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Appendices I and IV have been removed (published questionnaires).

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The Alzheimer's Disease Life Events study

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Abstract

The Alzheimer's Disease Life Events study examines whether there is a relationship between life events and Alzheimer's disease (AD). The ADLE study uses a mixed methods approach to answer the central research question:

Are life events a risk factor for Alzheimer's disease?

The central research question uses the following theory questions to examine:

1. Is there a difference between the number of life events between patients and controls, using the Life Events and Difficulties Schedule (LEDS)(Brown and Harris, 1978) as a measurement tool?

2. Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and in the range of emotions expressed when discussing life events between the patients and controls?

3. Are there any differences in the narrative constructions of life events, as interpreted by the Biographic Narrative Interpretive Method (BNIM)(Wengraf, 2001, 2008) between the patient and control groups?

4. Can the differences, between the patient and control groups, in the narratives be developed into a diagnostic marker?

5. Can the Emotion Word Coding (EWC)(Danner et al., 2000) be used as a diagnostic marker by being applied to text collected from patients and controls over a period of decades?

The ADLE study found that the patient group had experienced more life events in comparison with the control group as defined by the LEDS (Brown and Harris, 1978), and that the patient group had experienced more bereavements under the age of 51 years. The evidence supports the association between life events and AD

Even though there were significantly more life events experienced by the patients, the EWC (Danner et al., 2001) found significantly fewer discussions expressing emotion by the patients, particularly the negatively described ones. The range of negative and positive words used to describe the life events was significantly fewer too. This implies that the ways the patients express emotions about life events is substantially different from the controls. This finding was mirrored in the thematic field analysis of the BNIM interviews (Wengraf, 2001, 2008), which found differences in the content and structure of the narratives, and the emotional expression in the narratives about life events.

A tool has been constructed using the differences between patients and controls to contribute to the early diagnosis of AD. In addition, the ADLE study has contributed to a gap in the knowledge about life events and AD.

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Contents	Page
Chapter 1: Introduction	**1**
1.1 Life events and Alzheimer's disease	1
1.1.1 Aim and objectives of the ADLE study	3
1.1.2 CRQ, Theory Questions and Hypothesis	3
1.2. Life events models	8
1.2.1. Definition of a life event	9
1.2.2. The relationship between life events and illness	9
1.2.3. Model of life events and illnesses	10
1.3. The definition and prevalence of AD	12
1.4. Structure of the thesis	13
1.5. Conclusion	15
Chapter 2: Background information	**16**
2.1. Introduction	16
2.2. Alzheimer's Disease Life Events study and the Oxford Project To Investigate Memory And Ageing	16
2.3. Background to OPTIMA	16
2.4. The context of the ADLE study and research design of OPTIMA	17
2.5. Demography of the ageing population	18
2.6. Pathology and diagnosis of AD	19
2.7. The implications of AD for the individual and his or her family	21
2.8. Symptoms of AD	23
2.8.1. Cognitive changes	24
2.8.2. Non-cognitive symptoms	24
2.8.3. Behavioural problems	25
2.9. Neuropsychology of AD	26
2.10. Summary	27
Chapter 3: Literature review	**29**
3.1. Introduction	29
3.2 Theory Question 1: Is there a difference between the number of life events between patients and controls, using LEDS to measure?	29
3.2.1. How are life events thought to be a risk factor for AD?	35
3.3. Theory Question 2: Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and in the range of emotions expressed when discussing life events between the patients and controls?	41
3.3.1. Pennebaker's *Linguistic Inquiry and Word Count*	42
3.3.2. Garrard's Lexical and Syntactical Analysis	45
3.3.3. Kemper et al. (2001) and the Nun Study	48
3.3.4. Danner et al. (2001) and *Emotion Word Coding*	51
3.4. Theory question 3: Are there any differences in the narrative constructions of life events, as interpreted by the Biographic Narrative Interpretive Method between the patient and control groups?	56
3.4.1. Foucault's approach	56
3.4.2. Narrative analysis	59
3.4.3. BNIM	61
3.5 Conclusion	63
Chapter 4: Methodological and ethical issues	**64**
4.1. Introduction	64
4.2. Phase 1: The researcher as a multicultural subject	64
4.2.1. Respect for autonomy and nonmaleficence	66
4.2.2. Beneficence	69

4.2.3. Justice	69
4.3. Phase 2: The theoretical paradigms and perspectives	71
4.4. Phase 3: Research strategies	71
4.5. Phase 4: The methods of collection and analysis	72
4.6. Phase 5: The art, practices, and politics of interpretation and evaluation	73
4.6.1. Validity	74
4.6.2. Reliability	76
4.6.3. Credibility and trustworthiness	78
4.7. Conclusion	81
Chapter 5: Methods	**82**
5.1. Introduction	82
5.2. LEDS interviews and sample selection	82
5.3. The interview	84
5.3.1. Interview content	84
5.3.1.1. LEDS interviews	84
5.3.1.2. BNIM interviews	87
5.4. Points encountered in the LEDS and BNIM interviews	88
5.5 Method of LEDS analysis	89
5.6. Method of narrative analysis	91
5.6.1. Are the codes generated by an American team, for use on American text, suitable for use with a non-American text?	91
5.6.2. Sample selection for narrative analysis	102
5.6.3. Narrative analysis using computer program	103
5.7. Quantification of data	113
5.8. Saturation	113
5.9. BNIM interview for TQ3	113
5.10. Conclusion	117
Chapter 6: Results	**118**
6.1. Introduction	118
6.2. TQ1: Is there a difference between the number of life events between patients and controls, using LEDS as a measurement tool?	122
6.2.1. Potential dilemmas encountered in the interviews	122
6.2.2. Confidentiality	123
6.2.3. Missing data	124
6.2.4. The family tree	125
6.2.5. Emotional vulnerability of the interviewee	125
6.2.6. Results of the LEDS interview analysis	126
6.2.7. Similarities between the patient and control groups who had LEDS interviews	127
6.2.8. Camcog and IQ	127
6.2.9. Comprehension and expression	129
6.2.10. The differences in the neuropsychological scores of the LEDS interview patient group and control group (Table 6.2)	130
6.2.11. Other scores indicative of the diagnosis of AD in the patient group	133
6.2.12. Life events and difficulties in the patient group and control group	135
6.2.13. Research questions about life vents and difficulties data	135
6.2.14. Conclusion of results for LEDS interviews analyses	140
6.3. TQ 2: Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and the range of emotions expressed when discussing life events?	140
6.3.2. Description of demographic data on EWC analysis (n=24)	141

6.3.3. TQ2(a): Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups?	144
6.3.4. TQ2(b): Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's emotional coding?	145
6.3.5. Differences between LEDS events categories in the EWC	147
6.4. TQ3: Are there any differences in the constructions of life events in providing narratives of life events, between the patient and control groups as interpreted by BNIM?	151
6.4.1. Biographic Data Chronology	153
6.4.1. Told Story	157
6.4.2. BNIM microanalysis of passages form the transcripts	165
6.4.2.1. Mr HF case history	169
6.4.2.2. Mrs HN case history	174
6.5. Conclusion	180
Chapter 7: Analysis and discussion	**181**
7.1. Introduction	181
7.2. TQ1: Is there a difference between the number of life events between patients and controls, using LEDS as a measurement tool?	181
7.2.1. TQ1(d): Is there any difference in the number of bereavements under the age of 51 years old that have occurred? (p=0.032)	182
7.2.2. TQ1(a): Is there any difference in the number of life events between groups? (p=0.039)	184
7.3. TQ2. Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and the range of emotions expressed when discussing life events?	185
7.3.1. TQ2(a): Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups?	186
7.3.2. TQ2(b): Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's emotional coding?	186
7.3.3. Health LEDS category	192
7.3.4. Work LEDS category	192
7.3.5. Bereavement LEDS category	193
7.4. TQ3: Are there any differences in the constructions of life events in providing narratives of life events, between the patient and control groups as interpreted by BNIM?	197
7.4.1. TQ0: How did the interview process go, and what implications has this for the different subsequent TQs relating to my CRQ?	197
7.4.2. Structure of BNIM interviews	200
7.4.3. Content of BNIM interviews	204
7.5. TQ4: Can the differences, between the patient and control groups, in the narratives be developed into a diagnostic marker?	212
7.5.1. TQ4(a): In which topic of discussion is the most obvious difference noted?	212
7.5.2. TQ4(b): What questions will need to be included in a questionnaire that would elucidate narrative that can be analysed?	213
7.6. TQ5: Can the diagnostic tool be applied to text collected from patients and controls over a period of decades?	215
Chapter 8: Conclusion	**217**
8.1. CRQ: Are life events a risk factor for AD?	225
8.2. The ADLE study objectives	226
References	**230**

Appendix I – LEDS questionnaire and LEDS coding of events and difficulties	246
Appendix II – LEDS patient invitation letter, information sheet and consent form	256
Appendix III – Example of life events and difficulties of patient number 9	259
Appendix IV – EWC from Danner et al.	260
Appendix V – BNIM questionnaire	264
Appendix VI – BNIM patient invitation letter, information sheet and consent form	265
Appendix VII – Mr HF transcript of BNIM interview, TSS chunks, thematic field analysis	269
Appendix VIII – Mrs HN transcript of BNIM interview, TSS chunks, thematic field analysis	287

List of figures, tables and text boxes	Page no.
Table 1.1. Wengraf's CRQ-TQ model (2001)	4
Table 1.2 CRQ, TQs and subsidiary TQs for ADLE study	5
Figure 1.3 Based on Brown and Harris' model of life events (1978)	11
Table 2.1 Subcategories of *Camcog*	27
Figure 3.1 Glucocorticoid cascade hypothesis (Adapted from VD Deshmukh and SV Deshmukh, 1990).	38
Figure 3.2 Diagram of Latour's black box.	58
Text box 5.1. Example of a catastrophic reaction	86
Table 5.2 Patient number 10 – life events data	90
Text box 5.3 – negative emotion words	93
Text box 5.4 – neutral emotion words	94
Text box 5.5 – positive emotion words	95
Text box 5.6. Additions to Danner et al. (2000)	96
Text box 5.7. Example of coding of 'no emotion, facts only'.	97
Text box 5.8. Example of coding of 'stoicism'	98
Text box 5.9. Example of coding of 'ambivalence'.	99
Text box 5.10. Example of coding of 'resentment'.	101
Stage 1 of LEDS coding	105
Stage 2 of LEDS coding	106
Stage 1 of EWC process	107
Stage 2 of EWC	108
Stage 3 of both coding processes	109
Table 5.11 for examples of LEDS and non-LEDS events	111
Table 5.12 for examples of LEDS and non-LEDS events.	112
Text box 5.13 Wengraf's DARNE codes	115
Text box 5.14 Transcript section	116
Text box 5.15 TSS of transcript above	117
Text Box 6.1 CRQ and TQs	119
Table 6.2: Descriptive data of neuropsychological data of patient and control groups.	131
Table 6.3. Significant differences in demographic and neuropsychological data between patients and controls	132
Table 6.4. Table showing p values for research questions	139
Table 6.5. Profile of patient and control matches in the ADLE study analysis	142
Table 6.6. Significant differences in demographic and neuropsychological data between the patients and controls	143
Table 6.7. Significant differences in life events and difficulties data	143
Table 6.8. Significance between the total number of life events (LEDS and non-LEDS) and difficulties between patients and controls	144
Table 6.9 Significance between the total number of LEDS life events and difficulties only, non-LEDS events excluded	145
Table 6.10 Difference between the range of emotions expressed by patients and controls.	146
Table 6.11 Differences between the patients and controls emotional expressions about LEDS categories	148
Table 6.12. Differences between the two in-depth BNIM interviews	153
Text box 6.13. Brief background of Mrs HN	155
Text box 6.14. Brief background of Mr HF	156
Text Box 6.15. Structural hypotheses for Mr HF	159
Text 6.16. Testing of Structural Hypotheses with TSS chunks	160
Text box 6.17 Structural hypotheses for Mrs HN	160
Text Box 6.18 Testing of Structural Hypotheses with TSS chunks	161

Text box 6.19 Order of topics discussed in the transcript and number of lines.	162
Text box 6.20. Order of topics discussed in the transcript and number of lines.	163
Text box 6.21 Microanalysis of Sub-session 1 of Mr HF.	165
Text box 6.22 Microanalysis of Subsession 1 of Mrs HN.	173
Table 7.3 Number of bereavements in patient and control groups	183
Text Box 7.4. A control discussing his father's and mother's deaths	187
Text Box 7.5 A patient discussing his father's death, when he was a teenager.	188
Table 7.6 Difference between the range of emotions expressed by patients and controls in LEDS and non-LEDS events.	190
Text Box 7.7 Factors that would be taken into account during the process of diagnosing memory problems.	196
Text box 7.8. P1 opening narrative	201
Text box 7.9 C1 opening narrative	201
Text box 7.10. C2 opening narrative	202
Text box 7.11. P2 opening narrative	203
Text box 7.12 Differences between patients and controls BNIM interviews	211
Text box 7.13. Diagnostic tool	214
Table 8.1 CRQ and TQs	217

List of abbreviations

A-CRQ	Answer to central research question
AD	Alzheimer's disease
ADLE	Alzheimer's Disease and Life Events
AS	Alzheimer's Society
BDA	Biographic data analysis
BDC	Biographic data chronology
BNIM	Biographic Narrative Interpretive Method
CRQ	Central research question
DASNI	Dementia Advocacy and Support Network International
EWC	Emotion word coding
FAD	Familial Alzheimer's disease
GCH	Glucocorticoid cascade hypothesis
GSRQ	Geriatric Social Readjustment Questionnaire
GTT	Glucose-tolerance test
HPA axis	Hypothalamic-Pituitary-Adrenal axis
LEDS	Life Events and Difficulties Schedule
LIWC	Linguistic Inquiry and Word Count
LOAD	Late-onset Alzheimer's disease
MCA	Mental Capacity Act
MMSE	Mini-Mental State Examination
MTL	Medial temporal lobes
NART	National Adult Reading Test
NFT	Neurofibrillary tangles
NSF	*National Service Framework*
OPTIMA	Oxford Project To Investigate Memory and Ageing
PIN	Particular Incident Narrative
PTSD	Post-Traumatic Stress Disorder
PWiD	People with dementia
SH	Structural hypotheses
SQUIN	Single Question aimed at Inducing Narrative
SRE	Schedule of Recent Events
TFA	Thematic field analysis
TQ	Theory question
TSS	Text structure sequentialisation

Chapter 1: Introduction

1.1 Life events and Alzheimer's disease

The relationship between events that happen in our lives (life events) and illness has stimulated a profusion of research studies using a variety of methodologies over the last 40 years (for example see Brown and Harris, 1978; Rahe, 1978; Paykel, 1987), but no research has addressed the relation between the narratives of life events and Alzheimer's disease (AD). This study, the Alzheimer's Disease and Life Events (ADLE) study, attempts to address the gap in this body of knowledge.

The decision to study the association between life events and AD grew from the ideas and observations of participants with memory problems and those without memory problems, and of relatives and team members in the *Oxford Project To Investigate Memory and Ageing* (OPTIMA) study: there was a gap in the knowledge about the effect of life events on the development of AD.

OPTIMA is a longitudinal, case-control research programme that assesses people with memory problems. Participants with a diagnosis of Possible or Probable AD will be known as patients in this thesis; participants with no cognitive problems, and no diagnosis of Possible or Probable AD, will be known as controls in this thesis. For convenience, in the ADLE study, as well as having patients and controls, those who help the patients live their lives as independently as possible are usually spouses, relatives or close friends, and are referred to in the context of the ADLE study as 'carers'.

Patients and controls have parallel investigations, which include neuropsychological, neuroradiological and physical assessments (these assessments will be described in detail in *Chapter 2: Background Information*).

In the OPTIMA programme patients and relatives have retrospectively associated decline in memory and mental function with traumatic events in the patients' lives, which led them to ask: '*Is there a relationship between life events and AD?*'. As the patients and relatives recounted their stories, the OPTIMA research team began to recognise patterns that seemed to confirm the 'theory' of the patients and relatives. However, these patterns needed to be formally evaluated within the context of OPTIMA, where the OPTIMA clinical team have, due to the long-term, longitudinal nature of the research, an established relationship with participants. This regular contact and relationship develops over the years, in some cases up to 20 years of research, continuing until the participant's death, and with the family during the post-mortem with the subsequent provision of feedback of the neuropathological findings.

In line with current approaches of user involvement, incorporated in research governance procedures, the patients' and relatives' questions and perspectives should be central to the philosophical approach chosen for the design and interpretation of the findings (Department of Health, 2005). The patients' and relatives' have also contributed the central research question (CRQ). The theory questions (TQ) for the ADLE study have been derived from previous life events research (Brown and Harris, 1978; Jorm et al., 1991). The CRQ and TQs aim to fill a specific gap in the present knowledge about life events and AD.

This ADLE study aimed to explore associations between life events, as social factors, and AD. It examined how experiencing such life events might be a predictor for AD, and how any associations might subsequently inform an appropriate methodology for the early identification of the symptoms of AD, as an aid to diagnosis. This study aims to provide an evaluation of the associations between life events and AD through the mixed-methods approach. It is intended that this will inform, methodologically, further studies exploring the relationships between life events and AD. This study, since the original submission, has been refined using Wengraf's (2001) model described below in Table 1.1.

1.1.1 Aim and objectives of the ADLE study

As noted above, the aim of the study is to answer the CRQ. The objectives of this study were guided by the patients, carers and members of the OPTIMA team, previous life events research (Brown and Harris, 1978; Jorm et al., 1991) and narrative research (Danner et al., 2000, 2001; Wengraf, 2001, 2008; Plummer, 2001). The objectives are:

- To explore the narrative accounts of patients and controls, in relation to AD and life events, and address a gap in the body of knowledge
- To develop the methodology of life events research through the interpretation of narratives given by patients and controls using a mixed-methods approach, viz. *Life Events and Difficulties Schedule* (LEDS) (Brown and Harris, 1978), Danner's emotional word coding (EWC) and the Biographic Narrative Interpretive Method (BNIM)
- To determine whether there is a relationship between the LEDS interview scores and neuropsychological data
- To develop supportive practice in the field of dementia care
- To provide current, relevant and new information for healthcare professionals, patients and relatives about the association between life events and AD
- To build a diagnostic tool that would aid the process of an early diagnosis of AD

1.1.2 CRQ, Theory Questions and Hypothesis

The CRQ was specified by the patients, relatives and the OPTIMA research team to address the gap in the knowledge of the relation between the narratives of life events and AD. The biological mechanism by which it is thought that life events are associated with AD is the glucocorticoid cascade hypothesis (GCH) (Deshmukh and Deshmukh, 1990), whereby a life event is seen as a stressor that activates the hypothalamic-pituitary-adrenal (HPA) axis, this results in the excretion of cortisols which can damage the hippocampal neurones (where our memories are stored) when over-activated. This is explained in greater detail in *Chapter 3: Literature review.*

The CRQ has been broken down into further research questions, known as 'theory questions' (TQs), based on the model of Wengraf (2001), as shown in *Table 1.1.*

Table 1.1. Wengraf's CRQ-TQ model (2001)

Research questions	Interview processes for the two interviews	Interview A	Interview B	Research literature	Answers to each theory question
Central research question (CRQ)					
Theory question (TQ) 1	Interview processes				Answer to TQ 1 (A-TQ 1)
TQ 2					A-TQ 2
TQ 3					A-TQ 3
TQ Z					A-TQ Z
Review and summation of questions and material					
					A-CRQ

This model enables the CRQ to be subdivided into other questions, the answers to which build up a body of evidence, which either supports or refutes the hypothesis, and answers the CRQ. The theory questions incorporate planned questions and emergent questions. TQ1 and TQ2 are broken down further into more specific 'subsidiary theory' questions. The use of this model will be discussed in more depth in *Chapter 4: Methodology and Ethical Issues.*

The hypothesis is:

Life events are a risk factor for AD.

The theory questions, originating from the CRQ, are shown together with the additional information needed to answer them in Table 1.2:

Table 1.2 CRQ, TQs and subsidiary TQs for ADLE study

Research questions	Interviews - patients	Interviews - controls	Research literature
CRQ: Are life events a risk for AD?			
1. Is there a difference between the number of life events between patients and controls, using LEDS as a measurement tool? (a) Is there any difference in the number of life events, which have occurred between patient and control groups? (b) Is there any difference in the number of life events, which have occurred below the age of 51 years old, between the patient and control groups? (c) Is there any difference in the number of bereavements, which have occurred between the patient and control groups? (d) Is there any difference in the number of bereavements, which have occurred under the age of 51 years old, between the patient and control groups? (e) Is there any difference in the number of difficulties between the patient and control groups (f) Is there any difference in the number of difficulties, which have occurred below the age of 51 years old, between the patient and control groups	20 LEDS interview	20 LEDS interview	- Life events literature and AD - Glucocorticoid cascade hypothesis (GCH) and Hypothalamic-Pituitary-Adrenal axis (HPA axis) - Post-Traumatic Stress Disorder (PTSD)

(g) Is there any difference in the total length of difficulties, which have occurred between the patient and control groups? (h) Is there any difference in the total length of difficulties, which have occurred under the age of 51 years old between the patient and control groups I? (i) Is there any difference in the number of major difficulties, which have occurred, between the patient and control groups? (j) Is there any difference in the number of major difficulties, which have occurred below the age of 51 years, between the patient and control groups? (k) Is there any difference in the total length of major difficulties, which have occurred between the patient and control groups? (l) Is there any difference in the total length of major difficulties, which have occurred under the age of 51 years old between the patient and control groups?			
2. Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and in the range of emotions expressed when discussing life events between	12 LEDS interview transcripts and EWC	12 LEDS interviews transcripts and EWC	• EWC • Emotional processing

the patients and controls? a) Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups? b) Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's EWC?			
3. Are there any differences in the narrative constructions of life events, as interpreted by the Biographic Narrative Interpretive Method between the patient and control groups?	3 BNIM interviews: 1 in-depth, 2 less in-depth, thematic field analysis	3 BNIM interviews: 1 in-depth, 2 less in-depth, thematic field analysis	- Emotional processing
4. Can the differences, between the patient and control groups, in the narratives be developed into a diagnostic marker? • In which topic of discussion is the most obvious difference noted? • What questions will need to be included to trial a questionnaire that would elucidate narrative than can be analysed? E.g. Does pt moan/complain more/less, are feelings expressed more/less, • Is a lack of emotional expression a risk factor for those for whom it is the norm, as well as a marker of change?			

5. Can the EWC be used as a diagnostic marker by being applied to text collected from patients and controls over a period of decades?			

The study and the research questions have evolved through the use of the mixed methods approach, using the LEDS (Brown and Harris, 1978) and the Biographic Narrative Interpretive Method (Wengraf, 2001, 2008). The LEDS is a semi-structured questionnaire, which showed significant quantitative differences in the number and nature of life events between participants with AD and participants with no cognitive problems. Here, as part of the administration of LEDS, differences were noted in the way the patients and controls spoke about and recounted the narratives of their life events. Such differences were analysed using Danner's emotional coding scheme. This analysis showed significant differences, between patients and controls, in the use of emotional descriptions of life events. To explore further the antecedents and emotional underpinnings of such narratives (BNIM; Wengraf, 2008) was used to structure interviews with a new set of both patients and controls. The mixed methods approach, epistemologically, will be described more fully in *Chapter 4: Methodology and Ethical Issues* and *Chapter 5: Methods.*

1.2. Life events models

When a disease such as Alzheimer's develops, there are several factors that might be considered to have interacted in its development, which can lead to many approaches to its treatment and research into AD. Since social and cultural factors affect our health from conception until death (Freund and McGuire, 1991), such factors provide the opportunity of seeing how the individual's social or emotional life might affect physical health (Freund and McGuire, 1991).

One social factor that can affect a person's life is a 'life event'. Life events can be defined in many ways. The definition of a life event will be discussed briefly, and the relationship between life events and illness will be portrayed using different explanatory models.

1.2.1. Definition of a life event

A life event is a social factor that has an influence on our health and lives: this influence could be a positive effect as well as a negative influence. Definitions of the concept of a life event will be discussed in *Chapter 3: Literature Review*, though most authors agree that a life event would include both positive and negative events, for example death, marriage, divorce, childbirth, redundancy, accidents and severe illness (Brown and Harris, 1978; Creed, 1985, 1993; Holmes and Rahe, 1967; Jorm et al., 1991).

1.2.2. The relationship between life events and illness

Orrell and Davies (1994) discuss three different models of how life events are seen to contribute to illness:

- Life events can be seen as stressors.

- Life events can be seen as markers of developmental transitions, and can be 'normative' for that developmental stage of life, or 'non-normative', leading to increased stress and psychological distress.

- Life events have also been seen as disrupting the roles by which people define their worth and self-esteem. If people lack an alternative reinforcement of their worth and self-esteem, life events can interfere with their view of themselves and cause increased stress and psychological distress.

Creed (1993) also describes how life events are viewed within social psychiatry.

> *Life events are seen as stressors that require adaptation, make demands on resources and that cause or trigger psychological distress and the onset or relapse of psychiatric symptoms and illness.*

The epidemiological study by Brown and Harris (1978) (as described in *Chapter 3: Literature Review*) supports this model.

The ADLE study will use the first model, as described by Orrell and Davies (1994) and Creed (1993), and supported by Brown and Harris (1978); life events are seen as stressors.

1.2.3. Model of life events and illnesses

As the ADLE study utilised the LEDS, a concise portrayal of the LEDS model of life events and illness is presented here, and how Brown and Harris' (1978) study also linked life events to depression. This model of life events and illness was taken into account when the CRQ and TQs were refined, although as will be discussed in *Chapter 4: Methodology and Ethical Issues*, the Brown and Harris model has evolved over time and has been simplified.

Brown and Harris (1978), using LEDS, concluded that life events will lead to depression in women only if there are factors present that make them vulnerable. They found that the women developed depression when they had any of the following 'vulnerability factors' in their lives:

- Loss, before the age of 11 years old, of their mother
- Three children at home under the age of 14 years old
- Lack of employment outside the home.

These factors were determined from interviews with 458 randomly selected women in Camberwell, and Brown and Harris replicated the research with 154 women in North Uist (Outer Hebrides).

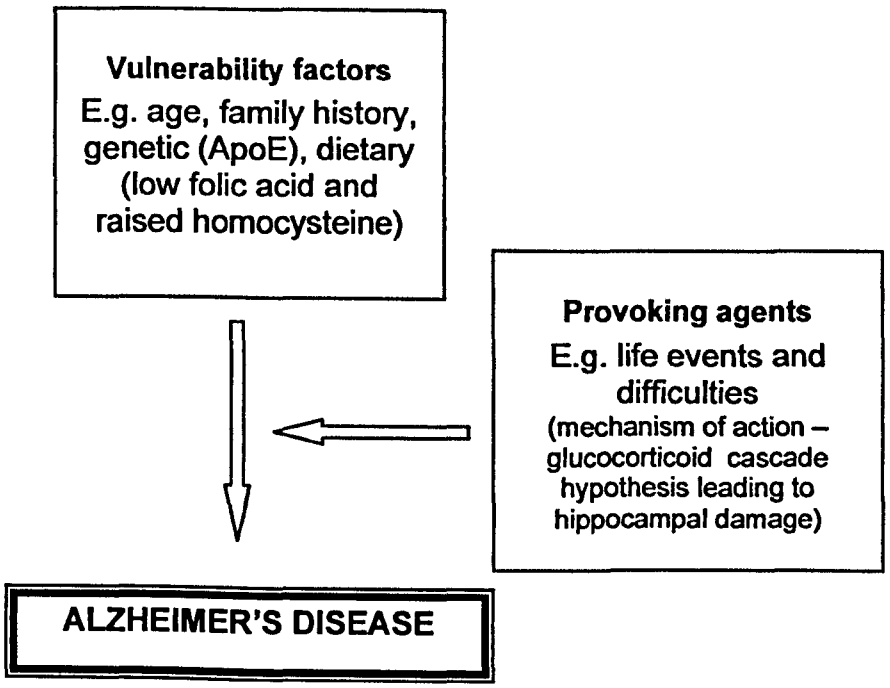
Other studies have shown associations with illness and life events in 'physiologically vulnerable people': for example, the first episode of Multiple Sclerosis can be brought forward in a person's life by stressful life events (Grant et al., 1989). Studies showing a connection between life events and AD will be reviewed in *Chapter 3: Literature Review.*

Figure 1.3 uses Brown and Harris' model to show the complex interaction of factors that are known to affect the development of AD, and how life events are thought to be stressors that contribute to AD. How the other vulnerability factors interact, for example dietary factors or genetic factors, is not yet fully understood within this field of research.

Figure 1.3 Based on Brown and Harris' model of life events (1978):

Vulnerability factor: a factor that causes a subject to become vulnerable to developing a disease in the presence of a provoking agent

Provoking agent: a factor capable of producing a disorder



Many studies in the field of AD research are based on quantitative research, and are based on the positivist methodology. These studies have led to genetic, biochemical and neuropathological advances in the diagnosis and understanding of AD. The ADLE study uses a mixed methods approach to gather quantitative and qualitative data that is complementary to each method and presents different aspects of the same problem.

1.3. The definition and prevalence of AD

AD is a type of dementia that has many factors involved in its development, some known and many as yet unknown, and is a disease that has far-reaching effects on the individual and society. There are many causes of dementia, some of which are reversible: AD is the most common form of dementia and is not reversible (Jorm, 2002).

Dementia is defined by the International Classification of Diseases (WHO, 1986) as:

> *a syndrome caused by disease of the brain, usually progressive in nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The cognitive impairments are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation. This syndrome occurs in AD, in cerebrovascular disease and in other conditions primarily or secondarily affecting the brain.*

How AD affects the part of the brain that deals with memory, in particular the effect of life events on the hippocampus, is discussed in *Chapter 2: Background Information.*

The United Kingdom prevalence rates for AD (Alzheimer's Society, 2009) are:

Age (years)	Prevalence
40 - 64	1 in 1400
65 - 69	1 in 100
70 - 79	1 in 25
80+	1 in 6

Although the United Nations (UN) reports the growth of systems of social and health care, in developed countries, it also notes major shortcomings and unmet needs leading to strains on such support systems. In developed countries, the older population is growing much more rapidly than that of younger adults (United Nations, 2002). The Alzheimer's Society believes that, in the UK, a sustainable state system for care, allowing for the increase in the number of those who have dementia, can be developed (Alzheimer's Society, 2009). In developing countries, the problems are not yet as apparent, but it is estimated that they will also reach the same levels, mirroring the more developed countries.

The Alzheimer's Society web site (http://www.alzheimers.org.uk) notes the extent of the problem. At present, there are 18 million people worldwide with dementia, with the number in the UK approaching 700,000, approximately 55% of whom have AD. Although dementia primarily affects people over 65 years of age, there are approximately 18,000 people under 65 years old in the UK with dementia. The proportion (62%) of those with AD could be considered a conservative estimate, because of the difficulty of diagnosing AD, and of differentiating it from other dementias and memory problems. By the year 2025, the number of people with dementia in the UK will be approximately 940,000. By 2025, it is expected that there will be 34 million people in the world with dementia.

Many research projects aim to extend our knowledge of this devastating disease, in an attempt to reduce the risk of developing the dementia or to treat the symptoms. Before finding out how a disease can be treated, it is necessary to understand the epidemiology and the pathology of the disease. One method of contributing to this knowledge is by looking at associations: if an association is found between a particular factor and the disease, then this can indicate an area that needs researching in more detail. Associations can lead researchers to a better understanding of the pathological process and how it is manifested as signs or symptoms in individuals. A better understanding of the pathological process of a disease enables treatments to be developed, and an earlier, and more accurate, diagnosis to be reached. The methodology of the research examining AD needs to be developed concurrently with the advances in improved understanding of AD, to ensure the validity and reliability of the research.

1.4. Structure of the thesis

This chapter, *Chapter 1: Introduction*, has provided a brief overview of life events, AD, and the research objectives and questions of the ADLE study.

Chapter 2: Background Information will provide detail on the pathology and diagnosis of AD, the demography of the ageing population, the implications of AD for the individual and their family, and the context of OPTIMA.

Chapter 3: Literature Review will include a critical review of the literature about studies linking life events and AD, why life events are thought to be a risk factor for AD, and the reasons for choosing the LEDS, EWC and the BNIM.

Chapter 4: Methodology and ethical issues will discuss the rationale behind the choice of design and method for the ADLE study. The methodology of the ADLE will be examined using Denzin and Lincoln's (2005) five research processes, and the ethical issues will be examined with Beauchamp and Childress' four ethical principles of autonomy, nonmaleficience, beneficence and justice. This will be done with reference to research on vulnerable adults.

Chapter 5: Methods will discuss the methods used when designing the ADLE study, and the consequences of such choices. The LEDS and BNIM interviews will be discussed, and the rating and coding of the LEDS interview data, in preparation for analysis. The Danner et al.'s Emotional Word Coding (2000) is explained and aspects of the additional coding demonstrated.

Chapter 6: Results will describe the results of:

- The LEDS interview analyses
- The Emotion Word Coding and
- The BNIM interview analysis

The data is analysed and the results described in relation to the Central Research Question, the Theory Questions, and the subsidiary theory questions.

Chapter 7: Analysis and Discussion will include the results of the theory questions in relation to the literature and the ability to process emotions. The findings of the theory questions will be used to construct a diagnostic tool for use in Memory Clinics and the current research project Cognitive Archaeology (Garrard, Haigh and de Jager, 2009). The aim of the Cognitive Archaeology study is to find a pre-symptomatic diagnosis for AD in linguistic changes.

Chapter 8: Conclusion will consider the findings from the ADLE study and whether they have answered the theory questions and ultimately the CRQ. How the results of the ADLE study can be applied in current practice, as a diagnostic tool for early AD, and providing patients, carers and health professionals with information about the association between life events and AD, will also be explored.

1.5 Conclusion

In summary, the ADLE study aims to contribute new knowledge to the field of life events research and AD. This new knowledge has been captured through the use of the mixed methods approach and has been used to construct a new tool to aid the diagnostic process. The diagnostic tool will be employed in the Cognitive Archaeology study by Garrard, Haigh and de Jager (2009), with participants that have normal cognition, Possible or Probable AD and other dementias. The recent National Dementia Strategy advocates early diagnosis of the disease, and Professor Clive Ballard, of the Alzheimer's Society, states they '*look forward to further research into potential linguistic markers for dementia*'.

Chapter 2: Background information

2.1. Introduction

This chapter will include a description of the context of the ADLE study and OPTIMA, and the background information to the ADLE study such as the demography of the ageing population and the definition of dementia. The implications of AD on the individual, and their family are reviewed. The hypothesis linking life events and AD is explained, through the glucocorticoid cascade hypothesis and the HPA axis, and that the therapeutic vimplications of this process should be researched. The neuropsychological examination of the Camcog is explained, in order to understand the relationship between these scores and the diagnosis of AD in the analyses of the ADLE study.

2.2. Alzheimer's Disease Life Events study and the Oxford Project To Investigate Memory And Ageing

It is within the context of the OPTIMA research that the ADLE study originated from the thoughts and observations of, and was initiated by, participants and their families in discussion with the OPTIMA team. An understanding of OPTIMA is needed to help set the context of the research questions for the ADLE study, as well as to understand the information available to be studied.

2.3. Background to OPTIMA

OPTIMA is a longitudinal project, which began in 1988, to develop a research protocol to pursue accurate ante-mortem diagnosis and post-mortem validation, and to study the natural course of dementia and normal ageing. It is the world's largest longitudinal, prospective, pathologically verified cohort with, and without, dementia, which includes detailed sequential neuropsychological, biochemical, genetic, neuroradiological, neuropathological and biographical data. At the time of writing, OPTIMA has over 1000

participants, of whom 437 have died, with a 85% post-mortem rate. This creates a wealth of data about a particular cohort that can supplement the information gained from the ADLE study, and provides the basis of the practising philosophy, which underpins the ADLE. The rigour of the ADLE study would be compromised without this supplemental information, which is essential for the inclusion criteria, based on an accurate diagnosis.

2.4. The context of the ADLE study and research design of OPTIMA

The OPTIMA protocol was designed not only to facilitate the collection and analysis of data, but to ensure that participants are supported by the clinical research team (Smith et al., 1998).

The scientific basis of OPTIMA is the neurological paradigm where post-positivist theories and hypotheses are tested, and there is a quest for objectivity and distance to avoid personal bias (Benton and Craib, 2001). Underlying this practice within OPTIMA is an approach that is based on the idea that an interaction between a health professional and a participant can be therapeutic, even when the main aim is to collect data for research. When Kitwood's theories on dementia and malignant social psychology were published (Kitwood and Bredin, 1992), the team recognised that his theory underpinned OPTIMA's clinical practice, in conjunction with the neurological model being used for the research process. This approach of incorporating a therapeutic process whilst collecting data, and the combination of the scientific and social-psychological paradigms guided the inception of the ADLE study, and the planning of the research.

OPTIMA collects data about both paradigms to ensure that both the neurological and social-psychological paradigms are taken into consideration, with the person at the centre of the care and research process.

2.5. Demography of the ageing population

The world population is increasing, and the proportion of older people in developed countries is also growing (United Nations, 2002). The demography of the population in the UK is following this pattern National Statistics Online 2009. The over-65 age group is growing at a faster rate than the rest of the population, and this is set to continue. Over the last decade, women of childbearing age have been having smaller families, so the trend continuing until 2003, when the birth rate began to increase again (National Statistics Online, 2009). Advances in medical care have increased the average lifespan, and these advances are keeping those who are chronically sick or disabled alive for longer.

The impact of this increase in the ageing population can be seen in several trends, increasing demands on the medical, nursing and social care systems. These demands are concerned not only with the amount of available human resources, but also with financial pressures. The population able to financially support the increasing number of older people is decreasing, as shown by data collated by the National Census 2001 and analysed by the Office of National Statistics (2009).

The present government is planning for this demographic change within the following reports, initiatives and guidelines: *National Service Framework* (NSF) (Department of Health, 2001); *Everybody's Business – Integrated mental health services for older adults: a service development guide* (CSIP, 2005), *Dementia: Supporting people with dementia and their carers in health and social care* (NICE/SCIE, 2006), *Dementia UK: The full report*, (AS, 2007); *Improving services and support for people with dementia* (NAO, 2007); *High Quality Care For All – NHS Next Stage Review Final Report* (DoH, 2008); *Living well with dementia: A National Dementia Strategy* (DH/SCLG&CP/SCPI/SR, 2009).

The NSF aims to treat the older person as an individual, and is founded on knowledge-based practice and partnership between all agencies, organisations and individuals working with the older person (DoH, 2001). The care for people over the age of 65 years

with dementia will be planned within the NSF for Older People (DoH, 2001), to enable the estimated number of 750,000 older people with dementia to have care that is individual and co-ordinated for each person and his or her family and carers. People under the age of 65 years who have dementia will have their care planned within the NSF for Mental Health (DoH, 1999). The more recent reports have stated that care services should be integrated and based on an assessment of needs (DH/SCLG&CP/SCPI/SR, 2009); the profusion of reports over recent years indicate a greater level of political awareness of the problem of dementia, and the lack of appropriate and inadequate care in many areas.

2.6. Pathology and diagnosis of AD

AD is the most common of all the irreversible dementias. At post-mortem, neuropathological findings in brain tissue include the presence of numerous senile plaques, many neurofibrillary tangles, some Hirano bodies in the hippocampus, and reduced weight and volume of the brain (Esiri and Nagy, 2002). These findings all reflect neuronal cell death due a to a physical disease process in the brain tissue, which has many consequences for the individual; these will be discussed later in this chapter. Each person who develops this disease can have a slightly different presentation and progression of the disease, perhaps because of the many genotypes of AD, and their interaction with environmental factors. The signs and symptoms of AD represent what is happening in the individual's disease process. The disease is thought to begin in the medial temporal lobes (MTL) of the brain (Smith, 2002). The structures that comprise the MTLs include the hippocampus (containing the neurones responsible for our memory), subiculum, parahippocampal gyrus and amygdala (Smith and Jobst, 1996). These are all part of the limbic system. The limbic system is concerned with our learning, memory and emotion (Selkoe, 1993): thus, our memories and emotions are intrinsically linked. Shrinkage of these areas is found on CT scans and MRI scans (Smith and Jobst, 1996), as well as on neuropathological examination after death (Nagy et al., 1995).

Diagnosis of AD, in life, is made using either the DSMIV-TR (2000) criteria or the NINCDS-ADRDA (McKhann et al., 1984) criteria. These criteria are based on recognised clinical findings, which indicate an underlying pathology of AD, and are defined by an increasing probability of the symptoms being caused by the underlying pathology being AD: Possible AD means that the clinical findings mean there is a possibility that the symptoms will be caused by AD pathology and an additional pathology (or pathologies) present, which will be found in the brain at post-mortem; Probable AD means that the clinical findings indicate there is a much higher probability that the person's symptoms will be caused by an underlying AD pathology; a Definite AD diagnosis relies on clinical findings with neuropathological findings. Neuropathological changes are only found after a person has a brain biopsy (almost never performed in the UK), or after neuropathological examination at post-mortem. Therefore, there is no definitive diagnosis of AD in life at present; the one used is based on the possibility or probability of AD pathology causing the symptoms. An early and accurate diagnosis of this disease is needed in order to initiate early treatment of the disease, before extensive damage is done to the brain; and, for research, to enable studies to include those for whom AD trials of treatment are appropriate.

The NINCDS-ADRDA criteria for AD (McKhann, 1984) are:

Probable AD may be indicated by:

A. Clinically documented dementia
B. Progressive worsening of memory and other cognitive functions
C. Deficits in two or more cognitive areas
D. Onset between 40 and 90
E. Absence of systemic or brain disorders that could account for deficits

Probable AD is supported by:

A. Progressive deficits in language (aphasia), motor skills (apraxia), and perception (agnosia)

B. Impaired ability to function in everyday activities

C. Family history of similar disorder

D. Consistent laboratory results, such as CT scan showing cerebral atrophy

Possible AD includes the possibility of there being other pathology present as well as the pathology that causes AD.

There is a constant search for various types of biomarkers that will identify the start of AD pathology in order to be able to treat the disease. This study aims to formulate a biomarker that is acceptable and easy to administer, and contributes towards the accuracy of the diagnostic process. This is based on the significant differences, between patients and controls, in the use of emotional words in the descriptions of life events.

2.7. The implications of AD for the individual and his or her family

Dementia has a terrible and uncompromising effect on the person experiencing it, on the family, and on local and national resources.

AD is a disease that robs people of their memory. This loss begins insidiously: being unable to remember recent events, names of close friends and family, losing objects, forgetting appointments and the like. It progresses at varying rates in individuals, affecting them in slightly different ways, depending on their own strengths and weaknesses. How it affects the individual has been described by Diana Friel Mcgowin (1994) as 'living in the labyrinth', with all the accompanying twists and turns. Friel Mcgowin, who wrote this book after being diagnosed with AD, states that life becomes a maze and a challenge at every level, with the potential for losing the ability to do something at any moment. Control over that of which one previously had mastery comes into question.

To understand the chaos that AD can create among our brain cells, we have to understand what our memories mean to us. Memories connect us, as an individual, to our

environment. Our environment consists of other people and where we spend our time. It is not just the present, but also the past. The past brings with it happy memories and the remnants of past emotional traumas, some of which we have dealt with successfully, others with which we struggle or try to ignore. The future is, to a large extent, unknown, though we all have expectations of the future. We cope with concerns about the future by drawing on past experiences.

All these different situations depend on a person using memories in a way that is flexible and analytical. If our memories are being eroded, we have less experience upon which to draw in every situation we come across. Our coping skills are stretched and are not always effective. The present becomes transient and separate from a previously remembered environment. In AD, everything has the potential to be unpredictable if not remembered, disconnected from familiarity and anxiety-provoking.

Part of our being, as humans, is in the retelling of our lives. This happens on a day-to-day basis with those with whom we share our lives, by telling them how our day has been, and all the ups and downs contained within it. On a more general basis, we share amongst our peers things that have happened to us, to strengthen present relationships and to forge new ones. Each time we tell of something that has happened to us, we give something of ourselves. If we are unable to share in this, because we cannot remember what has happened to us during the day, week, month or year, we are unable to participate in this reciprocal way of communication and strengthening of relationships.

We are all affected by our environment and the people whom we see regularly. At times there might be a subtle effect, at other times it forces itself on us and we cannot ignore it. For a long time, there has been the belief that there is a link between a person's health and the events that have occurred in a person's life, and a relationship between stress and illness, which will be discussed in *Chapter 3: Literature Review.*

Kitwood (1997) describes two separate processes of change in a person with dementia: the deterioration of the brain function caused by degeneration, and changes in relationships because of altered interactions with those around them – one is neurological, the other is social-psychological. Kitwood says that the dementia process is a result of both.

The neurological degeneration of the brain has been researched extensively by using empirical scientific techniques, leading to many new and promising findings about dementia. The scientific disciplines have contributed to an improved accuracy of diagnosis, treatment and medical care of people with dementia. The other ingredient of good care is the social-psychological care, which nurtures the person as an individual, and is what the expert practitioner brings with their knowledge and skills – whatever their profession. There is a danger of reductionism, if a practitioner uses either the scientific paradigm or the social-psychological paradigm only, and of overlooking the individual as a whole.

When we consider AD as a pathological process, it can be from the holistic stance of the individual within their environment, and how these different factors (such as lifestyle, diet or genetic factors) interact: or it can be reduced to either the neurological or social-psychological paradigms, as described by Kitwood (1997).

The neurological paradigm underpins many published papers that discuss AD. This is because much of the funded research is to find answers to specific research questions, which emanate from the scientific paradigm, in order to reverse the pathological process.

2.8. Symptoms of AD

There is much clinical heterogeneity in AD, and Lovestone (2002) suggests the phenotypic variability reflects the genotypic variability. The two main phenotypes that can

be identified are: Familial AD (FAD) and Late-onset, or Sporadic-onset AD (LOAD). LOAD tends to occur in later life, and is thought to be caused by many different factors: within this group, there are those persons who develop the disease in the same way as relatives have before them, and there are also those who are truly sporadic. FAD is an autosomal dominant disease, and usually presents before the age of 55 years old, but symptoms can start when people are in their thirties. The age of onset, rate of progression, and patterns of cognitive and non-cognitive symptoms are all thought to be related to the individual's genotype (Lovestone, 2002).

2.8.1. Cognitive changes

Memory loss is the most common presenting symptom of AD. Initially, it starts with loss of memory of recent events: the person misplaces objects, or forgets appointments. Gradually, the loss begins to affect more areas of memory, becoming more severe as it progresses, leading to disorientation, and the learning of new skills is affected. Visuo-perceptual difficulties can mean the individual fails to recognise familiar faces, which can be extremely upsetting for a spouse or relative caring for them should they not be recognised. Objects, too, are not recognised: one of the common objects not recognised is the toilet, which can cause distressing consequences in behaviour that are not always understood or identified. Language difficulties, affecting the comprehension and expression of language, frustrate the person and those with whom they are communicating (Thomas and O'Brien, 2002).

2.8.2. Non-cognitive symptoms

Non-cognitive symptoms include paranoia, delusions and hallucinations. Depression, caused by mood changes, is very common in AD, and affects the quality of the individual's life, but can be addressed with medication, counselling (Thomas and O'Brien, 2002) or other appropriate social interventions. Problems with co-ordination and balance can also occur (Thomas and O'Brien, 2002).

2.8.3. Behavioural problems

Behavioural problems, such as hyperactivity, apathy and lack of initiative, can become much worse as the disease progresses. Abnormal sleep patterns, and the disruption of the circadian rhythm, can lead to carer stress, the feeling of having a '36-hour day' (Mace and Rabins, 1999) with no relief in sight, and endless exhaustion for the carer. Abnormal eating patterns include binge eating, the inability to use cutlery leading to dependence on others for feeding, and a gradual inability to swallow, resulting in malnutrition, weight loss and an increased risk of choking. Aggression, verbal or physical, can also be a distressing and frightening problem for both carer and patient, and is a common reason for admission to hospital and transfer to full-time residential or nursing care. Sexual disinhibition occurs in a minority of individuals with mild AD, but becomes more common as the severity of the disease progresses, and causes a great deal of distress to carers (Thomas and O'Brien, 2002).

In addition to those symptoms already mentioned, there are also personality changes, which can occur early on in the disease, and neurological changes, which tend to occur later in the disease. Incontinence is a characteristic of 94% of individuals with severe AD (Burns et al., 1990; Thomas and O'Brien, 2002). Other physical changes include weight loss and a general decline in health. The age at the onset of AD is a predictor for the rate of decline an individual may experience: the earlier the onset, the more rapid the decline. Palliative care is needed in the late stages of AD, during which the person has become mute, immobile and incontinent, and can last several years. Although it is not certain if AD causes death directly, it is a major contributory cause. Individuals often develop an infection or complications of physical decline, which may be the specific cause of death (Thomas and O'Brien, 2002).

2.9. Neuropsychology of AD

Neuropsychological data are particularly relevant to the differential diagnosis of dementia. Different tests can reveal how a person's mental function is working, by analysing how they perform in the relevant tasks. Primarily, AD affects memory, and there are several tests available that have been designed to identify memory problems: the OPTIMA protocol uses the *Camcog* (Roth et al., 1988) and the *Mini-Mental State Examination* (MMSE) (Folstein et al., 1975), as a baseline from which changes can be evaluated, as well as a combination of other similar tests.

The tests selected needs to be reliable and valid. The test should not show a ceiling effect on the first or subsequent use with an individual, and not show a bias to age, gender, education or social class, and be sensitive to cognitive decline (Huppert et al., 1995).

A test that reveals pre-morbid abilities is also requisite for those who have begun to dement. An estimate of pre-morbid IQ is provided by the use of the *National Adult Reading Test* (NART) (Fromm et al., 1991).

The scores are included here to give meaning to the inclusion criteria of the ADLE study, as well as to the analysis of the results. The *Camcog* produces a score that can be broken down into sub-categories: the maximum score for a *Camcog* is 107. The subcategories are described below in *Table 3.2* with the total score for each subcategory.

Table 2.1 Subcategories of *Camcog*

Camcog subcategory	Total score of subcategory	Area of testing
Orientation	10	Orientation in time, person and place
Comprehension	9	Understanding simple instructions, for example 'Close your eyes
Expression	21	Fluency and word finding
Remote memory	6	How well facts from the past are remembered
Recent memory	4	Short-term memory
Learning memory	17	Ability to learn and remember a new fact
Attention	7	Ability to attend to a task without being distracted by other things going on
Praxis	12	Dexterity and the ability to organise movements to achieve a task
Calculation	2	Simple mental arithmetic
Abstract thought	8	Think in abstract or concrete terms
Perception	11	Recognition of everyday objects from obscure views
	Total 107	

Roth et al. (1986), in their study, stated that a cut-off value of 79/80 was found to discriminate between demented and normal participants. It has been found that total *Camcog* scores can be affected by age, gender, education, and social class: thus, a definitive cut-off point for calculating whether a subject is demented or not is not recommended (Huppert et al., 1995). In practice, within the OPTIMA study, the scores from the different categories are examined together in the context of the physical tests, the brain scans, the information from the informant (usually a relative), and the medical history, to see if these are consistent with a diagnosis of Possible or Probable AD. Thus, a diagnosis of Possible or Probable AD can still be given when the score is above 80. This is particularly relevant if the person was functioning previously at a high level and has a score much below what would have been expected for someone at his or her level of

functioning. Patient number 34 fell into this category: as someone who was fluent in five languages, and had a high-powered job, his *Camcog* score was above the cut-off described above. However, in the context of all the other investigations, it was considered that he had Probable AD, because of the reduced function in the context of his previous abilities. Diagnoses are reviewed annually, to ensure current clinical findings are taken into account in the diagnostic process.

2.10. Summary

In order to understand the context of the ADLE research and analysis, the components of the OPTIMA database that were used in the analysis have been briefly described. The data gained from the ADLE interviews can be related to the OPTIMA data from the *Camcog* neuropsychological test (Roth et al., 1988).

This chapter has explored the definition, demography, diagnosis of AD and how AD can affect the individual and his or her family. This ADLE study fits into the plan of research studies that complement the scientific OPTIMA data by studying the social factors of AD.

Chapter 3: Review of literature and methodology on life events and narrative analysis

3.1. Introduction

This chapter covers the literature related to the fulfilment of the TQs. The topics covered are:

- For TQ1: studies linking life events and AD
- Why life events are thought to be a risk factor for AD
- Reasons for choosing Danner et al.'s EWC
- Reasons for choosing the BNIM

Initially, this literature search was carried out using electronic databases, manual searching and from references quoted within appropriate articles, underpinned by Boolean logic. The databases searched were CINAHL, Psych Lit, Sociological abstracts, Medline, the British Nursing Index and the RCN journals database, as well as the search engines PubMed, TDNet and Google. The topic headings used were: life events, life events and dementia, life events and AD, life change events, life story, stressful events, Life Events and Difficulties Schedule, narrative research, narrative analysis, and discourse analysis, as well as recognised author names from the fields. Years searched were from 1965 to 2009. Relevant books were consulted, and advice gained from specialists in the field, several of whom had authored or edited the books. The literature chosen to review here was selected because of its pertinence to answering the TQs.

3.2. TQ1: Is there a difference between the number of life events between patients and controls, using LEDS as a measurement tool?

The key literature sources surrounding this theory question will be explored, covering the studies linking life events and AD, and the reason why life events are thought to be a risk factor for AD. How the ADLE study will fill this gap in the literature will also be explained. Previous studies analysing the link between life events and AD have suffered from a number of problems, which will be addressed for each study in turn.

Alois Alzheimer published papers about the disease in 1907, however, there were no common diagnostic criteria until 1984 when the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association published those which are in common use now (McKhann et al., 1984). This has implications for the cohort included in the first published study on the link between life events and AD, by Amster and Krauss (1974). Amster and Krauss (1974) examined 'the relationship between life crises and mental deterioration in old age' by interviewing 25 females who had 'mental deterioration' over the previous 5 years. There is no specific definition of mental deterioration in this paper, and no discussion of whether this dementia was due to a reversible illness or to a progressive disease process. The authors state that those who had the mental deterioration were able to correctly answer no more than one of the 10 items of the Mental State Questionnaire (Amster and Krauss, 1974). The details collected about the life events were collected from an informant, usually from the participants' next of kin, close relatives or acquaintances. Details of the life events were collected from the 5 years immediately preceding the mental deterioration, and for the controls from the 5 years immediately before the interview. Those with mental deterioration were age matched with the controls. The life events were measured by using the Geriatric Social Readjustment Questionnaire (GSRQ), designed by Amster and Krauss, which is based upon the Schedule of Recent Events (SRE) questionnaire (Holmes and Masuda, 1970). The most obvious criticism of this study is that it does not have a cohort with a specific diagnostic process for those who have 'recent mental deterioration', or those who have normal cognition. By default, it is likely that the study included participants with AD, because of the high incidence of AD in the older population (see *Chapter 2: Background information*), but they will have been unidentifiable and their data will have been included with participants who had mental deterioration from unknown causes. In this study, the poor diagnosis of the 25 females who had mental deterioration renders the life events data of no useful value. The questionnaire used by Amster and Krauss was a 'geriatric' version of the SRE of Holmes and Masuda (1970). The SRE was a list of life events that had been created as an instrument to measure stress: the number of life events that occurred within a specified time was an indicator of the amount of stress

that was affecting a person. This version of the SRE had been developed so that a panel of geriatricians defined the life events, and then the events were given to 30 multidisciplinary experts in geriatric problems in order to rank the events in order of the distress caused to the participant. The SRE was the initial attempt to measure stress in a way that could be applied to a cohort: it has been used in many different forms (Masuda and Holmes, 1978), and has the advantage of being quick to administer to large populations, but does not specify many of the aspects necessary to know about the life events that contribute to a life event (whether the life event was experienced to the person, or someone else, how recently has it happened, what type of lasting effects were there etc). The GSRQ has the disadvantage of not including the perspective of those who are elderly, and the ranking of the events was done by those who work with older people, not by older people themselves – affecting the construct validity of the instrument. Another criticism of this instrument is that the life events mentioned are unspecific: for example, 'change in living conditions or environment' could be interpreted as the upheaval of having a new carpet put down, or as having your house burnt down – arguably at different ends of the spectrum of stress. Over all, the Amster and Krauss study has a lot of faults that can be learnt from.

Five other case-control studies, by Broe et al. (1990), French et al, (1985), Amaducci et al. (1986), Chandra et al. (1987) and Hofman (1989), were included in a meta-analysis of risk factors for AD by Jorm et al. (1991). One of the risk factors examined was a limited number and type of life event, the data were collected from informants, which were counted whenever they occurred, so these events could have occurred after the symptoms of AD began. The life events reviewed included:

- The death of a spouse
- Death of a child
- Divorce

Other studies were included in Jorm et al's meta-analysis which used data that could be inferred from the medical notes, such as the participant's marital status – the authors considered the fact that the participant may have got remarried after divorce or death of a

spouse, but still decided to include these data, as they would have reduced the frequency of the divorces and widowhood. These studies used protocols that were in agreement with the NINCDS-ADRDA criteria to diagnose probable AD in the cases. The analysis of the life events included a cohort of those with probable AD of 284 cases and 229 controls in total, across 5 different studies (Netherlands, Australia, Italy, USA – Denver and Minneapolis). Amaducci et al. (1986) acknowledge that the accuracy of the clinical diagnosis is one of the most important problems to overcome: this has been addressed with the protocol consistent with the NINCDS-ADRDA criteria. Jorm et al, by their own admission, point out that the assessment of the life events is not as accurate as it could be, by virtue of including inferences from the medical notes, rather than data from patients or informants. The limited numbers of life events are all classified as 'major life events' (i.e. of significance in the LEDS research) according to the definitions by Brown and Harris (1978). The analysis shows no associations between AD and life events, except when the Netherlands study is included, which Jorm et al. consider biased because the cases are not matched with the controls. Jorm et al. (1991) state that 'further research on life events as a risk factor for AD would seem unprofitable'. Although this has been stated, the many difficulties with this meta-analysis indicate that this study had flaws that could be rectified in another study, thus improving the reliability and validity of the results. It is of note that, despite having 4 different countries and 5 different study sites and being over a number of years, the total number of study participants with probable AD totalled 284, an average of 56 per site. A meta-analysis of this types would be expected to generate more than this number of participants from each country (the ADLE study recruited 20 participants with AD, which is a study being managed by one person in comparison to a worldwide meta-analysis). However, this demonstrates the difficulty of recruiting participants that fit the criteria needed for studies researching AD.

In 1995, Grimby and Berg published a study examining a longitudinal cohort of 275 elderly persons, living independently at the age of 70 years old. They were then interviewed at the age of 76 years old, and cognitive testing was done at both ages. At the latter interview, they were interviewed by the psychologist and expected to spontaneously

report any life events that had occurred between the ages of 70 and 76 years old. The interviewees were not given any cues as to what they should discuss: the categories of life events were health- and death-related events, their children's divorce, change of dwelling, and 'miscellaneous'. The results showed that the entire cohort had experienced a decline in intellectual functioning, although it is not clear to the reader what clinical diagnoses were present amongst the cohort. Those that had experienced a bereavement (at an unknown time) had declined more than those that had not, and this applied especially to men. The impediments of this study are the lack of an accurate clinical diagnosis, a period of only 6 years over which a life event could happen (between the ages of 70 and 76), and no systematic way of assessing the occurrence of the life events in this time frame. The authors conclude that

> *Healthy elderly citizens seemed to withstand the harmful influence of stressful life events, possibly with the exception of bereavement in men.*
> (Grimby and Berg, 1995)

Another key paper on life events and AD was published by Orrell and Bebbington (1998), who examined the link between life events and admission to hospital in those who had dementia. Orrell and Bebbington (1998) used the LEDS interview with the participants' informants. The LEDS interview, by Brown and Harris (1978), is designed to capture data about a life event through a semi-structured interview (see *Appendix I*), including factors such as who the event happened to, when did it happen, what effect did it have, how long did the effect last etc. The interviewer collects data on the objective details of the life event and the subjective effects of the life event, all of which are separately rated. These dimensions of the LEDS interview are rated by Brown' and Harris' team and complied in a manual that enables coding of participant's life events. Groups of study participant's life events can then be statistically compared, and inferences made. The LEDS has been used in many studies examining the effect of life events (Ford et al., 1987; Neilson et al., 1987 Chen et al., 1995; Farmer et al., 2001) and was assessed by Katschnig (1980) as a more reliable and valid method for measuring life events than the questionnaire method. The criticisms of the LEDS interview are largely concerned with the length of time the

interview takes, and the cost implications of this rather than the quality of the life events data (Cohen et al., 1997, Eysenck, 2004).

By default, Orrell and Bebbington (1998) will have included those who have AD, but a differential diagnosis was not included in the selection of the patients. The study included 70 people with dementia, and 50 people with normal cognition. The results found that life events were associated with depressive symptoms in both groups of participants, but that life events were not associated with hospital admission unless the participants required adaptation of daily routines. It can be seen again that there is a problem with an accurate clinical diagnosis of those in the cohort, as well as the research not addressing the risk of life events over a long period of time, or before the symptoms of dementia are evident.

A different approach was taken by Tom Kitwood, who published his 'psychobiograpical approach' (1990), which examined the effect of life events in a person's life. Kitwood's ideas are based upon 'malignant psychology' (i.e. poor care) contributing to the neurobiological effect of dementia (1992). To counteract the effect of the malignant psychology, he suggests an in-depth life history based upon psychotherapeutic techniques in order to understand the person's life in 14-year segments. This method requires a researcher to be communicating with the person who has dementia, and for another researcher to be observing and taking notes of what is going on during the interviews needed. Data are also collected from an informant. These data are constructed as a narrative, and analysed for themes, in the same way as many narrative analyses are compiled (Plummer, 2001). These data enable the carers to provide a more understanding way of caring for the person, but is very labour-intensive, which needs to be taken into consideration. It could be argued that the credibility and trustworthiness of the results are difficult to ascertain because of the lack of details about the process of analysis.

The studies discussed above are a complete review of research linking life events and AD. From examining the studies discussed above, there is an obvious gap in the

literature and a need for a case-control study that has an accurate clinical diagnosis, and a reliable method of recording a lifetime of significant life events (the method of recording life events will be discussed in *Chapter 4: Methodology and ethical issues*), and this is the purpose of the ADLE study.

In summary, the LEDS was chosen for the ADLE study as its method is regarded as reliable and valid (see *Chapter 4: Methodology and ethical issues*), which is important in the context of OPTIMA, in which this study will be evaluated in practice. The choice of the LEDS eliminated flaws within the previous studies of examining the association between life events and AD. LEDS provided a more accurate measure of the difference in the number and type of events between patients and controls in answer to TQ1 and TQ2, and was within the resources given to the researcher. There is no other study published examining whether life events are a risk factor for AD which has involved:

- A diagnostic process to ensure the appropriately diagnosed participants are engaged in the study
- Uses mixed methods that address the need for quantitative and qualitative data in answering the central research question

Therefore, a gap in the literature has been identified, which the ADLE will fill, and as such the LEDS interview was considered both a methodologically sound and the expedient choice.

3.2.1. How are life events thought to be a risk factor for AD?

The reasoning behind this question stems from the GCH, which involves the HPA axis (Deshmukh and Deshmukh, 1990), as mentioned in Chapter 1. The literature supporting this theory's relationship to AD will be reviewed here.

Lupien et al. (1999) discuss how the study of cognitive ageing evolved after the Second World War. It became apparent from the cross-sectional studies published, using different age groups, that there was a greater heterogeneity in the cognitive performance of the older population in comparison with the younger population. The disparity in these results showed that some people manage to age more successfully, physically and

psychologically, than others, enabling them to retain their cognitive abilities, while other people do not age as successfully and develop cognitive problems (Lupien et al., 1999). This disparity raises questions about how our body manages stress, or allostatic load, successfully; and whether there is a 'norm' for cognitive ability in the older person.

Allostatic load is defined by Seeman et al. (2001) as a 'measure of the cumulative physiological burden exacted on the body through attempts to adapt to life's demands'. These demands include positive and negative experiences. Allostasis is when the body has adapted successfully to the environment. When the body has not managed to meet all the challenges that the environment and life have thrown at it, and the body's adaptive responses in the regulatory systems are incapable of meeting allostatic needs, then allostatic load accumulates.

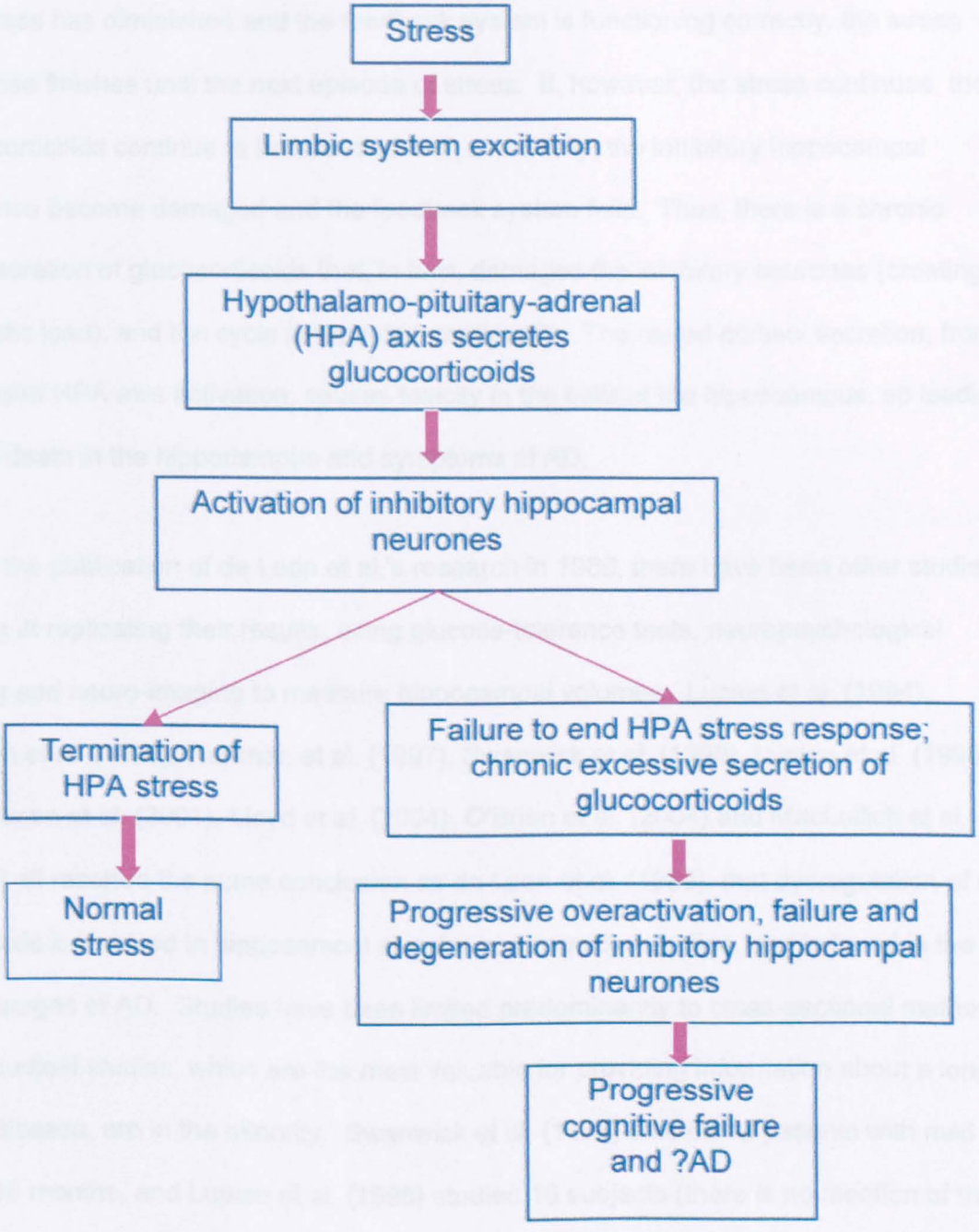
The HPA axis was implicated in the regulation of stress, or allostatic load, after research using animal studies. In the late 1960s, McEwen and his colleagues discovered the presence of adrenal steroid receptors in the extrahypothalamic limbic regions of the rat brain (McEwen et al., 1968). They found the most adrenal steroid receptors in the hippocampus, containing the neurones responsible for our memory.

Reduced blood flow and degeneration of the hippocampus are typical of AD (Esiri and Nagy, 2002; Jagust et al., 2001). de Leon et al. (1988) suggested that the animal study observations showing degeneration of the hippocampal neurones after sustained stress (and increase HPA axis activity), so creating an allostatic load on the hippocampus, could be applied to the human brain. The study by de Leon et al. (1988) found raised cortisol levels, in response to a glucose-tolerance test (GTT), in nine patients with mild to moderate AD. Although the patients in the study did not have neuropathologically confirmed AD, the same tests were used with patients who had multi-infarct dementia, and were found to be negative, except for one patient who had hippocampal atrophy on CT scans. Controls, who underwent the same GTT, were found to have normal cortisol levels. de Leon et al (1988) suggested that the normal person, with an abnormal GTT

cortisol response and minimal hippocampal atrophy, would be at risk of cognitive deterioration in the future because of the raised cortisol secretion, from increased HPA axis activation, would lead to cell death in the hippocampus and thus the symptoms of AD.

In 1990, Deshmukh and Deshmukh proposed the glucocorticoid hypothesis as a mechanism of developing AD, which is a hypothesis that includes the dysregulation of the HPA axis, as shown in Figure 3.2. The hypothesis is based upon the suggestion that the hippocampal neurones become damaged through a chronic stress adaptation failure, which involves the HPA axis leading to memory difficulties (see Figure 3.1).

Figure 3.1 Glucocorticoid cascade hypothesis (Adapted from VD Deshmukh and SV Deshmukh, 1990).



In this model of the glucocorticoid cascade hypothesis of AD, a stressful experience leads to the limbic system being activated, which, in turn, activates the HPA axis, so that glucocorticoids are secreted to help in the fight and flight response. The hippocampal neurones are responsible for inhibiting the secretion of glucocorticoids, meaning that, if the stress has diminished and the feedback system is functioning correctly, the stress response finishes until the next episode of stress. If, however, the stress continues, the glucocorticoids continue to be released and, eventually, the inhibitory hippocampal neurones become damaged and the feedback system fails. Thus, there is a chronic oversecretion of glucocorticoids that, in turn, damages the inhibitory neurones (creating an allostatic load), and the cycle is repeated continually. The raised cortisol secretion, from increased HPA axis activation, causes toxicity in the cells of the hippocampus, so leading to cell death in the hippocampus and symptoms of AD.

Since the publication of de Leon et al.'s research in 1988, there have been other studies aiming at replicating their results, using glucose-tolerance tests, neuropsychological testing and neuro-imaging to measure hippocampal volumes. Lupien et al. (1994), O'Brien et al. (1996), Hartman et al. (1997), Swanwick et al. (1998), Lupien et al. (1998), Rasmuson et al. (2001), Lloyd et al. (2004), O'Brien et al. (2004) and MacLullich et al. (2005) all reached the same conclusion as de Leon et al. (1988): that dysregulation of the HPA axis is involved in hippocampal atrophy and cognitive decline, and is found in the early stages of AD. Studies have been limited predominantly to cross-sectional methods. Longitudinal studies, which are the most valuable for providing information about a long-term disease, are in the minority. Swanwick et al. (1998) studied 12 patients with mild AD over 18 months, and Lupien et al. (1998) studied 16 subjects (there is no mention of their age or gender) over five years, selected because of their raised cortisol measurements. Lupien et al. (1998) found that there was a significant relationship between reduced hippocampal volumes, impaired memory test results and raised cortisol levels. As yet, there has been no published study with a longitudinal follow-up until death, with neuropathologically confirmed AD, nor any study with more than 16 subjects.

As well as patients with AD having dysregulation of the HPA axis with hippocampal atrophy present, these findings have been reported in patients who have other illnesses related to the HPA axis, such as Cushing's disease and Post-traumatic Stress Disorder. Cushing's disease, which causes prolonged elevated cortisol levels, also leads to dysregulation of the HPA axis and hippocampal atrophy (Lupien et al., 1998). Post-Traumatic Stress Disorder (PTSD) has been associated with hippocampal atrophy and dysregulation of the HPA axis. PTSD, by its nature, involves significant life events; studies examined in this review involved patients who suffered from either combat stress, from the Vietnam War (Mason et al., 2002), or who suffered abuse as a child (Elzinga et al., 2003). The dysregulation of the HPA axis in PTSD is inconsistent; some studies show higher cortisol levels, others show lower cortisol levels (Elzinga et al., 2003; Mason et al., 2002). Reduced size of the hippocampus in studies involving neuro-imaging has, however, been consistent (Bremner, 2002; Pitman et al., 2006). Again, longitudinal studies with neuropathological analysis are needed to examine the relationship between PTSD and the HPA axis and hippocampal atrophy.

Based on a study of 9 participants with AD (although only 6 completed the study), Pomara et al. (2003) treated participants to either a steroid (Mifepristone 200mg) or a placebo. Those that were on active medication showed an increase in their neuropsychological tests, those that were on the placebo had diminished neuropsychological functions. Although this was a small number of participants, the results are encouraging and Pomara et al. (2003) have suggested that the HPA axis abnormalities have therapeutic implications and suggest that this area of prevention and treatment of AD should be developed further.

In summary, there is significant evidence for the GCH causing a disruption in the HPA axis, which in turn causes damage to a susceptible hippocampus, leading to memory problems and neuropathologically diagnosed AD. This evidence suggests a biological reason behind why life events are a risk factor for AD. Though this is a necessary factor for assessing an association between research studies, it is also knowledge that should

cause a re-evaluation of how stressful life events are managed as individuals and as a community, from childhood onwards, so that healthy practices are begun early. This would prevent the damage to a person's hippocampus and reduce the risk of developing AD. The National Dementia Strategy (2009) discusses living well with dementia, but also seeks to be positive about prevention - although the sentence closes with '*...if this is at all possible*'. Ambivalent statements such as these do not engender confidence in either clinical practice or research findings that support advice for the prevention of dementia.

In conclusion, the background literature concerning TQ1, is inadequate to test the hypothesis that life events are a risk factor for AD, but a plausible biological basis for the hypothesis does exist. The literature will be discussed with reference to the results of the ADLE in *Chapter 7: Analysis and discussion.*

3.3. Theory Question 2: Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and in the range of emotions expressed when discussing life events between the patients and controls?

Alzheimer's disease markedly influences the patient's ability to use language and also has an effect on their emotional responses. Theory question 2 was therefore formulated to see if these might impact on their descriptions of life events. It will be shown that patients and controls discussed many events from the whole course of their lives, the interviews included events that were considered significant by the LEDS (i.e. that fitted the criteria of the LEDS). Events that were not considered as significant by the LEDS, but were considered significant enough by the participants to be mentioned and discussed by them, were called 'non-LEDS events' for convenience.

The following research questions were formulated:

a) Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups?

b) Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's EWC?

Danner's EWC (Danner et al., 2000) was considered the most appropriate method of analysis for determining this: the reasons for these decisions will be explained.

The LEDS interviews give different perspectives on life events and how individuals perceive these events to have affected them in a holistic way, i.e. practically, emotionally and spiritually, and how the events affected the participants' relationships with others and with their environment (Brown and Harris, 1978). Discussed in this chapter is a selection of different approaches that could have been used to answer the TQ2. These are:

- Pennebaker's Linguistic Inquiry and Word Count *(LIWC)* (Pennebaker et al., 2003)
- Garrard (2008) and Garrard et al. (2005)
- Kemper et al. (2001) and the Nun Study
- Danner et al. (2001) and Emotion Word Coding

3.3.1. Pennebaker's Linguistic Inquiry and Word Count

Pennebaker maintains that the words we use reflect who we are, and that word choice can serve as a key to people's personalities and social situations (Pennebaker, 2005; Pennebaker and Chung, 2008). Pennebaker considers that the construction of a narrative about emotional events is vital to a person's good mental and physical health (Pennebaker and Seagal, 1999).

Pennebaker's linguistic analysis uses a word count strategy, which analyses the content (what is being said) and style (how it is said), the LIWC (Pennebaker et al., 2003). The strategy is based on capturing information in standard language categories (i.e. pronouns, articles, etc.) about psychological processes (i.e. positive and negative emotional word categories, etc.). Relativity-related words (i.e. time, verb tense, motion, etc.) are included, as are the traditional content dimensions (i.e. sex, death, occupation, etc.). Normally, a computer program is used for the word count, which is analysed statistically for significant differences. Despite this statistical base, Pennebaker acknowledges the importance of the psychological processes that these results reflect such that the results of the data are

applied in an interpretive manner, giving emotional meaning to what has been said by the participants.

Significant results that reflect psychological processes have been found in Pennebaker's research. Pennebaker and Stone (2003) found that, as adults age, their tense use changed, they used fewer negative words, more positive words and fewer self references, and demonstrated a general pattern of increasing cognitive complexity. This particular study examined the writings of more than 3,000 research participants, between the ages of 8 years old and over 70 years old, who had spoken about emotional events or experiences. The cohort was 58.2% females, the females being more prevalent in the older age groups. The main disadvantages of this study were that it was a cross-sectional study, rather than retrospective or longitudinal, so there is the influence of cultural differences on each age group of participants to be taken into consideration, and that the group of adults over 70 years old comprised only 44 participants (from more than 3,000).

Reviews by Pennebaker et al. (2003) and Chung and Pennebaker (2007) state that the use of particles (pronouns, articles, prepositions, conjunctives and auxiliary verbs) can serve as markers of emotional states, social identity and cognitive styles. Earlier studies have used analysis to diagnose mental health problems (Pennebaker et al., 2003). Thus, psychological and physical health can be reflected by the choice of words, and this is shown in the study by Cohn et al. (2004), who examined the regular diary entries of over a 1,000 users on a United States website for the 2 months before and the 2 months after the September 11th, 2001 (9/11) terrorist attacks. The diarists were 53% female, with an average age of 24.7 years (SD=8.3). Although the researchers acknowledge that the cohort is atypical of the average person, in that the diarists are comfortable about sharing their private lives with a worldwide audience, the cohort is approximately representative of the racial and educational composition of the United States. The changes in psychological health were determined by the changes in their word use. Immediately after 9/11, there were more negative emotions expressed. Participants were more cognitively and socially engaged (to gain support from their friends and family), and were more

psychologically distant (defined by the use of longer words, more articles, avoiding the present tense and first-person singular). These variables were monitored for the 2 months following 9/11, by which time the only variable that had returned to normal was the expression of negative emotions (Cohn et al., 2004). Although there are ethical issues surrounding the analysis of the diaries, which have not been addressed in this paper, this type of study could provide an opportunity to study the long-term effects of trauma on the use of words, and have this correlated to physical and psychological health status.

Pennebaker et al. (2003) suggest future research studies on several areas in linguistic analysis: the analysis of particles, traditional content dimensions, and emotions. Pennebaker et al. (2003) state that previous research on the expression of emotional words has shown that, approximately, only 5% of the words that we speak can be classified as emotional, and that the emotional words used are not a strong predictor of people's emotional state. However, Pennebaker et al. (2003) also found that the use of language revealed whether or not people had adjusted to traumatic events. In this study, the researchers examined the language people used to talk about a very recent bereavement, and to predict their subsequent mental and physical health, using models developed in the initial stages of their research. From interviews, 2 and 4 weeks after the bereavement, they found that these could predict the physical health 1 year later: the use of more negative emotional words and fewer positive words was associated with more negative outcomes – thus, the expression of positive emotions is tied to better health (Pennebaker et al., 1997). Those subjects who used very few negative emotions and a very high rate of negative emotions were the most likely to have persisting health problems after the study. The negative emotional word use was positively related to illness change (Pennebaker et al., 1997; Pennebaker and Seagal (1999)): so, a moderate expression of negative emotions is related to better health.

Pennebaker and Seagal (1999) state that the expression of emotion is therapeutic only when it is accompanied by cognitive processing, and that catharsis alone is unhelpful. They suggest that, once a complex event is translated into a narrative, it is simplified and

made more understandable, and there is less effort needed for the mind to bring structure and meaning to the event. The narrative becomes coherent and organised, enabling the person to manage the emotions and meaning attached to it, and allowing the person to 'forget' the event more easily, resulting in better health (Pennebaker and Seagal, 1999). A disadvantage of the LIWC) which is based upon analysis by a computer programme, is that the reliability and validity would need to be established before using it in the United Kingdom, where the English language is used differently from the United States. The LIWC does not take into account the context of the words spoken, nor whether there was irony, sarcasm and other types of humour or expressions used to express feelings in a different culture, which is certainly the case in the UK and was noted in the LEDS interviews.

Pennebaker started his research in the 1980s, after the feminist movement had been well established, but within a research context that required empirical knowledge to further science. Pennebaker has used national traumatic events, such as 9/11, to expand his research, without publicly addressing the ethical issues surrounding the methods, which could have implications for future research in this area. The theoretical background of Pennebaker's research has similarities to the LEDS used by Brown and Harris (1978), in that it has a positivist grounding, the results of which aim to represent psychological processes, in order to help the individual.

3.3.2. Garrard's Lexical and Syntactical Analysis

Garrard (2008) and Garrard et al. (2005) examined the writing of the well-known and prolific author Dame Iris Murdoch and the Prime Minister Harold Wilson. Garrard et al. (2005) wanted to distinguish whether the psycholinguistic properties of the vocabulary used in her last book *Jackson's Dilemma,* published in 1995 (Murdoch, 1995) – written, they argue, during the early stages of AD – differs significantly from two books written earlier in her career (*Under the Net*, 1954, and *The Sea, The Sea,* 1978). In retrospect, Iris Murdoch had shown symptoms of AD as early as 1993. In November 1996, she

scored only 20/30 on the MMSE and, by the summer of 1997, she scored just 10/30 (Garrard et al., 2005). Iris Murdoch died in February 1999, and neuropathological examination confirmed that AD was present (Garrard et al., 2005).

Garrard et al. (2005) suggested that any writing shows the products of cognitive operations at work, and, as such, can be used to examine and monitor the progress of the disease in the brain pathologically from the earliest stage. The authors analysed Murdoch's writings, using grammatical and lexical analyses: in particular, they analysed:

(i) The overall structure and vocabulary
(ii) Syntax
(iii) Lexical characteristics.

(Garrard et al., 2005)

Manual and automated methods were used: the manual methods entailed selecting random samples of 100 words from each book, to elicit an alphabetical list of words used and their frequency. Automated methods also elicited an alphabetical list of words used, and the frequency of their repetition, in the entire text of each of the three books. Dialogue was excluded because of the possibility of the text reflecting the choice of words by the character rather than the author. Grammatical analyses were also used, differentiating the classes of words into nouns, verbs, adjectives, adverbs or function words, and the complexity and length of sentences.

It was found that there were no significant differences between the three books in the use of grammatical complexity or classes of words (i.e. nouns, verbs, adjectives, adverbs and function words), nor length of words used (Garrard et al., 2005). Nevertheless, there were significant differences found between *Jackson's Dilemma* and the other two books in the size of vocabulary: Iris Murdoch's first book (*Under the Net*) has a smaller vocabulary than the book *The Sea, The Sea*, published at the height of her success as a novelist and academic. *Jackson's Dilemma* has a significantly smaller vocabulary than either of the earlier books analysed. Garrard et al. (2005) suggest that this difference is an enrichment

of vocabulary between the early and middle stages of her writing career, the diminished vocabulary in *Jackson's Dilemma* reflecting the pathological process of AD in her brain.

Although the sample selected is small (three books), and despite acknowledging this weakness, the authors do not discuss any future plans to expand this selection (there are 26 books in total by Iris Murdoch). They describe further plans to use these techniques, and other automated techniques, to probe different qualities of the writing – potentially demonstrating deviations from normality, before anyone had any suspicions about Iris Murdoch's intellectual decline.

Garrard (2008) has also examined the Hansard reports of Harold Wilson in Prime Minister's Question Time, which identified lexical changes in his language prior to his sudden resignation. The Official Site of the Prime Minister's Office (2009) reports that his mental deterioration from AD was apparent soon after his resignation and retirement. Garrard et al. (2005) do not discuss how they would use this linguistic information practically. However, in Garrard (2008), this knowledge is recognised as a potential diagnostic marker, which could be added to the development of a diagnostic indicator of AD in the pre-clinical phase, as suggested in the ADLE study.

In response to this paper, the Alzheimer's Society has commented that they '*...look forward to further research into potential linguistic markers for dementia*' (2008). Garrard, Haigh and de Jager (2009) have commenced a study, funded by the Medical Research Council (MRC) (Cognitive Archaeology, IRAS no. 09/H0502/72), to look at these changes in language in more depth to identify further changes in written text, such as diaries and letters.

3.3.3. Kemper et al. (2001) and the Nun Study

A similar linguistic study, using data from the Nun Study, has been published by Kemper et al. (2001), and will be reviewed in more detail later in this chapter. The study analysed small amounts of text written by nuns entering their vocation and, when compared with their cognitive state five decades later, significant differences were found in the areas of a low density of ideas and low grammatical complexity. As a comparatively new theory, although one that has been through a necessary process of peer review before publication, it has not had adequate time to be replicated or developed, except in the context of the ADLE study.

The Nun Study was initiated in 1991 and enrolled American nuns, born before 1917, who were part of the School Sisters of Notre Dame order. It is a longitudinal study of ageing and AD, in which 678 sisters agreed to take part. The sisters completed annual physical and neuropsychological assessments, and consented to post-mortem and neuropathological examination of their brains (Snowdon et al., 1996). The structure of the Nun Study is similar to OPTIMA, except that the Nun Study has a cohort of unmarried, childless, college-educated, female teachers who share a similar environment, and live with the same ethos underpinning their lives and goals.

In 1996, Snowdon et al. published research stating they had found that linguistic ability in early life is associated with cognitive function and AD in later life. The researchers had been able to examine short autobiographies written by the sisters after they had completed 4 years training in the convent, but before they committed themselves to their religious vows. The autobiographies were in response to a request to each sister to 'write a short sketch' of her life. This account was

> *...not (to) contain more than two to three hundred words and should be written on a single piece of paper ... it should include the place of birth, parentage, interesting and edifying events of one's childhood, schools attended, influences that led to the convent, religious life, and its outstanding events*
>
> (Snowdon et al., 1996).

The 93 autobiographies chosen were handwritten, to ensure that they were composed by the sisters themselves, written at an average age of 22 years old, and validated by 10 sisters who were interviewed about the other authors. The autobiographies were analysed to examine the linguistic ability of the authors: (i) idea density, usually associated with educational level, vocabulary and general knowledge; and (ii) grammatical complexity, associated with working memory, performance on speeded tasks and writing skill (Snowdon et al., 1996).

Idea density was defined as the average number of ideas expressed per 10 words: ideas corresponded to elementary propositions – such as a verb, adverb, adjective or a prepositional phrase. Complex propositions that stated or suggested relationships (causal or temporal) between ideas were also included (Snowdon et al., 1996). Grammatical complexity was assessed using a score ranging from 0, for simple one-clause sentences, to 7, which included complex sentences with multiple forms of embedding and subordination (Snowdon et al., 1996). Results were analysed, after taking into account additional years of education with a regression analysis, and low idea density and grammatical complexity were associated with low cognitive ability in later life (at least 58 years after the original autobiography was written). Of the 25 nuns who had died, 10 had had neuropathologically confirmed AD, and a greater number of neurofibrillary tangles (NFTs) in the hippocampus and neocortex, than those who had high idea density ($P = <0.001$). Grammatical complexity was not as strongly associated with the number of NFTs in the hippocampus ($P=0.61$) (Snowdon et al., 1996). Snowdon et al. (1996) also suggest that low linguistic ability may accelerate the development of the NFTs and senile plaques associated with AD later in life. Despite the lack of knowledge regarding the mechanism, Snowdon et al. (1996) propose that low linguistic ability in early life is a potent marker for both the risk of AD and the extent of the neuropathological damage present at death.

These results, if representative of a universal process of neuropathological degeneration, have enormous implications for preventative health strategies. There are some criticisms of the research, some of which are acknowledged by Snowdon (2001). The cohort of sisters resident in a convent is a unique population: this can be construed as an advantage, as there are less confounding factors (one of which is extra years of education), and as a disadvantage, because the cohort is not representative of the general population, leading to questions about the applicability of the findings for others.

The history of the study is recounted by David Snowdon in his book *Aging with Grace* (Snowdon, 2001), who, as an epidemiologist, needed to have a research project and came across the School Sisters of Notre Dame through a graduate student in his department, one who had previously been part of this community. Snowdon states that he had already done some research with other religious communities. This later research study probably grew from pressure by colleagues, a need to find his 'niche' within his department, and from his own previous personal interest. Although intending originally to study the sisters only by way of thousands of questionnaires and the subsequent impersonal data, Snowdon soon realised that he needed to know the sisters as individuals, in order to discover what made them what they were, and to refine his original research questions. Snowdon then discovered the convent's detailed historical records on each individual sister and the community, enabling him to design a study that supplemented the retrospective data with prospective data (Snowdon, 2001). This has led to the publication of research findings that are based upon a positivist philosophy, personalised by Snowdon's accounts of individual sisters that represent the findings, using mixed methods of positivist research using quantitative data and individualised accounts that lend themselves to qualitative post-positivist methods of analysis. Studies using a cohort of nuns had already been used successfully to investigate risk factors for both breast and cervical cancers (Snowdon, 2001), and so was not a new cohort. The Nun Study, however, broke new ground regarding the longitudinal prospective element of the study, combined with neuropathological examination after death. The only

comparable study is OPTIMA, using similar annual cognitive and physical assessments, but with a wider cohort and more detailed annual assessments.

3.3.4. Danner et al. (2001) and Emotion Word Coding

Danner et al.'s approach (2001) evolved from Snowdon's reading of the autobiographies, during which he was struck by the differing amounts of emotion contained within the writings (Snowdon, 2001). He chose Deborah Danner, a psychologist who specialises in emotion research, to explore this further. Danner was influenced by Pennebaker's work on written language being used as a means to understand how physical and emotional health is influenced by our emotions (Danner et al., 2000). There are two papers published about EWC, of which Danner is the main author. The first is *Emotion Word Coding: Nun Study Autobiographies,* by Danner, Friesen and Snowdon (2000): it is the method of EWC, and comprises personal communication from Danner to the researcher (AMH). The second is *Positive emotions in early life and longevity: findings from the Nun study* by Danner et al. (2001), and is the paper about the analysis of the results of the EWC on the Nun Study autobiographies.

The hypothesis of the study is that there are '*Universal, patterned emotional responses that affect physiology in ways that are potentially damaging or beneficial*' (Danner et al., 2001). Danner et al. (2001) state that the early-life autobiographies are an opportunity to examine the emotional expression in written language, and its relationship to health later in life, by analysing the responses to stressful life events. The types of response to the life events can provide insight into the reactions of the sisters, and whether they were able to avoid suppression of emotions and resolve concerns around the stressful life events, potentially leading to beneficial effects on health and longevity. As stated before, the sisters have lived in similar environments, had similar occupations and socio-economic status, and have had the same reproductive and marital histories, therefore excluding or minimising many confounding factors that are in the analyses of cohorts in other studies.

Pennebaker used the computerised LIWC that includes EWC, together with other codings, as described earlier in this chapter. Danner et al. (2000) developed a manual EWC that codes emotional words into negative, neutral and positive categories, which can then be analysed quantitatively. This method was designed specifically for the Nun Study, and used to analyse the autobiographies within the convents.

Two coders, working independently, identified all the words related to emotional expression contained in 180 autobiographies (from two convents), and classified them as negative, neutral or positive. A third coder then checked for accuracy and determined the '*specific type of emotional experience or state referenced by each word*' (Danner et al., 2001). It is unclear from this phrase whether it is the particular state of emotion expressed by the sister that was referenced, or whether it was the emotion produced by a specific life event, consequently referring to the association between the emotional expression and the specific life event.

Criteria for the words coded are:

- To code words that, in context, described the emotion that was experienced and behaviours subsequent to emotional arousal
- To include the words that conveyed emotion as experienced by the writer or others.

Criteria for words not included are:

- Those words that are descriptions of possible elicitors of emotion
- Those words that convey positive or negative values or connotations, such as 'good' or 'bad'
- Those words that might imply an emotional reaction, but do not directly describe an emotional experience.

(Danner et al., 2001)

Sentences containing emotional words were also coded and quantified. Danner et al. (2001) also state that, when necessary for comprehension, the coders were instructed to identify and code phrases rather than single words, presumably to gain additional understanding from the context.

Inter-rater reliability was 0.78 and above for all measures, with the neutral codings having the lowest correlation of 0.79, and the positive codings having a correlation of 0.97 between the two coders (Danner et al., 2001). Ordinal variables were used to rank the percentile and quartiles to enable comparison. The two convents were ranked separately, and together, for the analyses. Analyses were all age and education adjusted, to account for the different times and stages of life at which the autobiographies were written.

The first analysis examined the relationship between the risk of mortality and the percentile ranking of the number of positive-emotion sentences, negative-emotion sentences and non-emotion sentences in the autobiographies. Inverse relationships were found between the percentile ranking of the number of positive sentences and the risk of mortality in later life, within each separate convent, and the combined convents (Danner et al., 2001). Danner et al. (2001) state that, for each 1% increase in positive-emotion sentences in the autobiographies, there was a 1.4% decrease in the mortality rate of the sisters. There were no statistically significant associations between the negative-emotion sentence or the non-emotion sentence percentile rankings and the risk of mortality (Danner et al., 2001).

The second analysis examined the relationships between the risk of mortality and the quartile ranking of the number of positive-emotion sentences, positive-emotion words and different types of positive emotion words (i.e. categories). Inverse relationships were present between these measurements as quartiles and the risk of mortality, as in the first analysis (Danner et al., 2001).

The third analysis examined age-adjusted survival curves (length of life) as a function of the quartile rankings of positive-emotion sentences, positive-emotion words and different categories of positive-emotion words (Danner et al., 2001). Inverse relationships were again present, implying that the less positive an expression was present, the more it affected survival.

In the discussion of their results, Danner et al. (2001) state that the study found a very strong association between the expression of positive emotions in the early-life autobiographies and longevity six decades later. Therefore, length of life (in the sisters) is associated with the expression of positive emotions. This begs the question whether there is a physiological connection between long life and the expression of positive emotion, and, if so, does this apply to any individual or are there other factors involved that are particular to the sisters? Linguistic ability was associated with long life and the expression of positive emotion, which also lends itself to the question: does a higher ability of writing in early life, representing a higher IQ, help with longevity? An interesting analysis would be to examine whether the late-life current neuropsychological data on the nuns involved were associated with the expression of positive emotions in early life and current cognitive state, or were the last cognitive assessment possible. Riley et al. (2005) found that low idea density in early life is related to an impaired cognitive state in later life, and these associations imply that education can have a masking effect, hiding the effects of AD, on the brain in later life.

There are disadvantages to their study, which Danner et al. (2001) acknowledge:

- The sisters could have been aware that their superiors would read the autobiographies, and this might have altered the content of their writing.
- The sisters would have been expected to feel positive about their future, because they were to embark upon their life choice.
- Negative emotional expression was minimal, so it is difficult to make assumptions regarding the negative emotions expressed. The coding made use of 'uncoded' categories – therefore leaving some emotional expressions not named and coded.
- There are no other measures, for example personality or temperament measures, from the time when the autobiographies were written.
- Generalisation of the findings to other cohorts is limited, by reason of the nature of the Nun Study cohort. These findings might shed light upon the physiological effects of expressed positive emotions, but do not take into account behaviours, for instance risky behaviour, that might occur in others who do not share the same lifestyle as the sisters.
- Autobiographies by sisters who died before the Nun Study began are being sought, to explore whether there is the same association present. Should there be an association, the positive emotions expressed would be expected to be less than those in the low percentiles and quartiles.

There is potential to research many other aspects surrounding the process of expressed positive emotions leading to longevity, which would further knowledge about the physiological process of ameliorating stressful life events in early life and longevity.

Of all the approaches reviewed, the EWC developed by Danner et al. (2000) in the Nun Study is considered the most appropriate for answering the TQ2 and defining the emotional expression within the LEDS interviews:

- It has proved reliable and valid with the written autobiographies from the Nun Study, and is a method that can be used in an original way to analyse the transcripts of LEDS interviews for research studies in the ADLE study
- It can be culturally adjusted to accommodate a British perspective, or other cultural perspectives, if needed
- It does not need a special computer programme, such as the LIWC
- It does not need specialised grammatical knowledge, as does Kemper et al.'s approach
- It incorporates the context as integral to the interview
- Garrard et al.'s approach is applicable when there are large pieces of writing from different stages of life, as in the case of Iris Murdoch. These circumstances are very uncommon (the ADLE study does not have access to such data): however, they do help to chart the process of cognitive decline.
- It has the potential to be transformed into a practical diagnostic marker of AD, should differences be shown between the emotional expression of patients and controls, with further research and development.

If significant results are found between the data for the patients and controls, the method can be developed as an aid to diagnosis, improving the overall probability of the diagnostic process. It can contribute to a therapeutic approach for those who are unable to, but wish to, bring together disparate elements about emotional events into a coherent story, and construct narratives in order to promote good mental and physical health (Baldwin, 2000; Pennebaker and Seagal, 1999) – at any age, from childhood to adult.

The characteristics of diagnostic markers that aid early diagnosis:

- Have a high sensitivity and specificity

- Are quick to learn and easy to administer
- Contribute to the overall assessment of the person

These are all essential when the available medication can hold the disease for only a limited amount of time.

3.4. Theory question 3: Are there any differences in the narrative constructions of life events, as interpreted by the Biographic Narrative Interpretive Method between the patient and control groups?

If there are differences between the ways patients and controls recount their life events during the LEDS interviews, then a way is needed to gain qualitative data that could enrich the data from the LEDS interviews. The method needs to provide data that:

- Complementary to the data already gained, to triangulate the LEDS and EWC data
- Includes unstructured and unguided narratives about life events
- Allows for greater exploration of life events, resulting in much richer data

A number of different methods were considered that would be appropriate to gaining qualitative data that would fulfil the above requirements. The key literature discussed includes Foucault, narrative analysis approaches, and the Biographic Narrative Interpretive Method (BNIM), which could answer TQ3.

3.4.1. Foucault's approach

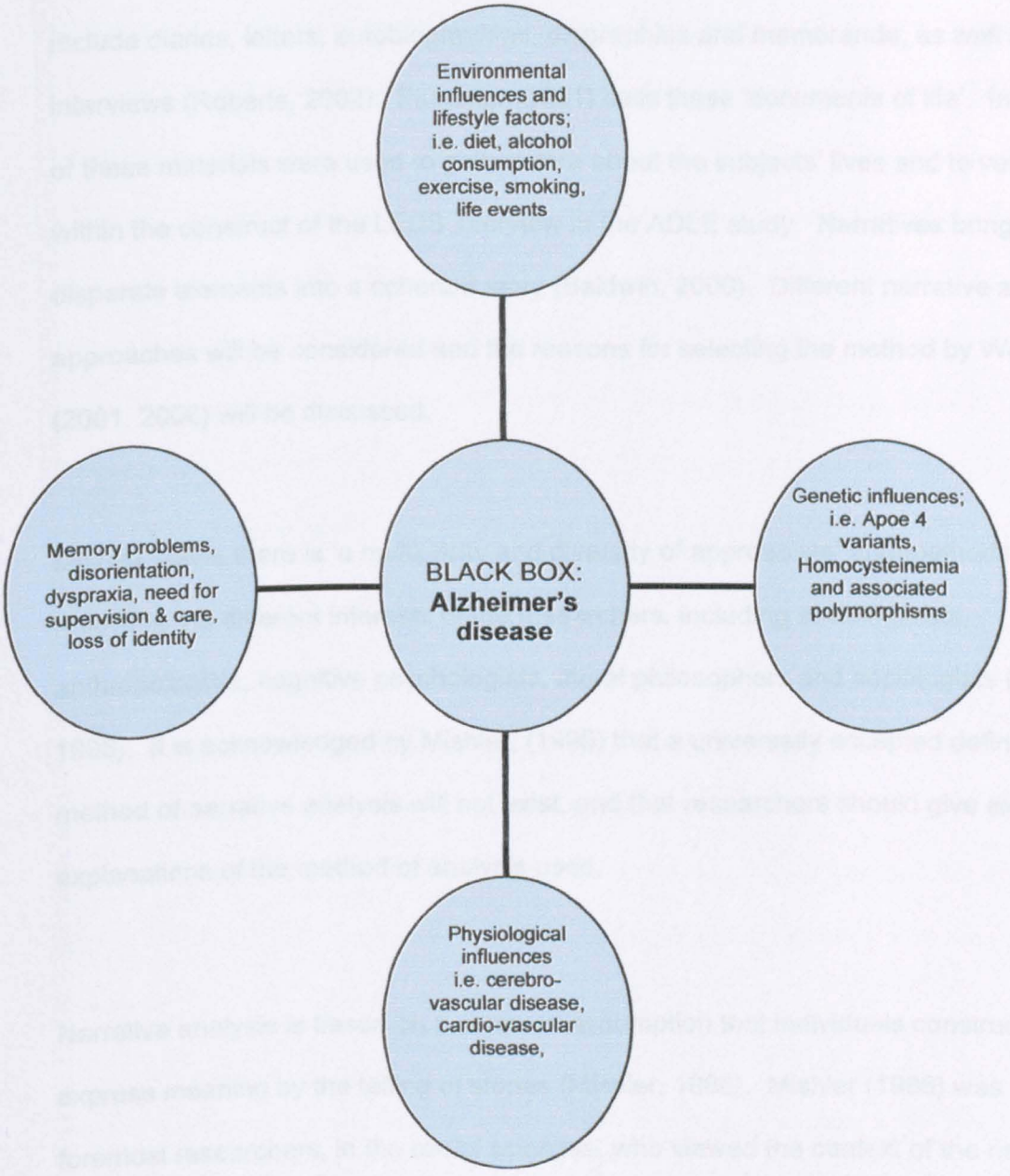
Foucault examined problems throughout history. He used a problem-based approach to history, rather than a period-based approach (Kendall and Wickham, 1999), as well as examining how systems contribute towards a phenomenon, whilst understanding how the particular phenomenon relates to other phenomena (Kendall and Wickham, 1999). Foucault has his own method of discourse analysis, which is not purely about language (Kendall and Wickham, 1999). The discourse analysis is a method of describing how a phenomenon came into being, by deconstructing the circumstances and examining the various factors that brought it about. The phenomenon, in this case, would be Alzheimer's disease, and one of the various factors would be life events and difficulties. Other factors

would include those listed in Figure 3.4, in the three circles that represent influential factors. The advantage of using this method is that it is possible to see how Alzheimer's disease is constructed by health and social systems, and how it is then subsequently researched and managed.

Foucault's analysis of knowledge was applied to science by Bruce Latour, who, as Foucault did, used a problem-based approach and a description of the conditions that allow the scientific knowledge to emerge (Kendall and Wickham, 1999). Latour used the 'black box' method, which simplifies what is being studied (Kendall and Wickham, 1999). The 'black box' method is used when scientists are examining something too complex to understand at that time. The scientists draw a black box around whatever is too complex; arrows to indicate what goes into the black box and what goes out of the black box; the actual contents and workings of the black box are not examined (Kendall and Wickham, 1999). Kendall and Wickham (1999) state that a strong piece of knowledge will be black-boxed further and further in, so that the unknown complex part will become smaller with each new knowledge gain.

Latour's idea of the black box could be used in the analysis of the interviews (see Figure 3.2) below.

Figure 3.2 Diagram of Latour's black box.



Whilst Foucault's approaches are useful in examining the overall construction, management of, and research into, AD, they do not facilitate the answering of the specific theory questions of this study, and could lead to a method that is reductionist in nature, rather than enhancing the depth of the data.

3.4.2. Narrative analysis

The narratives of the life events lend themselves to narratives analysis. Narratives can originate from either speech or writing and, usually, are primarily autobiographical. Biographical research considers a wide variety of materials as suitable for research; these include diaries, letters, autobiographies, biographies and memoranda, as well as interviews (Roberts, 2002). Plummer (2001) calls these 'documents of life'. Indeed, some of these materials were used to gather data about the subjects' lives and to verify dates within the construct of the LEDS interview in the ADLE study. Narratives bring together disparate elements into a coherent story (Baldwin, 2000). Different narrative analysis approaches will be considered and the reasons for selecting the method by Wengraf (2001, 2008) will be discussed.

Mishler states there is 'a multiplicity and diversity of approaches' and methods of analysis, reflecting the different interests of the researchers, including sociolinguists, anthropologists, cognitive psychologists, moral philosophers and sociologists (Mishler, 1995). It is acknowledged by Mishler, (1995) that a universally accepted definition of the method of narrative analysis will not exist, and that researchers should give explicit explanations of the method of analysis used.

Narrative analysis is based on a common assumption that individuals construct and express meaning by the telling of stories (Mishler, 1986). Mishler (1986) was one of the foremost researchers, in the social sciences, who viewed the context of the narrative response as essential to the process of understanding the meaning of what was being said, rather than as a complication that needed to be managed, as in the positivist experimental process used by other researchers who focused on behaviour and variables. Mishler (1986) views any interview as being constructed jointly by interviewer and respondent, and issues of discourse, context and meaning are fundamental to his theory of narrative analysis. In summary, Mishler does not advocate a particular prescribed method of narrative analysis, but upholds the belief that the narrative should be analysed

in context. The context gives the narrative meaning, and it is the construction and expression of the narrative that gives it the meaning, as well as the stories themselves that are of interest in the ADLE study.

Polkinghorne (1995) discusses two paradigms of narrative analysis, which are described as *narrative analysis* and *analysis of narrative*. *Analysis of narrative* uses inductive analysis, to refine conceptual categories (Roberts, 2002). *Narrative analysis* is 'a story, or a storied episode of a person's life' (Polkinghorne, 1995), which is seen as an explanatory story (Roberts, 2002) of the events recounted. Both methods are used in the ADLE study and complement each other in their diversity. The ADLE study uses the EWC, as an analysis of narrative, to examine the emotional expression of the life events. This gives information about how the life events are constructed piece by piece. *Narrative analysis*, it could be argued, is based on methods that are more holistic in origin, seeing the narrative as a whole, portraying and constructing what the person wants to convey.

Plummer (2001) describes narrative analysis as being comprised of key elements that need consideration: story, plots, characters, themes and story-lines, genres and structures, speech acts and the conversational unit and tropes (metaphors, images and irony). Plummer (2001) also states that if life narratives are to work well they need the following:

- A sense of ordering of events
- A sense of the person behind the text – a coherent identity and stability, with predictability
- A sense of voice and perspective, an identifiable narrator
- A sense of causality – plots matter, people are motivated to do things and there are reasons things happen, 'if this, then that'

There are many different methods of constructing a narrative of someone's life; Plummer (2001) mentions only thirteen of them. The discipline is still evolving, and this is evident from debates within the field; Narrative and Memory Research Group (2009), BNIM group discussions (2009). The Biographic Narrative Interpretive Method by Wengraf (2001,

2008) of interviewing was chosen because it was able to meet the points stated by Plummer (2001) and would fit the requirements of the ADLE study, as discussed above:

- The BNIM complements the data already gained, to triangulate the LEDS and EWC data
- BNIM includes unstructured and unguided narratives about life events
- BNIM allows for greater exploration of life events, resulting in much richer data

3.4.3. BNIM

Wengraf describes the BNIM as a 'lightly structured depth interview' (2001) as it initially restricts interviewer interventions to a single question: interviewer interventions are left until a later stage. Wengraf also describes the approach as a biographical reconstruction that can contribute to the sociological understanding of a person (as acting units in society) and towards understanding society in its historical and social structures (limiting and enabling interaction). The BNIM has combined aspects from Roberts, Plummer and Mishler, arriving at a tool that can successfully incorporate a wide variety of different research questions that can be posed within the structure of the BNIM (2001).

The details of how the interview is constructed are described in *Chapter 5: Methods*, a brief overview is given here.

In subsession 1 of the BNIM interview, the Single Question aimed at Inducing Narrative (SQUIN) used in the ADLE study BNIM interviews was:

> *Please tell me the story of your life, all the events and experiences that have been important to you personally; begin wherever you like, I won't interrupt, I'll just take some notes for afterwards.*
>
> (Wengraf, 2001)

After the single question, the interviewer is limited to making facilitative noises and non-verbal support, in order to allow the participant to present their life history in the way they wish to, without being disturbed or interrupted by the interviewer. The participant usually ends subsession 1 themselves by concluding their life history, by running out of things to

say. After a short break after subsession 1 before subsession 2 begins (or it can follow on immediately after subsession 1). Subsession 2 requires the interviewer to ask further SQUINs about the life events and experiences recounted by the interviewee to develop further details of the life event or experience mentioned, and to produce narratives (Particular Incident Narrative or PIN). PINs take the form of 'he said...then she said...and then...' and so on. The SQUINs must be asked in the exact order of the events relayed during subsession 1 to protect the mode of presentation, which is essential for the analysis. Subsession 3, if done at all, is done at a different time to the others, and is used to ask about and fill in knowledge gaps (usually questions about what happened when). The transcripts of the first two subsessions are summarised into sections, and then analysed into two strands: *the lived life* – a chronological order of events; and *the told story* – how the person presents their life in narrative form. These two strands are each examined by separate panels of people, to help the researcher interpret what was happening during the person's life at that point. These strands are then combined into a case history, and chosen pieces of text in the transcript are 'micro-analysed' to give greater depth to the data and case history. From this data, the CRQ and TQs can be answered.

The researcher has found no published critiques of Wengraf's BNIM approach, although there are heated debates, in the email group (BIOGRAPHIC-NARRATIVE-BNIM@JISCMAIL.AC.UK), about issues arising from the BNIM approach. Although presumably those who do not agree with the BNIM approach are unlikely to join the email group, it could be argued that this is a preliminary peer review process, the group being open to anybody. The BNIM approach is a good introduction to both narrative analysis and biographical approaches, it gives structure and meaning to the research interview process, whilst preserving the unstructured essence of the narrative interview (and allowing the interviewee to talk), and narrate their own life history. In the ADLE study, it facilitates the answering of TQ3 in a way acceptable to the participants and researcher, and contributes a context and meaning to the qualitative data and research process,

whilst focussing on the response of TQ3. The detail of its use with ADLE participants is discussed in *Chapter 5: Methods*.

3.5 Conclusion

This chapter has reviewed the relevant literature concerning:

- Studies associating life events with AD
- Brown and Harris's LEDS approach
- How life events are biologically linked with AD
- The emotional expression of life events and how to measure them with:
    - Danner et al.'s EWC
    - The BNIM approach.

These approaches will answer the CRQ and TQs by using a mixed-methods approach that will ensure triangulation within the ADLE study, to complement, supplement and corroborate each method (Denzin and Lincoln, 2005; Patton, 2002). Furthermore, *Chapter 3: Literature review* has identified gaps in the literature regarding the association between life events and AD, which the ADLE study addresses, as well as identifying potential contributions to the diagnostic process of AD. *Chapter 4: Methodology and ethical issues* explores the methodologies in more detail.

Chapter 4: Methodological and ethical issues

4.1. Introduction

This chapter will discuss the rationale behind the choice of design and method for the ADLE study. The methodology chosen emerges from the CRQ and TQs (see *Chapter 1: Introduction*). The CRQ (Are life events a risk for AD?) was the result of questions asked by participants, their relatives and OPTIMA team members. The CRQ was addressed using mixed methods.

Also in this chapter the ethics of the ADLE study will be explored with reference to the Mental Capacity Act (2005) (MCA) and the Code of Practice (2007).

The methodology of the ADLE will be examined using Denzin and Lincoln's (2005) five research processes of:

- Phase 1: The researcher as a multicultural subject
- Phase 2: Theoretical paradigms and perspectives
- Phase 3: Research strategies
- Phase 4: Methods of collection and analysis
- Phase 5: The art, practices, and politics of interpretation and evaluation

These will be discussed in relation to the CRQ and the TQs.

4.2. Phase 1: The researcher as a multicultural subject includes the history and research traditions, conceptions of self and other, and the ethics and politics of research.

The history and research traditions of the ADLE study originate from the post-positivist research of OPTIMA and those who constructed the CRQ: the participants, the relatives of the participants and the OPTIMA team members. Because OPTIMA works within the post-positivist paradigm, all of the substudies use quantitative methods and the participants envisage all the studies they participate in to be of the same genre: involving causal relationships between variables, enabling research to be generalisable, and

producing empirical 'truth'. OPTIMA functions within the post-positivist paradigm, rather than a positivist paradigm, as the values underpinning OPTIMA are based upon findings that are 'probably true', whilst recognising that the vagaries of human physiology are such that there are variations within any real 'truth' about a disease. The influence of OPTIMA on the ADLE study was from the beginning when the CRQ was constructed by the participants, the relatives of the participants and the OPTIMA team members. Giddings (2006) states that careful consideration must be given to the assumptions underpinning the research approach, to ensure congruence between the chosen methods and the research question, and that a sensible research approach to the research question needs to be identified first (as it was in the ADLE study).

In the context of the post-positivist paradigm, TQ1 and TQ2 are both based upon needing answers that require measurement and need data that can be generalisable to others. TQ3 was designed to capture experiences that would be missed in TQ1 and TQ2, and to add data that brought richness and depth to the ADLE study. TQ3 used a qualitative methodology to complement the quantitative data. The ADLE study has been the first one within OPTIMA to use a qualitative method: it has been received and supported positively and with interest from both members of the team and the participants, who have recognised its integrative function in the overarching aims of the research unit.

Part of the reason behind the positive reception is that OPTIMA is a longitudinal study: some people have been participants for up to 19 years, and relatives still keep in contact following the participant's death. The participants would not have remained within the study unless they were treated as valued and respected participants. The respect and value come from the OPTIMA research teams viewing the participants as individuals whose contribution to the research process is essential. These values intrinsically affect the research process of the ADLE study.

Action research and participant inquiry were not considered as options for the ADLE study because of the context of the research. Although both action research and participant inquiry can include mixed methods, and be more responsive to those disadvantaged (for example those who have memory problems), these methodologies would have been considered too radical for the post-positivist OPTIMA research team, within which the ADLE researcher was located. An introduction to qualitative research including a mixed-methods study, which shows how qualitative data can enhance quantitative data, was a more acceptable method of change for the research team. The foundations have been laid and can be built upon.

The ethical principles that govern undertaking research on vulnerable adults are respect for autonomy, nonmaleficience, beneficence and justice (Beachamp and Childress, 2001). These four principles are one of the most commonly used frameworks within medical ethics (Slowther et al., 2004) and are an aid to balance judgement. These four moral principles have been selected by Beachamp and Childress (2001) by examining considered moral judgements and the way that moral beliefs are united. Beachamp and Childress describe principles as 'general norms' that leave space for judgement and reflection for identifying and reflecting moral problems (2001). They can be used to underpin decisions. The four principles will be discussed in turn, with relevance to research on vulnerable adults and the MCA (DoH, 2005).

4.2.1. Respect for autonomy and nonmaleficence

This covers the definition of autonomy, capacity of choice, what is capacity, decision-making, issues of informed consent and the MCA.

Personal autonomy is self-rule free from both controlling interference by others and from limitations that prevent meaningful choice, for example inadequate understanding (Beachamp and Childress, 2001). Downie and Calman (1994) describe an autonomous person as having the ability to be able to choose for oneself or to be able to formulate and carry out one's own plans. This is inextricably linked with having the capacity to choose

what to do in everyday life as well as making more extensive decisions. The definition of nonmaleficence is a concept based on intentionally refraining from actions that cause harm (Beauchamp and Childress, 2001).

Mental capacity is defined by the MCA (DCA, 2007) as being able to make a decision that affects normal daily life, as well having the ability to make a decision that may have legal consequences. The ADLE study was given ethical permission as long as all the participants were assessed as having capacity: thus, the researcher needed to be aware of what this involved. The MCA has five statutory principles that will be addressed as they become relevant to the ethical principles discussed here. The first three are:

> 1. A person must be assumed to have capacity unless it is established that they lack capacity.
>
> 2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
>
> 3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
>
> (DCA, 2007)

The first statutory principle is determined by respect for autonomy, and the second and third are determined by nonmaleficence. Because informed consent is an ongoing process, the assessment of capacity is ongoing too. For the ADLE study, the question of capacity was based upon previous neuropsychological assessments (see *Chapter 2: Background*) as well as the capacity shown during the discussion of the ADLE study and consent to it: capacity was assumed unless they demonstrated they lacked it, as in the first statutory principle. The moral principle of nonmaleficence underpins the second and third statutory principles of the MCA, which involves the researcher not imposing risks of harm or inflicting harm. The concept of harm is defined by Beauchamp and Childress (2001) as 'thwarting, defeating or setting back some party's interests'. In this context, this relates to the second statutory principle of the MCA, when a person must be treated as having the ability to make a decision, and not be thwarted from doing so unless 'all practicable steps have been taken without success'. This would include ensuring communication strategies are appropriate and effective, such as: a clear, simple explanation that can be heard, a participant information sheet in big type, and other ways

of adapting to problems. None of these were needed during the ADLE study, and each participant was assessed, by the researcher, as having capacity to make the decision to participate in the one interview. The participants would be considered as fulfilling Stage 1 of the Test of Capacity (DCA, 2007) if they have a diagnosis of Possible or Probable AD, as it requires a diagnosis of a condition that impairs or disturbs the person's mental functions. Stage 2 of the Test of Capacity involves assessing whether they can make that specific decision when they need to. Points to consider are whether the person has:

1. Understood the relevant information about the decision
2. Retained the relevant information
3. Used that information in the decision-making process
4. Communicated their decision

(DCA, 2007)

The participants had at least 2 weeks to think about the study, and discuss it with their family, friends and health professionals. One person declined to take part in the BNIM interview phase of the ADLE study because she had just been informed that she needed to have a course of chemotherapy, and felt it would be too much for her to take on.

The participants needed to weigh up the risks they were to be exposed to. The risks the participants were exposed to include the risk of feeling emotionally upset due to the discussion of difficult life events, and of a catastrophic reaction (discussed in *Chapter 6: Results*). These are risks of which the researcher has experience and is used to preventing, identifying and managing on a daily basis. The ADLE study was approved by the Research Ethics Committees for both the Oxford Brookes University and the approved National Research Ethics Service, who considered the risks within the ADLE study acceptable.

With regards to the third statutory principle of the MCA, whether agreeing to participate in the ADLE was an unwise or wise decision is something the researcher cannot answer for the participant. It is the participants' perception of wise and unwise that needs to be taken into account, without judgement from others. The information was offered in the Participant Information Sheet, a letter of invitation and in discussion with the researcher and the patient's spouse or family.

4.2.2. Beneficence

The third moral principle of beneficence is described by Beauchamp and Childress (2001) as:

> 'Principles of beneficence potentially demand more than the principle of nonmaleficence because agents must take positive steps to help others, not merely refrain from harmful acts'

This principle is acted out in the fourth statutory principle of the MCA (DCA, 2007):

> 4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

Beneficence is different to nonmaleficence as it involves action to help others. The fourth MCA statutory principle demands that the action should be in the best interests of the person. There were no obvious benefits to the participants in taking part in the ADLE study, although many of them said they had enjoyed it and found it thought-provoking. The participants contributed knowing that they would not directly benefit, but that later on others would benefit from this study. This imbues the researcher with a moral obligation to use the results of the study profitably for the benefit of those the participants represent.

Without the third moral principle of beneficence, the first two moral principles of respect for autonomy and nonmaleficence could not be implemented. All three moral principles are interdependent in creating a research study that protects those that society would consider vulnerable, i.e. those who lack capacity.

4.2.3. Justice

Beauchamp and Childress (2001) define justice by defining what it is not, i.e. that of inequality in access to resources such as healthcare. Beauchamp and Childress (2001) state that the principles of justice are elusive and indistinct from the other ethical principles, but say that justice can be interpreted as:

> 'Fair, equitable and appropriate treatment in light of what is due or owed to persons.'
>
> (Beauchamp and Childress, 2001)

Thus it can be applied to the fifth statutory principle of the MCA (DCA, 2007), which is:

5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Even though the ADLE study was not given permission to recruit people with a lack of capacity, it was designed to take these conditions into account as there was nobody within OPTIMA, the Brookes University Ethics Committee, the local Research Ethics Committee or the Oxford University's Clinical Trial and Research Governance team who was able to give advice to the researcher on how the MCA Code of Conduct should be applied in this instance it was the first ethics application with regard to the MCA that they had all dealt with. Hence, the ADLE study was designed with reference to the MCA code of practice to ensure that the highest standards were realised. The decision to design the ADLE study this way was also taken with regard to ensuring that it was the most effective way of capturing the relevant information about life events, and that it would be generalisable to others, i.e. fair to all those participating and those who will benefit in the future.

The fourth moral principle of justice incorporates the 'fair opportunity' rule that requires that they receive the benefits needed to ameliorate the unfortunate effects of life's lottery (Beauchamp and Childress, 2001). The definitions of which properties demand being addressed is a constantly debated issue within society, and changes as society's morals change. It is as part of this change that organisations such as the Alzheimer's Society and the Dementia Advocacy and Support Network International (DASNI) are campaigning for the rights and recognition of people with dementia (PWiD): this includes the right to be included in research studies, and not be excluded because of paternalistic beliefs that protect them when they have the ability to make their own decisions. These judgements are not based on current values. This process of how values are articulated within this society is shown in the most recent UK Dementia Congress, which included a plenary session that centred on two PWiD giving an address. The National Dementia Strategy (DH/SCLG&CP/SCPI/SR, 2009) has included one PWiD in each group, although they are four people out of 55 (7%) in the project groups giving guidance for the strategy. It is hoped that the positive experience of including PWiD will encourage policy makers to involve a greater number in the future.

The ADLE study researcher views the researcher as a collaborator, and a vital partner in the research process, although this view is more congruent to the interpretivist, rather than the positivist or post-positivist. This reflects the aetiology of the CRQ and the ethos of OPTIMA.

4.3. Phase 2: The theoretical paradigms and perspectives that underpin

any research affects every aspect of the study. As already mentioned, the ADLE study has a mixed-methods approach. Whether the '*mixed-methods*' research process is considered as a '*third paradigm*' or a methodology is debated by researchers (Johnson and Onwuegbuzie, 2004; Denzin and Lincoln, 2005; Giddings and Grant, 2006; Greene, 2008). There is a view that the mixed-methods research process has its own paradigm and ontology of pragmatism (Johnson and Onwuegbuzie, 2004; Greene, 2008,) that guides the decisions made in the research process, while others (Denzin and Lincoln, 2005; Giddings and Grant, 2006) surmise that it has evolved from post-positivist research, and can be located in any ontology. Denzin and Lincoln (2005) state that mixed-methods research that is derived from post-positivist research includes qualitative research as a secondary research method. For convenience, or pragmatic issues, the ADLE study has used the post-positivist structure as the primary structure, as the comparison of case-controls extends into both the quantitative and qualitative components.

The interpretive paradigm has influenced the answering of TQ3 and underpins the research strategy and method chosen, in order to produce findings that illuminate the complexity of the quantitative findings (Giddings and Grant, 2006).

4.4. Phase 3: Research strategies include the design of the study. The TQ1

and TQ2 require strategies that involve measurement, and the case-control semi-structured interviews with a selection of the participants were random and convenience-based.

TQ3 used the BNIM interview, which could be considered to have its roots in grounded theory: discussions with Tom Wengraf (Personal Communication, 2009) state that it is a blend of many approaches, and that it can be used in many different ways. Wengraf's (Personal Communication, 2009) assessment of the epistemology of the BNIM is allied to Johnson and Onwuegbuzie (2004), who state that methods should be chosen not for their epistemological knowledge of the method, but for pragmatic reasons, and that boundaries between qualitative and quantitative fields should be well traversed. The pragmatism of the method is behind Giddings and Grant's (2006) affirmation that it can collect comprehensive information about a phenomenon that can then guide decisions about research practice. The ADLE study sampling method was based upon convenience (pragmatic) concerns: participants who fitted the criteria were identified from the OPTIMA database and identified for each case-control group.

Three interviews in each group were considered enough after discussion with Tom Wengraf (Personal Communication, 2006), and reviewing the literature. Wengraf (2008) states that quality not quantity is the priority: in a European study, Wengraf (1998) used six interviews for each category in each country, analysing one or two in depth. The remaining studies were analysed in much less detail as partial or contrast cases, and their transcript examined for important variations. Because of the richness of the data gained, three per category has been found to provide the necessary data to answer the research questions (Wengraf, 2008). The two chosen (i.e. one patient and one control) for the in-depth data were chosen because of the quality of the interviews, guided by the researcher's sense of what was the most interesting and rich in potential for answering the CRQ (Wengraf, 2008).

4.5. Phase 4: The methods of collection and analysis are the tools that have been chosen to carry out the research. For TQ1, the LEDS interview was chosen as the appropriate tool for the collection of data about life events, as the most reliable and valid method for the context (reliability and validity will be discussed in Phase 5). For

TQ2, Danner et al.'s EWC was the method of analysis for the emotional expression. Analysis was computer-assisted, using SPSS and QSR N6.

TQ3 used the BNIM interview method of data collection and analysis: the interviewing process of the BNIM is unstructured (as described in *Chapter 3: Literature Review*), and produces much richer data during the interview. The analysis is similar to the grounded theory, using predictive hypotheses, and the multiplication of counter-hypotheses and tangential hypotheses (Wengraf, 2001) (this is described more fully in *Chapter 5: Methods*). Thematic field analysis is used throughout the generation of hypotheses, to make the researcher aware of the other possibilities that could have occurred. The other elements identified in the BNIM approach include life history, biographical interviews, narrative analysis and psycho-analytic interactionism.

4.6. Phase 5: The art, practices, and politics of interpretation and evaluation include the criteria for judging accuracy, policies and practices of interpretation, writing as interpretation, policy analysis, evaluation traditions and applied research. The criteria for judging accuracy are different for the post-positivist and interpretivist approaches. As per post-positivist approaches, TQ1 and TQ2 were approached with a view on their validity and reliability, aiming for a 'value-free' study (Holstein and Gubrium, 2005). Post-positivism acknowledges that research cannot be completely value-free, as positivist research used to attempt to be. TQ3 was approached with a view to understanding credibility and truth for the qualitative component.

The method used for TQ1, the LEDS interviews, has been used in over 30 years of research studies, and is well respected within the life events research field. The validity and reliability will be discussed in relation to their use in the ADLE study.

Shapiro (1979) critiques the validity and reliability of the LEDS, described in *'The Social Origins of Depression'* by Brown and Harris (1978), which explains the link between life

events and depression from the studies undertaken by Brown and Harris. The two critical aspects of the book concerned with validity are:

- The methods of selecting patients are open to contamination by the views of the investigators (validity)
- The procedure for eliciting life events is unvalidated

The three critical aspects concerned with reliability are:

- the assessment of the severity of life events is based almost entirely upon the subjective judgements of a handful of investigators
- the methods of analysing data appear to be selective and ambiguous
- important conclusions often seem to be inconsistent with the findings.

Criticisms of the reliability and validity, raised by Shapiro, are important to review, so they can be avoided in the ADLE study.

4.6.1. Validity

Shapiro (1979) states that the method of selecting patients is open to contamination by the views of the investigators because of the method of recruitment. Brown and Harris recruited women, for their study on depression, directly from the community, and the diagnoses of depression were given from the interviews that the project workers (who were not trained in the psychiatric field) rated themselves: they were sometimes checked by the research psychiatrist, but not always. Shapiro's argument is that the project workers were not independent, and so were potentially biased. Shapiro (1979) suggested that it would have been potentially less biased if the depressed women had been recruited from those already diagnosed as depressed by a clinically responsible psychiatrist. As the ADLE study recruited people from OPTIMA who have been through a diagnostic process, thus preserving independence and objectivity in the process, this potential source of bias is reduced.

The selection of 'normals' (or controls) is also criticised in *the Social Origins of Depression* for having an invalid, or biased, measurement of depression. The controls were women selected at random from households, and who were screened for depressive symptoms,

rather than clinically screened for depression. This point is crucial. It meant that those women who were interviewed by the non-medical project workers, and were found to be experiencing depressive symptoms, were classified as depressed - even though they may have only had depressive symptoms, not a clinical diagnosis of depression. Shapiro reports that the interview used (the Present State Examination) was not able to discriminate between symptoms of a stressful period in a person's life and depression. This led to all those who had symptoms, such as depressed mood, muscular tensions, worrying, irritability and early waking, being classified as having depression (cases). Those that were classed as depressed by the non-medical project workers were added to the clinically diagnosed cases. Because it is likely that severe life events can produce the same symptoms, the result was that all those who had symptoms (and, therefore, were probably undergoing life events) were, in the cases, potentially skewing the results. However, it is known that depression is underrecognised and underdiagnosed by general practitioners and, even in the 21st century, according to the DSM-IV criteria (Krupinski and Tiller, 2001), only 28 per cent of general practitioners were able to diagnose accurately a major depressive disorder. With this lack of an accurate diagnosis of depression, and so many cases of depression being untreated (this point could be questioned ethically), it could be argued whether there were as many cases of depression as those reported by the Brown and Harris team.

Shapiro (1979) also questions how the randomly selected women were motivated to take part in the research, what they were told about the purpose of the survey, and how this influenced what they said. This raises the question of what motivates people to join research projects. Some of the reasons for joining OPTIMA (and therefore the ADLE study) are altruism, having an interest in AD because the participant has had a relative with AD, or because of having personal worries concerning their memory. Had an interviewee, from any of the studies, been asked why he or she had agreed to take part, the reason given as an answer might have been the one that the interviewee thought the interviewer expected them to say, rather than the 'real' reason. Many expectations surround the relationship between the research interviewer and the interviewee, who,

again, comes with his or her own world view, shaped by individual experiences that have been conceptualised as thoughts, ideas and concepts (Benton and Craib, 2001). This makes every interview, no matter how standardised or objective, a unique interview with a distinct context, as stated by Mishler (1986).

In the ADLE study, the controls were recruited from the controls who are part of OPTIMA and, although the OPTIMA team may never know the real reason why the person joined the study, a relationship is built up over the years, and people are seen in their own dynamic environment, their home – their context, which provides additional information about people and their lives.;

Shapiro (1979) disputes whether the elicitation and assessment of life events (in *The Social Origins of Depression*) should have been considered 'valid', but without clarifying what he would consider 'valid'. Shapiro suggests that Brown and Harris should have carried out a study to compare the results of their interviewing with the results of consultation of other sources to verify the life events. The ADLE study included the consultation of other sources, particularly with the patients, which, in Shapiro's view, would increase the validity (i.e. making the study value-free) of the use of the LEDS. These aspects of validity that have been incorporated in the ADLE study, and ensure that the validity is of a higher standard than the life events studies reviewed in *Chapter 3: Literature Review.*

4.6.2. Reliability

Shapiro (1979) states that the assessment and rating of the events are subjective, and that this is a criticism of Brown and Harris's book: once again, he does not suggest a method to correct this subjectivity. The ADLE study will follow the ratings of the LEDS, and so would be under the same judgement from Shapiro: the use of the LEDS to discuss life events over their lifetime, with people who have early AD, had not been undertaken before. With the confirmation of life events from other sources, it has been shown that this is a reliable method of eliciting life events, within the post-positivist approach. The

inclusion of the TQ3 redresses this balance, giving the participants a voice of their own about life events and experiences.

Shapiro's (1979) opinion that the methods of analysis are selective and ambiguous have some justification: there is a lack of coherence about the examples in *The Social Origins of Depression.* The manual for the LEDS by itself is, however, a huge quantity of data to assimilate, and to summarise for others to read coherently in one manageable book. The same reason could be posited for the important conclusions being inconsistent with the findings. Equally, Shapiro could be concluding that the book is incoherent because, by his own admission, he had not read chapters 7 to 16 (inclusive), despite stating that Brown and Harris do not analyse their work as a whole.

In 1994, a project was initiated to preserve all the data from the studies by Brown and Harris, which would enable others to use the data for further studies with (protected) access via the internet (Corti and Ahmad, 2000). This does not seem to be the actions of researchers who wish to conceal any problems with invalid conclusions or inconsistencies.

Shapiro (1979) ascertains from *The Social Origins of Depression* that 'it is apparent that the main emphasis was placed, at every step, upon the subjective judgements of the project workers', and regards this as a negative contribution to the research: yet he answers this criticism from his own statements, with the following extract from the same paper on the subject:

> *Relative subjectivism may, perhaps, be regarded as a tendency of the investigator to regard his own judgements and decisions as primary. He will therefore focus his investigations upon those judgements and decisions as primary. The relative objectivist would, on the contrary, try to minimise the role of his own judgements and to maximise the relative independence, from his judgements, of the phenomena which he is observing. It is probably impossible to achieve this aim completely; hence the term 'relative objectivism'.*

Shapiro (1979) has encapsulated the problem he has with *The Social Origins of Depression* and the LEDS: Brown and Harris's work is based upon a subjectivist

epistemology, as confirmed also by Harris's quote that 'reality is a social subjectivism' (Harris, 1997), and Shapiro's work is based upon an objectivist epistemology (Shapiro, 2002). Shapiro acknowledges that relative objectivism is not absolutely objectivist, but does not recognise there is a continuum between the objectivist and subjectivist. Accepting this continuum, whilst recognising the shortcomings of both epistemologies, enables the positive contributions that arise from both epistemologies to be realised and the research process enhanced. As stated by Crotty (1998), objectivity and subjectivity need to be brought together and held together indissolubly: constructionism does precisely this in the interpretive component of the ADLE study.

Interviews based on structured or semi-structured questions, and involving two human beings, each with their own peculiarities, bring inconsistencies in the context and content of the interviews. As Mishler (1986) states, context should be seen as an essential component of the interview, and the expression and meaning contained within it, rather than as a technical problem that has to be overcome. During the collection of positivist data, a quandary occurs concerning the idea of the context being part of the interview that has to be assimilated into the method. The effect of incorporating the context disrupts the positivist theoretical perspective, the observational and experimental methodology, and, ultimately, the objectivist epistemology. This disrupted positivist research is now recognised as postpositivist (Denzin and Lincoln, 2005), acknowledging that only partially objective accounts of the world can be produced, because all research methods are flawed.

4.6.3. Credibility and trustworthiness

Instead of reliability and validity, the evaluation of the methodology for TQ3 will use credibility and trustworthiness. Patton (2002) states that the credibility of qualitative research is dependent on three inquiry items: rigorous methods, credibility of the researcher, and the philosophical belief in the value of qualitative inquiry. These will be examined with reference to the qualitative component of the ADLE study.

Methods are considered rigorous if they yield high-quality data that are analysed in a systematic manner, depending on the researcher's ability to recognise a pattern (Patton, 2002). The researcher needs to be able to report a systematic search for alternative themes, divergent patterns and rival explanations, involving a search for data that prove other explanations, and looking for the 'best fit' of pattern to explanation (Patton, 2002). The ADLE study uses the BNIM (Wengraf, 2001) interview method and the system of analysis that includes the attributes mentioned above, i.e. recognition of patterns in the data that involve an active search for other explanations with the use of the BNIM panels and the strategy of seeking data for alternative theories. Patton (2002) suggests an adversarial method of testing the data, and whether it fits the pattern. However, the BNIM panel is a preferable method of opening up the researcher's mind to alternative theories because it does not force the data into one theory or another (i.e. the 'right' one or the 'wrong' one), but panel members create other theories in addition to those the researcher might have already. This enables the researcher and panel members to evaluate how the data fit the theory, and supports the rigour of the study (see *Chapter 5: Methods* and *Chapter 6: Results* for details of panels).

Patton (2002) suggests the use of various types of triangulation within studies to increase their rigour and therefore credibility. Triangulation within the ADLE study uses data from the mixed methods (i.e. TQs 1 and 2, which complement TQ3), and reveals different aspects of the experience of life events being studied, so adding to the richness of the data and the analysis. This increases our understanding of the experience of life events and AD, and the new data the ADLE has to contribute to the potential diagnostic properties of narrative analysis and the gap in this field of knowledge.

The recognition of how the design of the study can affect the results must also be noted, as Patton (2002) states that the researcher must '*consider the rival methodological hypothesis that the findings are due to methodological idiosyncrasies*'. To remedy this, the study methods must be discussed in detail to allow the reader to decide for themselves (Patton, 2002): the ADLE study has been discussed in detail in *Chapter 5:*

Methods, and the reader can judge whether any methodological differences would have affected the results.

In addition to the criteria of credibility of Paton (2002), the criteria of Charmaz (2005) are included. Criteria for grounded theory studies from Charmaz (2005) also include originality, and whether the study has fresh categories, new insights, or a new conceptual rendering of the data. The ADLE study fulfils all of these criteria: it has fresh categories within the analysis that no other study has examined in the field of AD research, it is providing new insights through the use of methods that have not been used in these situations before, and the new conceptual rendering of the data is shown in *Chapter 7: Analysis and discussion* onwards in this thesis. Charmaz (2005) also questions the social and theoretical significance of the study and how it challenges, extends or refines current ideas, concepts and practices – these questions will be addressed in *Chapter 7: Analysis and discussion* onwards.

The credibility of the researcher is essential to increasing the credibility of the research study (Patton, 2002), and evaluating the competencies and biases of the researcher. The ADLE study researcher has been trained in the use of the BNIM, and practised the use of it with similarly trained colleagues and those with expertise in qualitative research, as suggested by Wengraf (2008). Having completed the LEDS interviews and analysis before the BNIM interviews, it is possible that this has led to researcher bias. These issues need to be highlighted in the study, and the reader can arrive at their own conclusions about whether the researcher has been biased in the ADLE. The researcher has over 20 years of experience working with people who have dementia, of which over 13 years are in the field of dementia research: therefore, the researcher is familiar with the subject and its application in a number of different settings, and would be considered a credible researcher by others in the field.

The philosophical belief in the value of qualitative inquiry is the Patton's last measure of credibility (2002), and questions whether the researcher has a fundamental appreciation

of the whole qualitative research process. Patton suggests an understanding of both quantitative and qualitative research, their limitations and differences, is needed, and which data is needed for which purpose is needed. In the ADLE study it is clear what the different types of data have contributed, and the shortcomings of both methods are complemented by each other. In the discussion about the philosophical belief in the value of qualitative inquiry, it becomes apparent that what underlies the statement by Patton are the two different approaches to the definition of truth. Post-positivist research recognises that there is no absolute truth, but suggests methods of measuring and quantifying the data in order to obtain truth: interpretivists recognise that there is more than one truth or reality. Patton (2002) gives the following advice in determining how truth is demonstrated in research studies:

> *'Describe them and what you bring to them and how you've reflected on them, and then let the reader be persuaded, or not, by the intellectual and methodological rigour, meaningfulness, value and utility of the result.'*

4.7. Conclusion

This chapter has reviewed the choices behind the mixed-methods approach for the ADLE study, using Denzin and Lincoln's five phases of the research process in relation to the CRQ and TQs. Beauchamp and Childress's four moral principles were used to examine the ethics behind the mixed-methods approach of the ADLE study, with reference to the five statutory principles of the MCA (2005) and the Code of Conduct (2007). Methods of evaluation of both the post-positivist and the interpretivist approaches have been discussed, so that the reader can assess the methods of answering the TQs, and consequently the CRQ. In the researcher's opinion, the ADLE study is more reliable, valid, credible and trustworthy than those reviewed in Chapter 3: Literature Review, and therefore is contributing to the knowledge gap in the field, and influencing future research in this area that is contributing to:

- The field of life events and AD
- The potential diagnostic properties of linguistic analysis.

Chapter 5: Methods

5.1. Introduction

This chapter will discuss the methods used in relation to the design of the ADLE study, and the consequences of such choices. The LEDS and BNIM interviews will be discussed, and the rating and coding of the LEDS interview data, in preparation for analysis. Danner et al.'s EWC (2000) is explained and aspects of the additional coding demonstrated.

Before using the LEDS (1978) in the ADLE study, the LEDS was trialled in two pilot interviews, one with a person with memory problems, and one with a person without memory problems. This was to ascertain the feasibility of using the LEDS with people who have a largely intact long-term memory but short-term memory loss, as occurs in the symptoms of early AD.

The BNIM (Wengraf 2001, 2008) was chosen as a qualitative research method to complement the data already captured through the LEDS interview. As discussed, the LEDS interview is a semi-structured interview: therefore, the data gathered are, to some extent, lead by the interviewer, as there are specific questions to elicit specific topics. This ensures that data about the whole of the person's life are captured through their life events. In contrast, the BNIM interview begins with a question that enables the interviewee to take control of the interview and to frame their life events as they wish.

5.2. LEDS interviews and sample selection

The study is a case-control study, using data from the patient and control groups.

The criteria for the LEDS interviews included participants from the patient group who had DSM-IV or NINCDS-ADRDA diagnoses of Probable or Possible AD, and who were able to remember their life history as shown by:

- Neuropsychological testing of their remote memory, using the Camcog (Roth et al., 1988), in particular the comprehension and expression subscores
- Comparison between their past medical and family history and information acquired from a close relative (as in the *CAMDEX* interview (Roth et al., 1988))
- The medical history from the medical and research case notes.

The patients, recruited consecutively from the OPTIMA database, had already attended the discussion session with the results from their first assessment. This also ensured that the patients were in the earlier stages of the disease, and judged as having mental capacity, as discussed in *Chapter 4: Methodology and ethical issues*, and able to give an informed consent to the ADLE Study. There were 21 participants in the patient group, and 21 in the control group. 42 interviews being done in total: however, one of the patients died and was found to have a neuropathological diagnosis of Lewy Body dementia (this is not unusual in an early diagnosis of cognitive impairment). This participant and his age-matched control were removed form the analysis, leaving 40 participants in the analysis, 20 in each group.

For the BNIM interviews the criteria included participants who:

- Have a diagnosis of early Probable or Possible AD and are able to understand instructions
- And express themselves clearly, as defined by their neuropsychological testing.

The controls for the LEDS interviews were age matched (within 5 years) and gender matched with patients, and had never had a DSM-IV or NINCDS-ADRDA diagnoses of Probable or Possible AD (see *Chapter 2: Background information*). Controls for the BNIM interviews also had never had a DSM-IV or NINCDS-ADRDA diagnoses of AD or dementia, and were able to understand instructions and express themselves clearly, as defined by their neuropsychological testing. All Controls were recruited from the OPTIMA cohort, where Control subjects are defined by the lack of significant cognitive deficit over a period of at least two years, with cognitive testing repeated each year.

5.3. The interview

The participants were invited to take part in both interviews for the ADLE study by letter, and 2 weeks later received a telephone call from the researcher to discuss the study and to ascertain if they would like to meet for the LEDS interview. A stamped addressed envelope was provided for the BNIM interview. The meeting would include discussing consent to the study and, by agreement, the interview. In fact, this was all carried out in the same session for the ADLE study participants: it was a process with which the cohort was familiar, having already shown interest in the research by joining OPTIMA.

5.3.1. Interview content

For the majority of participants, the interview was conducted in his or her home as this was a familiar place. The LEDS and BNIM interviews lasted variable amounts of time, from 1 to 3hours.

5.3.1.1. LEDS interviews

For the LEDS interviews, participants occasionally needed non-verbal encouragement, additional prompts and statements to clarify what was being said, so that they were not subjected to a barrage of questions, which they would have felt intrusive when discussing such personal issues. The interview with each patient was arranged so that the patient's relative, spouse, friend or carer was not in the room, to provide a confidential setting. The researcher might have enquired about subjects that the participant did not want revealed to the carer, although no one indicated that this provision was required. There was often a time arranged after the discussion, when the carer joined the interviewee and the interviewer to verify the dates, or any details about which the patient was unclear.

There became an unexpected benefit of interviewing people at home, which was that the interview often took place in the living room, or sitting room, and, in these rooms, often there would be many family photographs, maps or pictures relevant to the life of the

participant, and other personal and family mementoes. These often supplemented and confirmed the information given during the interview. On occasion, reference would be made to these during the interviews, as prompts. One particular, well-travelled lady, who had AD, took the interviewer on a tour of her house, during which she showed all the pictures that she had of her family, past houses, and her favourite views of where she had lived: it was an illustrated review of her life. Although it was not practicable to record the ensuing conversation, it was written down in the field notes of the interview. Other mementos that clarified dates or places such as death certificates and their own family trees were also shown to the interviewer.

One of the possibilities, during the interview, was that the patient could have a 'catastrophic reaction'. This occurs when people who have memory problems have a sudden, overwhelming emotional reaction to something that has been said or has just happened. It can be precipitated by a period of insight into their problems, when suddenly they realise what is happening to them and the implications of this, and are deluged by emotions. Catastrophic reactions are best managed by prevention, or, if they are not preventable, by the interviewer remaining calm and reassuring around the person having the reaction. Usually, catastrophic reactions last for a few minutes only, distraction can help sometimes. There were times when participants felt upset and, on one occasion, the participant asked for the tape recorder to be turned off during a particular discussion. The participant said it was something he had done and of which he was ashamed. The following episode illustrates the phenomenon of a catastrophic reaction (see below in *Text box 5.1)*

Text box 5.1. Example of a catastrophic reaction

A male patient did have a catastrophic reaction during the interview. He burst into tears suddenly, without any warning to either himself or the interviewer. The situation was handled by the researcher remaining calm, offering to stop the taping and the interview, which the participant did not want to do, and by him changing the subject (distraction). Later on in the interview, after the participant reintroduced the subject we discussed it briefly and he stated that he had never experienced such a reaction before and that the emotions took him completely by surprise. He was reassured that this is something that does happen occasionally. He did not want his reaction removed from the tape, as he wanted the interview to be used to help others. It is of note that, in the narrative analysis, his interview was one of the texts that demonstrated the extreme differences between the patients and controls. The interviewer made sure that the patient was managing his emotions before leaving, and the next day telephoned to enquire after him. The participant's wife said he had been fine when she had returned home from work, shortly after the interviewer had left the house. It is possible that the participant, because of his memory problems, had forgotten the incident before his wife had returned home. If the participant had remained upset or distressed in any way, the interviewer would have stayed until his wife came home and, if this had not resolved the situation, would have contacted, and been guided by, the carer and support services involved in the patient's care.

Another patient, who had previously been treated for depression, found the interview too tiring. After reviewing the situation, it was agreed that the interviewer should arrange another date, as the female patient wanted to take part, rather than withdraw. The interview continued on another date, and she found it easier the second time. The MCA states that participants should be allowed to make their own decisions, and this participant wished to carry on the interview on another day.

The participants were always telephoned within a few days of the LEDS interview, to ensure that they were not experiencing unpleasant or recurring memories that were causing them any problems. None of the participants reported any problems, and several of the carers commented on how the patients had enjoyed discussing their lives, and had

details that had been missed during the discussion.

Once the interview had finished, the researcher compiled field notes. The tapes were listened to as often as necessary for the dating and rating of the life events. The dating and rating of the life events with the patients was a comparatively easy process, because of the style used to discuss the events: with the controls it was more difficult, ascribed to the apparently random manner in which they spoke of the events. When rated, the participants had a list of events and difficulties that were in date order, with concurrent ages, and rated using the LEDS criteria, for all the dimensions mentioned in *Chapter 3*. The ratings were checked against the LEDS criteria and the numerous scenarios, with suggested ratings, in the manual for the LEDS (Bifulco et al., 1989), which included many similar situations to those encountered in the LEDS interviews. Competency of the interviewer was checked many times throughout the LEDS course attended by the researcher (Brown and Harris, 1997) and afterwards, with two taped, post-rating interviews being checked by Tirril Harris (co-author of the LEDS, 1978). If needed, there was access to advice from Tirril Harris, or her colleagues, for any events and ratings about which the researcher was not confident.

It was at this early stage that the initial difference was noted between the way in which the patients and controls recounted their life events, and the research questions for the narrative analysis began to form. This difference led to the BNIM interviews being undertaken to see if this difference was evident in an unstructured interview as compared to a 'semi-structured' interview.

5.3.1.2. BNIM interviews

The BNIM interviews were conducted in the participants' homes, except for one person who preferred to come to an interview room at OPTIMA. Confidentiality was also maintained, two participants preferring to keep their spouses present during the interviews. Both spouses present took a 'back seat' to the interviewee, and only gave

found it encouraging. This telephone call also enabled the interviewer to check anv

information when called upon by the interviewee, usually of a factual nature. In three cases, the two subsessions of the BNIM were blended together, as suggested by Wengraf (2001). None of the interviews needed a subsession 3, adequate information being found in the original subsessions 1 and 2.

5.4. Points encountered in the LEDS and BNIM interviews

For the LEDS interviews, a high-quality microphone was purchased to ensure a good-quality tape-recording from which to work: it, and its replacement, were found to be unpredictably unreliable. Forty-two people were interviewed and 32 (76%) of the interviews were considered audible enough (i.e. able to be transcribed and checked as correct). The interviews chosen for Danner et al.'s EWC (2000) needed a transcription that was as near word perfect as possible: this left 25 (60%) of the 32 interviews. The interviews not considered acceptable were those that contained parts where the interviewee had lowered their voice and the exact wording had not been decipherable, or where the microphone had been unreliable. This exacting selection was considered important because the accuracy of the coding was based on the accuracy of the vocabulary and semantics in the transcriptions.

For the BNIM interviews, a digital recorder was available and produced a clearer tone than the analogue recorders used for LEDS. Although there were a few words not heard during the interviews, it was of the same standard as the interviews selected for the Danner et al.'s EWC. Field notes were made both during and after the BNIM interviews, which aided later analysis.

Notes taken during the LEDS interviews were used to increase and ensure the reliability of the life events data. The ratings and events were verified again when the transcriptions were being checked for accuracy, and once more when Danner's emotional codes (Danner et al., 2000) were being used to analyse the emotional expression in relation to

the life events for each person. Thus, the reliability and consistency of the rating were checked at least three times, using different approaches.

5.5. Method of LEDS analysis

Brown and Harris's Life Events model states that the life events that affected the women's depression, in their original study (Brown and Harris, 1978), are known as provoking agents. Brown and Harris use a system to assess whether such life events are contributing to the illness, in this case AD. This system involves rating and coding the life events to evaluate their 'severity' and the length of time for which they had a significant effect. To make this a valid and reliable method, specific knowledge is needed about each event, which is gained through the interview questions.

Information about an event was gained from the subject, but the rating was always done by the interviewer. To avoid 'contamination' of the standard ratings from the individual's reaction, two ratings were done. The first rating takes into account the context of the situation, which includes the facts about the event and the surrounding context of the situation, and does not include any of the person's reactions. The second rating takes into account the individual's reaction to the event. These ratings were made at two time points: firstly, on the day the life event occurred; and, secondly, 2 weeks later. The ratings are also classified on a four-point scale as: marked, moderate, some, none. 'Severe' life events are those that are rated as marked or moderate, and lasted for longer than 2 weeks. Brown and Harris (1978) state that it is severe life events that have an effect on health.

The classification of the events involves categorising the event into one of the following: education, work, reproduction, money/possessions, housing, health, crime/legal, marital/partner relationship, other relationships (including children), miscellaneous and death/bereavement. Whilst asking about the nature of these events the interviewer needs to gain data about:

- When did the event occur?
- Is it a revelation and does it involve an actual change?
- Is the event related to an illness or disorder?
- Who is the focus of the event?
- How unpleasant is the event, initially and after 2 weeks?
- Did the person's coping mechanisms have an impact on the event?
- Did the event involve a loss of any kind?

These aspects are all rated, and give the researcher a concept of the nature of the life events that have occurred and their effect on the participant. The life events for each participant are listed as below, in *Table 5.2.* and then quantified as shown in *Appendix 1.*

Table 5.2. Patient number 10 – life events data

Events	Year	Age of pt	Life events – patient no. 10
E1	1961	33	Found out 1st wife was having an affair, from sons
E2	1961	33	Found out 1st wife was pregnant by another man
E3	1962	34	Found out 1st wife was pregnant again by different man, had termination of pregnancy
E4	1962	34	Divorced from 1st wife
E5	1962	34	Found out 1st wife had put son in cupboard when little
E6	1962	34	Changed job to teaching, had holidays off
E7	1969	41	Father in law of 2nd wife died
E8	1976	48	Son 1 divorced
E9	1977	50	Son 2 divorced
E10	1977	50	Son 2 had child by different woman
E11	1980	53	Son 2 left above women and remarried 1st wife
E12	1986	58	Step daughter said she was bisexual
E13	1986	59	Mother died, short illness
Difficulties			
D1	1961	33	Wife unfaithful, affairs and pregnancy
D2	1962	33	Divorced from wife
D3	1962	33	Childcare difficulties, changed job to teaching
D4	1966	35	Daughter of 2nd wife only slept for about 2 hrs a night for first year

Each individual's life events data can then be examined on their own, as part of a group or as categories to identify trends.

5.6. Method of narrative analysis

The following TQ 2, and its subsidiary-theory questions (see *Chapter 1:Introduction*), arose from listening to the tapes and reading the transcriptions, and led to the latter being analysed using Danner et al.'s (2000) approach:

Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and in the range of emotions expressed when discussing life events between the patients and controls?

a) Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups?

b) Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's EWC?

The coding focuses on three types of emotional codes: negative, neutral and positive emotional expression. Danner et al. (2001) record that they read the autobiographies of the nuns, as discussed in *Chapter 3: Literature review*, and coded the text according to the emotional (negative, neutral or positive) description of the event. The codes had been tested on the sisters' autobiographies in the USA only, and Danner et al. (2001) state that there were very few negative events discussed in their text, perhaps, as noted earlier, because the sisters did not want to appear too negative to their superiors, when on the verge of a lifetime commitment. There were several difficulties to be overcome before the Danner et al. (2000) coding would be applicable to the ADLE study narratives: these were:

- The codes were used in an American culture, not in an English context
- The codes were used on written text, not narrative transcriptions
- There would be many codes needed to augment those already suggested by Danner et al. (2000).

These difficulties are addressed below.

5.6.1. Are the codes generated by an American team, for use on American text, suitable for use with a non-American text?

George Bernard Shaw's famous quote about England and America being two countries separated by a common language explains why potential misunderstandings could occur: England and the USA have different meanings for the same words. Danner et al. (2000) have prepared a thorough coding paper, which describes all those emotions attributed to

each one described (see *Appendix IV*) and used in the analysis of the sisters' autobiographies. Given that the ADLE study reveals many negative events, not covered by Danner et al. (2001), there were new emotional expressions that had to be named and described. The emotional expression codes by Danner et al (2000) include the following text boxes 5.3. – negative emotion words; 5.4. – neutral emotion words; and 5.5. – positive emotion words:

Text box 5.3. Negative emotion words

Key word definition	Words that are coded	Words that are not coded
Negative emotion words		
Anger – a state of being annoyed to enraged	Anger, mad, furious, rage, annoyed	Argument, fight, disagreement
Anxiety – a state of restlessness leading to concern and worry	Anxious, anxiously, worry, concern, restlessness	Sleepless night
Confused – a state of bewilderment	Confused, bewildered, confusion, doubt, turmoil, perplexed, undecided	Perplexities, hesitation
Contempt – a state of despising	Contempt, despise, detest	
Disgust – a state of feeling repulsed by something	Aversion, repulsed, repulsion	Regurgitate
Dislike – a state of not being attracted to something	Dislike, disinclined, not attracted, not fond, loathing, hate	Unattractive
Fear – a state of dread to terror	Fear, afraid, dread, frightened, terror, terrified	Danger, threat
Frustration – a state of being impeded from reaching a goal	Frustrated, frustration, disappointed	Frustrate, disappointment, struggle, temptation, crosses, trouble, burden, difficulty, obstacle, struggle, trials, hardships
Hopelessness – a state of feeling without hope	Hopeless, despair, depressed	
Sad – a state of feeling the loss of something valued	Sad, sadness, grieving, grief, feeling blue, sorrow, forsaken, homesick, lonely	Blue
Shame – a state of feeling sorry	Regret, sorry, ashamed, guilt	
Suffering – a state of extreme and sustained physical or psychological pain	Pain, suffering, hurt	Wound, disease, illness, sick, harm
Uninterested – a state of being bored or disinterested	Uninterested, disinterested, bored, apathetic	No peace of heart, did not feel the call
Unspecified – miscellaneous negative emotional words where the relationship to a particular concept is unclear	Unhappy, displeased, miserable, resented, shocked, tears, crying, weeping, heartbroken, unsatisfied, dissatisfied, discouraged	Sacrifice, weary, clouded, dreary, lost, bad, evils, no good, pathetic

Text box 5.4. Neutral emotion words

Neutral emotion words	Words that are coded	Words that are not coded
Surprise – a state of being suddenly alerted in neither a positive or negative way	Surprise, surprised	Shock, alarmed, afraid
Startle – a state of being alerted suddenly and unexpectedly		Shock, alarmed, afraid
Alerted – being aware of environment without being attracted or repulsed	Awakened	Felt strange

Text box 5.5. Positive emotion words

Positive emotion words	Words that are coded	Words that are not coded
Accomplishment – feeling good about reaching a goal or being given an honour	Pride, honoured, fulfilled, fulfilment, success	Overcome difficulties, felt bigger, privileged
Amusement – feeling amused	Amused, laughed, humorous	Joke, funny, prank
Contentment – feeling comfortable, satisfied and content	Contented, felt at home, satisfied, peaceful, found peace, reconciled, not negative emotion (e.g. no fear), no regret	No obstacle, carefree, peace, harmoniously
Grateful – feeling thankful	Grateful, thankful, appreciate, indebted	Fortunate
Happy – feeling joyous	Happy, joy, cheerful, cheered, delighted, enjoying, glad, jolly, pleasant, pleased, smiling, rejoicing	
Hope – feeling positive about something in the future		
Interest-general – feeling focused and attending	Interest, excited	
Interested-attracted – feeling attracted to an idea or person	Admire, admiration, appealing, attracted to, awe, enraptured, enthusiastic, fascinated, inclined, prefer	
Interest-desire – wanting something not yet available	Anticipated, desire, determined, eager, fervently, want, wish for, long for, waiting anxiously, yearning for, an urging to, looked forward to	
Love-attached – feeling close, attached or belonging with	Affection, beloved, cherish, fond, love, treasured, dearest	Dear, holy, esteem, esteemed
Love-committed – feeling committed to a person or idea	Affection, beloved, cherish, fond, love, treasured, dearest	
Relief – feeling relieved	Relief, relieved, free	
Unspecified – positive emotion word not fitting any category unambiguously	Filled with emotion, like, liking, feelings filled my heart, protected, safeguarded	Good

The new words added are below, in Text box 5.6:

Text 5.6. Additions to Danner et al. (2000)

Negative emotion words	**Words that are coded**	**Words that are not coded**
Resentment – harbouring or expression of ill-will at something considered wrong or unfair	A description of an event in which there is apparent ill-will harboured	Words that express an acceptance of what has occurred with a forgiveness or reconciliation
Neutral emotion words	**Words that are coded**	**Words that are not coded**
Stoicism – an expression of long-suffering in the face of adversity, with a repression of feelings	Resignation about a life event or situation, with an apparent repression of feelings	Patient, impassive, dispassionate, sad
Ambivalence: Expression of conflicting or contradictory ideas about the same life event	A mixture of two different kinds (*i.e.* positive, neutral or negative) of emotion words, about the same circumstances or life event	Hesitancy about expression of an emotion
No emotions, facts only	Description of a life event that has facts only and no emotional expression, in semantics or tone of voice	Any description of a life event that includes emotional expression in either semantics or tone of voice

Each time the researcher encountered a new coded emotional expression, whilst reading the narrative, which was not covered in the codes by Danner et al. (2000) the expression was added to the codes. Technical difficulties experienced with the computer program (QSR N5) necessitated codes being applied twice to all the text, which inadvertently ensured consistency, accuracy and reliability.

The coding of the text was done, following Danner et al. (2001) did, using both single words and, where necessary, phrases to provide comprehension and context. Emotions are shared during interviews (Wengraf, 2001), and the reality of this should be represented by the narrative analysis. Danner et al. (2001) explained that few negative life events were discussed in the autobiographies: thus, the codes that needed to be added were neutral and negative (see Table 5.X). The code of 'no emotion, facts only' represented narrative concerning the life events discussed where the participant

described the event without any emotional expression, either in the words spoken or the tone of voice: an example of this is in *Text box 5.7* below:

Text box 5.7. Example of coding of 'no emotion, facts only'.

Interviewer *And what happened when you left school?*
Respondent *I started work. My mother was I suppose ... so we had to, 'we' being my elder brother and myself, she, she couldn't afford, my father died when I was about 16. So we were a bit short so we both had to work, go out but we had a day a week off and we studied. We both are graduates.*
I *Gosh, you did well then.*
R *I wouldn't recommend it.*
I *No, hard work.*
R *It impinges on one's social life rather too much.*

This quotation from one of the interviews shows how, in a discussion about working, the participant who had left school early because of his father's death discloses severe life events that contributed to the situation without expressing any emotions. Further on in the conversation, the interviewee reveals that his father had died very suddenly and prematurely and that, despite having to leave school because it was essential that both brothers help their mother financially, the participant described this situation in the way one imagines he would ask for the sugar to be passed to him.

The dictionary definition of stoicism is 'repression of feeling, austere' (Onions, 1988). There was no repression of feelings in this narrative: thus, it did not qualify for the 'stoicism' coding because of the lack of any recognition that there should be any feelings associated with this type of discussion about life events. The difference between 'stoicism' and 'no emotions, facts only' is subtle, but present. An example of text for 'stoicism' is shown in Text box 5.8 below.

Text box 5.8. Example of coding of 'stoicism'

Interviewer *Can I do a family tree do you think so that I can, because I know you've got a lot of children haven't you?*

Respondent *Yes, and so, so and then, and I lost my first baby, I think through ignorance and* (medical term) *but anyway I had then John a year later.*

I *Did you lose your baby quite late on?*

R *Um.*

I *Oh gosh.*

R *But somehow one had no one to advise you see, my husband was as ignorant as myself and it was just in between two visits to my doctor, who was awfully nice and very good advice and everything but as I say I didn't realise I was ill. So it was too late.*

I *Yes, you can feel quite well with it can't you?*

R *Yes, yes, that's it you see, just a bit sort of uh, you know, I, I should have gone to him, afterwards, but anyway I was lucky enough to have John then.*

The example of text with the coding for 'stoicism' shows some emotional expression in the words spoken: however, the main emotion is the manner in which the words were spoken. The woman concerned was very articulate normally, but this piece of narrative displays an uncharacteristic hesitancy about being able to tell the researcher the circumstances of the stillbirth. The stillbirth happened when she was about 7 months pregnant, so she would have been looking forward to the birth of her first baby, which arrived stillborn, and unseen by her. Later in the interview, the woman felt able to ask what a baby would look like at that stage of pregnancy, whether it would have been well formed and recognisable as a baby. It is suggested that having the choice to see a foetus which has been stillborn can be an important part of grieving for the mother, and contributes to the mourning process, and that this participant did not have this choice at that time, which was the norm (Hughes, 2002). This piece of text is also an example of a story that should be put into words and told as a coherent narrative, to expedite the process of organising and thinking

about the trauma. It can then be summarised, stored and forgotten more efficiently (Pennebaker and Seagal, 1999). It could be inferred, from this narrative, that this woman has had limited opportunity to carry out the process for this life event. This is an example of how a memory is recalled, yet cannot be expressed clearly because of a lack of emotional processing at that time or since. The recall of the memory was distressing for the participant at that time, as shown by her hesitancy in her expression of it, and as noted by the interviewer.

The neutral emotional expression code of 'ambivalence' was also introduced to Danner et al.'s (2000) codes. The dictionary definition of ambivalence is:

> *... the state of having two opposing and contradictory attitudes or feelings towards an object, person, etc.* (Allen, 2002).

This definition was applied to the phrases in the narrative text that described contradictory feelings towards something or somebody. An example of ambivalence is in *Text box 5.9* below:

Text box 5.9. Example of coding of 'ambivalence'.

***Respondent** So it was quite, and I had an amazing old lady who used to look after my son – who was too young at one stage to go to school – she was unbelievable.*
***Interviewer** Why?*
***R** She was great but she was, I don't know my poor son tells me after all these years how ghastly it was.*
***I** Does it make your hair curl?*
***R** Yes it does, yes, yes.*
***I** Was she terribly strict then?*
***R** No, well she was, she was, she was chaotic. I don't know how I got her but she was handy and she was there when I needed her and probably pretty ghastly.*
***I** Did he tell you at the time?*
***R** Yes, yes and I used to say 'It's no good saying anything, I'm not in a position to change it.' But anyway during that time, the following three years I got to re-know some XXX friends, one of whom was then living in XXX, had moved to XXX, and we married each other.*

This woman had been widowed with three young children, and had to work to support her family. Here, she expresses clearly how the old lady was 'handy' and 'there when I needed her' to care for her young son, but she was also 'unbelievable', 'chaotic' and 'pretty ghastly'. This example encapsulates the two contradictory feelings about a person: this participant was completely dependent upon the 'handy', yet 'pretty ghastly', woman. Ambivalence is not incorporated in Danner et al.'s (2000) codes. It is interesting to speculate whether ambivalence would be an advised emotion to express when discussing a lifetime vocation, even if the nuns had been experiencing it. It is not clear how Danner's list of emotion codes was generated, whether Danner et al. (2000) had developed the codes directly from the autobiographical text, or had a list, previously generated, that was then applied to the text.

The negative emotional expression of 'resentment' is described as an 'indignant sense of injury or insult received' (Onions, 1988), or as the harbouring or expression of ill-will at something considered wrong or unfair (Allen, 2002). This is shown below in *Text box 5.10*:

Text box 5.10. Example of coding of 'resentment'.

Interviewer *And how would you describe your childhood?*

Respondent *Deprived.*

I *In what way?*

R *Well, in today's life according to the way my son and grandson were brought up, it was very deprived. There was XXXX, XXX children. And there was never very much money and my parents, well they didn't really talk to each other, they didn't. Just generally we were a burden rather than a joy.*

R *I always seemed to be the odd one out and have continued to be the odd one out, because I'm the only one that's had a profession and gone away and everybody else has stayed there. I think they thought I set out to be something that thinks I am better than they are, which is not the case at all. They want the sort of life they have, that's fine by me, but I wasn't prepared to stay in it.*

R *When I went to start as a student nobody came, my parents didn't go with me to XXX, I went on the bus on my own and their parting shot was 'Oh give her two weeks, she'll be back.'*

I *Was it quite difficult to get a place?*

R *Yes. It was quite difficult because I'd left school at 15 and I had no qualifications and I'd been apprentice to a XXXXXX, which I hated.*

This woman was expressing a long-standing resentful feeling she had harboured against her family for years, and how it originated from their expressed ill-will, about her wanting to be different from them. There is ill-will illustrated on both sides here, and no sense of forgiveness or reconciliation from either party. Had an impression of forgiveness or reconciliation been given in the narrative, it would not have been coded as 'resentment' but more likely as 'sad' or 'hopelessness', or other more passively expressed negative emotions. It could be speculated, again, that 'resentment' would not be an emotion likely to be expressed in any of the autobiographies of the nuns.

Humour had not been coded or analysed by Danner et al. (2001), and it was not coded in the ADLE study, because there were different ways in which it was being used during the interviews. Humour was intertwined with the narrative about the life events that were

discussed. It was used to illustrate points, to make the meaning clearer, to lighten the mood from something serious and, sometimes, in a way similar to punctuation – to create a break or emphasis, to deflect a comment, or to change the subject. In searching the databases (those mentioned in *Chapter 3: Literature review*), no research was found on how humour is used in narratives, and what function it has, in Britain or anywhere else. In the observational anthropological book by Fox (2004), she states that:

> *... the most noticeable and important 'rule' about humour in English conversation is its dominance and pervasiveness.*
>
> Fox (2004)

Fox is, by her own admission, not writing an academic paper, but is observing the unwritten generic rules of English behaviour. The unwritten rules of humour, she suggests, are complex and consist mainly of irony, understatement and self-mockery, which we (the English) cannot function without, especially if feeling uncomfortable or awkward. The overriding rule then is '*when in doubt, joke*'. These observations, of many complex uses of humour, are borne out in the narrative text of the interviews for the ADLE study. How humour is used to manage and cope with emotions would aid our understanding of coping mechanisms that could then be used therapeutically, but that is beyond the scope of this study.

It was decided that the 'unspecified' code used by Danner et al. (2000) in both the negative and positive emotion codes (see *Text boxes 5.3 and 5.5*) would not be used in this study. It would be interesting to analyse the 'unspecified' words and phrases coded by Danner et al. (2000, 2001) using the additional codes in the ADLE study, and to ask the coding team the reasoning behind them leaving some emotional expression coded as 'unspecified' or, essentially, uncoded. This ensured that all text with any emotional expression whatsoever was coded by a specific named and described code.

5.6.2. *Sample selection for narrative analysis*

Of the 25 tapes that were considered of a high enough standard to analyse, there were 13 participants from the patient group, and 12 participants from the control group: however, one patient had a post-mortem examination that showed Lewy Body disease, not AD.

This patient was excluded from the narrative analysis, which resulted in interview text for narrative analysis from 12 patients (6 females and 6 males) and 12 controls (5 females and 7 males). The demographical details of the patient and control groups are discussed in *Chapter 6: Results.*

5.6.3. Narrative analysis using computer program

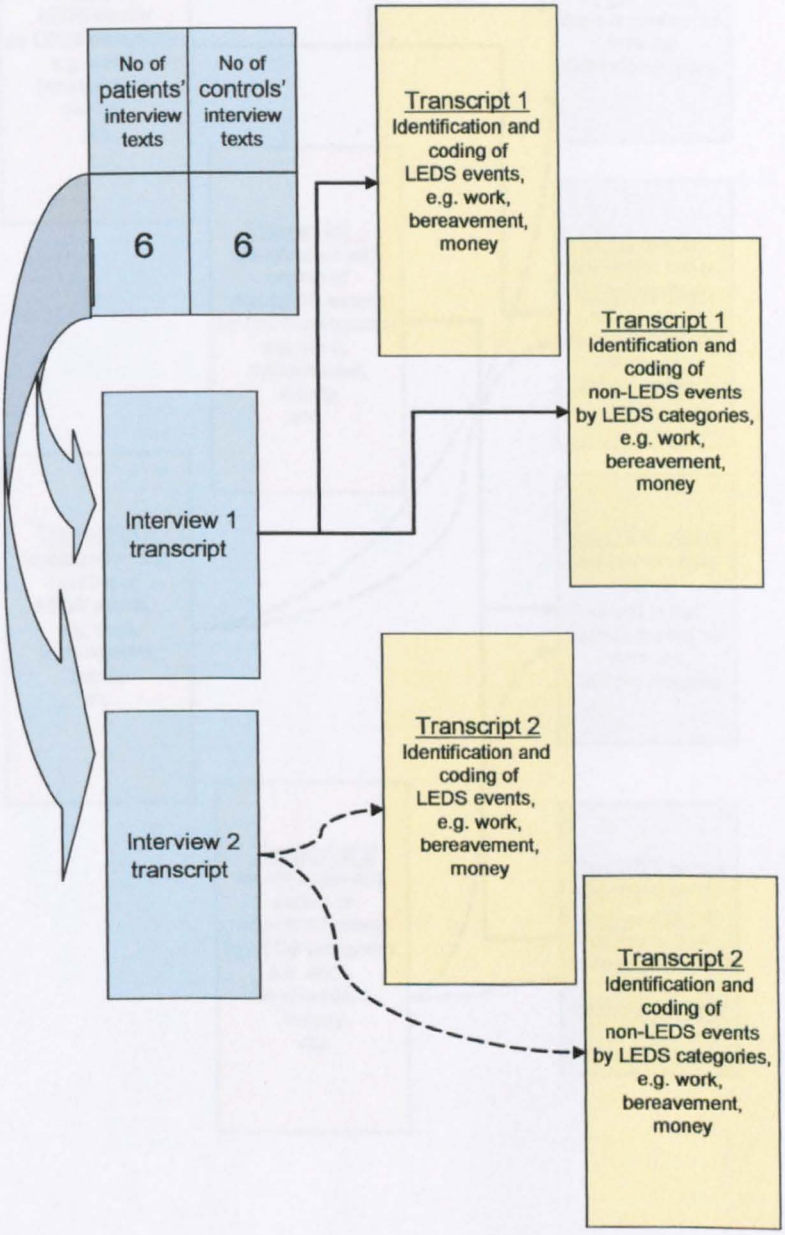
The program used for the initial analysis was QSR's N5 program, enabling content analysis of the narrative data using Danner et al.'s (2000) codes and the additional codes, and also reporting on analyses to be performed, to aid the generation of data to answer the TQs. The initial analysis and reports were found to be generated incorrectly by the computer. Because the researcher knew the data thoroughly, this was noted as soon as it happened. The problem was rectified, using QSR's N6 program, and all the interview transcripts were coded again, ensuring reliability in coding the text. The N6 program produced only two incorrect pieces of coding within the reports: the researcher amended both of them in readiness for the analysis.

The narratives included descriptions of 'severe' life events, and were therefore considered significant by the Brown and Harris criteria (Bifulco, 1989). These are known from now on as 'LEDS events'. The life events described in the narratives that did not meet the criteria of a severe life event are known as 'non-LEDS events'. These non-LEDS events were mentioned by the interviewee, but not considered severe enough by the Bifulco criteria (1989), and have not been shown as significant in the analyses of other studies and illnesses (Brown and Harris, 1978,1989).

The method of preparing the text, with the LEDS and non-LEDS events, for statistical analysis is documented in stages in the following flow charts. There are two analyses of the text, one for the LEDS codes, and one for the Danner emotional expression codes: initially they are separate processes, which are then combined. The LEDS coding

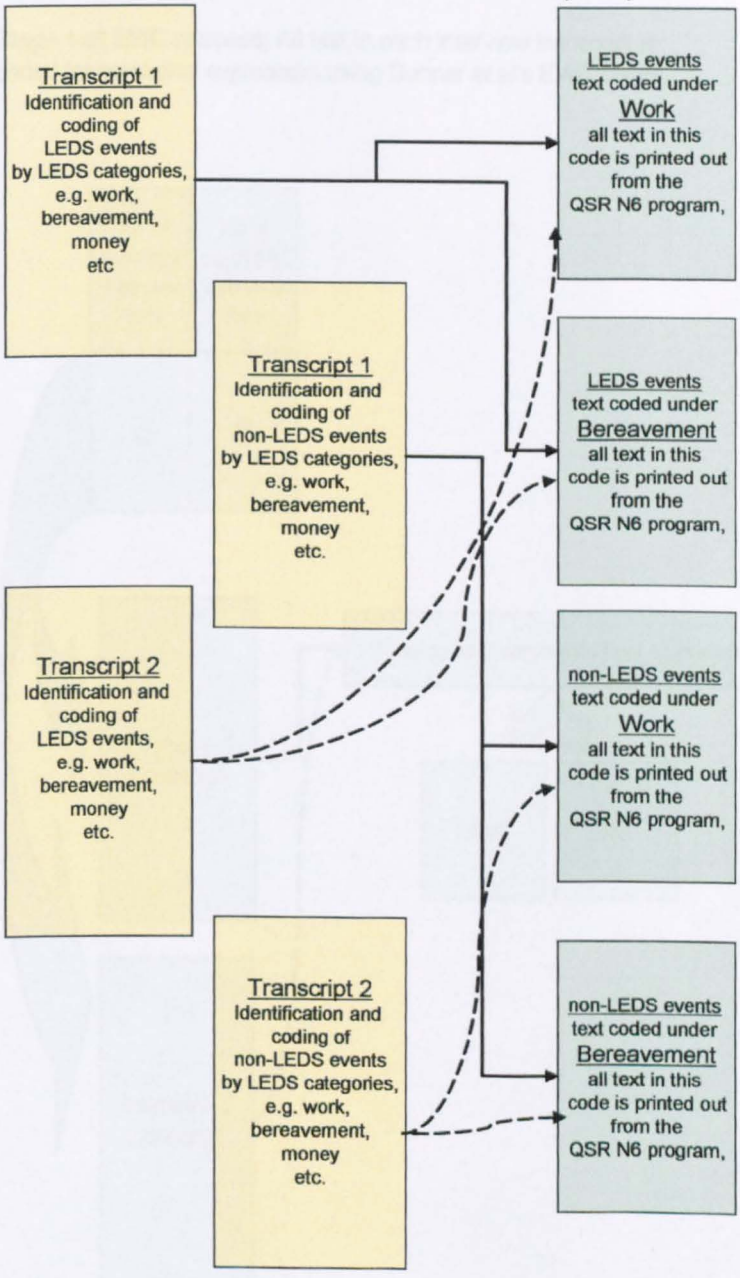
process will be described first, then the emotional expression coding process, and finally how they are combined to produce data that can be quantified and statistically analysed.

Stage 1 of LEDS coding: Each interview transcript is coded for life events, LEDS and non-LEDS life events

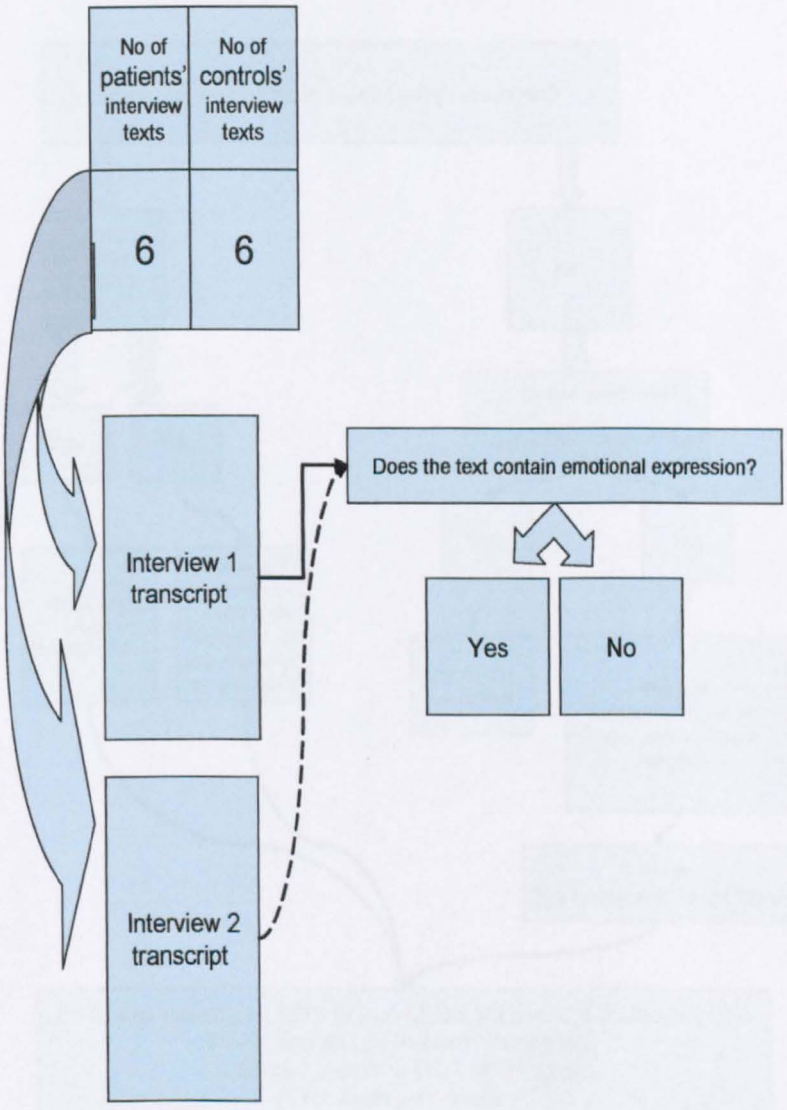


- LEDS event – defined as a Brown and Harris 'severe' event, which has to last at least 2 weeks, involve the participant or a very close member of the family
- Non-LEDS event – defined as a life event which is significant enough for the participant to mention when asked about life events, and does not fit the criteria for a Brown and Harris severe life event, but still coded under LEDS categories of work, bereavement, money etc.

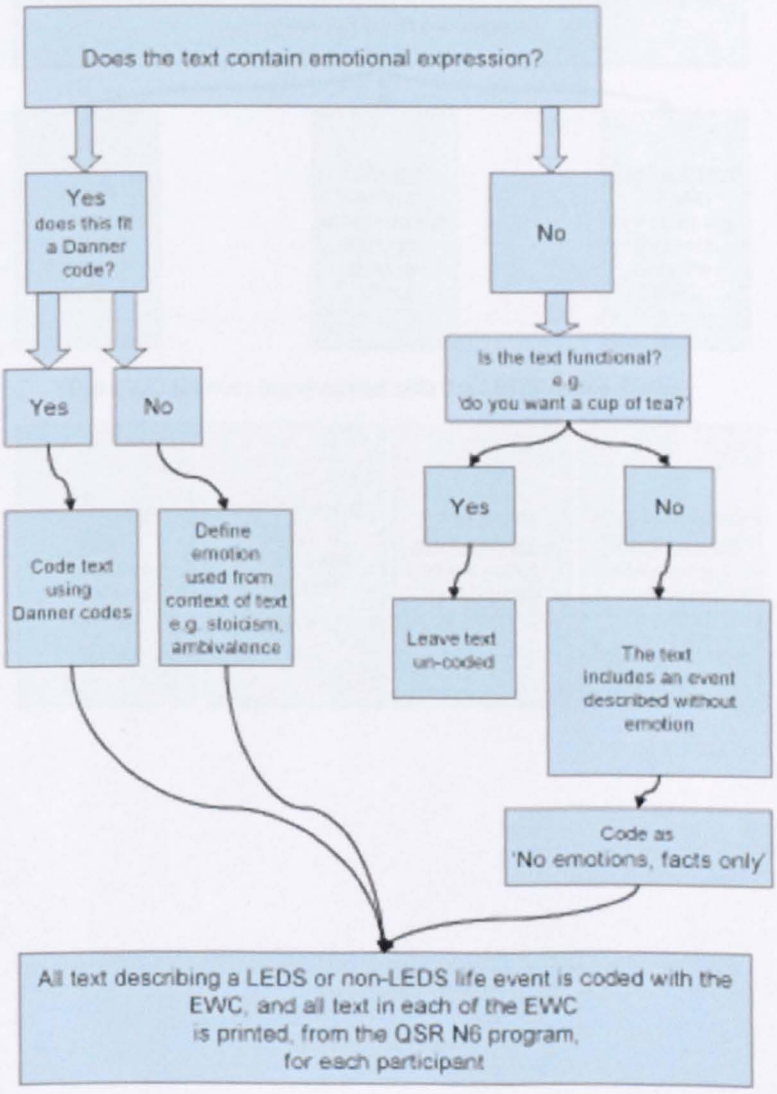
Stage 2 of LEDS coding: text describing LEDS and non-LEDS events is separated into the LEDS categories, LEDS events are checked with Part I life events data for each participant



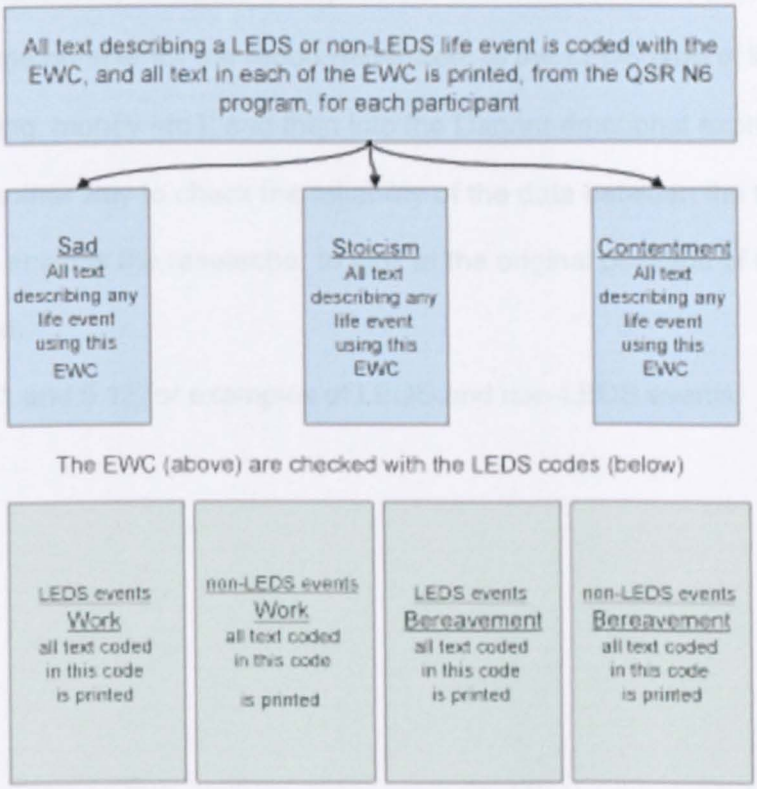
Stage 1 of EWC process: All text in each interview transcript is coded for emotional expression using Danner et al's EWC codes



Stage 2 of EWC: continuation of the flow chart



Stage 3 of both coding processes: the passages of text coded with EWC method are checked against the events in Stage 2 of the LEDS codes, to ensure accuracy, and 'inter-rater reliability'.



Following the method of coding of text passages, two tables (Tables 5.11 and 5.12) can be produced for each modified Danner code, of LEDS events and non-LEDS events, listing the passages of text that have:

- Negative, neutral and positive emotional expression
- Where to find the passage in the text
- Subject identification number

- The LEDS code under which the event is coded
- A brief description of the event, with narrative included if appropriate, to remind the researcher of the passage of text.

These tables show the data have been transformed so that they can be quantitatively assessed and statistically analysed. It is possible to follow an event from the interview text, with the page number for the report generated, to the LEDS type of life event code (i.e. work, housing, money etc.), and then into the Danner emotional expression code. This enables another way to check the reliability of the data between the two coding processes, and enables the researcher to look at the original passage of text for a more accurate context.

See Tables 5.11 and 5.12 for examples of LEDS and non-LEDS events.

Table 5.11 LEDS events for coding of 'stoicism'

patient/ control	page no	participant no	LEDS code	description of stoicism event (LEDS event)
control	8	15	bereavement	After father died, participants's mother also lost both her parents within x mths. 'we always made a joke of the fact that we lived in digs but I think it was unsettling really, really that one had no real house that one thought of as home'
control	8	15	housing	After father died, P's mother also lost both her parents within x mths. 'we always made a joke of the fact that we lived in digs but I think it was unsettling really, really that one had no real house that one thought of as home'
control	9-10	15	bereavement	Husband's death; 'But it is still a lot to get used to, the fact that you're on your own, kill your own spiders and that sort of thing you see!'
patient	2	08	health	Mother had TB twice, caught from P's father, 'she just got on with it really', as did P in helping around the house
patient	16-17	17	crime/legal	Living in XXX with v few services etc, i.e. no phone, and post once a week via ox-wagon, 'You know it was, that was just how things were', 'it was quite tough, so that I think that things were taken for granted'
patient	48-50	27	bereavement	Found father dead 'I had to open up the *(business)* and carry it on', 'I just took over, carried on'
patient	63-64	31	bereavement	After husband died 'bottom dropped out'. 'you know it's no good just moaning what you don't have, you also have to rejoice in what you did have'. 'after all my mother was left a widow with young children, who am I to complain'.

Table 5.12 non-LEDS events for coding of 'stoicism'

patient/control	page	participants no	LEDS code	description of stoicism event (non-LEDS event)
patient	2	7	education	Studying took up a lot of his time, whilst working, 'damped my feathers a bit'
patient	3	8	miscellaneous	War troubles in xxxxxx, 'it just goes on and on, you just get on with it'
patient	15	17	other relationships	P got used to being in one place for no longer than 18mths, and friends going off again. 'you got used to it'
patient	19-20	18	work	Made a mess of his xxx yesterday, got 'to do it properly this time!'
patient	20	18	health	P's sister cannot find the right words to say, like self, P ' can sit and say "oh to the hell with it!" '
patient	47-48	26	money	After father died, family was very hard up, 'it couldn't have been easy for her *(mother)* because there were xxxx boys in the family. My eldest brother went to work, he was 14 at the time so he went to work'
patient	53-54	31	health	Eyes are getting better in old age, but 'my mind had also taken a leap back into my younger past, but you can't have everything'
patient	54-56	31	work	Work traditions in the home, and no place or work for women in the village.
patient	60-61	31	work	Great sense of community in village and if 'the buzzer blew every woman was on the doorstep saying 'I wonder what's happened', because it could mean a man had been killed, or he'd been hurt, one or the other.'
control	9	15	reproduction	Didn't have much of a gap between x children, 'not much of a gap really but of course one didn't have any help. And one thought one might as well get on with it you see'

5.7. Quantification of data

The tables of modified Danner coding are quantified by counting each passage of text coded as LEDS and non-LEDS totals for each emotional expression code for both patients and controls. The number of times each patient expressed an emotion was counted, and is known as the frequency of emotional expression. The different emotions expressed were counted for the range of emotions. The differences between the patients and controls were compared using a non-2-tailed parametric statistical analysis, the *Kolmogorov-Smirnoff* test, and the *Exact* test of significance (Field, 2005).

5.8. Saturation

With the additional codes, which derived from the themes within the narrative text of the ADLE study interviews, added to the Danner et al.'s EWC, saturation of themes and their subsequent coding was achieved. The identification of Brown and Harris LEDS events and non-LEDS events thus represented the wide range of life events and situations covered in the discussions with participants.

5.9. BNIM interview for TQ3

The question that initiates the BNIM interview process is as follows:

> *Please tell me the story of your life, all the events and experiences that have been important to you personally: begin wherever you like, I won't interrupt, I'll just take some notes for afterwards.*
> (Wengraf 2001)

The importance of this question should not be underestimated, as it allows the interviewee to give their account of their life history as they wish it to be seen by the interviewer (Wengraf, 2008). The interview is split into three subsessions (see *Appendix V*):

- Subsession 1 – this consists of the 'Single Question aimed at Inducing Narrative' (SQUIN) and the interviewee takes as long as necessary to answer it, leaving the interviewer with a spontaneous and unguided life story. The SQUIN used is noted above as the initiating question.

- Subsession 2 – this follows on from the first subsession, and enables the interviewer to use cues and ask questions about what was told to gain more in the

'Particular Incident Narratives' (PINs), and subsequently greater depth of information about an event. A PIN is where the lived experience is recounted, and the interviewee is involved in saying 'he said xxx, so I said yyy, and then zzz happened'. Events have to be asked about in the order they were mentioned, and if not mentioned during the interview then they should not be asked about.

- Subsession 3 – the necessity of this is decided by the interviewer, it is done at a later date, and the session is used to fill in any details of information needed for the analysis.

Wengraf (2001, 2008)

The participants invited for the interview consisted of three participants with Possible or Probable AD, and who were able to understand instructions and express themselves clearly, as defined by their neuropsychological testing. The three participants in the patient group consisted of two females and one male. The control group included those who had never had a diagnosis of Possible or Probable AD, and were able to understand instructions and express themselves clearly, as defined by their neuropsychological testing. The control group also consisted of two females and one male. One participant was chosen from each of the patient and control groups for the in-depth qualitative analysis: the other interviews have been analysed in less depth as suggested by Wengraf (2008).

After the participants' consent had been discussed and agreed, the first subsession of the BNIM interview began. The participants were all, regardless of their cognitive state, able and keen to discuss their life history, and to answer the SQUIN. This process was encouraged by the interviewer using active supportive and non-directive listening strategies as discussed by Wengraf (2008). Some of these demonstrated techniques can be seen in the anonymised interview transcripts in *Appendices VII and VIII.*

The BNIM interview data is used to prepare two types of analysis (Wengraf 2008): the 'Biographic Data Chronology' (BDC), which tells the story of the person's life chronologically, and the 'Told Story', which tells the story of how the participant presented their life to the interviewer. The BDC involves the preparation of the chronology of the person's life, using the life events discussed in the interview, as well as any other sources of information. The BDCs for both in-depth qualitative analyses are in *Appendices VII and*

VIII. The Told Story is prepared by using Wengraf's Text Structure Sequentialisation (TSS) (2001, 2008). The TSS is described as

> *. . . the way in which those events and actions were experienced and are now understood from the perspective of the person giving the interview.*
> (Wengraf 2001)

To do the TSS, a transcript of the interview is needed, which then undergoes a process of reduction, and the words spoken in the interview are transformed into a summary of what was told to the interviewer. *Text boxes 5.14* and *5.15* show a section of transcript that has been summarised into a TSS section: the full transcript and TSS process is in *Appendices VII* and *VIII.* The TSS is carried out by summarising test sequences: a text sequence is defined by a section of the transcript that discusses a particular topic, and the next part of the text section is defined by a:

- Change of speaker
- Change of topic
- Change in the way a topic is discussed (see Text box 5.13 Wengraf's DARNE codes)

The section is also coded by the themes, as defined in *Text box 5.14.* These themes identify a change in the way the participant is discussing the current topic, and are able to give a summary of the structure of the transcript within the Told Story life history. This will be explored further in *Chapter 7: Analysis and discussion.*

Text box 5.13. Wengraf's DARNE codes

DARNE	Description of
Description	Certain entities have certain properties, in a timeless and historical way. No attempt is made at story-telling/narration:, it is a sort of timeless anthropological present about the person or situation, e.g. 'it was always was like', 'never a dull moment'
Argumentation	Development of argument and theorising, from present or past time perspective. Usually in a stand- alone form, occasionally explicit disagreement with an alternative position, usually implicit
Report	A form in which a sequence of events, experiences and actions is recounted, from some distance, in a 'thin' fashion. Provides an overview of a range of events, some which are detailed, often covers a relatively long period of time (bare chronology)
Narrative	Telling of a story by which X followed Y, in rich detail, occasionally in present tense, virtually reliving from close up. Direct speech, quotes.
Evaluation	Moral of the story, before or after the story-telling

Text box 5.14 Section of transcript

I: Now what I'd like you to do is to tell me story of your life and all the events and experiences that come to mind that are important to you, and you can begin wherever you like, doesn't have to be in any order, and I'll just take some notes, but I won't interrupt you.

R: I was a spoilt brat when I was small, I had a mother I never saw my father but I suppose he was somewhere but he'd gone away, but I never knew him, if I 'd have fallen over him in the street I wouldn't have known who he was so as I grew older I thought well that was a strange way of things happening, but people in those days didn't tell you things

I: Um

R: You were there and things were happening but they didn't tell you other things do you know what I mean

I: Yes

R: And it was very disconcerting, cos I used to imagine all sorts of things and I used to if people came to the house and there was a man I used to think I wonder if that was my father but I never knew, and I lived with my grandmother and my mother was there because there was no father so I got all suspicious as I grew older but noone spoke about it so I never really knew,

I: Gosh

R: I was told a name and that he came from W

I: right

R: but I never, I looked it up and I got someone to look the name in the whats it called you know the book,

I: the electoral register was it

R: yeh but yeh but, they couldn't find it so I don't know to this day, who my father was

I: gosh

R: and its very disconcerting

I: yes

R: but I suppose I must have got around so otherwise I'd have maybe only had one leg ha ha

I: haha

R: but no it was very upsetting and I, and that upset me for a long time then I got over it and I think whats happened has happened and whats that's what your not given or not given and you've got to get on with it and make the best of it, and what else can you do and so I'm afraid theres not much else to tell you. Except I'm lovely ha ha

Text box 5.15 TSS of transcript above

page/ line no. start/ finish (no. of lines)	(Speaker) textsort	topics-gist (for later TFA) mostly minimalist paraphrase, but their keywords in single quotes
p. 1	SQUIN	
p. 1	Desc/Report/ arg	Spoilt brat when small, had a mother, never saw my father, as grew older thought this was a strange way of things happening, people didn't tell you things then. Used to imagine all sorts of things, and if other men seen in at her house were her father. Lived with grandmother and mother, got disconcerted and suspicious as grew older. No one spoke about it, so never knew. Tried to find him, unsuccessfully. Very disconcerting. Jokes about it. Very upset for long time, then got over it, 'what's happened has happened and what's that's what your not given or not given and you've got to get on with it and make the best of it, and what else can you do'. Jokes again.

The combination and analysis of these two different aspects of the participants' lives will be explained further in *Chapter 6: Results* and *Chapter 7: Analysis and discussion.*

5.10. Conclusion

In conclusion, this chapter has discussed the practicalities of the methods used in the design and execution of the ADLE study. How the Danner et al. (2000) codes have been modified has been explained. The intrinsic characteristics of the LEDS, EWC and BNIM methods have been examined, and how the different types of interview data can be analysed quantitatively and qualitatively. The results of the analyses will be examined in the next chapter.

Chapter 6: Results

6.1. Introduction

This chapter will describe the results of:

- The LEDS interview analyses
- The EWC and
- The BNIM interview analysis

These results are presented in relation to the CRQ, the TQs, and their subsidiary questions. These are shown in *Text box 6.1*, and will be addressed sequentially. The literature discussing these questions has been explored in *Chapter 3: Literature review*, and the results will be examined in relationship to this literature in *Chapter 7: Analysis and discussion*.

Text Box 6.1 CRQ and TQs

Research questions	Interviews - patients	Interviews - controls	Research literature
CRQ: Are life events a risk for AD?			
1. Is there a difference between the number of life events between patients and controls, using LEDS as a measurement tool? (a) Is there any difference in the number of life events, which have occurred between patient and control groups? (b) Is there any difference in the number of life events, which have occurred below the age of 51 years old, between the patient and control groups? (c) Is there any difference in the number of bereavements, which have occurred between the patient and control groups? (d) Is there any difference in the number of bereavements, which have occurred under the age of 51 years old, between the patient and control groups? (e) Is there any difference in the number of difficulties between the patient and control groups (f) Is there any difference in the number of difficulties, which have occurred below the age of 51 years old, between the patient and control groups (g) Is there any difference in the total length of difficulties, which have occurred between the patient and control groups? (h) Is there any difference in the total length of difficulties, which have occurred under the age of 51 years old between the patient and control groups?	20 LEDS interview	20 LEDS interview	- Life events literature and AD - Glucocorticoid cascade hypothesis (GCH) and Hypothalamic-Pituitary-Adrenal axis (HPA axis) - Post-Traumatic Stress Disorder (PTSD)

(i) Is there any difference in the number of major difficulties, which have occurred, between the patient and control groups? (j) Is there any difference in the number of major difficulties, which have occurred below the age of 51 years, between the patient and control groups? (k) Is there any difference in the total length of major difficulties, which have occurred between the patient and control groups? (l) Is there any difference in the total length of major difficulties, which have occurred under the age of 51 years old between the patient and control groups?			
2. Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and in the range of emotions expressed when discussing life events between the patients and controls? a) Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups? b) Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's EWC?	12 LEDS interview transcripts and DD's EWC	12 LEDS interviews transcripts and DD's EWC	- EWC - Emotional processing

3. Are there any differences in the narrative constructions of life events, as interpreted by the Biographic Narrative Interpretive Method between the patient and control groups?	3 BNIM interviews: 1 in-depth, 2 less in-depth, thematic field analysis	3 BNIM interviews: 1 in-depth, 2 less in-depth, thematic field analysis	- Emotional processing
4. Can the differences, between the patient and control groups, in the narratives be developed into a diagnostic marker? • In which topic of discussion is the most obvious difference noted? • What questions will need to be included to trial a questionnaire that would elucidate narrative than can be analysed? Eg. Does pt moan/complain more/less, are feelings expressed more/less, • Is a lack of emotional expression a risk factor for those for whom it is the norm, as well as a marker of change?			
5. Can the EWC be used as a diagnostic marker by being applied to text collected from patients and controls over a period of decades?	100 participants, with AD, or other dementia with pieces of text that includes 1,000 words per decade	100 participants, with normal cognition, with pieces of text that includes 1,000 words per decade	

6.2. TQ1: Is there a difference between the number of life events between patients and controls, using LEDS as a measurement tool?

To answer TQ1, the LEDS interview data from the patient and control groups were analysed. The data about life events and major difficulties included:

- Until 5 years before the onset of their symptoms
- Up to the age of 50 years old.

This is because there is thought to be a period of time during which the disease is present but not diagnosable (Smith, 2002; Tyas et al., 2007). The period of time up till the age of 50 years old corresponds with the research, suggesting that it is a prolonged period of significant stress that activates the glucocorticoid cascade hypothesis, subsequently affecting the limbic system and, in particular, the hippocampus (see *Chapter 3: Literature review*). Additional data from the Camdex interview (see *Chapter 2: Background*), done nearest to the time of the LEDS interview, shows data on the total *Camcog*, comprehension, expression and related scores of MMSE, IMC, *Blessed, Hachinski, Organicity, Depression* and IQ.

During the course of the interviews, considerable personal information was given whilst discussing the life events the participant had experienced that would make it possible to identify them if read. Therefore, to protect the confidentiality of the participants, it is not possible to include an example of an interview in the appendix. Instead, there will be summaries of the life events, in which it is possible to anonymise examples of the codings, which include vignettes of single life events. Potential dilemmas encountered during the interviews will be discussed to set the results in context, before exploring the results of the statistical analysis.

6.2.1. Potential dilemmas encountered in the interviews

The method of the LEDS interviews has been reviewed in *Chapter 5:* the method raised matters that will be considered here.

6.2.2. Confidentiality

Issues of confidentiality are important to address: they are central to the Nursing and Midwifery Code of Conduct (NMC, 2009) and to how nurses practice.

If issues arose during the interviews that the interviewer considered should be addressed clinically, the subject's permission was sought before the interviewer referred it to the clinical team. When this did arise, the subjects were grateful for the opportunity to discuss the issue, and to have it followed up by the relevant health professional.

On two occasions, the interviewer felt the need to consult the senior nurse concerning difficult problems that arose during the interview. The reasons for this will be explained.

On the first occasion, the participant had suffered a very distressing experience. The participant had borne this alone because friends and family were ignorant of this area of the person's life. The participant had talked it over with their general practitioner (GP) at length, and had discussed it previously with other OPTIMA team members: it was not recorded in the notes, in order to respect the participant's confidentiality, and so was new information to the interviewer. The participant acknowledged that they had not resolved the issue, and still found it very upsetting to talk about. Permission was sought for the interviewer to discuss this with the senior nurse, and the interviewer left the interview feeling very unsure whether the right course of action had been taken. Although the interviewer had suggested various routes of potential help or resolution, the person did not want to take these up.

The interviewer and the senior nurse decided that nothing more could be done to help the participant at that time, as the participant has the right to make decisions which are considered unwise by other people (DoH, 2005). The person's GP was aware of the situation: information had been provided for the participant, and avenues had been left open for the participant to come back if he or she decided to do so later.

The reasons why the interviewer discussed the issue with the senior nurse were to explore whether the right course of action had been taken within the interview, as well as to share the burden of the knowledge about this distressing experience. Nobody could do more unless the participant decided it was right for them: nevertheless, it was still distressing for the interviewer to see the person remain in a situation that was causing so much grief, despite it being that person's choice not to do anything to relieve it.

The second occasion when the interviewer found it necessary to confer with the senior nurse concerned a past crime committed by a participant. It had been dealt with by the appropriate agencies many years previously, but had remained a great influence on the course of the participant's life: only a few family members or friends were aware of the offence. The crime was painful to listen to in the course of the interview, and the interviewer felt the need to discuss it with the senior nurse because of the nature of the crime. During the interview, the participant had felt able to talk about the issue at length, albeit in a hesitant and remorseful manner. The fact that the participant felt able to tell the interviewer about the crime indicated that the interviewer maintained a professional attitude throughout. In this situation, it was the interviewer's own feelings that prompted the need to discuss the issue with someone else. As a professional, the interviewer was aware that such experiences should be shared with someone to avoid the long-term emotional consequences from being overburdened by issues at work that subsequently affect professional effectiveness. Confidentiality was maintained by keeping the participant anonymous during the course of the conversation, although in reality it would have been possible for the senior nurse to work out who it was if they had so wished – because of diary entries and Lone Working policies ensuring that colleagues knew where each other's visits were.

6.2.3. Missing data

As discussed in *Chapter 5*, there were technical difficulties with the tape recording at times: this is a common difficulty (Wengraf, 2008). This made the field notes and the

family tree details taken during the interview all the more necessary. If, after listening to the tape recording and looking through the family tree and notes, the data were still not clear, the subsequent phone call was used to clarify anything either with the participant or family member.

With one participant, there was some confusion over the dates of events because the participant was unclear. The spouse was unable to help, because it was a recent second marriage. The participant's son was approached and, although unable to find exact dates, managed to recall dates to within 10 years of happening, and whether the events had occurred before, or after, the subject became 50 years of age.

6.2.4. The family tree

As briefly discussed in *Chapter 5*, the family tree was of particular use. This was valuable in two ways: firstly, it enabled the interviewer to understand which family members were being referred to at any one point; secondly, it allowed the subject to be proactive and share the task during the interview. This method empowered the subject to share information, without being bombarded by a list of questions from the interviewer. It also helped establish a more equal partnership in the process of eliciting data from the interview, so allowing the subject to feel more in control over what was happening.

The family tree permitted the interviewer to ask open questions, such as, 'Tell me about your brother Fred', which usually provoked much reminiscence, which could be guided and used to determine how the subject felt about the person under discussion and how close the relationship was.

6.2.5. Emotional vulnerability of the interviewee

Plummer (2001) discusses how the researcher is party to the telling of a life story, which names previously un-named traumas, so solidifying and consolidating these episodes in their life. This can be the cause of consequences that may not be anticipated by the

interviewees or the interviewer. Recognising this, the follow-up phone call endeavoured to identify and raise any of these issues.

Although the LEDS interview covered topics not usually raised in an unguided interview, as discussed in *Chapter 5*, once the information needed for a severe life event was discussed there was no need for the interviewer to ask what could be construed as further intrusive questions. However, if the subject had begun to discuss issues, and carried on with these issues, then he or she continued with them. It would have been discourteous and disrespectful of the interviewer to cut short the disclosure whilst the subject was revealing intimate, and sometimes painful, details about his or her life. This volunteering of additional data also aided the EWC. The interviewer was always careful to allow the subject enough time to do this, in order to prevent the subject feeling rushed and 'cheated', or the interview ending abruptly. The interview took approximately an hour and a half, but sometimes it was less, sometimes more. The shortest interview was 45 minutes, the longest 4 hours. The shortest interview was brief because the subject reviewed the events in his life very concisely, and appeared not to want to discuss them in any more detail than was needed. The longest interview was with someone who was renowned for talking at great length and expected to be listened to.

The presence of a tape recorder was found to be unacceptable to one person whilst he/she was discussing a painful issue, and the participant requested that it be turned off. Notes of the event were made, as an alternative. The subject was happy with that, and felt more comfortable in the ensuing discussion.

6.2.6. Results of the LEDS interview analysis

The demographic and LEDS interview data were analysed using the non-parametric test, the *Kolmogorov-Smirnov Z* test, and the *2-tailed Exact* test of significance. The *Kolmogorov-Smirnov Z* test examines whether the patient and control samples have come from the same populations, has more power than the *Mann-Whitney* test, and is particularly suited to sample sizes under 25 (Field, 2005). The *2-tailed Exact* test of

significance is more appropriate than the *Asymptotic* test when the sample is a smaller sample, and has an uneven distribution (Field, 2005). When calculating the statistics, the two sample groups were treated as matched groups, not as matched pairs. The subjects were treated as matched groups not matched pairs because it was not possible to match the genetic factors or biochemical factors that can exert an influence on whether a person develops AD.

6.2.7. Similarities between the patient and control groups who had LEDS interviews

The characteristics of the two groups of participants are described in order to examine whether they have similar demographics. Similar demographics in both groups are necessary for a statistical comparison of life events. The data set consists of 20 patients and their controls matched for age and gender: it is possible that age and gender can exert an influence on the development of AD. Group 1 (patients) were recruited consecutively, and matched for age (within 5 years) and gender with Group 2 (controls). There were 13 males and seven females in each of the groups. Year of birth of Group 1 ranged from 1910 to 1938, and for Group 2 ranged from 1913 to 1936. The difference in the year of birth, between the patients and their matched controls, varied from less than a year to 3 years. In the year 2000 the average age of the control group was 76.4 years old, and that of the patient group 77.25 years old. As can be seen in Table 6.2, there was no significant difference between the two groups for age, enabling the two groups to be identified as demographically similar, and for their life events data to be compared.

6.2.8. *Camcog* and IQ

As discussed in *Chapter* 2, Roth et al. (1986), in their study, stated that a cut-off value of 79/80 on the *Camcog* was found to discriminate between demented and normal participants. It has been found, in the research at OPTIMA, that there are some people who have a score above 80 on the *Camcog*, yet are considered to have Possible or

Probable AD. These are usually the people who are well educated, and, previously, had a very high level of functioning that has diminished, but not to a level that is represented as below 80 on the *Camcog*. These people scored highly on the NART (Fromm et al., 1991) (see *Chapter 2: Background information*), which indicates the person's premorbid IQ.

There is a significant difference between the scores of the two groups (p=0.004): the control group has a mean NART of 123.4, with an SD (standard deviation) of 5.113; the patient group has a mean of 111.579, with an SD of 11.335. Both groups are above average: the national average IQ is 100.

This finding could reflect two differing theories. The first theory is that those who have AD are more likely to have difficulties with language expression, which happens in many cases - although the NART is intended to take this into account (Folstein et al., 1975). This theory can be demonstrated by participant number 26. This male patient, despite having a *Camcog* of 87/107, was unable to read the collections of letters as words in the NART and found this very distressing. The patient group mean was calculated taking into account one less NART.

The second theory is that AD has a greater initial effect on those who are less intelligent, because these people have less 'reserves' of cognition to call upon. It is thought this can be explained by the tests being insensitive to lower education levels (for example, a person with poor education will be less able to complete the tests as easily as someone who has been well educated), and that those who have a lower IQ have a reduced capacity to 'absorb' damage (Thomas and O'Brien, 2002) because they have a smaller number of neuronal connections.

By way of illustration, participant number 34 was fluent in approximately five or six languages. He scored 94/107 on the *Camcog*, was aged 79 years, and had a NART of 120 (and English is not his mother tongue). He had held down a high-powered, internationally based managerial job, and, taking into account his fluency and ability with

languages, scoring 94/107 was not what should be expected for a man of his ability. So, although 94/107 is above the cut-off for dementia, it reflects some of the problems that both he and his spouse reported. When he was younger, participant number 34 probably made a great deal of neuronal connections in his brain (as discussed earlier in *Chapter 2*), which were used and kept active within his job. It could be suggested that he might have had more neuronal connections and pathways than the average man who speaks one language. The increased number of neuronal connections made by participant number 34 might have enabled him to use other pathways to achieve the same end, albeit a bit slower than previously. Thus, he sustained the same amount of damage as other patients with AD, but had a greater reserve that he used to keep functioning at a reasonably high level. This point could also be illustrated with participant number 26, who was unable to read words of any kind at all. In the past, he had held down several senior jobs in mechanical engineering: it might be presumed that his forte was in the mathematical area, and language less so. In consequence, when the damage from AD began, he could have had less capacity to cope with it linguistically, potentially explaining why this was the first area to be severely affected.

6.2.9. Comprehension and expression

The *Camcog* scores of comprehension and expression were examined to see if there was any difference between the two groups.

The comprehension scores are almost identical: the control mean is 8.75/9, the SD 0.55, and the patient group mean is 8.35/9, the SD 0.875, ($p=0.176$), demonstrating no significant difference between the two groups in this area of cognition. This reflects the careful selection of patients for the patient group. The researcher wanted to make sure that the patients had the ability to understand not only what the study involved, but also what information was needed for the study.

On the other hand, the expression scores show a significant difference (p=0.001) between the two groups. The patient group has a mean of 16.55/21, with an SD of 2.929. The control group has a mean of 19.6/21, with an SD of 0.995. This reflects what the researcher observed whilst conducting the interviews, which was a paucity of expression in the patient group by comparison with the control group. This result can be explained by two possibilities: that the patients' expression scores were affected by AD pathology, or that their lack of expression contributed to their pathology. The latter possibility will be discussed in *Chapter7: Analysis and discussion.*

6.2.10. The differences in the neuropsychological scores of the LEDS interview patient group and control group (*Table 6.2*)

A significant variation within the two groups might indicate a problem with the original diagnoses of AD in the participants comprising the patient group.

Abbreviations for neuropsychology scores in *Table 6.2*:

Age at year 2000 (AGE2000)
Camcog: total score possible 107
Comprehension (Comp): total score possible 9
Expression (Express): total score possible 21
Mini-mental state examination (MMSE): total score possible 30
Hachinski score (Hach)
IMC: total score possible 10
Organicity (Org)
Depression (Dep)
Multi-infarct dementia (MID)
Full IQ: indicates IQ prior to dementia, using NART

Table 6.2 Descriptive data of neuropsychological data of patient and control groups

	AGE2000	CAMCOG	COMP	EXPRESS	MMSE	HACH	IMC	BLESSED	ORG	DEP	MID	FULLIQ
Patients (n=20)												
Missing	0	0	0	0	0	0	0	0	0	0	0	1
Mean	77.250	78.650	8.350	16.550	22.700	3.756	7.550	2.750	7.950	3.800	2.100	111.579
Std. Error of Mean	1.890	2.404	0.196	0.655	0.865	0.441	0.373	0.347	0.816	0.592	0.340	2.600
Median	76.500	80.500	9.000	17.000	23.000	3.505	8.000	2.500	8.000	3.500	2.000	110.000
Mode	68.000	68.000	9.000	19.000	23.000	3.000	9.000	1.000	10.000	1.000	1.000	101.000
Std. Deviation	8.453	10.752	0.875	2.929	3.868	1.970	1.669	1.552	3.649	2.648	1.518	11.335
Variance	71.461	115.608	0.766	8.576	14.958	3.881	2.787	2.408	13.313	7.011	2.305	128.480
Range	28.000	37.000	3.000	11.000	13.000	7.990	7.000	5.000	12.000	8.000	5.000	42.000
Minimum	62.000	57.000	6.000	8.000	15.000	0.010	3.000	0.500	2.000	0.000	0.000	86.000
Maximum	90.000	94.000	9.000	19.000	28.000	8.000	10.000	5.500	14.000	8.000	5.000	128.000
Controls (n=20)												
Missing	0	0	0	0	0	1	0	1	1	1	1	0
Mean	76.400	101.150	8.750	19.600	28.600	3.685	9.800	0.289	0.947	2.053	1.000	123.400
Std. Error of Mean	1.540	0.719	0.123	0.222	0.311	0.446	0.092	0.103	0.449	0.301	0.229	1.143
Median	75.500	101.000	9.000	19.000	29.000	4.000	10.000	0.000	0.000	2.000	1.000	124.000
Mode	69.000	103.000	9.000	19.000	30.000	3.000	10.000	0.000	0.000	1.000	0.000	118.000
Std. Deviation	6.886	3.216	0.550	0.995	1.392	1.945	0.410	0.451	1.957	1.311	1.000	5.113
Variance	47.411	10.345	0.303	0.989	1.937	3.783	0.168	0.203	3.830	1.719	1.000	26.147
Range	23.000	13.000	2.000	3.000	5.000	6.000	1.000	1.500	8.000	5.000	3.000	15.000
Minimum	64.000	93.000	7.000	18.000	25.000	1.000	9.000	0.000	0.000	0.000	0.000	116.000
Maximum	87.000	106.000	9.000	21.000	30.000	7.000	10.000	1.500	8.000	5.000	3.000	131.000

Table 6.3 Significant differences in demographic and neuropsychological data between patients and controls

	AGE2000	CAMCOG	COMP	EXPRESS	MMSE	HACH	IMC	BLESSED	ORG	DEP	MID	FULLIQ
Kolmogorov-Smirnov Z test	0.474	3.004	0.791	1.739	2.372	0.632	2.372	2.214	2.214	0.791	0.791	1.643
Exact Sig. (2-tailed)	0.937	**0.000**	0.176	**0.001**	**0.000**	0.710	**0.000**	**0.000**	**0.000**	0.447	0.263	**0.004**

AD is, as has already been described in *Chapter 2: Background information*, a disease that first affects the memory, and then becomes a global impairment. This is reflected in how the participants scored in the *Camcog*. The patient group was found to have a mean score on the neuropsychological test of the *Camdex* (the *Camcog*) of 78.650 out of a possible total of 107, with a standard deviation of 10.752. The control group had a mean *Camcog* score of 101.150, with a standard deviation of 3.216. This difference in neuropsychological scores is also seen in the MMSE scores (see Table 6.1). The mean *Camcog* and MMSE scores for the patient group fall below the diagnostic cut-off for both tests, which are 79/107 and 24/30 respectively. The IMC shows less of a difference, demonstrating that it is a less sensitive tool: it scores out of 10.

6.2.11. Other scores indicative of the diagnosis of AD in the patient group

Other tests included the *Hachinski* scale, the *Blessed scale*, *Organicity score*, *Depression score*, and the MID (see *Table 6.2* and *6.3*), which are also indicative of the diagnosis of AD.

In the *Hachinski score*, a high score is used to signal whether the dementia was primarily vascular, due to strokes. There is no significant difference between the two groups ($p=0.71$), indicating that the two groups had something other than vascular damage separating them.

The *Blessed scale* reflects the amount of care given by a carer. The control group score is 0.289/17, with an SD of 0.451. The patient group scores 2.75/17, with an SD of 1.552. The patient group, although receiving more care than the control group, remains at the

lower end of the scale, reflecting the early onset of the disease. There is a significant difference between the two groups in the amount of care needed by each, $p<0.001$.

The *Organicity* scale is designed to indicate to the clinician that the problem is organic, rather than functional. Again, there is a significant difference between the two groups ($p<0.000$). In this case, the control mean is 0.947/30, with an SD of 1.957: the patient mean is 7.95/30, with an SD of 3.649. This indicates an organic problem with those in the patient group. AD is an organic problem.

The *Depression scale* is higher in the patient group, 3.8/26 with an SD of 2.648, as opposed to 2.053/26, with an SD of 1.311, in the control group. The patient group scored higher, but is not significant ($p=0.447$), and is below the cut-off that would indicate depression. AD is known to be a cause of depression, both because of the chemical effect on the brain following AD damage to it and because AD brings with it a series of bereavements, and a reduced capacity to solve problems. Neither group show signs that would suggest they could be depressed, which would affect the narrating of their life events.

The *MID (Multi-Infarct Dementia)* score needs to be greater than 11 to demonstrate a high chance of the dementia being caused by strokes. Here, too, the scores and standard deviations for both groups are well below this (see Tables 6.2. and 6.3.), and are not significantly different ($p=0.263$), indicating a very low chance of the memory problems, within the patient group, being caused by strokes.

The above scores evince that the patient group is significantly different from the control group, especially in the neuropsychological tests indicative of AD. The scores are consistent with signs of AD in the patient group. The AD is in the early stages and so the patient group was able enough to contribute accurately towards this piece of research. Family involvement also guaranteed accuracy and reliability, in conjunction with the

research medical notes and hospital notes. This provides a good foundation for the analysis of the life events research.

6.2.12. Life events and difficulties in the patient group and control group

Having looked at the neuropsychological differences between the patient group and the control group, and examined the implications for diagnosis, the difference in life events and difficulties between the two groups will be explored. This chapter will give the results and the results will be discussed in context in *Chapter 7: Analysis and discussion.*

6.2.13. Research questions about life events and difficulties data

The number of life events and difficulties was calculated for each subject by the method of Brown and Harris. The scores for patient and control groups were compared, using the *Kolmogorov-Smirnov Z* test and the *2-tailed Exact* test of significance. In accordance with the hypothesis that there is a link between vulnerability factors (negative social factors), provoking agents (severe life events and difficulties as defined in the *Life Events and Difficulties Schedule* (Brown & Harris, 1978), and AD, the following questions were posed, in order to compare both groups of data.

(a) Is there any difference in the number of life events between groups?

(b) Is there any difference in the number of life events below the age of 51 years old between the groups?

(c) Is there any difference in the number of bereavements that have occurred?

(d) Is there any difference in the number of bereavements under the age of 51 years old that have occurred?

(e) Is there any difference in the number of difficulties between groups?

(f) Is there any difference in the number of difficulties below the age of 51 years old between groups?

(g) Is there any difference in the total length of difficulties between groups?

(h) Is there any difference in the total length of difficulties between groups under the age of 51 years old?

(i) Is there any difference in the number of major difficulties between groups?

(j) Is there any difference in the number of major difficulties below the age of 51 years between groups?

(k) Is there any difference in the total length of major difficulties between groups, or in the total length of major difficulties under the age of 51 years old?

The results are shown in Table 6.4, and below. The total number of life events was calculated to 5 years before the onset of symptoms for the patients, to allow for any disease process before the time at which the diagnosis was made. The date for the onset of symptoms was taken from the *Camdex* data that asks the informant when they first noticed any changes in the patient. Events, for the controls, were collected up to the same age as for their matched patients, so there was an equal amount of time in which events could happen for both patients and controls.

(a) Is there any difference in the number of events between groups?

There is a significant difference in the number of events between the patient group and the control group with more events in the patient group (**p=0.039**).

(b) Is there any difference in the number of life events below the age of 51 years old between the groups?

There is no significant difference (p=0.409).

(c) Is there any difference in the number of bereavements that have occurred between the two groups?

Bereavement of a close relative, close friend or confidant was chosen as an event to examine whether it could discriminate between the two groups. This type of event could be considered common to all subjects, and, by definition, has the most effect upon the subject. There is no difference in the number of bereavements between the two groups (p=0.507).

(d) Is there any difference in the number of bereavements under the age of 51 years old that have occurred?

There is a significant difference between the two groups in bereavements under 51 years of age with more bereavements in the patient group (p=0.032).

(e) Is there any difference in the number of difficulties between groups?

The definition of a severe difficulty is a life event that lasts longer than four weeks (Bifulco et al., 1989). There is no significant difference between the two groups (p=0.994).

(f) Is there any difference in the number of difficulties below the age of 51 years old between groups?

There is no significant difference (p=0.301).

(g) Is there any difference in the total length of difficulties between groups?

Difficulties can vary in duration, so adding together the duration of the difficulties for both patients and controls can provide an understanding of the burden of accumulative stress that subjects endure. Because a subject can have several difficulties occurring concurrently, there is no limit to the total number of years a subject can experience difficulties. There is no significant difference (p=0.535).

(h) Is there any difference in the total length of difficulties between groups under the age of 51 years old?

Under the age of 51 years old, there is no difference (p=0.267).

(i) Is there any difference in the number of major difficulties between groups?

A major difficulty is a severe difficulty that has lasted at least 2 years, and, if a 'health' difficulty, would have an effect on other areas of the subject's life as well. The number of major difficulties between the patients and controls is not significant (p=1.0).

(j) Is there any difference in the number of major difficulties below the age of 51 years between groups?

There is no significant difference (p=0.78).

(k) and (l) Is there any difference in the total length of major difficulties between groups?

The difference in the total length of major difficulties between the two groups proved insignificant (p=0.52), as did the total length of major difficulties under the age of 51 years old between the patients and controls (p=0.479).

Table 6.4 Table showing values of significance for research questions for TQ1

	Total no of events	Total events under 51	Total no of bereave-ments	Total no of bereave-ments under 51	Total no of difficulties	Total no of difficulties under 51	Major difficulties	Major difficulties under 51	Total number of years of difficulties	Total number of years of difficulties under 51	Total number of years of major difficulties	Total number of years of major difficulties under 51
Patients	165	128	64	48	70	62	43	40	649	619	621	595
Controls	130	95	55	31	68	52	39	33	406	380	379	362
Kolmogorov-Smirnov Z	1.265	0.791	0.632	1.107	0.316	0.791	0.158	0.474	0.791	0.949	0.158	0.474
Exact Sig. (2-tailed)	**0.039**	0.409	0.507	**0.032**	0.994	0.301	1.000	0.780	0.535	0.267	1.000	0.780

6.2.14. Conclusion of results for LEDS interviews analyses

In summary, the analyses of the LEDS interviews examined the demographic and neuropsychological profile of the groups of patients and controls, and how life events and difficulties are associated with the patient and control groups.

The demographic analysis shows that there are no significant demographic differences between the age- and gender-matched patient and control groups. The neuropsychological analysis shows that there are significant cognitive and memory function differences between the patient and control groups, confirming the diagnoses of Possible and Probable AD in the patient group.

The data on life events and difficulties, as defined by Brown and Harris (1978), and, in particular, the total number of life events and the number of bereavements under the age of 51 years old, represent differences between the two groups that will be discussed in *Chapter 7* in relation to the glucocorticoid cascade hypothesis, HPA axis and PTSD.

6.3. TQ 2: Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and the range of emotions expressed when discussing life events between patients and controls?

The EWC (Danner et al., 2000) used narrative to examine whether there are unique characteristics of speech associated with differences between the patient and control groups of participants and life events, and to answer the following research questions:

c) Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS), between the patient and control groups?

d) Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's EWC?

EWC of the interviews provides additional data on the patterns of people's lives in the form of narrative text. Initially, the data on the two groups will be described demographically, then the results of the EWC narrative analyses, to ensure the two groups are diagnostically different. The previous method of non-parametric *Kolmogorov-Smirnov Z* with the *2-tailed Exact* test of significance was used to examine any differences in the demographic, neuropsychological and life events and difficulties data sets between these reduced size groups.

6.3.2. Description of demographic data on EWC analysis (n=24)

60% of the original group of interviews were transcribed adequately for the EWC giving 12 patients and 12 controls. Of the group of 24 interviews in this EWC analysis, there are 10 pairs of age-gender-matched controls: two patients and two controls are not matched for age. The average age of the patients in this group is 76.5 years old: the average age for the controls is 75.17 years old. There are five females and seven males in both groups. The details are shown in *Table 6.5.* below.

Table 6.5. Profile of patient and control matches in the ADLE study analysis: all participants were interviewed with the LEDS (n=40): those with N next to their number had interviews transcribed for EWC analysis (n=24)

f= female
m= male
E=interview transcript was able to be used for EWC

Patient participant number	Narrative analysis	Age at year 2000	Age at year 2000	Narrative analysis	Control participant number
1f		68	68	E	13f
2m		73	74		10m
3m		87	85		11m
4m		75	76		14m
5f		84	83		12f
6f	E	84	84	E	15f
7m	E	70	66	E	19m
9m		73	73	E	25m
8f	E	67	69		22f
18m	E	68	69	E	21m
17f	E	75	75	E	20f
23f	E	80	80	E	28f
16m	E	87	85		29m
24m		90	87		30m
26m	E	69	71	E	38m
27m	E	80	80	E	33m
31f	E	85	85	E	32f
34m	E	78	76	E	37m
35m	E	75	75	E	40m
39m		62	64		42m

It can be seen from *Table 6.6* that there is no significant difference between the ages of the participants in the two groups. The neuropsychological data show the same significant differences between the patients and controls as previously (see *Table 6.6*), thus demonstrating the same differences between the patient and control groups, except for IQ. No significant difference is shown between the groups for IQ, while in those that had LEDS interviews, a significant difference was found. There is no difference between the patient and control groups in the total number of life events (p=0.508), in contrast to the larger groups; but there is still a difference between the patients and controls in the number of bereavements under the age of 51 years old (p=0.05) (see *Table 6.7*).

Table 6.6. Significant differences in demographic and neuropsychological data between the patients and controls

	Age at year 2000	Camcog	Compre-hension	Expression	MMSE	Hachinski	IMC	Blessed	Organicity	Depression	MID	IQ
Kolmogorov-Smirnov Z	0.612	2.245	0.612	1.225	1.837	0.545	1.837	1.907	1.907	1.129	0.584	0.871
Exact Sig. (2-tailed)	0.727	**0.000**	0.400	**0.018**	**0.001**	0.528	**0.001**	**0.000**	**0.000**	0.072	0.617	0.297

Table 6.7. Significant differences in life events and difficulties data

	Total no of life events	Life events under 51yrs	Total no of bereave-ments	Total no of bereave-ments under 51yrs	Total no of difficulties	Total no of difficulties under 51yrs	Total no of major difficulties	Total no of major difficulties under 51yrs	Total no of years of difficulties	Total no of years of difficulties under 51yrs	Total no of years of major difficulties	Total no of years of major difficulties under 51yrs
Kolmogorov-Smirnov Z	0.408	0.816	612.000	1.225	1.021	1.021	1.021	1.021	0.816	1.021	0.816	0.612
Exact Sig. (2-tailed)	0.987	0.438	0.648	0.500	0.203	0.157	0.159	0.139	0.468	0.241	0.520	0.811

6.3.3. TQ2(a): Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups?

The complete record of all life events (LEDS and non-LEDS) was used in two different ways. The data comprise the total number of life events mentioned in the interviews, i.e. those that fit into the LEDS category (LEDS), and those that do not (non-LEDS), and any difficulties discussed by patients and controls: all these have been separated into positive, neutral and negative categories, as shown in *Tables 6.8* and *6.9*.

Table 6.8. Significance between the total number of life events (LEDS and non-LEDS) and difficulties between patients and controls

Test Statistics

	Total number of events discussed	Negative events discussed	Neutral events discussed	Positive events discussed
Patient total	485	126	187	235
Control total	692	297	160	172
Kolmogorov-Smirnov Z	1.225	1.633	0.816	1.225
Exact Sig. (2-tailed)	**0.092**	**0.005**	0.477	0.100

Table 6.8 shows that there is a significant difference (p=0.005) between patients and controls in the total number of combined negative LEDS and non-LEDS discussed, with the patients discussing fewer events. There is also a potential trend in the difference between the total number of events being discussed by the patients (p=0.092).

Table 6.9 Significance between the total number of LEDS life events and difficulties only, non-LEDS events excluded

	total LEs and Ds discussed	total negative Life Events and Difficulties	total neutral Life Events and Difficulties	total positive Life Events and Difficulties
Patient total	330	95	144	91
Control total	535	254	128	153
Kolmogorov-Smirnov Z	1.429	1.633	0.612	1.225
Exact Sig. (2-tailed)	**0.018**	**0.007**	0.854	**0.070**

When the non-LEDS events are removed from the data before testing for significance, there are significant differences between the patients' and the controls' in the total number of LEDS life events and difficulties discussed (p=0.018). The difference between the negative events is the greatest (p=0.007); the controls discussing negative events significantly more than the patients. There is a possible trend between the number of positive LEDS life events and difficulties for patients and controls (p=0.070), in the same direction as the negative events discussed, with only the number of neutral LEDS events proving an insignificant difference (p=0.854) between the patients and controls.

6.3.4. TQ2(b): Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's EWC?

The data on all the life events and difficulties (LEDS and non-LEDS) have been used to examine whether there is a difference between the range of emotions (i.e. the emotions used to describe the event) expressed by patients and controls when discussing life events, as seen in *Table 6.10*.

Table 6.10 Difference between the range of emotions expressed by patients and controls.

	Total range of emotions	Range of negative emotions	Range of neutral emotions	Range of positive emotions
Patient total	154	55	42	57
Control total	222	96	49	77
Kolmogorov-Smirnov Z	1.225	1.429	0.612	1.225
Exact Sig. (2-tailed)	**0.068**	**0.016**	0.543	**0.039**

The most significant difference was found in the range of negative emotions expressed by the patients and by the controls: the patients used a diminished range of negative emotions compared with the controls (p=0.016). The next significant difference between the patients and controls is the difference in the range of positive emotions expressed by the patients compared with those expressed by the controls; the patients range of emotions expressed is significantly less (p=0.039). There is a possible trend in difference between patients and controls in the total range of emotions, with the patients using a more limited total range of emotions expressed (p=0.068); the range of the neutral emotions is not significant (p=0.543).

In summary, the patients' negative emotions were significantly diminished in both the amount of times they were discussed (p=0.007) and the range of words used to express negative emotions (p=0.016) used to describe the events. The range of words used to express positive emotions expressed was significantly less in patients (p=0.039), but showed only a trend in the amount of LEDS life events and difficulties discussed (0.070) with positive emotions. The total number of LEDS events discussed by the patient group was significantly less than the controls (p=0.018), and there was a trend in the range of words discussed in the total number of life events (negative, neutral and positive). There were no significant differences in any of the analyses for the neutral emotions, either the number expressed or the range expressed. The difference in the types of emotion expressed will be discussed in more detail in *Chapter 7: Analysis and discussion*.

6.3.5. Differences between LEDS events categories in the EWC

The *Kolmogorov-Smimov Z* test with the *2-Tailed Exact* test of significance was used to examine which of the LEDS categories (*i.e.* work, reproduction, housing, money/possessions, crime/legal, health/accidents, marital/partner, other relationships, miscellaneous and death and education) showed the greatest difference between the patients and controls.

The life events have been split into the coding categories, and the following sub-categories contain (see *Table 6.10*):

- The total number of LEDS and non-LEDS life events in that category
- The total number of LEDS life events, excluding the non-LEDS life events
- The total number of non-LEDS life events, excluding the LEDS life events
- The total number of negative emotions expressed whilst discussing the LEDS and non-LEDS life events
- The total number of neutral emotions expressed whilst discussing the LEDS and non-LEDS life events
- The total number of positive emotions expressed whilst discussing the LEDS and non-LEDS life events

Any particular area that is significantly different between the patients and controls, would merit further research and analysis, as will be discussed in *Chapter 7: Analysis and discussion.*

Table 6.11 Differences between the patients and controls emotional expressions about LEDS categories

Grouping Variable: patient status	total no of bereave-ment LEDS and non-LEDS	total no of bereave-ment LEDS	total no of bereave-ment non-LEDS	total no of bereave-ment negative	total no of bereave-ment neutral	total no of bereave-ment positive
Kolmogorov-Smirnov Z	0.41	0.61	0.41	1.02	1.43	0.61
Exact Sig. (2-tailed)	0.99	0.76	0.83	0.14	0.02	0.52

	total no of crime/ legal LEDS and non-LEDS	total no of crime/ legal LEDS	total no of crime/ legal non-LEDS	total no of crime/ legal negative	total no of crime/ legal neutral	total no of crime/ legal positive
Kolmogorov-Smirnov Z	0.20	0.41	0.61	0.41	0.20	0.20
Exact Sig. (2-tailed)	1.00	0.48	0.22	0.48	1.00	1.00

	total no of education LEDS and non-LEDS	total no of education LEDS	total no of education non-LEDS	total no of education negative	total no of education neutral	total no of education positive
Kolmogorov-Smirnov Z	0.20	0.61	0.41	0.41	0.20	0.41
Exact Sig. (2-tailed)	1.00	0.39	0.74	0.59	1.00	0.48

	total no of health LEDS and non-LEDS	total no of health LEDS	total no of health non-LEDS	total no of health negative	total no of health neutral	total no of health positive
Kolmogorov-Smirnov Z	1.63	1.84	0.61	1.84	1.02	1.22
Exact Sig. (2-tailed)	0.01	0.00	0.61	0.00	0.11	0.04

	total no of housing LEDS and non-LEDS	total no of housing LEDS	total no of housing non-LEDS	total no of housing negative	total no of housing neutral	total no of housing positive
Kolmogorov-Smirnov Z	0.41	0.20	0.61	0.41	0.20	0.20
Exact Sig. (2-tailed)	0.93	1.00	0.32	0.59	1.00	1.00

	total no of marital/ partner LEDS and non-LEDS	total no of marital/ partner LEDS	total no of marital/ partner non-LEDS	total no of marital/ partner negative	total no of marital/ partner neutral	total no of marital/ partner positive
Kolmogorov-Smirnov Z	0.41	0.61	0.61	0.61	0.20	0.20
Exact Sig. (2-tailed)	0.88	0.46	0.41	0.29	1.00	1.00

	total no of marital/ partner LEDS and non-LEDS	total no of marital/ partner LEDS	total no of marital/ partner non-LEDS	total no of marital/ partner negative	total no of marital/ partner neutral	total no of marital/ partner positive
Kolmogorov-Smirnov Z	0.41	0.61	0.61	0.61	0.20	0.20
Exact Sig. (2-tailed)	0.88	0.46	0.41	0.29	1.00	1.00

	total no of miscellaneous LEDS and non-LEDS	total no of miscellaneous LEDS	total no of miscellaneous non-LEDS	total no of miscellaneous negative	total no of miscellaneous neutral	total no of miscellaneous positive
Kolmogorov-Smirnov Z	0.41	0.41	0.41	0.41	0.20	0.41
Exact Sig. (2-tailed)	0.86	0.94	0.48	0.89	1.00	0.73

	total no of money/possessions LEDS and non-LEDS	total no of money/possessions LEDS	total no of money/possessions non-LEDS	total no of money/possessions negative	total no of money/possessions neutral	total no of money/possessions positive
Kolmogorov-Smirnov Z	0.61	0.20	0.20	0.20	0.20	0.20
Exact Sig. (2-tailed)	0.54	1.00	1.00	1.00	1.00	1.00

	total no of other relationships LEDS and non-LEDS	total no of other relationships LEDS	total no of other relationships non-LEDS	total no of other relationships negative	total no of other relationships neutral	total no of other relationships positive
Kolmogorov-Smirnov Z	0.82	1.02	0.61	0.82	0.82	0.61
Exact Sig. (2-tailed)	0.45	0.23	0.69	0.39	0.28	0.58

	total no of reproduction LEDS and non-LEDS	total no of reproduction LEDS	total no of reproduction non-LEDS	total no of reproduction negative	total no of reproduction neutral	total no of reproduction positive
Kolmogorov-Smirnov Z	0.61	0.61	0.20	0.41	0.41	0.61
Exact Sig. (2-tailed)	0.52	0.33	1.00	0.59	0.59	0.22

	total no of work LEDS and non-LEDS	total no of work LEDS	total no of work non-LEDS	total no of work negative	total no of work neutral	total no of work positive
Kolmogorov-Smirnov Z	1.63	1.22	0.41	1.43	1.02	0.61
Exact Sig. (2-tailed)	0.01	0.08	0.98	0.01	0.12	0.62

Those areas that show significant differences between the patient and control groups, with the patients having fewer discussions about the life events in each case, are summarised as follows:

- Total number of bereavements expressing neutral emotions, **p=0.02**;
- Total number of health LEDS and non-LEDS events, **p=0.01**;
- Total number of health LEDS events, **p=<0.00**;
- Total number of health events expressing negative emotions, **p=<0.00**;
- Total number of health events expressing positive emotions, **p=0.04**;
- Total number of work LEDS and non-LEDS events, **p=0.01**;
- Total number of work LEDS events, **p=0.08**;
- Total number of work events expressing negative emotions, **p=0.01**.

The two main areas of significant difference are those of health events and work events, with just one area of bereavement being significantly different from the controls.

The EWC analysis, using the emotional expression coding by Danner *et al* (2000), has verified the differences between the patient and control groups that the researcher intuitively noted during the interviews and during the repeated listening to the tapes. Plummer is quoted in supporting of this, saying that:

> *Life stories, perhaps more than any other method, can sensitize the researcher to key issues. Life stories can help generate miniature sensitizing concepts, built up through listening closely to what people have to say about their lives*
> (Plummer, 2001)

6.4. TQ3: Are there any differences in the constructions of life events in providing narratives of life events, between the patient and control groups as interpreted by BNIM?

To answer TQ3, TQ0 must be answered first, i.e.:

How did the interview process go, and what implications have this for the different subsequent TQs relating to my CRQ? (Wengraf, 2001)

The answer to this question gives context to the two interviews, as knowledge of this is essential to the judgement of the credibility and trustworthiness of the data analysis (Patton, 2002).

Mr HF

The interview with Mr HF was the first BNIM participant interview conducted. He was chosen to be the first one because he and the interviewer have known each other over the past 10 years. Mr HF is articulate, has normal cognition and agreed to be interviewed for the ADLE study. As previous interviews with Mr HF had gone well, it was a good grounding on which to base the first BNIM interview.

The interview went as prescribed by Wengraf (2001, 2008). The participant raised many life events, in varying depths of narration, during the course of subsession 1. He was aware from the correspondence and consent process that this was what the interviewer wanted him to discuss (although not specifically why until after the interview), and therefore willingly complied, checking that this was what was wanted during the course of subsession1. Subsession 2 began after a natural break, and the interviewer managed to keep the order of the events from subsession 1. The interviewer was an active listener, as seen in the transcript, and the participant was able to demonstrate how Wengraf's SQUIN (2008) prompted a life story that was shaped by the participant, and how the participant was able to begin and end it as they wished in subsession 1, and then how the interviewer could ask for more detail and PINs in subsession 2.

Mrs HN

The first subsession was very short in this lady's case. Wengraf states that the interviewer should not be concerned if this is the case (2001, 2008), and that many PINs can come out of a short subsession 1. Mrs HN's engaging character drew the interviewer into exchanges. These exchanges could have easily diverted the interviewer from the objective of the interview, which was to get the interviewee to talk about her life events and experiences. This pattern of interchanging communication was very different from the active listening to Mr HF. These differences can be seen in the *Table 6.12* below:

Table 6.12. Differences between the two in-depth BNIM interviews

Differences in subsession 1	Mrs HN	Mr HF
Long		Y
Short	Y	
Description present	Y	Y
Argumentation present	Y	
Report present	Y	Y
Narrative present		Y
Evaluation present	Y	Y
PINs present		Y
Long accounts of narration		Y
Short interactive accounts	Y	

How these differences influence the results will be examined in Chapter 7, where the rest of the TQs will be addressed.

The results for TQ1 include LEDS interview data on demographics, cognitive scores, and life events and difficulties. The results for TQ2, which includes Danner et al.'s (2001) EWC, are discussed, and the results for TQ3 use the data from the BNIM interviews.

Of the six interviews, two were analysed in depth, the other four contribute to the microanalysis, and the supporting or refuting of the TQs. After the Text Structure Sequentialisation (TSS) and Biographic Data Chronology (BDC) were performed (see *Chapter 5*) the results of these two texts were presented to two different groups, known as panels (Wengraf, 2008). These will be described separately.

6.4.1. Biographic Data Chronology

This tells the story of the person's life chronologically, not in the way that it was told. Wengraf states that it is possible to do the analyses on your own without any panels (2001), as long as particular attention is paid to keep an open mind. In an ideal world the panel, should comprise a group of people (i.e. more than two) who are from different backgrounds with different life experiences, who have a half-day to spare to discuss one person's biographical details. The aim of the panel is to expand the

researcher's social imagination (Wengraf, 2001) – hence the need for the different backgrounds in the panel members. The panel is presented with a section of the person's life and asked to predict what happened next, without knowing what did happen next. This leads to the panel coming up with a variety of hypotheses at each stage, Wengraf calls them the:

- Original hypothesis – what is the obvious prediction
- Counter hypothesis – the opposite of the original prediction
- Tangential hypothesis – a hypothesis at a complete tangent to the other two.

The section in the person's life are delineated by turning points that have had the subjective information removed; the background information given to the panel members is shown with the turning points of the two BNIM interviews are detailed in Text box 6.X. The panel members consisted of people who were interested in the BNIM method, and came from either a health or social care background. The panel process was done by email, to make it much quicker, as a group meeting of half a day was not practical due to the number of commitments of the panel members. The BNIM interview method has an active following, cultivated by Tom Wengraf through courses and an email discussion group. Researchers from this email group often discuss different ways of carrying out a BNIM interview. Wengraf is open to suggestions of ways to improve the use and availability of the BNIM himself, and the email method has been discussed with him (Personal Communication, 2009), as a way of carrying out the panel method. Four out of the six panel members had attended a BNIM course, and the sections of the person's life were sent out in separate emails, enabling the panel member to reply when convenient to them, without knowing what came next. The longest total length of time it took for a panel member to reply from the first email to the last was 35 minutes, the shortest time being 17 minutes. Four panel members were able to contribute and their emails replies are shown in the *Text boxes 6.13* and *6.14*. Their replies did not fulfil the variety of hypotheses for each section as suggested earlier, but they did fulfil the aim of expanding the researcher's imagination.

Text box 6.13. Brief background of Mrs HN

Brief background of Mrs HN

Mrs HN is a white lady of working class background, who is now in her mid 80's.

Chunk 1

She was born to an unmarried mother in a small village on the edge of a small city. What do you think happened next?

Chunk 2

Mrs HN lived with mother, who went out to work, in grandmother's home with 2 aunts and 2 uncles too. Mrs HN was never told anything about her real father, and, when people visited the house for any reason, and there was a man, she always wondered if he was her real father. Her mother remarried and asked her 12 yr old daughter, Mrs HN, if she would like to go and live with them. What do you think happened next?

Chunk 3

Mrs HN prayed that she wouldn't have to go to her mother and stepfather's house, and her grandmother allowed her to carry on living there with her. She always felt her stepfather had taken her mother away from her. One day Mrs HN was 'really cheeky' when she heard her stepfather bossing her mother around, and said 'if I was her I'd do what I wanted', and her stepfather went clonk on the side of her face, so hard it rocked her head and she saw stars. What do you think happened next?

Chunk 4

Mrs HN's mother said 'I will never forgive you for that, her uncle wanted to attack the stepfather, and her grandmother persuaded him to leave it be. Mrs HN never, ever forgot it, and decided to keep her stepfather at arms length so they wouldn't fall out. She was eventually told the name of her real father and the (local) area from which he came. What do you think happened next?

Chunk 5

Mrs HN looked for him, but never found him or anything about him, and still doesn't know to this day who he was. She had a stepsister and 2 stepbrothers who she often visited. She then had a Scottish boyfriend from the air force. What do you think happened next?

Chunk 6

Mrs HN got engaged and married to him, in Scotland and went to live on a remote Scottish island. What do you think happened next?

Chunk 7

They had their first child, a son, and Mrs HN was desperate for a little girl too. What do you think happened next?

Chunk 8

Mrs HN's husband said 'we're not having a another child, I'm not saying we're not having another child at all but we're not having another child until we've got a house'.
Her mother-in-law died, and husband asked her if she wanted to move back down South (to her village). What do you think happened next?

Chunk 9

Although everybody was very kind to Mrs HN on the remote Scottish island, she wasn't keen on living there, and her husband asked her if she wanted to move back down South, which she jumped at. And they were able to buy a house. What do you think happened next?

Chunk 10

Mrs HN and her husband tried and tried to have another baby, and it just didn't happen, they didn't know why, but no child came. What do you think happened next?

Chunk 11

Mrs HN said 'well there we are, if that's how it is that is, and X(son's name) is so nice he's made up for it'. They lived very happily, in her birth area, and in later years went to live in a flat attached to her son's house. They celebrated their Diamond Wedding Anniversary. Her husband developed dementia in the last few years, had to go into a nursing home, and died a few years ago. But she still says she is a very lucky person, and continues to live in the flat attached to her son's house.

Text box 6.14. Brief background of Mr HF

Brief background of Mr HF
This man is in his 70's, and is white and of middle class background, retired from a professional job, and does voluntary work in spare time.

Chunk 1
Grammar school boy, left after 'breaking up' library with others. What do you think happened next?

Chunk 2
Taken, by parents, to Headmasters Conference for careers advice, advised to go into accountancy. What do you think happened next?

Chunk 3
Mr HF became Articled Clerk in London firm of accountants, travelled to clients all over country with a friend and colleague. Had revelation that he didn't want to do this for rest of life and asked to be released from articles. What do you think happened next?

Chunk 3
Next did national service in army, offered officers job. What do you think happened next?

Chunk 4
Refused officers job. Volunteered instead to go to Asia, ran small newspaper for forces, and did all sorts of things in division. Army quite an influence. What do you think happened next?

Chunk 5
Back from army aged 23, decided he wanted to work with children. Proposed to girlfriend. What do you think happened next?

Chunk 6
Married girlfriend. Did some teaching, first in ESN school prior to training, got methods of discipline sorted out there, never had problem since. Trained and became teacher in primary school. What do you think happened next?

Chunk 7
One of pupils fell off a wall and fractured his femur, so Mr HF took it upon himself to teach him at home, in his spare time. Became very aware of boy's working class background, the boy's parents' aspirations for him, and the 'warmth' of a close family, different to his own experiences as a single child. Decided teaching, though 'worthy' profession was not enough. What do you think happened next?

Chunk 8
Trained as Childcare Officer, finished as 3rd child was born. What do you think happened next?

Chunk 9
Climbed social work ladder into management, wife also became very competent social worker. 4 children by now, all growing up, leaving home and studying. What do you think happened next?

Chunk 10
Wife died suddenly, no warning or previous illness. What do you think happened next?

Chunk 11
Mr HF not coping, needed people to come in and look after him for about 2 yrs, as by this point all children had left home. Realized he would end up like clients he had seen, with papers all piled up around house. What do you think happened next?

Chunk 12
Mr HF realised he needed a partner and that he knew someone who would be suitable (P). Also realized he was good at counselling aspects of his job as social worker. What do you think happened next?

Chunk 13
Moved in with P for 2/3 years, helped do her old cottage up. Took early retirement from social work. Trained as counsellor with voluntary organization. What do you think happened next?

Chunk 14
Married P, since been very happily married for nearly 20yrs. Has had many counselling cases (has reduced caseload now), and has done may roles within this voluntary organization. Spends lot of time having good holidays.

The hypotheses received for both cases are in *Appendices VII* and *VIII*. These are compiled altogether and the hypotheses either refute or confirm the choices the people made in their lives. A summary is produced of the BDC, called a Biographical Data Analysis (BDA), which gives the researcher better preparation for relating the told story to the context, as well as producing a case history with a greater understanding of the decisions that were taken in that person's life (Wengraf, 2008). The two participant's hypotheses and summaries are in *Appendices VII and VIII*. The summaries and transcripts can be examined for patterns and hypotheses made about the patterns noted. For Mr HF, the following patterns could have been noted:

- A story of a happiness thwarted – attempts at being happy have been met with various life events that have been frustrated
- A story of a life guided by other's events – no clear direction of his own, events of other people have created profound changes in his life
- A story of a life of several careers but no specific goal
- A story of highs and lows of a life
- A story of the rewards of a life helping others

Mrs HN could have the following patterns noted:

- A story of a life of not knowing - a conspiracy of silence
- A story of an absent father and an effect on the rest of her life
- A story of dominant females
- A story of family ties
- A story of a life of frustrations

These different hypotheses prepare the researcher for a variety of interpretations of the told story, and to listen for the less obvious or hidden story lines. The hypotheses are then examined to see if the evidence within the transcript confirms or refutes them.

6.4.1. Told Story

The told story is, as has been described previously, the way the interviewee has described their life, and presented it to the interviewer. The TSS chunks are examined, and the way in which they change between the chunks can show the:

- Emotional experiences of the past that the narration is about
- Emotional experiences of now telling in the present, or not-telling or partly-telling (Wengraf, 2008).

The TSS chunks now go through the same process as the BDC with a panel, in order to do the thematic field analysis (TFA). A different panel was convened of fellow nursing colleagues, and an hour was spent briefly discussing the chunks, and what the told story reveals about the emotional experiences of the past, and how they are spoken of (or not) now. Both panels are ignorant of the other's information, only the researcher is aware of the whole picture, and must put that information to one side (Wengraf, 2001) for the meeting time of the panel.

Wengraf states that the question posed during the panel discussion is:

At this point in their life, why, in this interview, did the subject improvise their telling of the story in the way they did?

The panel discussed a number of hypotheses (known at this point as 'structural hypotheses' Wengraf, 2001, 2008) that underpinned the way that he presented his life history in subsession 1, and for Mr HF, the following structural hypotheses (SH) were considered, in *Text Box 6.15.*

Text Box 6.15. Structural hypotheses for Mr HF

Page nos in TSS document Appendix VII	Topic/PIN	Hypothesis
1-2	School library, vegetarian diet, leaving articles	**SH1**: Not afraid of being unconventional, doesn't take safe route
2-3	Army, teacher training, proposal to wife	**SH2**: Hostage to fortune, reactive and not taking initiative
4	Teaching in primary school, teaching boy at home	**SH2**: Not toeing line but still reacting to what's in front of him
4	Changed career and climbed management ladder	**SH3**: Success - not due to lots of ambition, accidental
4	Wife became Social Worker	**SH4**: Didn't want a rival to challenge him
5	Sudden death of wife and lack of coping for 2 years	**SH5**: Reacted to event in dysfunctional way -
5	Hand stopped working - retirement	**SH2**: Reacting to an event again rather than planning this – hostage to fortune again
6-7	Seeking partner, unsuitable or suitable?	**SH6**: Settled for 'suitable' partner after wife's death – going for safe option this time. Compartmentalises life, needed functional partner after dysfunctional reaction to wife's death
all	Had 4 children, only mentioned very briefly	**SH7**: Mentions his children and his role as father – because he feels successful or unsuccessful in this?

These hypotheses were then tested against the following TSS chunks and transcript in *Text box 6.16.*

Text 6.16. Testing of Structural Hypotheses with TSS chunks

Page nos in TSS document Appendix VII	Topic/Pin	Structural Hypothesis
7-8	Leaving articles	SH1 supported
9	Bridge playing with officers	SH1 and SH3 supported
9-10	Attacking bully, teaching boy at home, SW training and experiences	SH1, SH2 and SH3 supported
11	Care for abandoned children - didn't do this conventionally	SH1 supported
12-13	Gladiatorial boxing (didn't want to learn about artillery) and 'blood lust'	SH2 and SH3 supported
13	Is this being recorded? Haha!	SH2 supported
13	Closing sentence after interview finished; most painful – death of wife	SH5 supported

The structural hypotheses that were the most supported by the evidence in the TSS document are SH1, SH2 and SH3, these can be combined into:

Is a hostage to fortune, in that he reacts to events going on around him rather than seizing the initiative, he is not afraid of being unconventional, and success has come of these characteristics.

For Mrs HN, the following structural hypotheses were considered from her subsession 1, which was much shorter than Mr HF, see *Text box 6.17.*

Text box 6.17 Structural hypotheses for Mrs HN

Page nos in TSS document Appendix VIII	Topic/PIN	Hypothesis
1-2	Always joking, take no notice	**SH1:** Life is a joke, whatever happens
1-2	No knowledge of father's identity, upset for a while	**SH2:** Rejection, but triumphed over adversity
2	Grandmother saved her	**SH3:** Owes happiness to others - Grandmother

These hypotheses were then tested against the following TSS chunks and transcript, in *Text box 6.18.*

Text Box 6.18 Testing of Structural Hypotheses with TSS chunks

Page nos in TSS document Appendix VIII	Topic/Pin	Structural Hypothesis
2	Everybody kind to her, except for one, just the way	SH1, SH2 and SH3 supported
2	Identity of father	SH1 and SH2 supported
2	Mother married, but Mrs HN stayed with Grandmother	SH3 supported
2	Step-father slapped face, probably deserved it, she pretended he didn't exist	SH2 supported
2	No dad to see things at school	SH2 supported
3-4	Joking about slap from step-father	SH1 supported
3-4	More people good to her than not, wanted baby girl as well as son, never happened	SH2 supported
5	No baby girl arrived, despite trying lots	SH2 supported
5	Living in a lovely place now	SH2 supported
6-7	Untidy house jokes	SH1 supported
9	Happy marriage, joked about glaring moments	SH1 supported
9	Step-father took away mother from Mrs HN	SH2 supported
11	Step-siblings arrived, Mrs HN loved looking after them	SH3 supported
11-12	Wedding trip to Scotland, all Mrs HN's family went up and called it a holiday	SH2 supported

The structural hypotheses that were the most supported by the evidence in the TSS document are SH2, and less so SH1, these can be combined into:

Rejected, but triumphed over adversity, and, whatever happens to you, life is a joke.

Wengraf (2001) calls the structural hypotheses that have been tested the 'statement of the theme', as they characterise the narration as a whole. Mr HF's

Is a hostage to fortune, in that he reacts to events going on around him rather than seizing the initiative, he is not afraid of being unconventional, and success has come of these characteristics.

Wengraf (2008) suggests analysis of the order that the TSS chunks, or topics in the transcript, are discussed. Mr HF discussed experiences in the following order, with the amount of narrative shown in *Text Box 6.19*:

Text box 6.19 Order of topics discussed in the transcript and number of lines.

Order number	Topics in order, as discussed in subsession1	Number of lines (sub-sessions 1 + 2)	Total no of lines for each subject
1	Wartime boy	6	6
2	Grammar school	4	4
3	Articles	52	52
4	Army	64	64
5	Teaching	37	37+54=91
6	Proposal of marriage	6	6
7	Army	57	57
8	Teaching	54	
9	Social work	83	83+14=97
10	Family – 3rd child born	3	3
11	Social work	14	
12	Wife's career as a social worker	7	7
13	Wife's death	12	12+12+3=27
14	Early retirement	21	21
15	Wife's death	12	
16	Went for bereavement counselling	3	
17	Relationships	16	16
18	Trained as a counsellor	9	9
19	Illness	21	21
20	2nd marriage	3	3

Mrs HN discussed her experiences in the following order, with the amount of narrative shown in *Text Box 6.20*:

Text box 6.20. Order of topics discussed in the transcript and number of lines.

Order number	Topics in order, as discussed in subsession1	Number of lines (sub-sessions 1 + 2)	Total no of lines for each subject
1	Absent father	17	17+4+3=21
2	joke	2	2+2+1+1+1=7
3	Absent father	4	
4	joke	2	
5	Kindness shown to her	5	5
6	grandmother	12	12+3+9=24
7	Mother and step-father	4	4+12+6+4+10=36
8	grandmother	3	
9	Step-father	12	
10	Absent father	3	
11	Spoilt behaviour	7	7
12	Step-father	6	
13	joke	1	
14	Step-father	4	
15	Grandmother	9	
16	joke	1	
17	son	5	5+6=11
18	Infertility	1	1+6=7
19	husband	10	10+8+8=26
20	Family planning	9	9
21	Infertility and son	6	
22	Tour of flat + family photos	34	34+14+8+3=59
23	Wedding + husband	8	
24	Tour of flat + family photos	14	
25	Step-father	10	
26	Living in Scotland	12	12
27	Tour of flat + family photos	8	
28	Step-sister	9	9+8=17
29	joke	1	
30	Tour of flat + family photos	3	
31	Step-sister and siblings	8	
32	Wedding + husband	8	

Text boxes 6.19 and 6.20 show the amount of time and the order in which they spoke about the topics Mr HF chose. This enables the 'shape of the telling' to be explored, and the

- Emotional experiences of the past that the narration is about
- Emotional experiences of now telling in the present, or not-telling or partly-telling (Wengraf, 2008).

This focus helps to place the narratives told in the situated subjectivity of the person telling them, and for the researcher to set the interviews in a personal and socio-historical context. It also serves to focus the researcher on the TQ3:

- Are there any differences in the constructions of life events in providing narratives of life events, between the patient and control groups as interpreted by BNIM?

Patterns that are present within the 2 interviews will become noticeable, and it is immediately clear that Mr HF speaks:

- with fewer and with much longer sections on the topics chosen
- has a way of speaking that demands listening (makes statements that he is comfortable with and does not engage the listener for their opinion)
- is able to discuss the trauma of the life events – with difficulty about his wife, but does not use jokes or other strategies to avoid further explanation of the subject

On the other hand, Mrs HN speaks:

- in a way that engages the listener and draws them, by using jokes, or questions that she expects an answer to
- She discusses fewer topics overall, but more frequently and in much shorter sections
- She uses jokes to deflect from uncomfortable discussions about the effects of the topics being discussed

The data from Text box 6.19, Mr HF's interview, shows a more coherent flow of thought in comparison to Mrs HN's interview data in Text box 6.18, which hops around in a way that is initially incoherent. This data is used in the formulation of the case histories, to clarify the underlying differences between the 2 narratives.

The life events are discussed in the BNIM in a free-form manner, encouraging the interviewee to select the life event and experiences they feel are appropriate to their narrative. Unlike the LEDS, it does not cover set topics or set questions, letting the interviewee decide on the facts told. This enables the researcher to explore the structure of how the life events are presented through microanalysis. Microanalysis of the opening narratives of the other participants are compared in *Chapter 7: Analysis*, to illustrate the analysis.

6.4.2. BNIM microanalysis of passages form the transcripts

Puzzling or potentially revealing passages of the subsession 1 transcripts are chosen to look at in detail (Wengraf, 2001), in order to construct hypotheses about why they described life events in a particular way, and to '*illuminate the significance of the speaker's choice*' about which way was chosen, and the alternatives (Wengraf, 2001). Mr HF's microanalysis is shown below in *Text box 6.21*, and Mrs HN's microanalysis in *Text box 6.22*.

Text box 6.21 Microanalysis of subsession 1 of Mr HF.

Datum	**Experiencing**	**Prediction of next words in text with Following Hypotheses**	**Effect on hypotheses of later date**
Datum 1 I yielded to my parents' wish having broken up the library in our school, or being part of breaking it up, terrible when I think about it, in the 6th form. I left suddenly, at the end of 45, and my parents took me to the Headmasters conference. The headmaster's conference said well yes you are good at this, good at that, we think you would be a very good chartered accountant.	1.1 Shame 1.2 Concern for accuracy 1.3 Concern to conform	1.1 Would do what parent's wished for him i.e. become an articled clerk 1.2 Tells precise times and order of events 1.3 Conforms to what Headmaster's Conference suggested – becomes an articled clerk	1.1 Supported by Datum 2, and in other parts of transcript 1.2 Supported by Datum 3 1.3 Supported by Datum 2
Datum 2 I suddenly had this tremendous moment (a), if I wish to be a chartered accountant I could, (b) instantaneous follow on, I wasn't going to be as I did not wish to be.	2.1 Shame as had failed first exams ever 2.2 Had experience of choice about future	2.1 Would go back and retake exams and become accountant 2.2 Now he had failed the exams, he could choose what to do with the rest of his life	2.1 Not supported by Datum 3, or in other parts of transcript 2.2 Supported by Datum 3

Datum 3 was offered to become an officer, though I said no because if I do another 6, because I'd done 6 months training by this time, if I did another 6 months training then I wouldn't be ...abroad, and I wanted to go abroad, might as well...in the army, so I volunteered for Malaysia, having read Spencer Chapman the jungle is neutral,	3.1 Refusing to conform – wanted to go abroad 3.2 Experience of choice 3.3 Wanted same experiences as Spencer Chapman	3.1 Decline officer's post and ask to go abroad 3.2 Could choose to take or reject officer's post 3.3 Would have similar experiences to Spencer Chapman	3.1 Supported by this Datum 3 and in other parts of transcript 3.2 Supported by this Datum 3 and in other parts of transcript 3.3 Not supported by any Datum here, or in other parts of transcript
Datum 4 I remember the moment to this second, walking in the must have been lights on in the park, it must have evening, about march time, I proposed to my wife, and it was such a shock to me that I had actually done it I couldn't really believe it but there it was 1954, and we were married in March 1956.	4.1 Anticipation of positive response 4.2 Terror of negative response	4.1 Would be happy and plan future with wife 4.2 Would have to plan future without wife	4.1 Supported by this Datum 4 and in Datum 10 4.2 Not supported by any Datum here, or in other parts of transcript
Datum 5 one young lad fell off a wall, running round the school and cracked his thigh, very bad, and he couldn't read or write. And so I thought right, I used to go to his home, this was in the back streets of O, C was it, um and to a mining family, where he came from, and I taught him after school twice a week, voluntarily, so I was invited into the family eventually and given their cracked cups of tea and so on, and er I complained bitterly that this boy was being left, nobody was doing anything, except me, so what do you do with a rebel, you bring him in.	5.1 Compassion, that the boys would miss out in education even more 5.2 Frustration and anger at no one doing anything for the boy 5.3 Realisation he was being rebellious	5.1 Had choice about whether to go and visit boy's home or not 5.2 Vented anger at authorities 5.3 Realised he was not conforming and that they dealt with his frustration well	5.1 Supported by this Datum 5 and in other parts of transcript 5.2 Supported by this Datum 5 5.3 Supported by this Datum 5 and Datum 6

Datum 6 that I decided that I'd helped other children get referred to child guidance and I thought I'm in the wrong place to do this, I'm a teacher I'm not doing all these other things you got to do something, so revelation little revelation tiny revelation now, cor I could go into social work	6.1 Realised he was in wrong place to help a lot of these children 6.2 Little by little realised he could choose to help these children by training as a social worker	6.1 Could teach them as best he could, or could help with their social problems as a Social Worker 6.2 Had choice about staying or going	6.1 Supported by this Datum 6 6.2 Supported by this Datum 6
Datum 7 big thing this, my wife who had herself had been to university early went back again to train as a social worker up in Xxxx . And er when I was in my forties, well she certainly was, yeh we both were in our forties she having had 4 children, and became a very able person, to my surprise, and you might say annoyance as a man, as I didn't like her eventually being better than me	7.1 Surprise at wife being good at 'his' job 7.2 Annoyance at her (a woman!) being so good or even better than him in 'his' job 7.3 Pride in her achievements	7.1 Taken aback, and didn't know what to say about this 7.2 Showed lack of support for wife's new role 7.3 Discussed her achievements with pride and admiration	7.1 Not supported by this datum, or other datum in transcript 7.2 Not supported by this datum, or other datum in transcript 7.3 Supported in this datum, with tone of voice, and in Datum 8
Datum 8 And then she died. And I suppose of all the times which you are going to ask me about that was, (pause) well, (pause) it was unbelievable and er for months and months I had people come in and look after the house and cos all my children were away, er the youngest child was at college and poophh	8.1 Devastation at wife's sudden death 8.2 Inability to express what it all meant to him, it meant so much 8.3 Unbelief at what had happened to him and his family	8.1 Not knowing what to do with the empty void 8.2 Lack of coherent explanation about what wife's death meant and means 8.3 Still in state of shock about how he and his children had been left so suddenly without her	8.1 Supported in Datum 10 8.2 Supported in this datum and other parts of transcript 8.3 Supported in this datum and in Datum 10

Datum 9 I kept on working until, this is another moment, ha ha, I've had several moments, my daughter finished her exams on Saturday, I er was working on the following Monday, I 'd been to some meeting and I was scribing some, come back to the office, and was scribing for myself some notes that I wanted to present, somewhere or the other, I don't know where, but I was doing some report, and as I was writing the hand stopped and I looked at it, ha ha ha, and I thought that's it I'm going to cease this, I've seen my last child through college I can't take any more of this,	9.1 Shock at hand no doing what he wanted it to do 9.2 Sudden realisation that he didn't want to carry and didn't need to carry on 9.3 Sudden realisation that he couldn't take anymore of the stress of work	9.1 Seek help about hand function 9.2 Had a choice about whether to carry on working or not 9.3 he could seek help with his stress, or give up the cause of the stress (i.e. work)	9.1 Not supported by this datum, or any other parts of the transcript 9.2 Supported in this datum 9.3 Supported in this datum
Datum 10 I suddenly realised (a) I didn't want to be by myself after 2 years, cough, I was useless, and (b) there was a person around whom I had known for 20 or odd years who had who might manage to get fully trained she'd then left, cos she was a worthy person, who had become a guardian to our children, she became a family friend, and there she was a single woman, by herself, and I plucked up courage, we started to live together after 2 and a half yrs in 3 yrs I bought this place,	10.1 Loneliness of being a widower did not suit him – he was useless on his own 10.2 Sudden realisation that he could ask this person to be his partner, she had all the right characteristics 10.3 He was afraid of asking her and needed to pluck up courage, in case of rejection	10.1 Would ask someone to be his partner 10.2 He could ask this person to be his partner 10.3 He could choose to give in to the fear of rejection and not ask her, or he could pluck up courage and ask her	10.1 Supported in this datum 10.2 Supported in this datum 10.3 Supported in this datum

The next step in the analysis is to write a case history, using the data from the BDC, told story and the microanalysis.

6.4.2.1. Mr HF case history

Mr HF was born to middle class parents and went to a grammar school, which he left quite suddenly after breaking up the school library with others. He describes being taken to the Headmaster's Conference, a place where they used to advise on careers, he describes this himself as:

I yielded to my parents' wish having broken up the library in our school, or being part of breaking it up, terrible when I think about it, in the 6th form. I left suddenly, at the end of 45, and my parents took me to the Headmasters conference. The headmasters conference said 'well yes you are good at this, good at that, we think you would be a very good chartered accountant', so I swung into the chartered accountancy firm, and they took me on er I became an articled clerk.

This is the first example of him explaining his reaction to events, rather than him being directive and ambitious. The life events seem to have steered him, rather than him having a particular aim in his life that he is fixed upon attaining. The experience of being an articled clerk included a revelation about his future, after he had failed 2 of his exams – something he had never done before – his reaction at this time was:

I suddenly had this tremendous moment (a), if I wish to be a chartered accountant I could, (b) instantaneous follow on, I wasn't going to be as I did not wish to be. I was so overtaken by this that I went out and had a cup of coffee at Joe Lyons

This was discussed in depth with his good friend, also an articled clerk, whilst visiting an estate to do the accounts there. Mr HF recognised that his friend did him a service by allowing him to talk, and for his advice, which was to tell his parents. This all enabled him to articulate and express his feelings, break free of his parents, and 'find' himself.

After a few months Mr HF joined the army, for his National Service, and after training refused the Officer's post they offered him. He had some influential experiences in the army, one of which was that he realised that he could feel strong against bullies:

there were things that I now had that I could use if I wished to if wished to, which was to have greater strength than somebody like that.

He also had the experience of joining in a Bridge club with other more experienced and senior men in the army, and enjoying it, and becoming aware that:

I thoroughly enjoyed it and I did not feel in anyway out of, out of my rank as it were, I didn't, it didn't worry me at all, I just enjoyed the pleasure but that also made me realise that class rank position role doesn't have any differences who you are and what you are

that counts more than anything else so that was another very good learning positive learning experience.

Mr HF was not interested in artillery, or fighting, so to extricate himself from this, he began boxing training. He won fights and represented the battalion, and in a memorable fight he discovered his 'blood lust' after he had made his opponent's nose bleed and couldn't stop himself going in for more – despite having agreed with the opponent beforehand that they weren't going to hurt each other, he describes it as:

I caught poor X very hard, and I hit him just under the nose now not only is that extremely painful it is also bloody, (27.27) and when I saw blood I went berserk, I hit him he fell over, poor chap they got up again, and I hit him again and he fell over and he didn't want to get up again by now, and I realised that at that moment there is something called blood lust and it is horrifying but it is in each of us and if we don't know about it its time we jolly well time we did, and although I did fight um again , did 1 or 2 more bouts, in fact it was probably what got me.

His colleagues often asked him to fight again, but he refused.

Success came out of standing up to the bullies in the Army, in and out of the ring, and he was honoured by being made the 'Stick Officer'. The Major X and his uncle were influential in guiding him about what career to pursue following his National Service, and he chose teaching. He met and married his wife, after surprising himself with his proposal to her. They went on to have 4 children.

During his teaching he managed to increase the 11 Plus success of the primary school children he was teaching by getting them to practise, he also taught them social and practical life skills. During this teaching, one of his pupils fell off a wall and fractured his femur badly, so was unable to attend school for several months. Mr HF took it upon himself to go and teach him at home, after school, and he was eventually invited into the family. This gave him a different perspective about child welfare and families and impelled him to think of his next career, and training in Social Work. He trained as a social worker whilst he had a young family, and then gradually worked his way up the management ladder.

During this time his wife had also trained to become a social worker, and he found he was slightly annoyed at her success, in 'his' job. She worked her way up to the top of a division, and then, as after a short pause he says 'And then she died'. He describes this as:

And I suppose of all the times which you are going to ask me about that was , (pause) well,(pause) it was unbelievable and er for months and months I had people come in and look after the house and cos all my children were away, er the youngest child was at college and poophh, and she didn't want to go back

This description shows how after all these years it is still hard for Mr HF to put the experience into words, and he still cannot use the right words to describe it. It is still a shock that stuns him as shown in the pauses amongst other eloquent accounts.

This account of his wife's death is in contrast to all other accounts of life events. The other accounts of life events are well thought out and fluid, demonstrating thoughts and ideas that have been processed into a coherent narrative that can be categorised and filed away in his memory to be recalled at anytime. His wife's death is an account that still causes pain, and discomfort when remembering it, and as shown, he is not able to put part of it into words, despite having had bereavement counselling.

When the pattern of TSS segments are examined in the subsession 1 with the DARNE analysis (see *Chapter 5:Methods* and *Appendix VII*), it is noted that Mr HF's transcript is categorised as Report and Narrative, interspersed with bits of Evaluation. This indicates he is able to sum up the main events of his life using:

- Report - provide an overview of events, some of which are detailed, and cover relatively long periods of time
- Narrative – tells a story by which X followed Y, in rich detail virtually reliving the event from close-up using direct speech and quotes.

Within these reports and narratives he is able to sum up life events and experiences and uses

- Evaluation – the moral of the story

to do so, implying that he has thought about these events and has summarised them and the effect they have had on him. Indeed, even his wife's death has been summarised and

the effect on him realised in *Datum 10* (*Text box X*). There are no TSS segments that include the category of

- Argumentation - development of argument and theorising, from present or past time perspective, usually in a stand alone form, occasionally explicit disagreement with an alternative position, usually implicit.

'Argumentation' implies an irresolute or ambivalent perspective on a topic or life event, and a state of mind about something that has a lack of reconciliation and resolution. There are no 'Argumentation' segments in this interview, when it might be expected that they should accompany the painful re-telling of the death of his wife.

Work was difficult after his wife's death, but he 'stuck to it', and living seemed even more difficult, he had friends come in and look after him for some time, until he eventually came to a realisation that he was going to become like a client he had once met – surrounded by papers and dependent on paid help. After this experience he says he got some counselling and

suddenly realised (a) I didn't want to be by myself after 2 years, cough, I was useless, and (b) there was a person around whom I had known for 20 or odd years who had who might manage to get fully trained she'd then left, cos she was a worthy person, who had become a guardian to our children, she became a family friend, and there she was a single woman, by herself, and I plucked up courage, we started to live together after 2 and a half yrs in 3 yrs I bought this place, sold up.

He later trained as a counsellor, and still takes great pleasure in being able to help the organisation that helped him. Throughout his life he has had the opportunity and ability to discuss those things important to him, as shown from the discussion he had with his fellow articled clerk, to when he had bereavement counselling after his wife's death. He remains in a relationship that has been, and is, supportive of him during the worst of his life, his present wife being a close family friend (and his children's guardian) at the time of his first wife's death who helped them through it. It is significant though that after closing the interview, thanking him for his help and saying I would be turning off the recorder, that his last statement (lest it be forgotten) is:

The most painful was the death of my wife

- that which he could not put coherently into words.

Text box 6.22 Microanalysis of subsession 1 of Mrs HN.

Datum	Experiencing	Prediction of next words in text with Following Hypotheses	Effect on hypotheses of later date
Datum 1 I was a spoilt brat when I was small, I had a mother I never saw my father but I suppose he was somewhere but he'd gone away, but I never knew him, if I 'd have fallen over him in the street I wouldn't have known who he was so as I grew older I thought well that was a strange way of things happening, but people in those days didn't tell you things	1.1 Shame due to ignorance about father 1.2 Rejection by father 1.3 use of humour to divert attention from a life event	1.1 Would not ask mother and family about father (leading to less emotional expression about this life event). 1.2 Would discuss feelings of rejection 1.3 Would change subject with a joke, and not express feelings about life event	1.1 Supported by transcript and Datum 2 1.2 Not supported by Data or transcript 1.3 Supported by Datum 3 and 4
Datum 2 And it was very disconcerting, cos I used to imagine all sorts of things and I used to if people came to the house and there was a man I used to think I wonder if that was my father but I never knew, and I lived with my grandmother and my mother was there because there was no father so I got all suspicious as I grew older but no one spoke about it so I never really knew,	2.1 Disconcerted 2.2 All sorts of unsettling images from imagination 2.3 Wonder if any of the visitors were her father 2.4 Suspicious about who was father	2.1 Would explain why disconcerted 2.2 would explain what images that unsettled her 2.3 Would seek further information about her father 2.4 Would find out about father	2.1 Supported by Datum 2 2.2 Supported by Datum 2 2.3 Supported by transcript 2.4 Not supported by any Data or transcript

Datum 3 But no it was very upsetting and I, and that upset me for a long time then I got over it and I think what's happened has happened and what's that's what your not given or not given and you've got to get on with it and make the best of it, and what else can you do and so I'm afraid there's not much else to tell you. Except I'm lovely ha ha	3.1 Upset at ignorance about father 3.2 Has felt she had to 'move on' from this problem 3.3 Felt helpless in face of no knowledge about father 3.4 Felt unable to discuss in detail so joked	3.1 Would explain how she dealt with 'upset' feelings 3.2 Explains how she has been able to move on 3.3 Felt low about lack of knowledge and expression of low mood 3.4 Changed subject with joke	3.1 Supported by Datum 3 and 4, and by transcript 3.2 Supported by Datum 3 and 4, and by transcript 3.3 Not supported by Data or transcript 3.4 Supported by Datum 3 and transcript
Datum 4 Where's my handkerchief, no but I'm always joking take no notice. Well that's it, for a while I got very upset but er well that just had to go er everybody was exceedingly kind to me there was not a soul that wasn't kind to me except one person and she was a bit catty but I think she well she said I'd got everything and she'd got nothing but that's nothing, that's just by the way. My grandmother was my hero	4.1 Always joking, making life seem better than it is, knows should not do it all the time, so to take no notice 4.2 Very upset about father 4.3 had to dismiss feelings of being upset 4.4 hurt by someone who was catty to her 4.5 love for grandmother	4.1 Makes a joke after mentioning a negative life event 4.2 Will cry about father 4.3 Cannot discuss feelings about father other than superficially 4.4 Will mention this person as someone who was unkind to her 4.5 Mentions grandmother with love and affection	4.1 Supported by Datum 3 and 4 and transcript 4.2 Not supported by Data and transcript 4.3 Supported by this datum, and transcript 4.4 Supported by this Datum and transcript 4.5 Supported by this Datum and transcript

6.4.2.2. Mrs HN case history

Mrs HN was born to an unmarried mother in the 1920's. This was a time when being an unmarried mother meant blame, shame and no support from the father. The workhouses had not yet closed, and there was a stigma attached to being an unmarried mother as well as being the child of an unmarried mother. Often unmarried mothers would give their children up for adoption. Mrs HN's mother was well supported by her mother and her 4 siblings, and Mrs HN was brought up mainly by her grandmother, as her mother had to go out to work. Mrs HN found the conspiracy of silence about her father difficult to deal with;

at school, with no father to come and see things there; and at home, when a man came into the house (whatever the reason) she would wonder if he was her father, as she describes here:

And it was very disconcerting, cos I used to imagine all sorts of things and I used to if people came to the house and there was a man I used to think I wonder if that was my father but I never knew, and I lived with my grandmother and my mother was there because there was no father so I got all suspicious as I grew older but no one spoke about it so I never really knew.

This lack of knowledge permeated every bit of her life, and as a result of having no father Mrs HN considers her childhood self a cheeky and spoilt brat.

I used to go to school and that and when I was older and and other children had parents come in you know to things and she would come but there was no dad, hu hu, but you can't have anything can you but all the family I had 2 uncles who were brothers of my mother and an aunt, 2 aunts, 2 uncles and 2 aunts, and um they were all nice to me and I got spoilt I bet I was a horrid little beast I expect, cos I was spoilt. Well I was cos they were all sort of taking care of me in their way and I suppose I expect everything had come off the trees.

Mrs HN tried to find her father, she was given a name and told which village he lived in, and searched the Electoral Roll, but did not manage to find him. It is poignant that she does not mention asking those who were most likely to know and those who were closest to her, her extended family. After not managing to find him or anything about him she describes how this affected her and her subsequent coping mechanism:

but no it was very upsetting and I, and that upset me for a long time then I got over it and I think what's happened has happened and what's that's what your not given or not given and you've got to get on with it and make the best of it, and what else can you do and so I'm afraid there's not much else to tell you. Except I'm lovely ha ha!

This exert of transcript shows how she was so upset about the lack of knowledge about her absent father, she felt rejected by him, but had to deal with what she had been 'given' or 'not given' in life. It must have been lead to an ongoing battle within her, that those (her mother and extended family) who were most likely to know who her father was, were not going to tell her. It was an example of the 'elephant in the living room' – a subject that was so huge it could not possibly be ignored by those present, but was left completely unaddressed.

It also shows another coping mechanism, without Mrs HN realising it, she uses a joke to deflect form any further discussion of the subject at that point. In line 37 of the transcript

she does recognise that she is always joking, and to 'take no notice'. Jokes are included at lines 7, 28, 34, 104, 106, 122 129, 131, 182, 187, 198, 211, 216, 265, 282, 298, 308, 337. They are scattered throughout the interview, used specifically as jokes, as punctuation and also as deflection from a more serious topic.

Her Grandmother, who, she says 'saved my life', provided the stability in Mrs HN's life. Her mother remarried and Mrs HN did not get on well with her stepfather, echoes of the previous conflict, created by her lack of knowledge about her father, must have reverberated throughout this new relationship with her stepfather. Ultimately, she didn't want a stepfather (described by her as 'some man'), she wanted her real father. Her stepfather, despite recurring throughout the interview, is never named, unlike her grandmother and aunts and uncles. When her mother married, Mrs HN was given the choice of staying with her grandmother, or going with her mother, she describes it as follows:

So my grandmother was more a mother to me, oh she was lovely and when my mother then met some other person, some man, he was all right and then they got married and she wanted me to go with them and I prayed to my grandmother please could I stay with you please and she said of course you can well it was my home I think I would have run away rather than to go away from her so and I was all well there I am you see what an odd bod I am ha ha

The most significant memory Mrs HN has of her stepfather is the following:

The stepfather, he was never nasty to me but he was, I think would have fallen out with him because I thought that he used to boss my mother about, and I believed in my mind that it was him who'd taken her away from me, and that's how I looked at it but we never quarrelled never ever ever and um no we never quarrelled and he was never nasty, he slapped my face like that once, and my mum, I was a cheeky little monkey, and I deserved it, so he only once did that struck me there and my mum I can hear her saying it now, I'll never forgive you for doing that, and that's all she said, and he didn't do it he never did touch me again, but he was never nasty to me, but that was all so it to me he didn't exist, he was just a person who'd taken her away from me

This part of the transcript suggests that Mrs HN felt rejected by her mother and stepfather as a child; she must have been 10, or at the most 11, years old at the time, and though her mother wanted her to go with her and her new husband, Mrs HN felt that her stepfather was taking her mother away from her. It is of note that she thinks she 'would have' fallen out with him, not 'did' fall out with him, and poses the question of whether she gave him the opportunity of having a relationship with her. Mrs HN shut her stepfather out

of her mind, as though he 'didn't exist'. This must have taken a considerable amount of emotional work, but she had had to do this with the conspiracy of silence surrounding her absent father too, so past experience may have dictated future behaviour, and the employment of the same tactic.

The researcher hears more negative about her stepfather than positive, reflecting Mrs HN's thoughts about him. Mrs HN can understand now why she was slapped, though she was not happy to accept discipline from him when she was younger:

well I don't blame him for slapping me but nobody ever did slap me other than he was the only one who ever did that I expect I needed a good smack pants

It is unusual that she wasn't slapped y anyone else, in an age when corporal punishment was common at school and within the family. Had she let him, perhaps her stepfather could have been the father she never had. It is interesting that Mrs HN has expressed ambivalent feelings about him, by saying he was never nasty (said twice in the same paragraph: line 73 and 80 in the transcript), and that they 'never ever ever' quarrelled, but describes how hard he hit her, and what a shock it was. This is described on four separate occasions, it caused ructions within the rest of the family, her grandmother had to keep the peace (lines 111-115) and prevent Mrs HN's uncle from attacking her stepfather because of it.

Her mother had other children in her new marriage and Mrs HN continued to see her mother and the new family regularly, despite them being the other side of the city. Mrs HN still has a relationship with her stepsister, to whom she speaks every Sunday evening. Mrs HN's relationship with her stepfather does not seem to have changed in any way over the years, and the episode of the slap has dominated her memories of him. The process of reconciliation with what she knows now about this relationship cannot be easy i.e.

- That she was a spoilt brat then
- Her behaviour was not acceptable
- Those who loved her, her extended family around her at the time were doing the best for her at that time, and were 'taking care of me in their way' but created this way of behaving

This must have left Mrs HN with irreconcilable feelings about the experience: all those who cared for her thought what had happened was wrong, and yet she came to realise later that her stepfather was right, and her family (those who had cared for her, and provided for and protected her, when life was not going to be easy for her without a father) were wrong – a complete turnaround of ideas. From her narrative of this relationship, it is evident that she has made this turnaround cognitively (as she is able to articulate these thoughts), but not emotionally (her narrative includes contradicting statements) which reveal her true beliefs. This internal conflict creates a stress that does not go away unless it is resolved.

Mrs HN met her husband and says there '*was just him and nobody else*', he was from Scotland, and was living at a local airbase. Mrs HN describes her wedding in very positive terms, her in-laws were unable to come down to her area for a wedding because her husband's sister had just had a baby, and her husband's mother was helping her out. Mrs HN's family called it a holiday and all went up to Scotland for the wedding, and '*a good time was had by all*'. This could have been a bad start to married life, not being able to be married in her own place of home, but the whole of Mrs HN's family turned it into something positive. This is indicative of the underlying narrative; that of managing life by making a joke of traumatic, or stressful (positive and negative), life events.

Mrs HN describes her husband and his behaviour in very loving terms, she accepted his authority (as women commonly did in the 1950's) about planning their family: they had their son 10 months after getting married, and waited to buy a house before trying again. Mrs HN dearly wanted a little girl, which never happened; again she discusses this situation in a deterministic way by saying:

What happened we didn't have another child, and we had a house quite a while on but no child came, and we tried and tried and tried and it just didn't happen, but not cos, well I don't know why, but it just didn't occur, and I said well there we are if that's how it is that is and Xxx is so nice he's made up for it

Mrs HN had her son whilst living up in a remote part of Scotland, and although '*everybody was nice*', she wasn't really happy living there, so jumped at the chance of coming back

down to her home village after her mother-in-law had died. Another child never came along, but Mrs HN talks about her husband of over 60 years (who died just over 3 years ago) and her son in a way that shows she clearly adored, and adores, them both.

When the pattern of TSS segments are examined in the subsession 1 with the DARNE analysis (see *Chapter 5: Methods* and *Appendix VIII*), it is noted that Mrs HN's transcript is categorised with four out of five categories within the space of 42 lines. The absent category is 'Narrative', because of the lack of detail needed for this category is missing. The first paragraph skims the topic of her father's absence that is central to Mrs HN's narrative, and it introduces another theme of her narrative, that of disconcerting contradictions, managed with jokes.

'Argumentation', the development of an argument and explicit or implicit disagreement with an alternative position is present in the first paragraph, stating that she thought '*well that was a strange way of things happening, but people in those days didn't tell you things*' about the lack of her father's presence. This thread continues throughout all the events narrated, even her beloved husband had told her to wait to have another baby after their son arrived, they waited and then '*no child came, and we tried and tried and tried and it just didn't happen*'. Mrs HN's previous philosophy, about her father's absence, came in handy '*and I said well there we are if that's how it is that is and Xxxx is so nice he's made up for it*'. This, and Mrs HN's wedding, are the only events that include the 'disconcerting contradictions' and give the researcher the sense of resolution. This sense of resolution comes from how Mrs HN has conveyed her love for her husband and son, as seen in the transcript, as well as her non-verbal communication.

Using the 'Argumentation' category the TSS segments are able to identify the pattern of 'disconcerting contradictions' throughout the interview. The subsession 2 part of the interview was conducted in the same place as the subsession 1, until Mrs HN decided she would like to show the interviewer around her flat and the interviewer used the opportunity to carry on the interview and to ask about the topics raised, and achieve some PINs (see

Chapter 4 and 5), with the aid of the photos scattered throughout. This suited Mrs HN's engaging and chatty character, and we finished on a positive note, after looking at her wedding photos.

6.5. Conclusion

In conclusion, the patient and control groups used for both the LEDS and BNIM interviews were shown to have diagnoses consistent with the inclusion and exclusion criteria. Quantitative analysis of the LEDS interviews has shown that there are significant differences in the number of bereavements under the age of 51years old, between those that have Possible or Probable AD and those who have normal cognition. The EWC analysis has shown significant differences between patients and controls in the way that the experience of a life event is expressed emotionally. The patients' negative emotions were significantly diminished in both the amount of times they were discussed ($p=0.018$) and the range of emotions ($p=0.039$) used to describe the events. The range of positive emotions expressed was significantly less in patients ($p=0.039$), but showed only a trend in the amount of LEDS life events and difficulties discussed (0.070) with positive emotions, once the non-LEDS events had been removed. There were no significant differences in any of the analyses for the neutral emotions, either the number expressed or the range expressed. This difference in emotional expression has been observed in the emerging structural hypotheses of the BNIM interviews, through qualitative analysis. These results will be discussed in relation to the TQs in *Chapter 7: Analysis and discussion.* Microanalysis of the opening narratives of other BNIM interviews will be used to illustrate the analysis of these results in *Chapter 7: Analysis and discussion.*

Chapter 7: Analysis and discussion

7.1. Introduction

This chapter will describe the analysis of the results of the descriptive statistics and:

- The LEDS interview results
- The Emotion Word Coding and
- The BNIM interview results

These results are gathered in relation to the Central Research Question:

Are life events a risk for AD?

This CRQ is broken down into further Theory Questions, and their subsidiary questions.

These will be discussed in turn.

7.2. TQ1: Is there a difference between the number of life events between patients and controls, using LEDS as a measurement tool?

As discussed in Chapter 6, the *Camcog*, MMSE, IMC, *Blessed* and *Organicity* scores show significant differences between the patient and control two groups, and it has been established that the two groups are diagnostically different. This applies to the cohort of 40 participants, who did the LEDS interviews; and the cohort of 24 participants, those who had the EWC analysis on their transcripts. Without this confirmed difference in the patient and control groups, the life events data would be meaningless, and would not be applicable to a wider population.

TQ1 has been broken down into the following subsidiary questions:

(a) Is there any difference in the number of life events between groups?

(b) Is there any difference in the number of life events between the groups for participants below the age of 51 years old?

(c) Is there any difference in the number of bereavements that have occurred?

(d) Is there any difference in the number of bereavements that have occurred for those under the age of 51 years old?

(e) Is there any difference in the number of difficulties between groups?

(f) Is there any difference in the number of difficulties between groups for those below the age of 51 years old?

(g) Is there any difference in the total duration of difficulties between groups?

(h) Is there any difference in the total duration of difficulties between groups of participants under the age of 51 years old?

(i) Is there any difference in the number of major difficulties between groups?

(j) Is there any difference in the number of major difficulties between groups of participants below the age of 51 years?

(k) Is there any difference between the total duration of major difficulties between groups of participants of all ages, or

(l) Is there any difference between the total duration of major difficulties between groups of participants under the age of 51 years old?

The results of the questions that generated significantly different answers between the patient and control groups were:

a) Is there any difference in the number of life events between groups? YES, more in patients than in controls (**p=0.039**)

d) Is there any difference in the number of bereavements under the age of 51 years old that have occurred? YES, more in patients than in controls (**p=0.032**)

Both these results indicate an association between life events and AD. Question TQ(d) will be discussed because of the way that (d) influences (a).

7.2.1. TQ1(d): Is there any difference in the number of bereavements under the age of 51 years old that have occurred? (**p=0.032**)

There is a statistically significant difference between the numbers of bereavements in the two groups, the patients have experienced more bereavements under the age of 51 years old. This question was posed because the literature on the glucocorticoid cascade hypothesis and the HPA axis (as reviewed in *Chapter 3: Literature review*) provides a plausible a pathological pathway and explanation for this finding, which increases the risk of developing AD.

The reasoning behind discussing this question first is that it is possible that the high number of bereavements under the age of 51 years old in the patient group have also contributed to the TQ(a) being statistically significant, as the bereavements would also be counted in the total number of life events in question TQ(a). This explanation would

account for the insignificance of the number of bereavements in total. The death of a close family member (i.e. parent or sibling), or a very close friend, is a time of major psychological adjustment. The type of bereavement that contributes to this result are bereavements of a type that are less common when a person is younger than 51 years old, and grow more common as a person ages. Events up to, and including, the age of 50 years old were chosen because it was thought that the damage to the hippocampal neurones would demonstrate an effect by this age. – based upon the research reviewed and the observation of those who posed the CRQ originally. The number of bereavements under and over the age of 50 are shown in *Table 7.3*, which would confirm the theory of bereavements under the age of 50 years old being more important than those over 50 years old.

Table 7.3 Number of bereavements in patient and control groups

	Patients	Controls
Bereavements up to the age of 50	48	31
Bereavements over the age of 50	16	24
Total number of bereavements	64	55

The research papers on the associations between life events and AD, which were reviewed in *Chapter 3: Literature Review*, did not predict an answer to the TQ1 because of the problems with the methodologies used in these studies. These problems have made those results questionable. The methodology and method used in the TQ1 of this study, as discussed in *Chapter 4: Methodology*, has been shown to be reliable and valid.

The researcher has confidence in the results of this research question being generalisable to other similar populations, for the following reasons:

- The ADLE study reflects a mix of the population with both male and female participants, rather than having only single females as in the Nun Study (Snowdon, 2001).
- The ADLE study also reflects a mix of cultures that are similar in both patient and control groups; the majority is English, and there is one European in each group, two patients and two controls from the former British colonies, and an additional patient from Britain (not England).

- It could be argued that the number of participants in each group who have been divorced or widowed (both severe life events) would have affected the divergences between the patients and controls. A simple calculation of the total number of divorces and bereavements of spouses indicates that this is not so: there are seven experiences of divorce or widowhood in the patient group, and eight in the control group. This indicates that other severe life events have accounted for the differences between the patients and controls.

- A Type I error could account for this result: where it is thought there is a genuine effect in the population, and there is not one, because it is one of the 5% of results that could have occurred by chance (Field, 2005). On balance, because of the *a priori* hypothesis that there are pathological (i.e. the glucocorticoid cascade hypothesis and HPA axis) that are linked with the phenomenon of life events, this strongly suggests that it is not due to a Type I error.

7.2.2. TQ1(a): Is there any difference in the number of life events between groups? (**p=0.039**)

The simple answer to this question is that there is a statistically significant difference between the two groups, with the patient group experiencing more life events that the control group. This could be because there are more bereavements in the patient group that have occurred under the age of 51 years old that have been counted in this total number. By examining the answers to the other subsidiary questions in TQ1, which were not statistically significant we can infer some information about TQ1(a) and TQ1(d).

The other TQ1 research questions were posed to find out the about the type of life event would be associated with AD, and if there are any particular features. In the ADLE study we can deduce from those life events that were not found to be statistically significant the following characteristics:

- The number of difficulties
- The total duration of difficulties
- The number of major difficulties
- The total duration of major difficulties

And those under the age of 51 years of age:

- The total number of life events that included all types (i.e. all of Brown and Harris's categories such as housing, health, crime, bereavement etc)
- The number of difficulties
- The total duration (number of years) of difficulties
- The number of major difficulties
- The total duration of major difficulties

It is interesting that it is the number and total duration of major difficulties that are not significant (either under 51years of age or not under this age), as a major difficulty is a life event that lasts for two years or longer. It is possible that this is a Type II error and the life events that were found to be insignificant had other properties that were not able to be analysed in the LEDS analysis, because the data was either not asked about in the interview, or the property has not been identified as being of importance in the analysis.

In addition, there are many quantitative studies of value that have contributed to gaps in the knowledge about AD that are based on a similar sized cohort, or are case studies; many of the authors have gone on to build on these studies to develop their theories and knowledge base about AD e.g. Snowdon, 1997; Snowdon et al., 2000; Garrard et al., 2005; Garrard, 2008.

The difference in the number of life events, in particular bereavements under the age of 51yrs old, is of importance in the construction of a diagnostic tool, as it can be employed to indicate a person who is at a higher risk of developing AD; this will be discussed more thoroughly later on in this chapter.

7.3. TQ2. Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and the range of emotions expressed when discussing life events?

This theory question is broken down into two further subsidiary questions, which will be reviewed in turn:

a) Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups?

b) Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's emotional coding?

The transcripts of the LEDS interviews have provided additional data on the characteristics of the patients' and controls' speech, the analysis of which has determined differences that can be used in the design of a list of differences between those who have Possible or Probable AD and those who do not. This list can be used in the formation of a

tool which will contribute towards the diagnosis of Possible or Probable AD, this will be detailed later.

7.3.1. TQ2(a): Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups?

In each case of analysis of the life events discussed in the LEDS interviews, the p values became more indicative of significance when the non-LEDS events were removed (see *Table 6.8* and *6.9*). This indicates that Brown and Harris's definition of significant life events is an effective way of discriminating which life events matter in a disease process. This propensity has continued each time the non-LEDS life events were removed, therefore it can be assumed that there is a difference in the way the patients discuss life events, and the ones which will show a greater difference between patients and controls will be those classified as the LEDS events. This is important to note, as these differences are critical to developing a diagnostic tool, which will be discussed in more depth later.

7.3.2. TQ2(b): Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's emotional coding?

The analysis found that in the total number of LEDS and non-LEDS fewer negative emotions expressed by the patients when relating life events ($p=0.005$), and a possible trend with the patients revealing fewer life events overall, and fewer negative and positive emotions expressed once the non-LEDS events had been removed. The patients found it more difficult to express either positive or negative emotions when discussing their life events. An example of a control discussing his parent's deaths is in *Text boxes 7.4*, and an example of a patient discussing his father's death, when he was a teenager is in 7.5.

Text Box 7.4. A control discussing his father's and mother's deaths

R: Well yes I've been very lucky all three of the kids, because I've been involved closely with the family. I mean, after dad died, mother died first – fortunately – because if it had been the other way round it would have been much harder, she would have had a nervous breakdown and so forth.

I: What did she die of?

R: I never quite know, she was in a coma for a week.

I: Right. At home?

R: She just suddenly fell over – in XXX. We were going out to a restaurant and I had just let dad and mother out of the car and I was just about to park it and drive it away, when suddenly she just fell down to the ground. And I saw this, I jumped out of the car, just leaving it where it was and she was totally unconscious and I phoned for an ambulance and she never recovered consciousness.

She, I don't know is that a stroke or is it heart failure?

I: I don't know. It sounds more like a stroke doesn't it really?

R: Yes I think she had had some mini strokes before. There was a time when she was drinking from a cup of tea and the liquid was coming out of the side of her teacup. I, so I, she, I think it was probably that.

Dad died, I bathed him and he, and got him ready for bed and he, I remember he was saying 'Come on hurry up a bit I want, I want to lie down.' And I got him over to the bed and immediately he,you know, lay down he, he died.

I: Oh really.

R: Now I didn't know that you know, I wasn't sure whether he had died or whether he was asleep and I didn't want – let me get the door - its called aldomet or something and he died instantaneously that way.

I: You know it's a way for him to go but a bit of a shock for you it must have been!

Yes it was but no, its, for both of them actually, one hopes that mother's week in a coma that she was totally unconscious but one never does quite know. It is worrying, at the time I know one was worried, I mean the doctor said 'Oh well she can't feel any pain, she's not conscious so you needn't worry.' But one is concerned.

She was in intensive care, wired up to all these things and at the end actually I told, again, I mean because dad's being director of YYY uh, he knew many of the doctors and the professor in charge of the uh, of the intensive care. I told him towards the end of the week I said 'Look, I've been studying the bits and pieces that are wired up and I think I know what switches to turn off, I think its time to turn off.' They were very good about it in the hospital because they daren't turn off and it you know, I mean she couldn't have made a recovery after that period of time, she would have been just a vegetable and that would have been absolutely awful.

There, in ZZZ where we were, you were asking about what sort of social contacts. There were lots of her, mother's family is a very big, large ZZZ family that's been there for hundreds of years, they consider themselves absolutely salt of the earth. They run the place, or they used to run the place and uh, so there were many aunts and uncles and relatives and so on, there still are. But uh, it was not, it wasn't the younger people, not my generation, it tended to be the older generation that uh, so there were lots of contacts in that way.

Text Box 7.5 A patient discussing his father's death, when he was a teenager.

I: What did your father die of?

R: A cerebral haemorrhage.

I: Gosh.

R: Right as rain eleven o'clock on Sunday morning, by twelve he was dead. Well I think it's the best way to go.

I: Oh my goodness.

R: For both sides, it sounds brutal but to see somebody wasting away or deteriorating ...very, very painful deaths...and just like that, he just went, which was best.

I: Where did he die, did he die at home?

R: Hmm.

I: Did one of you come across him or did you realise?

R: No he just, I forget what he'd been doing, working in the garden or whatever and then he just said words to the effect 'I think I'm going to go and lie down lie down,' which he did. Fetched the doctor and my father was dead within the hour.

I: Gosh, and how did your mother cope?

R: Terrible, terrible, it was bad enough for us lads but for my other it was catastrophic. Still, one has to carry on.

I: Mmm. How old was your brother at the time?

R: He was a couple of years older than me so he was about 18 or so.

I: So did he do all the arrangements and things like that, and take over that role?

R: Well I've never really thought about this. I think we were both and everybody was getting this paper her and whatever. And its, its amazing how resilience, resilience, resilient most people are, you just accommodate.

I: Yes, because you have to.

R: You have to. And my mother had to go out to work. So we survived. For a time.

From these two examples a difference is evident in the way the two participants discussed their parents' deaths, and the EWC was able to identify these differences.

The reasons for these differences may be because there is a wide variation in the Camcog sub-score of verbal expression between the patients and controls. This might be because the EWC accentuates the difference between the patient and control groups by using a different method, or it might be that this is a predictive indicator, and that those people have never been able to express their emotions about life events and experiences. These findings are consistent with the research done by Pennebaker and Chung (2007), who state that:

> *In short, having any type of traumatic experience is associated with elevated illness rates; having any trauma and not talking about it further elevates the risk... The mere emotional expression of a trauma is not sufficient. Health gains appear to require translating experiences into language.*

This information can be used in three ways: it can be used to determine the difference between people who have Possible or Probable AD earlier on in the disease process, by combining it with other findings from the ADLE study; or it can be used as a diagnostic indicator within the diagnostic tool; and it can be used to inform patients and carers that emotional expression is a part of the disease process, and something that the patient cannot help doing because of the pathology of the disease – although encouraging emotional expression in the ways suggested later on, in *Chapter 8: Conclusion*, may help.

As well as having a reduced capacity for expressing positive and negative emotions, the patients also used a smaller range of words when describing their emotions, see *Table 7.6.*

Table 7.6 Difference between the range of emotions expressed by patients and controls in LEDS and non-LEDS events.

	Total range of words used to express emotions	Range of words used to express negative emotions	Range of words used to express neutral emotions	Range of words used to express positive emotions
Patient total	154	55	42	57
Control total	222	96	49	77
Kolmogorov-Smirnov Z	1.225	1.429	0.612	1.225
Exact Sig. (2-tailed)	**0.068**	**0.016**	0.543	**0.039**

When analysing the data on the frequency and valence of the emotions discussed, it became apparent that there was a difference between the ranges of emotion shown by the patients and controls when discussing both LEDS and non-LEDS life events and difficulties. On analysis, there were significant differences between the patients and controls range of words when describing their emotions in the areas of:

- Range of words used to express negative emotions (p=0.016)
- Range of words used to express positive emotions (p=0.039)

and a trend for:

- Total range of words used to express emotions (p=0.068)

It can be concluded that there is a much smaller range of words used by the patients than by the controls, in the negative and positive emotional expression of the life events in the LEDS interviews.

Again, the modified Danner method may be contributing additional information on how the verbal expression of patients is affected by AD. It is known that verbal expression is affected by AD (Harasty et al., 1999; Mok et al., 2004), but this function is usually tested neuropsychologically when the person is asked to either list as many animals as they can in one minute, and/or to describe a picture, often one known as the 'Cookie theft'. Neither

of these tests is an example of how people use language in everyday life, but give data about a specific component of cognitive function. Knowledge about how emotional expression in language can be affected by the disease would be helpful to patients and carers when discussing symptoms of AD. Carers and patients find it helpful to understand what is happening pathologically the patient's brain, and to see that it is an actual disease process rather than something that is an indistinct feeling of something 'just going on in their head'. Conflict can arise in relationships because the partner does not understand about how difficult it can be to process thoughts and emotions when there is a disease process in those parts of the brain required for those functions. Being able to clarify that there is a specific biochemical and pathological reason for the reduced speed in thinking, or reduced emotional expression is a way of explaining the symptoms that both the patient and their partner have to cope with. Even in a relationship which is committed and stable, these symptoms can cause great distress when the patient does not react in a way that the partner thinks they should. The lack of emotional expression may also be indicative of someone at risk of developing Possible or Probable AD because of a lack of processing of emotions, this will be discussed in more depth in the answer to TQ3.

Having found that there are differences between the patient and control groups with the frequency and emotional valence, and the range of words used to express emotions, when looking at life events, the areas in which the frequency and valence of the variations occurred was explored. The areas related to the LEDS interview categories of work, reproduction, housing, money/possessions, crime/legal, health, marital/partner relationships, other relationships, bereavement/miscellaneous and education (see *Table 6.11*). It was found that the areas of greatest differences were:

- Total number of LEDS and non-LEDS **bereavements** expressing neutral emotions, **p=0.02**
- Total number of LEDS and non-LEDS **health** events, **p=0.01**
- Total number of LEDS **health** events, **p=<0.001**
- Total number of LEDS and non-LEDS **health** events expressing negative emotions, **p=<0.001**

- Total number of LEDS and non-LEDS **health** events expressing positive emotions, **p=0.04**
- Total number of LEDS and non-LEDS **work** events, **p=0.01**
- Total number of LEDS **work** events, **p=0.08**
- Total number of LEDS and non-LEDS **work** events expressing negative emotions, **p=0.01**

The variations between the patients and controls were in the areas of work and health and, less so, bereavements.

7.3.3. Health LEDS category

Health had four areas of significant difference, where the patients related considerably fewer life events than the controls. This is, perhaps, surprising; it could be expected that those with a serious and incurable brain disease would be more preoccupied with their health than they were found to be, in talking about their health related life events. The only category of life events discussed more by the patients than the controls, was the neutral life events. Another possible reason is that those controls who join OPTIMA are unusually preoccupied with their health, hence the reason for joining the cohort, and this interest manifests itself in their conversation about life events. However, this possibility does not reflect the experience of the researcher who has been seeing participants in the OPTIMA cohort for over 12 years; as has been discussed before, controls volunteer for many different reasons. It is possible that the patients are grieving for their lost abilities, and are passing through a stage of denial about their health, as many people do who have been given a diagnosis of an incurable disease. This grief has been described by Friedell (a founding member of the DASNI group) as:

> *One thing that can't be overemphasised is the complex, overwhelming, often obscure and gradual yet irregular progression of losses that occur in dementia.*
> (Friedell, 2001)

7.3.4. Work LEDS category

The other main area of divergence in debating life events between the patients and controls is the category of work, where there are three significant differences in the areas

of LEDS and non-LEDS events, LEDS events and negative life events about work. Work holds a large place in the concept of who we are, and this is reflected in these results. Our previous achievements, on which we judge ourselves, may be through work, and these contribute to our sense of 'self'. From when we are young others ask what we would like to be when we grow up, this work ethic is deeply ingrained in our society. Through work we learn how to contribute to society and to interact with others, support our families, and ourselves; if this function is removed, it can leave a vacuum that shakes our values, and, what Kitwood and Bredin (1992) defines as our personhood. Kitwood and Bredin argues that our personhood is affected by how society treats and portrays dementia (Kitwood and Bredin, 1992). Therefore, there should be no surprise that this category shows differences between the patient and control groups, and less discussions than the controls involving the topic of work. Those who have AD are unable to contribute to society in the way they did previously, and society's view of dementia etches away at their personhood.

7.3.5. Bereavement LEDS category

Bereavements discussed using neutral emotions were found to be substantially less in the patient group. It could have been expected that the analysis of the bereavement life events would have had more notable variations, because there were more bereavement life events found in the patient group, up to the age of 51 years old, which are less expected and therefore construed as more traumatic.

The reasoning behind the significant difference in the discussions of neutral bereavements could be that the patients have not been able to process the emotions aroused by the experience and therefore cannot attribute an emotional label to the experience and describe it as such. This is explained by Pennebaker and Chung (2007):

> *Once an experience is translated into language, however, it can be reprocessed in a conceptual manner. In language format, the individual can assign meaning, coherence and structure. This would allow for the event to be assimilated and, ultimately, resolved and/or forgotten, thereby alleviating the maladaptive effects of incomplete processing on health.*

Hunt et al. (1997) relate how the present older generation have war experiences of one kind or another and that these heavily influence the emotional expression of traumatic events. Hunt et al. comment on the war stories that contradict the public versions:

> *These private stories were not for sharing; not only by their very nature were they difficult to tell, even to a sensitive listener, but the actual telling was officially discouraged as unpatriotic and potentially harmful to individual and national well-being.*

Most of the present older generation, and all those who participated in the ADLE study, have experienced their war memories when they were young (most commonly the Second World War), and this manner of dealing with their experiences would have endured for a number of years; long enough to establish a person's pattern of dealing with emotions that will have pervaded all other events and experiences. Even if the older generation weren't directly involved in a traumatic event, they were exposed to this mode of dealing with events, at an age and life stage when they were vulnerable to influences on behaviour for the sake of the nation at war. All these factors will have interacted with other experiences and will have had an effect on the way this generation have managed their emotions. The ways of managing experiences and feelings as patterns of behaviour and cognition are passed onto the next generation, recreating similar difficulties unless the cycle is recognised and broken (de Levita, 1997). The 'stiff upper lip' that accounts for politeness at all times, a failure to speak out and suppresses feelings, and does not allow demonstration of feelings, is still common in this generation (Dorset RDSU, 2009). Those who have been able to resist the 'stiff upper lip' will have been able to process emotions more effectively.

The difference in the range of emotions expressed concurs with Garrard et al.'s (2005) and Garrard's (2008) studies of Iris Murdoch's books and Harold Wilson's speeches (see *Chapter 3: Literature review*), where the number of different words used in both cases grew smaller in the book, or speeches closest to their diagnoses of AD.

In the Nun Study, positivity was associated strongly with longevity found, in the Nun Study (Danner et al. 2001). People with AD do live for a shorter time, therefore the controls who

expressed more positive emotions when discussing life events will live longer. Whether this is due to less positive emotions being expressed is something that cannot be inferred from the ADLE data, but can be explored further in the current study by Garrard, Haigh and de Jager (2009). The study by Garrard, Haigh and de Jager (2009), called Cognitive Archaeology, will be discussed later in this chapter.

Pennebaker and Chung (2007) found that those who could transform their life events into a positive experience experienced better health; and a life event transformed into positive experience is one that has been emotionally processed.

The practical application of the findings from the analysis of the LEDS interviews will now be discussed, with the construction of a diagnostic tool.

The findings from the LEDS interviews will be used to construct additional factors to be taken into account during the diagnostic process. This would be for use within such settings as the memory clinics that are part of the National Dementia Strategy (2009), and as part of best practice in early diagnosis. The tool would take the form of questions found to be pertinent from the LEDS data such as in *Text box 7.7.*

Text Box 7.7 Factors that would be taken into account during the process of diagnosing memory problems.

Factors to be taken into consideration during the diagnostic process

1. Has the person experienced a bereavement of their parents, sibling, partner/spouse or very close friend that has occurred when they were aged 50 years old or younger? (Please briefly describe below)

2. Has the person experienced a change in the way they express themselves, for example:

a) Has the person been a person who would normally fluently express their emotions, or do they tend to have a 'stiff upper lip'?

b) Does the person express less emotion than they used to, about things they usually care about?

Ask the person to spend about 5-10 minutes writing a paragraph about an event or experience that would normally evoke feelings.
For example,

- Something that is 10 sentences long (or more)
- Either something that happened recently or a long time ago
- It could include a holiday, birthday, Christmas or other celebration with family and friends, or something which has significantly affected your life
- It can be an event that is happy, sad, confusing or makes you cross

(include space for writing here)

Practically, this could be used when the health professional (i.e. Doctor or Memory Clinic Nurse) has a consultation with the person who has memory problems, or their partner or family member who attends the memory clinic (all people who attend a memory clinic are asked to bring someone who knows them well). It could also be given to people (the person with the memory problem and/or the person with them) to fill in whilst they are waiting for their consultation, it should take approximately 10-15 minutes to fill out. What the questionnaire will do is elucidate from the memory clinic patient whether they have been at risk of feeling chronically stressed, causing raised cortisols and damage to their hippocampus neurones (see *Chapter 3: Literature review*), just as cardiac risk factors and family history will highlight an increased risk of AD (Lovestone, 2002; Clarke et al, 1998). The tool does not need to be scored as it will provide an overall picture of those risk factors, and this will contribute towards the whole diagnostic picture. The memory clinic

patients do not receive a diagnosis initially as there are often other investigations that need to be carried out. The answers to this diagnostic tool can be read and assessed during this process, and then evaluated in the context of the other diagnostic tools. Differential diagnosis will need to be evaluated in the Cognitive Archaeology study before implementation in clinical practice, but because AD is a disease that is diagnosed by the risk of probability, any method that contributes towards this assessment is of value.

7.4. TQ3: Are there any differences in the constructions of life events in providing narratives of life events, between the patient and control groups as interpreted by BNIM?

The BNIM interviews and analyses have revealed a rich source of data about life events that has complemented and supplemented the data from the LEDS interviews for TQ1 and TQ2.

The analysis has revealed two types of differences noted in the interviews with the patients and controls: the structure of the narrative and the content of the narrative. These will be discussed after TQ0.

7.4.1. TQ0: How did the interview process go, and what implications has this for the different subsequent TQs relating to my CRQ?

Wengraf states that TQ0 must be answered before the BNIM interviews are analysed. As discussed, the two in-depth interviews were very different experiences: Mr HF had a much more eloquent style than Mrs HN, whose style was more participatory. Initially it was thought that this was a feature of their characters. On reflection the differences represented the way they recounted their life events, and the differences typified their approaches to their life events and experiences, as well as it being part of their characters – for our characters are represented by our behaviours (Solomon, 2007).

The essence of each of the first subsessions in the in-depth interviews can be summarised in this table. Similarities that they both possessed were having TSS chunks

that would be defined as 'Description', 'Report', and 'Evaluation' in Wengraf (2001, 2008). The differences are: the lengths of the subsession 1; the themes of 'Argumentation' and 'Narrative' present in the TSS chunks, the length of narrative when discussing the life events and experiences and the presence, or absence of PINs.

The contexts of the other interviews are also summarized here, so that TQ0 can be addressed in relation to the other BNIM interviews.

C1: This lady did not want to be interviewed at home because of the animosity of her husband towards all her activities, so she came to the OPTIMA offices, with which she is familiar. C1 did not wait to hear the end of the SQUIN before beginning to discuss her life; she started and then continued talking for about 90 minutes, with a few active listening comments made by the interviewer. She became tearful within a few minutes of talking after the SQUIN, as can be seen in the Text Box 7.X. She carried on talking about her life, and did not show signs of embarrassment about becoming upset. It was not possible to structure the interview into two subsessions; Wengraf (2001) states that this is not necessarily a problem as the three subsessions are seen as analytic entities, and a very productive and detailed narration subsession 1 can be seen as 1 and 2 blended together. There were PINs present throughout the entire interview, and emotions were clearly expressed both verbally and non-verbally. Although C1 did not see her self as having succeeded academically, she was articulate and able to convey what she thought about her life events and experiences. The interview was concluded by her ending it, with the researcher feeling that it had been on an emotional, but positive, journey for both, despite the interview containing recollections about events that had clearly upset C1 at the time and since. From the excerpt of the interview below, it can be seen that C1 needed little encouragement to talk, even though she expressed it wasn't a good time for her to be listened to, because she was feeling 'sorry for herself'.

C2: This lady was trained as a doctor, and practiced as such during her marriage and when her children were growing up. She was very welcoming and able to express herself

in a way that showed she had thought about things in her life as she had experienced them, analyzing them and summing them up eloquently. She had considered the positive and negative aspects of events, in a way that belied her positivist training as a medic, and had worked things through logically. This interview did naturally fall into two subsessions, as suggested by Wengraf (2001, 2008).

P1: This lady has been married for many years and has a husband who is clearly devoted to her. As sometimes happens with a very close couple when one of them has AD, her husband had no intention of leaving her on her own during the interview, and stayed throughout. Wengraf (2008) discusses such circumstances and suggests embracing the situation, and including the extra person during the interview, when appropriate. AD often affects the confidence someone has, as it undermines memories of what we have been and are, and this creates a tension that makes people more anxious. It became obvious that when P1 was unable to instantly recall a word or particular memory the participant looked anxiously at her husband who provided her with the answer, this relieved her anxieties, and his discomfort at seeing her anxious. This can be seen in Text Box 7.W below. So C1's husband played an integral part to the interview in which he filled in the bits of memory she was unable to recall at that moment. He did not structure what she said, but as people who have been in each other's company for a long time can, he usually knew what she wanted to say and supplied the gaps, and she informed him when he did not guess correctly! This symbiotic relationship allowed P1 to feel more relaxed as the interview developed and she began to rely upon her husband less. It can be seen from the excerpt of the interview in the text box below, that P1 needs her husband's intervention soon after the interview begins.

P2: This gentleman is married and has been for sometime, he and his wife married late, have no children and have been very involved in each other's lives. Again, the interview was conducted with P2's wife present, for the same reasons that P1's husband was included. P2's wife was needed much less often in the interview than the husband of P1. When she was needed it was to supply the name of an employer or a date. Although P2

was enjoying the process of discussing his life, at the points where he began to repeat himself, his wife began to shift around in her chair, as if she wanted to redirect him or stop him. As the interview progressed, and it was clear that the researcher did not mind him repeating himself, she became visibly more relaxed. P2 appeared unaware of the discomfort his wife was in when he was repeating himself. It can be seen from the excerpt in the Text Box 7.y that he began to repeat the same topic, about his father making him build a house with his brother, but using slightly different words or phrases each time. He was able to discuss other periods of his life quite easily; he occasionally had word-finding difficulties, but always returned to his father and the houses he and his brother built.

The answers to TQ0 above give further data about the BNIM interviews and the participants, which will inform the TQ3, and ultimately the CRQ. The differences noted between the two in-depth interviews have revealed themselves in the other interviews; these will be discussed with relevance to the form of the structure of the interviews and the content of the interviews.

7.4.2. Structure of BNIM interviews

The structure of the interviews was revealed by the analysis of the order that the TSS chunks, or topics, in the transcript are discussed. From the two text boxes previously presented in Chapter 6, Text box 7.e and Text box 7.F, there are some obvious differences. Mrs HN, who has Possible or Probable AD, has many more changes of topics discussed and it is noticeable from the number of lines of transcript attributed to each topic that her topics are much shorter in comparison with Mr HF, who has no cognitive problems. The topics discussed by Mr HF show that he was able to recount his life events in a way that is more coherent than Mrs HN's narrative, in comparison Mrs HN's narrative seems a fractured and fragmented version of her life.

Other BNIM interviews illustrate this in the subsession 1. Once the opening SQUIN has

been asked (which is the same in each interview), the participants' opening narrative is shown in the text boxes below:

Text box 7.8. P1 opening narrative

P1: Um, I was born in East London and well my family lived in East London until the war, and we came down here as a whole group, as a school, with our teachers as well, and um all lived in this area, and um oh gosh.

Husband: You were evacuated

Text box 7.9. C1 opening narrative

C1: Well I moved to XX when I was 7, there's six children in the family and I'm the 5th, so we've got girl boy, girl boy girl boy right the way down, touch wood we're all alive and we're all friendly. And after that then I just had a not a very happy beginning to my school life in XX because everybody believed because we came from YY we were country bumpkins, so they called us country bumpkins but we only stayed at this school, my my mother, who was really really lovely, cos you know it hurt her to seeing us upset, so she moved us quickly to another school, cos I'm a twin so I always had my brother to protect me really. Then my school life, I didn't achieve, really well, I'm just moderate I suppose I'm not sort of the brains of the family, but although because of that my working career hasn't done badly, but I'll come onto that. Then at a very young age, 16 I suppose, my first engagement which went to a really nice boy, a little bit older than me, and um he was in the airforce and my parents didn't agree with me getting engaged but we did and then for reasons I am not quite sure why we parted and then I had a sort of very nice different boyfriend, quite happy, quite normal and then I met my husband to be which wasn't really quite so good and um right from that beginning of meeting him he was the aggressor in our relationship and always and to be honest looking back if I'd been a stronger sort of person I probably would never have married him because my family were against it and he was of a different he was from a drinking family whereas my family well perhaps my dad liked his odd whisky I wasn't used to that type of life. Perhaps because everybody was against him, I was for him, I don't know, I've no idea, but from that I've had 2 lovely lovely children, who are super and 4 lovely lovely grandchildren. But I've still had a very unhappy life. (tearful) I've really perhaps come at the wrong time to you, because at the moment I'm going through a feeling sorry for myself, which has been right the way through my married life, well because my children said I should have left, but I should have left, many years ago but why I don't know the reason why I've stayed. I stayed because I said perhaps when the children grow up perhaps I'll leave.

I: I am sorry

Text box 7.10. C2 opening narrative

C2: OK. Well I was born in 19xx and I lived in A in B, and we lived by a tram route which took you from AC down to the um V, and you had (factory name), you had (factory name) and you could always tell it was going to rain by the smell cos it sort of stayed down, anyhow that went on until 1938 and then there was the question of whether we were going to go to war or not, but in fact I came from my grandmother's, cos I spent my summer holidays with my grandmother in S, and er in 1939 I was actually up there when war was declared. And my father rang up, the day after and said that he'd volunteered to go into the army, just like that, and he said you'll be staying with Granny, and so that was really a very major event, because children, adults and children, didn't discuss things and I knew that my grandfather had been killed in the 1st World War. So the fact that he said he was going to war said to me that he mightn't come back again, so that was a a very major thing, and my mother traipsed round the country after him er so that I was up with granny for 2 yrs, and it must have been quite a shock to her system to have a um a 10yr old to look after, she, as I say was a first WW widow who'd brought up 3 children the eldest of whom was 12 when her husband was killed and she'd done very well, and she'd worked very hard during the War, doing things with the WRVS, and running a canteen for soldiers and sailors and so forth, and also having Canadian forces for their leaves, because my grandfather had been in the Canadian force and so he ended up getting a British Empire medal for all this

I: Gosh

These three examples show how there are the same differences, as shown between Mr HF and Mrs HN, in the length of this opening narrative. P1 has a very short narrative before she runs out of what to say and looks to her husband for help; C1 and C2 both launch into quite long narratives, broken only by active listening comments. This mirrors what happens in Mr HF and Mrs HN. However, P2 does not mirror this, he also launches into quite a long narrative in comparison to P1 and Mrs HN, but he only manages this because he has started to repeat the content of the opening narrative approximately half way through.

Text box 7.11. P2 opening narrative

P2: Well, my father was a builder and em he had 2 sons, my brother, and 2 yrs after I was born, so that was the 2 of us and we joined into the er building trade I was very keen on carpentry, my brother was interested in more, so we built a pair of houses and put on the rafters and that for the roof and the tiles and then we had to get the plasterers in do the plastering and then we hung the doors. So that was em our training in the building which was adjacent with my father who was a builder, he did build a lot of houses around G and H and so on, and em, we continued to do that and my hobby then was to play about with batteries and electric lights and little electric motors to drive my meccano and so on and eventually I got a job, with um I've forgotten who it was where I am got um in charge of a group doing this sort of use of electro um driven equipment and I pursued that for most of my life because it was always progressing and em I found it um extremely lovely to find all sorts of things were being used that I had developed, but that that sort of covered my whole working period really ***(subsession 1 ends here)*** apart from em my dad said I want you and your brother to build a pair of houses, and we did. That was the first thing we did, before I started on this other thing I've just described, it took 2 yrs, it was in G and em, we built a pair of houses, my brother was 2 yrs older and he did most of the humping of the bricks and so on and progress was, the footings the laying out of the property the the it was em 2 houses, it was a twin, and when it came to the roof I put the roof timbers on and then we got Marley tiles on and put the tiles and then we got someone else to come in and plaster the walls. Then I hung up, the floors had been put down for this and then I used and we hung the doors and all that interior woodwork and em all the em whatsanames can't think of what the name is now

I: The skirting boards?

P2: Yes the skirting board you see, then hung the doors, hung the windows first then the doors...

It is useful to have this difference in the data as it provides a more comprehensive picture of what is happening in the interview structure. Wengraf (2001, 2008) states that it is the differences as well as the similarities that create typologies, and uncover the general from the particular. The examination of these similarities and differences in the particular case leads to typologies that can be of use in the general, and in the ADLE study it will help construct typologies that represent firstly normal cognition and secondly a diagnosis of Possible or Probable AD. From this data it can be reasoned that there are differences that contribute to the typologies of patients and controls, and these can be used in the

construction of a diagnostic tool, which will be detailed after the content of the BNIM interviews has been reviewed.

7.4.3. Content of BNIM interviews

The analysis of the narrative content of the BNIM interviews is guided by the thematic field analysis, which ensures credibility and trustworthiness to be determined through the process of supporting or refuting the structural hypotheses. The reader is left to judge for themselves as to whether the credibility and trustworthiness are congruent with the analysis of the data through the transparency of the presentation (Quinn Patton, 2002; Flick, 2008). The structural hypotheses that were supported for the in-depth interviews, known as a 'statement of theme' are:

Mr HF (Control)

> *Is a hostage to fortune, in that he reacts to events going on around him rather than seizing the initiative, he is not afraid of being unconventional, and success has come of these characteristics.*

Mrs HN (Patient)

> *Rejected, but triumphed over adversity, and, whatever happens to you, life is a joke.*

The comparisons of content are based on the way that the participants have described their life events and experiences, and the differences between those, particularly in the Sub-session 1 in the way that they told their story and presented their life to the interviewer. The told story is concerned with the:

- Emotional experiences of the past that the narration is about
- Emotional experiences of now telling in the present, or not-telling or partly-telling (Wengraf, 2008).

It is the differences noted here, in the context of the BDC, which represent how the participant has processed their life events by the way they have expressed their emotions and recounted them to the researcher. Chung and Pennebaker (2007) state that our natural language reflects our thoughts and feelings, and aspects of our personality. It is known that certain features of our language change when we have experienced a

stressful event and can show that we have emotionally processed it by giving it a narrative (Pennebaker and Chung, 2007). The emotional processing within these two case studies is quite different, by their own admission Mrs HN says in line 37:

> *no but I'm always joking take no notice.*

This demonstrates her way of coping with what has happened to her in her life. Mrs HN's jokes often come when it relieves her of not developing the topic of discussion any further (see lines 28, 34, 105, 280), as a distraction perhaps to herself as well as the listener. In Sub-session 2, lines 63-64, Mrs HN says:

> *Because my mum, I never knew my father so I think something fishy was about there,* ***we don't go****, they, nobody nobody told me so I don't know*

The 'we don't go' phrase, which was taken to mean 'we don't go there' because of the context and tone of voice, tell the listener about Mrs HN's pattern of thoughts about this topic; Mrs HN doesn't enter into that train of thought, and the listener should not do so either. We know from what she has told us that she was told 'not to go there' effectively by her mother, her uncles, aunts and her beloved grandmother (see lines 14-18). Mrs HN tried to resist this pattern, by looking for her father herself, unsuccessfully, and still does not know who her father is *'to this day'* (see lines 24-25). The tone of voice she uses is of a person who has tried hard to do something, but failed and then given up in the face of opposition; a learned helplessness. This learned helplessness was expressed in the way she describes how she has accommodated this life event into her day to day life (lines 31-35):

> *but no it was very upsetting and I, and that upset me for a long time then I got over it and I think what's happened has happened and what's that's what your not given or not given and you've got to get on with it and make the best of it, and what else can you do and so I'm afraid there's not much else to tell you. Except I'm lovely ha ha*

Interestingly, this statement of how she copes with this meaningful problem in her life, is sandwiched between two jokes delineating how far she will discuss the topic in-depth.

Another sadness in her life is when her mother married and she says about her step-father (lines 75-76, 84-85, 274-275):

I believed in my mind that it was him who'd taken her away from me, and that's how I looked at it ... he was just a person who'd taken her away from me, but I was sad about it really... I didn't care for him, cos well he'd in my mind, he'd taken her away from me you see,

The incident when her stepfather slapped her seems driven into her memory, even though she has rationalised his actions by saying that she was a

cheeky little monkey, and I deserved it

It had ramifications throughout the whole extended family, who Mrs HN says spoilt her (line 91). Mrs HN does not talk of forgiveness for him, he is a significant but un-named person in her life, and the pattern of behaviour that does not involve forgiveness is explicitly passed down to Mrs HN as her mother says (lines 280-282):

(and he went clonk on the side of my face, and of course my mum said) ***I'll never forgive you for doing that, and of course I never forgot it*** *and we kept at arms length I, ha ha, but it makes good reading, ha ha,*

Another interesting point is that although Mrs HN has experienced bereavements of significant people during her life, she has not mentioned any of these in the BNIM interview, except by implication of using the past tense when speaking about them. For example, her husband has died and she refers to him in the past tense, see lines 134-138; her grandmother has died and she refers to her in the past tense, see lines 41, 60-61, as well as her mother, see lines 63-65. She has balanced some of the negative events with positive ones; she discusses her grandmother with great affection, as well as her husband, her son and his family. She did not have a granddaughter either, but does not mention this, as some people might if they continue to carry this burden, this suggests she has processed this emotionally. At the time of wanting a baby girl she had a husband and son who she describes as 'lovely', amongst other affectionate terms, and her non-verbal gestures and facial expressions imply great affection for them, so she would have felt well supported at this time. She has defined her significant life events in her BNIM interview as:

- Not knowing who her father was
- Her mother remarrying
- Her stepfather hitting her
- Not having a baby girl

These are the life events Mrs HN has chosen to define in her story of life events and

experiences, and the first three are the ones that are referred to in the BNIM interview in a way that implies a lack of emotional processing. These events are often referred to and then the topic is deflected and closed with a joke (see lines 28, 34, 37, 92-93, 105, 122, 282)'. The lack of emotional processing is shown in an absence of emotional expression, further examination of these events reveals a repetitive mode of description; which describes initial feelings, but does not describe a process of resolution. Instead the description is often ended with a joke, not tears, as do each of the controls. The Dorset Research & Development Support Unit (2009), who study emotional processing, describe tears as

> *...a classic example of how emotional hurts can be released or worked through... Tears would appear, in miniature, to be an example of how emotional processing works.*

These events and the way they have been described support the statement of theme arrived at earlier for Mrs HN:

> *Rejected, but triumphed over adversity, and, whatever happens to you, life is a joke.*

Mr HF's way of processing his emotions associated with his life events and experiences are very different to Mrs HN methods of emotional expression. He describes how he had to deal with the revelation he had about not wanting to be an accountant. Mr HF says, in lines 325-329, and 339-342:

> *so it was a very real a difficult occasion for me I was having to confess something that I wasn't didn't want to do didn't want to break his friendship, because by this time we were friends, um but I did and I felt better for doing it of course, as I now know, the more you can talk talk, sometimes the better it can be for you, not always. ...he just listened and said yes I I understand if that's how you feel and what has happened you've got to go with what has happened to you, so that was a big occasion for me I was beginning to find myself, break free from parents*

This illustrates the patterns of emotional expression established in Mr HF's life. This pattern is repeated in descriptions of other events by telling the listener the actual emotional process he went through. For example in lines 346-384, he describes his horror at another soldier's eating habits, how he addressed this with him, how he was threatened by him, and then how later on he saw that this soldier was a bully, and from this he

realised that bullies are weak people, and this was a significant lesson for him to learn.

The only occasion when this pattern is not employed as completely, is when his wife dies. As Wengraf says (2001, 2008), it is the differences as well as the similarities that create typologies, and uncover the general from the particular. The time of his bereavement is one that is the exception to this rule, when Mr HF discusses it in subsession 1, he appears overwhelmed by the emotions of the circumstances on that day of the interview. Wengraf's structure asks for more details about events mentioned in Sub-session 1; on this occasion, it was not done for the following reasons. Mr HF knew that the researcher knew the circumstances of his wife's death, because the topic had been discussed in other OPTIMA research interviews, therefore it seemed crass and insensitive to ask for more details for the sake of the recording of this particular interview, when they were already known by the researcher. The circumstances of his first wife's death were very sudden and very sad, and it was obvious to the researcher that the recounting of her death in the Sub-session 1 had visibly moved him, and he was close to tears at this point, see lines 178-181:

> *And then she died. (pause) And I suppose of all the times which you are going to ask me about that was , (pause) well,(pause) it was unbelievable and er for months and months I had people come in and look after the house and cos all my children were away*

These 'rules' of the BNIM are discussed by Wengraf (2008):

> *It is important to bear in mind that no 'rule' can replace the necessity of being very sensitive to the unexpected emotions and emotional movements of any particular interview.*

Ethically, it is not appropriate to delve into somebody's experience and feelings when these feelings and memories can become overwhelming to them, the interviewer's practice should include the principle of beneficence, which actively promotes the good for the participant. With regards to Mr HF, it is of note that he had already had counselling for this in the past that had helped him process those emotions, and to begin a new relationship and remarry. Although the hesitation when Mr HF spoke about his wife's death indicates that, though difficult, he could not put it into words, and the tearfulness he experienced showed that he was able to process previously unearthed emotions still

(Dorset RDSU, 2009). People have different emotional triggers that can provoke emotions not fully processed, which can catch them by surprise, and it is known that the BNIM interview was approaching the time of the anniversary of his first wife's death, so this may have contributed towards Mr HF's distress that day. Whatever the reason, the interviewer did not want to contribute to that distress needlessly. Mr HF concluded the interview by ensuring that the death of his wife was recognised as the most painful event in his life (line 582):

> *The most painful was the death of my wife.*

The statement of theme for Mr HF was

> *Is a hostage to fortune, in that he reacts to events going on around him rather than seizing the initiative, he is not afraid of being unconventional, and success has come of these characteristics.*

The emotional expression occurred throughout his interview, and was explained within the narratives of the life events. Dorset RSDU (2009) describe how emotional processing has occurred by the very fact that there is an absence of symptoms of dysfunctional emotional processing. Mr HF is an example of how his pattern of emotional processing has resolved many issues during his life, shown in the narratives of emotion and resolution within his accounts of life events, and by having an absence of dysfunctional emotional processing.

The differences between how Mrs HN expresses her emotion in the recounting of her life events is different to the way Mr HF expresses his emotions in the recounting of his life events: Mrs HN has not been able to express her emotions during critical experiences of her life, and remains unable to process these emotions even now; Mr HF has been able to express his emotions throughout the majority of his life and has shown he is still able to do so. Both Mr HF and Mrs HN have had times when they have processed emotions successfully and unsuccessfully, it is the contrast in the ratios of successful to unsuccessful that makes the difference.

Theoretically, it is the unresolved life events that cause a level of background stress,

which causes higher than average cortisols to be released to cope with the threat to the integrity of the person's physical and psychological needs (Deshmukh and Deshmukh, 1990; Sapolsky, 1996; see *Chapter 3: Literature Review*). Graybeal and Pennebaker (2003) call this the theory of inhibition, and it is based upon the assumption that not disclosing important life events and experiences requires physiological work, and that this physiological work is a long term stressor, which is associated with ill health. Emotional processing requires the knowledge of how to execute the process, which includes the ability to recount the event, whilst reframing it and categorizing it ready for storage (Pennebaker and Chung, 2007). Danner et al. (2001) found that framing life events in a positive way is associated with longevity, and this has also been associated with health benefits (Pennebaker and Chung, 2007). It is known that patterns of behaviour can be passed down through the generations in families (de Levita, 1997) and from the analysis of Mrs HN's narrative (see above), it is clear she has inherited traits from her mother, grandmother and the extended family. She struggled against them when she was trying to find her father, but this was unsuccessful. These traits of not discussing emotions and ignoring, or suppressing, them are evident in the transcript. The anxiety that begins to make an entrance when discussing sensitive subjects is swiftly dispatched with a joke, and this can be seen in the transcript and heard in the recording.

The differences in emotional expression shown by Mr HF and Mrs HN are also depicted in the other control and patient BNIM interviews. In the C1 and C2 interviews it is seen that the first paragraph is similar to Mr HF's, in content, and the explanations of how they resolved their emotions about life events and experiences mirror Mr HF's. All controls became tearful at points, which the Dorset RDSU state is a sign of emotional processing, none of the patients became tearful; whilst this is an indicator of emotional processing it needs to be taken into context with the other factors, otherwise it could be construed wrongly as an indicator of AD on its own. Neither of the patients expressed any emotion in their opening narratives, whereas the controls did do so almost immediately. The differences in content, between the patients and controls, is striking when examined for evidence that life events are resolved, because of the lack of emotional expression in the

patient narratives.

To summarise, the differences in both structure and content between the patients and controls is evident in the following ways:

- Controls discuss their life events in a way that expresses emotions in the opening narrative after the SQUIN, and form a longer narrative than the patients, their discussion of life events is more coherent and is not as fractured as the patients' narratives.
- Patients discuss their life events in ways that do not express emotions in the opening narrative after the SQUIN, their narrative tends to be shorter than the controls, except in the case where there was a repetition of content very soon after beginning, their discussion of life events is more haphazard than the controls, and is fragmented.

These differences contribute to typologies that will aid the construction of a diagnostic indicator for Possible or Probable AD. From the BNIM interviews we can assume that the differences are in the areas shown in *Text Box 7.12.*

Text box 7.12 Differences between patients and controls BNIM interviews

1. Length of opening narrative, i.e. shorter (a few sentences) or longer (enough sentences to construct a lengthy paragraph)
2. Subject content of opening narrative, i.e. not repeated
3. Emotional content of opening narrative, i.e. emotional expression present or not
4. Structure of narrative i.e. a short fragment of a narrative or a more coherent narrative

The differences that Pennebaker and Chung (2007) report in physical and psychological health after disclosure (that has included the processing of emotions) reflect cognitive changes. Pennebaker and Chung (2007) have tried to induce the effects of physical and psychological ill health by changing the usage of language by participants in studies, all unsuccessfully; leading to the conclusion that the change in language is as a result of cognitive changes, and not a causal factor.

The analyses of content and structure of the BNIM interviews have defined the differences between the patients and controls and therefore answered TQ3. The differences will now be used in the construction of the diagnostic tool.

7.5. TQ4: Can the differences, between the patient and control groups, in the narratives be developed into a diagnostic marker?

(a) In which topic of discussion is the most obvious difference noted?

(b) What questions will need to be included to trial a questionnaire that would elucidate narrative that can be analysed?

(c) Is a lack of emotional expression a risk factor for those for whom it is the norm, as well as a marker of change?

The differences in the analyses from TQ1, 2 and 3 need to be combined in order to develop the diagnostic tool based on the differences found in the analyses of the ADLE study.

It was found in TQ1 that there is a difference in the number of life events overall, and a difference in the number of bereavements under the age of 51 years old. As the number of bereavements will have been included in the total number of life events, the most important result to be considered is the number of bereavements under the age of 51 years old.

The analysis of TQ2 found differences in the frequency and emotional valence, and the range of words used to express emotions, the patients used less in each case. The categories discussed with less emotional expression by the patients are found to be: bereavements, health and work.

TQ3 found differences in both content and structure between the patients and controls. These differences all contribute to the construction of a diagnostic tool, described here.

7.5.1. TQ4(a): In which topic of discussion is the most obvious difference noted?

There is a greater difference noted in the topic of bereavement, health and work, from the finding in TQ2. However, the differences between emotional expression were found in the BNIM interviews, despite only two controls (out of all six BNIM interviews) having discussed bereavements. Work was discussed in five of the BNIM interviews, and health was only discussed in one of the control interviews. Therefore, guidance on specific topics to discuss in the diagnostic tool is not needed, because the differences are evident as long as the writing concerns a life event or experience that would involve the processing of emotions.

7.5.2. TQ4(b): What questions will need to be included in a questionnaire that would elucidate narrative that can be analysed?

The factors from TQ1 and 2 are in text box 7.K, and an extra sentence has been placed in the text box (in bold) to include some emotional content, as well as advice for the Memory Clinic Doctor or Nurse who is evaluating the answers to these questions. The factors from TQ3 can be used to evaluate the paragraph at the bottom of the text box, to look for the content and structure, and in particular those items in *Text box 7.13.*

Text box 7.13. Diagnostic tool

Factors to be taken into consideration during the diagnostic process

1. Has the person experienced a bereavement of their parents, sibling, partner/spouse or very close friend that has occurred when they were aged 50 years old or younger? (Please briefly describe below)

2. Has the person experienced a change in the way they express themselves, for example:

a) Has the person been a person who would normally fluently express their emotions, or do they tend to have a 'stiff upper lip'?

b) Does the person express less emotion than they used to, about things they usually care about?

3. Ask the person to spend about 5-10 minutes writing a paragraph about an event or experience that would normally evoke feelings (without help). For example,

- Something that is 10 sentences long (or more)
- Either something that happened recently or a long time ago
- It could include a holiday, birthday, Christmas or other celebration with family and friends, or something which has significantly affected your life
- It can be an event that is happy, sad, confusing or makes you cross, **explain why you felt like this and how you feel about it now**

(include space for writing here)

(The following is advice for health practitioner after the piece of text is written)
Evaluate piece of writing for evidence of:

- **Emotional descriptions**
- **Emotional processing, or resolution, of event or experience described**
- **Is the description coherent, without any repetition?**

The evaluation of the diagnostic tool can be used in the memory clinics as suggested, and the triangulation of methods in the mixed methods approach has ensured that the data collected has complementary to the theory questions and each method (Flick, 2008). This has enabled different aspects of the problem to be evaluated and has contributed to a more effective analysis, and therefore a more encompassing diagnostic tool.

This study has found that the lack of emotion expressed is one of the identifying differences between the patients and controls. However, it is not yet known if the lack of emotional expression is a change in the person, or if it has always been there. If it has always been there, it would be a risk factor from childhood. Because the ADLE study is not longitudinal it is not known if these changes are a contributory cause of AD, or are there in people's normal behaviour and characteristics handed down through the generations, as suggested by de Levita (1997) and as seen in the case study of Mrs HN.

7.6. TQ5: Can the diagnostic tool be applied to text collected from patients and controls over a period of decades?

The elements of the text analysis in the diagnostic tool are being used in the Cognitive Archaeology study which has already commenced, using data from OPTIMA, as well as that requested from a public call (Garrard, Haigh and de Jager, 2009). This study will be collecting data from pieces of text (such as diaries or letters) spread over the three previous decades, it will be analysed for differences using a variety of tools, including Pennebaker's Linguistic Inquiry and Word Count (LIWC), and the diagnostic tool developed in the ADLE study. Demographic data will also be collected; in addition, data on health (the inclusion criteria require a diagnosis of normal cognition or differential diagnosis of dementia), education, and occupation will be included with a short memory test. There will be 100 participants with normal cognition, and 100 participants with Possible or Probable AD, or other diagnosed dementia. The Cognitive Archaeology study is aiming to find pre-symptomatic changes in the language of participants with AD, using

the techniques used previously by Garrard (2008) and the techniques developed in the ADLE study.

The Alzheimer's Society is very interested in the Cognitive Archaeology study because of the pressure to find non-invasive diagnostic indicators as soon as possible in the disease process. The National Dementia Strategy supports this direction, by encouraging practitioners to be preventative in their practice in order to identify the disease before it does a significant amount of damage that is shown as symptoms, when it is too late because the symptoms reflect the damage already been done. *Chapter 2: Background information* has shown why it is so important to identify the disease early on and risk factors in this disease, because there is treatment for AD at present, and the effects of the disease are extensive personally, nationally and internationally.

To summarise, this chapter has covered the data analysis and discussion of the theory questions. These theory questions contribute to answering the CRQ:

Are life events a risk factor for AD?

The answer to the CRQ will be determined in the next chapter. This chapter has answered the theory questions 1, 2, and 3, thereby providing data that has constructed a diagnostic tool to identify the changes in emotional expression in the narrative of life events.

There are no studies on life events and AD that have used a mixed methods approach, and this particular approach has resulted in new knowledge about life events and AD, and the emotional expression of life events; thus filling the gap in the previous knowledge by:

- Showing the importance of emotional expression in the narrating of life events
- Utilising such differences in the construction of a diagnostic tool.
- Utilising the parameters of different methodologies to capture such information.

Chapter 8: Conclusion

This chapter will review the ADLE study thesis with reference to the CRQ, the TQs and the subsidiary questions. These questions are set out in *Table 8.1*, with a concise answer to each of the questions.

Table 8.1 CRQ and TQs

Research questions	Interviews - patients	Interviews - controls	Research literature	Answers to each theory question
CRQ: Are life events a risk for AD?				
1. Is there a difference between the number of life events between patients and controls, using LEDS as a measurement tool? (a) Is there any difference in the number of life events, which have occurred between patient and control groups? (b) Is there any difference in the number of life events, which have occurred below the age of 51 years old, between the patient and control groups? (c) Is there any difference in the number of bereavements, which have occurred between the patient and control groups? (d) Is there any difference in the number of bereavements, which have occurred under the age of 51 years old, between the patient and control groups? (e) Is there any difference in the number of difficulties between the patient and control groups	20 LEDS interview	20 LEDS interview	- Life events literature and AD - Glucocorticoid cascade hypothesis (GCH) and Hypothalamic-Pituitary-Adrenal axis (HPA axis) - Post-Traumatic Stress Disorder (PTSD)	Yes: TQ1(a) p=0.039 and TQ(d) p=0.032 Patients had a greater number of bereavements under the age of 51yrs, and total number of life events – this supports the GCH which affects the HPA axis and the hippocampal neurones.

(f) Is there any difference in the number of difficulties, which have occurred below the age of 51 years old, between the patient and control groups (g) Is there any difference in the total length of difficulties, which have occurred between the patient and control groups? (h) Is there any difference in the total length of difficulties, which have occurred under the age of 51 years old between the patient and control groups I? (i) Is there any difference in the number of major difficulties, which have occurred, between the patient and control groups? (j) Is there any difference in the number of major difficulties, which have occurred below the age of 51 years, between the patient and control groups? (k) Is there any difference in the total length of major difficulties, which have occurred between the patient and control groups?				

(l) Is there any difference in the total length of major difficulties, which have occurred under the age of 51 years old between the patient and control groups?				
2. Is there a difference in the way (i.e. positive, neutral and negative) life events are discussed and in the range of emotions expressed when discussing life events between the patients and controls? a) Are there any differences in the discussion of life events as classified by the LEDS, or life events defined by the participants (non-LEDS) between the patient and control groups? b) Are there any differences in the unique 'characteristics' of speech used to provide narratives of life events, as determined by Danner's EWC?	12 LEDS interview transcripts and DD's EWC	12 LEDS interviews transcripts and DD's EWC	• EWC • Emotional processing	Yes: the patients discussed significantly less events, and of those, the patients discussed significantly more negative life events than the controls. A smaller range of emotions was used to describe the life events during discussion.
3. Are there any differences in the narrative constructions of life events, as interpreted by the Biographic Narrative Interpretive Method between the patient and control groups?	3 BNIM interviews: 1 in-depth, 2 less in-depth, thematic field analysis	3 BNIM interviews: 1 in-depth, 2 less in-depth, thematic field analysis	• Emotional processing	Yes: **the control** had a long opening narrative, using emotional content to describe life events and experiences, there was no repetition of the subject and it was possible to follow through the person's feelings about an event to resolution and emotional processing. **The patient** used a short opening narrative, with little detail in the description of life events and experiences, there was evidence of patterns of behaviour that did not involve emotional processing of events - the lack of

				emotional processing constitutes stress, leading to stress and impact on HPA axis, and vulnerability of hippocampal neurons.
				Answer to CRQ – In context of evidence from LEDS interviews, Danner coding and BNIM interviews and analysis: YES, certain life events are a risk factor for AD; in particular bereavements under age of 51 years old.
4. Can the differences, between the patient and control groups, in the narratives be developed into a diagnostic marker? • In which topic of discussion is the most obvious difference noted? • What questions will need to be included to trial a questionnaire that would elucidate narrative than can be analysed? Eg. Does pt moan/complain more/less, are feelings expressed more/less, • Is a lack of emotional expression a risk factor for those for whom it is the norm, as well as a marker of change?				**See diagnostic tool**

5. Can the EWC be used as a diagnostic marker by being applied to text collected from patients and controls over a period of decades?	100 participants, with AD, or other dementia with pieces of text that includes 1,000 words per decade	100 participants, with normal cognition, with pieces of text that includes 1,000 words per decade		**Cognitive Archaeology Study (IRAS: 09/H0502/72) with Dr Peter Garrard – in progress, to be completed by end of 2011, funded by MRC.**
				Diagnostic marker can be used in memory clinics, as part of Government National Dementia Strategy, as part of 'best practice' early diagnosis

The CRQ originated from the patients, carers, and the OPTIMA clinical team, and the author, and the thesis developed from this into a mixed-methods study. *Chapter 1: Introduction* established the CRQ and the TQs that contribute to the evidence towards answering the CRQ, and how the CRQ has shaped the objectives of the ADLE. These objectives will be discussed in detail later on. The model of life events by Brown and Harris was selected and its application to the CRQ was is described in *Chapter 6: Results.* The demography of AD shows the prevalence of this disease, in this country and worldwide, how it will become more prevalent in the future, and research in the field of AD.

Chapter 2: Background Information provides details about the pathology and how Possible or Probable AD is diagnosed, and why the process of the diagnosis of AD neuropathology is so important, especially in a research study. The context of OPTIMA and the ADLE study was reviewed. The affect of AD on the individual and their family was explored. The research on how stressors, such as life events, instigate the glucocorticoid cascade hypothesis and the activation of the HPA axis affecting the hippocampus was discussed.

Chapter 3: Literature review has examined the literature with reference to the TQs, concerning the following topics: why life events are thought to be a risk factor for AD, including the GCH and HPA axis, and the reasons for choosing the LEDS (Brown and Harris, 1978) EWC (Danner et al., 2001) and BNIM (Wengraf, 2008). This review concluded that all previous studies were methodologically flawed.

Chapter 4: Methodology and ethical issues discussed the rationale behind the mixed-methods approach for the ADLE study, and the five research phases of Denzin and Lincoln (2005) were used to explain the methodology. The mixed-methods approach is an unusual approach for a study in this field: during a literature search, only one other study was found to have used a mixed-methods approach in the field of AD (Anderson et al., 2004). Beauchamp and Childress' four ethical principles of autonomy, nonmaleficience,

beneficence and justice were employed to examine the ethical issues with reference to the MCA and research with vulnerable adults.

Chapter 5: Methods explored the methods of the LEDS interviews and how the life events were scored. The additional components of the EWC were defined and it was shown how the use of the EWC identified differences in the transcripts of the LEDS interviews. The BNIM interview method (Wengraf, 2008) was explained and how the data was prepared for analysis using thematic field analysis and panels to ensure the researcher thinks of the wider field of possibilities when creating structural hypotheses.

Chapter 6: Results revealed the findings of the analyses for TQ1, TQ2 and TQ3. The results of TQ1, the number of life events in the LEDS interviews, showed statistically significant differences between patients and controls for the number of life events and the number of bereavements under the age of 51 years old. The Brown and Harris model was reviewed, and the argument for a simpler model to be used explicitly was proposed, consisting of provoking agents without vulnerability factors. This simpler model was used implicitly, and not acknowledged, in all other studies using the LEDS (Brown and Harris, 1978).

For TQ2, the LEDS and non-LEDS life events were quantified and analysed, and each p value was more significant when the non-LEDS life events were removed from the analyses. Even though there were significantly more life events experienced by the patients, the EWC (Danner et al., 2001) found significantly fewer emotional discussions by the patients, particularly the negatively described ones for TQ2. The range of negative and positive words used to describe the life events was significantly fewer too; this implies that the ways the patients express emotions about life events is substantially different from the controls. This finding was mirrored in TQ3, the qualitative analysis of the results of the two in-depth analyses of the BNIM interviews (Wengraf, 2008), which will be described in more depth in the next paragraph.

Chapter 7: Analysis and Discussion included the results of TQ1, TQ2 and TQ3 in relation to the ability to process emotions. The findings of TQ1 showed that the patients experience a greater number of life events overall, but that it is the number of bereavements of immediate family (i.e. parents or siblings) or close friends (i.e. seen daily, or living with the participant) under the age of 51 years old that are the most critical, as this number also statistically contributed towards the significant number of life events overall. The findings of TQ2 showed how the differences between patients and controls are reflected in the expression of emotions. The number of life events discussed by the patients was fewer than the controls, and the range of emotions used by patients in the discussion of life events was fewer than the controls. This indicates a difficulty with expressing emotions whilst discussing life events, and in particular while discussing life events in a way that uses positive or negative emotions. The analysis of the two in-depth BNIM interviews revealed similar differences, which were supported by the other four BNIM interviews. The two patients, Mrs HN and P1, spoke with very short opening narratives: the exception is P2, who after a short narrative started to repeat himself instead. The opening narratives of the controls were all long coherent account of events that had happened, their feelings and reactions to them, with tearfulness, and how they had got through the event and had resolved their feelings about the event – none of which was included in the patients' narratives. There was an absence of emotional expression and emotional processing in the patient's narratives, with a fragmented version of events that indicates two possibilities.

These two possibilities are, firstly, that AD neuropathology affects the areas of verbal expression, which is reflected as an early change in the patient's language, reflecting AD pathology, or, secondly, that the patients have never learnt to express themselves emotionally or processed emotions adequately, because of behaviour patterns learnt when they were young. The argument for the second possibility is that a stressful life event starts a chain of reactions in the HPA axis, leading to an increased risk of AD pathology because of the vulnerability of the hippocampal neurons to increased cortisol levels. These findings are supported by the literature concerning the HPA axis, emotional

processing and changes in language, as well as other types of linguistic changes found to be associated with AD.

The differences found between the patients and controls have been used to answer TQ4 and TQ5, and to construct a diagnostic tool that can be used in a memory clinic, or as a diagnostic tool in research. It was found that the differences elucidated between the patients and controls were evident in the BNIM interview (Wengraf, 2008), which allowed a free narrative and no guidance on which type of life events to discuss for the participant. The elements of the text analysis in the diagnostic tool will be used in the Cognitive Archaeology study (IRAS no: 09/H0502/72; funded by the MRC) to determine differences in pieces of text, alongside other linguistic analyses. This type of non-invasive diagnostic process is one that is being encouraged by organisations such as the Alzheimer's Society because it is a non-invasive diagnostic tool, and can be employed in the best practice suggested by the National Dementia Strategy.

8.1. CRQ: Are life events a risk factor for AD?

After examining all the results and analyses from TQ1, TQ2 and TQ3, the evidence supports the association between life events and AD, with bereavements under the age of 51 years old being particularly important. Here, the way that we process the emotions arising from such life events is critical to the physiological and emotional health of a person's brain. The National Dementia Strategy is encouraging practitioners to promote dementia as preventable, as well as people having a timely diagnosis: these are aspects of the strategy that the ADLE study facilitates through gaining the specific additional knowledge of a diagnostic tool that can be used early on in the disease process, and identifying how to prevent or reduce life events becoming a stressor (leading to overactivation of the HPA axis and damage to the hippocampus) can be reduced by early recognition of, and modification of, a person's patterns of emotional processing behaviour.

8.2. The ADLE study objectives

The objectives of the ADLE study were as follows:

- To explore the narrative accounts of patients and controls, in relation to AD and life events, and address a gap in the body of knowledge
- To develop the methodology of life events research through the interpretation of narratives given by patients and controls using a mixed-methods approach, viz. *Life Events and Difficulties Schedule* (LEDS) (Brown and Harris, 1978), Danner's emotional word coding (EWC) and the Biographic Narrative Interpretive Method (BNIM)
- To determine whether there is a relationship between the LEDS interview scores and neuropsychological data
- To develop supportive practice in the field of dementia care
- To provide current, relevant and new information for healthcare professionals, patients and relatives about the association between life events and AD
- To build a diagnostic tool that would aid the process of an early diagnosis of AD

The narrative accounts of life events recounted by patients and controls and the subsequent analysis of them has addressed a gap in the body of knowledge and provided unique data on life events and AD.

The methodology of life events study has been developed by the use of the LEDS tool: it has never been used with people who have memory problems caused by a disease such as AD.

There are no other studies in the literature that address the association between life events and AD in this way. As mentioned above, in *Chapter 3: Literature review*, the previous studies addressing the link between life events and AD had methodological flaws that rendered their results unusable. The ADLE study has ensured that many of the flaws found in these studies are rectified: the benefit of a mixed-methods approach using triangulation to elicit two types of data about the same aspect (Patton, 2002), giving different aspects of the same problem through the use of the LEDS interview, EWC and the BNIM interview. The quantitative and qualitative of data have complemented each other, and have furthered the knowledge in this research field.

The objective of determining whether there is a relationship between the LEDS interview and the neuropsychological data has been fulfilled: the neuropsychological tests indicative of Possible or Probable AD show an association with life events, in particular with bereavements under the age of 51 years old. The significance of the bereavements under the age of 51 years old is because of the contribution these would have made to the overall number of life events.

The development of supportive practice in the field of dementia care has been realised through the development of new knowledge about life events and emotional processing. This can be used to inform patients and carers about the disease process, and the effects which can occur in some people. An understanding of symptoms can alleviate some of the anxieties of a journey into the unknown (Smith et al., 1998).

The ADLE study has provided current, relevant and new information for healthcare professionals, patients and relatives about the association between life events and AD through the conclusions reached in the course of this research study, as well as a recent the review of the literature underpinning this thesis. The ADLE study has generated information that can be used by the healthcare professional in their clinical practice, and to prompt further research: both objectives being included in the National Dementia Strategy (DH/SCLG&CP/SCPI/SR, 2009). The ADLE study has already contributed to collaboration with Dr Peter Garrard in the design of the Cognitive Archaeology Study (Garrard, Haigh and de Jager, 2009), which is being supported by the MRC, and is of interest to the Alzheimer's Society who were quoted as saying:

> *One in three people over 65 will die with dementia, yet there is no efficient way of diagnosing the condition. We look forward to further research into potential linguistic markers for dementia.*
>
> (Ballard, 2008)

The development of a practical tool to aid early diagnosis has been accomplished through the construction of the diagnostic tool, a practical tool that can be used in memory clinics that will contribute to the diagnostic process leading to Possible or Probable AD.

Finally, the theory questions, and ultimately the CRQ, have been fulfilled, as summarised in Table 8.1. The findings from TQ1, TQ2 and TQ3 have fulfilled TQ4 and TQ5, and aided the construction of a diagnostic tool for use in a memory clinic or research to identify these early changes in language. Early non-invasive diagnostic tools are needed to detect pre-symptomatic changes in a person's linguistic function. Early diagnosis aids treatment and enables patients and their carers to adjust to the disease, and to maximise the memory function they have remaining by making behavioural changes that effect lifestyle, such as the emotional processing of life events. Advances in treatment of memory problems will be aided by identifying the disease as early as possible to minimise the pathology present.

These unique contributions of new knowledge to the field of AD research by the ADLE study will help in the future diagnosis and care of people with AD. However, the ADLE study would not be in existence were it not for all those patients, carers and research team members that have nurtured the question of whether there is a relationship between life events and AD, and aided the researcher in the process of answering this question.

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Appendix II

Oxford Project To Investigate Memory and Ageing

UNIVERSITY OF OXFORD

OPTIMA Project
Radcliffe Infirmary NHS Trust
Woodstock Road
Oxford OX2 6HE

All telephone enquiries:
(01865) 224356 or 224699
Fax: (01865) 224099
E-mail: phar0023@ermine.ox.ac.uk

Dear

We are researching the problem of memory loss and mental deterioration in the hope of developing our understanding of how these conditions arise. As part of the research I am asking whether significant events in peoples' lives are a contributing factor to memory loss and mental deterioration. Examples of some significant events you would be asked about would include: getting married, having children, changing job.

In order to do this I would like to interview people are part of the Oxford Project To Investigate Memory And Ageing and Foresight Challenge study. If you are willing, this would simply involve one interview with myself, lasting approximately an hour and a half. This session would take place in your own home and would be tape recorded.

Everything you say would, of course, be confidential. You are free to decline to participate, and free to withdraw at any point. I shall telephone you in two weeks time to see if you would like to participte in this study. If you have any questions or worries at any stage, please do get in touch with me on the number below:

Oxford (01865) 224356

Anne-Marie Haigh
Research Nurse

OPREC No: 97.49

UNIVERSITY OF OXFORD

OPTIMA Project
Radcliffe Infirmary NHS Trust
Woodstock Road
Oxford OX2 6HE

All telephone enquiries:
(01865) 224356 or 22469
Fax: (01865) 22409
E-mail: alzheimer@ermine.ox.ac.u

INFORMATION SHEET

We are researching the problem of memory loss and mental deterioration in the hope of developing our understanding of how these conditions arise. As part of this research I am asking whether significant events in peoples' lives are a contributing factor to memory loss and mental deterioration. Examples of some significant events you would be asked about would include: getting married, having children, changing job.

We are interested to know how you felt about these events at the time, by interviewing you. This interview has been developed by experts in the field.It has been used a great deal over the last 26 years in many studies.

Everything you say would, of course, be confidential. You are free to decline to participate, and free to withdraw at any time without affecting your medical care. I shall telephone you in two weeks time to see if you would like to participate in this study. If you have any questions or worries at any stage, please do get in touch with me on the number below:

Oxford (01865) 224356

Anne-Marie Haigh
Research Nurse

Appendix II

Oxford Project To Investigate Memory and Ageing

UNIVERSITY OF OXFORD

OPTIMA Project
Radcliffe Infirmary NHS Trust
Woodstock Road
Oxford OX2 6HE

All telephone enquiries:
(01865) 224356 or 224699
Fax: (01865) 224099
E-mail: phar0023@ermine.ox.ac.uk

Title of project:
The link between events and difficulties in a person's life and Alzheimer's Disease

Name of Responsible Investigators:
Dr Robin Jacoby and Mrs Anne-Marie Haigh

Psychiatric Research Ethics Committee Application Number 97.49

Have you read the Patient Information Sheet?

[*Please circle your answer*] Yes/no

Have you had an opportunity to ask questions and discuss this study?

Yes/no

Have you received satisfactory answers to all your questions?

Yes/no

Have you received enough information about the study?

Yes/no

Who has explained the study to you?

Dr/Mr/Mrs/Ms

Do you understand you are free to leave the study

- **at any time**
- **without having to give a reason for leaving**
- **and without affecting your future medical care?**

Yes/no

Do you agree to take part in this study?

Yes/no

Signature .....
Date .....
[NAME IN BLOCK LETTERS] .....

Appendix III Example of LEDS events and difficulties

Event no.	Year of event	Age at event	Pt no 9 events
E1	1961	33	Found out 1st wife was having an affair, from sons
E2	1961	33	Found out 1st wife was pregnant by another man
E3	1962	34	Found out 1st wife was pregnant again by diff man, had termination of pregnancy
E4	1962	34	Divorced from 1st wife
E5	1962	34	Found out 1st wife had put son in cupboard when little
E6	1962	34	Changed job to teaching, had holidays off
E7	1969	41	Father in law of 2nd wife died
E8	1976	48	Son 1 divorced
E9	1978	50	Son 2 divorced
E10	1978	50	Son 2 had child by different woman
E11	1981	53	Son 2 left above women and remarried 1st wife
E12	1986	58	Step daughter said she was bisexual
E13	1987	59	Mother died, short illness
			Pt no 9 difficulties
D1	1961	33	Wife unfaithful, affairs and pregnancy
D2	1961	33	Divorced from wife
D3	1961	33	Childcare difficulties, changed job
D4	1965	37	Child with 2nd wife only slept for about 2 hrs a night for first year

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School of Health and Social Care

Oxford Project To Investigate Memory and Ageing

Appendix VI

UNIVERSITY OF OXFORD

Telephone enquiries:
(01865) 231453 / 231270
OPTIMA
Level 4, Room 4403
John Radcliffe Hospital
Headington
Oxford OX3 9DU

Alzheimer's disease and Life Events Study

21 November 2008

Dear

I am a Research Nurse at the Oxford Project To Investigate Memory and Ageing (OPTIMA) and am researching whether there is a relationship between stressful life events (such as weddings, divorces, or bereavements) and memory loss. As you are a participant in research with OPTIMA, I am writing to ask you whether you would like to take part in a study which will research the link between life events and memory loss.

You are under no obligation to take part, however if you would like to take part in the research into life events and memory loss, the attached information sheet will explain the study in more detail and will explain how you opt in.

Thank you for taking the time to read this letter. Please do not hesitate to contact us if you have any queries.

With best wishes

Yours sincerely

Mrs Anne-Marie Haigh
Research Nurse

Dr Paul Yerrell
Research Supervisor

NRES study number: 08/H1307/97
Version 4, 5.11.08

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Appendix V

Oxford Project To Investigate Memory and Ageing

UNIVERSITY OF OXFORD

OPTIMA
Level 4, Room 4403
John Radcliffe Hospital
Headington
Oxford OX3 9DU

Telephone enquiries:
(01865) 231453 / 231270
Emergency (John Radcliffe switch):
(01865) 741166
Fax: (01865) 231154
Email: phar0023@herald.ox.ac.uk

5 November 2008, Version 4

Alzheimer's Disease Life Events study

Study Title
The Alzheimer's Disease Life Events (ADLE) study

Invitation
You are being invited to take part in research being undertaken as part of a higher degree. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?
The purpose of the research is to study whether there is a link between stressful life events and memory loss. Your involvement with the study would be over the course of approximately 4-6 weeks, although the interviews will be done over the course of a year.

Why have I been chosen?
You have been invited to join the study because you take part in the research done by OPTIMA, there will be nine other people taking part.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you would be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect the standard of care you receive or your involvement with OPTIMA research.

What would happen to me if I take part?
If you decide to take part, you would be invited to be interviewed about your life story, and to tell me about some of the life events of your choice. This interview would be tape recorded, for me to listen to later. This would take 2-3 hours, and I would visit you 2-3 weeks later to clarify any questions that may have arisen from the information given to me, or that you may wish to discuss. There is the opportunity to discuss anything raised with someone independent from me, or OPTIMA, if you feel the need.

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2008

What would I have to do?
You would be invited to be interviewed, as described above; there would be no other involvement, in this research.

What are the possible benefits of taking part?
There are no benefits to you taking part in the interview.

Are there any risks to taking part?
There are no anticipated risks, although talking about significant life events has the potential to be upsetting. If this is the case, the interview can be stopped, or it is possible to discuss anything raised with either someone at OPTIMA, or independent of the study if preferred.

Would my taking part in this study be kept confidential?
All information which is collected about you during the course of the research would be kept strictly confidential. Any information about you which leaves the OPTIMA office would have your name and address removed so that you cannot be recognised from it. I would like to use anonymous quotes in the presentation of the research findings, but you will not be identifiable in any paper or presentation of the results. Anything that could identify you to other people will be removed, although it may be possible that you could recognise yourself.

What would happen to the results of the research study?
The results of the research will be published in journals, and presented at conferences. These will be written about in the annual OPTIMA newsletter to all OPTIMA participants, and a copy of any papers can be requested from OPTIMA.

Who has reviewed the study?
The School of Health and Social Care Research Ethics Committee at Oxford Brookes University have reviewed the study, as well as the Leeds West Research Ethics Committee.

Contact for further information
A stamped addressed envelope is enclosed for your reply. If you would like any further information, please do not hesitate to contact us on the following telephone numbers:

Anne-Marie Haigh
Research Nurse
OPTIMA
Radcliffe Infirmary
Oxford OX2 6HA
Tel 01865 617184

Dr Paul Yerrell
Senior Lecturer
School of Health and Social Care
Oxford Brookes
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Oxford OX3 0FL
Tel 01865 485295

OXFORD BROOKES UNIVERSITY

School of Health and Social Care

Appendix VI

Oxford Project To Investigate Memory and Ageing

UNIVERSITY OF OXFORD

Telephone enquiries:
(01865) 231453 / 231270
OPTIMA
Level 4, Room 4403
John Radcliffe Hospital
Headington
Oxford OX3 9DU

Title of Project: **The Alzheimer's Disease Life Events study (ADLE)**
NRES Study Number: 08/H1307/97 V2

Name of researcher: Anne-Marie Haigh

Contact Details:
OPTIMA, Room 4403, Level 4, John Radcliffe Hospital, Oxford, OX3 9DU
Tel 01865 231453

		Please initial box
1.	I confirm that I have read and understand the information sheet dated February 1st 2008. (version 1) for the above study and have had the opportunity to ask questions	☐
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected	☐
3.	I understand that regulatory authorities will monitor the study in accordance with the Research Governance Framework. I give permission for these individuals to have access to my records. Anonymous information given in the interviews may be discussed during the analysis with PhD supervisors or advisors.	☐
4.	I agree that any words I say during interview may be used, anonymously, in the presentation of the research	☐
5.	I understand that the interview may be audio taped and if I wish I may check the transcript	☐
6.	I agree to take part in the above study	☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

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2008

Mr HF BNIM interview

1 I: There we are it's recording now, that's it. So are you still doing your counselling with Zx?

3 R: Yes, yes

4 I: How many hours a week do you do now?

5 R: Oh very few, partly because I get tired. I was going to give it up but you know as I say I have had a very complex one for many months now which eventually meant that I only had one as the others tailed off. I haven't taken any more partly because we are going away for seven weeks you mustn't really let people er miss and partly because I have been recovering from heart failure and that's set me back a bit. I have had 3 stents put in my heart this year

12 I: Did you, I thought you sounded a bit more puffed out

13 R: Yes that's right, I have to watch my breathing. But I'm all right, I just don't do anything as much as I used to. Cough. I think my voice has changed as well.

16 I: Yes

17 R: Well there we are. Life.

18 I: Yes Right now **what I would like you to do is to tell me the story of your life, all the events and experiences that have been important to you personally and you can begin whenever you like and I won't interrupt, I shall just take some notes for afterwards.** *(SQUIN)*

22 R: Wartime boy, war passed me actually. I was, I was a grammar school boy, got a scholarship, and got told off by one of the prefects, when I was selling papers, not to wear school uniform. (Laughs). ... I yielded to my parents' wish having broken up the library in our school, or being part of breaking it up, terrible when I think about it, in the 6th form. I left suddenly, at the end of 45, and my parents took me to the Headmasters conference. The headmasters conference said **well yes you are good at this, good at that, we think you would be a very good chartered accountant**, so I swung into the chartered accountancy firm, and they took me on er I became an articled clerk. Oh oh here's the first big event

32 I: Uh huh

33 R: Oh oh apart from thwarted love affairs, and half thwarted love affairs um one of which sent me away to hitch hike round Hx er 1950. now what was I saying, the major thing that happened if you are wanting major events, was a revelation that shook me to the core whilst I was sitting working, doing some accounts for a shipping company. It was called the Captains accounts and as I was making sense of all this stuff that he had put in there in ZX, in London. **I suddenly had this tremendous moment (a), if I wish to be a chartered accountant I could, (b) instantaneous follow on, I wasn't going to be as I did not wish to be. I was so overtaken by this that I went out and had a cup of coffee at Joe Lyons,** how old was I then 20 I suppose I had done a lot of work previously er and then I just told the firm that I wished to be released from my articles, they were very upset, naturally they had put a few years into me by this time. Erm So off I went into the army, er few a few months later , 6 or 7 months later, and in the army was my 2nd choice, a big decision, I had partly because of upset tummies adolescence become a vegetarian, and I used to go to a vegan restaurant Leciester Sq a very good restaurant actually and **when I sat in the train going to Pxxx I realised once I got there there was a smell from the kitchen and I realised I was either going to starve or I was going to eat anything they gave me, decision, big decision, eat anything Fxxx, so I did.** Er,

N(Asia), served in N, volunteered very good, I trained as a in the RAEC, in the Royal Army Educational Corps, became a sergeant, was offered to become an officer, though I **said no because if I do another 6, because I'd done 6 months training by this time, if I did another 6 months training then I wouldn't be ...abroad, and I wanted to go abroad, might as well...in the army**, so I volunteered for Malaysia, having read Spencer Chapman the jungle is neutral, and then BX, Major X, who was our chief officer, whom I had great respect for, said to me, look here Fxxx, he said there's a position come up in er N, ...from frostbite what do you think, are you interested, so I said Yeess, lets go to N, so off to N I went. **(7mins)** Um which was OK, a small unit, in that small unit there was 4 sergeants a captain and major, 5 sergeants actually, one kiwi, one aussie, one canack, Canadian, and 2 of us, a captain and a major, that's it and we ran a newspaper for the forces, did all sorts of things in the division. um And I was had come across, how much of this detail do you want?

67 I: Well at the moment not too much, but maybe we could go back to that a bit later

69 R: Yeah Ok, let me know
Well the army was quite an influence in a number of ways, in a terrific number of ways without realising it, but we'll leave that for now. So come home, aged 23 I suppose, went into the army when I was 21. Um my uncle was an influence and **I said you know Uncle J** what a lovely name, **I wish to work with children, oh do you he said** , X also helped me in this, um B, B X, killed in the T war, **um why don't you teach?** If you want to get to know children one way of getting to know them is to teach them. So I thought about this and that's what I did, I became a teacher, taught, to training college, and taught. Then another significant event, one moment was in Hxxx park, **I remember the moment to this second, walking in the must have been lights on in the park, it must have evening, about march time, I proposed to my wife, and it was such a shock to me that I had actually done it I couldn't really believe it** but there it was 1954, and we were married in March 1956. A marvellous moment. Um. Teaching. Yeah. Cxx was our principle though I had previously said, or suggested, that X and my uncle was interesting was a senior civil servant undersecretary and er Id sent them both as my references, X was then killed when I was at college and I went to Cxx ,and I said I'd like to have his reference please, he said **'yeah you can have it when you've finished'** anyhow, and then I realised, that I really wanted to be flattered by what he'd possible written , which I wouldn't know of course. But he had made me the what is called the stick officer during training,

91 I: Uh huh

92 R: I, I was actually presented with a stick, the most (laughs) un soldier like person, according to a company sergeant major, by a field marshal, he couldn't believe I'd, **But X said I should have had it,** I did for various reasons, in his view, not mine, but in his. Er but I did, when I finally finished college, but **I thought no this is not right Fxxx the mans died, you don't really need this,** so I never did know what he thought of me. Teaching was interesting, um no problems with discipline, as I had had children totally out of discipline, totally out of my control when I was having some induction as it were, I offered myself to go to school for a term before I went into college, oo yes yes, and they sent me of all places to a school for er educationally subnormal as they were then ESN, boys, teenage boys

103 I: Yes

104 R: And I didn't have a clue. On one occasion, this is another moment by the way now I think about it , which decided me that's right, , that I wasn't going to give in this business of teaching was ha ha, we had a separate classroom, separate place for art, and I must have, **I'd been doing some preparation, as I'd tried hard, and I came into the classroom, and there was all hell to play, they were flicking crashing banging and what, and I thought I don't know what I thought, it was instantaneous, I picked up a boy, picked him up, marched him outside, beat him, marched him back inside,**

picked up the next one, big one this time, took him outside beat him, went back inside, Dead silence, not a flicker, and I then ranted, went up and down and ranted, and said how dare they do that, and that was my moment of realisation, that a that was no good anyway, you never do that sort of thing, I should have been drummed out forthwith, but that actually actually without my realising it I had found the ringleader, I'd done the ringleader, small lad, and his protector, the big boy,

119 R: Gosh

120 I: yeh quite without realising it, and **I didn't half hammer them, on their bottoms** um. **(14.17)**ha ha. erm And that when I began teaching I didn't even have to bother, to have, and I enjoyed teaching but I was there during the 11plus therefore I had to, I taught top year of primary going onto, who were either going to grammar school or not, and I learned I could push, push, push, push their IQ, at least their recorded IQ up between 5 and 10 points, that's quite a lot , and I did do, and I got some, but I didn't like it. I also moved to take a further qualification, an MA, in something or other in O and for some reason, I didn't get in, I think I can't remember why I didn't get in either they didn't do the course , I was misled by my headmaster I think. But whilst I was there I decided I would take the the lads, the class who were the top layer level, 11yr olds again, but who themselves were C rather than A, I don't know why I went to them, because I really wanted to do something useful, so I taught practical things, I taught a lot of teaching, I did a lot of work with them as individuals and with small groups, and while I was there one young lad fell off a wall, running round the school and cracked his thigh, very bad, and he couldn't read or write. And so I thought right, I used to go to his home, this was in the back streets of O, C was it, um and to a mining family, where he came from, and I taught him after school twice a week, voluntarily, so I was invited into the family eventually and given their cracked cups of tea and so on, and er I complained bitterly that this boy was being left, nobody was doing anything, except me, so what do you do with a rebel, you bring him in. They said **Mr F we'll pay you now for going specially to this boy.** So I taught him till he actually got back to school after 6 months. And that was a revelation for me, going into the family sitting round, the family taking note of everything, and me being a sort of seen as somebody special, which I didn't regard myself as as somebody special. And offering their son opportunity which I suppose I did do, I did get him to read, I must say I did do that thing for him. Um. And er it was then, about January, this happened in October I think , the first course the January when I started to work with him again, that I decided that I'd helped other children get referred to child guidance and I thought **I'm in the wrong place to do this, I'm a teacher I'm not doing all these other things you got to do something, so revelation little revelation tiny revelation now, cor I could go into social work,** and I applied to the Home Office and I managed to get on a special degree course, though I didn't have a degree, at B University, Mrs T's course, to train under the Home Office, to become a childcare officer. Which I did. During that time, at the end of it, my 3rd son was born, crikey, and I stayed home during May when he was born, and afterwards, to care within the family, and my tutor was so cross cos cos I didn't go back to do my revision for exams. She was furious. But I got through. And then I started social work, by which time I was 32.

161 R: Social work was fascinating, truly, truly fascinating um and I rose up the ladder. There's one way to rise up the ladder in most jobs, that is except except health, doctors can become professors, but they can still undertake work with clients, can't do that in lots of other practices. In social work you become a manager. More managing you do the less activity you do with clients the higher up. So I became a senior social worker, then a area chief social worker, then a divisional director, and I was there while er in this particular county I was part of the spreading out, allowing us to be to be our own bosses, reporting to the council and so on, running our own budgets and I did, I thoroughly enjoyed it, but I was getting less and less from the clients, at the same time, point number 3 coming up , big thing this, my wife who had herself had been to university early went back again to train as a social worker up in Xxxx . And er when I was in my forties, well she certainly was, yeh we both were in our forties she having had 4 children, and became a very able person, to my surprise, and you might say annoyance as a man, as I didn't like her

eventually being better than me, at interviewing people, she was became a principle social worker and ran a divisional adoption and fostering group, not in my division. And then she died. And I suppose of all the times which you are going to ask me about that was , (pause) well,(pause) it was unbelievable and er for months and months I had people come in and look after the house and cos all my children were away, er the youngest child was at college and poophh, and she didn't want to go back, and 10 days after Gxxxx, my wife's death, I and my second son who was doing his PhD at the time, (sigh) took her back to college and all the way down to Pxxx, it was then, we settled her into her digs, on the way back S my son, said to me **Dad I don't know if you realise this, but you were doing 100miles an hour all the way, and I didn't, I hadn't a clue.** A hundred miles an hour. Um **(22.51)** .But I stuck to it, I kept on working until, this is another moment, ha ha, I've had several moments , my daughter finished her exams on Saturday, I er was working on the following Monday, I 'd been to some meeting and I was scribing some, come back to the office, and was scribing for myself some notes that I wanted to present, somewhere or the other, I don't know where, but I was doing some report, and **as I was writing the hand stopped and I looked at it, ha ha ha, and I thought that's it I'm going to cease this, I've seen my last child through college I can't take any more of this,** and I went to see my chief officer I said, whom I phoned a couple of nights ago actually, um it was a good conversation huh, and **I said to her sorry um this is, and she said there are only 2 ways you can go Fxxx , and one is via your health, and we'll set you on this (24:33) cos we have a special health person and one of them isa In the interest of the service because you can't do your job so I went to the health person, the health person said, oh well Mr J if you had come to me two years ago,** cos I had, because I'd had, before my wife died I should have said this, I was 54, 1982, 29th September I had a massive heart attack, nearly died, saved by the NHS who gave me, 3, a year or so later who gave me a triple bypass. Um that was another event. All leading up to it, er how did that creep in. Triple bypass **(25:30)**... Gxxxx (wife's name)

207 I: You said you were going to leave work

208 R: Oh Yes, yes that's right, I was going to leave work, um and the um, **the health person said that , this independent Dr, and he said well, I'm sorry, if you had come to me 2 years ago, or whenever it was I'd have instantly signed you off as not able, but he said you have made a remarkable recovery, can't do it, sorry,** so eventually it had to go through a special committee in the county council, where I received really excellent support from the chief officer, and the special committee **said yes, not only will you go, but we'll give you a year's extra, the most they could possibly had givin me,** I had worked for them for 25 yrs ha ha. So, I came out of that far better than I really deserved, and I have enjoyed a good pension since . So um 1989 7th Jan was when Gxxxx died, and I was totally lost, ooh I don't know (big sigh) 2 yrs, probably 2 years, yeh at least 2 years. I remember that the papers used to pile up in the house, er I remember going to an ... I used to do a day, when I was a C director just to keep in touch what I didn't know as, what I would call as management by walking about, so I would spend the whole day with different groups, social workers, home helps, OTs, residential day care, which ever I which ever, so I would arrange for , or have someone arrange for me to have a whole day, and it was very interesting. The home help one was one of the most cos I remember going into one woman's place, who was sat there with this great fat leg on a chair, and it was one room and you could hardly move into her house because the sides of the er going into it were lined with newspaper, you could just squeeze by. And that's what I was going to become, tuh.

231 R: So I had to do something about this, and um I, oh this damn eye's going again, it stings, I mustn't touch it, um (sniff),

233 I: Do you want a tissue or anything

234 R: No it's OK, don't worry. Ohh, hard. It's Ok, right, so, I had um actually set up a Cxxxxxx, or been part of setting up of Cxxxxxx in my official hat, ha ha extraordinary if you think about it, before Gxxxx died, we were a local branch, and I joined Cxxxxxx and tried

to get into a relationship with a very excellent counsellor, thank god she resisted, um and then while I was working out all this, **I suddenly realised (a) I didn't want to be by myself after 2 years, cough, I was useless, and (b) there was a person around whom I had known for 20 or odd years who had who might manage to get fully trained she'd then left, cos she was a worthy person, who had become a guardian to our children, she became a family friend, and there she was a single woman, by herself, and I plucked up courage, we started to live together after 2 and a half yrs in 3 yrs I bought this place, sold up, she said we could move anywhere, and I said you'd put such a lot into (30:31) your little house that she had rescued from it's derelict state, it was derelict**

249 I: This one?

250 R: Yes

251 I: Um

252 R: Then I added this , and we did lots of other things to it and made it habitable, comfortable for us both, I moved in here and I've been here since 12th Aug 1988. so 20yrs, I've been retired for 21 yrs, I said to H, 21 yrs a few weeks ago, absolutely extraordinary how I've lasted and it was in 1989 that I was taken up with some, uhh it was in the Observer, some matter of deeds of children again, er and dying and death, so I thought I had better do something about this, so I er applied to get on a course and was accepted and trained trained as a counsellor of Cxxxxxx, took my first client April 89, so just coming up to 20yrs, crikey. **(31:35)**. And I've done everything, I've been a counsellor, a supervisor, been on the committee, I've chaired a committee, sub-committee of a branch, I've been a representative in for Cxxxxx in um a area, a whole area, variously, but I never lost my counselling self, I've decided that was too important to go under, because I was good at it. I not only knew I liked doing it was good at it, **I realised slowly I was good at it as well,** and that I used to take 6 counsellors, 6 cases at a time, work 2 days flat out for years and years and years until I had my um colon thing, by the way I had some thromboses ha ha, um, but I eventually got um I had part of my colon and part of my rectum removed and they took away all the er er bits for the lymph glands as well, because they fine with the liver, in 99, and that slowed me down, I was going on for 70, but I recovered and er worked hard again until I was about 75 and then I got prostate cancer, and they didn't want to operate because as they decided I was my inside had been crashed around enough, I've got scars from here to here, and from here to here there's only a little place in the middle ha ha

276 I: Is there?

277 R: So I'm on a special powerful drug called Zolatex, which works prevents, testosterone, which encourages the enzyme to form the cancer growth um and er holds it steady, but it also does one other major thing, it diminishes one's sexual self, I have no testosterone I'm oestrogen ha ha exponent, at least, ha ha, but in fact there's been, it's interesting really there are bizarre benefits as there are to everything, the benefits I've found is I'm much less aggressive of course much less competitive, I was still playing badminton when I was in my 60s, beating the chap, as hard as I could, and he was 12 years younger than me ha ha.

286 I: Ha ha

287 R: And er I didn't really bother about that anymore, and it was almost *a release, into a* new world of gentler, is perhaps too um kinder more, no I know who it is, more tolerant, cos I could be a very intolerant person, much more tolerant of people, and er generally, so it has had, it has also allowed me to retain, in a different form my counselling believe it or not, er better, er improved, strange isn't it how these things happen.

288 I: Yes it is

289 R: I married Rxxxx in 1991, to my surprise, 7 years well nearly 7 years after Gxxxx died **I decided legalise this,** so we married, and it's been a very good companionship, teuch. Plenty that's enough.

292 I: Well that's enough is it thank you, well we'll stop there for a minute

293 R: I need to go to the loo.

294 I: Yeh, you do that

295 R: These tablets **(36.14)**

Sub-session 2 recording

296 I: I Now what I would like you to do is to recall a particular event and to tell me about it in detail, there's was one you were going to tell me about, was it the revelation,

299 R: yes

300 I: when you said you didn't want to do the accountancy

301 R: That was very shaking to me, er um how old was I at the time, I must have been 20 by this time, um for the I I think, what what it emerged what it emerged from, well I don't know what it emerged from I had taken an examination that I 6 papers and I had failed 2 of them I had never failed anything in my life before or since, but I was so shaken by this, that **I thought, I was shaken by this (1.16) what's all this about, why have you done this, I mean I this must have been going on, why had this happened, I mean how could I have been so remiss to have let this er and it was from that, after that ,** that I er had this revelation and a week or two later I was going with a colleague whom I had , died a few years ago now, er who had been in the army, come out of the army, er come a tank commander, and he was also like me an article clerk, he went on to become a chartered accountant, and I went down with him to the Earl of Z's estate, it is, ha ha in XXXXX with all the xxx works and all his farms and the other stuff that he had down there and we er J and I would go down there together, we would go into these rap little offices, which were which were Dickensian, they still had these high desks up here that people would still be writing on, down in xxxx, and I had to tell Lx and I thought I can't keep this to myself any longer and I **I remember going out, walking out of the guest house we were staying in and braving myself, saying to Lx, Lx,** we were both articled clerks, right we were both on that path to a comfortable look, he older than me, by 6 or 7 years, and er **I remember him saying, right if that's so Fxxx you need to tell your parents and I wrote them a letter while we were down there er and I can remember going out of the place ,** if I could go down there and find the place I could show you the the exact path that we took while I was telling him, so it was a very real a difficult occasion for me I was having to confess something that I wasn't didn't want to do didn't want to break his friendship, because by this time we were friends, um but I did and I felt better for doing it of course, as I now know, the more you can talk talk, sometimes the better it can be for you not always, but sometimes, and ...(4.04) my parents, God bless them, never, er huh they were so disappointed, but they didn't actually they didn't castigate me, they didn't say you're throwing your life away, they didn't do anything like that, they allowed me, to be who I was becoming which was a grown up person, and by the time I got out of the house, cos I was still living at home, and er proved myself somehow or other, so that, that was quite a that that those two events the event in Ch Lane, going to Jo Lyons, and then the few weeks later, ha ha there **am I going into that house again, erm going with Lx and um trying to work with Lx and why, why this happening, and he didn't question me, he just listened and said yes I I understand if that's how you feel and what has happened you've got to go with what has happened to you,** so that was a big occasion for me I was beginning to find myself, break free from parents...(5.21)

343 I: And then you mentioned um about being in N and doing the newspaper

344 R: Yes, yes

345 I: And

346 R: Yes that was something else that happened to me going out there, which was significant at the time two things happened, both of which were, in their tiny way, these are these are small matters, but they are important to me one on the boat going out I was in the sergeants mess and eating there there was a chap with a, who was a um, I've, I've forgotten what he was, he wasn't he wasn't a company sergeant major, he was a staff sergeant anyhow, he had, he had one more bit on his shoulder than did I, and the army is very hierarchical, **and I remember saying to him, you know your eating habits are so poor I don't really want you to sit there,** I mean, I mean he was he was terrible, and he then, I mean I didn't say it, but that was the sum of it and he threatened me and he was going to get me and he was going to fix me he was going to do all sorts of things to me. When we got to N we were with the Common wealth division out there, and er in the sergeants mess, it was a very comfortable mess, a marquee and so on, where we used to go and have meals from time to time and er I saw him, this was months later, and I realised OK he was a bully, but then bullies are weak people, and I watched him pitifully drink it was really quite shameful to see a broken person try and hide, then I realised that there were things and er **I realised there were things that I now had that I could use if I wished to if wished to, which was to have greater strength than somebody like that.** So that was a a minor revelation. But the other one was sheer unadulterated pleasure, the best in the army er non-commissioned officers are the regimental sergeant majors that is the highest position for a warrant officer, and there were 3 of them who were in the REME, all electrical or mechanical engineers and they would throw bridges across the Ux, cos it was right by the Ux, they would do allsorts of things to try and maintain our communications between the front line and us in the rear and they played bridge , well I'd, well I was also a bridge player, I played all might when I was young, in my mid teens, and they invited me to play with them, on the hillside in the sun outside the mess and they would have, this was on a Sunday, regular, they would have they half crate of Sautern delivered, so we would have this Sautern of course as **(8.45)** but I was so tickled, he was I a young man of whatever I was 22, and there was these grizzled relatively mid-30s, late 30s, early 40s, perhaps well probably late 30s early 40s for their rank um experienced able men, having a little whippersnapper like me playing bridge and I thoroughly enjoyed it and I did not feel in anyway out of , out of my rank as it were, I didn't, it didn't worry me at all, I just enjoyed the pleasure but that also made me realise that class rank position role doesn't have any differences who you are and what you are that counts more than anything else so that was another very good learning positive learning experience.

385 I: Yes. And then um when you were invited into the family you know, that you taught the boy of

387 R: Oh yes

388 I: Can you recall any particular things that made you realise that this was what you wanted to do

390 R: Ohhoh huh I think the great thing is for my my working class family working class father who had aspirations for his son, who owned a car in the 30s, so it was pretty early on, he was also a struggling to find himself, and bought his own house and so on, so was moving up the grade and I was comfortably off in suburbia, I was a suburban boy. Um But here was a family that was of a different background, had different problems lived in a pretty rough council house but who had a great deal of warmth and had a great deal of warmth and affection for this one of their sons who I was seeing and it it was the clustering round I think of their family, sometimes dad would come in erm because it was

a mining family sometimes the mum would be there there would be other children around and it was a a sort of, ha I'm doing it (putting arms in a circle)

402 I: Yes

403 R: A gathering, a warmth experience of a total family that I realised I felt at home with this was good it was something beyond what I had experienced as a family but it was well worth having, and I think it was that, the beginnings of that that made me realise that school teaching is er um a worthy occupation, don't get me wrong and if I went back to teaching now of I had gone back to teaching years later I would have become I would have been a better teacher no doubt about it I I thing you can only do these things when you have got life behind you as well as in front of you really and truly to know what it is all about and I think that was a learning experience for me and by this time I was er pruhpruhprouh 31

413 I: Right

414 R: So it was, it wasn't like the erm students from Oxbridge going into the er Eastend, to try and rescue these communities it was too personal for that, it was me just going there, on a regular basis, twice a week, kept it to the whole school term to try and be part of what they were offering and they had a warmth a simplicity, and eagerness for learning for their boy, just the same as my father for me really, no different, erm but as a a different phase of what we could do, or what they could do, but that didn't matter either,

421 I: no

422 R: Just that he could become better so that that was something that changed me, changed me in a way that meant that I could go into families, work with families and enable families in crisis to survive, well of course when it came to it they didn't all survive

426 I: No

427 R: Erm I can remember dragging screaming children, out puh out from under the bed one of them, the mother was quite psychotic, gosh she was ill it took 2 or 3 was it National Health people to restrain her and police who get all these horrible things and for kids it was terrifying, terrifying, so that's the worst thing I did, but I did lots of placement of children as well er outside their family but I also worked with families to replace the children who were in care. I did have one such a family who ere evicted I remember the day of eviction, erm the social worker who should have been doing it wasn't able to, god I remember, so I was sent, she just couldn't couldn't stand this family being evicted, and I gathered the children, 5 of them there was, and took them to our er reception **(14.56)** God, they were pretty filthy but then worked with trying to find a place for them then gradually, gradually when there parents moved to the north I moved to get those children placed in the north in a National Childrens Home so that they could keep in touch er eventually some of them went from their home and some of them grew up and left, and they did come and see me, many years later

443 I: Um yes

444 R: So I mean there were good bits and I became, amongst other things, a guardian ad litum, a guardian ad litum is a person who acts on behalf of the court, either a magistrates court, or a county court, whoever be the judge, for adoption purpose so the guardian ad litum means your concern is the welfare, prime concern is the welfare of the child that has been placed and er I got so adept at doing these things, ha, but I also saw so many different families, hundreds probably during the time I acted. In those days this was in the 60's when adoption was very a very popular way of separating children from quotes bad parents and certainly before the pill took effect of the young teenagers I mean I had many young teenage mothers giving up their child. Not one not one when you when you went below the surface did it willingly never did I find one some of them who was only

too delighted, they were saddened and upset erm horrified by what had happened but again it was me learning about nature what happens all this as you might say has been grist to my particular mill ha ha all these experiences ha ha

459 I: Yes and what would you say was your particular mill then

460 R: My particular mill uhuh er hummm
Acceptance of other people which has been a long hard haul, But I think that this is the one that has emerged most strongly from all of that into bereavement work and that is is one word, and that is hope, hope that from worst the disaster can one phoenix like emerge and regain change and adapt oneself to new life and I believe that's that is my vision to what I try to do

466 I: Can you think of anything, without obviously betraying any confidences that one event maybe clarified that for you

468 R; Crumbs

469 I: Well there'd be hundreds you see of moments, coor poof poof fer,

470 R: Is there one that stands out

471 I: Well one that , I suppose that there are so many that stand out, they they are all different um but I can I can remember I'll just I'll give an example of one family because I did have a lot of work to do with the children, I can remember their names, but I won't disclose that this was when I was an area children's officer and I was called out by the police one night um to as a consultant as much as anything cos they didn't know what to do, erm a mother had died of a heart attack and the children were all at home and in bed and the father such as he was was a local drunk and had wandered off, he didn't know about, and there were these four children left in the house and they wanted them removed on the instant cos it was dangerous, they were asleep, so I went in there and I looked at the children and **I said no we're not going to remove these children I want a police woman in here, now. There was a police woman and i want her to stay overnight and I want her to stay overnight and I will arrange for one of my one of my staff to come (20:11) things in the morning and we will arrange things in the morning when the children come round, they are going to need lot of help,** and I remember those four children, young some of them, er preschool age they weren't all, one was about 9 or 10 I remember and having to decided best how we could help them cos the father, when we did find him, just wandered off again er and I placed those children together in a home in the north where we were, called D , coo crikey that's a memory for you, and we eventually moved those children, kept them together, all the time, er and helped them grow within a residential setting, cos I know, I could not I certainly couldn't find a foster home to take 4 kids and I didn't want to separate them, and I remember working with them for some years, well not me personally, well child care officers or seniors er to re-establish them, and I can remember at one stage one of them came to see me I forgotten his name, R, or was it GH, that was another one, no it wasn't it it was R, RH walked 16 miles to see me, erm, he came to see me to say how much they had, I don't know, whatever they have enjoyed, and I felt they've grown up now they're going to survive, their hope inside them selves hasn't been crumbled

502 I: Yes

503 R: Hasn't been reduced to nothing, and that is a just a simple example there are many of them and that is an example of the sorts of events one could could be working in within social work practice hundreds, hundreds and hundreds, and I have caused the removal of a child from a mother who certainly uh sexually abused a 3yr old boy by using him as her masturbator, er huh I mean even now I cringe when I ... **(22.41)** what she did to her child and broke his arm so doing. Er er And how I, that's one that made me most

most most angry about that and he was never ever allowed to go near her again, rather like Baby P could have been. Worse, much worse it was, her was deliberate.

513 I: Awful

514 R: Huh

515 I: And can you think of another life event that you might have mentioned that I haven't

517 R: Well I suppose um er um the FH was a big influence on me, when I was in training, this was my second bout of training, I had originally gone in and er I suppose ahh I'll give you another little learning experience actually, if you can take this

521 I: Yeh

523 R: The other learning experience is this this is also to my very very real surprise, in the Army I was first training in the Royal Artillary erm with a view to getting through to the RAEC, but I had to do 3 months training and I wasn't interested in guns, 25 pounders and the like erm and I was there with all these young youngsters, so I thought how can I get out of this, well the one way you could do anything in the army was to box I never boxed in my life, well, ooh yes I had, at school, at school I had, um **so I thought one way of this is to take up all this extra training they do you then don't have to go out and fight these silly guns all over the place.** So i did that and I became extremely fit and cooh they do train you hard running up and down these things and ...all the other stuff. And I then had to box, and I remember thinking crikey what do I do if this other chap, you see boxing is like a gladiatorial experience in the army, they're not allowed to shout except during the intervening period they have to be quiet during boxing, but between the rounds they can go hoarse, and they do. Really tough stuff, exciting, ha ha it's like a football mob and the officers are all at the front with all their braid and it's like that, so when your'e fighting, as I fought in a company to begin with then a battalion, I think it was something like that, it's just the same. And erm when I had this first bout **I can remember it must have been after about 2 months from when I was there, this chap, you know you sit waiting for your turn to come, you fight at different weights, like you do normally, and I was 11 stone, so I was light middle I suppose and I remember this chap coming up to me saying are you XX, are you yeh? We're fighting, I said yes we re having a bout we're not going to hurt each other are we, no I said I've no idea of hurting anybody I said, don't want to do that at all,** so he went away, anyhow came our turn and we were boxing the 1st round I can remember and um I don't know how ,when it occurred, but I I am left handed but I don't fight as a Southman, I lead with the left, so the left is always the strong powerful one that catches people unexpectedly I caught poor X very hard, and I hit him just under the nose now not only is that extremely painful it is also bloody, (27.27) and when I saw blood I went berserk, I hit him he fell over , poor chap they got up again, and I hit him again and he fell over and he didn't want to get up again by now, and I realised that at that moment there is something called blood lust and it is horrifying but it is in each of us and if we don't know about it its time we jolly well time we did, and although I did fight um again , did 1 or 2 more bouts, in fact it was probably what got me, one of those things that got me the old FG to give me something cos I fought a bully and again bullies are dead easy once you know them they are all bluster and fear is what drives them on, they don't know this er and I er fought a bully and I just had to weather him and then I destroyed him, so I know that there was a I knew then there was a pretty fierce not very nice streak inside me which could be called forth and I didn't like it but I had to recognise it was there and that was a very real learning experience. And when I got on a boat to go, there were a few of us who, I don't know, some there must have been going enroute oh yes, cos we dropped people off at M and J, so there were one or 2 other sergeants by this time who were coming with me, and they said you know F **you coo going to do some more boxing, and I said not on your nelly and I said I'd done my bit,** never did box again, I had 3 fights never did box again,

571 I: No um

572 R: Ha . 3 fights that was enough,

573 I: Yes

574 R: Is this being recorded? Ha ha

575 I: It is, is that allright?

576 R: Well your learning a bit more about me than many other people! Ha ha

577 I: Well I'm very grateful, well I think that's all I need to ask you though.

578 R: Good

579 I: Thank you

580 R: OK

581 I: I'll turn this off now.

582 R: The most painful was the death of my wife

583 I: Yes

DARNE (p244)	
Description	Certain entities have certain properties, in a timeless and historical way. No attempt is made at story-telling/narration, a sort of timeless anthropological present about the person or situation, eg 'it was always was like' 'never a dull moment'
Argumentation	Development of argument and theorising, from present or past time perspective. Usually in a stand alone form, occ explicit disagreement with an alternative position, usually implicit
Report	A form in which a sequence of events, experiences and actions is recounted, from some distance, in a 'thin' fashion. Provides an overview of a range of events, some which are detailed, often covers a relatively long period of time (bare chronology)
Narrative	Telling of a story by which X followed Y, in rich detail, occ in present tense, virtually reliving from close up. Direct speech, quotes.
Evaluation	Moral of the story, before or after the story-telling

Macro - Topic (for skimming TSS only) (fill in only at end of whole analysis, and only if obvious) **page/line numbers + approx no. of pages**		
page/line no start/finish (no of lines)	**(Speaker) textsort**	**topics-gist (for later TFA) mostly minimalist paraphrase, but their keywords in single quotes**
p.1	R: DESCRIPTION/report	Current state of hours, getting tired, only one now as others tail off. Have to watch breathing. Reduced activites.Voice changed.
p.1	I: SQUIN	
p.2	R: REPORT/narr	From grammar school boy to articled clerk (+ narr/pin Told off by prefect/broken up library / headmasters conference) love affairs, hitch-hiking
page/line no start/finish (no of lines)	(Speaker) textsort	topics-gist
p.2	R: NARRATIVE/PIN	Doing Captain's accounts, revulsion, wanted to be released from articles, firm upset (REP: went into army) Leicester Square decision "to eat anything"
p.2	REP/+ bits of PINs Narrative, bits of EVAL	Army career: trained, refused officership, volunteered for Malaysia; Major suggested N; small unit ran newspaper for forces, all sorts of things in the division
p.2	Interactive inquiry / response	How much detail do you want? Not too much, but we could go back to it later
p.2-3	REP (+ bits of narrPIN, bits of EVAL	Army "quite an influence" Back from army at 23; uncle suggests teaching. Got trained. Taught. 1954 proposed to wife in park and got married. I was made 'stick officer during training'. "Wanted to get Major's references...didn't

		push... never knew what he thought of me"
p.3	REP:	Teaching. Sent before college to ESN teenagers "no problems with discipline"
	NARR	"All hell to pay" in classroom, beat two boys. Should have been drummed out. Hammered them on their bottoms.
4	REP	Teaching after training – no problem. Top primary during 11+, raised recorded IQ, didn't get into do an MA, teaching top primary
4	NARR (bits of rep and eval)	Boy fell off wall, went to home to teach him, taught him at home for 6 months and paid specially.
4	NARR(bits of REP)	Decided to become a childcare officer: climbed the social work ladder Decided to train to be a childcare officer at B university. Time-off course for birth of 3rd son. Rose up but did less work with clients. Wife became competent social worker..
5	Narr (Pin)	Then she (wife) died. Had people come in and look after him and house, children away from home
5	Narr (pin)	Hand stopped working whilst writing report – decided to give up work "I can't take any more of this". Eventually got early retirement.
5	Rep and eval	Not coping after wife died, could see would end up like he had seen clients
6	Interactive	Eye weeping (had just had surgery)
6	Rep/narr/pin/ eval	Unsuccessfully tried to start r'ship with counsellor. Suddelnly realised he needed partner, someone around who would be suitable, moved into her house, sorted house out together
6-7	Rep, bits of eval	Trained as counsellor, many roles within organisation, realised he was good at it, health probs reduced activity
7	eval	Release from aggressive intolerant self
7	rep	Decided to marry partner to legalise it
End of first session		
7	SQUIN	
7-8	Narr/rep/bit of eval	Revelation about not doing articles, discussed with clerk friend, felt better for talking, as is usual, disappointed but permissive parental response, allowing him to find himself
8	SQUIN	
8-9	Rep/Eval and bits of N	On way to Asia, in mess confronted bully

		about eating habits, saw him again in Asia, realised he was a bully, pitied him, and that he had greater strength than the bully. Minor revelation
9	Rep, bits of Eval	Invited to play bridge with officers 'sheer unadulterated pleasure' made him realise that rank/class doesn't count, what you are counts. V good learning eperience
9	SQUIN	
9-10	Eval and rep	Disc re experience of teachg boy with broken leg, and comparison of boys and his backgrounds, and warmth of boys family. Disc re teaching and social work, learning exp, changed him. Experiences in SW of being guardian, caring for parentally abandoned children and doing best for them. Adoption situations, all 'grist to my particular mill'
11	Q What is partic mill?	
11	Eval	Acceptance of people – long hard haul, hope can emerge from worst disaster
11	Q one event that clarified this/	
11	REP/NARR/PINS/eval	Abandoned children, one child came to see him later, felt they had survived, hope hasn't crumbled
12	SQUIN	
12-13	Rep/narr/eval	Learning experience about gladiatorial boxing and 'blood lust', and how he got rewarded by Major for taking on the bullies. Never boxed again despite being asked
13	Interaction	Is this being recorded? Haha –learning more about me than other people! Ha ha
13	Thanks from Interviewer, 'we'll turn this off now'	
13	Closing sentence	'The most painful was the death of my wife'

Mr HF: Thematic field analysis from email panel members

BDC

Born in a middle class family in the suburbs of London. After leaving school, a decision was taken by his parents and the Headmasters Conference who decided that he should be an accountant.

Had place in prestigious firm in London, part way through he had a revelation and gave up his articles, much to the annoyance of his employers. His parents supported him. Next did National Service, refused an officer's place, and went abroad, he was influenced by a particular Major, who honoured him with becoming the 'Stick Officer'. Did some 'gladiatorial' boxing there – discovered he had a blood lust, common to all.

Came back from the army, went into teaching, after a short time gaining experience in an ESN school. Trained as a teacher, taught in primary schools, successfully. Surprised himself by proposing to his girlfriend. Got married.

Had another experience, where he taught a boy at home, opened his eyes to other social circumstances, and the closeness a family could generate. Decided to train as a social worker, had had 3 of 4 children by this time. Climbed social work management ladder. Children grown up and leaving home by now. Wife also became very good social worker, which he was not too sure about.

Very suddenly his wife died, and he became unable to cope with life, friends would come in and look after him, was very depressed, for about 2 yrs. Suddenly realized he would end up like a client he had see, surrounded by newspapers and living in a mess.

He realized he needed a partner, tried to make advances towards his counselor, who refused, and then realized he knew someone who was suitable. They lived together for a 2/3 years, then married. They have been very happily married for over 20yrs now, and he does voluntary work within the organization that helped him initially, as he realized he was good at it. Spends a lot of time visiting family and having good holidays.

Brief background of Mr HF

This man is in his 70's, and is white and of middle class background, retired from a professional job, and does voluntary work in spare time.

Chunk 1
Grammar school boy, left after 'breaking up' library with others. What do you think happened next?

H1: Went to university

H2: I think he rejected this advice and did something more adventurous like going into the City.

H3: Although a great shock - following period of grieving - returned to work and continued to do well

H4: Felt guilty went to see headmaster.

Chunk 2
Taken, by parents, to Headmasters Conference for careers advice, advised to go into accountancy. What do you think happened next?

H1: Refused advice and went into another career

H2: I think he rejected this advice and did something more adventurous like going into the City.

H3: Took parents advice but got bored very quickly with accountancy.

Chunk 3
Mr HF became Articled Clerk in London firm of accountants, travelled to clients all over country with a friend and colleague. Had revelation that he didn't want to do this for rest of life and asked to be released from articles. What do you think happened next?

H1:Left accountants and went to university to study history

H2: I think he was made to complete the articles and then he left.

H3: Decided to go travelling with a friend

Chunk 4
Next did national service in army, offered officers job. What do you think happened next?

H1: Left the army and got married

H2: I think that, when he left the army, he took a management position in the public sector, for example, the civil service

H3: Accepted officers job and was respected by those under him.

H4: Enjoyed army but decided to leave to broaden horizons

Chunk 5
Refused officers job. Volunteered instead to go to Asia, ran small newspaper for forces, and did all sorts of things in division. Army quite an influence. What do you think happened next?

H1: Went into politics 4

H2: I think that when he came out of the army, he trained to be a doctor.

H3: Accepted officers job and was respected by those under him.

H4: Got married and got job working with children

Chunk 6
Back from army aged 23, decided he wanted to work with children. Proposed to girlfriend. What do you think happened next?

H1: got married, went into social services

H2: I think he married his girlfriend and they both trained as teachers and went out to work in Africa, India or Asia for the equivalent of VSO.

H3: Built up a reputation in the army, showing entrepreneurial skills and positively influencing others

H4: Got married and got job working with children

Chunk 7
Married girlfriend. Did some teaching, first in ESN school prior to training, got methods of discipline sorted out there, never had problem since. Trained and became teacher in primary school. What do you think happened next?

H1: became headmaster of the school

H2: He went into the Church, trained as a missionary and went to Africa/India/Asia teaching deprived children and doing good works (with his wife).

H3: His career as a primary school teacher flourished.

H4: Enjoyed army but decided to leave to broaden horizons

Chunk 8
One of pupils fell off a wall and fractured his femur, so Mr HF took it upon himself to teach him at home, in his spare time. Became very aware of boy's working class background, the boy's parents' aspirations for him, and the 'warmth' of a close family, different to his own experiences as a single child. Decided teaching, though 'worthy' profession was not enough. What do you think happened next?

H1: Became a social worker

H2: He trained as a doctor.

H3: He went into voluntary work sector helping those from less privileged backgrounds.

H4: Left teaching and got into "caring profession" - social work?

Chunk 9
Trained as Childcare Officer, finished as 3rd child was born. What do you think happened next?

H1: Became involved in a childcare project of some sort

H2: He and his wife went abroad to set up Social Work training in Asia/Africa/India.

H3: Took a career break to be a home parent.

H4: Took up post working with disadvantaged children

Chunk 10
Climbed social work ladder into management, wife also became very competent social worker. 4 children by now, all growing up, leaving home and studying. What do you think happened next?

H1: He and his wife left UK and undertook voluntary work in a developing country

H2: He was devastated and turned to drink, developing a major alcohol problem.

H3: He started to think he wanted more from his life/work.

H4: Broke up with wife

Chunk 11
Wife died suddenly, no warning or previous illness. What do you think happened next?

H1: He left UK and worked for voluntary org. in developing country

H2: He started doing voluntary work through his local social services department and met a widow and go married again.

H3: Although a great shock - following period of grieving - returned to work and continued to do well

H4: Was devastated and developed depressive illness

Chunk 12
Mr HF not coping, needed people to come in and look after him for about 2 yrs, as by this point all children had left home. Realized he would end up like clients he had seen, with papers all piled up around house. What do you think happened next?

H1: He became involved in a support group for people unable to cope

H2: He proposed to P who turned him down (no one likes to be regarded as 'suitable'). On the rebound he married someone else (who was not 'suitable') and was very happy.

H3: He decided to turn things around and get his life back together and started some part time voluntary work

H4: Attempted suicide

Chunk 13
Mr HF realised he needed a partner and that he knew someone who would be suitable (P). Also realized he was good at counseling aspects of his job as social worker. What do you think happened next?

H1: Became involved in a bereavement counselling service, began relationship with P

H2: He set up a counselling service for older widows who were looking for 'suitable' women to marry.

H3: Took a counseling qualification and lived with his new partner

H4: Trained as a counselor

Chunk 14
Moved in with P for 2/3 years, helped do her old cottage up. Took early retirement from social work. Trained as counselor with voluntary organization. What do you think happened next?

H1: He was diagnosed with cancer. Didn't stay in relationship with P

H2: He became chief executive of the voluntary organisation but his relationship with suitable P broke up.

H3: The relationship ended - but he kept up his voluntary work as a counsellor.

H4: Married P

Chunk 15 (conclusion)
Married P, since been very happily married for nearly 20yrs. Has had many counselling cases (has reduced caseload now), and has done may roles within this voluntary organization. Spends lot of time having good holidays.

Mrs HN BNIM interview

1 I: **Now what I'd like you to do is to tell me story of your life and all the events and experiences that come to mind that are important to you, and you can begin wherever you like, doesn't have to be in any order, and I'll just take some notes, but I won't interrupt you.** *(SQUIN)*

5 R: I was a spoilt brat when I was small, I had a mother I never saw my father but I suppose he was somewhere but he'd gone away, but I never knew him, if I 'd have fallen over him in the street I wouldn't have known who he was so as I grew older I thought well that was a strange way of things happening, but people in those days didn't tell you things

10 I: Um

11 R: You were there and things were happening but they didn't tell you other things do you know what I mean

13 I: Yes

14 R: And it was very disconcerting, cos I used to imagine all sorts of things and I used to if people came to the house and there was a man I used to think I wonder if that was my father but I never knew, and I lived with my grandmother and my mother was there because there was no father so I got all suspicious as I grew older but noone spoke about it so I never really knew,

19 I: Gosh

20 R: I was told a name and that he came from W

21 I: right

22 R: but I never, I looked it up and I got someone to look the name in the what's it called, you know the book,

23 I: the electoral register was it

24 R: yeh but yeh but, they couldn't find it so I don't know to this day, who my father was

25 I: gosh

26 R: and its very disconcerting

27 I: yes

28 R: but I suppose I must have got around so otherwise I'd have maybe only had one leg ha ha

30 I: haha

31 R: but no it was very upsetting and I, and that upset me for a long time then I got over it and I think what's happened has happened and what's that's what your not given or not given and you've got to get on with it and make the best of it, and what else can you do and so I'm afraid there's not much else to tell you. Except I'm lovely ha ha

36 I: I know that ha ha

37 R: Where's my handkerchief, no but I'm always joking take no notice. Well that's it , for a while I got very upset but er well that just had to go er everybody was exceedingly kind to me there was not a soul that wasn't kind to me except one person and she was a bit catty but I think she well she said I'd got everything and she'd got nothing but that's nothing, that's just by the way. My grandmother was my hero

(End of Sub-session 1, beginning of Sub-session 2)

43 I: Was she

44 R: She was absolute the best

45 I: Yes

46 R: Old granny S

47 I: That's a nice name isn't it,

48 R: It is

49 R: Her name was B and the surname S, now how do you spell that

50 R: Is it XXX

51 I: No

52 R: XXXXXX

53 I: Aah

54 R: Bxxx Sxxx

55 I: And you were named after her

56 R: No

57 I: No no her name wasn't B , my mum

58 R: Oh you were HX before you got married

59 I: Yep yep

60 R: But my grandmother, she was wonderful to me I always she, I always this is true, I always think in my life she saved me

62 I: Did she how was that

63 R: Because my mum, I never knew my father so I think something fishy was about there, we don't go , they, nobody nobody told me so I don't know, but my mother got married to this person who was a very nice man but em I never saw them really then because I lived with my grandmother, she was well, well she was one of the best, Granny X she was.

68 I: You were talking *about her* saving you

69 R: Yes

70 I: How do you think

71 R: Well I think if I 'd have lived with my mother and and er stepfather now

72 I: Oh yes.

73 R: The stepfather, he was never nasty to me but he was, I think would have fallen out with him because I thought that he used to boss my mother about, and I believed in my mind that it was him who'd taken her away from me, and that's how I looked at it but we never quarrelled never ever ever and um no we never quarrelled and he was never nasty, he slapped my face like that once, and my mum, I was a cheeky little monkey, and I deserved it, so he only once did that struck me there and my mum I can hear her saying it now, **I'll never forgive you for doing that,** and that's all she said, and he didn't do it he never did touch me again, but he was never nasty to me, but that was all so it to me he didn't exist, he was just a person who'd taken her away from me

83 I: Yes

84R: And that was, we never quarrelled he was just a person who'd taken her away from me, but I was sad about it really

86 I: Yes

87 R: I used to go to school and that and when I was older and and other children had parents come in you know to things and she would come but there was no dad, hu hu, but you can't have anything can you but all the family I had 2 uncles who were brothers of my mother and an aunt, 2 aunts, 2 uncles and 2 aunts, and um they were all nice to me and I got spoilt I bet I was a horrid little beast I expect, cos I was spoilt
Well I was cos they were all sort of taking care of me in their way and I suppose I expect everything had come off the trees

94 I: Can you tell me what makes you think that you were spoilt, what kind of things happened

96 R: Well they just, if I said I liked something it seemed to appear you know it was as good as that, cos if Uncle X didn't buy it, uncle Y would, or Aunty K or Aunty M, and you know that's how it went, and I think it spoiled, well made me a little worse than I was **(8.31)** a little bit of a beast, yeh that's true, that's true em but everybody was very good to me I can't remember except as I say when that em L slapped my face, he only did that once, he never touched me again,

102 I: Can you remember what you said to him to make him so cross

101 R: No summink cheeky I expect cos you see I was well I was spoiled and I used to say everything, you know well I expect I was, well I don't blame him for slapping me but nobody ever did slap me other than he was the only one who ever did that I expect I needed a good smack pants, but he just needed it ha ha but he just went clonk like that and I really saw stars it wasn't a, it wasn't a pat it was a right wallop but that was all, that one and only time um I expect you can still see the marks ha ha

107 I: Ha ha

108 R: No that was true that was I am not exaggerating it wasn't a it sort of rocked my head you know it was really wallop

110 I: Unpleasant yes

111 R: Well I suppose I wasn't expecting such a thing to happen, my uncle was going to attack him, my uncle X because I can remember my grandmother saying **no you don't do that, no, no, you leave things be** and I think she was, it must have been very trying for

her cos she was more a mother to me than my mother cos my mother you see being as so she was sort of on her own she went to work

116 I: Yes of course

117 R: So my grandmother was more a mother to me, oh she was lovely and when my mother then met some other person, some man, he was all right and then they got married and she wanted me to go with them and I prayed to my grandmother please could I stay with you please and she said of course you can well it was my home I think I would have run away rather than to go away from her so and I was all well there I am you see what an odd bod I am ha ha

123 I: Ha ha

124 R: Yeh but throughout my life I can only say that there was more people that were ever so good to me than that weren't

125 I: That is nice, isn't it

126 R: Yeh, and that is true, really true, I think I was more lucky than i realised well I do realise it now, and then look at my lovely son

128 I: He's lovely

129 R: Oh he's beautiful he is, I call him XXXX ha ha

130 I: Do you

131 R: XXXX *(son's nickname)* **(11.43)**

132 R: But he is lovely isn't here

133 I: He is

134 R: I wanted a little girl as well but it never happened. My husband, he was smashing, there he is on there, Fxx. Scottish, from xxx down here, oh he was lovely Fxx was

137 I: Yes

138 R: Oh he was smashing, he was here, he was in the airforce and he was down here at um XXX it was a

140 I: Was it a base somewhere

141 R: Pardon

142 I: Was it an airbase

143 R: Yes, yes that's right, and he was staying here and well it was just him and nobody else you can see how nice he was, look at the little photo there looking at us that's in the garden, Xxx Xxx

146 I: That is a lovely photo, ever so nice

147 R: He's ever so nice

148 I: Yes

149 R: Xxx Xxx Just that's all his name was he didn't have a second name, just Xxx Xxx

151 I: Did you go through various important things in your life with him

152 R: Yes yes, all the usual things we had um Xxx 10 months after we were married because um well we were sort of donkey mad over one another you see and um I would have like to have a child so we had Xxx , and then I wanted to have a little girl but he said er he said **well, now look here**, cos he could be serious and I knew I had to sort of go by what he said, but he wasn't bossy,

157 I: no

158 R: And he said **we're not having a another child, I'm not saying we're not having another child at all but we're not having another child until we've got a house**

161 I: Right

162 R: Which was very sensible

163 I: Was

164 R: What happened we didn't have another child, and we had a house quite a while on but no child came, and we tried and tried and tried and it just didn't happen, but not cos, well I don't know why, but it just didn't occur, and I said **well there we are if that's how it is that is and Xxx is so nice he's made up for it**

168 I: He is

169 R: Good old Xxx. And I'm here and look at my nice room and all oh it's lovely and I got, have you seen my bedroom and all that

171 I: No

172 R: Come and have a look, ooh sorry have I done something

173 I: No that's OK, that's my little recorder

174 R: Ooh that's with what I said

175 I: Yes do you mind if I take it with us

176 R: No I don't care, I'm not saying anything wicked

177 I: No Ha ha

178 R: This is the worsest, getting up

179 I: Do you want a hand

180 R: No I'm allright as long as I've got this

181 I: All Xmas things

182 R: You can see how tidy I am ha ha can't you ha ha. This is my abode

183 I: Yes what a lovely kitchen and a nice round window,

184 R: Yep, nice to look out there

185 R: It is yeh, there's Xxx, the back of his house (coughs) excuse me

186 I: Do you want a drink

187 R: No eaty went down dinky hole. Now this is um where you can go to the um bathroom

189 I: Gosh that's very nice and spacious

190 R: Yep

191 I: Isn't it

192 R: Yep and there's a shower in there

193 I: Yeh

194 R: then this is my bedroom

195 I: oh this is nice too yes

196 R: it's all very tidy as you'll see

197 I: this is nice too

198 R: this is a big cupboard, look how tidy it is!

199 I: Enormous

200 R: Yes well it's difficult to be tidy when you haven't got much room

201 R: Yes. So that's the cupboard

202 I: Is this you and Xxx here

203 R: Oh that's Xxx look, oh he's lovely look at him **(16.23)**

204 I: Yes, that's a lovely photo, so who does Xxx look like you or him, or is he a bit of a mixture

206 R: I think he's a bit of a mixture, oh Xxx was ever so kind, Scotsman, from Xxx, full of fun

208 I: He looks like a happy soul there

209 R: Look

210 I: Aah

211 R: Ookey pookey!

212 I: Ha ha

213 R: What else can I show you, well this is just a cupboard as you can see there's nothing else really

215 I: You've got a lovely view out your bedroom haven't you

216 R: Here's teddy, he's in charge in the bedroom aren't you ted XXX used to wear that jumper

218 I: Did he gosh, that stripey one,

219 R: And the little trousers

220 I: And you kept it

221 R: Is this a picture of Xxx and Xx

222 I: Here's Xx

223 R: I can see the ginger hair now

224 I: So did you have ginger hair

225 R: A bit yes, just a little bit, and he was a little bit, not ever so much. That's Xx and Xx though with um

227 I: Xx and XX is it, that 's a lovely photo. There's another nice picture of you both isn't there

229 R: Ooh That's Xx

230 I: Yeh

231 R: Dear Xx

232 I: You were married for a long time

233 R: 60yrs, married , met Xx when I was 19 cos the war was on, and we got engaged when I was 20 and married when I was 21

235 I: Um

236 R: And we were married in Scotland, because all Xx's people were in Scotland, and Xx's sister had just had a er little baby and she couldn't come down

238 I: No

239 R: So my grandma and my people and my aunt and uncles could go up to Scotland, well the uncles was in the services um could go up to Scot, so we all went up to Scot and made it like that way

242 I: Oh lovely, shall I put it back for you

243 R: Yeh, that's Xx, he's lovely in the

244 I: Is that an old school photo,

245 R: Think it's Xx *isn't it*

246 I: is that him,

247 R: yes that's right, anything else, this is ted

248 I: can I have a look at your photos in the other room

249 R: yes sure, have I got any, what else is there to show you in there

250 I: you show me

251 R: the television um

252 I: oh look there's some more photos here

253 R: oh yes some up there

254 I: is this him in his airforce uniform is it

255 R: that's Xx, look at him, bless him, he was lovely

256 I: he has a nice kind face hasn't he

257 R: oh he was just look at him there, and there's my dear, look come and look at my grandma look

259 I: ah that's your grandma is it and is that you

260 R: oh no that was my cousin's little boy, now there's Xx look , that's a proper one of him

262 I: ah that's nice,

263 R: he 's giving me a peck

264 I: was that at a special party,

265 R: yeh, I've had one or 2 of these *(Drinking motion!)* look at my silly face

266 I: ha ha

267 R: oh but we were ever so happy, not that we didn't have our glaring moments

268 I: no

269 R: we used to glare at um

270 I: really, ha ha, what used to make you glare then

271 R: I dunno, I used to want to do something and he didn't, he was a great chap though, he honestly was, there's my sis, half- sister, Xx, that's not her horse

273 I: Did your mum go on to have more children

274 R: Yes she had my stepfather, he was all right, I didn't care for him, cos well he'd in my mind, he'd taken her away from me you see, cos but, thank the lord for my grandma, I could stay with her, I didn't want to go and live with her because he was too bossy (21.35), my stepfather

278 I: What made you think he was bossy

279 R: Cos he bossed my mum about, Xx do this , xx do that, Xx do something else, and I said **if I was xx I'd do what I wanted** and he went clonk on the side of my face, and of course my mum said I'll never forgive you for doing that, and of course I never forgot it and we kept at arms length I, ha ha, but it makes good reading, ha ha, but it's true, I

haven't exaggerated anything, I've told you really what happened, there he is look, oh look we've had a drink, isn't he lovely, that was at some celebration

285 I: Oh look you've got streamers over you there

286 R: Yeh I think it was Xmas or some time, but he was a thoroughly genuine nice person, look he's got his apple there

288 I: And you went to live in Scotland you say

289 R: Well when he came out of the services, well of course he went back to his old job, which was right up in the north of Sc, and of course I had to go and that was a bit of a wrench I didn't really want to, and I wasn't really happy up there, everybody was nice but I wasn't

293 I: Long way away

294 R: I like it up there for a holiday, but not to be for always, so we were up there for about 3 yrs, think it was about 3 yrs and then one day I can't remember quite clearly, but xx said **what about, would you like to be going back to Xx**

297 I: Um and what did you say

298 R: **Would I just ha**

299 I: Um

300 R: Well he liked it down here though he'd got used to it and he and he was quite happy to come down and his his mother and his father were dead so it wasn't as though he was leaving well I never saw his father, his father had died the year before I met Xx and um well there you are, am I keeping you too much

304 I: No sorry, I was just making sure I wasn't keeping you from your lunch

305 R: Oh my lunch is nothing, I'll have it anytime, I don't care about meals my love, I'm very chatty,

307 I: That's fine

308 R: You ought to tell me to be quiet, look at these, my dear grandchildren

309 I: Where is that photo taken

310 R: That was in the garden of my aunt and uncle in Xx, do you know xx, well that's where they lived, they went into that house, in Xx when it was built

312 I: Gosh

313 R: And that's my , oh look, oh

314 I: And where was that taken

315 R: That was in their garden, the back of the garden, that's Xx he's lovely , he's lovely, old Xx ha ha we had some good times, ever so good times, yeh see there's a nice garden

318 I: It is

319 (discussion about garden) (25.14)

(26.44)

320 R: That's Xx, my mum and stepfathers daughter, I I still know her and and see her, there's her and 2 boys younger, well I don't see the boys cos there er sort of away to school and that, but there's Xx, we usually ring on a Sunday and have a natter, she's nice, she's 12yrs younger than I am,

324 I: Is she

325 R: So how old am I, 80 something, 8x am I or 8z,

326 I: When were you born

327 R: xx

328 I: 19xx, so you'd be 8x if you've had your birthday I think. Which month is your birthday

330 R: Xxxx

331 I: Yes you're 8x

332 R: Yes she's nice, xx, we always have a good old chinwag for a bit for an hour on a Sunday on the phone ha ha

334 I: And do you still see her

335 R: Well not very much cos um she lives at Xx, doesn't she, just a minute, where does xx live yeh it is Xx, well she lives in xx, um well course it's Xx, course it is you fathead

338 I: Oh ha

339 R: Oh yeh well she lives there and there you are.

340 I: What about these photos over here

341 R: You what, oh that's my beautiful husband, and Xx

342 (photo and garden discussions again) **(29.41)**

(31.11)

343 R: Did I show you Xxx

344 I: You did yes

345 R: There's Xx, then there s Xx and then there's Xx, that's my half sister and 2 half brothers with my mum's er

347 I: Did you mind your mum having any more children

348 R: No, I liked them , I thought Xx when she was born, oohh loved her taking her in the pram, letting her down the kerb without jogging her,

350 I: Yeh

351 R: Oh she was a lovely little thing

352 I: Did you take her out on your own

353 R: Well not until later, we used to go out together because they lived at Xx, ohh she was lovely xx, dear little thing, well she's still nice, but she's a great big tall

355 I: Is she **(33.10)**

(35.10)

356 I: So they went all the way up to Xx for the wedding,

357 R: Well they called it a holiday

358 I: Yes

359 R: Well we weren't. we didn't want to get married in Xx really, but then x's sister, Xx, x but we call her Xx, she just had a baby boy, and he was only 3 weeks old, so they couldn't come down, well seeing as how X's mother was looking after Xx and the baby, she wouldn't come down, so all our people, my people could go up, so we they all went up and called it a holiday

364 I: Lovely idea

365 R: So it worked out all right

366 I: Yes

367 R: A good time was had by all

368 I: good

DARNE (p244)	
Description	Certain entities have certain properties, in a timeless and historical way. No attempt is made at story-telling/narration, a sort of timeless anthropological present about the person or situation, eg 'it was always was like' 'never a dull moment'
Argumentation	Development of argument and theorising, from present or past time perspective. Usually in a stand alone form, occ explicit disagreement with an alternative position, usually implicit
Report	A form in which a sequence of events, experiences and actions is recounted, from some distance, in a 'thin' fashion. Provides an overview of a range of events, some which are detailed, often covers a relatively long period of time (bare chronology)
Narrative	Telling of a story by which X followed Y, in rich detail, occ in present tense, virtually reliving from close up. Direct speech, quotes.
Evaluation	Moral of the story, before or after the story-telling

Macro - Topic (for skimming TSS only) (fill in only at end of whole analysis, and only if obvious) **page/line numbers + approx no. of pages**		
page/line no start/finish (no of lines)	**(Speaker) textsort**	**topics-gist (for later TFA) mostly minimalist paraphrase, but their keywords in single quotes**
p.1	SQUIN	
p.1	Desc/Report/ Arg/Eval	Spoilt brat when small, had a mother, never saw my father, as grew older thought this was a strange way of things happening, people didn't tell you things then. Used to imagine all sorts of things, and if other men seen in at her house were her father. Lived with grandmother and mother, got disconcerted and suspicious as grew older. No one spoke about it, so never knew. Tried to find him, unsuccessfully. Very disconcerting. Jokes about it. Very upset for long time, then got over it, 'what's happened has happened and what's that's what your not given or not given and you've got to get on with it and make the best of it, and what else can you do'. Jokes again.
p.2	desc	Always joking, take no notice.

Macro - Topic (for skimming TSS only) (fill in only at end of whole analysis, and only if obvious) page/line numbers + approx no. of pages		
page/line no start/finish (no of lines)	**(Speaker) textsort**	**topics-gist (for later TFA) mostly minimalist paraphrase, but their keywords in single quotes**
p.2	Desc/ eval	Upset for a while, everybody kind to her, except one person, that's just by the way. Grandmother was hero. Discussion about her and how to spell her name. 'in my life she saved me' **(End of sub-session 1)**
p.2	How?	
p.2	Arg/ desc	Never knew father, something fishy there, not told, but mother married a very nice man, but never saw them then really – stayed with grandmother.
P3	PIN ,Narr, Eval, rep, Arg	Stepfather – "never nasty to me", but would have fallen out with him, thought he bossed mother about, and she believed 'in her mind' that he had taken mother away from her. Never quarrelled, slapped face once, when being cheeky monkey, probably deserved it, mother said she would never forgive him. Never touched her again. 'He didn't exist' just a person who had taken her away rptd, sad about it. At school, no dad to see things. Spoilt by aunts and uncles, 'horrid little beast'.
P3	what makes you think that you were spoilt? SQUIN	
P3-4	PIN, Eval , arg	Everything would appear if she said she liked it, from one or other aunts/uncles. No blame for stepdad slapping her, expect I needed it, really saw stars. Jokes about still seeing marks. rocked her head, not expecting it,. Uncle was going to attack stepdad, grandmother stopped him, hard for her as more of mother than real mother. Didn't want to go to mother's new home with stepdad, would have run away. Jokes about being odd bod. More people were good to her than weren't. Really true. Look at lovely son. Jokes about his nickname. Wanted girl too, never happened, Smashing husband, in the airforce
P4-5	Was it an airbase? (filling in the word-finding gap)	
P5	desc	That's right, just him and nobody else. He's ever so nice (husband has died, but still present tense)
P5	SQUIN	
P5	PIN, narr, rep	Had son 10mths after married, donkey mad over each other, and wanted a child, had son, then wanted a little girl, but, on husband's recommendation, had to wait

		until they got a house, had a house quite a while but another child never arrived, tried and tried, don't know why. 'I said well there we are if that's how it is that is and Xxx is so nice he's made up for it' 'Good old Xxx'
P5	Eval	And I'm here and look at my nice room and all oh it's lovely and I got, have you seen my bedroom and all that
P5	Disc about recorder, Ok to take with us?	
p5	Arg?	No I don't care, I'm not saying anything wicked
P6-7	Disc re tidiness and jokes, tour round rest of flat – look at photos of family	
P7	desc	oh Xxx was ever so kind, Scotsman, from Xxx, full of fun
P7	You were married for a long time	
P8	desc	60yrs, married , met Xx when I was 19 cos the war was on, and we got engaged when I was 20 and married when I was 21, wedding arrangements, I Scotland because his sister had just had a baby.
P8 -9	Disc re photos and lovely husband	
P9	Desc, arg?	'oh but we were ever so happy, not that we didn't have our glaring moments' – can't remember why though – jokes about it all
P9	PIN, Narr/arg	'Yes she had my stepfather, he was all right, I didn't care for him, cos well he'd in my mind, he'd taken her away from me you see, cos but, thank the lord for my grandma, I could stay with her, I didn't want to go and live with her because he was too bossy, my stepfather' recounts story of being hit by him again, 'we kept at arms length'. Jokes about it, no exaggeration.
P9	SQUIN	
P9-10	Narr	Went up to Scotland after married, wasn't really happy, everybody nice, there for 3 yrs, husband asked if wanted to go back, jumped at chance, H was quite happy to come down, parents were dead.
P10	Disc re photos	
P10	rep	Photo of step sister and mum, still know her and see her, 12 yrs younger, has children. 'She's nice', spks every Sun eve on phone.
P11	Did you mind your mum having any more children SQUIN	
P11	rep	'No, I liked them , I thought Xx when she was born, oohh loved her taking her in the prm, letting her down the kerb without

		jogging her,' 'Oh she was a lovely little thing'
P11-12	Looking at wedding photos	
P11-12	Rep/ eval	Family called wedding trip to scot a holiday, cos of H's sister's baby.' 'she wouldn't come down, so all our people, my people could go up, so we they all went up and called it a holiday'. 'So it worked out all right'.

Mrs HN: Thematic field analysis from email panel members

BDC

Born to unmarried mother, well supported by grandmother, aunts and uncles. Lived in small village outside small city. Never told anything about her father, knew a name, tried to find him later on, unsuccessfully.

Mother remarried and she had choice of living with him –prayed to her grandmother that she could stay there, mother went out to work, so grandmother brought her up, more of a real mother to her.

Heard stepdad bossing her mum around, and said 'if I was her I would do what I wanted' He clonked her so hard that it rocked her head and she saw stars. Her mother said she would never forgive her step dad for that, uncle was going to attack him too. Grandmother told them to leave things be.

Decided to keep stepdad at arm's length, and got on OK after that.

Met boyfriend, aged 19, engaged at 20, married at 21, went to live in remote piece of Scotland with husband. Son born there 10 months after wedding. Mother-in-law died, and husband asked if she would like to move back down to her home, jumped at chance.

Wanted to have a little girl, husband said must wait till they had a house. Got one, and tried and tried, but never happened, don't know why.

Lived in birth area for rest of life with husband, had Golden Wedding,
And Diamond Wedding. Moved into attached flat with son and his family. Husband eventually developed dementia, went into a nursing home and died there. Now lives on own there.

Brief background of Mrs HN

Mrs HN is a white lady of working class background, who is now in her mid 80's.

Chunk 1
She was born to an unmarried mother in a small village on the edge of a small city. What do you think happened next?

H1: She was given up for adoption – later falsified by Chunk 2

H2: With the support of her family, the baby was raised by the mother

H3: Mrs HN was given up for adoption as a baby – later falsified by Chunk 2

Chunk 2
Mrs HN lived with mother, who went out to work, in grandmother's home with 2 aunts and 2 uncles too. Mrs HN was never told anything about her real father, and, when people visited the house for any reason, and there was a man, she always wondered if he was her real father. Her mother remarried and asked her 12 yr old daughter, Mrs HN, if she would like to go and live with them. What do you think happened next?

H1: Mrs HN decided to say in her grandmother's house

H2: She refused to go

H3: She went to live with her mother and (step) father – later falsified by Chunk 3

H4: I think she stayed with her grandmother, aunts and uncles and kept looking for her

real father.

Chunk 3
Mrs HN prayed that she wouldn't have to go to her mother and stepfather's house, and her grandmother allowed her to carry on living there with her. She always felt her stepfather had taken her mother away from her. One day Mrs HN was 'really cheeky' when she heard her stepfather bossing her mother around, and said 'if I was her I'd do what I wanted', and her stepfather went clonk on the side of her face, so hard it rocked her head and she saw stars. What do you think happened next?

H1: Mrs HN was too frightened to say anything to her mother in case in turned her mother against her – later falsified by Chunk 4

H2: She didn't know what to do and did not tell anybody – later falsified by Chunk 4

H3: Her mother saw what happened and defended her daughter.

H4: I think her mother left her husband and came back to live with her daughter, Mrs HN, and her mother – later falsified by Chunk 4

Chunk 4
Mrs HN's mother said 'I will never forgive you for that, her uncle wanted to attack the stepfather, and her grandmother persuaded him to leave it be. Mrs HN never, ever forgot it, and decided to keep her stepfather at arms length so they wouldn't fall out. She was eventually told the name of her real father and the (local) area from which he came. What do you think happened next?

H1: Mrs HN went to see her real father who didn't want anything to do with her – later falsified by Chunk 4

H2: She tried to make contact with her real father

H3: She tried to arrange to meet her real father but he had his own family and did not want to meet her – later falsified by Chunk 4

H4: I think Mrs HN carried on as she was, living with her grandmother, and did not try to find her father at that time. She finished school and got a job – later falsified by Chunk 4

Chunk 5
Mrs HN looked for him, but never found him or anything about him, and still doesn't know to this day who he was. She had a stepsister and 2 stepbrothers who she often visited. She then had a Scottish boyfriend from the air force. What do you think happened next?

H1: She married the scottish boyfriend and moved to another country with him – later falsified by Chunk 6

H2: She married the boyfriend and went to live with him

H3: They got married and moved to Scotland

H4: They got married and moved to Scotland.

Chunk 6
Mrs HN got engaged and married to him, in Scotland and went to live on a remote Scottish island. What do you think happened next?

H1: They had two children. Mrs HN found her real father on the island – later falsified by Chunk 7

H2: She felt isolated and cut off

H3: They started a family and lived happily for the next few years – later falsified by Chunk 7

H4: They started a family and lived happily for the next few years – later falsified by Chunk 7

Chunk 7
They had their first child, a son, and Mrs HN was desperate for a little girl too. What do you think happened next?

H1: Mrs HN had fertility treatment and then after a few years had another son – later falsified by Chunk 8

H2: she tried for a second child – later falsified by Chunk 8

H3: They had another baby but it was boy again – later falsified by Chunk 8

H4: I think they had two more boys before they had a baby daughter, whom the whole family indulged and spoiled – later falsified by Chunk 8

Chunk 8
Mrs HN's husband said 'we're not having a another child, I'm not saying we're not having another child at all but we're not having another child until we've got a house'.
Her mother-in-law died, and husband asked her if she wanted to move back down South (to her village). What do you think happened next?

H1: They moved back down South and Mrs HN found her real father – later falsified by Chunk 9

H2: She moved back down south

H3: They moved back down South and managed to get a house with some money her mother in law had left – later falsified by Chunk 9

H4: I think they moved back south to her village and had two more sons before having a daughter. She was close to her step-siblings and saw a lot of them, which made her happy – later falsified by Chunk 9

Chunk 9
Although everybody was very kind to Mrs HN on the remote Scottish island, she wasn't keen on living there, and her husband asked her if she wanted to move back down South, which she jumped at. And they were able to buy a house. What do you think happened next?

H1: Mrs HN had a second child: a boy and again started to look for her real father – later falsified by Chunk 10

H2: She wanted to have the second child

H3: After they had settled in the new house she was very keen to have another baby. Her husband agreed and they had a girl – later falsified by Chunk 10

H4: I think her husband got a job in a factory and worked his way up to be a manager. They eventually had a daughter and when she was older, Mrs HN went to work as a dinner-lady in her daughter's school – later falsified by Chunk 10