a narrative sequence (1988: 39). Consequently, qualitative constructionist approaches suggesting better opportunities for exploration and discovery of multiple and “ambiguous personal meanings” (Plummer 1983: 82) of a dialogically constructed self as well as opportunities to unearth individual differences were needed. It was concluded, at this point, that the research question necessitated a move beyond mere traits and types.

“It is difficult and probably impossible to conceptualize a model of personality that does not presuppose the existence of an adequately functioning autobiographical memory” (Bruhn 1990: 95). Descriptive metaphors were sought, therefore, that would not solely aggregate individual personalities into group descriptions “computed on the basis of data summed across individuals, that virtually precluded their appropriateness as grounds on which to infer anything about the consistency or inconsistency of any one individual” (Lamiell 1981: 279; emphasis in original). Narrative psychology seemed a viable alternative to the positivist paradigm (Sarbin 1986: vii); the centrality of context in narrative (1986: xiii) seemed crucial. Ultimately, the narrative became a meaningful metaphor for examining and interpreting human action (1986: 19), beyond traits and types.


**Theoretical Explorations**

As life stories are based upon an exploration of past events to (re)construct present-day meanings, so too exploring the historical path to a narrative psychology formed a fruitful labour. Life-span developmental theory, therefore, was examined as one possible theoretical foundation for a narrative method. The work of Erikson, whose concept of ‘generativity’ forms the theoretical basis of McAdams narrative efforts in the last decade (McAdams & de St. Aubin 1992; McAdams 1993; McAdams et al 1997), was explored. Erikson described generativity as a psychosocial stage concerned with such things as new beings, new products and new ideas that link generations and renew the adult’s life whilst contributing to the next generation (Erikson 1980: 215). Intriguingly, Erikson characterised generativity as representing care: “. . . generativity must concentrate its care on those one cares for and can take care of—and more or less reject all others” (Erikson cited in Harvard Educational Review Editorial Board 1981: 254). Generativity includes productivity and creativity as well as procreativity (1981: 254). Thus, “generative action . . . includes the behaviors of creating, maintaining, and offering to others” (McAdams & de St. Aubin 1992: 1004). McAdams and de St. Aubin’s conceptual model described generativity as a constellation of psychosocial features, centred on the personal and societal goal of providing for the next generation (McAdams et al 1997: 679).

Of particular curiosity to this study was Erikson’s notion, developed late in his career, of generativity “revised and renewed” over the life-span (Erikson in Harvard Educational Review Editorial Board 1981: 252). Erikson’s concept of social embeddedness of identity formation, however, stressed the person’s strivings for a continuity of personal character, a “selfsameness” (1981: 254). This insistence on a ‘selfsameness,’ and Erikson’s descriptions of circumscribed ‘stages’ of ego development linked to age, age-related tasks and marked by threshold social passages such as marriage, and so forth (Erikson 1980; Erikson 1984), ultimately became problematic for this study.

To explore interpersonal response and effect in the face of shared life events such as illness and its subsequent caring responsibility, an evolving and changing personality construct embedded in the social world seemed crucial. There was some evidence that Erikson’s concept of the individual included environmental factors and a social embeddedness to identity formation. As early as the 1950s, Erikson’s colleague David Rapaport singled out Erikson’s psychosocial theory of development and the “epigenesis of the ego as involving mutual coordination between the developing individual and the social environment” (Wallerstein 1998: 231). For this study, however, the potential of personality development continuing through the adult years seemed to be less than central in Erikson’s theory. Although there have been recent revisionist attempts to re-examine Erikson’s “way of looking at things,” including “Erikson’s identity concept as a potentially interactional and dialectical conception spanning the entire life course” (Seligman & Shanok cited in Wallerstein 1996: 177), his stage theory of identity appeared to leave little room for theoretical manoeuvrability for this study.

The dialectic as an approach to life span development, therefore, presented another conceptual level open to theoretical exploration. “The dialectical approach . . . can be a
useful one for developmental psychology because of its primary emphasis upon activity and change rather than stability and permanence” (Meacham 1976: 304). At this point, it seemed productive to investigate approaches to identity within a developmental theory that would more forcefully establish the social construct of personality in a dialectical framework that evolves and changes over the life span adding versatility to the life span developmental approach. “A dialectical approach to memories and memory abilities requires attention to relations of reciprocal causality, both between the individual and society, and also within the individual” (1976: 306). In fact, the study of autobiographies (life narratives) provides examples of remembering at its most dialectical (1976: 308).

Wrightsman’s (1981) dialectic conception of adult personality, (as opposed to trait theory, for example), conceived personality as reflecting opposition within pairs of characteristics, where each is an entity with a quality of its own; these contending characteristics are always in a state of tension and cyclical and changing rather than stable. In dialectic analysis, therefore, a concept of balance or homeostasis is of no permanent value—the nature of behaviour is always changing and change leads to a synthesis of opposites in the form of a new structural integration (1981: 375). Wrightsman explained:

Such pushes and pulls are certainly not foreign to life script and stage theorist, too. What is different in the dialectic conception is the assumption that no equilibrium is ever established, no resolution ever achieved. In life script theory, equilibrium is the goal; in Erickson’s stage approach, disequilibrium seemingly serves only to move the person toward resolution of conflict. By contrast, Klaus Riegel, a radical dialectician, proposed that developmental tasks are never completed: “at the very moment when completion seems to be achieved, new doubts arise in the individual and in society” [Riegel, 1976, p. 697] . . . The most appropriate methodology for a dialectic analysis requires a set of materials—observations, interviews, questionnaires, or other data—collected or produced over an extended period of time. (1981: 336-37)

Riegel’s developmental dialectic with its approach to individuals within an interactive framework with society provided an additional theoretical framework for exploration. Riegel’s seminal work in the 1970s forged a reconnection between American and European thinking about human development (Youniss 1999: 145). In Riegel’s dialectical theory, the individual develops through a continuous process of thesis, antithesis and synthesis. Both the organism and the environment are inherently active, reflecting a changing individual in a changing world. Rather than searching for final answers, dialectic logic is concerned with the contradictory origin of the endless sequence of raising questions (Riegel 1976b: 372). Four progressions of events or levels of organisation --the inner-biological, individual-psychological, the cultural-sociological and the outer-physical-- are seen to interact, creating conflict or crisis, leading to the next developmental step (1976b: 386).

Riegel proposed “an understanding of the changing individual in a changing world” (in Datan & Reese 1977: 15); this presents the paradox that individuals, through their activities, change the cultural-historical conditions at the same time as changing the
individuals (1977: 16). Riegel saw the major events affecting individuals over a life span as arbitrarily induced upon them by social and legal regulations and that only the inner-biological determinants seem to follow a predictable order (1977: 23). Riegel felt that experimental and developmental psychology had "failed to recognise that objectified expressions or products are experientially empty for the individual unless they are understood within the context of the individual's experienced past and anticipated future" (1977: 27).

Gergen (in Datan & Reese 1977), writing in the same volume as Riegel, (reporting on a conference in West Virginia to which they both contributed), paid tribute to Riegel's dialectical theory in supporting his own "aleatory" (depending on an uncertain event or contingency as to both profit and loss) framework (1977: 150). The aleatory orientation or "continuous change" is concerned with development during adulthood, changes in the life cycle and their effects upon personality and individual differences brought about by cohort effects (1977: 149). "At any point we may symbolically reconstruct our past, present, or future—with resounding consequences for our social conduct; . . . self-conception is constantly being reshaped as the individual engages in relations with others" (1977: 151). "Within the aleatory domain, dialectical theory has clearly had the strongest valuational impact. As dialecticians maintain, positive change depends on confrontation of thesis and antithesis; progress thus depends on crisis" p. 154).

Riegel (1975a) posited, "In moving beyond the concepts of stable traits and patterns of equilibrium toward developmental dialectics . . . a comprehensive view of the human being can be realised only when we conceive of changing individuals as the develop in a changing social-historical world" (1975a: 349). Dialectic theory seeks to describe concrete event sequences in the individual and equally concrete sequences in society (1975a: 394). Each individual co-ordinates and transforms the conflicting events of his experience into his own sequence of development (1975a: 400). Each individual, therefore, co-ordinates and transforms the conflicting events of his experience into her/his own (her/his)story.

Gergen’s social constructionism further elucidated “the processes by which people come to describe, explain, or otherwise account for the world in which they live” (Gergen & Davis 1985: 3). Social constructionism places the self-concept within the sphere of social discourse (1985: 11). Gergen believed that “people have experiential access to their psychological states. Such states are essentially given in personal experience. To the extent that this is so, psychological discourse might properly be grounded in people’s experience of self” (1985: 114-15). Shotter (in Gergen & Davis 1985) added, “If we are to discover what we are in our everyday activities to one another, then we must study our everyday accounting practices—not just a few selected activities taken as models for all the rest . . . but in the whole interlocking ecology in which such practices occur” (1985: 167). In these accountings of ourselves, “such tellings work to structure our mental capacities, our psychological makeup, as the persons we are” (1985: 170). Shotter argued that there is no such thing as “a self” within people to be investigated (1985: 171). Further, Gergen and Gergen (1983) had stated, “The manner in which the contemporary activities can be described depends
importantly on one’s understanding of the history of the participants. That is, one’s description of the moment is embedded within a historical narrative” (1983: 150). Conclusively, narrative forms are a chief means of self-portrayal (Gergen 1999: 9).

**The narrative approach**

It is an essential characteristic of narrative to be a highly sensitive guide to the variable and fleeting nature of human reality because it is, in part, constitutive of it. This makes it such an important subject of inquiry for the human sciences in general and for psychological and anthropological investigations in particular . . . . Narratives are both models of threshold and models of the self. It is through our stories that we construct ourselves as part of our world.

Brockmeier and Harré, 1997: 278-79

Freeman (1984), in an attempt to understand the relation between the particular and the general, looked to life-span developmental knowledge within a historical framework and, therefore, conceptualised development through a dialectically informed narration. Influenced by Gergen’s concept of the ‘aleatoric’ perspective (1984: 2) and Riegel’s dialectical orientation, with its emphasis on reciprocal interaction and as a “metacontext for the formulation of research questions and the organization of data interpretation” (1984: 11), Freeman proposed narrative as a way of ordering the “landscape of events” (1984: 7). “The fact that particular forms of knowledge derive from retrospection, from an essentially backward look over the terrain of experience, is an irreducible ‘peculiarity’ of the human being” (1984: 9). Freeman viewed the structure of the narrative as representing the imposition of a continuous account upon discontinuous data (1984: 10). Importantly, he saw non-normative life events becoming more salient in the adult years (1984: 11).

“For at least a portion of the task of a life-span psychology, the explication of human change can be nothing short of a narration founded not only on the dialectic of influences contributing to the formation and re-formation of the experiencing subject, but (of) the dialectic . . . . of the researcher and the researched. This leads us to the hermeneutical situation” (1984: 12). Additionally, the comprehensive study of development must involve the study of culture and society as well as individuals (1984: 15). Freeman suggested a “life course study” or a “life-span developmental anthropology” that reveals the self-constructed, perpetually revised ‘telos’ that emerges out of one’s “personal narrative” or “life theme” that one sets and attempts to approximate throughout the duration of the life course (1984: 15). Critically, Freeman saw the problem of development as the necessary dialectic between the researched and the researcher (hermeneutics) and that it is established at the intersection of immediate experience and recollection (1984: 16). “The shape” (Gestalt) “that emerges out of the past extends itself into the future. It is this temporal dialogue which can lay the foundation for a new conceptualisation of life-span developmental knowledge” (1984: 17).

It was concluded that adopting a narrative rather than an empirical mode of inquiry allowed this investigator to get closer to the phenomena studied in several ways. First,
the narrative provided access to the specific rather than the abstract; secondly, narratives allowed experience to unfold in a temporal way; thirdly, everyday language and its nuances were encouraged; finally, narrative allowed family dynamics to reveal themselves in the actions and relationships presented (Chesla 1995: 73.) The use of a biographical approach to understanding human concerns made sense in that its methodology transcended the barriers of self/society as well as those of past/present/future (Miller 2000: xiii). “The rising popularity of biographical research tools may well lie in their aptness for exploring subjective and cultural formations, and tracing interconnections between the personal and the social (Chamberlayne & King 2000: 9).

**Hermeneutics, or interpretive phenomenology**

The issue is not what methodology is ‘best’ . . . rather, the issue is, first, what it means to be a person; then in light of our answer, how we ask our research questions; and finally, how we answer the questions we pose. (Leonard in Benner 1994: 44)

The understanding sought in interpretive phenomenology considers historical change, transformations, gains, losses, temporality, and context. (Benner 1994: xv)

The goal of a hermeneutic, or interpretive, account is to understand every day skills, practises, and experiences; to find commonalities in meaning, skills, practices, and embodied experiences. (Leonard in Benner 1994: 56)

Gergen (1997a) stated, “Hermeneutical deliberations serve the valuable function of thwarting the modes of depersonalisation so common to the empirical research tradition” (1997a: 6). Freeman (1984) viewed life span psychology from a hermeneutical orientation, not concerned solely with the “properties” of development per se, but with its writing (1984: 12). It is the ‘mine’ and the ‘other’ that allows interpretation to take place, a circular movement. “Essentially, the task of interpretation necessitates critical self-reflection for there to be validity, a respect for the autonomy of the text” (1984: 12). The data itself, therefore, becomes the ultimate reference with its “seeming refusal to fit into tightly sealed categories or schematisms” (1984: 14).

Freeman continued:

A narrative perspective has not been set forth here simply because the influences at work are just so complex that prediction is not possible—though this is apparently the case; nor has it been set forth out of some blind urge to bring romanticism back in to psychology –though this is probably operating also. The belief in human freedom and purpose certainly enters in, but this has not been the main focus either. What calls for the recourse to narrative is the ineradicable asymmetry between the knowledge that derives from looking forward in time and that which comes from looking back. (1984: 14)
Science consists of many knowledge-generating activities, each with strengths and weaknesses (Hoshmand & Polkinghorne 1992: 59). In approaching the study of human interaction, and the experience of anything to do with meaning, such meaning must always be a case and product of interpretation (Shusterman in Hiley, Bohnan & Shusterman 1991: 102). Interpretation incorporates explanation, definition, explication and construction. Hermeneutics is the theory and practice of interpretation and understanding in different kinds of human contexts (Chesla 1995: 65). Hermeneutics itself is based on an interpretation of Martin Heidegger's philosophy of science that recognised science as a cultural practise; Heidegger saw the human sciences as a double hermeneutic, as interpretations of interpretations. Heidegger made a shift from considering the problems of epistemology to considering the problems of ontology, that is, of what it is to be a human being (Leonard in Benner 1994: 43).

Building upon the work of Heidegger, Bakhtin enriched hermeneutics with the concept that human beings are constituted in conversation with the implication therein that dialogue is at the centre of human activity. The fact that interpretation always takes place within some context or background further makes the claim for ‘hermeneutic contextualism.’ Hermeneutic practise in research recognises that there is the possibility of many equally acceptable interpretations. This possibility assumes that we share belief systems and practises with others with whom we engage in dialogue or practise common activities. In the Continental tradition, this method is identified as philosophical hermeneutics whilst in Anglo-American philosophy it is seen as a renewal of pragmatism. (Hiley, Bohnan & Shusterman 1991: 5-13) “In this pragmatic sense, theories are instruments for transforming reality, rather than mirroring representations of its putative essential and invariable features” (1991: 13).

Kuhn (in Hiley et al 1991) stated, “The social sciences . . . appear to be hermeneutic, interpretive, through and through. Very little of what goes on in them at all resembles the normal puzzle-solving research of the natural sciences” (1991: 22-23). Their aim is, or should be to understand behaviour, not discover laws. Rouse (in Hiley et al 1991) added, “The human sciences are essentially self-interpreting agents for whom their actions are significant, whereas the natural sciences deal with objects that need not be, indeed should not be, understood as self-interpreting” (1991: 43-44; emphasis Rouse’s). Hermeneutics is the attempt to converse across differing standards and vocabularies without reducing them to a common framework (1991: 45). According to Rorty (in Hiley et al 1991), the objects of hermeneutic inquiry include recontextualising what is at hand—the desire to know essence—characteristically a human concern (1991: 80). The desire to dream up as many new contexts as possible “. . . is manifested in art and literature more than in the natural sciences, and I find it tempting to think of our culture as an increasingly poeticized one, and to say that we are gradually emerging from scientism ...into something else, something better” (1991: 80).

“Hermeneutics insists on holding fast to the insider’s perspective as the source from which all reflection, including philosophy, ultimately originates” (Guigon in Hiley et al 1991: 96). Heidegger sensed of our ‘being in the world --Dasein,’ our contextual involvement, and this was the bedrock of all his theorising (1991: 99). Heidegger wrote,
"Dasein ist bei der Welt", meaning, "dasein inhabits or dwells in the world" (Blattner 2000: 5) Evaluating a history is not the same as the evaluation of a hypothesis in the natural sciences (Roth in Hiley et al 1991: 189).

“Located in a hermeneutic circle of (re)interpretation, narratives with common story elements can be reasonably expected to change from telling to telling, making the idea of empirically validating them for consistency or stability completely alien to the concept of narrative truth. Misguided efforts to verify findings (for example, the use of test-retest and interrater reliability kinds of measures) suggest a misplaced preoccupation with empirical rather than narrative standards of truth and a profound lack of understanding of the temporal and liminal nature and vital meaning-making functions of storytelling” (Sandelowski 1991:165). “The strangeness of the hermeneutical process is that the situation or context in which things come to be seen as the things they are, is constructed or articulated at the same time as the entities within it acquire their identity; the two develop together” (Shotter in Gergen & Davis 1985: 181).

RESEARCH PROCEDURES

Choosing a method
Because of the preceding exploration of the theoretical possibilities, a decision was made to use a hermeneutic approach, building upon a dialectic life-span theoretical metacontext, and based within the general rubric of social constructionism. A methodological framework was designed concentrating on biographical narrative interviews with a reflecting team approach (Gergen 2000a: 6) to in-depth field analysis of the data using inductive reasoning. A biographical interview technique was seen as the key data gathering event of the method, whilst the reflecting team approach to data analysis, with its inevitable plurality of perspectives, was conceived as a rigorous method of establishing validity through hypotheses building and testing and multiple viewpoints.

Mishler (in Sarbin 1986) reminded researchers that the false assumption exists in much of the literature on interview method that we all ‘know’ what interviewing means, at least if we are members of a research community, and that it is essentially unproblematic as a method (1986: 10). “Essentially, the mainstream tradition [of interviewing] has focused almost exclusively on problems of standardization, that is, on how to ask all respondents the same question and how to analyze their responses with standardized coding systems. This line of inquiry has been accompanied by almost total neglect of the intertwined problems of language, meaning, and context –problems that are critical to understanding how interviews work” (1986: 233-4). The gold standard of ‘semi-structured probes,’ used in much of social science interview research in the past several decades, is too often based upon the predetermined assumptions built into the researcher’s questions. This kind of interview schema seemed less that adequate for a hermeneutic, holistic approach. An interview method was explored, therefore, that incorporated the possibility of working with two key concepts: 1. That carers’ stories are unique and individually constructed wholes, and 2. That what they had to say about
their lives and self-concepts was much more illuminating than any specific research assumptions or questions could have been.

The interview/case-study approach ultimately selected for this research was based on training in a method of biographical-narrative interviewing and analysis developed by Chamberlayne and Wengraf, Centre for Biography in Social Policy, University of East London. The Biographic Narrative Interpretive Method (Chamberlayne et al 2000; Wengraf 2001) is based on a method developed in Germany in the early 90s by Rosenthal and others and evolving from Shuetze’s 1976 method of story and text analysis and Oevermann’s 1980 objective hermeneutical case reconstruction (Rosenthal & Bar-On 1992: 109). This dynamic and interpretive method, with its emphasis on action and latent meaning, distinguishes it within the broad and rich range of life history, oral history and narrative approaches (Chamberlayne & King 2000: 17).

“This objective hermeneutic method proceeds on a step-by-step basis, with each supposition or proto-hypothesis being immediately evaluated against interview transcript material. ‘Hermeneuetic’ since the researcher is aware that any material being produced by the interviewee has been generated with regard to both the interviewee’s subjective perception of his/her situation and history and the interviewee’s perception of the research and the relationship between the two of them” (Miller 2000: 131).

The nine-day Biographic Narrative Interpretive Method training took place in three three-day sessions over three months. The key features of this method lie in “distinguishing and then analysing the interplay between two levels of analysis: the practical life events and the self-biographising theory of the life” (Chamberlayne & King 2000). It is based in a grounded hermeneutic approach and refers to the social context for the interpretation of individual cases, actions and meanings (Millar 1998: 2). Although sociological in its approach to narrative analysis, this particular method seemed to offer manageability and adaptability within the social psychological constructionist framework of this study. Additionally, the Biographic Narrative Interpretive Method struck resonance with an earlier and similar social psychological method explored by the investigator that was developed by De Waele in Belgium in the 1970s.

De Waele developed his biographical method while working for the prison system in Belgium as a means of assessment of prisoners’ eligibility for parole (Van Langenhove et al c.1986). De Waele’s theory, called the ethogenic theory of human performance, grew out of the mounting criticism of trait theory in the mid 1970s. De Waele believed that information gathered and organised around a single individual enables us to conceive of a person as a process in time (Harré 1976: 221). Based on work by Shotter and others, De Waele believed that only by paying attention to biography could we understand individuality (Harré 1976: 191).

Harré (1993) later described De Waele’s two main methods: 1. The participant prepares an autobiography that is partitioned into time slices, each representing a distinct phase in life; a team of investigators is each offered a slice and has the task of reconstructing the rest of the biography, using common sense and psychological knowledge. The reconstructions are negotiated within the teams and then with the participant. In the
final phase, the products of these are brought together into an agreed version. 2. A different set of investigators is given a different partition of the autobiography, this time divided into theme slices, such as work, education, relations, and so forth. A similar process of reconstruction and negotiation is undertaken, and another agreed biography is produced. In the last phase of the investigation, the time reconstruction and the theme reconstruction are finally brought together. The participant is then expected to relive episodes and reflect upon his/her present life and experiences in the past (1993: 220-21). "The analysis of autobiographical material is not a self-contained technique. Its usefulness lies in its subordination to the more encompassing goal of biographical reconstruction" (Harré 1976: 213).

De Waele's method included four steps: 1. Identifying topics mentioned by the author; 2. Identifying elements then grouping them into units composed of coexisting or sequential elements; 3. Chronological ordering of the thematic units; and 4. Thematic units and focal analysis brought into correspondence by interviews with the participant who is encouraged to explicate the meanings therein (1976: 231). De Waele commented, "We are simply trying out some Gestalt-psychological ideas in the field of Personality Assessment" (1976: 235).

The main differences between the Biographic Narrative Interpretive Method and the De Waele method are found in the participant's role. In analysing and reconstructing the narrative, De Waele made more direct use of the participant. Secondly, the Biographic Narrative Interpretive Method protects the Gestalt of the narration by refraining from coaching the narrator with predetermined themes, categories or phases. Thirdly, in the Biographic Narrative Interpretive Method, because the participant does not take part in reconstructing the narrative, the main contribution of the participant is made in the interview narrative itself. Finally, a major methodological difference lies in De Waele's use of written autobiography as opposed to the Biographic Narrative Interpretive Method's use of a narrated life story.

**Overview of the Biographic Narrative Interpretive Method**

The Biographic Narrative Interpretive Method interview technique uses a single, initial narrative-inducing question ("minimalist-passive," [Wengraf 2000: 10]), for example, 'Tell me the story of your life,' to illicit an extensive, uninterrupted narration. "This apparently simple request has led to a quiet revolution in social science practice. For it even to be seen as a legitimate query required a shift in paradigmatic viewpoints about the nature of the social scientific enterprise" (Miller 2000: 1). This claim not to probe, guide or ask questions and its potential for revealing the flux and contradictions of everyday subjective reality, is in itself a theoretical orientation closely allied to symbolic interactionism (Plummer 1983: 123).

Alternatively, however, within the Biographic Interpretive Narrative Method, response can be more targeted by a single narrative question that is directed to a thematic or temporal area of the participant's life story, for example, "Tell me the story of your life as a carer." Nonetheless, the use of the 'whole life story' question, as opposed to an initial question more specifically targeted at participants' carer stories, was a major choice in
the decision-making process for this research. It was decided that the ‘carer story’ question alone might not necessarily elicit in-depth narration with the potential of extracting a developmental sense of personality and the participant’s journey ‘towards’ a caring role. The use of the ‘whole life story’ probe, it was hypothesised, had the potential to illuminate that personal journey. Rosenthal (1993) supported this decision: “If the interviewer does not set a specific topic but asks the biographers in a general way to tell their life story, the biographers themselves will select those topics that are relevant. This method has the advantage of allowing the researcher to learn how the biographers—if at all—are embedding the topic of research interest in the presentation of their life story” (1993: 89).

In the Biographic Narrative Interpretive Method, the first interview is followed by a second session, based upon the Gestalt of the first and reflecting the ordering of themes presented by the interviewee in the initial interview. Gestalt is central to the theoretical principles of the method and has been defined by Hollway and Jefferson (2000) as “a whole which is more than the sum of its parts, an order or hidden agenda informing each person’s life” (2000: 34). After the second interview session, additional material can then be utilised to build the case, including the possibility of a follow-up third interview with more focused probes as well as the collection and discussion of ancillary materials such as diaries, writings, photographs, and so forth.

Microanalysis of the narrative of the reconstructed life follows the interview stage. The ‘lived life,’ or chronological chain of events as narrated, is analysed sequentially and separately. The ‘told story,’ or thematic ordering of the narration, is then analysed using thematic field analysis, involving reconstructing the participants’ system of knowledge, their interpretations of their lives and their classification of experiences into thematic fields (Rosenthal 1993: 61). “The thematic field is defined as the sum of events or situations presented in connection with the themes that form the background or horizon against which the theme stands out as the central focus” (1993: 64). Objectivity is maintained by keeping each stage of the analysis discrete as well as involving different teams of researchers in a team process of hypothesising and developing the themes (Millar 1998: 3).

“Originally, life story referred to the account given by an individual about his or her life. When this personal account was backed up by additional external sources . . . the validated life story was called a life history. This concern with triangulation – the validation of narrated life stories through information from additional, preferably quantified, sources has not remained central to most current biographical practice. Nowadays, . . . ‘life history’ refers to a series of substantive events arranged in chronological order. . . . ‘Life story’ still refers to the account given by an individual, only with emphasis upon the ordering into themes or topics that the individual chooses to adopt or omit as s/he tells the story” (Miller 2000: 19).

“Life story and life history always come together. They are continuously dialectically linked and produce each other; this is the reason why we must reconstruct both levels no matter whether our main target is the life history or the life story” (Rosenthal 1993:
The biographical details and themes are then tested against in-depth analysis of the text, examining hesitancy, repetition, contradictions and pauses. Through hypothesising how the lived life informs the told story, the case history is then finally constructed from the two separate threads of the ‘lived life’ and the ‘told story.’ A case structure is then formulated that validates more than one event based upon the actions of the interviewee.

**Other narrative approaches**

“This is an exciting time for narrative researchers, a period of rapid growth in the number and variety of narrative studies in the human sciences” (Mishler 1995: 87). Mishler proposed a typology of approaches to narrative studies that focuses on which of three alternative problems are defined as the central task for narrative research:

- reference and the relation between temporal ordering of events and their narrative representation
- textual coherence and structure, and how these are achieved through narrative strategies
- psychological, cultural, and social contexts and functions of narratives.

Within each of these general categories, subclasses are distinguished in terms of the specific ways in which the central problem is addressed (1995: 87). An in-depth recounting of Mishler’s typologies will not be attempted here, except to say that within the subclass of psychological, cultural and social contexts, the category "Narrativization of experience: Cognition, memory, self" paralleled the aims of this study. Key to this category is “the construction of a personal narrative as central to the development of one’s self, of an identity” (1995: 108); this made sense within this project’s goals. Additionally, Mishler stated that reports of this process typically take the form of summaries of ‘cases’ (1995: 109).

Miller (2000) has proposed another typology to the approaches to biographical investigation: the Realist, the Neo-positivist and the Narrative approaches. The Realist approach uses unfocused interviews, focused around grounded theory techniques and is, therefore, inductive; the Neo-positive approach uses focused interviews, is deductive and theory testing; and the Narrative approach emphasises the active construction of life stories through the interplay of interviewer and interviewee where the past and future are seen through the lens of the present (2000: 10-13). “The three approaches delineated above can overlap considerably in practice” (2000: 14), however, there are real differences of substance between the approaches (2000: 18).

The approach chosen for this research (Biographic Narrative Interpretive Method) has resonance with Miller’s “Narrative approach.” Although distance is kept between the interviewer and interviewee by the nature of the single probe/active listening interview, the interplay between the interviewer and interviewee is still a central concern, but not until analysis. This minimal approach still acknowledges that the interviewer’s
characteristics are bound to affect the course of the interview and that this should be recognised (2000: 101). “Ultimately each interview is a product of the mutual interaction between speaker and listener” (Rosenthal cited in Miller 2000: 129).

McAdams (1996) has devised a framework for the narrative study of persons that includes investigating the psychosocial construction of life stories through which modern adults create identity. McAdams proposed that personality description encompasses at least three independent levels: (a) dispositional traits, such as the Big Five; (b) contextualized concerns, such as developmental tasks and personal strivings; and (c) integrative narratives of the self. The third level (narrative) is the level of identity. (McAdams et al 1997: 679). McAdams (1996), in analysing more than 200 accounts from life-story interviews, proposed the following as structural features of the content of life stories: Narrative Tone, Imagery, Themes, Ideological Setting, Nuclear Episodes, Imagoes and Endings (1996: 308-09). McAdams et al (1997) also developed a conceptual model of generativity, based in Erikson’s stage theory, as a constellation of seven psychosocial features, centred round the personal and societal goal of providing for the next generation (1997: 680).

McAdams et al (1997) combined qualitative emphases with the conventions of quantitative research by use of quantitative content analysis of the narrative data within the convention of a control group (1997: 681). The narrative-gathering process itself asks the participant to divide his/her life into ‘chapters,’ provide a title and plot summary for each, delineate and describe eight specific scenes or nuclear episodes divided into high-points and low-points, turning point, earliest memory, significant childhood, adolescent, adult and other significant memories. Next, the participant is asked to identify and describe the four people who have had the biggest impact on their story, identify a personal hero or heroine. After that, the participant is asked to describe what he or she sees as the future chapters of the story. The process continues, asking for more specific story related to such areas as hopes, dreams, and so forth, areas of conflict, ideology, religious beliefs, political views, philosophy, and so forth, and finally, a possible dominant theme or message in the whole of the story.

McAdams has sought a “methodological and epistemological middle ground” and believes that “careful” research can lead to the kinds of interpretations that are useful for life stories (1997: 690). The methodological underpinnings in McAdams’ work were considered more congruent with the aims of this study than was his research method itself.

Hermans et al (1992) have conceived the self as a dialogical narrator, a multiplicity of dialogically interacting selves (1992: 23). Hermans (2000) described three suppositions that underlie the narrative approach:

- Stories acknowledge both the perception of reality and the power of imagination
- Space and time are basic components of storytelling
Both the storyteller and the actors in the stories are intentional beings who are motivated to reach particular goals which function as organising story themes in their narratives. (2000: 4)

A narrative theory of the self, based on the metaphor of the motivated storyteller, is nested in Hermans' valuation theory. "The notion of story is expressed in the central term 'valuation' as a process of meaning construction" (2000: 8). Hermans' uses a self-confrontation method in which a person is invited to perform a thorough self-investigation constructing a set of valuations, elicited by a series of open-ended questions, rating each of the valuations and discussing the results (2000: 8-9). Hermans' self-confrontation method, like McAdams' method, is based on a combination of qualitative (valuations) and quantitative data (affective indices) (Hermans & Kempen 1993: 149). Valuation theory is not a final theory; "it is devised as an open framework in development . . . to investigate a diversity of psychological phenomena as a process of organization, disorganization, or reorganization of the valuation system" (1993: 23). Hermans' research takes place in a clinical setting and is, therefore, more therapeutically constructed than the design of this research effort.

Hollway and Jefferson's (2000) work is based in the theories of psychoanalyst Melanie Klein about how the self is forged out of unconscious defences against anxiety (2000: 19). These defences are intersubjective, that is, they come into play in relations between people (2000: 20). The authors incorporated this idea of the defended subject within a narrative method based loosely upon Chamberlayne and Wengraf's Biographic Narrative Interpretive Method, making a case for the relationship between people's ambiguous representations and their experiences, or "critical realism" (2000: 3). The inner and outer worlds of their subjects made up what the author's termed the "psychosocial" (2000: 4)

Hollway and Jefferson make use of free associations in order to elicit hidden meanings and incorporate the defended subject within the biographical interpretative method. Thus, ultimately, the authors remain indebted to psychoanalysis, both theoretically and methodologically. Their "subjects" are not only positioned within the surrounding social discourses, but are also seen as motivated by unconscious investments and defences against anxiety. The data production is based upon the principle of free association and data analysis is dependent upon interpretation (2000: 77).

Methodological tools are championed that parallel psychoanalysis, including the unconscious intersubjective dynamics of the interview relationship and therapeutic concepts such as countertransference, recognition and containment. The authors make a case for using "a method based on the principle of working with the whole data and paying attention to links and contradictions with that whole" (2000: 5), in contrast to the widespread tendency in qualitative research to fragment data by using code and retrieve methods.

The work of Hollway and Jefferson was important to this research in that it solidified concepts of reflective practise within the narrative interviewing experience and clearly delineated psychoanalytical concepts useful to a social psychological approach to
interpretation in narrative biography. The authors’ successful reinterpretation and expansion upon the original Chamberlayne and Wengraf method was helpful in substantiating this project’s diversions from the originating method as well.

**Sample size**
Because the Biographic Narrative Interpretive Method chosen for this research required extensive interviews with follow-up sessions as well as intricate and labour-intensive analytical procedures, the sample frame was necessarily small. A sample size was projected initially, but remained fluid throughout the research process (Benner 1994: 107). Sample size was limited by the size of the text that was generated and the number of colleagues and the amount of time available to analyse the text. Richness of data and thorough and meaningful analysis involving the assemblage of these colleagues into reflecting teams to explore and hypothesise themes necessitated the limiting of the number of interviews to be analysed in full. Efforts were made, nonetheless, to insure that the initial selection of subjects for interview included a diverse range of participants with varying demographic and family relationship backgrounds (Chamberlayne & King 2000: 16-17). Seven informal carers were interviewed. What may have been lost in not using a method with the potential for larger numbers of subjects, producing large data sets, was more than compensated for by the method’s capacity for deep and meaningful case studies. These case studies are rich with potential for the discovery of new material and room to generate further hypotheses, effect change in social policy and ultimately validate and illuminate informal carers’ lives.

It was decided, therefore, to engage in a research progress that would ‘narrow-in-place’ the final case studies to be presented. This process offered two advantages: 1. By beginning with a larger number of interviews than the number that were ultimately thoroughly analysed and constructed into full case studies, demographic diversity could be included in the preliminary and exploratory research and reflected upon in the final reporting; 2. Cases to be analysed in depth, using the reflecting team approach, were chosen selectively, based upon on-going feedback from the analytical sessions and the potential for further discovery through the reflecting team approach. This honing process assembled a few intensively explored case studies that benefited from the information and background materials built by the larger number of cases, while, at the same time, produced the depth of material and analyses that would have been impossible to attain with a larger sample study. Further, there was great advantage in studying an individual in depth and over ‘remembered’ time, as biographical work has shown (See Wrightsman, for a description of autobiographies as “repositories of self-schemata” [1981: 380].) The advantage to this study was that the scrutiny and time typically allotted to well-known individuals in biography produced a Verismo developed from the stories of people who, by comparison, live ordinary lives.

**The Interviews**
Leicester, because of its size and ethnic diversity, presented a rich pool of participants for this study. Letters were sent to local carer organisations requesting that they act as facilitators in recruiting participants for interview (Appendix: 202). It is important to
mention at this point that developing relationships, both personal and professional, with the facilitators within carer organisations was crucial to the on-going process of securing interviews. In addition, these developing relationships provided valuable resources after the interviews as well, including the processes of debriefing and reflection. Participants were encouraged to continue to ‘tell their story’ and use the resources of the carer organisations for support post interview. These facilitators also provided a crucial ‘bridge’ between the interview and available support services within the organisations.

One potential limitation in using carer organisations was that many informal carers continue to care with little or no contact with informal carers’ organisations and, therefore, would automatically be excluded from the frame. On the other hand, many carers who, for a time, cared in isolation and without the support of carers’ groups, and so forth, did eventually become involved with such organisations. The experiences and stories of these particular carers were valuable to the research in that they not only represented the history of isolated caring activity, but also presented the events and circumstances that formed the impetus to seek out support through a carers’ organisation. This use of a narrative research approach to data collection exemplified its advantages over more positivistic methods that would necessitate the categorisation of carer types, i.e., methodological limitations that would make it necessary to categorise carers who either attend carer organisations, or those who do not.

Once agreement to participate was secured, interview dates and times were arranged. Interviews were held at the facilitating carer organisation where the participant would feel comfortable and in familiar surroundings. Introductions were made and the participant was asked to read and sign a release form (see Appendix: 203). The participant was told that the interview would be tape-recorded and was given a clip-on microphone to attach to clothing. All interviews were audio recorded in their entirety. The interviews, based upon the Biographic Narrative Interpretive Method, began with the single probe,

*I would like you to tell me the story of your life. Take as much time as you would like. I am not going to interrupt you, but I will be taking notes. When you are finished, we will take a break for about 15-20 minutes. When we resume, I will be asking you a few more details based upon my notes of what you have told me.*

Except for confirming utterances, eye contact, body language, and so forth, no further interjections were made by the interviewer. If a participant was ‘stuck’ and did not know what to say or how to go on, phrases like “*Take your time,*” and so forth, were used to reassure the participant, but no new questions were posed. This attentive listening “*draws the stories out of their hide-away . . . expectant listening seems to be an indigenous part of all stories or narratives*” (Wyatt in Sarbin 1986: 200). Crucially, the Gestalt of the participant’s story was maintained by this method of non-interruption. “*Eliciting open-ended narratives provides a window on the very structure of individuals’ representations . . . stories allow researchers to see the Gestalt—the interrelations of*
structural linkages that individuals perceive among positive and negative attributes and experiences (Murray & Holmes 1994: 660).

Most initial interview sessions lasted from forty-five minutes to an hour. Usually the session was ended by the participant stating, “That's about it” or “Well, that's my story.” In no case was the session ended by the interviewer, even in cases when the participant was searching for something to say. Silences were maintained without interjection by the interviewer, unless the participant asked for help. In those instances phrases like, “Well, tell me more about your life,” and so forth, were used to help the participant. “If we allow respondents to continue in their own way until they indicate they have finished their answer, we are likely to find stories; if we cut them off, . . . if we do not appear to be listening to their stories . . . then we are unlikely to find stories” (Mishler in Sarbin 1986: 235).

During the interval the participant was ask to fill out a single sided questionnaire of background information (see Appendix: 204). During this time, the interviewer read through the notes taken in session one and looked for developing themes and phrases or areas of story that could be expanded upon. After the break, the participant reattached the microphone and session two began. The themes and stories to be elaborated upon were presented in the same order, using the same words that the participant had used in session one, and, therefore, maintaining the Gestalt of the narrative established in the earlier session. “The question is strictly for more story, designed to elicit more narration about the themes and topics initially raised” (Wengraf 2000: 19). Typically, the second session lasted a half-hour to forty-five minutes. The session ended with the interviewer asking if there were anything that the participant would like to add or felt that he/she had missed. If not, the interviewer then suggested a follow up telephone call for any further input from the participant and to have an opportunity to correct any biographical details such as names, dates, and so forth. The participant was then thanked and the session ended. At a later date, a thank you letter was sent to the participant (Appendix: 205) and the organised follow-up phone call was made.

In one early case, a third follow-up interview was conducted to test the method to its widest extent, but also to expand and enrich the material from the earlier two sessions. In certain circumstances, when important underdeveloped themes of a particular interview suggested productive follow-up questions, a third interview session is necessitated. At this particular interview it was possible to probe for more specific information that took into account the ‘read’ of the initial sessions and the interviewer’s impressions of the lived life and told story. Because this was the first time that the interviewer’s responses to the manifested data formed questions, the Gestalt of the told story had not been interrupted or broken. It was at this time and place that, finally, the interviewer directly responded to the participant’s story with enquiries based on the researcher’s reflections and early interpretations. The questions, nonetheless, were based upon dialogue from the story as presented in the original sessions, although not necessarily in the same order. Themes were drawn together and presented as probes, encouraging the participant to relate to the possible connections indicated by the
interviewer’s questions --based upon early interpretations of several possible themes. In this singular case, the participant was asked to bring photos, documents, and so forth, to the third session for discussion, exploration and elaboration of the life story. Such ancillary materials “acquired outside the boundary of the interview but still within the boundaries of the study” (Mishler in Sarbin 1986: 247) were crucial in building this case. Photographs were particularly helpful in unearthing periods or stories in the participant’s past that had been difficult to describe during the first sessions.

Session debriefing notes were compiled by the interviewer as soon after each session as possible in order to get down on paper the initial feelings, responses, concerns, and so forth, raised by the interview. Next, the researcher listened to the recorded interview and took notes from the ‘second hearing,’ ideally at least a week or two later. When the researcher typed the word-for-word transcript, notes were also made. These initial debriefings were necessary and central to understanding the interview process. These free associating exercises provide an opportunity to express the interviewer’s experience and ideas about the session, including obstructions (Wengraf 2000: 39). The accumulated notes became crucial documents for later reflection by the researcher and supported the use of relational metaphors in understanding “the problem,” the actions taken (or not) and the relationships “among the interlocutors themselves” (Gergen 1999: 8).

Next, the biographical data chronology of the life story was compiled. It was here that a biography (names, dates, events, and so forth), was constructed in chronological order and in a brief, telegraphic format. Finally, the text structure sequentialisation of the told story was constructed.

An exploratory full pilot interview (three interview sessions over two days) was conducted during and immediately following the period of the East London training. Because of the complicated spousal medical history presented by this initial participant, questions arose concerning her husband’s medical story. It was decided to set up a ‘case study’ session based upon the participant’s narrative description of her husband’s illness history. Two medical doctors in the General Practise Research Group at De Montfort University were asked to participate in a pilot analysis reflecting team session. The session was conducted in order to familiarise the researcher with the process, test the method’s applicability to the data at hand and begin to solve the health history puzzle of the interviewee’s husband. Initial reservations about the flexibility of the medical doctors to participate in a pointedly qualitative process were dissipated by their immediate grasp of the analytical process and method’s concept. Hunter (in Mishler 1995) reminded us that medicine is filled with stories and is, in fact, dependent on narrative, is essentially case-based knowledge and practice and that clinical judgement is “fundamentally interpretative” (1995: 112-113). An hour-long session based upon eight to ten lines of transcript provided rich hypothesising as well as generating materials for further analyses. “Once an interpretation of a text is developed, one may engage in a comparison of that interpretation with any other level of theoretical or cultural discourse offering critical reflection and comparison with the interpretive commentary” (Benner 1994: xviii). In analytic induction, no analysis is considered final.
The Data Analysis

Analytic induction, “from which Glaser and Strauss’s work on grounded theory derives” (Chalip in White et al 1998: 3), and, therefore, also the basis of the data analysis method used in the Biographic Narrative Interpretive Method, was first described by the sociologist Florian Znaniecki in 1934 (Ratcliff 2000: 1; Robinson 1951: 812). In the late teens of the last century, Znaniecki had developed the research-technique known as the analysis of human documents (letters, memoirs, life histories, and so forth) with the seminal work, *The Polish Peasant in Europe and America* (1918-1920; with W. I. Thomas). This approach to life and lived experience was later defined as the autobiographical method in sociology and located in the theory of symbolic interactionism (Plummer 1983: 40). Znaniecki was a member of faculty at the University of Chicago at the time when its Department of Sociology—the first of its kind in the U.S.—was known as “the Chicago School.” The life history method was central to this school (Miller 2000: 4) and “it was the first American university to establish an original collective school of thought: pragmatism” (Plummer 1983: 51). Znaniecki’s approach stimulated debate within both sociology and psychology over the next several decades. For example, Allport advocated, more strongly than anybody else, for the use of idiographic case study method in psychology. He proposed that its use overcame the pursuit of general laws about traits abstracted from individuals, which had ignored the unique constellation of traits in one individual (1983: 48).

Znaniecki held that analytic induction is the true method of the physical and biological sciences, and that it ought to be the method of the social sciences too (Znaniecki cited in Robinson 1951: 812). Inductive rather than deductive reasoning is involved, allowing for modification of concepts and relationships between concepts. The process occurs throughout the action of doing research with the goal of most accurately representing the reality of the situation. No analysis is considered final, since reality is constantly changing. The emphasis in analytic induction is on the whole, even though elements and the relationships between elements are analysed. A specific case need not necessarily be ‘average’ or representative of the general phenomena studied. It is crucial, nonetheless, that a case has essential characteristics and that it function as a pattern by which future cases can be defined (1951: 1). In 1950, Cressey summarised Znaniecki’s analytic induction as six steps:

1. A phenomenon is defined in a tentative manner.
2. A hypothesis is developed about it.
3. A single instance is considered to determine if the hypothesis is confirmed.
4. If the hypothesis fails to be confirmed, either the phenomenon is redefined or the hypothesis is revised to include the instance examined.
5. Additional cases are examined and, if the new hypothesis is repeatedly confirmed, some degree of certainty about the hypothesis results.
6. Each negative case requires that the hypothesis be reformulated until there are no exceptions. (Cressey cited in Ratcliff 2000: 1)
The Biographic Narrative Interpretive Method is based, in part, on grounded theory (Chamberlayne & Rustin 1999: 25). Analytic induction, however, contrasts to the now more widely used and invoked grounded theory (Glaser & Strauss 1967) in several ways. Analytic induction tests as well as generates theory and all data available must by used to test hypotheses (Ratcliff 2000: 2). Additionally, “in interpretive (hermeneutic) research, unlike in grounded theory, the goal is to discover meaning and to achieve understanding (Benner 1994: 10). Inductive data analysis, as an alternative to grounded theory’s “constant comparison method” (Thomas in White et al 1998: 1) “is typically qualitative; it makes use of comparisons (typically of cases); it often makes use of techniques which share some affinity with phenomenology and hermeneutics” (Chalip in White et al 1998: 3). By using analytical induction within a phenomenological or hermeneutic approach, a philosophical statement is made about the underpinnings of the analysis (White in White et al 1998: 5). It is, nonetheless, “perfectly feasible to interpret data obtained via particular methods . . . that are dissimilar from those who advocate (or even invented) those methods” (Chalip in White et al 1998: 6). In addition, Becker (1958) has shown that several ways of doing analysis in a study can be “triangulated” and this data used to speculate about what might be (1958: 654).

Analogous to Znaniecki’s and Robinson’s analytic induction, as well as the Biographic Narrative Interpretive Method methodology, is Mehan’s (cited in Ratcliff 2000: 2) “constitutive ethnography,” incorporating aspects of analytic induction. “The process of analysis is initiated with analysis of a small data set from which a tentative hypothetical framework is generated. Comparisons are made with additional forthcoming data resulting in changes in the framework until a group of ‘recursive rules’ are developed that comprehensively describe the phenomenon” (2000: 2).

The reflecting teams
In this research, in order to facilitate the group analytical process, other researchers known to the primary researcher were solicited to participate in the analytical sessions. (See Appendix: 206) Using a ‘reflecting team’ approach to data analysis facilitates the introduction of multiple voices, unsettling and creating a mix of meaning and encouraging communication and collective means of deliberation (Gergen 2000a: 4).

The process began by recruiting colleagues (two, three or more per team) from varying backgrounds (professionally as well as demographically) to be immersed in the transcript, at times ‘line by line’ and hypothesise at each new revelation of dialogic material. What was sought in using this procedure was an opening up of the possibilities in interpretation, rather than relying solely upon the primary researcher’s interpretation of the interview. The abilities required of group participants were openness and creativity/imagination rather than knowledge of specific research methods. In fact, diversity of approach to the material was solicited and encouraged. In this way, each participant brought his or her own social context or ‘lived life’ to the process and, therefore, contributed uniquely to the ways of seeing the lives of others.

Researchers were recruited through the email lists of the Mary Seacole Research Centre and others from the Faculty of Health and Community Studies, De Montfort
University, Leicester. Dates and times for sessions were established and co-ordinated with the schedules of interested respondents. Sessions lasted approximately three hours and were held at a campus location. The sessions took place over one year. Thirteen reflecting team meetings were held and four of the seven interviewee’s transcripts were analysed. Session teams were comprised of colleagues from a pool of 19 people. The lived life and told story were analysed in separate sessions, using different reflecting teams, to facilitate later comparing and contrasting of the lived life and told story.

The sessions began with the typical introductions of participants whose details were noted on a flip chart. Most teams were comprised of nurses, researchers, lecturers, and so forth. Next, the panel members were asked to tell something about themselves that one might not expect from the earlier professional descriptions offered. These were also written on the flip chart. Participants were then asked to bring to the analysis session that ‘other’ person whom they had just described. Through this introductory exercise, they were encouraged to engage in a dialogue with the text of the life of another and bring to that dialogue more than just their professional selves. Some examples of the team participants descriptions of their past experiences included time spent as a surveyor, working as a male fashion model, immigrating from Zimbabwe, having spent childhood as an evangelical missionary, having formerly been a fine artist, having been a failure at “A” levels, being raised as a Romany gypsy and membership in a hippie commune. Some of the team members’ past experiences were quite surprising too, considering their present activities and occupations. Participants’ ages included those in their 20s, 30, 40s and 50s to one nearing 70 years; gender was equally represented in most sessions. Of the pool of 19, four participants were non-white.

An important and interesting lesson was learned from the reflective team sessions. When time ran out and the end of the transcript was not reached, participants seemed somewhat dissatisfied. It became clear that team members needed to know the whole story, --have a beginning, middle and end-- as in any good story. Another observation was that team members, once immersed in the process, brought their personalities to the fore. For example, one member, who has a great sense of humour, often used humour or casual remarks when going through the exercise of hypothesising and analysing the transcript sentence by sentence. These seemingly flip remarks often held a great deal of truth, unknown to the panel at that particular stage of data analysis. In addition, the oldest panel member seemed to impart a special wisdom to the process from the strength of his life experience, something others did not have in such abundance. It was also observed that some members with nursing backgrounds initially had difficulty projecting possible outcomes from early databits in the lived life or told story. When questioned about this informally, they replied that their training made it difficult for them to make “value judgements” about the lives of others. “The value of the panel of analysts and of peer review lies in part in the capacity of different researchers to have anxieties that are different form those of each other and from that of the interviewee” (Wengraf in Chamberlayne et al 2000: 144). After some time working with
the method, however, those with nursing backgrounds were able to find their own way of hypothesising along with the others.

In the process of using the Biographic Narrative Interpretive Method, individual and unique approaches to data analyses emerged. It became clear to the researcher that the certain aspects of the method often got in the way of the data's potential to inform and illuminate; pragmatic considerations of working within a team setting produced a need to be flexible. In fact, the method's claim that it is an “advance on the intuitive approach of much qualitative research in Britain” (Chamberlayne & King 2000: 10) raised further questions: in asking reflecting team members to speculate about a life story, was not the potential of intuition ultimately a great advantage to this very process? (See Scheff 1997: 33-36)

The rigidity of the text structure sequentialisation tool (Wengraf 2001: 239-43) became difficult and unwieldy in producing data that was workable for the reflecting teams within the time allotted for analyses. The method seemed to require an adherence to consistencies within the told narrative, rather than uncovering links based on spontaneous association (Hollway & Jefferson 2000: 152). A concentration on the text structure appeared to restrict the reflecting teams’ possibilities of multiple, intuitive responses to the data. In addition, the configuration of the text structure sequentialisation categories seemed to be changing and becoming more complex with each new publication by it's authors (Chamberlayne et al 2000; Chamberlayne & King 2000; Wengraf 2000; Wengraf 2001). A decision was made, therefore, to reduce strict adherence to this particular process of the Biographic Narrative Interpretive Method and concentrate on the more instinctive and creative possibilities of the data analysis interface through selection of meaningful text upon which hypotheses and associations might be made.

It was decided for pragmatic reasons, therefore, to background the text sequentialisation process and foreground the microanalysis of selected text within the team setting. In certain instances, the text chosen for analysis was selected because it did represent shifts in the modes of narration by the interviewee (description, narration, argumentation, and so forth [Wengraf 2001: 239-43]). At other times, however, other text was selected for its ability to telegraph potential themes and their development, emotional states (such as anxiety and defence; see Hollway & Jefferson, 2000), and so forth. In one case, for example, the interviewee's use of sighs and/or laughter was microanalysed for meaning and theme development by analysing the dialogue surrounding these physical utterances (see Jones 2001). Nonetheless, all narrative microanalyses followed the order in which they were expressed by the interviewee.

In addition, the claim has been made that all interpretive work, however sociological, requires a theory of the subject (Hollway & Jefferson 2000: 59). This seemed key to this particular investigation of personality and its commitment to the concept of the individual within a social context. This centrality of the individual within a social context was imperative in illuminating the original research question. Strict adherence to what
in the end was a sociologically developed method seemed counterproductive to this study's social psychological agenda.

**Analogy of the analytical process**
The concept of this analytical process is not an easy one to envisage. It was explained to the reflecting teams that analytical process is similar to ‘brain-storming’. The principles of brainstorming embrace the ideas that all suggestions are considered valuable and that no idea or thought is negated or not included for possible hypothesis testing at a later stage. It is a process of freeing up participants from censoring their thoughts and reaching deeper levels of creative reflection and participation in a group process. By eliminating negativity, brainstorming encourages full member participation and contribution to the process.

By concentrating on analytical induction as a process of hypothesis raising and testing in the group setting, a clear cut agenda was set for the reflective team meetings. Members commented, in fact, that they found the process of revealing the life story a line or two at a time with no ancillary information available and then hypothesising on projected future possibilities quite stimulating and innovative. The principle of this analytical tool is based upon that of ‘abduction,’ developed by Charles Sanders Peirce. It involves “generating hypotheses contained in a given unit of empirical data, progressing to hypotheses as to further developments and then testing these with the empirical outcome” (Chamberlayne & King 2000: 213.) Because the team sessions had only minimalist data from the lived life chronology, revealed one ‘databit’ at a time, and the lines of dialogue from the told story revealed sequentially, there was no possibility to compare and contrast to the ‘whole story’ until that story was slowly and ultimately revealed. This ‘unveiling’ process of hypothesising and hypothesis testing seemed truer to the foundational inductive analytical method, rather than the concept of ‘constant comparative method’ employed by grounded theorists.
Analytical induction can also be conceptualised by an analogy with the painting of Chuck Close (b. 1940). Close’s work is considered “figurative narration” (Cole and Gealt 1989: 326). Close photographs his subjects and then concentrates his efforts on a single snapshot of their faces. This snapshot is subdivided into small sections of the picture to form a maquette or grid-like mock-up. Sometimes the maquette is created on a diagonal or in a circular format; this ‘askew’ positioning allows for a disturbed sense of horizon and enables the totality of the work to become obscured through the painting process of building upon relational aspects of the whole. The eye’s relationship to the whole is thus solely concentrated on the subdivisions of space containing specific informational, analytical ‘data’ clues.
Each small space (databit) or subdivision is analysed separately and independently in order to capture the primary essences of its shapes and colours, then transposed onto the corresponding space on the larger canvass, detail by detail. In this ‘blinded’ way, Close builds an overall picture from a process of analytic induction. This seemingly endless sequence of raising visual questions (hypothesising), bit by bit, results, ultimately, in a finished work that is exquisitely more than the sum of its parts. This larger than life-size version of a person, compellingly detailed, is achieved through the intimate glimpse into the world of photographic pixels, a mechanical technique that also allows Close to maintain a psychological distance from the subject during the process.

Similar to the Biographic Narrative Interpretive and analytical inductive reasoning more generally, the life story narratives are distilled into essences by the use of comparable maquettes or grids to produce a representation of a storied life. (For examples of “biographical data chronology” and “text structure sequentialisation” within the Biographic Narrative Interpretive Method, see Appendix: 207, 210) This painstakingly studied distillation of narrative episodes, themes, motifs, and so forth, separated, analysed and then reassembled, ultimately produces a picture of a person in the best sense of the genre of portraiture. The picture reassembled is not a literal portrayal or single perspective view of a person. Enriched through the maquette of abstraction, “The case studies present a highly interpreted and abstracted version of the person’s actual experiences and life events, representing a sociological interpretation of the life world, which is used for purposes of illumination of more general social processes” (Chamberlayne & King 2000: 215).

Parenthetically, Close’s work also supports the Verismo approach to the portrayal of an ordinary life. Close’s subjects are chosen from his everyday, local environment. Although some of his subjects have now gained fame in their own right (for example, the composer, Phillip Glass), at the time of their portraiture they were relatively unknown, ‘ordinary’ citizens.

ETHICAL CONSIDERATIONS

“Since the question of ethics is a question of knowing and thinking as well as choosing and everyday action, our subject matter concerns the ways by which we customarily establish bodies of knowledge and patterns of reflections, our way of producing and maintaining certainty, and our styles of good sense” (Scott 1990: 5). “Learning to name things anew, to become alert to exclusions and to forgotten aspects in a people’s history, to overhear what is usually drowned out by the predominant values, to rethink what is ordinarily taken for granted, to find out how to hold itself in quest: these are aspects of the thought of the question of ethics” (1990: 7-8).

Many of the proposed and emerging standards for quality in interpretive social science are also standards for ethics (Lincoln 1995: 286). Lincoln discusses several issues in qualitative research that enlarge the debate about standards:

1) Problems of the face to face encounter
2) The virtual impossibility of maintaining anonymity under some circumstances
3) Selecting and excluding material to be included in case study
4) Open and honest negotiations around data collection, analysis and presentation.

(1995: 287)

Using Lincoln’s standards as a guide, the following ethical issues were considered:

1) In the face-to-face encounters, relationships began with all the latent benefits and conflicts that any two strangers face. In addition, there were potential issues such as participants’ assumption of special expertise in the interviewer and, therefore, possible unrealistic expectations on their part of the interview process. There was also the chance that participants might expect solutions to or help with specific problems (see Miller 2000: 104). To counter these possibilities, the researcher began by establishing an atmosphere of egalitarianism with the participants by strongly acknowledging the contribution that participants were making to the research process as member of a partnership. Ultimately, of course, the most important responsibility of the researcher in the face-to-face encounters was to be a good listener. It was through such devices that the non-verbal dialogic manifested itself in the interview scene (Jones 2001). Through attentiveness and engagement, the interviewer was able to actively instil in the interviewees a sense of well being as well as one of co-participant within the research circle, re-enforcing their contributions to the process.

2) The virtual impossibility of absolute anonymity frequently presents difficulties. Interviewees were told that they would remain anonymous at public level and that pseudonyms would be used in any reporting or publication. The question remained, nonetheless, that because the interviewee was considered a ‘participant’ in the research process, should the participant have had full access to what was written about him or her and have an opportunity for feedback and/or comment on the research findings? Or, in fact, did the responsibility for the verification and analysis of the data rest solely with the researcher and the reflecting team? “Whether it is meaningful, or in a single participant’s interest, to show him or her an analysis based on his or her single case in debatable” (Hollway & Jefferson 2000: 91). “It is not sufficient, and may even be harmful, for the professional simply to confront the client with the stark results of the biographical analysis” (Fischer-Rosenthal cited in Chamberlayne et al 2000: 121). A decision was made to take a middle-ground position on this issue. Participants were asked to review the biographical chronological summaries (the lived life) constructed by the researcher and to make any corrections or additions that they felt were necessary. Secondly, follow up phone calls were made to the participants after the interviews in order to fill in any gaps, but also to give them an opportunity to raise any concerns, and so forth, that they may have had concerning issues of anonymity, conclusions drawn from the sessions, and so forth. This also gave them an opportunity to present problems that may have been raised by the interview process itself. In cases where problems did arise, the researcher urged the participant to follow up the discussion and take full advantage of the support systems in place and available through the facilitating organisation.
There are instances in researching people’s lives when sensitive areas may lead to potentially explosive interpretations being drawn in analysing them. Should such conclusions be presented for verification to participants themselves? Does the researcher have the right to publish such findings without the knowledge and/or feedback of participants? In cases where this possibility existed, the decision was made to fully represent the particular data as communicated by the participant and allow readers to make their own assumptions from the material as well as from conclusions drawn by the teams. In this way, the participant’s story was preserved in the way it was told and the initial agreement between participant and researcher is maintained.

3) Inclusion/exclusion of material: In building cases using analytic induction, all materials were available for testing hypotheses. The fact that full transcripts were compiled and then were reduced to a biographical chronology (the lived life) and verbatim text selected from the transcript (the told story) contributed two advantages:
   a) The reductions were powerful representations of the larger texts.
   b) The full text was always available to check and recheck hypotheses throughout the analytical process. (The full interview transcripts are available in the library of De Montfort University)

4) Concerning questions of openness and honesty in negotiations, the following were considered:
   a) Data collection: all participants and their facilitators were informed of the research process and the stated purpose; all negotiations remained transparent.
   b) Analyses benefited from the reflective team process that helped avoid projecting only the researcher’s individual world onto the world of the participants as well as the team members. The diverse backgrounds of reflecting team members encouraged multiple points-of-view, minority opinions and variance in theoretical approaches as part of the process; the rigorous and systematic procedures of text reduction and analysis further added to the transparency of the final analyses.
   c) Presentation necessarily worked within the constraints of a PhD dissertation whilst attempting to remain frank and candid about the writer’s background, interests, prejudices and limitations. As earlier invoked, the overarching conceptualisation of this work was that it is a ‘story about stories’ and this is ultimately the ‘thesis of the thesis.’

   The presentation suffers somewhat from being written in scientistic and dehumanising passive voice and third person rather than active voice and first person in the majority of chapters. “The use of the third person and passive voice in typical science reports and the severing of method from results and from interpretation are deemed ‘anti-narrative’ strategies that separate authors from their texts and mask the narrativity of science” (Sandelowski 1991: 161; also see Gergen 2000b).
Still, an attempt has been made to maintain the allegory of the narrative throughout this writing. Use of analogy and metaphor, especially visual comparisons and the expression of the research progress as a journey, were conceived as this effort’s presentational framework. These flourishes of presentational arabesques were the undertakings of a creative pragmatist, straddling the two mountains of personality and informal care, and simultaneously trying to transverse from the big picture to the smaller one. The Baroque pales in comparison! As Vermeer implored, when adding a caution along with his signature, “Als Ik Kan.” So too is this borrowed caveat in place in this effort.

CONCLUSIONS

But now old friends are acting strange
They shake their heads, they say I've changed
Well something's lost, but something's gained
In living ev'ry day

I've looked at life from both sides now
From win and lose and still somehow
It's life's illusions I recall
I really don't know life at all

“Clouds” Joni Mitchell, 1967

“Our task is to see persons as persons, as the complete beings that they are. We must collect together in an orderly and systematic manner what people must already know. We ourselves can be a source of such evidence” (Shotter in Gergen & Davis 1985: 175; emphasis Shotter's).

“The person’s stories testify to the state of his identity and its wants, frailties and foibles, mostly without consciously intending to do so. But he may wish to tell his story just because he hopes to assert his identity in the process, to defend it or at least to clarify what it could and should be like” (Wyatt in Sarbin 1986: 203).

What does it mean when we know a person (Jones 2000)? In truth seeking, are we merely comparing and contrasting our own everyday world with the worlds of others? Within the individual’s world and his/her tendency of ”revealing/concealing”, ”knowing/not knowing” (Heidegger in Krell 1993), by exploring the terrain, are we simply only portraying the process itself, its dialectical underpinnings – its thesis and antithesis? Or, in fact, do we, in our attempts at some sort of a truth (Verismo) stumble onto a synthesis after all, a moment of revelation that truly is wrenched by the individual in his/her self-knowing and revealed to us?
Asking a person to tell us about his/her life is just a beginning. By doing this, in a less than perfect way, we are at least starting by knowing the person in his/her world, his/her expectations, successes, failures and dreams. The swirl of a remembered past is (re)constructed by just such illusive characteristics. A narration of a life is, after all is said, a story, an illusion. "Any and all stories we might tell about ourselves are essentially fictitious; they are vehicles for warding off the flux and meeting our need for order – illusory though it may be to suppose that this order exists anywhere but in our own minds" (Freeman 1997: 379). Veracity, therefore, must remain secondary. What remains primary is that this is how one individual sees him/herself when asked to recount him/herself today (Plummer 1983: 57). "Reflecting on one’s life is fundamentally a metaphorical one, giving form to one’s previous and present experience" (Freeman 1993: 30).

As much as we try to elevate this metaphor to a discussion of objects, concepts, thoughts, and the like, to a higher plane, perhaps by exploring meaning within meanings of the language used to describe such things, we all still "bump into the furniture" (1993: 13). Perhaps the most any approach to knowing of others can produce in sensing the lives of others – that very ‘otherness’ – is a fleeting consciousness of what it is like to bump into their furniture, their own ‘selves’ through the stories that they construct via the illusory imagination of narrative. These are the illusions like the shapes, forms, monsters that one envisions in passing clouds. They reform back into a clouds again, and then pass from view, as we remain always expectant of another to appear. “It’s cloud’s illusions I recall.” The trick is to ‘get it down’ --this illusion, this configuration of momentary meaningfulness --before it escapes from memory. Such it is in illusion, so too in life stories.

“The project at hand is therefore ultimately a reconstructive one; it is a project of exploring lives in their various modes of integration and dis-integration, formation and de-formation, and, on the basis of what is observed, piecing together images of the whole" (Freeman 1997: 395). This whole becomes the imaginative subjective drama of an everyday life: the Verismo of the quotidian. Like an anticipating audience ushered into the hush of a darkened theatre, disbelief is mutually suspended and the possibility of shared comprehension is embraced.

It is with an excited state of expectancy that these stories of ‘others’ who care can now unfold.
CHAPTER 4: Presentation of Data & Resercher's Reflective Work

Carer sightings: Cameos of some reflected, relationally lived lives

“Indeed, it might be said that individuals are only the narrators, not the authors of their life story.” Wrigley, 2001:[3]

Introduction

A narrative biography is created from the artefacts of the past much in the same way that Renaissance scholars, artists and craftsmen rediscovered their past in antiquity and reinterpreted that past. That effort entailed a process that was as much based upon judgements, reflections, and current considerations of contemporaneous needs and expectations, as on any truth or validity of antiquity that may or may not have actually been available to them. Their efforts were an example of the mix of everyday needs and expectations seen through the prism of the past. The validity of their rebirth of antiquity rests not in how accurately they reconstructed the past, but in how useful the ‘products’ of these explorations were to their present-day needs. Both their reinterpretation of the past and the very process by which they reached their conclusions continue to be of importance to western culture today as it continues to reinterpret and make use of its own accumulative past. It is no small matter then that, in narrating one’s personal past, a similar exploratory recreative process is also employed in which the past and its artefacts become both symbolic and, at the same time, utilitarian. “The time is always the present. The event is always an ongoing dialogue” (Schaffer in W. J. T. Mitchell, 1981: 49). Ricour remarked that narrativity, from the outset, establishes repetition on the Heidegerian plane of being-with-others (1981: 184) or the narrative as a dialogical construct.

Carvings

Within the landscape of informal care dwelt the carers themselves--individuals, socially constructed-- whose potential for revelation remained untapped. In order to begin understanding, a ‘Cameo of each of the people who participated in the project is presented as description in this chapter. Each description or pen portrait (Hollway & Jefferson, 2000) was set out to describe in delicate or sharp relief the characters, places and events of a lived life.

These portraits or cameos were produced using the method’s process of assemblage of a descriptive, chronological picture of the chain of events, people, and so forth, that comprised the remembered life as told by the participant. Sometimes vast sections of a life, perhaps just the events and people that an audience would most like to hear, were left out of the story. The stories, nonetheless, reflected accurately the way in which the storyteller wished to communicate him/herself on the day the story was told and to a particular audience. “It is the way in which narrators understand the actual communicational situation during the interview and use it to come to terms with their memories and experiences, to construct and present a special concept of themselves.
and their world with their narrative and rhetoric devices, and to account for them for
themselves and for the listener” (Lucius-Hoene, 2000: [4]).

The process in creating such cameos has been one of réasemblage --a pulling together
of the bits and pieces of story and reconstructing the story chronologically. Its telling
became, therefore, transparently, a retelling and its own story in itself. By the use of
time as a template, an order was sought to enable better understanding. The
reconstruction brought about by this reordering offered as many clues in what was not
said and what was left behind, as did the chronological report put upon the page. If
nothing else, these reports created the skeleton that ultimately the told story rested
upon.

Each cameo is followed by “First impressions” (Hollway & Jefferson 2000: 46). It is here
that this interviewer’s initial reactions to the interviewee and the interview scene are
reported, generally based upon debriefing notes made soon after each interview.
Within First impressions two devices are described that have assisted the researcher in
getting an initial and often revealing take on the interview itself. First, early in an
interview, a few sentences into the interview, the participant often revealed in a line or
two what the story is about or a ‘motif.’ By being mindful of these phrases and the
construct within, then looking for addition clues that support the premise throughout the
transcript, a case could be made that these early declarations represented the central
motifs of the whole story. Like musical leitmotifs (Wagner comes to mind), a motif may
run through the text (the score) of the narrative, sometimes in the background,
sometimes underneath the recounting, creating and supporting the foundations of the
told story itself.

Secondly, the researcher looked for sentences that contained the word “want,” again
and ideally, early in the transcripts. The “I want” phenomenon was first explained as a
narrative technique that has been used in the story lines for West End or Broadway
musicals. Because the narrative story, or ‘book’ as it is called in musical theatre, is
often quite bare and sparse, a device is used to ‘set up’ the plot early on in musicals
with an ‘I want’ song. An example of this is in My Fair Lady when Elisa Doolittle sings,
“All I want is a room somewhere . . .” In this song, the central character is telling the
audience where she hoped to be by the end of the story. The researcher looked for the
‘I want’ phenomenon in the seven participants’ stories and found it in every one. These
were reported as First impressions because they gave clues to possibilities to be
uncovered later and in more detail in the analyses of the transcripts. They became
themes and motifs that percolated in the background throughout the analysis process.

‘First impressions’ are then followed by ‘Personal reflections,’ individual responses to
not only the interview itself and post-interview process, but also the researcher’s
ruminations during and after the transcription process. These sections represent the
layers of reflective activity, the trusting of instincts and often a dialogue within and
without that includes issues such as transference and counter transference. Using
Hollway and Jefferson’s psychoanalytical model, transference refers to the unconscious
transferring of other emotionally significant relationships onto the researcher by the
interviewee; counter transference to the researcher’s responses to these transferences, as well as his/her own transferring of emotionally significant relationships on to the interviewee (2000: 47). Bruer (2000: 7), building on the ideas of Devereux, recommended exploring counter transference as a tool to gain insight and the opening up of the perspective for creating a potentially concrete research method.

Because of the time limitations of reflective team members, four of the seven stories were chosen for in-depth team analyses; the results of these analyses are presented in the chapter following this one. In that chapter, four of the stories are analysed using the reflective team approach and each team’s separate consideration of either the lived life or the told story. Through the analysis process, the skeletal framework of the lived life presented in this chapter was compared and contrasted with the told story. It was crucial to the process, nonetheless, to begin with the lived life because it represents the possibilities of life choices that have been made (or not) by each individual and how these choices have been retold, reordered and reflected upon in the told story. All seven Lived Lives of people who where interviewed have been presented in this chapter. This was done to represent the diverse demographics of the people interviewed and to represent the richness of diversity across the lifespan of each individual interviewee as well as the diversity between interviewees. It also demonstrated the data resources achieved by the method, even in its earlier stages.

Case study is an ideal methodology for holistic, in-depth investigation (Tellis, 1997: 1), particularly when the investigation involves an action, in this case, the act of caring. It is also appropriate when the research concerns not just the voice of the actor, but also the relevant groups of actors and interaction between them (1997: 2), for example the cared for, other family members, wider social circles, and so forth. What is sought in case study is not oversimplification, based inappropriately in statistical generalisation, but an approach centred on a more “intuitive, empirically–grounded” generalisation, a “naturalistic” generalisation (Stake 1995 cited in Tellis 1997: 2). That the data generated by the study will resonate experientially with a broad cross section of readers is central to generating understanding of the phenomenon in question.

Finally, through the process of case presentation a new picture has begun to emerge that has the power to enlighten and inform and to begin to allow us to finally be able to speak of identity within the informal care role.
1. POLLY HUMBERSTON

_A lived life cameo_

Polly was born in 1937 in the English Midlands. During the war, her father went off to the army. Her mother's friend, Anna, also had a husband who was away in the army, so Anna moved in with Polly and her mother, bringing her children with her.

When Polly was eight, her father returned from the army and her parents decided to divorce. According to Polly, they were divorcing because her mother had been unfaithful to her father during his absence. Her parents sat her down and asked her whom she wanted to be with; she replied that she wanted to be with both of them. Her father gained custody of Polly and her mother moved out. Anna and her children stayed on to live with Polly and her father and he became self-employed. Later, Polly lived with her mother's friend, Anna, for a time. Polly considered Anna's children as her sisters and brother, but when Anna's husband came back from the war, he moved his family away from Polly and her father. Polly's birth mother eventually went on to have four more children, each parented by different fathers, but Polly does not consider them siblings.

Polly enjoyed cinema and going dancing during her teenage years. At the age of 16, Polly left home because she did not get along with her father. She wanted someone to respect and had none for her father. She moved in with Anna and her children, whom she always considered her true siblings.

At 19, she married Don, whom she had not known long and who was nine years older than her. In less than a year, a son, Carl, was born and three years later, a daughter, Sarah, was born. Their daughter had heart problems from birth and at four months had to have a heart operation. Sarah had another heart operation at age six. Because of Sarah's disabilities, Polly had to fight hard to get her into the right school.

When Polly was 44, her husband, Don, had a stroke. He was left partially sighted. He is also deaf and diabetic. Polly became his carer and this began to take a toll on her health. When Polly's first grandchild, Daniel, was born, she took care of him while his parents, Carl and Gail, went to work. Her next grandson, Martin, was born with autism. Polly is now crippled with arthritis. Her oldest grandson is also arthritic. Five years ago, her daughter Sarah's disabilities were finally explained with a diagnosis of Noonan's syndrome, a birth defect. Polly's daughter is now 40 and is having another heart operation shortly.

Three years ago Polly and Dan, along with their disabled daughter, Sarah, moved in with their son, Carl, his wife, Gail, and their two sons, Daniel, who is arthritic and Martin, who is autistic. Subsequently, four of the household members are now officially registered as disabled.

Polly has been attending the Carers' Centre and taking classes in the last 12 months. She is also involved in fighting for carers, which she desperately wants to do, by speaking to social workers and other groups about carers' concerns and rights. She
reported that she does not want sympathy but she does not want to see other carers go through what she has gone through.

Polly and her husband have taken trips to Malta, Belgium, France, Holland, Germany, Italy, Egypt, Yugoslavia and Austria since his stroke. Polly’s father died nine years ago. She does not know if her birth mother is dead or alive.

First impressions
Polly looked away from me all during the first interview session, although I was trying to maintain eye contact. In the second session, after a break of 20-minutes or so, she seemed to begin to engage in more and more eye contact. This may be because I was writing notes during the first session or perhaps, just because she is shy. Polly did appear to me to be quite reticent, even demure. This could be because I am a stranger and/or a man; perhaps she has made assumptions about me because I come from the university. Polly was apologetic throughout, and gave the impression that her story was not important enough to be heard.

Polly’s anger, particularly in contrast to her inhibited disposition, came across strongly, particularly her anger with institutions and her expressed anger with her father (but also with her mother who, basically, had abandoned her at a young age). I wondered, could her anger at institutional authority be a displacement of her anger at her parents and the authority over her life that they represented?

I was also struck by the possibility that this family may have ‘institutionalised’ disability and see its disability role as well as its subsequent carer role as major components in identity and family construction. The interchangeable roles that family members took in this continuum from carer through disabled and back again to carer also struck me. Work or occupations were never mentioned. I wondered if family members regarded the carer/disabled dyad as life work almost like a job and if Polly, as matriarch of this family of disability and care, had not been the architect of this outlook.

Personal reflections
Well, you have your ups and downs, a lot of downs but we do have good times its not all bad (1)*erm (sighs) (2) but you have to make your own way you have to find it for yourself you have to come to terms with it and it is very hard to come to terms with it.

(*Note: the numbers in brackets within sections of interview text represent pauses in number of seconds)

One could regard this statement, made by Polly very early into her story, as having been her initial summing up of what her story is all about. Although she was speaking in these lines of her caring role, did it also tell a story before her adult caring and going back to her childhood? “You have to make your own way” and “It’s very hard to come to terms with it.” What of the other events that were difficult for her to come to terms with? Her childhood? Her Mother leaving? Her uncaring father? The disruptive living
arrangements in her childhood? I wondered what solutions to these problems she may have continued to use in her carer role.

Mainly we laugh because we did a lot of crying, er, but then I thought, this isn’t getting us anywhere.

It became apparent that Polly and her son (see following section) referred to this panacea repeatedly: ‘Laughing to keep from crying.’ I wondered if there is an anger/rage in this humour, perhaps a kind of gallows humour? She brought up laughter again as a solution just a bit further on. It was at this point that I began to envisage this family of three generations, interchanging roles of carer and disabled, as Picasso’s painting of the Acrobats or roaming street performers. The individual parts each played in the collective whole of their uniquely constructed family strengthened the family. Like acrobats, each had a specific function to perform and needed to rely exclusively on a partner in an act. Like Picasso’s performers, Polly’s family separated itself from society by its differences and needed to protect its members and each members changing role in the support system of the family arrangement.

Figure 5: Famille de saltimbanques (Les bateleurs).
Pablo Ruiz Picasso
Paris. 1905. Oil on canvas. 212.8 x 229.6 cm. The National Gallery of Art, Washington.

Polly’s ‘wants’ included not wanting others to go through what she has gone through and “desperately wanting to fight in the corner for carers.”

Early in the first interview session Polly stated, “That’s really it; I don’t know, really, what you want to know”. (laughs) By this, she seemed to be summing up her story as if to
say, ‘It’s been a hard life, but we laugh’ (as she ended with a laugh). Was the laughter possibly a defence, a way of keeping others out/away from the deeper truth, the hurt, the rage?

I was struck by the possibility that Polly appeared resentful of a mother that left her with a father whom she did not like and wondered who was it then who was providing the care to Polly as a child? Where did Polly turn for care? Was it to Anna by moving in with her at 16? I was also struck with the fact the Polly had a past that included disrupted living arrangements (Anna and her family moving in and then moving herself in with Anna later). There may have been a parallel today when she, her husband and their daughter moved into her son’s house and it’s ready-made family unit, the extended, intergenerational family and the protective strengths of numbers of carers and numbers of disabled.

In summary, Polly Humberston told a story of raising a disabled child, then caring for an ailing husband, and an adult life that has been one of continuous caring duties. Nevertheless, she returned in her narration repeatedly to her childhood and its disruptive wartime home life, the traumatic experience of an eight-year-old child being asked to choose between her parents and the subsequent departure of her mother. These early lessons that Polly learned about forming new family alliances, seemed to have carried over to her life today. Polly presented a shy and apologetic person, but also giving the impression of a person full of rage and anger with her parents.

As a child, Polly seemed resentful of a mother who abandoned her and a father whom she did not like, but found strength by forming new family ties. In the present, she spoke from a standpoint of finding that same strength through familial re formations and intergenerational exchange. She may have realised the protective strength of numbers –numbers of disabled as well as numbers of carers within her current extended family.

Polly appeared to have institutionalised disability within her family unit as an insurance policy against further abandonment. The emphasis in her family construction seemed to be on disability, rather than care. She seemed to have created a continuum –from care through disability and back again—and interchangeable roles within this spectrum. Using dark humour and laughter, she gave the impression that she protected her family’s special construct from society’s gaze and criticism.

Because I had felt that the family dynamic was crucial to Polly’s story (and at this point in the interviewing process I had also began to believe that it had played an important part in the identities of other interviewees), I arranged an interview with Polly’s adult son as well. The story of his lived life follows.
2. CARL HUMBERSTON

A lived life cameo
Carl was born in 1958, the son of Dan and Polly Humberston. He was raised in a two up, two down house with no heat in the upstairs bedrooms. He cannot remember a time when there was not somebody in the family with a disability or life threatening illness.

Carl started school at age four, but he learned to read before going to school by reading comics. When he was eight or nine, he started private school. He reported that he was bullied at school because of his sister who had been ill since birth, but the bullying stopped when he moved to a senior grammar school. According to Carl, he was considered bright and got good results and this did not add to his popularity. He made the point that he never enjoyed school much and never felt comfortable there; he said that he was a bit of a rebel and a nuisance as well. He came out with reasonable results, although the pressures at home created by his sister Sarah's disabilities were constant. He does not have particularly happy memories of school where he was painfully shy, particularly around girls.

He got his first job in 1976, just after he flunked his ‘A’ levels, a temp job working for the council in the driving license department. After six weeks at this job, he was offered a job with the department of health and social security and took it. He met his future wife, Gail, there, the first person he had asked to go out with him.

He believed that he would be helping people in his job with social security, but soon found out that it was not that straight-forward. Still, he got a promotion in a very short time. A year later redundancies hit and he was the first out. He got a job in a factory two weeks later.

His wife, Gail, was very ill around that time, loosing a lot of weight. They took a short holiday together and Carl was able to begin to stabilise her weight by helping with her eating. In September of 1980, they decided to start a family and his wife became pregnant, and later gave birth to a son, Daniel.

Things started to go downhill at the firm and he was made redundant just before Christmas 1980. Two days later, his father, Dan (around 52 or 53 at the time), had a massive stroke. Carl started to look for work, but got into a depressive cycle for a short time. He was unemployed until August when he had an interview with the local job centre and was offered a job. He subsequently worked there for more than 13 years.

His second son, Martin, was born in 1985. It was not too long until they realised that Martin had autism. After some time, he and Gail joined the local autistic society and became active in it. Carl found that the people that ran it at the time were all late middle-aged and did not have a game plan. He began to get more young parents involved in the society and finally felt, “This is where we are, this is where we want to be.” He also realised at the same time that his other son was suffering from asthma.
He continued his voluntary work as well as his job for a time. At one point, he injured his back by catching Martin on the stairs and had to take quite a bit of time off work. Nonetheless, he continued his voluntary work, which he found more satisfying. He later resumed his job on a part-time basis for a couple of years but in 1995, he decided to leave his employment to look for work in the voluntary field. He made a decision to concentrate on his voluntary activities in order to build up his credentials. He stated:

I was enjoying doing that for the autistic society; . . . I decided, if I actually wanted to get in to that role in employment, the best thing to do would actually be (sigh) to do as much of that kind of thing in the voluntary sector as I possibly could manage.

In the meantime, Carl's mother, Polly, experienced more and more difficulties in caring for her husband. Carl and Gail, therefore, increased the amount of time that his parents spent staying with them in their home. In July 1997, his father came to live with them permanently. Knowing that his sister needed to have a heart valve operation, Carl and Gail decide to move the rest of the family in with them as well. After waiting for three years (at the time of the interview), social services had recently had a ground floor bedroom built for his mother and father. Carl and Gail hope to have an additional ground floor bedroom built for his sister as well.

At the time of the interview, Carl was actively looking for paid employment in the voluntary sector.

First impressions
There was something that I found annoying about Carl. Partly, his interview style made me feel that I was interviewing him for a job. If it had been a job interview, it certainly had gone on much too long for my liking. I felt as though I was being convinced of his expertise and ability on several levels and that his stories had been somewhat manipulated to do just that.

It is interesting then, that I perceived Carl’s battle between issues of health and care and issues of employment and authority as his identity mix. I also sensed his conflict between his well-developed role of carer/care manager within the family and the home and his identity outside of the family structure in the world of work. Carl seemed to tell a story of attempts to merge these two identity roles, early on in his social services job, his voluntary work and now in trying to find a position within the voluntary sector that would take advantage of his expertise in his ‘home role.’ On the other hand, in his carer role in the family, Carl appeared to have used his management skills and experience gained from the world of work to make things happen, manage outside agencies and to get things done.

When speaking of the time that he and his wife joining the autistic society, he remarked that "this is where we want to be." This was his first ‘I want’ (expressed, however as ‘we want’) statement and, although it came well into the interview, it was very telling. Carl
gave the impression that he wanted to be in a social and/or work setting, outside the
family where his carer profile was accepted as vocational credentials, thus incorporating
the two sides of his life and his identity up to that point: the intelligent employee and
hard worker combined with the expert care manager. Later, when talking about looking
for work in the voluntary field he mentioned wants again and how he wanted to find a
way to incorporate his voluntary role into an employment one.

My interview with Carl reinforced my sense of circus families or theatrical families,
outsiders in a ‘normal’ family sense. I had imagined a travelling troupe of acrobats and
when a child came along, a position was created in ‘the act’ for the new family member.
I saw Carl as the trapeze artist, trained since age two to fly without a net.

I was again reminded that health (ill health) appeared to be almost invariably
associated as the defining mechanism for a role in this family. It looked like being a
carer was just another health role and one could move from carer to cared for and back
again in Carl’s family. Each member seemed to find his/her ‘dis-ease’ and this
appeared to begin to define the individual and make him or her fit in with the family
while, at the same time, maintaining the second role as carer. Through this dynamic,
family members may have moved themselves through the possible roles available and
created a continuum in which “caregiving may be conceptualized as a ‘career’ that
changes through time . . .” (Pearlin & Aneshensel [1994] citied in Kramer & Lambert,

Polly may have raised her children with love and care (did she?) to be caring children,
but she had also gave the impression that she certainly taught them to be like her in her
anger with authority. One defining moment in Carl’s interview was when he described
himself as “someone who doesn’t like to lose a battle.”

I was also reminded of the literature on young carers and some of the mistakes that
may be made in generalising young carers by concentrating only on the negative
aspects of young caring (see Richards 1998) as well as ignoring the dynamics of the
family and its part in construction of identity (Dearden 2001). It became apparent that
the Humberston family actually shifted and manipulated several roles – carer, cared for,
not in need of care, and so forth. The non-carer siblings of a young person being cared
for (by parents an/or another sibling) may often have identical psychological profiles as
young carers themselves. Could this be because the siblings may perceive an
inordinate amount of the parental care being targeted on the sibling in need of special
care? Does particular care for one child causing an anxiety in a sibling because s/he
feels that s/he is not the recipient of an equal amount of care from the parent? It may
be possible that it is the dynamics of the care family environment with its multiple roles,
and not the hands-on caring role, therefore, which creates a certain ‘young carer’
profile.
Personal reflections

In transcribing Carl’s story, certain points were reinforced and other points raised for reflection: Carl began his story with, “It’s always difficult to know...” Hesitancy seemed to be the watchword from the beginnings of Carl’s narrative. I wondered if he was hesitant generally or taken back by the ‘whole life’ question and had been trying to get to his carer story, the story he had expected to tell in the interview. He mentioned that what I had asked for was “difficult.” I had also noticed in transcribing the tape that Carl stutters slightly and, at certain points, quite profoundly; this was something that I had not noticed during the interview. Particularly in a section where he is talking about his shyness in his youth, his speech had become stuttering and difficult. In contrast, Carl had come across as quite confident and sure of himself in person (his job interview posture?) and perhaps this had been working to mask a slight speech impediment that had not been noticeable to me in the interview.

Carl certainly seemed to have found ways to separate himself out from others at an early age, particularly demonstrated in his telling about his difficulties at school; there were several times in describing this period of his life that he appeared to have been defining himself as different than the group. His apparent joy at getting his first job may have been a reflection of finally finding acceptance within a social group and on his own terms.

Carl utilised a ‘looping device’ in his storytelling (particularly in the second session when asked more targeted questions) that many of the interviewed carers used as well. This ‘looping’ came about by answering a question by simply relating the question back to telling the story s/he wanted to tell (similar to what is called ‘staying on message’ in politics). This seemed to be a particularly useful device when interviewees seemed to need to deflect dialogue away from themselves (or a relationship other than the caring one) and return to stories about the person for whom they cared, even when they had been asked specifically for more story about their own personal lives. When I had asked Carl about time spent with his father, for example, he answered quickly, but then immediate shifted back into adult life, then to an injury and then to another story about his son’s difficulties. At another point when asked about his father, he related the question to his mother and again later when asked about his parents related his answer only to his mother.

In summary, Carl Humberston grew up in his mother Polly’s family of disability and care. He reported that he was bullied at school because of his sister’s disability and, therefore, may have never felt comfortable in social situations. He appeared to have become a shy rebel because of it. Eventually, he sought opportunities to care in his adult life, both at work and in his marriage. His second son’s autism may have cemented his role as lifelong carer and his prediction of a life of caring. His battle seemed to materialise between issues of health and care and issues of employment and authority and how to create a comfortable identity out of this mix through merging these two identity roles. Health (or, more precisely, ill health) had most likely become the defining mechanism for a position within his family structure; being a carer apparently was just another ‘health’ role. As a young carer, Carl may have learned how
one might shift and manipulate several roles, carer, cared for, not in need of care, and so forth. It may be this care environment dynamic that created the 'young carer' and not the hands-on carer role itself. Carl seemed to mimic his mother by using laughter and humour as a protective device, possibly a way of separating the family out, in order to stem off criticism or ridicule. At the same time, his story was told from the standpoint of finding ways to fit in and finally merge his unique carer identity within a larger social sphere.

3. MAHESH PARMAR

A lived life cameo
Mahesh, an eldest son, was born in India, but grew up in Kenya. His father was a goldsmith, making ornaments for the Asian market in Kenya. Mahesh was followed in the family by the birth of sister, born blind and with brittle bones, a brother, who is able, was born next and then another sister and brother were born, both also with brittle bones. His youngest brother was also epileptic. As his father aged and his eyesight began to fail, Mahesh took over for him in their goldsmith shop and because of this, Mahesh lost out on his education. He stated that he did not like the jewellery business very much and wanted to go into electronics and, therefore, studied at college in the evening to qualify as an electronic engineer. He eventually took a job with Sanyo and was able to support his family. He apparently never intended to stay in Kenya because he felt that he could not provide the necessary help for the needs of his brother and sisters, no matter how much money he earned there. He wanted to immigrate to the UK and to try to bring his family with him. This was complicated by the facts that he was an Indian citizen as were his parents; although his two sisters were British passport holders, his brother was an Indian passport holder like his parents. These facts seemed to make his plans for emigration very complex.

His parents arranged a marriage with an Indian woman from Tanzania who understood that she would be sharing his caring duties if they wed. She held a British passport. They married and she immigrated to the UK; Mahesh followed her later, but had to return to Kenya because no one was supporting his parents, brothers and sisters. He began to apply for his family to immigrate with him to the UK. Because his father was not yet 65 at the time, he was not considered Mahesh’s dependent by British immigration law. This made his brother and sisters, therefore, dependants of his father, rather than of Mahesh, under British law. Under Kenyan law, however, because Mahesh was sole provider for them, they were his dependants in Kenya.

In 1980, his company agreed to furnish him with a job in London, should he be able to immigrate there, and said that they would help him buy a house as well. He came back to London and worked for nearly two years, meanwhile applying for the visas for his family. The visa applications were rejected and, at the same time, there was a major coup in Kenya and his parents were feeling very insecure and frightened. Mahesh, therefore, requested that the company transfer him back to Kenya.
About two or three years after his return to Kenya, the government introduced a work permit for his position. His company bought the permit for several years, but he was tired of staying there without his wife, only seeing her once or twice yearly for visits. His son was staying with him in Kenya at the time. He decided that he wanted to apply again to take his dependants with him to the UK. This process took nearly one and a half years and included having to manoeuvre the intricacies of the Home Office, including requirements for the number of bedrooms in his house in London, adding an extension to his house, telexes back and forth and meetings with the high commissioner in Kenya. The situation reached a climax when he finally had permission to take his family to the UK, but by this time, having been out of work for some time, he now had no money for the six plane fares; in fact, the family had been living off the sale of whatever gold the family had left. By doing a favour for a friend high up in Pan American Airlines, he was given free tickets to take his family with him to London. His entourage included his blind, brittle boned epileptic brother, his sister who was also blind with brittle bones and very tiny because of growth problems, his mother who was over 60 by then and frail and himself. His son had gone back earlier to live with an uncle in London until the family’s arrival and to prove to the Home Office that relatives were willing to take up the burden of his family. Sanyo had told him that a job was waiting for him upon his arrival.

Eventually, the family decided to settle in the Midlands because of the social services available there for his family, so he joined another company to be nearer to his new house in the Midlands. His brother and sister began attending day-care in their new city. Mahesh had to prepare them in the morning and carry them downstairs at 6 a.m. to wait for transport before he went to work. They would then daily sit and wait for three and a half hours for the transport to arrive. He would come back at 6 p.m. and carry them back up the stairs. Social services suggested that they extend the house on the ground floor and provide new rooms for his sister and brother and his mother, who by this time had weak legs.

Social service began to provide respite for Mahesh and his wife so that they could get away on holidays. He was also able to send his mother, who had not seen her brothers and sisters for 40 or 45 years, to India for a visit. He took his wife and son to India a year later. Generally, because of the help social services was providing, they were able to get out and have a more normal life. Two years later, he and his wife went alone to India to visit an ashram. When they returned, his wife developed a fever; the doctor said that she had pneumonia and gave her an antibiotic treatment. A year later, the same symptoms reoccurred and his wife was taken to hospital where it was diagnosed that she had pneumonia again. Mahesh stopped going to work and stayed by her side in hospital. After three weeks, she passed away. At the time of the interview, it had been two years since she had died.

Mahesh continues to work and now assumes all of the caring duties for his family. He has also participated in voluntary work with the blind society producing audiocassettes for blind members of the Asian community in their language. He also participates on committees with social services and the local carers’ organisation. Since his wife’s death, he has also joined a class.
Mahesh firmly believes that by helping others unselfishly a person’s life in the future may be slightly better.

**First impressions**

Mahesh was fifteen minutes late for the interview and my anxiety was that he would not show. When I had just finished the initial “tell me the story of your life” question, Mahesh’s first response was,

*We could switch on the fan?*

Pardon?

*We could switch on the fan, please?*

Oh sure.

*Just put it on one*

That good?

*That’s fine, yeah, and erm because its hot and erm I find it a bit sweaty*

(laughs)

You’re right!

This was interesting on several levels that became more apparent during the rest of the interview. First, Mahesh’s work with electronics came to mind and the possibility that he would have wanted equipment to be working and working ‘properly’: “just put it on one.” Secondly, I thought of his ability to quickly size up a situation and master it, usually by taking charge. This was interesting in that he had been entering into a new relationship (the interview) where, normally, participants may not have felt in charge, particularly because, in these cases, they have had little prior knowledge of what to expect in the interview process.

Immediately after this interchange, Mahesh went right into his life story; he appeared to grasp the concept fully, something perhaps others who were interviewed spent some time getting their heads around. The complex and rich events of getting his family out of Kenya materialised as the major motifs of his life story. His ‘I want’ was expressed early on: “I want to go to UK for good.” Then later, “I want to go back to Kenya and stay with my family there” and, finally, “I want to take my family back to London.” Mahesh seemed to be projecting the hopeful story of wanting to get out of Kenya, but dissatisfaction with his exodus until he could bring his family with him. It became apparent that he wanted a better life for himself but was not satisfied unless he could share it with his family and execute his sense of familial responsibility. Mahesh was a kind and gentle man and this came through repeatedly.

I was struck with the fact that the details within this story of ‘the exodus’ were particularly thick and rich. This seemed to fit with the hypothesis that I was developing at the time and that is sometimes referred to as ‘flashbulb’ moments (Brewer 1986: 36), (but I disagree with this somewhat; see Jones 2001), that details around traumatic events and times are much more precise and three-dimensional than other narrative segments constructed using more general exposition.
He did not talk much about how he met his wife and the circumstances of his marriage in the first session, but then filled in the details when prompted in the second session. I wondered if he had been reluctant to bring up the concept of an arranged marriage to a Westerner?

Mahesh definitely gave the impression of a doer-problem solver-manager and this may be typical of male carers who bring their workplace skills into the caring environment. What was interesting in his case was that there appeared to be no less emotional content to his caring story than in many female stories; his approach to problem solving would be read by some as ‘typically male.’ On the other hand, he began to cry when speaking of his wife’s death two years ago and yet was able to place this tragedy within the construct of his faith.

I was astounded by his stoicism, his ability to accept his lot in life of caring for his siblings (and now also his mother) and the lack of any resentment about it. At the same time, there appeared to be a longing for ‘normalcy,’ --normal friendships, acceptance in the larger community, and so forth. This was more of a feeling for me than any specific evidence in the text. This quest for normalcy may have evolved out of a story of lifelong caring and/or a story of lifelong migrations. Nonetheless, he seemed to have no problem with his moves back and forth between England and Africa and this appeared to have been a natural thing to him. This sense of ease with migration and the expectation that his world might include it may have been inherited from his parents who had migrated from India to Kenya when Mahesh was a small boy. He never talked about his children and what it was like for them growing up in a household of disabled people and how they have reacted to that environment.

He stated that he was very satisfied with what social services had been able to provide for him and his family. His participation in carer groups and organisations seemed to be another example of carers finding identity within these groups, where there is opportunity for carers to do ‘identity work’ through reaching a sense of shared identity with each other.

**Personal reflections**

I really liked Mahesh quite a lot. I was particularly attracted to the spiritual nature of his story and life and this came across very clearly, almost from the beginning. His actions in life seemed to be totally congruent with his spiritual belief system and this reminded me of Buddhist concepts that I have encountered. My sense of romanticism was also brought into play by his migrations and their exotic locations. His narration of these events reminded me of a novel or film; perhaps this was because of the circumstances and places being so foreign (and, therefore, mysterious) to me.

I had imagined his taking this large family of disabled people on a plane to a new country and all that that must have entailed and how traumatic that could have been, yet there was no sense of any personal angst in this story. Perhaps I was transferring of my own anxieties around global travel in his case.
His need in our relationship on a personal level seemed to be for acceptance and friendship. I wondered if he was looking for the care and love that he had given out for so many years returned to him? As the concept of Karma informs us, would what he has given out come back to him eventually? He seemed to me to be one of the most compelling examples of carers’ acceptance of their lot that I have ever encountered, particularly considering the extreme circumstances and unending difficulties that he had endured.

He invited me to meet his family at one point in the interview. I had wondered at the time, was this his acceptance of me, or was he just being polite (or could this be a cultural difference of understanding)? It had come up just after he had openly cried about his wife’s death, so I believe his invitation may have come out of the intimacy of our sharing the closeness of that moment.

In summary, Mahesh Parmar presented the tale of the complex events involved in getting his Asian family out of Kenya and to the U.K. A first-born son in a family of severely disabled siblings, he apparently had lost out on the education he wanted because he needed to help his father in the business to make ends meet. Mahesh told his story as a doer-problem solver-manager, often typical of male carers, but with no evident lack of emotional content because of it. His was a story of life long caring and life long migrations. His spiritual belief system seemed to be the bedrock of his tenacity and endurance through extreme circumstances and unending difficulties. Although he gave the impression that he was aware that his chance at a normal childhood had been taken away by the difficulties of growing up within a family of disability, his commitment to family and his sense of responsibility in that family seemed to carry him beyond the anger or resentment one might expect. Still, he seemed to yearn for a ‘normal’ life, but with little hope of every actually achieving it fully. Through his work with voluntary and carer organisations, he appeared to have constructed an identity that would both extend his social circle and, at the same time, retain his long held identity system within the family and it’s sense of responsibilities.
4. MAUREEN ANDREWS

A lived life cameo
Maureen Andrews was born in England in 1938; soon afterwards, her family moved to Newfoundland, Canada, her father’s birthplace. When she was five, the family moved back to England. As a child, she cared for a time for her father who had cancer. She also cared for her mother.

Maureen married when she was 18. She went out to work at 19 and worked the rest of her life, up until her recent retirement. In her final job, she worked as a security guard in a tower block for 15 years. She enjoyed the job very much and felt that she was caring for the tenants.

Maureen had a son in 1970(?), a daughter was born in 1972 and the following year she adopted a girl. Shortly thereafter, she cared for her husband who was ill until he died. Maureen subsequently continued to work and raise her children on her own for nearly seven years.

Maureen married her present husband, Mr. Andrews, in 1980. He was born in the West Indies in 1926. They owned a large house and took in lodgers for a time. A Nigerian student, who had been lodging in their house had a relationship with her eldest daughter and she became pregnant. She was about 18 years of age at the time. The lodger, Obatunde, asked her to marry him and return with him to Nigeria. Maureen felt that her daughter was too young to go to Nigeria and so discouraged this and Obatunde returned to Nigeria to work. Their son, Emanuel, was born during this year. A year later, when the Nigerian came back for his bride-to-be, she was pregnant again with someone else’s child, so he returned, once more, to Nigeria alone.

She and Mr. Andrews have visited the West Indies many times over the course of their marriage and have built a house there. Mr. Andrews’ wanted to return to Jamaica but Maureen wanted to stay close to her family and felt that he was too sick to make the trip.

A short time after her first husband’s death, Maureen became a very active member of a fundamentalist black church, where she eventually met and married her second husband, 20 years ago. Today, when she needs help, she phones the church or prays. Maureen stated that she does not think it is proper to speak of personal matters and problems with other people; she believes that her church disapproves. Maureen has many friends, but her pastor and his wife are particularly important to her. She attends church at least three times a week, takes the teas round and enjoys cooking for celebrations and events.

Maureen has seven grandchildren all of whom she described as “half-caste.” The year that had passed just before the interview had been particularly stressful for Maureen. Her husband had had two heart attacks just before Christmas that year, resulting in her decision to retire from her job as a security guard. She had been mugged twice and her
house had been broken into twice. Maureen suffers with arthritis and diabetes and continues to have fainting spells from time to time and Mr. Andrews' health continues to deteriorate. He has sickle cell anaemia, angina and an enlarged liver. Maureen is his primary carer, although a West Indian male friend helps from time to time.

According to Maureen, her grandson, Emanuel (fathered by the Nigerian lodger, Obatunde), became addicted to drugs and was, at the time of the interview, in prison for burglary, but was expecting to be released before Christmas. Another grandson, Charles, (her son's son) got his steady girlfriend pregnant when they were both 18 and, subsequently, she had an abortion. Charles, upon hearing of the abortion, committed suicide in his father's car. Maureen did not know where her son (Charles's father) was at the time of the interview.

Maureen felt that her one daughter only came around when she was in a crisis or wanted to borrow things and then, never replaced them. Her other (adopted) daughter was living about 30 miles away.

Maureen and Mr. Andrews kept pet birds. She had budgies and reported that one of them could say, "Where's me Dad? Where's me Dad?" Maureen wanted to find a way to get her "son-in-law," Obatunde, back from Nigeria; she considered him the important person in her life story. She wanted to do this so that he could see his son, Emanuel, after 17 years. She had been trying to do this for years and continued to plot and plan how to make it happen.

**First impressions**

Maureen was a white woman whom I interviewed in an African-Caribbean day-care setting. She had her hair done up in blonde African–type braid extensions and walked with a cane to which she made a point of calling attention. She was an attractive woman, smallish in height and a bit overweight, but nonetheless, well kept. Maureen was the most difficult of the seven interviews I conducted. She refused to answer the initial single probe, "Tell me the story of your life." She did not seem to want to tell her story and felt that she did not have one to tell. She resisted with statements such as:

*I thought you were gonna ask me some questions and I would answer you and that was it, y'know?*

*I don't think this is gonna work!*

*I thought you were firin’ the questions and I was givin’ you the answers, y’know?*

I tried repeating the initial question, rephrasing it, and so forth. After several tries at this, she began to name the 'characters' that might comprise her story. Still, she refused to begin to narrate and describe, saying that she belongs to a fundamentalist church and,
I don’t really think I should go telling people things like that, people, outside people that is, problems and things like that, should I?

After a few more stabs at the initial probe, I decided to end the opening session of the interview. My sense was that Maureen wanted me to ask her questions and would not volunteer information without being asked more directly and specifically about her life. I was given the impression that, because of Maureen’s religious beliefs, she was possibly unable or unwilling to volunteer information of a more personal nature, but might be more forthcoming if topics were put to her more exactly in the form of questions.

By moving to the second interview session, I was able to form questions out of the few clues that she had initially given me and ask her to elaborate on each word or phrase that she had used. Subsequently, without destroying the gestalt of the initial responses and moving into the second phase of the interview process, I began to elicit a long narrative, rich in description and a spilling out of detailed stories of a quite complex life.

It was during the break that I became convinced that it was the case that Maureen wanted to be asked questions so that she could reveal. I asked her to fill in the demographic questionnaire (Appendix: 204) to which she replied that she did not have her glasses. I suggested that I would read the questions to her and she readily agreed to this arrangement. Again, she appeared willing to answer when asked. By the end of the questionnaire, she was beginning to give me story so I started the tape again; her answer to the first probe was a continuation of what she had just been telling me ‘off-mike.’

Maureen’s ‘I want’ seemed to be expressed in two ways: one in the second person and the other in the third. In the first way, she was asking me, “What do you want me to tell ya?” By her asking this, as well as her refusal to respond to the initial probe, she may have been giving me a clue to how she gives up information. I wondered if Maureen was willing to answer questions, but not willing to offer up any information, unless it was asked for. Perhaps this was her way of being faithful to her belief that to talk to strangers about personal matters was forbidden, but to answer when asked was acceptable. Could her story have been one of confrontation, manipulation and secrecy in negotiating life’s roadblocks?

Secondly, Maureen projected the ‘I want’ story in the third person: speaking of the Nigerian father of her grandson, she expressed, “I know he wants to get over just to see him.” How did Maureen know this? Had there been contact and communication between herself and her grandson’s father in Nigeria? She did not say. Or, was this a case of Maureen projecting her needs and wants on to the other characters in her story? She began her story by stating, “The people that are important in my life story are not even there” (she means ‘here’?) “they’re in Nigeria. I planned for years to get my son-in-law back to see my oldest grandson …” Maureen’s use of “they” instead of ‘he’ was interesting. It had reminded me of how some people in speaking of a same-sex partner or lover will use the term “they” so as not to reveal the gender of the person with whom they are having the relationship, as a way of masking a truth or secret in
narrating. On the other hand, Maureen had used the description, “son-in-law,” for a man whom her daughter had never married. Was this Maureen’s need to legitimatise this ‘illegitimate’ relationship? Or had it been a way of placing heightened importance on a relationship that is more crucial to her than it might be to her daughter, the mother of the grandson in question? Questions about Maureen’s possible attachment (attraction?) to the Nigerian lodger were present from early on in the interview process.

Maureen apparently had not wanted to tell me anything about her earlier life, her childhood, how she met her first husband, raising her children, and so forth. Her whole focus seemed to have been on her grandson who was about to be released from prison, his mother (her daughter) who disappointed Maureen and the grandson’s father, Obatunde, the young lodger who had gone back to Nigeria before her grandson was born.

In the end, Maureen had given me a lot of story and it was the story that she had probably intended to tell, albeit reluctantly or within the framework of her ‘do ask, do tell’ variation on a theme. Apparently, she had not been interested in telling a chronological ‘life history.’

I wondered if there was something in her past that had produced a major ‘life shift’ for her? Had she divided her life before and after such an event? Perhaps it had involved the shift between her first marriage, a white husband and white children and then her second marriage to a black man, having “half-caste” grandchildren, and so forth? Or was the clue to this major shift hidden within the seven-year period between the two marriages that she was reluctant to report? Perhaps the answer rested in this period, for it was during this time that she had joined a black fundamentalist church and shifted her world from a white one to a black one.

Maureen gave the impression that she had assumed the caring role at several points in her life. She told of caring for her parents, particularly her father when he was ill and she was 19. She had also cared for her first husband up until his death. She had also talked about her job as a security guard as a caring role, which was quite an interesting and surprising description of a job that would seem more perfunctory. On the other hand, she had also mentioned that her present husband cared for her until he became ill about a year ago — another example of the carer/cared for duality so typical in a family-constructed care dynamic and the family’s potential for individual roles within that unit.

**Personal reflections**

I wondered if Maureen had been made uncomfortable by the interview situation, her perceptions of me, my being a male, my background, and so forth. The discomfort that this situation had caused for me also needed to be considered too. I had felt as though I were being sabotaged in some sense (or that the research interview was) by her rigidity and pugilistic manner in the beginning of the session. (See Tietel 2000 for an example of a parallel interview experience of a “mismatched encounter.”)
In addition, Maureen had come across to me as slightly suspicious of my motives and me. In two pre-interview phone calls, this issue had already come up for me and I had sensed then that I might be about to interview a difficult person. On the other hand, she had also seemed to have a good sense of humour and certain lightness, despite the grimness of the story she told and all of her resistance. Could this have been a person who was coming to terms with the concept that bad things happen to good people? Had this been her way of making sense of the tragedies in her life within her strict religious faith?

I wondered about her identity as a white woman married to an (older) black man and what this had meant for her. Did this union make her special and allow her to stand out? Or had she conceived of this marriage as the seal of approval for having chosen a black community midlife? Had this been a reaction to being different as a child (immigrating back to England from Canada at age five)? By entering into another new community, (a West Indian church community) had she repeated a pattern of migration? Had this migration been reflected by ‘migrating’ from her first marriage to a white man to her second to a black man?

During Maureen’s initial protestations about the interview format, she said,

I’m stuck! I didn’t even realise this is what it was, y’know, I thought it was talkin’ about West Indian livin’ within, with, with, eh, whatever, and things like ‘at, I didn’t think it was goin’ to be the story of my life

At the time, I thought it was odd that she would assume that I would ask a white woman about West Indian culture and wondered if she was too immersed in her adopted culture to realise this or, had this been another ploy to avoid speaking about herself and her life?

I saw Maureen several months after the interview at the day centre where I was doing a focus group with carers. Maureen was part of the group. She did not participate in the discussion and I wondered, did she think that I had as much as I was going to get from her? Was it again the case that she would not reply to requests for information, unless they were specifically directed at her as questions? She gave me a sense of our being co-conspirators too. I felt that her glances and apparently ‘knowing looks’ during the focus group may have represented a pact we had not to reveal anything she had told me previously, which, of course I would not do. I also sensed from Maureen’s body language that she and I were on a different plane from the others, because of our ‘shared’ experience, the ‘secrets’ that she had previously shared with me in her interview.

In summary, Maureen Andrews was reluctant to tell her life story; she seemed willing to answer questions, but apparently did not want to volunteer information. Her story implied one of migration. She first migrated from England to Canada as a small child, returning at age five. She appeared to migrate again as an adult from her white community and family to a black community and church, after the death of her first
husband. Finally, she emphasised that she held out hope for the return of the migrant Nigerian who impregnated her daughter 17 years ago and produced her first grandson.

As a child, Maureen had cared for her father, up until his death. She later cared for her first husband, again up until his death and now cares for her ailing second husband. She seemed to accept caring as a duty that a woman was expected to perform. Although a strong character herself, she gave the impression that she turned to the males in her life, particularly within her fundamentalist church, for approval and advice. She told a story of bad things happening to good people and her attempt at making sense of all of this through her strict faith. Maureen repeatedly focussed on the return of her “son-in-law” from Nigeria to be reunited with his son. Although she seemed overwhelmed with familial responsibility and tragedy, above all else, she seemed to cling to the possibility of this reunion as a kind of salvation.
5. SALLY GREEN

A lived life cameo
Sally was brought up in the 50s and 60s, as “a typical little girl.” Her mother had instilled in her that a girl gets a job, gets married, stays married for life, looks after her husband in the home and the family that comes along with it and that is how life is. Sally, therefore, had looked forward to a life of being a wife, a mother and a worker.

Sally's first marriage had been to a member of the British armed forces who was away a lot of time. They had three sons and Sally raised the boys, much of the time, on her own. When they returned to Britain, Sally found that her husband had had numerous affairs. They separated and divorced and Sally brought up the boys on her own for a time.

Sally later met Peter and they were married. Their son, Graham, was born in April 1985, the last of Sally's four boys. From the beginning, Sally knew that something was not right with Graham because he cried constantly. His father could not cope with this and they rowed all of the time. Peter was working days and Sally was working 12-hour shifts at night. Finally, they split up. After about 13 months, Sally began to give Graham bland meals and, for the first time, he slept and did not cry. Her doctor told her that she had discovered, by accident, that Graham was hyperactive and would need a special diet.

Graham started nursery at three but was not toilet trained and could not talk properly. They tried speech therapy but, by age six, Sally ended up teaching him to speak herself. He wore glasses at school and was bullied. He did not play with other children and was destructive; he set fire to the house and wandered. At age nine, Graham finally was moved to a special unit of the mainstream school but was not recognised as disabled, rather just as hyperactive with a learning disability. He became more of a target for the bullies in their neighbourhood because he went to a special school.

Sally reported that, even today, Graham's father will not have him, nor will his grandparents. Sally's father particularly cannot accept that there is anything wrong with Graham.

Sally said that she goes to the cinema when she can and enjoys romances mainly; her favourite film is Sleepless in Seattle. She would love to be swept off her feet and for everything to be all “hunky-dory rosy.” She likes the concept that there is someone out there for you. She also enjoys historical films where she can pick up extraneous knowledge and surprise people with it.

Sally stated that caring for Graham had cost her her livelihood, her marriage, friends, freedom, money and health. It had also affected her other three sons. Sally used to throw things to release her frustrations and anger but now she works in the garden to vent her pent up anger. Sally said that she did not have an identity of her own except
through caring for her disabled son, Graham. She said, “Me’ has been missing for such a long time I’m not sure who I am anymore.”

**First impressions**
Sally began the interview by immediately reading out a three-page document detailing the story of her son, apparently, a speech she had prepared for presentation at a local organisation. Feeling that this was her way of beginning, I did nothing to stop this process, but rather allowed it to proceed. In this way, Sally seemed to be expressing her own gestalt and perhaps revealing clues about her identity within this very act. This was her story and this appeared to be how she had decided to tell it –in a formal, presentational way. Ostensibly, this was the result of her preparatory thought about the interview scenario.

It was her son’s story and little reference to her own life materialised, except as a carer and the problems that she had encountered in that role. The only major point she mentioned about her ‘self’ was how caring had ended her marriage. She looked up from the reading from time to time; I could not tell if she had been almost speaking extemporaneously or if she had known the script so well that she had been able to recite it and maintain eye contact with me at the same time.

Sally was very open about the fact that she did not have an identity of her own and did not know what it might be. I had the sense that she was beyond even caring about it at that stage, possibly an indication of deep depression. Even when pressed in the second session to specifically talk about issues relating to her self, she continued to talk about caring for her son (another example of the ‘looping’ phenomenon that came up again and again in these interviews).

She seemed to know that this was not a good state to be in, but only wondered about whom she might have been if she had not been a carer for 15 years. She told very little about her life, marriage and other three sons before her caring role began. She said very little about her own childhood, except in terms of what her expectations of her life had been.

She gave the impression of being beyond blaming anyone, either for her husband leaving or her son’s disabilities, although she stated that her husband had blamed her. She appeared to have little concern for what else life might be for her.

Sally gave the impression that she had found her place in the carer’s organisation and may be helped with ‘identity work’ in that supportive environment; first, by possibly identifying with other carers in similar situations and then, slowly, beginning to carve out her own identity within this mix.

Sally brought up the importance of the thin line between the care involved in mothering a child and that involved in caring for a disabled child as a lifelong job. She seemed able to define these two roles quite well.
Sally’s ‘I want’s were apparently divided by her identity through her son and her own shrinking identity as a person. She wanted “them” to understand how difficult he can be and she wanted “them” to understand how angry she felt sometimes. Through this, Sally appeared to be seeking validation for her caring role from without. She did not seem to want to fight anymore, but what she needed and what she wanted, apparently, “goes by the board.” She could “honestly” say that she had wanted to run away and that she had wanted to be able to do things as ordinary as going to the cinema. She had never wanted to be a failure but felt that she was because of her failed marriages. Sally described a negative and depressing ending to her story through her wants. She spoke from the standpoint of wanting understanding and not getting it, being tired of fighting and just wanting to run away (escape) and feeling, ultimately, that she had been a failure. Sally painted a picture of a woman who probably was at the end of her inner resources and in need of a great deal of care herself.

**Personal reflections**

I was personally struck by the fact that Sally’s situation and story was, in many ways, different from the others. She was one of three interviewees (herself, Polly and Carl) caring continuously for a child of their own and with no end in sight. The potential for the inescapability and inevitability of lifelong carer role for the parent of a disabled child came into deep focus in her story.

I liked Sally and identified with her as a romantic. I was even more astounded, however, that after the heartache and disappointments she had experienced in her life that she apparently still maintained a romantic, almost childlike fantasy idea of the perfect partner or relationship.

After the formal interview was complete, we talked about visual images and how people form a picture of a person when reading a book or listening to a story. She then asked me to describe how I saw her son and I did so. She then showed me a photo and I had been correct on all counts, his hair colour, kind of eyes, kind of smile, and so forth. He was a quite good-looking child.

It was interesting in writing this description that very few Personal reflections of my interview with Sally come back to me. I wondered if this was because Sally, the individual, had become so totally identified within the existence of her son and so transparent that she disappeared, leaving few traces in my memory.

In summary, Sally Green recalled her childhood as a typical little girl, raised by a mother who instilled in her that a girl works, gets married and stays married for life, looking after her husband and children. Sally, however, had one failed marriage and when her second marriage produced a disabled son, her second husband left too. Still, through all that caring for a disabled child entailed, Sally appeared to hold on to the romantic idea that there is someone out there for you.

At the time of the interview, her total identity appeared to be wrapped up in her son’s story and caring for him. She expressed that she sometimes wondered about who she
might be if things had been different, but clearly understood that caring for a disabled child meant caring for life.

She felt that she never wanted to be a failure, yet, because of her mother’s early instruction and expectations, Sally found that she had not been the wife that she should have been. Sally seemed to embrace her romantic fantasy ideal of life, but in reality, appeared to suffer from deep depression and even remorse.

Her apparent lack of a sense of self portrayed someone who was almost transparent. Sally had begun to be involved with a carers’ organisation and, hopefully, through this kind of activity, she may begin to establish a sense of identity for herself.
6. SHEILA CONNER

A lived life cameo
Sheila Conner, age 58, an only child, was born to Gail and Jack Roberts in an English northern city in 1942. When Sheila was five, her Dad, Jack, moved to Leicester to work; a few months later Sheila and her mother followed. Sheila made a school friend, Mary, who was also an only child and their families took holidays together.

Sheila started working at the telephone exchange in Leicester at sixteen. When she was nineteen, she did a week at a nearby Exchange and was introduced to Donald Conner (b. 1936, d. 1996) by a worker from the Exchange and her husband. Donald was the youngest of 12 children. A week later, he moved to Leicester and moved into Sheila’s parents’ house. They were engaged six months later and six months after the engagement in 1961, Sheila married Donald. Eleven months after their wedding, Sheila and Donald moved into their own house.

Sheila stopped working for the telephone exchange in 1962. Sheila and Donald had two children, Joan, 36 (b. 1962) and Dan, 34 (b. 1965). Sheila stayed at home caring for her children for seven or eight years. She then began to work part-time in a hospital serving meals, cleaning, and so forth, for about four or five years. Donald held various jobs including jobs in engineering and printing.

Donald suffered from arthritis from childhood and had a hip replacement in 1982 at age 46. Shortly after the hip replacement operation, their daughter, Joan, 20 at the time (Sheila’s account stated her daughter’s age as 18, 19 or 20 at the time of the interview), moved out of the house, not giving a reason for her sudden departure. Upon leaving home, Joan may have moved in with her boyfriend, Pete, at the time in his 40s. Perhaps she moved in with him later; Sheila is not sure. Joan had no contact with her parents for the five or six years following her leaving home.

During these years, Donald worked through Re-Employ, a job service for the disabled. Sheila began working with mentally handicapped people in private care homes around 1989-90 and continued to work in them for about seven or eight years.

Sheila’s mother, Gertrude Robinson, died in 1993. Around the same time, Donald began to have angina attacks while he was working shift work. The company told him he had to finish work due to ill health. At that point, Sheila continued working mornings or afternoons. Donald and Sheila switched roles now with Donald beginning to do some of the housework and Sheila bringing home the paycheque.

In January 1995, Donald had a heart operation at a private hospital and by June his condition worsened. He was referred to a memory clinic and a community psychiatric nurse. In February 1995, Sheila asked for a brain scan but was told that it was not necessary. Around this time, Sheila cut her work hours in half in order to care for Donald. Sheila wanted to be there to care for Donald, but, at the same time wanted to be out, remarking, “I daren’t leave him.”
In September 1995, Sheila and Donald took a coach holiday to the Isle of Wight. Whilst on holiday, an emergency doctor advised them to go home. Upon arriving in Leicester, Sheila took Donald to A & E at 3 a.m. with “epileptic fits or something.” At this point, a doctor said that it was a medical problem, not a mental health problem, and to get a brain scan done. The scan equipment was not working, however, so the scan was not done until one or two weeks later. Donald was then admitted to a mental hospital on the advice of their GP. He remained in the hospital for 12 weeks.

At the end of November 1995, Donald came home. Just after Christmas, Donald got violent and Sheila arranged respite care for one week. In respite care, Donald was having falls and mini-strokes and was subsequently admitted to the hospital again. Whilst Donald was in hospital, Sheila was advised to find nursing care for Donald. He went into a nursing home, but two days later was back in the hospital for a fortnight. He then returned to nursing care with the doctor advising that it was “a matter of time.” Donald lasted about 11 days and died in March 1996. The Death Certificate stated cause of death as bronchopneumonia, blocked carotid arteries and Parkinson’s disease.

Sheila’s son, Dan, was married to his girlfriend, Sally, in the Caribbean in the following October 1996. Sheila attended the wedding. Joan was invited to her brother’s wedding, but did not attend. In December of the same year, Sheila started her own group at the Carers’ Centre with a friend, Susanna, from her teenage school days. Their sons had played together as children. In June of 1997, Sheila and Susanna took a four-day holiday in Devon together when her friend’s husband went into nursing care.

Sheila left her job in the last care home in April of 1997 and subsequently went to work for Crossroads (a carers respite organisation) in December of 1997 and worked for them two days a week for about 18 or 19 months. During this time, Sheila took care of a patient named Peggy, who was in her seventies at the time, who later died. Sheila felt very attached to Peggy and attended Peggy’s funeral.

Dan and Sally had a daughter, Marnie, born in September 1997. Joan refused to call her brother’s baby by its name initially.

Sheila’s friend Susanna’s husband died in February of 1999. Sheila last saw her friend in April 1999. She received a letter from her in August but has since lost contact with her friend this year and does not know where she is now.

Dan owns a new house and has a job that includes a car. Joan’s boyfriend, Pete, now in his late 60s is more or less housebound, having had a stroke. According to Sheila, Joan has a lot of mental health problems. She has been in mental hospital; she cuts herself and is frightened to go out. Additionally, Joan was recently assessed for community living arrangements, but “couldn’t stick it” and moved back to her home. She is now attending day hospital. Sheila’s father, Jack, is still living and visits her regularly. Sheila continues to organise her carers’ group activities.
First impressions

The first thing that struck me after the interview was that she had never mentioned her husband by name in the interview, but had given her children’s names as well as the names of others. Had this been some sort of clue about her relationship to her husband and intimacy? Or, did the seemingly consistent reference to “husband” have something to do with a system of formalising identity through that relationship?

The second thing that had seemed problematic was the story of her daughter, Joan, and her running away to live with an older man. Sheila had seemed to blame this relationship for her daughter’s mental health problems. Had this been smoke screen? Sheila’s description of her husband’s illness had seemed to me to indicate some sort of dementia but she had never mentioned this as a diagnosis and instead concentrated on his heart problems. Late in the story of his illnesses, she did mentioned pre-senile dementia on the death certificate.

Sheila’s ‘I want’ seemed to centred around what she wanted her husband to do: she wanted to have him home, she wanted him to do as she wanted him to do but knew he “couldn’t help it.” She also appeared to want for herself: “I want to, want to get away from it, but then again, as soon as I was out I want to get back to it cause I daren’t leave him.” And again, after his death, “I wanted to be out of the house, didn’t want to be on me own, go out, didn’t matter where.” The theme of being trapped in and wanting to get out materialised repeatedly in Shelia’s story. Her daughter, Joan, had run away from home and then apparently trapped herself in her new home with her own agoraphobia, over-eating and self-harm. Shelia also told a story of holidays and the importance of them in her life. She gave the impression that holidays represented a ‘getting out’ for her, perhaps an escape of intolerable situations.

Sheila seemed to have unresolved issues around her daughter’s plight as well as her own possible anger with her husband. She did not remember her own childhood and I wondered if anything major had happened to her as a child. She also had said very little about her own children and their childhood in the home.

Sheila’s care for Peggy in the nursing home up until her death and attending her funeral may have represented her finally expressing her emotions around her husband’s death. It also may have been an example of “second chance phenomenon” (see Jones 1992) when carers return to the caring role after a family death, often caring for someone outside of their immediate circle. This phenomenon represents a chance to go back to the carer role and to get it right the second time around.

Sheila apparently had started a carer’s group with an old school friend, but then the friend disappeared and Sheila did not do anything about finding her. This inability to pursue lost friends or relations seemed to be a theme in Sheila’s story. This more recent incident did appear to mirror her past behaviour when Shelia’s daughter, Joan, ‘disappeared’ and nothing was done to find her. Was this so that no one would be
blamed and no secrets would be revealed? Had Sheila shared secrets with her friend? Did Sheila feel guilty in cases when people ‘ran away’ from her?

Sheila appeared to see herself as independent. She seemed very proud of her son, but gave the impression that she saw her daughter as full of problems. Perhaps she saw herself in her son and her husband in her daughter and her husband’s dementia reflected in her daughter’s self-harm. Questions began to be raised for me about the root of these problems and what the problems shared in common, particularly, what had been the father’s role in these problems? Had the self-harm been a result of sexual abuse by the father and/or sexual identity problems for Joan?

There seemed to be a large chunk of her life that she was not telling or willing to tell or remember. She seemed to have jumped to the caring role with her husband very quickly, even skipping past her employment as a carer to older women in her story.
Personal reflections
A moment developed in the first interview session when Sheila was speaking of her imagining seeing her husband after his death, a common occurrence in some people’s bereavement process. Because I have experienced a ‘difficult death’ in my own history, I was personally familiar with this phenomenon. Within the interview process of head nodding, eye contact and “hmmm” and “uh-huh”ing, of course, there is little other room for communication. Still, at this point in Shelia’s story, she seemed to know that I understood what she had been describing and on a personal level. It was from this point in the interview that our relationship changed and she began to become more open and forthright. It was as if she knew that I knew and we were, somehow, co-conspirators in this shared experience that some others might find unbelievable. This was an example of how non-verbal communication is a powerful tool within the interview process (see Jones, 2001).

Within the setting of the first interview session, I had become alerted to the possibility that there might have been a history of sexual abuse within the family and that this might have explained much of the family dynamics. Within the interview method, that was not a question that I could ask directly, and, on a personal level, I was glad of it. Still, I had felt that it was necessary to explore this possibility carefully and in any way I could; the clues in the text had been too strong to ignore. For example, in explaining her daughter’s running away, Sheila had commented:

*Didn’t hear from her for a week and she came home she said that she was worried about her husband/abdomen her father, worried about her father, she didn’t like to see him, cause he couldn’t put his foot down on the ground.*

One could regard Sheila’s classic Freudian slip in referring to her daughter’s father as her ‘husband’ then catching herself and correcting the slip mid-word as too compelling to dismiss. Further on, Sheila wondered:

*She cuts herself (1) and she says it’s because of how her and her Dad were. (1) But I still can’t get to the bottom of it.*

*I will say to her, now why don’t you just tell me what the problem is? And she just can’t bring herself to tell me, so that’s got me thinking, well, what happened, has anything happened (1) in the past*

Finally, Sheila seemed to bemoan the fact that her daughter had “wasted her life with an older man” referring to Joan’s boyfriend who was the same age as her father. Or was Shelia subliminally referring to her daughter’s problems being a result of her relationship with another older man, her father?

I left the first interview sessions knowing that this was the sticking point of this story. I met with a colleague who is an expert in self-harm to get her opinion on the situation and she agreed that there is a distinct possibility that Sheila’s story of her daughter’s
self-harm is also a story of sexual abuse. I went back to a final follow-up interview with a list of specific questions, including, “How does it make you feel as a mother that your daughter does this to her body?” I had hoped that by exploring Sheila’s past through this more direct question, she would finally be able to express her feelings about her daughter’s self harm and possible roots of the problem.

In summary, Sheila Conner’s father moved from a northern city to Leicester when she was five; Sheila and her mother following a few months later. An only child, she seemed to have little memory of her childhood, yet the story of the move was apparently pivotal and central to her narration and her first early memory. She seemed to present a story of being in and moving out; the theme of being trapped in and wanting to get out came up repeatedly.

Because she could not or would not remember most of her own childhood, a veil of mystery seemed to shroud her upbringing. Holidays were one representation of getting out and one she referred to specifically in her own childhood as well as in her children’s upbringing. Sheila’s story presented clues to the possibility of the sexual abuse of her daughter by her husband, the person who is central to her carer story. Her narration of caring for her husband included twists and turns of not knowing what the diagnosis was, struggling with the medical establishment for oversight of his care and his worsening mental condition throughout the process.

The main episode of Sheila’s story however, was her daughter Joan’s sudden departure from the family at age 18 and not reappearing for another six years. The fact that little fuss was apparently made about her exit at the time, suggested that there might have been secrets in the family. The fact that she went to live with a man who was the same age as her father at the time also seemed significant. Sheila reported that Joan cuts herself and has many psychological problems, possibly indicating that there may have been severe trauma in her daughter’s childhood home life. Sheila spent a good part of her story speculating that Joan’s problems all stemmed from having left home to live with an older man or that she was jealous of her brother.

Sheila seemed to have been overwhelmed within her parental role and appeared to shift to her role as wife and carer, rather than confront any possible lack of mothering skills. Because of her professed lack of childhood memories, particularly ones around her own upbringing, a big piece of the puzzle of her life and ultimately her family’s life appeared to be missing. A parallel piece of the puzzle of her children’s upbringing was also missing. The surface facts of Sheila’s life and caring activities may have belied the fact that a web of secrets and buried memories may have been present, to be tapped through the analysis of the narration itself.
7. TANSY JOHNSON

A lived life cameo

Tansy was an only child born to a traditional black British couple late in their lives: her father was 59 and her mother 54 when she was born. She believed that she had been brought up to be seen and not heard within a very strict system of child rearing. She was taught to respect her elders and that family members are supposed to look after each other. Tansy’s mother had often told her about the time when she was younger and how she had cared for and nursed Tansy’s grandmother, after she had had a stroke and until she passed away. According to Tansy, it had been drummed into her head that this was the correct way to be—to care.

When Tansy was eight her father, suffering from diabetes, had to have his leg amputated. Her mother cared for him. When he was in hospital, for about six months, Tansy went back and forth each day to visit him, expressing that she had no choice in the matter. Because of hardening of the arteries, her father passed away in hospital in October of 1980.

Her mother had arthritis as well. When Tansy was 14, her mother went into hospital and had a knee replacement, then went back the following year to have the other knee done. Tansy cared for her until she got back on her feet. Her mother’s mobility was affected, however, and this is when Tansy’s caring duties started in earnest. Nonetheless, she can remember earlier periods too when she would do the shopping, house cleaning, and so forth, to help her mother. It was at 14, however, that her caring duties really began to increase. For example, she would accompany her mother to hospital for check-ups and go with her when she had to take taxis, amongst other duties.

Tansy expressed that she had been a violent person as a teenager and was referred to an educational psychologist. She also had started hearing voices when she was 14 and the psychologist put it down to her losing her father at such a young age. At 17, Tansy went to hairdressing college, but decided that the potential wages were too low and, therefore, took a job in a bowling alley working behind the bar.

Before Tansy went to college, she met an older man: “You know, that was the best thing in my life and I calmed down then.” When she was 17, however, he dumped her and married another woman, and moved in around the corner from Tansy and her mother. Her mother said that they were going to move because she was fearful of Tansy’s threats against the other woman. For this reason, and because her mother could no longer negotiate the stairs, they moved into a flat. Tansy was working at the bar at the time and had to cut her hours down. She was then cooking three meals a day for her mother, helping with her medication, and so forth.

Tansy also recalled that she was out partying every night of the week, school or no school, from the age of 15. She had felt she was parted out by age 20 and decided to have a child. Tansy became pregnant at 21 and had a little boy, Andy. This meant that
now she was a mother as well as a daughter, caring for two people. Because of caring for her mother, she felt like her life was on hold and she used to get angry and upset sometimes. She felt that it was love and duty that had kept her in her caring role as well as what the black community might say about her if she did not assume her caring role. Around the same time, her mother had found out that she had cancer, but kept this information from her daughter.

Two years before her mother died, Tansy met another man, but she soon realised that he loved the drink more than he loved her. Nonetheless, she felt she could not let go until she had someone else to depend on and, particularly after her mother died, she was scared of being on her own. Tansy had been on anti-depressants for the last six months of her mother’s life. Andy was almost three at the time of his grandmother’s death and Tansy was 24.

Tansy had had a relationship with another man for four years at the time of the interview; he is a bit younger than she and is white. About a year ago, her boyfriend’s mother had mental health problems and, since no one in his family knew how to cope with the situation, Tansy took over the caring role. She thought it was wrong that the daughters and sons did not know how to handle the caring and felt that they were frightened to do it.

Particularly because of caring for her mother, but also because of other caring roles she has assumed in her life, Tansy decided that she might as well go into social work, something in the caring field. At the time of the interview, she ran a carers’ group in an African Caribbean day centre. Tansy admitted that it might be the same for her son, Andy, and that perhaps he will have to care for her or might go into the caring field eventually. Tansy has Multiple Sclerosis, but feels that she has been lucky so far with her disease.

Tansy expressed the rationalisation that her mother had looked after her mother, Tansy had looked after her mother and now perhaps her son will need to look after her. Tansy admits that there may come a time in her life when she might have to start caring for someone again as well.

First impressions
I liked Tansy very much. She was young, attractive and very much a ‘people’ person. Another reason for having liked her might have been the fact that she was black. I come from an American city that is 50 per cent white, 50 per cent black, and there are times living and working in Leicester that I find myself missing daily social interaction with black people.

Like the bulk of interviewees, she definitely had expected to tell a carer’s story and this is what she did. It was in the second session that, when probed, she shifted into more of her own personal story and how she, as an individual, related to her ‘carer story.’
The motif of Love and Duty to family and the black community seem to be the motivational forces behind a carer role for her. She appeared to be a good fit for the phenomenon developed through this research that carers demonstrate the parental care that they need for themselves by caring for others, whether in childhood itself or throughout their adult lives. One explanation may be that her father had died and because she was missing him, she became angry over her loss. Then, instead of receiving the love and understanding from her mother that was absent because of the loss of her father, she was required to become her mother’s carer.

Several times she touched upon the volatile nature of her relationship with her mother, yet always retreated into the mantra of “but you have to care” and “I love her really.” She very well might have had unresolved anger with her mother for robbing her of a normal childhood and perhaps even blamed her for the loss of her father. For instance, it would not be uncommon in the eyes of an eight year old to imagine that her mother did not care for her father well enough and so he died. Then instead of caring for her, Tansy was trapped into the role reversal incumbent in caring for her mother.

Tansy’s ‘I want’s were negative and positive, perhaps projecting a fear of mixed outcomes in the future of her story. For example, she expressed that she wanted to get pregnant, that she wanted to be able to go out and that she wanted someone that she could depend upon. She seemed to project her life script as one of freedom and responsibility, but tempered by someone dependable. She expressed that she did not want to be on her own and that she did not want to make the same mistakes twice. By saying this, had Tansy been revealing her fear of a compulsion to repeat these very ‘mistakes’?

Tansy brought up the fact that she has MS at the very end of the interview. Had she saved this as a surprise ending? It seemed odd that it was not mentioned earlier. She talked about it only in reference to the possibility of her son becoming her carer eventually and this role being handed down through three generations in the family. Was her own late-life birth an accident or, with a darker read on the family history, might one question her parents having had a child so late in life and the possibility that this child was conceived to be a ‘carer child’ for their old age? That Tansy’s ‘I want’ began with wanting to get pregnant herself, could raise the question of her own motivation in procreating her own offspring as a potential carer, thus continuing the family dynamic.

**Personal reflections**

Tansy’s relationship with an alcoholic boyfriend made me wonder if she puts out carer ‘signals’ to others. Her comment that she could not leave him because she did not want to be on her own could be regarded as troubling. Did it indicate a need to seek out a dependent partner who would also respond to her dependencies?

There seemed to be something of a time bomb quality to her and I could not put my finger on it. She seemed to have her story ‘down’ and appeared to be self-aware but still looking for an answer, a clue or help with deeper issues. She had mentioned depression several times over the course of her story. I had sensed that she was
looking to me as a confidant, someone who would understand, offer answers, and so forth. I felt as if she had been looking for a mirroring of herself in me, someone who would almost share a secret with her.

In summary, Tansy Johnson, a late-life child of a black British couple, was brought up in a strict system that included being seen and not heard, respect for her elders and that family members are supposed to look after one another. According to Tansy, her mother made a point of teaching her that she had cared for her mother and that the same was expected of Tansy. She reported that her caring duties began in earnest at age 14 when her mother became immobile. As years past, this made Tansy feel like her life was on hold, particularly after the birth of her son. She felt that it was love and duty and fear of what the black community would say that kept her trapped in a caring role.

Tansy has Multiple Sclerosis and considered that there is a possibility that her young son may someday have to care for her. It seemed ironic because Tansy clearly demonstrated that the death of her father and her subsequent caring roll with her mother had made her volatile and depressed. She appeared to blame her mother for robbing her of a normal childhood and even, perhaps, robbing her of her father. Still, she appeared to return to the mantra learned at her mother’s knee that family take care of each other, no matter what the consequences may be. Tansy emphasised that it boiled down to Love and Duty and what the Community might say.
Conclusions
The lived lives of all seven interviewees have been presented in this chapter, representing the diverse demographics of the pool of subjects as well as the richness and diversity of individual lives across the lifespan. Through the products of narrativity, the past and its artefacts became both symbolic and utilitarian. A pen portrait or cameo of each interviewed individual informal carer has been presented as a process of assemblage of a descriptive, chronological picture of each remembered past. These reconstructed chronological stories have created the skeleton upon which the told stories rest.

‘First impressions’ then fleshed out each of the stories with the interviewers initial responses to the interview scene and included two devices. First, by the uncovering of motifs presented early in the stories and, secondly, by the ‘I want’ phenomenon –early themes that express the narrator’s projected outcome of the story. Next, ‘Personal reflections’ detailed the interviewer’s personal responses to the text, both during and after the transcription process, including issues of transference and counter transference, using these tools to gain insight.

This work now proceeds to the next chapter in which the stories of four of the participants outlined above will be analysed by the reflecting team method as described in the Method Chapter.
CHAPTER 5: Reflecting Teams’ Analyses of Data

Pounding on the walls of the house of language
to uncover doors to meaning

Is this not precisely the joy of the creative mathematician? . . . It is to pound on the walls of the house of language in hopes that we may find our way outside. Yet it is this very language that must serve as the resource for the effort.

Gergen 2001:429

Introduction

The analysis of biographic narrative texts using a team approach was the centrepiece of this research’s biographic interpretive narrative method and it is in this chapter that the results of those analyses are presented. The previous chapter established the skeletal frameworks upon which the told stories hang. It formed a beginning point to begin interpretation by teasing out the facts—the names, places, people, and events of these lived lives.

This chapter presents the results of the data analyses of the separate teams that were involved in the study each of the ‘lived lives’ and ‘told stories’ of the four participants selected for depth analyses. Beginning with hypothesising inductively (using Cressey’s [cited in Ratcliff 2001:1] six steps as a template as summarised from Zananiecki) from the bare bones facts of a ‘lived life,’ each team drew a set of conclusions that could eventually be compared and contrasted with the conclusions evoked from the analysis of the ‘told story’ by its separate team. It was in the narrations themselves, hypothesising inductively bit by bit, that the ‘told-ness’ of the stories, where the bulk of interpretive analyses took place. “The more global meaning of these events and reports is developed in the story which is told after the fact and which cannot be said to simply correspond to any of ‘the facts” (Kerby, 1991:96).

If “narrative is a metacode, a human universal on the basis of which transcultural messages about the nature of a shared reality can be transmitted” (White, 1980:6), then it follows that narrative can be decoded, unpacked and deciphered by others through their capacities of such a shared reality and through the universality of their humanity. This research’s analytical process was always envisaged, however, as a dialogical one and not a judgmental one. Crucially, similarities and differences between team members and interviewees were used as bridges to understanding, rather than a means to distinguishing ‘others’ as separate from and, therefore, somehow outside of team members’ concepts of the mainstream or quotidian.

“The other must be brought into some significant relation to my present, must be reconstructed (configured) within a life context (social, cultural, etc.) that can be understood by extension from my own” (Kerby, 1991:95). Emphasis was on shared cultural and societal resources or the “habitus –our second nature, the mass of conventions, beliefs and attitudes which each member of a society shares with every
other member” (Scheff, 1997:219). The *habitus* was at the base of each team discussion; but further, the use of intuitive tools beyond the confines of social, cultural and economic boundaries were also necessary.

Because the aim of this research was to speak in terms of development *within* individuals rather than in terms of implicit or explicit comparisons between individuals (Freeman & Robinson, 1990:60), the focus, therefore, was on transformation and process (Mey, 2000: [11]) as a bedrock of developmental study as well as the foundation of qualitative research. Ultimately, going beyond mere ‘coping’ studies, this research attempted to focus its efforts on the “inner side” of human development and of its “emotional life” (2000: [13]). By concentrating centrally on the individual --in relation to and constructed by an individual’s interaction within his/her particular social sphere-- we could begin to speak, finally, of ‘emotional capital.’ Emotional capital is the fourth supporting column of resources available to sustain an individual, a structure that is typically conceived in terms of social, cultural and economic capital (see Bertaux & Delcroix in Chamberlayne et al, 2000:80-82; Miller, 2000:43-44).

Emotional capital was explored as a critical resource, supporting and helping to explain a given told story. By doing this, narratives packed with choices and directions contrary to a ‘norm’ began to become more comprehensible and familiar when conceived of as alternative uses of available resources --including emotional ones. Thus, the emotional capital available and transferred from generation to generation within families --the primary mechanism for transferring social, cultural and economic capital (Miller, 2000:43)— became particularly poignant in light of these stories of care.

Emotional capital or currency gains particular significance in terms of value: “In experience we cannot really separate emotion and value; together they contribute to the meaning or significance our life has in most, if not all, if its less mundane episodes … Values arise in the dramas of our life, especially the choices this life involves” (Kerby, 1991:55).

Equally, each team member came to the analyses sessions with his/her own emotional capital with which to compare and contrast the unfolding dramas and events and the subsequent choices made by the interviewee. The narrator’s choices and their consequences may have presented quite a different mix from results analysis team members might themselves have experienced or expect to experience in similar circumstances. Nonetheless, the folk wisdom of ‘playing the hand we are dealt’ enabled the team members to brush aside differences and empathise and identify with the universality within the *process* of making lifecourse choices and decisions. It may be said that people come to any situation in life with a set of options constructed and complicated by their past individual, interactive experiences. Nonetheless, variations and diversities of human experience still allow for the understanding of the experiences of others through common practises and tools –through shared processes. It is this concentration on the universality of process and its levelling of differences that became so valuable to team members in exploring the lives of strangers.
Within the biographical perspective, ‘process’ has a particular double-edged meaning. When a person’s lifetime is viewed as a whole, the idea of their ‘history’ can be apprehended at two levels. First, the individual has their own history of personal development and change as they ‘process’ along their life course. Second, a considerable amount of time passes as they move along their life course. In this respect, historical events and social change at the societal level impinge upon the individual’s own unique life history.

Miller 2000:9

Another tool that team members brought to the analyses sessions was their natural ability to consider issues beyond the more standard considerations of race, gender and class. Often the biographical perspective ignores the importance of time-related concepts and thus, the historical context itself (Miller, 2000: 37). Within the team sessions, however, subtleties such as issues of age effects, cohort differences and historical effects were raised frequently. Teams often spent time placing narrators within certain period contexts, using their knowledge of history, age cohorts, cultural differences, and so forth. This phenomenon developed spontaneously; its occurrence may simply be the result of the narrative construct itself and the way that stories conjure up a setting placed in time, evoking a natural sensitivity to historical context. Equally, it could result from the fact that the very nature of a team approach to analysis allowed for a multiplicity of viewpoints evolving from a wide variety of age, cohort membership and cultural and historical backgrounds amongst the team members.

If a narration itself is a revision of the past, fuelled by selective memory of life experiences, half-remembered incidents and people (Freeman 1997), then the recipients of that narration do no more than bring their own selective pasts to the habitus of its understanding. Team members in this research’s analytical process used a variety of strategies to understanding including their historical, cultural and professional knowledge (and all were participants in healthcare professions in one guise or another). They also brought the more subtle use of their immersion in popular culture—from film, television and novels to art and theatre as well as the accumulated folk knowledge or wisdom often referred to as pop psychology that has particularly grown out of the field of psychoanalysis and spread into everyday life for over a century now.

The teams’ interpretations of the texts of carers’ narrations of lives were, ultimately, themselves constructions or dialogues –dialogues with the text and its author, but also with each other and the shared habitus or culture. In building consensus by inductive reasoning (the academic version) team members were also engaging in the quotidian need to discuss (akin to gossip in a positive sense) or to reach agreement about the particulars of an other (the back garden fence version). Rather than dismiss that process, this research embraced it. At the other end of the dialogical equation, team members were doing no more or no less than what the narrator had done in the first place: imaginatively and creatively building a story of a life and, therefore, an identity, out of the flotsam and jetsam, *les temps perdu*, of a remembered life.
The analyses that follow, therefore, are not embedded in nor tethered to any strict sense of a psychological or a sociological theory or practise. What remains instead are the traces of these conversations or dialogues with the text, in all of their ordinariness and heterogeneity. It is crucial to this process to remember that “the material of recollection is analogous to archaeological finds that still require interpretation for their precise temporal location and sense” (Kerby, 1991:23). As imagination played an important role in recollection (32), so too imagination was significant in the interpretation of these recollections as well. The presentation of these larger dialogues is, ultimately, a *bricolage* of moments in time, using whatever was a hand for the team members, just as it was for the narrators and, finally, this writer. On any other day, perhaps, the analysis may have been different and this research report not only reflects, but also celebrates, that fact. These concerns are raised because it is important for the reader to realise how this research has worked to assemble the accounts that are presented and that any truths in the analyses, where they exist, have been established interpersonally (Brown et al, 1996:1571), through the frailties as well as the strengths of teamwork. On the other hand, the stories that carers told were not naïve constructions, but rather precisely knowledged and informed (1575); it is emphasised here that so too were the analyses of the narrations as well as this final reporting.

The bulk of this exploration of the stories of others was done through examination of spoken language converted to text. Working purely from transcripts of narrated lives, the teams’ emphases were necessarily on language. The joy of working with teams of colleagues from divergent backgrounds was that each individual brought his or her own special skills and attitudes towards language itself and how to decipher it. Rather than rigorously sticking to one discourse analysis method or another, team members were given free reign to interact with the text, creating their own hypothetical dialogue with the narrator in the process. By doing this, team members both freed up the text as well as themselves. This dialogic process was at its best when this very process was evident; it was at these points that the intuitive skills of those participating came to the fore.

In other ways, the team environment resembled a jury room of an intensive trial (see Wengraf, 2001:227-29) -- evidence was examined piece by piece; hypotheses were tested and retested and then saved or discarded; theories were expressed and argued and conclusions were drawn—or not. It must be made clear, however, that the analogy of the jury room only works up to a point; team members were also hypersensitive to their responsibility to the integrity of the individual and his/her story and not to ‘sit in judgement’ at any point. This was particularly important to this study because discovering the individual beneath the textural evidence was central and crucial. Ultimately, the goal of the research, including the process of team analysis, was to find ways to improving the human condition and “enriching the forms of societal practice” (Gergen, 2001c:431), rather than just theorising abstractly. Knowledge was thus produced through a creative process of interpretation—a social event.

It is imperative to remember that many of the most breathtaking ‘finds’ in the analyses sessions were singular ‘ah-ha’ moments, creative flashes that were contrary to any
logic. These moments of human clarity stand out in great relief in the synopses that follow. Team members demonstrated that when they were trusting their instincts, these moments were almost always penetrative, within the bounds of a profound expression of human understanding and identification with an ‘other.’ This quality of thought is usually referred to as intuitiveness: “the ability to understand a complex issue without any obvious attempt or labor” (Scheff, 1997: 225).

Liebrucks, revisiting Geertz [1973] and Winch [1958] (Liebrucks 2001: 384), directed us to the concept that “meanings are intrinsically intersubjective phenomena, and, therefore, cannot be found in the individual mind. In order to elucidate the meaning of the actions of person, one must interpret their conduct with reference to the rules and conventions that are inherent in the everyday activities of the community to which they belong” (2001: 384). Nevertheless, biographic work frequently raises the issue of agency and theoretical arguments surrounding the concept of agency. The pragmatics of doing biographic research, however, necessitate taking a middle ground on this issue. “The biographic perspective centres itself midway between social structure and the individual social actor . . . The biographical perspective is about the interplay between actor and social structure –how the individual has negotiated their path through a changing societal structure” (Miller, 2000:75), and, in these cases, particularly the actor and his/her family.

White reminds us that the “plot of a narrative imposes a meaning on the events that comprise its story level by revealing at the end a structure that was immanent in the events all along” (1980:23; emphasis White’s). The profound result, nonetheless, of this particular team approach to biographic narrative texts was the uncanny ability of the assembled teams to uncover early on in transcripts the underlying themes or motifs that would develop throughout the rest of the story. So, not only was the structure often revealed by the end of a narrative, as White has suggested, but it was also revealed at the very beginning –through the early discovery of motifs that permeated the balance of the story. It was concluded that people’s native narrative ability to assemble their life story around the construct of ‘here’s what I am going to tell you – here’s what I am telling you and –here is what I have told you’ was evident throughout these cases.
CASE ANALYSES

Sheila Conner – “They say the wives don’t know”

Sheila’s story, one of the earliest interviews completed, is also one of the most thoroughly analysed of the seven interviews. Sheila’s participation consisted of two initial sessions and a follow-up third session a few weeks later. Sheila was asked to bring photographs to the follow-up interview in hopes of jogging her memory, specifically about her childhood. Other ancillary data was also compiled from the ‘case notes’ Sheila had kept during her husband’s illnesses that gave a retrospective slant to this particular case study. In addition, Sheila brought along a poem about carers that she had written to share with the researcher. At the analytical stage, a separate team session was held to discuss Sheila’s husband’s medical conditions. Because of this session, further medical literature was explored. A discussion was held with an expert in self-harm to explore the roots of Sheila’s daughter’s self-harm. The more formal team sessions analysing Sheila’s lived life and told story included five three-hour meetings. All of these explorations made Sheila’s story an excellent target for a classic case study approach.

A lived life and a told story
Sheila delivered her story in a clipped style: “Came over the following Saturday. Got married, or got engaged, ahhh, (1) let me think, less than six months later. Married in another six months.” Her sentences were generally short and often ended in an upward voicing, which suggested to the analysing team that she may have been questioning what she was saying herself or if the listener understood her. She often left definite articles out of her speech, which is typical in a northern, working class dialect.

Sheila presented a story one could regard as represented by the motifs of ‘inside’ and ‘outside’ and movement between these two poles from the beginning, through the story of her move to Leicester when she was five. The team hypothesised that, as an only child, she may have felt alienated and probably had limited views of relationships because of it. She told of an uneventful life up until her marriage. She remembered little from her childhood, even when probed and an early motif of isolation and emptiness was developed in the teamwork by exploring her feeling that she did not belong and her lack of any real sense of identity before her marriage. She spent some time talking about the things that she “can't remember,” indicating to the team a possibility that she was thinking about the things she cannot remember but could not or would not express them.

Her story did not seem to really begin until she started to talk about her husband, how they had met, his moving in with her parents, and so forth. She began to speak of her husband in a defensive manner immediately: “Erm, went to work part-time in the children’s ward, but then (1) couple of jobs, uhm,...he suffered a lot from arthritis right from a child he had arthritis but it didn't stop him from going to work.” Sheila mentioned the birth of their son and daughter, but then immediately shifted from these births to talk of her husband being one of 12 children and his childhood. One interpretation was that
perhaps she spoke of her husband’s childhood because she sensed something was lacking in her own childhood or that of her children’s. Sheila appeared to have spent this part of her story building up her husband as a good person. She mentioned no ‘outside’ interests for either herself or her husband; what was meaningful to her seemed to be what was ‘inside’ the marriage and nested within that was the centrality of her husband to her concept of self.

Sheila did not talk, to any extent, about her children growing up or their family life but rather jumped immediately to the story of her children leaving home. Sheila spoke of her daughter, Joan, moving “out” and moving “in” with her boyfriend and her son, Dan, moving “in” with his girlfriend. Again, this was envisaged by the team as a motif of inside/outside and movement between these two poles, embedded in her narration since the opening of her story. She said nothing about her self in these passages –and the team read this as a denial or at least submersion of her self.

Sheila then shifted to the story about her husband’s illnesses, again not telling anything about her own story, except that they switched traditional roles, Sheila going ‘out’ to work and her husband staying ‘in’ and doing housework. Again, he is ‘in’ and she is ‘out’ –in relationship to the physical home and all that it seemed to represent symbolically to Sheila as constancy. Sheila’s language was particularly mysterious in describing this reversal of roles: “I went out, which he enjoyed.” The team wondered, had she misspoken and really meant to say that she enjoyed going out, or did she really mean that her husband enjoyed having her out of the house? And, if so, why would he want his wife out of the house at his time of illness?

Sheila next spoke of an operation that her husband had had and how she had berated herself, at the time, for not questioning why it was being done: “I felt angry, angry that no body believed that there was something wrong. Guilty –could I have done more, could I have pressed for more to be done?” Thus, the first real mention of her ‘self’ in her story appeared to be through self-blame. To the team, Sheila seemed to be revealing how her happiness was dependent on how her husband felt and to Sheila, the success of the operation was based upon her husband’s feelings about it too, rather than any actual medical outcomes: “Then after the consultant came through and his reaction was,’walk about for a half an hour and if the wound’s not seeping, you can go home’. (sigh) I wasn’t very happy with this because my husband said the day after the operation, I don’t think I’m all right, because he didn’t feel right.”

Sheila’s ostensibly well-rehearsed story of her husband’s illnesses was, to the team, the focus of much of her life story; in many ways, she appeared to be telling her version of his story. His medical saga, as conveyed through his wife, was portrayed as one of a failure of the health service –a failure of the medical profession both to include the spouse and others in treatment planning, a failure to consider a holistic approach and a failure to trust its own medical intuition. The primary care researchers’ analysis session suggested the following: Juvenile arthritis, from which Sheila’s husband suffered, is quite unusual and devastating, and can include pain and suffering from an early age; his psychological, sociological and educational development would have been affected.
This would also have had an impact on relationships such as friendships. According to the analysis team medical doctors, arthritis limits the life span and an early death is often expected. In addition, his hip operation, also at an early age, would have significantly impaired his functioning, affecting his work and sex life. His movement would have been limited and the drugs he would have taken would have had side effects.

Sheila spoke throughout the passages describing his illness story of her need to find a clear-cut physical cause for his psychological symptoms. It was at this point of describing her interactions with the medical establishment that the team felt that she began to tell a story that included “I.” This was the “I” that represented her taking responsibility for managing her husband’s illness and treatment: “I mean, was selfish in a way, but... If I went out I’d feel that, you know, I want to... want to get away from it, but then again, as soon as I was out I want to get back to it cause I daren’t leave him; I didn’t leave him on his own.” The team sensed that she seemed to be beginning to come into her own through talk of this activity, but even then, the perception was that she had questions around blame and responsibility—the two sides of the same coin for her.

Her husband’s condition worsened while he was in nursing care and then again, in hospital; he never came home again. But to Sheila, he died symbolically when he left the house, or, when he went ‘outside.’ Sheila remarked, “His last words were when he left the house,” but then she never did say what those last words were. Sheila seemed to have lost control over his care or become much less involved in it at that point. This was presented as a loss of control generally—and the team read this as the outside world impinging upon and overwhelming her inside, safe and secure world of home and husband.

Sheila blamed herself for much of her husband’s illness, yet finally expressed her anger at the medical establishment and the fact that they had not believed her when she told them that something was wrong with her husband. Sheila mentioned neither a wider social support network nor support from her children during her caring period. Sheila appeared to have let things happen to her and expressed a profound duality in her summing up of his death: “Well, as I’d say, it was a shame, but (1) at the end it was a blessing.” This detached global assessment and its unfinished duality brought up several questions: was anything wrong in this family and was it a shame for him or really a shame for her? Why was “shame” involved at all? “Shame is one of the terms of emotion that explain the dynamics of a relationship. Shame signals and generates alienation. ... Denial of shame generates self-perpetuating cycles of alienation.” (Scheff, 1997:74)

**Revisiting the told story in a second session**

* I can’t remember the actual move, I can remember odd things about where I used to live in Nottingham and, ‘cause I’ve queried it with me*
father to say, ‘did that happen, did that happen’ uhm, but my earliest memory—I can’t even remember the move to… father came first, he was here a few months before, came with me mother; I can’t even remember the journey here.

The team revelled in Sheila’s language that was constantly ‘on the move’ in this passage; its meandering was seen as a kind of journey in itself. She could not remember the actual experience of moving and yet, dates her life, ironically, as beginning at the time of the move. Questions were raised in the team session as to whether the experience of her father going away from her (as a five year-old child and on an emotional level, she may have had little concept of the fact that they would be shortly reunited) was at all traumatic. The team wondered, was this a story about her moving or her father leaving?

Sheila followed this by stating that she could not remember the house that she moved to and could not even remember going to school, except to remark about a school friend from that period of her life with whom she continues to be friends after 50 years. Rather than remembering her family life, she spoke of this friend. The team noted that Sheila appeared to remember things that represented continuity to her like this friend or a house and a team member suggested that objects give continuity. There was, nonetheless, an odd blanking out of vast sections of her life, particularly the normal childhood processes one might expect, especially in reference to her own parenting. Sheila’s need for continuity also seemed present when she continued to discuss this old school friend:

And, uhm, she was an only child as well; her parents and my parents used to see each other every three weeks; we went on holiday together as two families, just to say I’m still friends with her; my daughter was her bridesmaid when she got married. (1) But, I’ve got very vague memories of the past.

Sheila’s need for security through routine, “to see each other every three weeks” was apparent to the team; she seemed to consistently find continuity through patterns and security through routines. She sought commonality in a friend who was an only child like herself. Equally, she apparently saw holidays early on as part of a pattern, a routine and, therefore, stability.

When she was speaking of “vague memories of the past” it was important for team members to remember that she was speaking in the present and from a present point-of-view. It seemed vital for Sheila to make the point that she cannot tie her present life to her past one, except through the continuity of a friend who is unswervingly included throughout her story. Was there something in her present life that was making her insist that the past was vague and was she placing a meaning upon this very fact by stating it? Clearly, she did not want to tell about the past, and what she did say about it should not, perhaps, be taken at face value. Elements of the past were important in the present, but the team concluded that she was unable or unwilling to see the
connectedness of her past with the present. To one to whom constancy was seemingly so important, this attitude seemed strangely out of place to the team.

When asked to elaborate on her children growing up and her time spent as a mother, she immediately referred to her daughter as “a little mother to him” (“him” referring to her son and her daughter’s brother, Dan). The team found it odd that instead of speaking of her own caring role as a mother, Sheila spoke of her pride in her little daughter’s mothering of her son. By this, Sheila seemed to have an idea of what parenting was that was based on a child’s version. In fact, it was a child –her own daughter-- that may have been demonstrating it to her by caring for her son. There was a strong indication to the team that it was as though she did not have a past, either as a mother or as having been mothered herself, and needed to deflect this conversation about motherhood from herself and on to her daughter.

Sheila then began to speak of annual holidays, confirming to the team what the use of the word, ‘holiday,’ might have meant to her: her definition of a good childhood seemed to be one where holidays were a yearly event: “went on holiday every year, when we eventually got a car of our own went to the Isle of Wight; didn’t go abroad with them.” Again, ‘holiday’ apparently defined the self through its guarantee of continuity and routine, and these were forays into the outside world used as markers for both her own up-bringing and that of her offspring.

Sheila next began to speak of her husband’s hip operation while simultaneously reporting on her 20 year old daughter leaving home around the same time: “Uhm, (1) me husband had a hip, hip op/hip replacement operation in 1982, so Joan would a’ been (1) almost (1) twenty that year …and, (1) without any word of warning, uhm, no trouble, no arguments, she left home.” These two events seemed very connected in Sheila’s narration somehow, but not yet by any explanation or revelations. She appeared to present this information in a matter-of-fact way, and the team raised the possibility that she was trying to make it sound routine in order to fit with her sense of the inevitable and ordinary, perceived of as a coping mechanism for her.

Team members believed that these two unexpected and unplanned events had rocked Sheila’s world, but, rather than seek explanations, she had continued to find ways to make them fit into her normal scheme of things. Sheila summed up the event of her daughter leaving thus: “No trouble, no arguments.” –perhaps an attempt to make it acceptable somehow. Apparently, Sheila saw everything as all right, as long as she did not rock the boat. Team members pointed out, however, that this masking of her feelings may have revealed cracks in her armour: she remembered the exact day of the week and placed in time, “the Friday night,” that her daughter left. This kind of remembering of detail (and the use of the definite article instead of an indefinite one, or even no article, which was her habit) often gives important clues to traumatic or defining events (see Jones 2001) and was quite out of character, in relation to her frequent inability to remember events and/or details of them.
Sheila seemed to have accepted Joan’s explanation, given a week or so later at the time, that she had left because she was “worried about her father, she didn’t like to see him, cause he couldn’t put his foot down on the ground.” Was this turn-of-phrase an indication that someone needed to ‘put a stop to things’—put their foot down? Was it the father who could not put his foot down, or the daughter who, by finally leaving home had put her foot down? Her daughter left again with no argument and did not come back or contact her parents for about six years. According to Sheila’s version, there was nothing that they could have talked about, all had been left unspoken and Joan was saying ‘No’ to any discussion: the team believed that an argument would have meant the possibility of revealing the pain and the detail. To Sheila, however, confrontation represented ‘no going back’ and no subsequent chance to fix things, making it inevitable that she would not be able to make things right again. Team members viewed Sheila’s passivity as representing her acceptance; in fact, Sheila had spoken of their “acceptance” of the “circumstances of how she’d moved out” and yet, still had continued to try to negotiate reconciliation, while avoiding any truth-telling:

_Uhm, (1) and I think as years went by we had a better relationship, (1) although it is still (1) not right because she’s had a lot of mental health problems, she’s been in mental hospital but she doesn’t know why. She cuts herself (1) and she says its because of how (?) her and her Dad were. (1) But I still can’t get to the bottom of it._

At this development in the dialogue some team members wondered, who really did not know why she was in a mental hospital, Joan or Sheila? Was this Sheila’s ‘get-out clause’ and was any reason valid as long as there was an acceptable version? Members saw the use of the verb “were” in relation to how Joan was with her Dad as indicating a reference to actual times and acts in time in the past. Could Sheila not get to the bottom of it because, ultimately, it represented a ‘bottomless’ pit, once opened? Sheila appeared to team members to be negotiating in her head through the interview process and trying to make things right for everyone concerned:

_I wish she, I wish I knew because I can’t/ she wont tell me. She has told us, what I have heard from Joan is, she has told (1) the hospital that she never got new clothes, she never went anywhere. (1) In fact, she’s told them a whole lot of lies and I can’t get through to the hospital to tell them –there is a barrier, I mean, I’ve had this problem now since, uhm, when did it start? Funny enough, uhm, a friend rang me up to say that Joan was refusing to go out, she wasn’t going anywhere, uhm, frightened to go out, and then I heard from a friend, uhm, who’d been sworn to secrecy from me daughter, not to tell me: she’s cutting herself, anything she get her hand on, she’ll cut herself. I didn’t even know she was in the mental unit of the hospital, uhm, a friend had been sworn to secrecy but a friend actually broke down and said that she got to tell me. But, (1) that’s the only way I could find out what’s going on is to keep in with a friend not to let me daughter know that a friend is/ cause if not, daughter wouldn’t speak to her friend._

123
Joan’s only explanation—one that Sheila had heard second-hand (and reinterpreted?)—was that Joan never got new clothes and she never went anywhere as a child. The team hypothesised further: was this her daughter’s expression of being restrained and her loss of freedom to a parent—the parent as jailer? Or was Joan expressing, obtusely, the fact they she had been unable to escape a repetitive sexual act? According to Sheila, her daughter continues to cut herself today as a cry for help. Joan did not want to say what went on, and Sheila, if she knew, seemed to need to deny; the team wondered, did Joan, therefore, become the ‘liar’ to save the secret? Sheila reported that she did not even know that Joan had been in a mental unit for some time until a friend “actually broke down” and said that she had to tell her. The team concluded that, to Sheila, revealing a secret was breaking down. By saying, “actually” (representing truth) she may have been revealing what truth-telling meant to her.

Several team members remarked on a theatricality to this particular section of her story, explaining that it seemed to be represented by dramatic and emotional raw language: “cutting,” “broken,” “frightened,” “mental,” “lied,” “sworn.” It seemed as though Sheila was verbally imitating cutting oneself and expressing a physical pain in textual form, so that the listener could feel it. As a mother, Sheila may have learned from her daughter’s behaviour how to deal with the dramatic and emotional through narrative expression and language.

Sheila stated that she believed that Joan regretted having had wasted the last 15 years of her life by moving in with an older man (the same age as her father at the time that she left home). It was concluded that Sheila was looking for any reason to believe that the answers to Joan’s mental health problems were outside of her own nuclear family.

Sheila then told how Joan became particularly agitated when her brother’s wife became pregnant: “She’s cutting herself, anything she get her hand on, she’ll cut herself. I didn’t even know she was in the mental unit of the hospital, uhm, … Uhm, it all started really when me son announced him and his wife were expecting a baby.” The team viewed Joan’s agitation as a result of her brother (“she was a little mother to him”) getting his wife pregnant. Was this a result of a ‘surrogate’ mother’s jealousy of her ‘son’s’ wife? Sheila reported that around that time, Joan began saying things about her father: that “he didn’t want her” and he “turned her out of the house.” Here, Sheila, on an unconscious level, may have been connecting up events relating to her children’s sexuality: her son getting his wife pregnant may somehow have been connected to her daughter’s rantings about her father. At the same time, this raised more questions in the analysis session: the language of “didn’t want her” was telling and sexual: was a father supposed to “want” his daughter? Had the son ultimately redeemed his father’s possible bad behaviour by producing a ‘normal’ family in his mother’s eyes? Sheila saw Joan as “wasted” because she “was the one that always loved children” and wanted to have children. Team members finally pondered, had not Sheila wanted children? Did not her son?
Sheila appeared to be using the interview to talk to Joan, often an indication of an impotent and ineffectual communicator, according to the team. Near the end of the session, Sheila projected a typical conversation with her daughter:

*And I will say to her, now why don’t you just tell me what the problem is? And she just can’t bring herself to tell me, so that’s got me thinking, well, what happened, has anything happened (1) in the past?*

Sheila seemed to be shifting the guilt to her daughter through the questions that she will (would?) “say” to her. One team member wondered if Sheila had not wanted to be asked those very questions herself in the interview. Sheila seemed to have then finally connected “what the problem is” with something that “happened in the past” and perhaps at this point in the interview Sheila wanted to be asked these specific questions herself. She added, “I have feelings about what was wrong.” Without the facts, Sheila appeared to be unwilling or unable to talk about possible truths about the past and what event(s) had so devastated her daughter’s young life. Or, was Sheila also referring to her own past, the distant past of her own childhood: “Has anything happened in the past?” This was a past that she could not or would not remember, apparently, a past ‘outside’ of her present concept of herself.

*So, I think to myself, well, (1) perhaps one day I’ll learn what the problem was. As I say, it is getting better, it is improving. (2) I have feelings about what was wrong.*

Sheila used the phrase, “perhaps one day I’ll learn what the problem was” twice in the interview to refer to the ‘secret.’ Team members interpreted this as saying that something ‘wrong’ had happened in the past and that she did not speak of it because it was about “feelings.” They saw Sheila as expressing, through this device, her sense of ‘getting there’ and the text seemed to improve in this passage; she seemed to be using the interview to exorcise her inner most emotions by this point, in the estimation of the analysis team.

But then, Sheila immediately retreated from this bout of too much candour with her well-rehearsed excuse for Joan’s problems:

*I think it’s because she knows she’s wasted her life with an older man. (2) and she’s got no escape. Although he’s told her, he told her right from the start, that if you ever find anybody your own age, (1) I won’t stop you going. I mean, he’s very good to her. But then again, he is more or less housebound, he’s had a stroke, so she’s more or less (1) stuck with him*

Which older man was Sheila really referring to here –Joan’s boyfriend or Joan’s father? Did Sheila also view her time as a carer to her husband as being “stuck with him” as well? Her story here began to remind team members of a Greek tragedy through the repetitive nature of the “stuck” role so prevalent in carer stories. By speaking of Joan’s imprisonment in a caring role, Sheila may have also been reflecting upon her own
caring role with her husband and its justifications and compromises: “I mean, he’s very good to her.” In fact, Sheila began her own story by telling how “good” her husband was in his early role as a husband. Sheila seemed to justify taking on the care of someone because they were good to you.

Ultimately, the team concluded that security with a “good” man at all costs ran throughout Sheila’s story. In her poem to carers, one line stated: “At times you feel there’s no place to go,” re-enforcing the sense imprisonment carer roles can sometimes entail. To Sheila, finding a safe place to be ‘in’ could represent an end to a life of moving in and out, and finally finding freedom and security. The team concluded that there was “no place to go” outside of the marriage anyway, in Sheila’s story.

**A follow-up session and finally, a revelation**

The third and final interview was conceived as an opportunity to explore further Sheila’s childhood through the use of photographs and a last chance to ask about her daughter’s self harm and the possible reasons for it more directly. It did not seem accidental that the first photograph Sheila showed was one of her mother’s engagement. This paralleled Sheila’s own life story that began in earnest when she told of meeting her husband-to-be and their engagement and marriage. Sheila seemed to assume that it was the natural start of her mother’s story as well and treasured a photograph of the event.

Sheila then showed a picture of herself as a small girl with her mother and again, reiterated how she could not remember anything from that part of her life, except going to hospital on one occasion for an eye examination. She then immediately began to show pictures of her husband from his youth and talk in detail about him and his childhood. Again, she shifted quickly from the one clear memory of herself as a child to speaking of her husband’s childhood (another example of ‘looping’); this was a device that she used repeatedly throughout her story –deflecting the focus from herself to another person, particularly her husband. Speaking of her husband and his brother, she added:

*There was only about 14 months between them they were more or less like twins, that’s his sister and her friend, that’s two boys, two youngest (1) that was with a football, village football team they travelled about as their mascots they went.*

Sheila then showed a photo of herself when she was seven or eight with her parents on holiday, followed by another photo on holiday and then, a third one on an Easter visit to relatives. Sheila remembered details from these childhood holiday events, but little else. As discussed earlier, the importance of holidays (getting out, getting away and the recurrent pattern of annual ‘getaways’) was particularly pervasive in her story.

*(Phew)* to be quite honest I can’t remember my childhood at all its as if there’s a mental block and I’ve always said this, people can’t believe that I
can’t remember my childhood which I can’t. Little snippets (2) come to me now and again but I can’t honestly remember my childhood (2)

Sheila next turned to a group photograph from one of her school classes. She could remember all of the names of the students and the teacher’s name. It seemed odd to the team that she could remember facts like names so well, yet protested that she had no memories of childhood activities, happenings, processes –other than holidays, or getting away. Sheila then began to actually remember school days and how much she had loved playing hockey, stating that she enjoyed school. Even in recollecting school days, the major event she recalled was a school trip away from home to Wales where she would be able to participate in activities such as rock climbing and canoeing. According to Sheila, these were activities of which her parents would certainly not approve, had they known about them: “If my parents had seen me I mean what we were doing there they would have had a fit.”

The following photographs were ones from the time when Sheila met her husband. The next photos were of her wedding and, typically for Sheila, with much more discussion about his large family than about her own small one. Pictures of their honeymoon followed.

Sheila then showed photos of her children; a comment was made by the interviewer that her daughter looked like her and her son like his father:

No the other way round

The other way round?

Dan’s the spitting image, well I’ve always thought so, people say, I think it depends on how you catch them erm (2) no I can’t see where Joan looks like me, I don’t know (3) that’s Mary’s wedding that’s Joan as bridesmaid. (3)

To the interviewer, Sheila seemed clearly uncomfortable with the possibility that her daughter looked like her and immediately shifted attention to the next photo, Mary’s wedding, to change the subject. Sheila showed a few more pictures of her children up until they were about 12 and 13, and then the photos of them stopped. Sheila was asked if there were any photos of Joan between the age of 13 and when she left home at 20, but there were not. Sheila’s next photos were of the recent wedding of her son.

After a few follow up questions concerning her children and their childhood, Sheila began to talk about her own childhood, finally:

I’m afraid my mother and father didn’t talk to me much at all as to (1) I ca.. I mean I’m saying this that I can’t remember erm I think being an only child I was piggy in the middle, if ever they had an argument or between themselves I was sort of like in the middle of it, if I agreed with me mother I
was wrong in me father’s eyes if I agreed with me father I was wrong in me mothers eyes and (2) I’m not saying I didn’t have a happy childhood as far as I can remember I was always taken on holiday (2) but I never felt very close to me mother for some reason even when she was ill. She wasn’t a person I could go up to and cuddle and I’m not a cuddly type of person I can’t be that sort of person, you get some families as soon as they see each other they’ll give them a kiss and put their arms around, I’m afraid I can’t and I think that stems from me childhood and I feel very guilty about it at times.

Finally, Sheila was revealing some of the pain of her own childhood that was conceived by the team as playing a major part in her development and her ability later to mother and to care. Sheila’s use of the phrase, “I can’t” was pervasive throughout her narration (She used it 14 times in just the excepts taken from the transcripts on these pages). Rather than saying, ‘I won’t’ or, for example, instead of expressing, ‘I am not that sort of person’ she said, “I can’t be that sort of person.” In a certain sense, ‘can’t’ connotes a lack of permission or ‘not allowed to’ as well as an inability to do or perform a certain act or function.

When asked about what kinds of stories she liked as a child, Sheila recounted:

I remember one story book and I couldn’t have been very old and whenever me mum and dad always read it to me they used to miss bits out making it go a bit quicker and I used to know that they’d missed bits out.

The investigator wondered, could Sheila have been describing they way that she had told her own story by ‘missing bits’ out to make it go a bit quicker (and less painfully)? She was telling that she knew when “they’d missed bits out,” possibly saying by this that she was more aware of what is going on around her than people may think. One assessment was that Sheila seemed to be telling a sad story of an only child, lacking any affection, unwanted (“a piggy in the middle”), tricked by bedtime storytelling, whose only relief was in being taken on holiday, or out and away from her home life.

Pressed for more stories from her childhood, Sheila remembered an Aladdin pantomime that she took part in at about age eight and even remembered her line in it: “Aladdin, Aladdin, he’s never about, but pretends not to hear me, however I shout.” The fact was that she remembered this line, while having had difficulty in remembering more than brief moments from her childhood generally. This raised several questions in analysis: was this rhyme remembered because it resonated with her inner most memory of her childhood –one of parents who would not talk to her and one of being ignored? This possibility is given special weight in looking at her recent history. Or, could this line say something about her relationship with her husband and how he pretended and ignored her? Had Sheila learned the lesson long ago through this rhyme that no matter how much you shout, no one will pay attention, so she remained quiet?

Finally, Sheila was asked again about her daughter’s self harm and how that made Sheila feel as a mother and what possible reasons there could be for it. Once again,
Sheila speculated that it was because Joan was living with an older man and that she had wasted her life with him: “I think it’s because she feels that she’s wasted her life with [her boyfriend] he’s much older than her much much older” She then proceeded to say it was also because of her reaction to her brother’s wife and birth of his daughter and her inability to create a family of her own: “and I think that was alright until Dan got married and I think she realises now her chances of having children probably gone (2) erm her chances of having a life like Dan’s gone and I think she regrets now that she ever did it, and I think this her way of punishing herself.”

When pressed about what the reasons may have been for Joan’s running away in the first place, when she was 20, Sheila finally no longer dodged the issue:

Well she said she couldn’t cope with seeing her dad the way he was. He’d just had that operation, but she could never explain (2) I mean its gone through my head did he ever abuse her but she wont let on to it and all these things that go through your head was one of the reasons, you know how they say the wives don’t know

You read of these things or you hear of these things where the husband’s been abusing the child and the mo.. wife doesn’t know anything about it and those sort of things all went through me head.

And there would be no way to know unless Joan told you?

Unless Joan talks about it I mean I am only surmising that it is at the moment jealousy with Dan and her but was it jealousy then did she think Dan was getting, well she told me Dan got all the better treatment, Dan went on holidays, Dan had new clothes she didn’t, now why is she saying all these things about her younger years which are all lies and until she can come out and tell me the truth.

Do you think there could be something else she doesn’t want to talk about and that’s why she’s putting the spotlight on these other things that she’s making up?

Hmm and that’s why at the back of my mind I’m thinking did anything happen between her and my husband.

How would you feel about that if it had happened?

Very angry to think that I didn’t know that I hadn’t picked up on it I mean I’ve er (sighs) I’ve had to make myself think that way could that have happened I mean at first when it.. I didn’t want to think that that could have happened, I still don’t want to think that that could have happened you obviously don’t but at the back of me mind its there.

It keeps coming back?
Yeah its still there but I can’t ask her outright I want her to tell me.

Do you think that would help you resolve that in your mind?

It would probably make me feel better towards her it would probably change my whole opinion towards her.

When Sheila said “the mo ..wife doesn’t know” she was, perhaps, expressing her unconscious choice that her ultimate role in this situation, if it had happened at all, was as wife and not as mother.

The important fact in all of this appeared to be that Sheila “can’t” ask, not that she would not ask or could not ask. One conclusion reached was that Sheila was encased in an emotional deep freeze of alienation and shame that began long before her marriage or children were born. It appeared to be buried deep within her childhood and seemed unavailable, or at least unspeakable, for Sheila.

When she spoke of being potentially willing to ask about the possibility that her husband may have sexually abused her daughter, her response was surprising. Instead of speaking of an anger she would have focused on her husband, she would have been “very angry at herself for not realising it, not picking it up.” Thus, it may be assumed that it was safer for Sheila to be angry with herself (inside) that anyone outside of herself. She may have been angry at herself as a wife; could she have been a better wife? She did not seem angry as a mother, however, wherein would lie the possibility of a rage at the actions of her child’s father.

After a few more questions, Sheila was asked if she thought she would ever remarry: “I wouldn’t want to because I wouldn’t find anybody like him in my opinion I wouldn’t he was very good about the house good with the children.” Clearly, even after her recent admission to herself and another person that her husband may have sexually abused their daughter, Sheila seemed have retreated to the ‘inside’ and her resolute wife’s view of her husband as a good provider and loving father. “You know how they say the wives don’t know.” As a mother, it seemed possible that Sheila was simply not there.
MAUREEN ANDREWS  “Where’s me Dad?”

Maureen responded to being asked to tell the story of her life by exclaiming,

“I'm stuck!  I didn't even realise this is what it was, y'know ... I haven't got one, really.  We're gonna be sittin' here ages! ...I thought you were gonna ask me some questions and I would answer you and that was it, y'know?”

Maureen gave the interviewer the impression that she expected a more structured interview and fought against the open-ended format of this method from the beginning.  It seemed possible that she did not like feeling unprepared and, therefore, insecure.  On the other hand, she also appeared to be jousting for control of the interview and making a power play; after all, she was the one with the information, and therefore, a certain amount of the power in the interaction.  She reiterated her stance several times in response to additional rewording of the initial question.

Well, what comes to mind first for you, about you.  Just tell me who you are -- basically.

(2) (huge sigh) (3) (shuffles) I don’t think this is gonna work!

Give it a go.  (1)  I think some/most of the time when people/once you get started then you’re okay.

(defensively again) Well!  I haven’t got much to say really!

And then just a bit later:

(agitated) If you told people exactly how it works and they would say yes or no ‘cause I’m a very direct person and I give ya a very direct answer.

It seemed to the analysis team that this was a game for her, but with serious issues at stake that she did not want to put on the gaming table.  She finally came up with the excuse, “You’re born, you die, you go to church ...and that’s it, you know,  it’s not really a life story, is it?”  This phrase appeared to contain a certain fatalism and an inability to let go or expose herself.  Yet, it was still a dialogical encounter, revealed by her questioning, “you know?” and, “is it?” --language of engagement, indicating that this possibly was a game two people were playing.  Her linear progression in summing up life --born, die, church (or did she mean to say, born, church, die?)—indicated to the team a view of a life full of banality that, in her expressed version, ended only in death but that church (salvation) comes in at the end to intervene.

Maureen’s protestations then led her to jump to a global assessment of the key saga of her life, the Nigerian boarder, Obatunde, who impregnated her daughter at age 18.
The people that are important in my life story are not even there. Not even there, they’re in Nigeria. I planned for years to get my son-in-law back to see my oldest grandson and I and I know that’s an impossibility, that is an impossibility for me.

She said, interesting, that “people” and “they” (more than one? Is she covering by using “they” to refer to a ‘he’?) are not even “there.” Did she mean here? Or was saying “there” a reference to his placement within her life story, that ‘he’ was not even “there”—in her life story where she wanted him to be. The team wondered, is this Maureen’s regret for not having had the relationship she might have had with this young Nigerian man? Was Maureen telling of how unhappy a person she was, of the negative things in her life and of being full of regret about the people who were ‘here’ as opposed to one who was “there?”

Maureen then immediately censored herself by naming a male church member who had told her before the interview, “Don’t talk about it to people because I’m New Testament Church and don’t go to any people –things that have happened like that.” That began to make her reluctance to tell her story translucent to the interviewer: Maureen may have had things to tell but did not seem to have permission to tell them, particularly to volunteer them without being asked for specific information and certainly not to just “any people”like a stranger.

Maureen’s initial protestations about the format of the interview were then making more sense in light of this statement. It also made it clearer to the interviewer that these were the very things she may have wanted/needed to talk about, but that her church would have disapproved, had she volunteered information in such an open format. The team noted that she appeared to have turned to a male church member for ‘religious instruction’ in regards to the interview, rather than another woman church member. She continued to try to backtrack on what she had let slip with phrases like, “Nothing to tell you! Not a bit! What I’ve told you, that is, that is is (1) happened to me.”

Even by offering this small amount of information, she appeared to signal that she felt as though she had gone too far in talking with a stranger about her personal life. On the other hand, there was a sense that there was more to come and that she was testing the interviewer too. At this point, the fact that the interviewer was not asking specific follow up questions with the potential of penetrating her stonewalling, seemed to frustrate her. Nonetheless, she let the dam break a bit anyway:

I’ve been mugged twice, I’ve had a break-in twice. I’ve been mugged (2) all my grandchildren are half-caste grandchildren from Nigerians to Jamaicans (1) What do you want me to tell ya?

Maureen’s checklist of issues and the summation, in the form of a challenge, “What do you want me to tell ya?” seemed a kind of instruction to the interviewer about where to dig for more information. It appeared clear that she had wanted to be asked specific questions so that she could give herself permission to tell. At this point of the interview,
she seemed, by then, to be giving broad clues to the areas in which she wished to be probed, a catalogue of the issues that dominate her life. For example, as a white woman who later in life married a black man, it seemed odd that she was lumping the racial make-up of her grandchildren with bad things that had happened to her. The term ‘half-caste’ itself can have negative connotations. Was there turmoil around her whiteness? Or, was the turmoil created by her because she had migrated, after the death of her first husband who was white, to a vastly different culture and colour, turning her back on her ‘culture-of-birth’?

**Beginning to tell**

She then began to tell a more linear life story, beginning with her birth. Maureen’s move, as a toddler, from England to Canada and back again in the midst of the Second World War at age five, was a theme that the team saw resonating throughout the rest of her story and bits and pieces of a migratory motif surfaced throughout her narration. “I was born over here; my father was from Canada, Newfoundland and I went to live there for five years, I cam back over here when I was five and I’ve been here ever since!” This was seen as interesting because the team saw issues of things being beyond her control coming up repeatedly.

Her language, in speaking of her return at age five to the U.K., (“I’ve been here ever since!”), indicated the possibility that she may have lived as a child with the expectation of returning to Canada somehow. This motif of disruption of locus and expectation of a return was perceived of as full-blown later in her life story within the main leitmotif of wishing to see the Nigerian, Obatunde’s return to the U.K. to see his son.

Maureen was married at 18 and went out to work at 19, working the rest of her life up until her then recent retirement. She seemed to tell a story of endurance through this period. Maureen had a son and a daughter and adopted a second daughter, but never explained the circumstances surrounding the choice to adopt.

As a child, Maureen had cared for her father who had cancer. Around the time of the adoption of her daughter, her husband became ill and she cared for him until his death. This was the second time, then, that she had cared for a terminally ill person and both were key figures in her life. An earlier caring role, as in so many carers’ stories, had resurfaced again. Caring may have contributed to her endurance and she may even have enjoyed caring, but the team believed that it also represented a possible loss of childhood experiences and an anger, probably with a mother who could not cope with caring for her father—at least in Maureen’s eyes.

After her husband’s death, Maureen raised her children on her own for six or seven years. It was during this period that she joined a black fundamentalist church. Eventually, she met and married her present husband, a West Indian immigrant to Britain, through the church. He was quite a bit older than she and owned a large house locally where they took in lodgers. It was at this time that a Nigerian student lodger got Maureen’s daughter pregnant and asked to marry her. Maureen advised her daughter against the marriage and emigration to Nigeria: *It’s probably my fault why* (inaudible)
because she was so young; he was a student lodging at my house when I said to him y’know, we got the wedding dress and everything and I said to ‘im, I don’t think she should go—over to Nigeria, not at that age, y’know, she’s thousands of miles away from me or otherwise I would have said, y’know, go.”

Maureen’s story began to unfold in a way that seemed to indicate to the team that, by this point in her life, she had made the transition to a total identity within a West Indian lifestyle on many levels. It was also around this time that her adult white children began to meet and have children with black partners. Her new lifestyle appeared to be intensified and codified by the rather rigid and authoritarian black church that, in her mind, apparently had placed a demanding code on her family and its activities.

Finding a new community and being exposed to another culture, indicated the possibility of massive shifts in Maureen’s outlook. The team read this as her relying more and more on a concept of herself as a powerful mother figure, controlling, dominating and protecting her offspring, but, at the same time herself remaining acquiescing and submitting to the dominant male figures in her new world –both in her marriage and in her church.

In her job as a security guard, Maureen conceptualised her position as a caring one:

Oh, enjoy working with people! I enjoy/I used to work every other weekend, used to get off and , you know, I had a weekend off come to work Monday morning, coming down Monday morning, “Maureen, this happened at the weekend, that happened at the weekend” and I cant do that now, I cant bring it all out (inaudible) “The other security guard, he don’t listen to us, y’know; he don’t tell us this or he don’t tell us that and with him downstairs he don’t (inaudible) to answer us.” (Inaudible) Muslims, Indians, all sorts.

But eventually, she made the decision to leave this job that she enjoyed to care for her ailing, West Indian husband. This return to a more traditional carer role re-enforced the team’s conception of her enduring nature and her sense of the dutiful fate of a woman. Maureen spoke of her current caring duties in a matter of fact way, as a responsibility one should accept, and one’s lot in life: “Well, it comes natural don’t it, bein’ a carer, it comes natural. He’s ill, got angina, sickle cell, I look after him the best way I can.” It seemed to be a duty like all other duties: ‘you’re born, you go to church, you die.’

Her grandson, Emanuel, who was in prison for robbery at the time of the interview and Maureen’s problems with his mother, apparently had exacerbated her anger, particularly with her daughter. Her other grandson, Charles’ suicide only seemed to add to her troubles:
And then my grandson Charles is, you know, is what made me ill. Emanuel’s gone and done that and then Charles, he’s me oldest grandson with my/from my son and uhm, all in space of a year, six months now, Charles commits suicide in his father’s car –put the hose on.

All of these tragedies appeared to be played out within Maureen’s rather rigid faith. She seemed to believe, however, that if you had led a good life, good things would come out of it; nevertheless, the conflicts and turmoil that whirléd about her life were interminable.

**The ‘second coming’**

Maureen appeared to need a formal framework to make sense of life’s difficulties, but the template she had chosen through her church only seemed to work up to a point and then broke down, repeatedly. Once more, the team noted that Maureen came up with a linear structure as her support system: “I believe nothing’s past what God can do for you, what the healing can do for you and you take, you take your baptism, you take your church seriously.” The team saw this as Maureen’s solution to horrendous events, God—baptism—healing—church. Maureen stated that she believed that an unhappy or troubled family member should go to church. At the same time, her church had the potential to expose her family to the fact that they were not meeting the church’s expectations of them—a double bind, in the team’s estimation.

Maureen returned time and again to the fact that she wanted to find a way to get her “son-in-law” back from Nigeria to see his son: “It’s up to Emanuel to behave hisself and see what we can muscle up together to bring him over. I cant see ‘im coming Xmas though, y’know. (1) It’s probably my fault why (inaudible) because she was so young.” Team members pondered, was this because Maureen felt guilty that she did not let her daughter go with him to Nigeria all those years ago? The team felt that she did not seem to be concerned about his return for her daughter’s sake, but perhaps more plausibly for her grandson’s sake. Or, they wondered, was it, after all, for Maureen’s own sake, ultimately? “Emanuel keeps giving me, ‘I’ll never see my Dad again that’s why I did it; I’ll never see my Dad again.” By placing Emanuel’s statement in the first person, “I” and repeating the plea at the close, Maureen may have been voicing (and assuming) his role, and it may have been she who unconsciously might have been saying that she would not see her Dad again. Perhaps Maureen wished to insure that there would be a father figure for Emanuel. A possibility also existed that she may have been reflecting backwards to a long-standing need for a satisfactory father figure of her own and one that would ‘fit’ her assumed culture as well.

Speaking of her pet budgies, Maureen told of how the birds recognised her husband:

*Ah, I can feed ‘em, clean ‘em out but it’s not me that (inaudible) He only got to yawn or put his foot out of bed and we get, “Where’s me Dad, where’s me Dad, where’s me Dad?”*

The team noticed that the birds repeated what Maureen had reported that Emanuel had said and, perhaps, what Maureen was unconsciously proclaiming herself. It was
hypothesised that the birds had to have learned this phrase from someone; it was more plausible that Maureen had taught it to them than her husband. It also may be assumed that Maureen had ‘taught’ her grandson the concept of the father’s return as well as instilling in him the need to see his father; after all, he had never really known his father at all. Because of this, the phrase, “see my Dad again” seemed ultimately authored by Maureen, who had, indeed, seen him before.

In her narration, Maureen compulsively returned to the leitmotif of the Nigerian “son-in-law’s” ‘Second Coming’ and how to get him back: “It’s up to Emanuel to behave hisself and see what we can muscle up together to bring him over.” She then revisited the initial story of her daughter becoming pregnant and Obatunde having wanted to marry her and take her to Nigeria with him. The fact that he came back a year later to collect her and their baby and found that she had become pregnant again by somebody else, made Maureen conclude that her daughter had “messed up” her own life and that Maureen considered herself not really to blame. Maureen’s fatalistic outlook came into play along with the running theme of uprooting and migration in this passage:

She messed her life up and she wonders why the kids are messing their lives up like they are because she’s she’s (inaudible) My other daughter, she great, my adopted daughter she’s great. Y’know. (inaudible) “I love you Mum” and the next minute she cant get her own way I don’t see her for weeks and weeks and you don’t see the kids for weeks and weeks; she’s gone back to Grant and Grant’s just come out of prison—it’s/it’s something you shouldn’t be talking about, it’s things that she’s doing, she’s not helping, she’s not helping the children, she’s not helping herself. The team recognised Maureen’s shuttling back and forth as a major component of the way she told her story. For example, once she had opened up and had been telling the troubles of her family for some time, she continued to throw in phrases like, “you shouldn’t be talking about, it’s things that she’s doing …” The church appeared as censor and remained omnipotent and omnipresent throughout the interview.

Maureen mentioned very little about her husband’s involvement in or response to these situations. Notwithstanding, she appeared to return to talk of him for a father-like affirmation of her judgements of her daughter and grandchildren. The team perceived that a male system dominated Maureen’s decision-making through such final judgements, whether it was her husband, the brethren from the church or the pronouncements of the church itself.

The team concluded that Maureen’s story was one of disappointment and trying to endure her life of difficult circumstances through the support of her adopted church. She continually seemed to be struggling to make some sense of the chaos around her by using her past experiences without much success. Her’s seemed to be a story of crossing cultural borders coupled with a story of the coping skills necessary for a woman to succeed at life in a male dominated world. Her disappointment in her family seemed to express a missed opportunity for self-realisation through her offspring. Her
sense of self, therefore, was not seen as strong. She appeared to latch on to key things such as culture, church and men to create a structure in her life, but never really internalised them to construct an identity of her own.

Maureen was seen as wanting religion to be a prescription for the chaos in her life. Ultimately, she gave the impression that she was disappointed in the church for not taking care of her and her family problems in a more tangible manner. Her sense of how things should be in life apparently was played out by events that went off helter-skelter in different directions. The team finally concluded that she expressed an inner dialogue between the rigidity and simplicity of her religious concepts and the realities and complexities of her daily family life. The church gave her the formula, but her life seemed to remain battered by a grim reality.

Maureen’s obsession with the young Nigerian’s ‘Second Coming’ was the central, consuming theme of her life story as well as its analysis. One possible assessment was that by marginalizing her own daughter in this saga, she may have positioned herself to assume the maternal/spousal role in this imagined triad composed of Obatunde, Emanuel and herself. Maureen’s actively manufactured family construct conceptualised an idealised father role for a long-absent male whom she had anointed, sanctified and legitimised (called “son-in-law” when he was not) through her ruminations and projections.

The team believed that the male who was physically present, Maureen’s husband, did not participate in these daydreams of reunification and was relegated to the role of ‘wise old father’ in the sense of being Maureen’s fatherly authority figure. Even the birds had been taught to believe in this family/father construct when they too wondered, “Where’s me Dad?”

As a carer, Maureen built her own identity from the people she cared for and attempted to draw others into this identity circle. “Well, it comes natural don’t it, bein’ a carer, it comes natural.” When life presented conflicts, Maureen seemed to try to escape them through structures that made sense of her tumultuous life --the church and male authority figures; she appeared to place her dutiful caring role strictly within this construct. The team had unearthed a theme of migration permeating her story early on, one constructed upon the anxiety of getting back, a return at all costs. At the end of the day, Maureen may have reconstructed a community of care from ‘strangers’ by migrating to the community of a culture other than her own. Ultimately, it appeared that this new community had let her down too; care (‘care’ equalling ‘understanding’ in this case) seemed to be non-existent in regard to the troubles that consumed her. In her projected ideal scenario, her own children and husband may have been marginalized in order that she could construct her ultimate familial triad --mother, father and son. The team concluded that Maureen, tirelessly and continually, had sought the return of the one supreme father figure to make his triumphant return and care for her and his progeny. Making it happen had seemed “an impossibility” for her, as she had stated. Yet, she gave the impression that she clung to this caprice unflinchingly and for dear life.
POLLY HUMBERSTON and the Magnificent Seven

Well most of my life I have been a carer for 40 years, I have been a carer, first for my daughter and then for my husband (1) mainly, that’s, its been caring for most of my life and still am erm (2) (laughs) I am not quite sure what you want to know.

This opening global assessment clearly encapsulated for the team a view of a life of inescapable caring that would continue until the end, with little choice in the matter and out of Polly’s hands. Thus, she began her life story, described in terms of continual caring with its inevitable exhaustion and a lack of hope, of no alternatives and no control, compounded by anger and rage. Ironically, Polly described a world that would, most likely, include caring for other family members in the future. She presented a story of self-sacrificing, without any suggestion of who it was that would care or has cared for her in the past. The team sensed a story of weariness and exhaustion, even in her language.

Polly grew up during the Second World War in England, experiencing social disruption, alternative living arrangements and the beginnings of liberation for woman—all as a part of her everyday childhood life. She saw hardships and difficulties and experienced an early life with her father away in the army. Because of the necessities of wartime home life, her mother and her mother’s friend, Anna, gathered their children together into a combined household. Those early experiences, particularly ones of women heading the household and life in an extended family, were seen by team members as significant in her early development with threads of those experiences continuing into the present day.

When Polly was eight, her father returned from the army and her parents divorced shortly after. These events were seen by the team as producing both a kind of strength in this little girl and, simultaneously, emotional conflict and a sense of abandonment.

I can remember the night that they did split up  erm it was a wet night, I saw my mother go out I didn’t know where she was going I thought oh – I shouted after her, she said nothing she just walked out, my father then called me and he said we are going out I asked whether mother was and he said she wont be coming with us (1) again ever and that’s (1) that was the night they finally split up before the divorce. I can so clearly .. and I .. my mmi er (1) I don’t know I felt devastated and then there was a meeting in the house at my fathers house in the front room and I can remember it so clearly, he was sitting in the armchair (1) in the corner, my mother was on the settee near the window and (3) they was asking me who I wanted to be with (1) and I said but I want to be with both of you I can remember it so well (2) and I .. I was supposed to pick who I wanted to be with (1) I think that was awful of them now, in hindsight I think it was dreadful, and I couldn’t pick I loved them both (1) oh yes I remember it very well !
This was a very intense and detailed part of her story: she described the atmosphere ("wet night"), movement (mother walking out), then the meeting in the front room, remembering who was sitting on which furniture, near the window, and so forth. She was describing it like one would describe a dream, clutching at details to make it more real. Yet, when she was stumbling, she was reflecting her inability to verbalise something, a feeling. These were important pauses to the analysis, because she was trying to ‘paint’ an exact picture: “I can remember it so well.” Her visualisation was viewed as taking over from the verbal telling, whilst the verbal was trying inadequately to paint the picture that was much stronger in the unconscious.

For most of the interview, Polly seemed generally incapable of talking about herself, except through others and only really talked about herself through a third person, for example, “he is like me.” This traumatic event, however, imprinted on Polly’s memory so intensely, was the first time that she spoke of her feelings and emotions. She thought it was “awful” and “dreadful” of them, yet she loved them both. This poignant confrontation was conceived of by the team as presenting Polly with early lessons in relationships, commitment, choices and rejection; the team read this episode as being boxed in and the hurt of it and how she might escape impossible quagmires.

For Polly, this episode may very well have established a lifelong conflict around love, care and loss; eventually, care giving may have become a front to mask her own emotional needs. It was hypothesised by the team that if her parents did not care about her at all, from then on she would make sure that those around her knew how much she cared for them. In showing how much she could care, she may also have been demonstrating how much care she really needed for herself. The team believed this unfulfilled childhood need for security and care was a template upon which Polly based the rest of her life as well as her identity. Polly’s conclusion from this experience seemed to be that any family that she created in the future would ‘stick together,’ no matter what:

*My father got custody of me which is very unusual in those days but he got custody of me because my mother had nowhere – no abode to go to so erm my father had custody of me. And erm my mothers best friend er came to live with my father (1) with her children to look after me, erm, I can always remember, er he used to come in from work – my mother – she used to let my mother in to see me – she wasn’t supposed to, I found that out in later on, er, my father came home early from work because he was self employed he would come in the front door and my mother would shoot out the back door, er (1) oh yes I remember it very vividly its something that has always stuck in my mind and I knew that (1) I had made up my mind that if I ever got married it would be for permanent I would never put my children through, put them through what I went through when I was a child, I would never divorce, it would have to be something extremely erm (1) serious for me to do that it would have to have been cruelty or something but if a man hit me I*
would not hesitate to hit him back I wouldn’t be a beaten wife that’s for sure.

Er, oh no I remember it very clearly.

Her father coming in the front door and her mother ‘shooting’ out the back door appeared to re-enforce Polly’s visual metaphor of being forced to make a choice between her parents; if one stayed the other would have to go, literally shooting out the door. The team viewed this unresolved conflict, created by being asked to choose between her parents, as having far-reaching effects, even after the decision to separate had been made. Anna may have been grasped conceptually as the lifeboat, representing a continuity that Polly would return to, both figuratively and literally, the rest of her life. By ‘shooting’ out the door of Polly’s world, her mother had been catapulted from her life by her father’s re-entry into the home, an environment that the two women had created and made safe, in the first place.

Her father gained custody and her mother eventually moved away. Meanwhile, her mother’s friend, Anna, and her children stayed on with Polly’s father for a time. Interestingly, Polly’s version told of her mother moving out and then Anna moving in, when, in fact, Anna had been living in the household all along (according to her daughter-in-law, in conversation with the author). Perhaps Polly needed a story of one mother moving out, with the emptiness quickly filled by another ‘mother’ moving in, to satisfy her need for someone to fill a void.

Er, my father was a very difficult man to live with erm (1) he would sulk he wouldn’t speak for days if there was something that he disagreed with what you did he wouldn’t speak to you, he wouldn’t tell you what you had done wrong he would never hit me, he would never touch me, he never hit me at all but I would far rather have been told what I had done wrong . . .

Team members concluded that a lesson that Polly learned from her father’s silent treatment was to keep anger (and hurt) inside. The fact that he had never hurt her physically, which she described in terms of ‘never touching her,’ concealed the probability that he had also never hugged her or showed any other affection either. She indicated that she would have rather had been told what she had done wrong; his silence seemed to have told her that just by being her, she was wrong.

The disruption of the war may have had its consequences, but the disruption within Polly’s family unit appeared to be even more unsettling and prophetic. Polly decided to move away from her father, with whom she did not get along, when she was 16. She moved into Anna’s house --in many ways reliving and mimicking the kind of disruptions and subsequent solutions that she had become used to as a younger child. Importantly, it also may have fulfilled her natural need for a mother figure, something that had been absent for the last eight years of her life, at the time. Polly had learned early on that care, particularly familial care, was transposable and something that could be organised through movement and regrouping, a theme to which the team kept returning. Polly’s disappointment in and intense dislike for her natural mother appeared to have stayed with her, nonetheless, and only grew over the years.
Erm, when I speak of mother, brothers and sisters and of, they are my foster brothers and sisters we were brought up together from that time until I got married and I left home I went to live with them, erm (1) erm, we were separated for a few years but they’re my family, my father was never my family, erm, no they were my family, they supported me through everything.

Reflecting on this period of her life, Polly said “family” three times in the one sentence above, clearly indicating to the team how important and intense her desire for a concrete sense of family was, then and now.

Polly believed that she had an otherwise normal, happy and conforming childhood. At 18 or 19, she married Don who was nine years older than she was. This marriage at a young age (“I got married early…”) seemed out of character for the independent Polly that she had portrayed at an earlier age. Still in her teens, the team believed that an older man could conceivably be seen as representing a father figure to her.

Well my husband’s parents were divorced so we both knew that it had got to be – we had a lot of opposition because he was that bit older than me (1) erm we hadn’t met, we hadn’t known each other very long (1) and I said but we’d discuss very seriously and (1) and I had to ask permission because I wasn’t 21 it was 21 at that time it isn’t now but we had to be 21 (1) and erm it won’t last that is what everyone told us well we’ve been married 43 years I think we’ve made a point now.

They were a couple that both may have had an agenda to demonstrate to the outside world from the very onset of their marriage: they both came from ‘broken’ homes and, therefore, may have had something to prove and something to make up for and put back together.

Their son, Carl, was born within the first year of their marriage. Three years later, their daughter, Sarah, was born with heart problems and had to have operations. Polly’s commitment and protection of her daughter may have been demonstrating her response to her own lack of protection and care by her mother in her childhood. Sarah was headed for a school life with the potential for being teased for being different, perhaps something Polly knew a bit about because of her own alternative family background and particularly, her absent mother.

When Polly was 44, her husband had a stroke and Polly became his carer. At that time, continuing to care for her daughter (by then a adult), she now had two people to care for. The team wondered, who was caring for her? And what about the guilt that must have come from her situation? Her son had married and moved out by this point and it presented a difficult transition for Polly.

I found it very hard when my husband had his stroke erm when .. when my son is married and left home by then erm (2) it was very hard on my own
before I lived with my son and his family because I had both my daughter and my husband to take care of.

Polly’s difficulty was not necessarily only in the caring, but perhaps more importantly, in the abandonment by her son. He had left her, walked away from the family, walked out on her just as her mother had, even though it was for legitimate reasons. Team members saw Polly’s use of caring as a way to lessen the hurt, and that the hurt was probably in the leaving.

By this point, the onus of care seemed to have become a life. When her first grandchild was born, she stepped in to care for him so that his parents could go out to work. This caring was also seen by the team as re-enveloping her son and his new family back in her family structure. The added burden of additional caring duties clearly re-enforced her singular identity as a carer; she seemed to know that to care meant at least the potential for reciprocal attention. This kind of circular activity re-enforced the hypothesis that absent childhood care will be continually demonstrated in the obsessive caring activities of adult informal carers. The adult carer is demonstrating through his/her caring activity the missing care from the childhood experience. Like a child, Polly could only express her need by acting it out through assuming the active caring role; the passive role of needing care had never worked. The team concluded that, because she attempted to satisfy a childhood need as an adult, it was a need was never met and the behaviour became repetitive.

Her second grandson was born with autism, although it was not identified immediately. By this time, Polly had become an expert at dealing with care systems and bureaucracies: “erm, I wouldn’t want anyone to go through that but I am a lot wiser now and I wouldn’t let them [social services] get away with it now, in fact, they don’t.” Polly was by now herself crippled with arthritis, a fact that she only raised through a reference to her elder grandson who is also arthritic.

Polly, her husband and daughter moved in with her son, his wife and two boys three years prior to the interview. This was seen by the family as a natural solution to her waning physical abilities to care for her daughter and her husband. The team viewed it as a symbolic way for Polly to reassemble the extended family group in which she had grown up. Interestingly, by this joining of forces, the family household again numbered seven, the same as it had been all those years ago during the war.

Polly was proud to remark that four of their newly assembled household’s members were registered disabled and quickly added the complaints of the remaining three.

My son is now my daughter’s carer. Erm, my husband is very disabled in many ways not just the stroke, he is also partially sighted, deaf and a diabetic, as I say most of my life I have been a carer for different disabilities. Erm, we moved in with my son and his family, er, nearly three years ago.
There are seven of us and, erm, there's four of us registered disabled now (laughs), probably another one soon I don’t know! (laughs) . . .

Yeah, my daughter in law is the only one who can really control him and she is only five foot one and very small and erm he does hurt when he gets stressed, so I wouldn't be a bit surprised if Gail doesn't have back problems before long; erm, they have already started.

In addition, Polly mentioned her son having problems with his back as well from the physical stress of the care of his son. The last of the seven,

The oldest grandson he is like me got arthritis he is 19 he has got rheumatoid arthritis, er (1) he is not registered disabled as yet . . .

“Three generations of disability”
The theme of ‘illness attracts illness’ and the concept of an identity in terms of disability were raised repeatedly by the analysis team that interpreted Polly’s life story. They saw disability as a way of uniting, for this particular family. It was something the family had/wished to have in common and it became the glue of the family structure. One team member saw it as, symbolically, wheels within wheels. Possibly, because of Polly’s own insecure and disrupted childhood, she may have seen a need to create stability in the family structure through the labelling of disabilities. Disability could be viewed as something they shared in common; it demonstrated relationships and kept the family together. Having a disability was also perceived of by team members as one way to keep the family immobile. Five years before the interview, Polly’s daughter’s disability was finally diagnosed as Noonan’s Syndrome; by finally naming it, it validated her daughter’s identity and gave credibility to the system of family construction by complaint. This family’s constellation of disabilities also may have had the potential for singling the family out as cursed or stigmatised, but, not being their fault (disability as a fault of nature), they seemed to find solidarity through it.

The themes of family, parenting and divorce were the constants that the team raised and that Polly returned to repeatedly in her story.

I don’t know if my mother is alive or not I think so but I am not sure, I have no idea whatsoever because I have got no respect for her either, erm (1) truth be known, she had, after she divorced my father she had four children with four different men so I have no respect for her whatsoever. The divorce was through her adultery, er, no no respect at all for my parents, my foster parents yes they have been marvellous with me, they couldn’t have been if they were m – in fact they were better than my own parents the respect that I have for them is renown, I have more respect for them than I have for anybody.
Polly’s use of the word “renown” seemed an odd choice of language to one investigator; perhaps she used such an antiquated word in order to support her own ‘tale’ and her own foster family legend-building and found a sense of security and substantiation in the use of the very word.

Polly’s needs may have been fulfilled by her foster parents, but her anger at her natural parents was perceived by the team as unending. Her conceptualisation of her own mother appeared to be one of a Madonna/Whore complex, according to the team; she did not seem capable of separating out the two opposite components within her conceptualisation.

Although self-identification as a carer was strong throughout her narration, caring activity itself appeared marginalized and fulfilling some other purpose. Care giving was almost parenthetical: “It’s family life I suppose with caring thrown in.” When actually speaking of care giving, the team noted that Polly moved into a superficial mode that she used to shield from view the things that were important to her, particularly relationships.

Polly’s narrative described the shifting, interchangeable roles on the continuum of care—from able to disabled, from carer to cared for and back again. The ‘loading’ or ‘piling on’ of disabilities may have been used in order to justify or legitimise the repetitive and unrelenting nature of her role as the archetype carer and matriarch in the family. Identity for family members, through the sought-after ‘registered’ status, and the prognoses of future disability status goals (“as yet”) for other family members, appeared to re-enforce a system of legitimising this family’s construct around disability. The team wondered, was it possible that, in the end, by keeping them ‘officially’ disabled, Polly was keeping them from leaving? She certainly demonstrated that identity and acceptance within the inner circle of the family was apparently assured and re-enforced through each family member’s disability.

The team believed that Polly found her strength by maintaining the extended family unit, a solution she stumbled upon all those years ago in her youth. She saw herself as the glue in the family structure, but the structure itself was the illness-disability –carer continuum.

_I would never have believed all those years ago that I would finish up with a disabled family so er (2) yes (5) yes there is three generations of disabled in the family now erm huh, I hadn’t thought of that before there is, (laughs) yes there are three generations, all with different needs and wants but, erm, yes. (7) (laughs) I honestly really don’t know what you want (laughs) its about caring really erm I don’t know anything else, not now (sighs) no I don’t know, as I say that’s basically it, caring and but now fighting for the carers._

Polly’s summation of her life was interpreted as spoken with pride and defiance. Her family was special and unique and she may have found comfort and protection from the
‘outside’ world through this conceptualisation. In fact, it appeared that she dared anyone to challenge her alternative lifestyle and was ready to fight to defend it.

Polly’s exploitation of laughter came through clearly to many team members as a device used to express irony and, ultimately, anger. On the surface, Polly’s laughter within the interview seemed to indicate a certain amount of discomfort with the process and particularly, the open-ended life story question. According to Polly, however, her use of laughter was a tool that she and her family had learnt to use as a weapon:

Er, its easier now I can get out more but we still have good times, we make sure we have good times because if you didn’t you would want to er finish it (laughs), but no erm mainly we laugh because we did a lot of crying er but then I thought this isn’t getting us anywhere, it doesn’t achieve anything so we came to a pact my husband and I that we wouldn’t cry anymore we would laugh, no matter what it was or how serious it was we would laugh because crying doesn’t get you anywhere and nobody wants to really know so we we laugh a lot we still do.

In the team’s estimation, Polly may have been expressing her anxiety around loss of control and her way coping with it through this. By this camouflage technique, she may also have been covering any emotion. Once again, it apparently was a family technique (“we would laugh”), not an individual one, this use of a kind of gallows humour. One team member saw this as drama and a black comedy, willingly performed (“if you didn’t you would want to ,er, finish it” (laughs). This performance may have been her family’s way of enveloping and protecting the family unit from outside scrutiny (“nobody wants to really know”) and disapproval, and, at the same time, revealing the target of her anger. It was possible that, by being first to laugh, they were able to diffuse the possibility of any laughter or criticism from the outside. What was underneath this tactic? The conclusion from the team was that her fear of abandonment had created this complex ruse, in the first place.
CARL HUMBERSTON, Heir Apparent

(1) It’s always difficult to know where to start on something like this. Uhm, I, am, was born 42 years ago, almost, uhm, (1) and (3) I, the one thing that (2) I suppose is (1) unusual, to some extent, at least is that (1) I don’t really remember a time when there wasn’t somebody in the family—the immediate family—who had ah, a disability or a life threatening illness or (1) something of that nature.

Carl began his story with hesitancy: “It is always difficult to know . . .” and the team saw indications of this timidity resurfaced throughout his story. This hesitancy continued until he was able to bring the story around to the disabilities in his family.

Carl told the story, indirectly, of a ‘young carer’ from a close knit family, who could be perceived of as negative and pessimistic. He told a story of having had little hope for change from the beginning, always seeing himself as a carer or caught up in the cycle of care in his family, in one way or another. The team saw this early identification with ‘carer’ as continuing throughout his story as a label and as an identity. Caring appeared to the team to be the focus of his life and self-definition. On the other hand, the team perceived a subtext of wanting to get away from the role and the family and from his constrained social view and limited social circle. He presented himself as someone who wished to demonstrate how good he could be, if only he could develop his real potential. He expressed his global assessment of his life as someone who had experienced a different kind of life, right from the beginning. His life in a family of care may have presented him with a profound and painful component of his life of isolation, where the ‘grass was always greener on the other side.’ For these reasons, the team assessed Carl as being more of an introvert than an extrovert.

(1) Ah, ‘cause my sister was born when I was about two. Ah, with a condition known as Noonan’s Syndrome. Ah, which, in her case, affected her heart quite seriously. And at the age of 3 and a half she went to have, ah, open heart surgery. This was in 1960. (2) I don’t remember much about that time. There are little things that I remember, uhm, (1) sometimes going to the hospital (1) and seeing her. Uhm, (1) Probably the earliest memories I have. (3) And I remember my sister being ill or very frail (2) from that time on. It/it’s difficult to (10) It/it’s difficult to do this straight off the top of the head.

Again, Carl’s hesitancy came through, a theme returned to often in his story: “It’s difficult to do.” He ultimately told a story of becoming a complex child—a mixture of his shyness and passivity and his aggressive and rebellious nature. Learning to be a young carer, he also seemed to have learned how to fight to get needs met.

Carl presented himself as a bright young lad, learning to read by himself, self-motivated, independent and with an inquiring mind. At the same time, this introverted, solitary child seemed also to be held back by the care construct of his family life. The team believed
that the possibility loomed from an early age that this would limit his educational and, eventually, his professional development (see Reardon 2001).

He was bullied at school because of his sister, but it stopped when he was moved to a different school. He expressed that he was considered bright and he felt that this did not make him popular. He also acknowledged that he was a bit of a rebel: “I didn’t, I didn’t go along with that. Which made me a little bit of a rebel, which made me a little bit of a nuisance as far as the staff were concerned, and I can understand that and I’ve got to feel the same way to what I did in class! (Chuckles).”

Carl portrayed himself as not one of the crowd, and the team considered one possible reason for this might have been any potential stigma attached to his sister’s disability. He was an ‘outsider’ from the very beginning. He was the one that was always picked on, yet he simultaneously displayed feelings of not getting the attention he deserved.

"Uhm, (2) but (1) that was the strange thing about school, that would, that I was one of the children who wasn’t even given a book, let alone read until I was six. Uh, by which time (1) we were covering things that I wasn’t really interested in, (laughing while speaking here) because I was reading other stuff that was more interesting; I remember that, but I don’t remember much else!

According to the team, Carl was finding ways to single himself out from the rest at a very early age and defining himself as different from the group.

He later seemed to express some guilt about his childhood; some team members related this to his sister’s disability whilst others related it to the fact that he did not live up to his potential. His early identity manifested itself as a product of his home life, his sister’s disability and the general pressures of the home life that her disability entailed. Even his school life, which may have offered some escape, was apparently defined by his home life; demands at home with his sister were constant, according to Carl. He was painfully shy, particularly around girls.

Well, I suppose the best example really is that the first person that I ever went out with was my wife. Ah, the first person I asked to go out with me was my wife, or became my wife. Ah, because I was painfully shy, particularly around girls. Ah, in my schooling in terms of secondary school it being all boys, all male and that is a bad thing, in many ways, erm, and it certainly didn’t help me/the amateur dramatics helped a bit (1) and since then, having to argue cases, to get the services that we need, has/has done remarkable things for my confidence. I don’t think anyone would describe me as shy now (laugh) ah, but I still do much better when I’ve had time to prepare.

Team members pointed out that his difficulty with girls may also have been a result of his embarrassment around his sister’s condition, as her physical development would have been abnormal in some respects.
At eleven he got interested in photography and joined a camera club with his father. This was the first time in his lengthy story that he mentioned another family member and activity outside of home life/school life. His new hobby was possibly a way for him to connect with his father and allow both of them to escape their home life of care and disability. Carl expressed it as “one of the few things we actually had in common,” indicating the possibility to the team that a fuller relationship had not been available. His interest in photography clearly demonstrated to the team a creativity and sensitivity and a yearning for something that he could be good at. The team speculated that perhaps by joining this club and remaining in it for ten years until he married, Carl (and his father) were provided with an escape from their unrelenting home life of care.

Carl then began to tell the long story of his employment history. His early job history told of grasping at first opportunities and looking for immediate security within the job market. Carl appeared to have found contentment in employment with its stability and security as well as its ordinariness, in direct opposition to the home life he had become accustomed to.

_I'd applied for a more permanent job with the department of health and social security with the civil service, and ah, I was offered a post with the dept of health and social security so I took it; better pay and permanent and reasonable prospects. That where I met my wife! So whatever else came out of it I'm quite pleased with the results!_ (chuckles) (4) (sighs)

As Carl had mentioned, his future wife, Gail, was the first woman he had ever dated. His employment story and dating story was interrupted, nonetheless, by Carl remembering the dramatic society he joined in the year that he met his future wife: “I was always a bit on the shy side. Erm, (2) and to an extent I think that helped.” The team viewed this as another example of Carl as the introverted extrovert and noted that actually, being shy and acting often go together. Recognising his inadequacies and character weaknesses, Carl had apparently made a move to correct and compensate for them. By seeking out social interactions through a very formal organisation, Carl probably was repeating his earlier tactic of his participation in a photography club, indicating that friendships and social activities may have been lacking and needed to be formalised, because of his home life. He may also not have been a social mixer in view of the fact that he was bullied in his childhood.

His outlook seemed to have brightened a bit with a new job, new wife and new hobby: “And then (1) that September time, 1980 (2) after we decided that yes, the time was right, things were going well in the job, and the pay was good, there was a chance of over-timing doing stores clerk work in a, a book distributors, and, erm, (2) we decided to try to start a family and in September we found out that we had indeed started”. One might expect that upon marriage, Carl may have separated from his family of care and made his own, independent life. The outside world seemed more of a manageable reality for Carl at this juncture. Or, team members wondered, would he continue to care someway within his marriage?
Carl’s job with the social security was seen as way to help people, but he reported that he soon realised that it was not going to be that direct or simple. Anyway, redundancies hit and he was first out; he went out and found a factory job. To Carl, it seemed as if when he got something good, something else good was taken away. Carl defined himself by his employment, which is common, particularly amongst males of his social class. Nonetheless, a pessimistic and looser streak seemed to be suggested in Carl’s use of phrases like “I stuck it out,” “I might as well” and “I was one of the first out (laughs).” The team believed that Carl almost expected to lose, and in a fatalistic way, it appeared to be inevitable to him.

His wife was very ill at this same time, loosing weight. Carl seemed to automatically shift into the familiar worrier/carer role in his story. The team saw him as waiting for this role in his new adult life and he immediately took the reigns as care manager in the marriage. For some team members of the analysis team, caring gave Carl’s life meaning and, therefore, gave Carl meaning. Carl may have been ‘hooked’ on caring because of its omnipresence in his background, and to him caring may have produced a kind of ‘carer high.’ A carer high is conceived of as one explanation for the satisfaction and “a kind of joy” (Ungerson 1987: 144) found for some through the act of caring, possibly explaining the repetitive nature of caring and the return to care duties time and time again. To other team members, Carl and his wife had been like poles that had attracted one another; he had found a partner who had the potential to be ill, weak or inadequate, someone he could care for (dominate?). Because of his own low self-esteem, he needed to find another ‘loser’ who would not be a threat to him, where he could be in control. A team conclusion was reached that Carl had persuaded himself and his wife that she was ill and he had begun the process of building up the story of her illness. Carl described their holiday to the seaside:

But my wife was very ill around that time as well; she’d been loosing a lot of weight – we still don’t know why. She was constantly being sick, constantly having problems keeping meals down and nobody could find a reason for it. We think it probably, it was the beginnings of hiatus hernia problems that she’s had since, but we still don’t really know. So, with the money that we’d got put to one side, we actually took a quick holiday, ah, for a week or so; I think it was actually ten days. Ah, on the east coast; miserable cold weather, typical spring, ah, with a biting wind and we had a great time and (1) it was about then that things started to work out better; we, in terms of her health, erm, that started to turn round there. We found this little café that did nice toasted sandwiches so we were able to go in and have a toasted sandwich and off we’d go have another walk round and perhaps go back a bit later in the day ‘cause it was a nice place to go and just walk (excited laugh) And, uhm, ah, (1) by snacking like that she was actually able to keep things down a little easier…

“Miserable cold weather”. . .” with a biting wind and we had a great time and it was about then that things started to work out better.” The team pointed out that apparently misery equalled a great time for Carl and a way to make life better. “We, in terms of
her health . . .” indicated his ultimate definition of the relational “we” for his family: identity within the family unit appeared to be constructed through health status.

One interpretation of his story of the little sandwiches was that it read like a romantic novella (La Traviata comes to mind). His wife as the windswept heroine, in failing health, being brought back to life by Carl’s gentle and persistent attention and care, like a child feeding a wounded bird with an eyedropper. This romantic tale reached its climax when Carl reported that “we decided to try to start a family and in September we found out that we had indeed started.” It can be concluded that Carl’s tale of care and attention to his ailing partner brought about the ultimate results of care; care appeared as equal to love and the consummation of that love produced offspring. Another explanation is that caring represented an emotional high or, a ‘carer high’ for him, not so unlike a romantic ‘high.’

Some team members also interpreted this as a story of Carl’s success at his first attempt at being a primary carer outside of his immediate family environment. Carl had re-enforced the possibility that to him care equalled love and love equalled care and that he had been successful at it, in real terms and in the adult world. One conceptualisation by the team was that his ill wife has been ‘cured’ by him and become pregnant because of his care (love).

Carl and his wife, Gail, had their first son, Daniel later that year. Life seemed back in his control again. But then, just before Christmas 1980, Carl was made redundant and two days later, his father had a massive stroke. (‘Good things happened, good things were taken away.’) He described it as “not helpful” and a “really rough patch” indicating to the team by his use of such tepid language that his character did not allow for strong words or strong emotion in response to devastating life events. To the team, it also signalled that misfortune seemed inevitable in his life, a life where it seemed he had no control over events.

He also had again connected employment and health issues, a connection that the team perceived as a constant device throughout his story. He referred to his attempts at finding employment: “looking and trying, but it was not as energetically as it should have been …”. His use of “it” instead of a first person reference, seemed to represent his lack of acceptance for his responsibility in all of it to the team. Out of work for the next nine months, he finally was offered a job at the local job centre, where he worked for the next 13 years. Carl referred to it as “a bloody marvellous job,” indicating how happy he was about what he was doing, being back in a helping, ‘caring’ employment role again or, possibly, back again to chasing the ‘carer high.’

His second son, Martin was born five years later. A short time later, they “found out” that he was autistic. “And funnily enough, at the same time, my son who had an awful lot what we were lead to believe by the doctors was common colds, bronchitis, etc. was asthma.” Instead of being diagnosed with or ‘told that’ their son was asthmatic, they “found out.” “Funnily enough” indicated Carl’s use of humour as a weapon of defence to some team members. Some of the analysis team read Carl’s laughter throughout the
interview as painful and unpleasant and with little general amusement, but rather with a darker purpose. A case was made by members in the session that dark and cynical laughter may have been used as ways of shielding his emotions, ways to handle his lot in life and how life was mistreating him, just as his mother, Polly, had used laughter to shield herself (see previous section).

Finding out that both sons would be living with disabilities only re-enforced the team’s belief that the family’s code of strength of identity was through illness and disability. To Carl, this appeared to be a positive outcome. “We got the diagnosis eventually after a lot of battle.” The family was used to fighting for everything because nothing was automatically given to them, in their estimation. The team reached a conclusion that this was possibly their way of separating themselves out from others, remaining different through their battles. It was as though he needed to battle to insure that his children were, indeed, sick and disabled, a situation necessary to maintain his carer high.

He and Gail started to get involved in the autistic society, becoming quite active in it. They both learned to drive around this time too. These activities seemed to be an awakening for them, a way of finally going ‘out there’, a chrysalis, to one team member. Still, friends were not mentioned; but then, none had been mentioned in his childhood story either. One explanation from the team was that this could have been a result of his embarrassment around his sister and fear of taunting from any friends whom he may have wanted to bring home in his early days.

He did voluntary work as well as his job for a time, but then hurt his back and took time off work. He returned to work part-time for a few years. “Work was just one more hassle we could do without when it was not actually providing us with anything.” Carl justified deciding to give up his job and even made it out to have had nothing to do with him or his responsibility. Eventually, he decided to leave regular employment entirely and look for work in the voluntary field. Again, this seemed to reflect his link between work and illness and how illness was central to his self-concept. He had been struggling ever since his first job at the social security office to find a way to combine his past caring experience with employment. He was finding his niche and this time, finally, it was his choice to leave regular employment.

Because Carl’s mother, Polly, was having more and more difficulty caring for his sister as well as his father, Carl moved them into his house.

_Uhm, (1) during (sighs) the last few years it’s become more difficult because, I suppose, another reason, in part why I finished work/in fact while I was part time it happened, was that my Mum was having increasingly difficult time; she’s been a carer since well, as far back as I can remember, with my sister and my father and the strains and stresses on one individual looking after two people, and they’re the only two people she has daily contact_
Carl appeared to laugh often and sigh frequently in the interview. By using these physical events or gestures as markers and then looking at what Carl was talking about just before and just after a sigh or a laugh, patterns emerged in the analysis. Carl seemed to sigh around decisions and that may reflect how overwhelmed he often seemed to have been by his lot in life and what to do about it. These moments all appeared to the team to be centred, in some way or another, on Carl’s employment story. Carl appeared to have been more comfortable within his family/care cocoon and less comfortable in the outside world of work. The team viewed Carl’s identity battle as one between roles within health and care versus roles available in the world of employment and authority. Carl seemed to have told a story of attempts to merge these two identity rolls, but never successfully.

***

Trouble is, that I was one of the last to join the firm, so that nearly a year later when redundancies hit, I was one of the first out (laughs).

And for some of the time I actually ran what’s called the job club, erm, which involved (sighs) well, effectively it was the teaching people to find work.

And, (sighs) I stuck it out, I suppose two and half years, ah (sighs) and I decided that if I wasn’t actually going to help people then I might as well go into something like industry.

That was unfortunate (laughs) because things suddenly started to go bad at the firm and yet again I was made redundant, this time just before Christmas.

Cause you can do that when you’re not feeling too bad for an hour or so and you can stop when you’d like; cant do that at work. (laughs)

... and that didn’t include the petrol it was costing to get to work. (sighs)

Ah, I’ve put in four job’job applications (sighs) in the field and one I’ve not heard from yet.

During (sighs) the last few years it’s become more difficult because, I suppose, another reason, in part why I finished work/

... and in many ways it’s not easier now (laughs) and work was just one more hassle we could do without when it was not actually providing us with anything.

... because I haven’t had paid employment experience in this field. Ah, so that’s been a bit of a boost but I haven’t quite got past (laughs) I know that in at least two of the interviews that I’ve had ...

152
And that's what I'm up against at the moment in the market, but time will tell. Eventually, I'll get there. Ah, Hopefully. (laughs)

As reported above, Carl’s mother was having more and more difficulty in continuing to care and Carl was having difficulty in continuing to work; ultimately, these two difficulties may have presented him with an opening to assume the top job in the family as chief carer. His mother had been caring for his sister for years and more recently his father. One way to view this could be that she had looked after two people for years—not three, not Carl. One team member’s view was that the deteriorating situation at his parents house represented an opportunity for him to reassemble the family unit under his roof and finally apply for the ‘top job’ as chief carer. Perhaps by this move, he would get the care he never had had from his parents (particularly his mother) in his childhood when his sister got all of the care and attention. It had seemed worth a try. Carl, like many carers, did not ask for this directly, but rather by demonstrating it: ‘Please recognise me/care for me through my role as a carer.’

One explanation may be that Carl, by this point of his life, was becoming conscious of a crucial fact. What he may have been seeking in paid employment—to be in charge, to help and care for people, to be accepted as normal and to increase his self-worth, to be cared for himself—was probably never going to happen in the workplace, or only in a limited way. He finally may have realised that all of these things were only possible within the ‘family firm’ of disability and care. It was like a light bulb had gone off:

So I said, come stay with us for a few weeks and while that happened/while they were there, Gail turned around to me and said, this is getting really, really hard now and we’ve got two choices: we keep going as we are, and they stay with us longer and longer or we bite the bullet and say, come and live with us. And so, in July 97, my Dad came to live with us.

His excited state during this passage re-enforced the possibility that having more people to care for would only increase his carer high. Shortly after this event, his mother and sister came to live with him, too. This read to team members like a self-fulfilling prophecy, an unsurprising turn of events, and waiting in the wings to happen. Carl and his wife fought social services for three years, but eventually had ground floor rooms built on the house for his parents. Again, these major environmental living decisions were linked to illness and disability. The team made the point that crises seemed to make Carl the person he was.

At this point, it seemed that Carl had found a way to earn a living without working in regular employment and do all of the things that came naturally to him. The reassembled and extended family appeared to have become their own cottage industry, ‘The Magnificent Seven,’ and the big show was now all under one tent. Finally, he might get to be the ringmaster; or at least it appeared that he hoped that he would be.
Conclusions

This chapter presented the results of using a reflecting team approach to data analyses, hypothesising inductively, and concentrating on interpretations of the narrations themselves. The team process was a dialogical rather than a judgmental one, based within the habitus and the collective beliefs of team members’ attitudes within a shared society. The interpretations explored human development within specific individuals and case by case, focussing on transformation and process within a historical construct. By concentrating on the individual, emotional capital was uncovered as one of the supports constructed by individuals and transferred from generation to generation within families along side of social, cultural and economic capital. These explorations of the universality of process were key to the teams’ understanding of the ‘other’ vis à vis age effects, cohort differences and historical effects. By concentrating on shared values and processes, the interpretations moved beyond abstract theorising and into the realm of the social production of knowledge with potential for finding ways to improve the human condition.

These explorations were accomplished by the examination of spoken language and, in part, by using intuitive skills. One of these was the ability to uncover themes of motifs early on in the story and map their development throughout the remainder of the narration. This very process was also reflected in the structures of the stories themselves and how experiences and events, early on in the lives, often developed as leitmotifs and driving forces behind later life behaviours.

As case studies, these stories remain ‘stand alone’ and should remain as such. It would be counterproductive to the methodology and aims of this research to go beyond the constructs of interpretive hermeneutics and begin to consolidate or extrapolate theory or generalisations about informal care from these case studies. The knowledge gained from each unique life story is knowledge that first benefited the story’s teller and his/her sense of identity. Secondly, by knowing each individual as unique, a contribution was made to wider knowledge about the individual and his/her construct within a particular family unit and then the family’s interface with society.

Still, there were pervasive discoveries within this small nest of stories that seemed to transcend individuality and began to indicate possible shared similarities of experience and consequent outcomes. These were not events, however, that should in any way be aggregated to form generalisations and categorisation by typologies or lists of attributes about informal carers and their lives. Rather, these tentative conclusions, at best, indicate directions for further study. More importantly, some of the myths about informal care can now begin to be unpacked and even, in certain cases, be set aside because of the results of this research. (Both of these points will be addressed more fully in the following chapter.)

Early in this exploration of informal care and personality, it was hypothesised that, perhaps, the experience of a young carer role had had an effect on later life decisions to take on additional caring activity. One possible explanation that was considered was that because individuals had cared as young children, they had learned to place a
positive value on this experience and, therefore, sought out new opportunities to repeat this behaviour later in their lives. These case studies, however, can now begin to expand those assumptions and propose alternative or more complex ways of understanding adult care giving behaviours and their motivations and antecedents derived from childhood experiences.

This chapter’s depth analyses of individual case studies have indicated that the narrators’ perceived lack of care in their childhood has had profound developmental outcomes for these particular carers. Those early experiences may have propelled them into adult lives of role-seeking in which they could demonstrate or mirror, through their own care giving activities, the care that may have been lacking or truncated in their own childhood encounters. Further, the repetitive nature of their informal care roles may often have been the result of lack of resolution in this mirroring process or demonstrative behaviour. It is hypothesised that by trying to indicate the nurture and care that they may have lacked at crucial developmental stages in their childhood by providing care/nurture to someone else as adults, their message was probably never clear or direct. This could be because instead of compensating for their perceived lack childhood care, their adult mirroring of care had never sent out a clear message. Realistically, the world of adults probably could not have held the potential of filling emptiness from a lack of nurturing or a traumatic childhood. Caring for others, intensely and with little reward, may have often been a convoluted cry for attention and care for themselves. This ‘do unto others’ behaviour may have been a call for help, attention and validation, but a convoluted message that was seldom heard. The evidence in the four stories analysed in this chapter supports this hypothesis. The stories and the conclusions reached through the team process of analysis are presented in the synopses below.

**Sheila Conner’s** early life of alienation and emptiness, cold parents who treated her as “piggy in the middle,” and her grasping at holidays as some sort of escape from a loveless home life, all seemed to propel her into an adult life of identity seeking through early marriage and a possible submersion of any sense of self into her husband’s persona. Because of the possibility of her lack of parenting in her own childhood, she appeared to suppress her childhood memories and thus became uncomfortable in her own parenting duties, possibly allowing her mother role to be usurped by her daughter. Through the in-depth interview process, Sheila eventually revealed some of the pain of her own childhood that had apparently played a major part in her development and possibly her later ambivalence around her ability to mother and to care. The probability that her husband and daughter had had sexual relations was compelling and one that Sheila, at times, herself even considered. Sheila seemed to have unconsciously allowed her daughter to assume her role as mother. Had she also, by her silence, made a space for her daughter to be her husband’s sexual partner as well? Sheila expressed how she had learned as a child that no one would pay attention anyway, no matter how one shouted. This emotional capital was probably passed on to her daughter and demonstrated through her self-harm. Her daughter’s cutting herself may have materialised as Joan’s attempt at finding a way to be heard, taken to a new and painful extreme.
By taking responsibility for managing her husband's illnesses, Sheila appeared to finally able to come into her own and take charge. Through the informal care role, she seemed to demonstrate her conception of what care meant: care appeared to involve forgiveness and understanding beyond measure. Possibly through her system of self-blame and shame, Sheila apparently was able to continue to dismiss the possibility that her husband had sexually abused their daughter, potentially indicating how much forgiveness meant to her. Forgiveness seemed to be demonstrated as care, possibly because Sheila herself wanted to be forgiven by her parents for some imagined indiscretion in her own childhood, perhaps the only reason that she could conjure up for their lack of care.

Maureen Andrews presented an interactive style that appeared as jousting for control and a power play within the interview scenario. By her initial unwillingness to engage, she seemed to display an inability to let go or to expose herself. She also appeared to have things that she wanted to tell, but did not believe that she had permission to do so, particularly from her church. She seemed to portray her life with a sense of fatalism, with emphases on the negative aspects and regrets about the outcomes.

Maureen's migration as a toddler from England to Canada and then back again in the midst of the Second World War at age five resonated throughout the rest of her story. A migratory theme seemed to permeate her story and she expressed a sense of things being beyond her control. The motif of disruption of locus and the expectation of a magical return appeared to be personified in her wish to see her grandson's Nigerian father return to the U.K.

Maureen had cared for her father as a child until he died; later in life, she repeated this duty by caring for first husband up until his death. In a certain sense, her father may have 'abandoned' her by dying and then later, her husband had done the same thing through his death. It appeared that it was at this point that Maureen made the decision to make a radical life change and join a black church and a black community. Eventually, she married a West Indian immigrant, a member of her new church, who was quite a bit older than she. Maureen gave the impression of vacillating between a concepts of herself as a powerful mother figure and, at the same time, a role of an acquiescing and submissive woman and wife, dominated by the male figures in her world. Even when describing her job as a security guard, she conceived it as a caring role. By leaving her 'caring' job to attend to the needs of her ailing husband at home, Maureen appeared re-enforced her enduring nature and her sense of the duty and fate of women.

Maureen's grandson's suicide and her other grandson's imprisonment, her daughter's lack of respect for her and disruptive lifestyle --these were all events that were apparently played out within her rather rigid faith. Her childlike view of life and her attraction to what some might perceive as a simplistic fundamentalist faith, where everything was presented in terms of black and white and right and wrong, re-enforced her apparent need to return to a childhood that had potentially troubled her and left her lacking. This leitmotif of return seemed to be played out in the drama of finding a way to
bring her “son-in-law” back from Nigeria. This, in turn, appeared to reflect a long-standing need for a satisfactory father figure—one who might abandon her, but would eventually return, a kind of second coming. Additionally, through her apparent obsession with the Nigerian’s return, she may have selected a father figure to fit her assumed culture as well.

Maureen seemed to struggle to make some sense of the chaos around her; she appeared to have crossed cultural borders and appeared to use her coping skills to succeed in a male dominated world. In spite of these efforts, she seemed to have failed to gain self-realisation through her offspring. She may have hoped to accomplish this symbolically through the return of her grandson’s father. Her carer role appeared to be constructed within her sense of duty to authority figures, first caring for her father and then, later, her husband. For Maureen, however, care ultimately seemed to mean understanding, but care for herself personally seemed to be virtually non-existent through her church. Maureen, therefore, appeared to cling to the belief that by the return of the one supreme father figure, she might finally receive the care and understanding that she needed.

Polly Humberston had been a carer for over 40 years at the time of the interview. Her life could be described as a typical classic carer’s life of inevitable weariness and exhaustion, lack of hope, no control and anger and rage. She appeared to be self-sacrificing to the extreme, and said little about who had cared for her in the past. Polly grew up during the Second World War in alternative living arrangements, a kind of extended family unit, when her father was away in the army. These alternative living arrangements may eventually have been replicated in her arrangement of three generations of disabled family members under one roof at the time of the interview. Polly’s childhood experience of her parent’s divorce and being asked to choose which parent she wanted to live with apparently had been traumatic. Through this experience, she may have learned early lessons about relationships, commitment, choices and rejection. For Polly, this may have established a lifelong conflict around issues of love, care and loss and care giving became a front to mask her own emotional needs. Since her parents did not care for her, she professed that she would make sure that those whom she loved knew how much she cared. By this, she was potentially demonstrating how much care she needed for herself. Her unfulfilled childhood need for security and care seemed to be the basis of Polly’s activities and her identity for the rest of her life. From her father’s silent treatment, Polly had probably learned to keep anger and hurt inside. Her apparent need for a mother figure drove her to inventively seek out and organise potential care through movement and regrouping.

Polly’s marriage at a young age to a somewhat older man may have been an attempt at finding the missing father figure’s care. Then, when her daughter was born with heart problems, she seemed to become a protective mother, possibly shielding her daughter from any possibility of the lack of care that she had experienced. When her son was grown and left home to marry, Polly may have felt abandoned again, but seemed to use caring to lesson the hurt. To Polly, caring appeared to represent the potential for
reciprocal attention, a circular activity. Polly, therefore, began to care for her son's children as well as her daughter and her husband who had had a stroke.

At the time of the interview, Polly, her husband and daughter had recently moved in with her son and his wife and their two boys. To Polly this reassemblage of the extended family unit appeared to be a natural solution, one that reflected the living arrangements in her childhood all those years ago. Polly stated that she took pride in four of her family members' registered disabled status. This particular family's concept of identity through disability seemed strong and apparently was used as a way of uniting them. Because of the disruption in her childhood family, labelling of disabilities may have been used by Polly to demonstrate relationships and keep family members immobile so that no one would leave. The strong themes of family, parenting and divorce seemed to help to form Polly's outlook on life. The act of caring itself appeared to be virtually parenthetical and marginalized in Polly's story almost as a superficial act. It looked like it was the relationships that were important. Polly's strength seemed to be found in the extended family unit within a continuum of illness—disability—care. Her apparent fear of abandonment, established within the chaos of her childhood, appeared to be expressed through her cynical use of laughter as an anxiety control, possibly covering any emotion. It also may have been a way of protecting her specially constructed family unit from outside scrutiny and criticism—a family unit built to insure that no one would ever leave again.

Carl Humberston, Polly's son, told the story of a young carer who had always seen himself as personifying the role. Caught up in the cycle of care in his family, care appeared to be the focus of his life and self-definition. Because of this, he was somewhat negative and pessimistic and presented a subtext of having wanted to get away from the carer role as a youngster. He seemed to know that he had led a different kind of life, right from the beginning and, therefore, a rather isolated one. He also reported that he had been a difficult child, shy and passive, but also aggressive and rebellious too. As a young carer, he had apparently learned how to fight to get his needs met. He saw himself as having been bright and self-motivated, independent and with an inquiring mind, but a youth who had seemed to be held back by the care construct in his family. He had, therefore, singled himself out as an outsider and often displayed feelings of not getting the attention he deserved. On top of this, he reported that he had been painfully shy as a youth, yet seemed to have been creative and sensitive and yearning for something that he could be good at. The team perceived Carl as an introverted extrovert; he had made efforts to compensate for his self-described inadequacies by seeking out social interactions through formal means, such as clubs.

Carl gave the impression that he defined himself by his employment. His employment story told of trying to combine his care skills with work, but, nonetheless, he grasped at first opportunities for security and a way out of the family home. He told of eventually marrying and separating from his family to make an independent life. Shortly after his marriage, however, his wife became ill and Carl eagerly stepped back into the carer role. To him and his family, caring seemed to give life meaning and individuals an
identity. For Carl, apparently, care equalled love and love equalled care. The sense of a ‘carer high’ and the addictive nature of caring activities for some, seemed to materialise repeatedly in his story.

Still, misfortune appeared to be inevitable in his life and when something good came along, he felt that something good was taken away. He found jobs and then lost them, at no fault of his own, according to Carl. Jobs that represented care appeared especially important to him. Carl, like his mother, Polly, seemed to use ironic and cynical humour as a way of shielding emotions, and for him, particularly around work issues.

Having found out that both of his sons would be living with disabilities gave the impression of re-enforcing the family’s code of strength of identity through illness and disability. It also seemed to be a way of separating themselves out from others in a protective way. Carl appeared to need to battle to insure that his children were sick and disabled. Eventually, he had decided to leave regular employment and seek work in the voluntary field on a full time basis. Thus, his link between identity, work and illness seemed to be complete. The illness-carer continuum appeared to be central to his self-concept, and work became a place to validate this self-construct.

At the time of the interview, he had recently reassembled the extended family unit under one roof in his home. Perhaps by doing this, he would finally get the attention (care) from his parents that had always been centred upon his disabled sister. Like many carers, therefore, Carl did not ask for this directly, but rather, asked by demonstrating his need through assuming the carer posture. Carl now appeared to hold out hope of being the head of the family firm of disability and care. Crises seemed to make Carl the person he was.
CHAPTER 6: Conclusions & Implications

“The Long Now/In Search of Lost Time”

‘Now’ is never just a moment. The Long Now is the recognition that the precise moment you’re in grows out of the past and is a seed for the future. The longer your sense of Now, the more past and future it includes.

--Brian Eno, “The Big Here and the Long Now,”
Long Now Foundation 2001

A person does not...stand motionless and clear before our eyes with his merits, his defects, his plans, his intentions with regard to ourself exposed on his surface...but is a shadow which we can never succeed in penetrating...a shadow behind which we can alternately imagine, with equal justification, that there burns the flame of hatred and of love.

--Marcel Proust, The Guermantes Way (Part I) 1920

Introduction
Validating this thesis’ effort at understanding and its contribution to knowledge requires a return to the questions raised at the end of the literature search. As a result, new pieces have been uncovered that fit the puzzle presented by the review of the literature on informal care and help to make the picture clearer. This investigation of informal care attempted to answer McAdams’ questions of “why it is, or what makes it tick” and “how it came to be” in relation to “the causes, origins, roots, determinants and reasons for ‘what is,’ be those reason nature or nurture, internal or external, be they biological, social, cultural, economic or whatever” (McAdams 1995: 369). The research endeavoured to redefine informal care in an encompassing way and looked for meaning embedded within dialogically unfolding, relational scenarios. It has contributed to Gubrium’s call for a critical, deconstructive examination of the taken-for-granted language in the informal care literature (Gubrium 1995: 267-8).

Moving beyond the bulk of the literature on informal care and its concentration on tasks, activities and outcomes, the research returned to the source—the individual—and his/her world of relationships. Depersonalising and devaluing models of informal care investigation, based upon a matrix of gender, age, economic status, and so forth (Parker 1985; Horowitz 1985; Orbell 1996), were explored, and then were set aside. The research went beyond studies of measurement of stress and burden (Mac Rae & Costa 1998, for example) to explore meaning behind these very terms. The research answered Freeman’s call that it is time we started looking more closely at people through the stories they tell of their lives (Freeman 1997b: 171). Instead of shop-worn approaches, the point that informal care is part of a history and a process of human socialisation and interaction was established and emphasised throughout this work.
The basis for this exploration was the fact that carers often care for years and assume multiple care roles over a lifetime. The idea that there are positive affect and rewards from caring was examined at deeper, socio-psychological levels, often uncovering troubling extenuating factors. The conclusion was reached, because of these tidings, that informal care is about personal stories, motivations, expectations and characteristics as seen through the prism of relationships, their commitments, frailties and disappointments—both present and past. Individual differences have been forefronted in this examination and unique patterns have been uncovered. As a proactive form of communication, informal care can now be seen as constituted by the individual in relationship to others and grounded within a personal history, interfacing with psychological and sociological contexts. These contexts include the inner-biological (e.g. illness, incapacitation, death), individual psychological (e.g. childhood, parenting, siblings, spouse, friends, employers), cultural-sociological (e.g. communities, housing, language, customs, kinship, faith) and outer physical (e.g. wars, emigrations, depressions, unemployment) (Riegel 1976). Resurrecting the complexities of individuals, who care through this conceptualisation, has provided evidence that enriches, enlightens and broadens the field of informal care and contributes to the study of personality in a general way.

The everyday and ordinary—the quotidian—became the wide canvas on which the research was carried out. In-depth knowledge of individual carers—their stories, their motivations, their dreams and their nightmares—were all used to begin to describe their ‘selves.’ Narrated biography was employed as a method to reveal these particular individuals in all of their complexity and over time. The question whether a narrated life is completely factual or not, was put to one side, in order to emphasise that narration is a insightful device to expose a person’s self-concept at the time of the telling—or in the “Long Now.”

This investigative process began with a question: what is it within the construct of these ‘selves’ that propels them into seemingly ‘selfless’ activity? It was hypothesised that the resurrection of the self, not unlike Coleridge’s Ancient Mariner, was in the narration of the past. By delving into those pasts in a dialogical way, the research was able to uncover motivations, precedents, expectations and patterns that swirled about, relentlessly, and to co-construct a portrait of the individual in his present-day activities and thoughts.

**Contributions to knowledge**

These new pieces now fit into the puzzle of informal care, contributing to knowledge and understanding, making the picture clearer. In addition, the biographic narrative interpretive method has been extended in its usage by this research. Chamberlayne and King’s (2000) use of this method, for example, in *Cultures of Care, Biographies of Carers in Britain and the two Germanies* is a seminal work that investigates informal care using a narrative method. The authors approached care as a biographical project, “in which past life events and experiences, expectations and aspirations for the future, as well as the recent circumstances, are formatively involved in the development of informal care” (2000:129). Their interviews were conducted in three geographical
locations (the U.K. and the ‘two’ Germanies) in the early 1990s, and at a time when this interview and analysis method was new to these particular two investigators.

Chamberlayne and King used an opening prompt asking carers to talk about their experience of caring, how it had developed over time and what caring meant to them personally (2000:15). That approach seemed somewhat problematic as a probe, in light of this research’s initial question. Their use of the more directed ‘story as a carer’ prompt, rather than the ‘story of your life’ prompt used in this research, produced significant differences in results. Because Chamberlayne and King asked for a story of a carer, they got ‘carer stories.’ By asking the more basic and open-ended life story question, this research achieved quite different results, particularly in unearthing early-life precedents to the carer role and in depth.

This project’s interviews were carried out within carer organisation settings and, therefore, participants seemed prepared to tell a carer story before the interview began; in most instances, participants in these interviews had well-rehearsed carer stories to tell as well. By the use of the life story question, (although, at times, initially throwing the participant off balance), richer and deeper historical and contextual material was more often elicited in the interviews. Frequently, ‘behind’ a carer story, a rich vein of autobiographical material was waiting to be tapped. By not asking a ‘story as a carer’ question, the initial expectation of telling a carer story was minimised and deeper levels of experience were revealed. By using the life story probe, encouraging interviewees to go beneath and beyond the expected carer story, narrators ultimately expressed a more natural and revealing recounting.

Chamberlayne and King’s work, although not designed to generalise abstractly (2000:19), did tend to move quickly to comparisons at the societal level. This work’s focus, however, was always conceived of as an exploration at the level of the individual and within the family, concentrating on exploration of individual differences and development at this more micro level, in order to emphasise personality and identity. Although placing caring in the context of wider life experiences (2000:130), Chamberlayne and King’s work concentrated on the caring acts themselves as conclusive and generalisable in order to move swiftly to comparisons between cultures. In contrast in this work, the importance placed on individuality and multiplicity within the caring act, as but one more manifestation of each unique personality dynamic, kept the analysis at the micro level and closer to this research’s original question. Chamberlayne’s further work (2001:4), particularly, uses biography to uncover how individual people handle social change as the very products of social (societal) transformation. Her work is ultimately, then, focussed at that macro level.

In the analysis process, Chamberlayne and King discount intuitive approaches (2000:10) and emphasise Grounded Theory (2000:18) as a methodological approach to their narrative investigations, moving quickly to comparing and theorising at individual cultural levels, and then, finally, developing typologies, an already well-developed practise in informal care research (Parker & Lawton 1994; Pruchno et al 1997, for examples). These emphases are counter to the conclusions that naturally evolved in
this research’s methodological considerations as well as in the team analyses process. (See Chapters 3, 4 & 5). “Explanation at the individual level often occurs, not through the deductive application of universal generalizations, but rather through processes such as searching for the individual’s reasons for acting in a particular way” (Runyan 1982: 8). Conclusions were, thus, reached inductively in this research. These differences in approaches to narrative biographic work and informal care may speak, however, more to the flexibility of the biographic narrative interpretive method, rather than to any precise differences between the two studies and their slant. Ultimately, the contrast between the two approaches may be that Chamberlayne and King’s comparative work is more sociological and policy driven, whilst this study’s work at the individual level is more social psychologically and developmentally rooted.

Chamberlayne and King’s (2000: 9) conceptualisation of social capital as “the capacity to mobilise support and resources in the informal sphere...” is central to their research. This work’s inauguration of ‘emotional capital’ as an additional support and currency available to individuals at the micro level of the individual and transferred through families extends the use of the method and the synthesis of interpretation. In some ways the introduction of emotional capital responded to Lazarus’ call for a move away from stress measurement to the consideration of emotion, including the coping processes underlying emotions (Lazarus 1990: 12). The concept of emotional capital was central to this work’s descriptions of critical personal historical resources, supporting and helping to explain the told stories. Its value was played out in the dramas portrayed by individuals in their making sense of their caring activity and its antecedents.

“By analysing not just pathology but also strengths and adaptive capacities and by studying formative influences not just in childhood but throughout the lifespan,” (Runyan 1982: 209) this research’s life story approach integrates the psychological, the social and the historical within Riegel’s (1976a) dialectic framework. Although the roots of many care giving activities have been unearthed in this study as beginning in childhood, it is important to re-emphasise the codicil that these are reconstructed childhood memories, very much products of the present-day, story-telling scenario –the Long Now. The effects of childhood experiences are, therefore, mediated by intervening experiences and contingencies of personalities that continued to be shaped throughout the life cycle (Runyan 1982: 212) as well as through the narrative process itself. Importantly, this study not only examined childhood experiences, but also explored the possible paths that individuals may or may not have chosen from those experiences and how these choices were woven into the narrations and, ultimately, into their present-day activities.

Conclusions about the research questions
The questions that initially sparked this study are now reviewed. Are there personality ‘types’ that assume caring roles? The review of methodological literature in Chapter 3 clearly indicated that types and traits were only one starting point and certainly not the best direction for this study to take. To speak of ‘categories’ of human beings or typologies, after this in-depth study of individuals, would not only be counterproductive,
but superficial and as useful as an exercise in pinning butterflies to a board. It was concluded that moving beyond traits and types provided richer opportunities for understanding the informal care phenomenon and the sheer diversity of background in the demographics of this small band of carers demonstrated just that.

*In what social activities and outlets do ‘carer types’ involve themselves; who are they ‘the rest of the time’?* Many carers in this study appeared to be immersed in caring and in their roles in families more generally. Time away from caring and family was usually conceived of in terms of special breaks such as holidays, and even these were family functions. The ‘rest of the time’ was seldom spoken of and, indeed, activities outside of caring and home life were rare, the exception being carers’ involvement through carer organisations or the two men to whom employment was central. Once removed from home and their caring duties, the carers studied consistently sought ways in which to reconcile and reconnect their carer identity to the larger external environment, re-enforcing “self-concept within the sphere of social discourse” (Gergen & Davis 1985: 11).

*Are they involved in voluntary or religious activities?* Because of the way in which interviewees were solicited for this study, through carer organisations and support groups, all participants in this study were involved in these kinds of programmes. Few mentioned religious activities, except for Maureen, whose church activities were central to her life. Mahesh’s faith, however, seemed to be central to his way of life and coping style. He was also involved in services for the blind as well as his carer organisation. Carl was involved with the autistic society and carer organisations. Sheila had started her own carer support group, through an organisation.

*Have they participated in or had a desire to participate in ‘caring’ professions?* Carl was seeking paid employment in a carer organisation at the time of the interview and had had positions of authority in volunteer carer organisations. Sheila identified with medical television programmes and had worked in paid caring roles. Maureen considered her job in security as a caring role. Tansy was running a carer support group at the time of the interview. Thus, forays into the volunteer and other care giving sectors re-enforce Shotter’s (in Gergen & Davis 1985: 167) sense of a “whole” interlocking ecology.

*What background differences and/or personality differences, if any, exist between family carers and volunteer (non-related) carers?* This research supported earlier research by the author on volunteer carers (Jones 1992) in several aspects. The need to seek out caring roles was prevalent in both studies as was the second chance phenomenon, the seeking out of a carer role after the death of a spouse or partner for whom a participant had cared. In both studies, childhood experiences played a crucial role in predicting later-life carer activities, whether taking on a carer role in childhood or other intensive childhood experiences that were developmentally influential. This research also supports earlier informal care research’s finding that expectancies about the availability
of others for support and attachment style are based partly on early relationships, particularly attachment figures (Markiewicz et al 1997: 128).

*What enables them to maintain their psychological integrity? What are they “actually doing and telling themselves in an effort to cope?”* (Lazarus 1993: 244) Even in the most extreme of the cases studied, justifications for their caring activities were pervasive. Primary to the carers' sense of integrity in this study, crucially, was their ability to construct a narrative that ‘hung together’ and made sense to them as well as to the outside world through their recounting it—a “continuous account upon discontinuous data” (Freeman 1984: 10).

The fact that there is a omnipresent 'need to tell' a carer’s story supports narrative theory and the concept that ‘telling themselves’ is not enough; the story needs to be constructed through a narration to others. Carers are compelled to tell others and through this act co-construct the carer story and an identity with the listener; through this process, a sense of ‘who they are’ —their identity—therefore, emerges. The fact that interviewees were eager to tell a carer story, one that many had even rehearsed and/or often had told before, began to lend credence to an understanding of the compulsive and repetitive nature of caring generally, and equally, its mirroring within the narrative act. Their retellings also indicated that the narrative—and, therefore, the individual—is never finished.

*What are the histories of their lives and in relation to caring activities over the lifespan?* These reconstructed histories revealed insightful clues to the motivations behind the caring act. Particularly, through their childhood histories, these carers demonstrated that a perceived lack of care from their parents had the potential to produce lifelong consequences. It is proposed that the seeds of adult carer role-seeking remained dormant, often for years, within the sometimes remembered, sometimes repressed, memories of those earlier years. These memories were (re)constructions of past events, places and people that propelled the actions of adult carers, often resulting in a quest for resolution and synthesis (Riegel 1976a). These adult carers often reflected on their childhood and presumed a lack of parental care. Those perceived traumatic events then catapulted the child’s needs into an adult life of compensation seeking. Thus, this supported a sense of the Gestalt or “shape that emerges out of the past extends itself into the future” (Freeman 1984: 17). Through the ironic role reversal of demonstrating those very needs by performing the care act themselves, the adult carers were trying to demonstrate their remembered childhood lack of/need for care.

Because the child’s world can be viewed as often myopic and self-centred, these needs created in childhood have the potential for never being satisfied in an adult world. These adult carers often performed caring duties repeatedly, without ever achieving a necessary resolution. It became, in many of these cases, a situation of ‘do unto others’ taken to a compulsive and sometimes self-destructive extreme. Additionally, through their expression of their own care needs, carers may also be asking for a more caring
world in general, their perceived lack of it explaining some of their anger often targeted at the larger social sphere.

Have traumatic or difficult illnesses and/or deaths occurred in their pasts? Have they cared for a family member as a child or teenager? Tansy reported that her father's death had a profound effect on her behaviour at the time of her loss. Polly's loss of her mother through divorce was a crucial turning point for her. In an earlier hypothesis, the possibility that being a young carer was a positive experience and, therefore, a motivating factor in later life care giving was considered. Two of the interviewees in this study cared for a parent as a child (Tansy and Maureen); two others cared for siblings (Mahesh and Carl). Resentments towards parents (Tansy, Polly, Carl, Sheila, Maureen and, possibly, Sally) and a sense of loss of their own care appeared to be pervasive to varying degrees in all of the cases studied; it is put forward now that these experiences translated into later life 'demonstrative' care activities.

What else are they, other than carers? Who else are they? Most of the carers interviewed seemed only to imagine life outside of a carer role. Sally, particularly, stood out as one extreme example of this. Even some of the carers studied who were engaged in employment (Carl, Mahesh, and Maureen for a time, for example) seemed both bound by and compelled to find ways to integrate their carer role into a wider world. Others found identity within carer organisations, but this was an identity that was, in the end an extension of their more private carer identity.

What are the social factors that influence carers in assuming caring roles? What part does family, birth order, and early family caring experience play in later life development of caring roles? What personality factors and roles influence one family member to assume the caring role and other members not to? Clearly, the family and particularly parents were both central to the development of carer roles in later life in all the participants who were interviewed (see Table 2). An important finding is the fact that all five of the women were 'only' children (Tansy, Sheila, Maureen, Polly, Sally); the two men (Mahesh and Carl), on the other hand, both grew up in families where siblings were disabled, so, in a certain sense, they were only children, too. Carl summed up his assessment of a childhood as a brother of a disabled sister: "It's a issue for siblings in so many ways -- that all the choices are based around that individual; even if you don't do it consciously, you do it subconsciously. But the sibling knows why, all the time, and they're always aware of it and you feel like a second class child."

Polly was an especially interesting and unique case. A biological 'only child' of her parents, she was raised, for a time, with her mother's friend Anna and her children, then lived alone with her father until about age 16 when she then rejoined Anna and her 'adoptive' family.
### Table 2: Family factors involved in carers’ early lives

<table>
<thead>
<tr>
<th>NAME</th>
<th>ONLY CHILD</th>
<th>DISABLED SIBLINGS</th>
<th>YOUNG CARER</th>
<th>ANGER WITH PARENT(S)</th>
<th>EARLY LOSS OF PARENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polly Humberston</td>
<td>*</td>
<td></td>
<td></td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Carl Humberston</td>
<td></td>
<td></td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Mahesh Parmar</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td>*</td>
</tr>
<tr>
<td>Maureen Andrews</td>
<td>*</td>
<td>*</td>
<td></td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Sally Green</td>
<td>*</td>
<td></td>
<td></td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Sheila Conner</td>
<td></td>
<td></td>
<td></td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Tansy Johnson</td>
<td>*</td>
<td></td>
<td></td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

Perhaps one of the most important factors in predicting a young carer role in this study was availability – who in the family was available to care for a parent or a sibling. In fact, family structure is one of the factors that influence the extent and nature of young carers’ tasks and responsibilities (Dearden 2001). In a certain way, it was down to happenstance for these particular young carers; they happened to be there, and as only children or an only child who was not disabled, they were the 'only child' available for the young carer role. In work on young carers by Becker, Aldridge and Deardon evidence has been found to support a case that some young carers experience impaired psycho-social development with far reaching consequences and that caring can have a negative impact on some children’s well being, including difficulties relating to their peers and forming long lasting friendships (Dearden 2001).

**What part does the community itself play in personality development and influencing carers’ roles?** Carl brought up the issue of bullying at school as a result of having a disabled sibling. Feeling different because of a young carer role or other childhood disadvantages had major consequences in some of the lives studied (Tansy, Carl, and Mahesh). The community also played a part in Tansy’s references to the black community and what they ‘might say,’ if she did not care for her mother. Mahesh’s Asian background and community provided a base for his problem-solving network and a spiritual base for his coping mechanisms. Maureen assumed a new culture within a black church community, a resource to which she turned frequently in her difficulties. Carl’s use of the voluntary sector as a place to find a wider identity and resolution of his conflicts between home and the outside world was persistent.

**What values, traditions, economic forces and other social forces come into play in forming and contributing to personality development and adjustment to a caring role?** Most of the cases in this study came from lower income households and with that came
a set of values and traditions, too. Duty and commitment to family, and particularly parents, came up repeatedly (Tansy, Sheila, Mahesh, Carl, and Maureen) as a reason for sticking at a caring role. In lower income families where life is often fraught with economic insecurities, family solidarity may often be regarded as a buffer to outside forces. A certain sense of inescapability was also present in many of the stories and this may well be a result of economic restraints and/or class distinctions — real or assumed. A theme of fantasising a 'way out' was raised often, too (e.g. Sheila, Mahesh, Carl, Tansy).

**How do carers define themselves and their caring role in relation to available health, social and voluntary services?** Many of the carers saw health and social services as the enemy and spent long sections of their narrations recounting their 'war stories' of doing battle with authorities, from social services to the local GP. Voluntary services, on the other hand, were generally viewed more positively, perhaps because of a perception of them as places where carers were listened to and where others were able to identify with their story. Often large segments of these stories were about the very problems that they have had with health and social services. These shared stories had the potential to give individuals a sense of a mutual identity and a first step towards much-needed identity work. The concept of the 'lifeboat' phenomenon, developed in earlier research (Jones 1992), helps to explain the tendency towards a group identity and solidarity that follows and develops in cases of shared or similar traumatic and stressful experiences.

**What formal and informal supports are available in the community towards which some carers may gravitate and some do not?** How do these support systems help or fail to help the carer define his or her role in relation to the definition of 'self'? The seven cases in this study all had their origins from within the carer organisation/carer support group system. Because carers that are more isolated were not included in this study, little can be said about their particular supports. Of these seven carers, however, two came to a carer organisation after their caring duties had ended through a death (Tansy and Maureen). They seemed to be trying to find some sense of closure at the time, but also a way of integrating their carer pasts within their present-day sense of self. More will be said about the work that support systems can do to support identity work within their organisations under Implications for policy, which follows later.

**Conclusions about the research problem**
The research process began by asking the following:

- **“Why do individuals gravitate toward the informal care role and, at times, even voluntarily seek out the role?”**
- **"What makes informal carers continue to care in the face of the seemingly overwhelming obstacles involved?"**
This research has established the fact that many of the informal carers who participated in this study often chose to accept a caring role, based upon a complex mix of their personality and the personal, historical construct of their contextual background. Influences on these life paths included personality, self-identity, life histories, cohort effects, shared values and traditions, and family background and caring experiences. All of these effects have been thoroughly investigated through the process of this research’s in-depth case study of the biographic narratives of these particular informal carers.

It has been argued here that the stories that these carers created to elaborate the meanings of their lives supported their indications that caring episodes were often seen in a positive light – particularly in relation to definitions of character and, importantly, were, therefore, identity affirming and self-fulfilling life events. These facts, in turn, illuminated the dichotomy of the hassles and uplifts of everyday caring and, generally, the enigma of fulfilment through a seemingly often-unrewarding role. Nolan, Grant and Keady have pointed to the fact that little is known about the sources, types and frequency of carer satisfactions (Nolan, Grant & Keady 1996: 3) and that sources of satisfaction could be rooted in the intrapsychic and intrapersonal lives of the individual (Grant & Nolan 1993: 156). In the particular cases studied for this research, the satisfactions in care giving were frequently self-fulfilling because the action of care giving was ‘close to the bone’; that is, at least by demonstrating the carer’s deeply buried needs, those needs were brought closer to the surface. In some cases, those repetitive acts were the result of seeking a kind of emotional release or ‘carer high.’ This may, in part, explain Ungerson’s earlier puzzlement of cases where she observed “an extraordinary kind of joy” (Ungerson 1987: 144). Suis and David, (1996) in studying coping processes in informal care settings, observed that “habitual behaviors may involve little conscious awareness or control;” the concept of carer high may begin to explain this phenomenon.

On the other hand, the frustrations, anger, exhaustion, and so forth, of caring went beyond the obvious physical wear and tear of care giving. The emotions and spent emotional capital of care giving may also have been the results of the frustrations of personal psychological needs that were often never met by the awkward and convoluted expressions of these needs in these cases.

Deeper biographic analyses supported the hypothesis that these informal carers were often catapulted into caring roles because of developmental constructs in their earlier lives, particularly in their childhood and/or teen years. It is proposed that, because of needs that were unfulfilled in their young lives, these carers continued to attempt to fill those voids by demonstrative behaviours that paralleled their own remembered care needs; that is, they displayed, by their caring activity, the care that was lacking in their childhood, in the first instance. Psychologically, these adult care givers may have been, more often than not, the members of the care dyad most in need of emotional care. Those needs apparently ran historically deep and may have been compounded by an adult reconstruction of childhood needs that were never satisfied, in retrospect. It can be viewed as a cycle that continued to turn back on itself, unrelentlessly. This was the
most singular finding of this research and makes a distinct contribution to knowledge in the field of informal care.

**Implications for theory**

The research presented can be judged in terms of a substantial list of criteria for case study work:

1. Providing ‘insight’ into the person, clarifying the previously meaningless or incomprehensible, suggesting previously unseen connections;
2. Providing a feel for the person, conveying the experience of having known or met him or her;
3. Helping us to understand the inner or subjective world of the person, how they think about their own experience, situation, problems, life;
4. Deepening our sympathy or empathy for the subject;
5. Effectively portraying the social and historical world that the person is living in;
6. Illuminating the causes (and meanings) of relevant events, experiences and conditions; and
7. Being vivid, evocative, emotionally compelling to read.

--Runyan 1982:152

The reader has been encouraged to focus attention at the level of individuals, through the portraits of the seven informal carers presented in Chapter 5. In Chapter 6, four of the individuals’ lives, as told through records of their own voices, interfaced with assembled groups of members of the *habitus*. Through this device, these individual stories brought to the surface inner subjective worlds, including the unconscious and the repressed. By continuing to pay attention to the individual and his/her uniqueness and individuality, it was then possible to make connections and hypotheses at the level of family. It was at the level of the family that events relevant to the individual’s concepts of care had been constructed. By expanding the focus beyond the family to the larger world of work, friendships and institutions and their meanings to particular individuals, another layer of understanding was constructed. This comprehension was accomplished by references to the historical world in which the individual manoeuvred, whether it was a childhood in 1940s war torn England or experiences as a child of immigrant West Indian parents in the 1970s.

In Chapter 6, finally, the individuals were considered in relation to the research problems; it was through this interface that the previously incomprehensible aspects of informal care began to take new shape and form. In all of these reports, a sense of compassion for the individual was central to the portrayal of these seven lives. It would be easy to recoil from the more devastating episodes of many of these stories. By concentrating the focus at the individual level, however, --by getting to “know” them-- it was hoped that this would not be the case and that a state of empathy could be reached between the reader and the subjects as it was throughout the analyses.
Through this presentation of case studies using a narrative biographic approach, an attempt has been made to strike a deeper vein than has been struck, heretofore, in research on informal care. By using this method to investigate informal care, the research, by putting a personal face on caring, has overcome “the continuing reluctance of caregiving research to consider personality as an important predictor of how people negotiate the stressor associated with caregiving” (Hooker et al 1998: P80). Beyond stress, the study has also demonstrated how people attach meaning to the role and extended the literature on carer meaning (Farran et al 1991; Cohen et al 1994).

The use of a biographic interpretive narrative method has extended the use of case study to investigate personality and the method itself has been enriched and extended by this research’s efforts. The small amount of literature on personality and informal care (McKee et al 1997) has been extended and moved well beyond the study of coping strategies. By concentrating on a whole life approach to a specific research area or problem, the work has produced strong evidence supporting the fact that a holistic and historical approach to the study of social psychological phenomena uncovers subtleties and nuances and produces in-depth knowledge in the field. By setting aside the assumptions and/or findings of past research on informal care that too often repeated the known and established viewpoint, this research has been able to uncover motivations and explanations for seemingly perplexing behaviours and activities. The ultimate contribution that this effort can make is finally to enable researchers, health practitioners and social and voluntary workers to begin to ask, “Who were you before you began to care?” Through this kind of approach, the informal carer will begin to be seen in terms of a shared humanity, instead as an anomaly. Carers and those who support them can then begin to do meaningful identity work, getting to the root of the informal care phenomenon and the phenomenon itself can finally be put into a healthy perspective.

**Key concepts**

Key concepts developed and supported in this research that make original contributions to the fields of personality and informal care include:

- **Carer high**: an explanation of the phenomenon that many carers find satisfaction and a “kind of joy” (Ungerson 1987: 144) in the caring act, helping to explain its repetitive nature under difficult circumstances.

- **Lifeboat phenomenon**: the solidarity and unity of identity achieved through sharing at group level the difficulties and frustrations of the care role, thereby beginning new identity work within the group.

- **Emotional capital**: the concept that, not unlike social capital, resources exist within the psyche of the individual that are called upon to support their actions. These are resources that can be transferred from one to another, particularly through the family and intergenerationally.
• **Second chance phenomenon**: the concept that a carer, particularly after a difficult period of care followed by death, will seek out a new opportunity to assume the carer role in order to 'get it right' the second time around. This phenomenon is particularly useful in explaining the behaviours of a carer who, after a family death, will move on to a voluntary or quasi-professional caring role outside of the family. *(This concept was first raised by Sister Eva Heymann of the Terrance Higgins Trust in conversation with the author in 1992)*

• **'Do Unto Others' phenomenon**: the concept that informal carers will unconsciously demonstrate or mirror though their caring activities their own perceived care needs (sometimes repressed childhood needs), to the person they care for and their social world in general.

• **'I want' phenomenon**: takes a device used in West End or Broadway musicals of placing an 'I want' song early in the play in order to tell where the story may end. By looking for 'I want' phrases early in interview transcripts, motifs and predicted outcomes were unearthed in the analyses.

• **'Looping' device**: a narrative device that carers often use in their stories, particularly when asked more directed questions about themselves, to deflect the narrative back on the person(s) cared for.

**Implications for policy**
As this research has demonstrated, many of the 'problems' that may be presented to social, medical and voluntary bodies working with informal carers are, in fact, surface indicators of much deeper embedded struggles resulting from lifelong developmentally bound constructs. Reliance upon informal carers to provide 'stop-gap' long term care solutions to health economic problems is, too often, re-enforcing these very constructions and keeping carers encased in their problems, rather than moving them into solutions. Policy is needed that embraces the concept of the whole individual and puts their individual needs first.

Emerging policy on informal care has begun to consider informal carers, but in an aggregate way. Meaningful outcome indicators that demonstrate how lives are changed are still required, not simply another set of figures that support outputs rather than real outcomes. Still, the old counting systems endure; for example, in one section of a recent government document, *The National Strategy for Carers* (DOH 2001), listed possible outcomes of Carer Support services in Oxfordshire. Except for survey measures of carers’ satisfaction with services, the total of the “outcome measures” were numerical and economic programmatic outputs such as numbers of carers, number of new carers, number of referrals, number of volunteer hours, amount of funding and amount of in-kind support (2001: 67). An earlier paper, *Consultative Conference on a National Strategy for Carers* (DOH 1998), urged government policy based upon qualitative principles such as recognising that caring takes place with a human relationship and that not all carers are the same (1998: 2). Key points that were raised in working discussion groups at that conference included:
• Asking how the carer is doing from time to time as a form of support (23)
• Asking how they are feeling (24)
• Asking whether carers wanted to be carers (24);
• A need for recognition generally and to be recognised as a group (29)
• To be listened to (36)
• To be seen in context within the family (36)
• To be able to identify themselves as carers (37)

These are all concerns, which fit within the general rubric of ‘identity work’ through a dialogical interactive approach, an area that services to carers need to develop, supported by government policy and action.

Carer support organisations and agencies need to begin to encourage the identity work that is necessary if informal carers are to come to terms with their backgrounds and motivations in taking on a caring role. Carer organisations were portrayed in this study’s cases as places where carers went to share their stories – stories that included the trials and tribulations, the frustrations and successes of informal care. “Autobiographical work always contains loops within loops…Somewhere inside these loops…one person puts some version of his or her life into words and someone else decides what these words have to do with the life he or she is living” (Frank 2000: 148). The carer organisations in this study represented to carers an end to isolation and the beginnings of constructing a shared identity within the group by identification. “Community is constructed in the very process, in which two of more people construct a story about what has happened, which is understandable for them both. And whenever these shared stories becomes a part of the implicit horizon of understanding of a social group, they function as a guarantee for mutual solidarity” (Hermans & Dupont 2000: 2).

The work beyond this – the loop from identity through group process and back again to the reconstruction of the individual -- however, has yet to be achieved. The use of a personal sense of security possible through group work is recommended as the starting point for building upon and expanding the current identity work that takes place.

Examples of group work that use narrative as a theoretical base are considered. First, the imagework of Iain Edgar uses active imagination and visualisation as a powerful therapeutic method that also has research and teaching/learning potentials. His narrative picturing technique works well to articulate aspects of personality and to reach suppressed and repressed memories whilst incorporating the participants’ interpretations (Edgar 1999). This work can be facilitated in a group setting and is ‘user’ friendly in that it is not off-putting to participants who may be suspicious of more intensely psychotherapeutic methods.

Secondly, Alida Gersie’s Therapeutic Storymaking (TSM) approach strengthens participants’ ability “to engage with greater efficacy with their informal social network” (Gersie 1997: 5). Through its therapeutic process “levels of directed awareness are supported by creative expressive group procedures, which are designed specifically to strengthen the participants’ commitment to create and process stories, and to clarify
ideas, memories and feelings linked with stories" (1997: 72). Through Gersie’s Therapeutic Storymaking, participants learn to reconstruct their own narratives and through this process, reconstruct their identities.

Thirdly, and perhaps more cautiously recommended, would be frameworks from the recovery movement, "only one of many options available for constructing a relational self" (Eastland 1995: 311). The recovery movement offers a structure for individuals to make sense of themselves and their experiences (1995: 293) and to make a shift from passive victim to active participant in life (1995: 297) through the reconstruction of personal history and individual identity (1995: 302). This reconstruction involves both reinterpreting and re-experiencing the past with a simultaneous construction of a new identity (1995: 308). The fact that recovery programmes are based upon democratic group work within a leaderless setting may have appeal to self-help carer groups, particularly where an aversion exists to more traditional types of individual face-to-face therapies and authority figures, particularly from the health or social services establishments.

Limitations
This study did not include isolated carers, that is, informal carers who continue to care without the support of organised carer groups or services. Although the study was able to unearth a few carers who came to organisations late in their caring duties or after those duties had finished, the research does not include carers in continual isolation. The research was somewhat limited by the number of cases studied. Also the number of cases that were analysed through the team process was limited by the time available to team participants.

The case analyses are limited by the expressions of a few people from a shared habitus, each with his/her own individual background, personality, prejudices and contexts, interfacing with the transcribed narration of a stranger’s story. This dialogical interface can never be the ideal. Rather, it is one of several possible methodological constructs that attempt to represent an understanding of an ‘other.’

Implications for further research
Further work on informal care would benefit from survey work developed from this research and its findings. Instead of concentrating only on present-day needs, expectations, and so forth, a survey might successfully investigate past experience and histories, particularly childhood experiences that informal carers may hold in common, potentially supporting this work’s findings. Further autobiographical work is needed, particularly in the area of isolated carers; these stories may, in fact, tell a very different story.

The Humberstons’ stories of a mother and son raised the potential for the study of one family of carers over three generations and with multiple carer/cared for roles. An in-depth study of just such a family, analysing narrated biographies of each family member, would be intriguing and have the potential for deeper and more complete knowledge of informal care as embedded within family structures.
Another option for further research might include participatory research, perhaps using some of the narrative therapeutic methods (recommended above under Implications for policy) and testing them for their effectiveness as paths to meaningful identity work in group settings.

By returning to the research questions raised at the end of the literature search, conclusions have been drawn that add to knowledge of informal care and the individuals who perform caring acts in their worlds of relationships. In addition, a contribution has been made to extending the use of a biographic narrative interpretive method to investigate phenomena. Implications for theory, policy and further research have been addressed and limitations noted.
Afterward, or Later

By reading the end into the beginning and the beginning into the end, we learn to read time backward, as the recapitulation of the initial conditions of a course of action in its terminal consequences. In this way, the plot does not merely establish human action ‘in’ time, it also establishes it in memory. And memory in turn repeats—re-collects—the course of events according to an order that is the counterpart of the stretching-along of time between a beginning and an end.

Yet the concept of repetition implies still more: it means the ‘retrieval’ of our most fundamental potentialities, as they are inherited from our own past, in terms of a personal fate and a common destiny. The question, therefore, is whether we may go so far as to say that the function of narrative—or at least a selected group of narratives—is to establish human action at the level of authentic historicality, that is, of repetition.

Paul Ricoeur 1981:179-80

Some may ask, “Aren’t these analyses just psychoanalytical logics of inference, attributing properties to these carers and their early lives? Perhaps these accounts were just ‘made up’ to suit the interview? Isn’t caring really something we all do when there is no one else around to do it and isn’t this really what is going on here in many of these stories?”

In the Method Chapter, it was explained that these are the ‘inferences’ of two discrete teams of people, each group analysing a particular aspect of the individual case. One team was responding to the ‘factual’ account of events, places and people in a lived life; a separate team absorbed the told story, at times line by line, and responded to its telling using not only their professional skills, but also their abilities gained from common knowledge and the shared *habitus*. In the end, the two distinct teams came up with very similar readings of the stories independently.

The possibility that psychoanalytical ‘jargon’ and inferences came up frequently and consistently may be more a result of the history we share (or for some team members, have become acclimated to) and its popular culture, than anything about a specific theoretical stance or particular position on the stories themselves. The fact that many of these carers’ stories were embedded within an emplotment of childhood distress speaks more to the nature of narrative than to any adherence to strict psychoanalytical grounding, by either of the groups of people who engaged in the analyses or this writer. In fact, the analyses were conducted within the framework of the psychosocial and are not reducible to simple psychology, but rather considered as “complex responses to events and people in the social world, both past and present” (Hollway & Jefferson 2000: 24).
There exist as myriad a set of possibilities for analyses and reporting of case histories as there are “an indefinitely large number of other research community contexts for which cases …could be written up differently” (Wengraf 2001: 364). Many of these particular cases were perceived by the reflecting teams as well as this writer as valuable as social psychological studies of responses to particular, early traumatic events in families. Because the analyses led to “‘complexes’ which are laid down in early childhood and then tend to persist” (Sloan cited in Wengraf 2001: 364), does not make the conclusions drawn any less valid.

It helps to recall that the turn to narrative has also included a natural return to and a revisionist take on the psychoanalytical, its literature and its narrative approach and this is well reported (see Hollway & Jefferson 2000; McAdams et al 1997, for examples). Hollway and Jefferson (2000: 78) reminded us that psychoanalysis is, after all, an art and not a science. Further, Rustin remarked that psychoanalysis was unusual among the social sciences “in rejecting the opposition between scientific and imaginative methods, between typification and the investigation of the particular” (Rustin in Chamberlayne et al 2000: 37). Gergen alerted us to the concept that, in our attempts to generate intelligibility, we must inevitably draw from preceding traditions. This is accomplished by integration of preceding intelligibilities and realignment of existing ones and their practices (Gergen 2001: 430).

It comes as no surprise, then, when reading stories about and by people and with a brief to taking an analytical viewpoint that the language of psychoanalytical discourse comes to the forefront. The point to be made through the analyses presented in this work and their glissements into a ‘psycho speak’ of a particular variety is that this “integration of preceding intelligibilities” is accomplished by allowing the investigators to remain transparent and active participants in the story making. Not exercises in truth or falsehood, these investigations were polyvocal attempts at interfacing with cultural/relational/linguistic accounts of the real. They are, therefore, interpretations and not truths in the positivistic sense. On the other hand, did we, “in our attempts at some sort a truth (Verísimo) stumble onto a synthesis after all, a moment of revelation that truly is wrenched by the individual in his/her self-knowing and revealed to us” (Jones 2000: [22])?

*Were these stories just made up to suit the interview?* In several cases, participants’ childhood experiences were not even at the forefront of their narrative script (Maureen’s refusal even to begin to tell a chronological narrative, or Sheila’s professed inability to remember her childhood, for examples). Often, it was through probing within the interview protocol and the following astute hypothesising by the teams that possibilities of those particular childhood experiences were unearthed. Most of the interviewees fully expected to tell a ‘carer story’ and many had difficulty, initially, beginning a ‘whole life’ narrative. These teething troubles substantiated our belief that the whole life question had been successful in encouraging the participants to carve a narrative on the spot – one that we could look to for some spontaneity, naturalness and believability and the beginnings of a sense of individual identity sculpted through storytelling.
Isn’t caring something we all do anyway? In all probability, the case is that ‘we’ do not care in the same way or to the degree that these people do. Their stories support the conclusion that caring is sometimes one of life’s choices that some had little say in, especially those who cared as children. The fact that they continued to take up carer roles later in life was always one of the phenomena driving this investigation. With others, the detail that they automatically assumed that they would take on the carer role is something that not all of us would mechanically do. We may care, but we often have a battery of solutions to the need for care in others that includes helping another person to find care or get to care. We do not routinely assume that we will provide the care itself, nor that no one else could possibly do it.

Because the carers in these stories often assumed that they are the (only) ones capable of doing the caring (almost as though they have been ‘chosen’ somehow), many often minimised or dismissed outside help with care, including professional care. Most of us, even if we do provide some sort of ‘hands-on’ care for another person, move on in (and back to) our ‘normal’ lives after the experience. We do not later join a carer organisation in order to make sense of our selves and our experiences at caring, as often these people have done.

That is why the concept of the ‘lifeboat’ phenomenon is so helpful. These particular caring experiences were akin to the same sort of intensity as surviving a sinking ship or the Ancient Mariner’s plight: the story of it needs to be told and retold because an identity was (re)constructed through the experience of doing it and was being (re)assembled again, through (re)telling it. Recounting your particular story to a group of people who have shared a lifeboat with you often produces the best audience of all, hence the popularity of carer organisations, carer support groups and the carer movement, generally.

It is important to remember that the concept of ‘informal carer’ is about 20 years old in the literature (see Chapter 2) and only about 10 years old in popular language. “‘Carers’ did not exist as such prior to the development of the discourse of informal care in policy and other discursive domains” (Heaton 1999: 768). The history of informal care clearly informs us that the concept came from the research and policy literature into popular culture and not the other way round. The term and concept itself were a result of strategising for long term healthcare costs by the statutory-medical-social services establishment in order to extend its surveillance into the home, once it had decided to place the financial, physical and psychological burden of care needs within the family. The establishment found its solution in the creation of the concept of the informal carer as a relay of the medical gaze (771).

The informal carer movement, in a certain sense, is a response to that gaze. Many carers’ stories, filled with vitriolic antiestablishment rhetoric and sentiment, can, in some ways, be viewed as exercises in regaining their personal space, autonomy and sense of identity within the home and family that has been usurped by the establishment’s intervention. Ricoeur’s concept of repetition in terms of shared fate and common destiny rings true here. For those reasons alone, the informal carers interviewed for this
project seemed to have a special need to form an identity around caring issues by joining forces within carers' organisations and by reinventing themselves through their repetitive storytelling, thus re-establishing a sense of personal space and autonomy.

The stories (re)created in the analyses here reflect cultural resources at every level reflected through the narrator, the interviewer-writer, the analyses team members (and now, the reader). A part of that shared culture is our sense of family, particularly parenting, and how we have experienced it, that we bring to the stories themselves. Most of family life (and parenting) occurs behind closed doors in our culture and in this, one may assume, lies much of the fascination in the childhood and parenting stories of others. One need only listen to most freshman students (during their adjustment to their first time away from home?) recounting their childhood experience and complaining about their parents to each other (a nostalgia for the parental ‘gaze’?) to see how much this need to compare our childhood and parented backgrounds is often a routine part of our culture.

This could be one reason that the teams (and this researcher) seemed to find childhood experiences of the narrators so compelling and imbued them with truthfulness, meaning and motivation. On the other hand, a childhood is also something we all have in common and a starting point for understanding each other. We generally do not tell ‘our stories’ without at least some reference to a beginning, usually a childhood beginning. Beginnings predict endings in stories and, sometimes, in lives.

To ignore the traumatic and devastating stories of childhood recounted in these specific stories as having had any impact on the later life experiences of the tellers would not only be insensitive, but also naive. To negate totally or dismiss the analyses of these reported early memories, as no more than mere psychologising by curious others, would be tragic. Equally, it would be unfortunate and shortsighted to believe that, as adults, these carers can do nothing to move beyond their childhood experiences or change their narratives (and some may have already begun to do so in through the telling of the narrations retold here). Optimistically, this sort of process is what is envisaged for future informal carer programmes, thus, the recommendations for changes in policy and services for informal carers that were made in the preceding chapter.

So, are we reifying stories of ‘difficult childhood experiences’ and setting them in stone in this research as the be-all and end-all of later life difficulties? Aren’t these just parts of their stories and told for whatever reasons that the tellers may or may not have had on the day of the interview? The conclusion reached here is that it is best to remain less suspicious on both counts. The second question above actually embeds its own answer. The fact that difficult childhood experiences were raised as part of a life story, rather than as responses to direct questioning, strongly indicates that those experiences continued to be important in the narrator’s sensed ‘present’ and ‘on the day.’ The difficulties with which participants divulged these particular parts of their stories tells us a great deal about what life held out to them at less autonomous periods of their younger lives. We may recoil from particular episodes in these stories; this does not
make them any less believable or any less important to the adult who recounted them, for whatever reason. The fact that these stories attempt to integrate “the psychological with the social and historical, by analysing not just pathology but also strengths and adaptive capacities, and by studying formative influences not just in childhood but throughout the life span” (Runyan 1982: 209) lends great credence and support for this particular narrative method.

A leap to disbelief may ultimately be more problematic than any overemphasis on a psychological explanation, in whatever theoretical guise, in this research’s conclusions. The fact that these were the messages that interview participants wished to convey to another human being speaks to their natural abilities to communicate within a dialogic world, who they are and how those messages were received and interpreted. Conversely, only to notice what the interviewee is saying, in a way helping them to accentuate consistency and suppress contradiction in their stories through the analytical process, would overlook or ignore a lot of the evidence scattered around in the data – inconsistencies, contradictions, changes of tone and other textual interruptions (Hollway & Jefferson 2000: 57; Jones 2001). This is why the reflecting team approach to data analysis is so productive in bringing to our attention both detail and contradictions—bringing different points-of-view to the data whilst still allowing the interviewee his/her voice.

Another interpretation of these circumstances or another point-of-view could also be taken on any given day by another set of researchers. The conclusions presented here simply represent the best possible effort of the reflecting teams involved with the information and materials that they had at hand at the time. If, by engaging with these stories through this particular lens, the reader is disturbed, even inflamed or enraged, but subsequently prodded to rethink informal care from a new perspective, then the effort put forth here is justified. By reading the beginning (childhood) into the end (adulthood), the end into the beginning and tacking between the two, we are, after all, just participating in good storytelling and through this process, participating in “enriching the forms of societal practice” (Gergen 2001: 431).

In the best narrative work, descriptive/interpretive analysis is a story about stories. When it veers from this basic concept, it goes off course. When I, as a narrative researcher, look for stories to tell there is another overarching story to tell in how I came to be in this particular landscape in the first place. What was it about me (my peculiar interface with society, policy, trends, and conventions) that led me on the particular path I took? If I disclose this half of the circle then the second half makes sense. It is within the fullness of this circle that the hermeneutic process becomes complete. Only when I can find myself in an ‘other’ can I begin to understand what is unique and individual about an ‘other’ and ultimately what is distinctive about myself.

Jones 2000: [15]
BIBLIOGRAPHY


Jones, K. (2000) Big Science or The Bride Stripped Bare by Her Bachelors, Even. Review essay. Forum: Qualitative Social Research:1(3). Available at: http://www.qualitative-research.net/fqs-texte/3-00/3-00review-jones-e.htm


190


Reardon, C. (2001) *Young Carers: The UK Research Findings.* Available at: [http://www.careuk.co.uk/Library/PDF/](http://www.careuk.co.uk/Library/PDF/).


**Webster Dictionary** (2001) Available at: [http://www.m-w.com](http://www.m-w.com) Merriam Webster.

