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Liberating Qualitative Research Findings From The Dusty Shelf Of Academia: developing a translational methodology illustrated by a case study of the experience of living with dementia

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ABSTRACT

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Liberating qualitative research findings from the dusty shelf of academia: developing a translational methodology illustrated by a case study of the experience of living with dementia.

The exponential growth of qualitative health and social care reports in recent years has generated a dialogue about the utility of qualitative research findings. The traditional methods of dissemination often result in the findings remaining on 'the shelf' with the result that they have little impact on practice, policy, or members of the public.

In this study I develop a generic framework for synthesizing and communicating qualitative research findings that are already in the public arena. The framework is comprised of four stages: - Stage 1 is a strategy for identifying relevant and useful studies in the area; Stage 2 develops relevant and useful criteria for selecting studies: the quality of a study is assessed by its; substantive contribution, aesthetic merit, reflexivity, impact and expression of reality; Stage 3 draws upon the philosophy of phenomenology and hermeneutics as a way of synthesising the selected studies, providing an experiential description of the phenomenon of interest (called a structural textual synthesis). Stage 4 offers principles by which the structural textural synthesis can be transformed and communicated to lay audiences in more aesthetic and understandable ways.

The above framework is applied to the phenomenon of living with dementia from the perspective of the partner with dementia and their care partner. The structural-textural synthesis is transformed into a script, which has been performed, and recorded on DVD.

The transferable implications of this framework are considered for their potential to communicate qualitative research findings already in the public arena to the public in ways that facilitate understanding and empathy

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Chapter 1: Introduction

The focus of this study is how to make the findings of qualitative health and social care research useful to a wider audience, in particular to one audience that is often overlooked and excluded, that is lay members of the public. The proliferation of qualitative health and social care research and the resulting exponential growth of reports in recent years has generated a dialogue about the utility of qualitative research findings. The dominant discourse for presenting research findings is an academic one situated in subject specific journals, professional conferences, and books. This form of dissemination has been cited as a barrier to the utilization of qualitative research findings by its exclusionary nature, in particular by its ability to reach, and to be read, and understood by a limited audience, thus limiting its impact on policy, practice, and members of the public who might benefit from the findings.

To allow me to develop research findings in ways that are useful to an audience that includes members of the public, and health and social care professionals I have evolved a framework for synthesizing and communicating qualitative research findings. In order to develop this model, I have drawn on literature relating to the synthesis of qualitative research, and the utilization, and communication of qualitative research findings. The area that I have chosen to test the framework is the experience of living with dementia from both the perspective of the person with dementia and their care partner, (I use the term care partner throughout to mean spouse or significant other). My reasons for using dementia to illustrate the framework are twofold: one stems from a personal interest that relates to previous experience of working with people with dementia and the second is the increasing national concern relating to dementia because of the demographics of an increasingly ageing population in the UK.

This research aims to answer the following questions: -

- How can the findings of research be appropriately contextualized?

- Who might be interested in the information?

- What is the appropriate vehicle for disseminating information to them?

<div align="right">(adapted from Paterson et al 2001:128)</div>

In this chapter I will first present a brief overview of the study area, to provide the rationale for the study and to illustrate the complexity of the issues relating to the utilization and communication of qualitative research findings. A three-part literature review relating to the synthesis of qualitative research findings, the utilization and communication of qualitative research findings, and an overview of dementia research will follow this. In conclusion I will summarize how the literature has informed the aims of the study.

<u>Overview of the Study</u>

Utilization and Communication of Qualitative Research Findings

Qualitative research findings are defined as, 'the grounded theories, ethnographies, phenomenologies, and other integrated descriptions or explanations produced from the analysis of data obtained from interviews, observations, documents and artifacts, (Sandelowski 2004:1374). Qualitative health studies have grown exponentially since the emergence of qualitative health research in the 1980,s, with the result that there are now large numbers of reports that relate to topics of interest that are important to health and social care professional, researchers and consumers of health research, (Sandelowski 2004).

The move towards evidence based practice in health care has resulted in increased interest in how qualitative research findings might be used to gain

important insights into the culture, practices, and discourses of health and illness (Evans & Benfield 2001, McCormick, Rodney & Varcoe 2003), in order to inform health policy and practice (Campbell *et al* 2003). Dixon-Woods *et al* (2003), argue that the synthesis of qualitative research is essential to address uncertainties in many areas of health care, answering questions that are not easily addressed by experimental methods. In addition a number of policy documents; (Health in Partnership (DoH 1998), A Quality Strategy for Social Care (DoH 2000), Shifting the Balance of Power (DoH 2002), Creating A Patient-led NHS, (DoH 2005)), have emphasized the need to examine the impact of health and social care services from the service users perspective.

An increase in the number of qualitative studies and published research findings in health sciences in recent years (McCormick *et al* 2003), has however not led to the building of a cumulative knowledge base (Britten *et al* 2002). Sandelowski (1997) questions the ethics of asking 'persons who are already vulnerable' (as a result of health conditions or personal circumstances) to participate in yet more research and proposes that more effort be directed to developing methods to utilize existing research thus making findings of qualitative research 'accessible'. There is therefore a need to establish a method for appraising, synthesizing and disseminating qualitative research findings, (Lloyd Jones 2004). This study seeks to develop a method that will 'peel away the surface layers of studies to find their hearts and souls' (Sandelowski, Docherty & Emden 1997:370) and to 'make meaningful the voices…. of often-overlooked and undervalued' (Jones 2004:97) health and social care consumers.

A number of terms have been used to describe the synthesis of qualitative research and a variety of strategies have been proposed for carrying out the task, (Finfgeld 2003). However this has resulted in a 'confusing array of techniques and (the) disparate philosophical stances of qualitative meta-analytic methods' (McCormick *et al* 2003:935). Much of the debate around methodology has centred on what constitutes 'quality '(Sandelowski & Barroso 2002), 'what counts as evidence' (Pearson 2004) and what establishes 'trustworthiness' (Koch 1994) in terms of establishing rigour, reliability and

validity in qualitative research (Koch 1994, Whittemore *et al* 2001, Morse *et al* 2002) and whether quality should be of any concern at all, (Lincoln 1995).

The dissemination of knowledge is however not synonymous with the utilization of knowledge (Farkas *et al* 2003: 48). Academic discourse is the mainstream model used to disseminate research findings via peer reviewed journal articles (Cleary & Peacock 1997). Largely written for other researchers using 'dense "research-ese" and statistical jargon' (Funk *et al* 1995:401) the findings of the report are often intelligible only to a limited audience thus serving as a barrier to the findings utilization, (Sandelowski 1998). This study will seek to identify a method of dissemination that 'will make sense and have impact" (Sandelowski 1998: 375) to an identified audience. In this study the target audience will be the care partners of people with dementia.

One audience often overlooked in disseminating research is the public at large. An example of this can be found in a paper by Britten *et al* (2002:213), in which they discuss a meta-ethnographical synthesis they performed relating to medication compliance. They view their potential audience as including, 'practitioners (doctors, nurses, pharmacists), policy-makers and qualitative researchers'. Because our academic training typically orients us toward academic vehicles for research dissemination, many of us do not consider the impact that more creative and accessible strategies might have (Paterson *et al* 2001:129).

The subject of my study is the impact of dementia on the person with the disease and their carer; and focuses on the 'the challenging shared journey of being together'. Whilst the experience of caring for a partner with dementia is well documented in the literature, with the stress/burden model providing the dominant theoretical perspective, it is not until the last decade that there has been a change in emphasis, with a move to a subjective/emotional/experiential understanding providing a broader view of the caring experience, (Hellstrom et al 2007). At the same time the number of studies that have actively engaged **with** people with dementia rather than carrying out research **on** them has begun to increase, (Cowdell 2006). To date very few studies have focussed on

the relationship between the person with dementia and their carer, as experienced by both parties (Forbat 2003). My study has drawn together literature that focuses on the experience 'of the dementia journey' from both the perspective of the partner with dementia and their care partner.

I will now move to the first part of my literature review, which relates to the development of approaches to synthesize qualitative research findings.

Synthesis of Qualitative Research Findings

Introduction: Emergence of Metasynthesis in Health Related Research

In response to the call for evidence-based health care decisions and best practice a new species of inquiry, metasynthesis is emerging (Estabrook *et al* 1994, Jensen & Allen 1994, Jensen & Allen 1996, Sandelowski *et al* 1997, Schreiber *et* al 1997, Bondas & Hall 2007a). The term metasynthesis (sometimes referred to as meta-synthesis) has become a generic term for a collection of methodological approaches for synthesizing qualitative findings, (Thorne *et al* 2004). Schreiber *et al* (1997) identified the emergence of three distinct purposes for qualitative metasynthesis:

- theory building, (whereby data from diverse sources is used to develop formal theory)

- theory explication, (whereby a single abstract concept is 'fleshed out' resulting in the reconceptualization of the original phenomenon)

- theoretical development, (whereby a synthesis of findings is transformed into a 'thickly descriptive and comprehensive' final product)

(Schreiber *et al* 1997, Kearney 2001a, Finfgeld 2003)

These models are not exhaustive or exclusionary and may be complementary and overlapping (Schreiber *et al* 1997) nor do they reflect all metasynthesis possibilities but are 'a mechanism for thinking about how projects have been approached in the past and ways in which they might be developed in the future', (Finfgeld 2003:897).

Qualitative metasynthesis is not a trivial pursuit, but rather a complex exercise that aims to produce a new and integrative interpretation of findings that is more substantive than those resulting from individual investigations, allowing for the clarification of concepts and patterns, (Finfgeld 2003:894), and not mere aggregation to achieve unity, (Thorne *et al* 2004). It's appeal lies 'in 'our hunger for more true, more accurate, or more real explanations of phenomena and

more coherent ways to make sense of them', (Paterson *et al* 2001:110). However Beck (2003) cautions, that researchers involved in metasynthesis walk a fine line between analyzing the studies in enough depth to maintain the integrity of specific studies and not being so immersed in the details that the end product is not usable.

Metasynthesis refers to, 'the theories, grand narratives, generalizations, or interpretive translations produced from the integration or comparison of findings from qualitative studies', (Sandelowski *et al* 1997:366). These are themselves interpretive synthesis of qualitative data, including ethnographies, grounded theories, phenomenologies, or otherwise integrated and coherent descriptions or explanations of phenomena, events or cases, (Sandelowski & Barroso 2003a). However, the "meta" in metasynthesis differs in meaning from the meta in meta-analysis, (Noblit &Hare1988). Meta-analysis involves aggregating data and metasynthesis involves interpreting the data, (Beck 2002b: 453). In quantitative meta-analysis the assumption is that there will be a, 'fundamentally right answer, a singular truth to be discovered', (Thorne *et al* 2004:1361). Rather than providing the means to a 'greater truth', qualitative metasynthesis is another 'reading of data' (McCormick *et al* 2003:936), that aims to provide an integrative, coherent and illuminating construction of human experiential phenomenon, that is bound within temporal, spatial and epistemological locations, (Thorne *et al* 2004). It is not necessarily 'a more accurate or truthful account by virtue of having more data collected by multiple researchers in different settings' (McCormick *et al* 2003:936).

A number of approaches for synthesizing evidence from qualitative research studies have been identified from the literature. In the following section I will trace the history of the development of methods for synthesizing qualitative research, their application to health and social care related research findings, and the type of knowledge the approach seeks to generate.

Grounded Formal Theory

In the late 1960's and early 1970's (Glaser and Strauss 1967,1971), produced a synthesis of four studies relating to the process of dying and other major life transitions using a method they described as grounded formal theory. Grounded formal theory uses the same basic steps as substantive grounded theory but applies them to pre-existing analyses rather than to new observations or whole data sets, (Kearney 1998:497). The resulting formal theory is grounded in the theories from which it is derived and produces a higher level of interpretation and theory-building, (Kearney 1998(a), Dixon-Woods *et al* 2004). The aim of grounded formal theory, 'is to explain variations in behavioral outcomes based on differences in sample, study, context, participant context and other influences, (Kearney & O'Sullivan 2003:137). The method focuses on developing a theoretical explanation of differences rather than producing a summative description of an experience, (Kearney 2001a, Kearney & O'Sullivan 2003). Initially proponents of formal grounded theory used their own original research to formulate their theories, (Kearney 2001a).

Kearney, proposes that the method be used to synthesize, 'extant findings of multiple qualitative health research studies into newly integrated wholes', (Kearney 2001a:229), in order to, 'consider possible locations of our patient's experiences in the landscape of experiential variation and identify an array of routes along which we can guide them toward health', (Kearney 2001a:244).

Kearney used grounded formal theory to, 'develop a midrange theory of women's addiction recovery from multiple substantive reports', (Kearney 1998a:495). She noted that, 'because little resource material has been available on using the grounded formal theory method to serve a clinical profession, this must be considered a trial effort', (Kearney 1998a:497).

Kearney has since developed a, 'target for formal theory development' to produce 'relevant and recognizable' models of specific health phenomenon, using multiple studies of a single phenomenon aiming for a broader theory (lower-mid-range theory), that extends beyond health-related contexts, (Kearney 2001a:228). She proposes that rich 'designer' grounded theory

studies can be used to construct 'ready to wear' formal grounded theory syntheses that, 'will be clinically useful theoretical models of how individuals manage related intrapersonal and situational changes in health' that will allow clinicians to 'gain deeper awareness of issues facing their clients', (Kearney 1998b:185).

Grounded theory studies are regarded as the 'essential fabrics' for constructing formal theory, with phenomenological reports and content analyses considered as 'raw material' that can provide confirmatory support or challenge in the building process, (Kearney 1998b:182). As with grounded theory, sampling is not limited to a predetermined number, but begins with an initial data source and stops when 'saturation' is reached and the 'phenomenon is no longer recognizable as a discrete experience, or the theory becomes so general as to be rendered clinically useless', (Kearney 1998b:182-183).

With the exception of several studies by Kearney; for example, women's adjustment to illness and trauma, women's experiences in violent relationships, (Kearney 2001a:228), individual's efforts to change unhealthy behaviors, (Kearney & O'Sullivan 2003), there are as yet few examples of the use of grounded theory for synthesis (Dixon-Woods *et al*, 2005).

In summary, grounded formal theory is a method for synthesizing qualitative research findings, which appears to be well suited to providing theoretical knowledge to inform clinical practice. The number of studies included in the synthesis are restricted by its sampling strategy, which ceases when saturation is reached, thus limiting the number of studies that are included in the synthesis. Unlike some other strategies for synthesizing qualitative research, in particular those of systematic review, it does not seek to identify all research in the target area thus opening up the possibility for the task to be undertaken by a sole researcher. The goal of formal grounded theory is to provide theoretical models of health and health behaviours, in order to inform clinicians and other health professionals rather than to provide a description of an experience. In particular Kearney proposes that formal grounded theory be used to allow health professionals to better understand the 'issues' facing their patients in

order that they may 'guide' them 'toward health'. This rather paternalistic stance appears to exclude the possibility of using this method to allow patients to gain a better insight into their own condition.

Meta-analysis

Meta-analysis is a term used in quantitative research, to describe a method whereby the results of a number of studies using similar instruments, data sets and analytic methods are reanalyzed in the aggregate, (Paterson *et al* 2001), using statistical methods. The purpose of meta-analysis is to predict future outcomes for situations with analogous conditions, (Doyle 2003). The data is normally derived from randomized controlled trials. Stern & Harris (1985) are the first in the nursing literature (Walsh & Downe 2004, Zimmer 2006), to use the term 'qualitative meta-analysis' (Stern & Harris 1985:152), to refer to the synthesis of the findings from seven qualitative nursing studies into one, 'explanatory interpretive end product', (Schreiber *et al* 1997:312). They used the word *meta* to mean, 'later, more highly organized or specialized (in) form ……more comprehensive: transcending', (Stern & Harris 1985:152), and aimed to use, 'old data to answer new questions' through the 'integration of findings the analysis of analysis', (Stern & Harris 1985:152). They 'traced the variable self-care through the data and findings' using grounded theory techniques, 'to discover the limits, dimensions, properties, and contexts of the variable', in order to develop a 'guide to self-care readiness that the nurse may use in practice', (Stern & Harris 1985:152).

Britten *et al* (2002:209), argue that meta-analysis, 'is not transferable to qualitative research', and that, statistical methods for aggregating data are, 'inapplicable to qualitative research'. However Schreiber *et al,* define qualitative meta analysis as the;

> 'bringing together and breaking down of findings, examining them, discovering the essential features, and in some way, combining phenomena into a transformed whole'.
>
> (Schreiber *et al* 1997:314)

Used in this context to describe the synthesis of qualitative research findings, it would appear that the term, 'meta analysis' has been 'borrowed' from quantitative research in an early attempt to find a name for the methodological technique of synthesizing qualitative research findings, and not to denote the application of quantitative methods to the synthesis of qualitative research findings. The use of the term meta analysis in relation to qualitative synthesis seems to have generally fallen out of use and to have been replaced by the generic term metasynthesis. One recent exception to this is a study by McCormick *et al* (2003), Reinterpretations Across Studies: An Approach to Meta-Analysis, in which, the authors undertook a qualitative meta-analysis of their own studies to examine the context of healthcare and healthcare relationships. They use the term qualitative meta-analysis to mean combining the results of several studies to create interpretations at a higher level of abstraction, (McCormick *et al* 2003:943). They state that they, 'followed the steps identified by Noblit and Hare in their 1988 monograph' to perform the synthesis however they returned to their raw data 'to verify, contradict, extend, or enrich interpretations', (McCormick *et al* 2003:939).

McCormick *et al* (2003:937-938) performed their synthesis on research findings from their own studies (ethnographic studies with differing theoretical perspectives), returning to their raw data for clarification purposes. They state that they had 'intimate knowledge' of their own studies and 'familiarity' with each other's studies through their long association and work together. They argue that this 'afforded them a richer understanding of the material' as they had a closer relationship with the data than would commonly be available to researchers undertaking qualitative metasynthesis.

In summary the term meta-analysis is usually understood to refer to the statistical aggregation of quantitative research data. Its use to refer to the synthesis of qualitative research findings does not relate to a distinct method or approach, for synthesizing qualitative research but, like the term 'metasynthesis', it appears to be a generic term for a collection of approaches.

Meta-ethnography

Noblit & Hare's (1988) monograph 'Meta Ethnography: Synthesizing Qualitative Studies', represented anthropology's attempt to synthesize and theorize its own body of research findings through a systematic cross-comparative interpretive strategy, (Paterson et *al* 2001), 'in a fashion similar to the ethnographer interpreting a culture', (Noblit & Hare 1988:7). Noblit & Hare (1988:9) describe the meta-ethnographic approach as 'a rigorous procedure for deriving substantive interpretations about any set of ethnographic or interpretive studies'. Interpretive studies are defined as studies that include not only ethnographic studies, but also all types of interpretive research, such as phenomenology. They outlined a seven-step method for conducting a meta-ethnography:

1. Getting started: identifying an area of interest that qualitative research might inform.

2. Deciding what is relevant to the initial interest: search for and selection of relevant studies (purposive search, i.e. may not need to be exhaustive or comprehensive).

3. Reading the studies: to identify metaphors/concepts/schema retaining where possible the original terminology and remaining faithful to the original meanings.

4. Determining how the studies are related: by compiling a list of the key concepts/metaphors/phrases/ideas used in each of the studies and juxtaposing them.

5. Translating the studies into one another: by looking at and comparing the similarities and interactions between the key concepts/metaphors/phrases/ideas in the individual studies.

6. Synthesizing translations: to produce a new interpretation or conceptual development.

7. Expressing the synthesis: communicating the synthesis in a form that is relevant and appropriate to the audience.

(Noblit & Hare 1988)

Meta-ethnography involves three major strategies for relating and synthesizing studies:

- Reciprocal translational analysis: used where accounts are directly comparable.

- Refutational synthesis: used when accounts are oppositional.

- Lines of argument synthesis: used to examine similarities and differences between studies to integrate them into a new 'interpretation'.

(adapted from Dixon-Woods *et al 2004*:17)

The resulting derived or synthesized concepts may not have been identified explicitly in the original studies but are in fact third-order constructs; where first order constructs are those of the original participants; second-order constructs those of the original authors; and third-order constructs those of the synthesizers, (Campbell *et al* 2006).

Initially this approach was used in education but it is now gaining ground in health-related research. An early example of this is, 'A Synthesis of Qualitative Research on Wellness-Illness', a study published by Jensen & Allen in 1994. They undertook a 'synthesis' of qualitative nursing literature on health, disease, wellness, and illness in order to 'derive substantive interpretations' to produce a 'dialectic model of wellness-illness', (Jensen & Allen 1994:349). More recently a number of studies, (Paterson *et al* 1998, Nelson 2002, Beck 2002a, Beck 2002b, Britten *et al* 2002, Campbell *et al* 2003) have been conducted using meta-ethnography within the field of health.

Britten *et al* (2002) provide a worked example to demonstrate the benefits of applying meta-ethnography to the synthesis of qualitative research. They state

that they 'arbitrarily' chose four papers about the lay meanings of medicines, three of which related to studies undertaken by some of the researchers conducting the synthesis, (Britten *et al* 2002:211). They claim that the production of third order interpretations, justify the claim that meta-ethnography achieves more than a traditional literature review, as they represent a conceptual development that provides a fresh contribution to the literature. They indicate that their worked example has generated middle-range theories in the form of hypotheses that would be amenable to being tested by other researchers. Emphasis is placed on returning to the original data to check the analysis and they,

> 'think it likely that other researchers using this method will want to consult original authors - to test the validity of the third-order interpretations and the extent to which they are supported by the primary data'.
>
> (Britten *et al* 2002:215)

They view the potential audience for this 'kind of synthesis' as practitioners, policy makers, and qualitative researchers.

Meta-ethnography has however been criticized for being a context-stripping activity, not an interpretive one, (Estabrooks *et al* 1994) and for not having an explicit goal, (Estabrooks *op cit*). Jensen & Allen (1996) also propose that it should only be used to synthesize studies within a single paradigm. Kearney (2001:231-232), argues that meta-ethnography was originally conceived as an interpretivist, non-theorizing method. The original aim was to reconcile, 'different ethnographers' interpretations of the same phenomena', in order to capture the 'similarities and differences in the individual studies'. The end point being a product, that explicates the differences in a common set of terms, rather than in a unified summary, as has been the practice with followers of the method in nursing. Kearney (2001:234) has noted, 'that derivations of meta-ethnography are more theorizing than their parent method'. Indeed in their worked example, Britten *et al* (2002), propose that meta-ethnography is capable of generating theory to inform policymakers.

Two recent reviews of published metasynthesis studies in the health and health care arena, (Dixon-Woods *et al* 2007, Bondas & Hall 2007b), have identified meta-ethnography as the method dominating the research area. However although meta-ethnography is the most commonly cited method both papers highlight the fact that 'modifications' (Bondas & Hall 2007b:101) and 'innovations' (Dixon-Woods *et al* 2007:415) have been made to the method. Jones (2004), notes that meta-ethnography is beginning to gain ground in the field of systematic review. The move from its original conception as a purely interpretivist non-theorizing method, into 'derivations' of the method, which are capable of generating theory may account for this methods appeal to those engaged in systematic review.

Noblit has acknowledged 'amazement' that meta-ethnography is being used to inform policy and practice within healthcare. He asks us to consider both the context in which it is being used and to question whose interests are being served; those of the policy makers' and the clinicians' or those of the patients', 'we must consider who is to be served by the knowledge and in what way', in order that we, 'do not simply allow health care to become more powerful in the lives of patients', (Thorne *et al* 2004: 1349-1351).

In summary meta-ethnography is a method to translate, refute, and examine differences, and similarities between studies, and to integrate them into a new whole, in order to produce new interpretations and conceptual and theoretical developments of the phenomenon under study. In their worked example Britten *et al* (2002) propose that the authors of the original studies be contacted to consider the applicability of the third-order interpretations produced by the meta-synthesis to their own work. In practice it is difficult to see how viable this would be in terms of: the ability to locate and contact the original researcher (particularly if the study was conducted outside of the UK), their ability to participate (in relation to their own work-load and circumstances) and the time frame in which the meta-synthesis has to be conducted.

'Aggregation' of qualitative study findings

Estabrooks *et al* (1994) used the term 'aggregation' of qualitative study findings, to describe a process whereby findings of studies focusing on similar populations or themes that share the same research methodology are aggregated using a four stage model to 'greatly enhance the generalizability of the original studies and produce(s) a relatively solid mid-range theory', (Estabrooks *et al* 1994:503). The model that they propose for synthesizing the findings from multiple studies has four processes: -

1. Comprehending
2. Synthesizing
3. Theorizing
4. Recontextualizing

(Estabrooks *et al* 1994:504)

They use the term aggregation to describe a method, which employs interpretive techniques to sustain the nature of the context. They argue that this differs from the use of the term aggregation in meta-ethnography where it is used to denote context-stripping, (Estabrooks *et al* 1994:505). They 'aggregated' a total of 112 qualitative studies relating to wellness-illness, by grouping and synthesizing the studies according to the methodology used in the original studies, finally combining the resulting synthesis from each group into a global summary. Their intention was to develop theory whilst using interpretive techniques to retain the context of the studies.

In summary this approach was used to synthesize a large body of research from differing methodologies, to enhance the generalizability of the studies and produce a mid-range theory. Unlike other approaches where a synthesis is performed on the total number of selected studies, in this case studies are first grouped and synthesized according to research methodology, before being combined into a global summary. They are not explicit about the 'interpretive technique' they used to synthesize the studies. This approach appears to have had little uptake and 'is likely to be overtaken by some of the approaches that are developing more rapidly'. (Dixon Woods *et al* 2004(a): 19).

Metastudy

Metastudy, (Paterson *et al* 2001), is a particular form of metasynthesis grounded within a tripartite analytic process:

- Metatheory
- Metamethod
- Meta-data-analysis

(Thorne 2001, Thorne *et al* 2004)

Metastudy was developed over a period of years by Paterson in collaboration with six other researchers (Paterson 2001:21), and is, 'an application of an approach articulated by Zhao (1991) and Ritzer (1991) for use in synthesizing social theory', (Thorne *et al* 2004:1356). It is grounded within the interpretivist, constructivist paradigm, seeking to understand how people construct knowledge about the phenomenon under study, (Paterson 2001). The aim of metastudy is to analyze and synthesize large numbers of primary research studies in order to generate new or expanded theory about the phenomenon under study, (Patterson 2001). It is able to deal with, 'complex problems arising from large quantities of data collected under different conditions and yielding somewhat dissimilar kinds of knowledge', (Thorne *et al* 2002:438). Paterson (2001:22) provides defined procedural steps for undertaking the tripartite analytical process of metastudy.

These three analytic processes provide a tool for critical inquiry into each study separately, each study in relation to the other, and the body of work as a whole. Meta-data-analysis involves reinterpretation of the findings in individual studies in light of data and findings from other studies. Metamethod involves examination of the way in which the methodological approach used shapes the findings that emerge from a particular study. Metatheory involves the examination of each individual study to examine the theory used to identify the research topic; frame research questions, and determine such factors as inclusion criteria, angle of vision, and interpretive lens, (Thorne *et al* 2002).

Unlike other approaches to metasynthesis, which focus on the analysis of

primary research findings, metastudy differentiates between the process of analysis and synthesis. In metastudy the findings, methods and theory of individual studies are analyzed with focus on the sociocultural and historical context prior to synthesis, in order to generate new and more complete understandings of the phenomena under study. In the synthesis phase no 'procedural steps' are 'codified', as, 'in contrast to the concrete analytical phase, synthesis is a creative, dynamic and interactive process that defies procedural codification', (Paterson 2001:22).

Thorne, proposes that metastudy 'serves us far better as a method', for rigorously and systematically deconstructing existing bodies of qualitative research findings than it does as a technique for synthesizing powerful new products' (Thorne *et al* 2004:1357), leading to a clearer, deeper, more 'socially responsible' theoretical understanding of a phenomenon, (Paterson *et al* 2001:111). Paterson *et al* (2001:109-110) suggest that other methods of qualitative metasynthesis reflect only the process of meta-data-analysis and as such do not constitute true syntheses as they ignore the insights that arise from the analytic meta-method and meta-theory procedures.

Thorne *et al* (2002) provide an example of a meta-study conducted on chronic illness. They reviewed over a thousand reports, before finally identifying 292 reports that satisfied their inclusion criteria. They developed an instrument to manage the large volume of data in order to capture sample characteristics, methodological applications, evidence of inductive analysis, fieldwork strategies, grounding illustrative data, accountability measures, and auditability. Major findings from each study were summarized. Data extraction was conducted separately by at least three members of the research team, and the resulting consensus of the combined results was entered on an electronic database. This data set was then visually scanned to answer an extensive series of questions deriving from the metastudy components to inductively generate a number of theoretical claims relating to the body of research. They state that by 'systematically examining this body of qualitative research through the meta- study lens' they were able to 'conclude that the complexities inherent in chronic illness experience could not be neatly captured in any of the existing

theorizations', (Thorne *et al* 2002:439).

In summary metastudy is a method for synthesizing large numbers of research studies from differing epistemologies, in order to generate new or expanded theories about the phenomenon under study. Its aim is not to provide an experiential description of a phenomenon but to provide a theoretical understanding of a phenomenon that is situated in the sociocultural and historical context in which the original research took place. The primary goal of meta-study is to develop mid-range theory, it's originators claim that it, 'can also generate new or expanded theoretical frameworks, spawn health and social policy' and 'support practitioners in their interpretation of qualitative research findings' to better inform their practice, (Paterson *et al* 2001:14).

As demonstrated by the meta-study on chronic illness, meta-study involves large numbers of studies, which in turn generate large amounts of data, thus rendering, this method beyond the scope of a sole researcher.

Descriptive metasynthesis

Descriptive metasynthesis refers to the comprehensive analysis of a particular phenomenon, unlike the theoretical explication approach that focuses on the analysis of a single concept. It involves the synthesis of data from the unaltered texts of qualitative research findings and results, and, in keeping with the descriptive intent, findings are not deconstructed but are translated across studies, (Finfgeld 2003). Descriptive metasynthesis is a technique for synthesizing qualitative research findings proposed by Schreiber *et al* (1997). The approach involves, 'the synthesis of findings into a final product that is thickly descriptive, and comprehensive-somewhat like a meta-phenomenology', (Schreiber *et al* 1997:315). Phenomenological analysis is principally concerned with understanding how the everyday, inter-subjective world (the lifeworld) is constituted, (Schwandt 2000). Schreiber *et al* (1997) propose that the technique can be used to synthesize qualitative studies arising from differing methodologies, in order to produce a synthesis, which fulfils one or more of the following outcomes, to inform policy, identify gaps in knowledge, or to discover

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substantive theory. In addition the findings should resonate with and be 'immediately recognizable to those who have experience with the phenomenon of the study', (Schreiber *et al* 1997:317). This makes this approach particularly relevant to those researchers wishing to explore the lived experience of a particular phenomenon.

There are few examples of published studies, (Fredriksson 1999, Fredriksson & Eriksson 2001, Arman & Rehnsfeldt 2003, Lundgren 2004), that have adopted a meta-phenomenological approach to metasynthesis. The authors of the following three papers; Fredriksson (1999), 'Modes of relating in caring conversation: a research synthesis on presence touch and listening, Fredriksson & Eriksson (2001), 'The patient's narrative of suffering: a path to health?, and Arman & Rehnsfeldt (2003), The Hidden Suffering Among Breast Cancer Patients: A Qualitative Metasynthesis, have all adopted a phenomenological hermeneutic approach using an interpretive lens.

To date there appear to be few examples of studies, in the health and social care literature, which have taken a purely descriptive approach to metasynthesis. An exception is a study by Lundgren (2004), describing the experiences of pregnancy and childbirth, focusing on women's and midwives' experiences of the encounter during childbirth, and the experience of pregnancy from the women's perspectives. Four qualitative studies were synthesized, 'following the description of Giorgi', (Lundgren 2004:369). The phenomenological method proposed by Giorgi, entails pure description of the investigated phenomenon unlike other phenomenological approaches, which involve interpretation of the investigated phenomenon.

The fact that few studies have adopted a meta-phenomenological approach to synthesis fails to acknowledge that,

> 'phenomenological research is of great value to clinicians, policy makers, and ordinary persons because of its distinctive emphasis on making human behavior and experience intelligible with reference to the point of view of the actor'.

In summary this approach provides an approach to metasynthesis, which provides thick description of the phenomenon under study. Its broad inclusion criteria allows studies from differing methodologies to be synthesized, thus foregrounding the importance of the descriptive content of the research report and its ability to both engage and resonate with the reader, over the concern of combining studies from differing epistemologies. In addition its aim to resonate with those who have experience of the phenomenon under study makes it an appropriate method for researchers who wish to disseminate their metasynthesis to a wider audience that includes members of the public.

Systematic Review

Systematic reviews are the mainstay of EBM (Evidence Based Medicine), predominantly focused on randomized controlled trials to determine the effectiveness of treatments, (Pearson & Evans 2001). Sackett (1996:71) defines EBM as the 'conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual'. EBM also referred to as EBH or EBHC (Evidence Based Healthcare) and EBP (Evidence Based Practice), is becoming a 'growth industry' (Estabrooks 1999:274), and it has become, 'one of the newest mantras in health care', (Sandelowski 2004:136). So pervasive has the evidence based ideology become that qualitative researchers 'feel(ing) the hot breath of the EBHC movement on their necks' feel compelled to defend the place of qualitative research in health care in order to secure its future (Grypdonck 2006:1371).

Macdonald (2003:4) defines systematic review as 'one in which reviewers have sought systematically to identify all relevant primary studies, which they have then systematically appraised and summarized according to an explicit and reproducible methodology'. Intended to bridge the gap between research and practice EBM is depicted as 'a dynamic methodology' that:

- Systematically retrieves all evidence concerning the treatment of a clearly specified clinical problem.

- Ranks the evidence in an evidence hierarchy.

- Evaluates the evidence using quality criteria.

- Synthesises the evidence using clearly specified research techniques.

- Translates the evidence synthesis into practice guidelines.

- Implements the guidelines in practice settings.

- Evaluates the implementation against clearly specified outcomes.

- Subsequently refines the practice guidelines derived from this evaluation.

(Adapted from Sandelowski 2004:1369)

Within this tradition qualitative research has tended to be excluded or marginalized, (Dixon-Woods *et al* 2001), as the use of hierarchies of evidence assume that the randomized control trial (RCT) is the gold standard in inquiry, thus devaluing or excluding qualitative study findings, (Sandelowski 2004).

In 1998 Popay *et al* (1998:342) argued that there was a need to develop criteria or standards for undertaking systematic review of qualitative studies as;

'in the absence of any attempt to develop standards, there is a danger that qualitative research evidence will be misunderstood and judged inferior by those whose field of vision is firmly fixed on a hierarchy of evidence that makes (RCT's) the gold standard'.

They proposed the following as 'preliminary markers' that required 'further development', as evaluation criteria to be used in the selection of qualitative studies for inclusion in systematic reviews:

- Does the research, as reported illuminate the subjective meaning, actions, and context of those being researched?

- Is there evidence of the adaptation and responsiveness of the research design to the circumstances and issues of real-life social settings met during the course of the study?

- Does the sample produce the type of knowledge necessary to understand the structures and processes within which the individuals or situations are located?

- Is the description provided detailed enough to allow the researcher or reader to interpret the meaning and context of what is being researched?

- How are different sources of knowledge about the same issue compared and contrasted?

- Are subjective perceptions and experiences treated as knowledge in their own right?

- How does the research move from a description of the data, through quotations or examples, to an analysis and interpretation of the meaning and significance of it?

- What claims are being made for the generalizability of the findings to either other bodies of knowledge or to other populations or groups?

(Popay *et al* 1998:345-349)

A decade on, methods for reviewing qualitative research in a systematic way are still emerging, and there is much ongoing development and debate, (Thomas & Harden 2007).

The synthesis of qualitative research findings is being promoted by a number of

agencies including the Cochrane Qualitative Methods group, (http:/www.joannabriggs.edu.au/cqrmg/about.html), whose aim is to incorporate synthesized qualitative study findings into systematic reviews on the effectiveness of health care interventions and the Campbell Collaboration (http://www.campbellcollaboration.org/MG/index.asp) who prepare, maintain and disseminate systematic reviews relating to social interventions. In the United Kingdom this stream of work includes the Evidence for Policy and Practice Information (EPPI) Centre and the Social Care Institute for Excellence (SCIE)

The EPPI Centre conducts systematic reviews across a range of topics including social care and health promotion, and receives funding from the Economic and Social Research Council (ESRC), government departments, charities, and national and international partners. They collaborate with the Cochrane Collaboration in health care and the Campbell Collaboration for social interventions.

SCIE's, stated aim is, 'to improve the experience of people who use social care services by developing and promoting knowledge about good practice in social care' by pulling 'together knowledge from diverse sources', (SCIE 2006a), in order to 'create, maintain, disseminate and implement the evidence base for policy and practice in social care' (SCIE 2006b:1). To achieve this aim, in 2002 it established interim guidelines to govern the conduct of systematic reviews these guidelines have now been updated to reflect the changing state of the art in systematic review methods, in order to produce knowledge reviews, (SCIE 2006a). Knowledge reviews comprise several elements: a review of the knowledge available through research, a practice survey to explore knowledge not reported in the literature, accounts by service users and carers, and the contextual knowledge provided by policy, organizational change processes and legislation, (SCIE 2006a, SCIE 2006b). The resulting review is then developed into practice or resource guides.

Knowledge reviews are conducted by teams of researchers and include the involvement of stakeholders (defined as service users and carers, practitioners,

policy makers, researchers) to: -

- ensure relevance of the review to stakeholders.

- empower service users and carers.

- assist in steering the project at various decision points.

- identify additional sources of literature, including user testimony and agency literature not identified through other sources.

(adapted from SCIE 2006a:16)

A recent published review (SCIE 2006b); on older people's views of hospital discharge was supported by an advisory group comprised of service users and carers who had experience of the review subject.

Dixon-Woods & Fitzpatrick (2001:765), suggest that 'a natural tension' exists between qualitative research, an approach that they infer relies on 'interpretation and reflection' and systematic review an approach that seeks to 'expunge the potential for anarchy' that is associated with 'such ungovernable processes'. Following this ideology, 'many attempts at systematic review of qualitative research have 'simply borrowed and sought to impose a template designed to evaluate quantitative work', (Barbour & Barbour 2003:180). Within this tradition Daly *et al* (2006:43), outline explicit criteria for assessing the, 'contribution of qualitative empirical studies in health and medicine' in which they propose a 'hierarchy of evidence for practice', which mirrors the hierarchy of design criteria, used to judge the strength of quantitative evidence in evidence based medicine.

In addition computer software has been developed to aid the systematic review of qualitative evidence. Two examples of software developed for this purpose are the JBI QARI (Joanna Briggs Institute Qualitative Assessment and Review Instrument) and the EPPI Reviewer. The JBI QARI is designed to facilitate critical appraisal, data extraction and meta-aggregation of the findings of

qualitative studies. It is available as a downloadable module, to assist researchers to manage and document a review, from: - (http://www.joannabriggs.edu.au/services/sumari.php). It attempts to establish the results of non-quantitative research as appropriate evidence for health scientists and health practitioners, (Pearson 2004). The EPPI Reviewer is a 'web application that enables researchers to manage the entire lifecycle of a review in a single location'. Users are able to upload studies for screening, complete keywording and data extractions and analyse the results over the internet, (http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=184).

Sandelowski & Barroso (2003b:226, 2003c:154), in an ongoing methodological project to develop a 'usable and transparent protocol', for combining the results/findings of health-related qualitative studies, describe a technique that can be used to create metasummaries of qualitative findings, using 'analytic techniques' that permit conceptual as opposed to narrative synthesis of data, (Sandelowski & Barroso 2003b:158). They define qualitative metasummary as, 'a form of systematic review or integration of qualitative findings in a target domain that are themselves topical or thematic summaries or surveys of data', (Sandelowski & Barroso 2003c:227). Focused on report findings that they argue are 'summaries or surveys- as opposed to interpretive synthesis of data', that do not lend themselves, 'well to the translation or grounded theory techniques' of metasynthesis, (Sandelowski & Barroso 2003b:156), they create metasummaries using the following techniques: extraction of relevant statements of findings from each report; reduction of these statements into abstracted findings; and, calculation of effect sizes, (Sandelowski & Barroso 2003c:228). They propose that 'the calculation of effect sizes constitutes a quantitative transformation of qualitative data' that supports the extraction of more meaning from the data, and the verification of the presence of a pattern or theme, thus uniting the empirical precision of quantitative research with the descriptive precision of qualitative research, (Sandelowski & Barroso 2003c:231).

As Barbour & Barbour (2003) indicate there is a danger that the approaches for synthesizing quantitative studies may be applied to the synthesis of qualitative

research studies. Grypdonck (2006:1373) warns of a 'snake in the grass' alerting us to the danger that the ideology of EBM and quantitative research may affect the roots of qualitative research and endanger the quality of qualitative research. Britten (2002:209), cautions that, 'the attempt to find methods for synthesising qualitative research is not about fitting the round peg of qualitative research into the square hole of quantitative methods but about developing separate methodologies', nor should it be a case of the tail (the checklist) wagging the dog (qualitative research), (Barbour 2001). Jones (2004:108) argues that the systematic review of qualitative research is best served by reliance upon qualitative methods themselves. He warns us that by borrowing the terminology of checklists, standards, matrices, hierarchies of evidence, from the 'arsenal of the quantitative camp', to 'pepper qualitative ground like so many cluster bombs', in our rush to imitate quantitative procedures, that we are in danger of producing a 'mission drift', (Jones 2004:95-96). Zimmer (2006:318) reminds us that 'it is important that interpretive approaches to inquiry not be trivialized, or seen as only laying the foundation for more important 'scientific inquiry'', but should be valued for the 'rich and meaningful ways' in which they can inform relational and aesthetic aspects of practice.

Conclusion

The findings from qualitative studies have the ability to provide a rich evocative medium and evidence resource that would benefit health and social care professionals and the users of health and social care, (Zimmer 2006). However as yet the methods of synthesis remain under-developed, (Dixon Woods *et al* 2001). Zimmer (2006:311), noted that 'the challenge of combining analysis and interpretation from studies……. may prompt synthesists to create new and innovative approaches', and as this review of the literature has shown approaches are still developing.

The method or approach that is chosen to synthesize qualitative research findings will depend on the intended outcome of the synthesis, in terms of the

type of knowledge it aims to generate, and the intended use to which this knowledge is to be put. Reason (1998) identifies three domains of knowledge:

- Propositional knowing- or knowledge *about*, which takes the form of ideas, propositions, and theories.

- Practical knowing, or knowledge *how to*, which takes the form of skills and abilities.

- Experiential knowing, or knowledge by *encounter* from sustained acquaintance face-to face, which is tacit, intuitive, and holistic.

(adapted from Reason 1998:4)

Burnard (1987) further defines propositional knowledge as 'textbook' knowledge that is contained in theories or models, practical knowledge as knowledge developed through the acquisition of skills, and experiential knowledge as knowledge gained through relationship with a subject, person, or thing. Experiential knowing, is knowing through participative empathic resonance with what there is, so as a knower, one feels both attuned with and yet distinct from it, (Heron & Reason 1997).

Methods and Approaches and their Intended Outcomes

Grounded formal theories produce theoretical model of health and health behaviours with the intention of informing policy makers, clinicians and practitioners, through the use of both propositional and practical knowledge.

The original aim of meta ethnography was to derive substantive interpretations from a set of ethnographic or interpretive studies about the same phenomena. To produce new interpretations and or conceptual developments, in a form that is relevant and appropriate to the intended audience, although Noblit and Hare are not specific about whom the intended audience might be. Meta-ethnography is the most commonly cited method used by qualitative researchers engaged in metasynthesis particularly those engaged in systematic reviews. However it has

been noted that modifications to the method are taking place, and it is now evolving into a method that is capable of generating theory, producing both propositional and practical knowledge to inform policy and practice.

Metastudy, is a distinct tri-partite method that produces propositional and practical knowledge by providing a theoretical understanding of a phenomenon that is situated within the sociocultural and historical context in which the original research took place. It does not seek to provide an experiential description of a phenomenon, but to develop midrange theory that is capable of informing policy and practice.

Descriptive synthesis is a distinctive approach to synthesis that aims to describe human behaviour and experience from the 'point of view of the actor' (Halling 2002). In addition to producing propositional and experiential knowledge it seeks in particular to create empathic understanding in its readers or audience, by producing an evocative description of the phenomenon being studied. The potential audience is seen as clinicians, policy makers and unlike some other approaches includes members of the public.

Systematic reviews of qualitative health and social care research findings aim to bridge the gap between research and practice, by producing both propositional and practical knowledge. Their intention is to inform both policy and practice by translating the evidence synthesis to inform policy, and to produce practice guidelines, and resource guides.

Finally, Sandelowski cautions that although the appeal of metasynthesis to qualitative health researchers is akin to the allure of Mount Everest to those who love climbing, we should be mindful that our knowledge claims remain 'grounded in a mantle of humility', and the 'measure of our product is determined by criteria from both art and science' (Thorne *et al* 2004:1362). In addition as Noblit warns, we should be mindful of whose interests we are serving, in order that metasynthesis does not become a 'method' for legitimizing policy and practice in a way that devalues and ignores the experience of the patient or client.

Direction this study will take

The aim of this study is to synthesize qualitative research findings, and communicate them in a way that will make sense to, and have impact on a target audience, which for the purpose of this study will be lay members of the public. I seek to provide a description of the experience of living with dementia from both the perspective of the person with dementia and their care partner, which will engender resonance and create empathetic understanding in the audience. In order to meet this aim and explore the phenomenon of the life world experience of living with dementia from the perspective of the 'actors', (Halling 2002), I will adopt a phenomenological approach to metasynthesis.

I will now move to the second literature review that I undertook relating to the utilization and communication of qualitative research findings.

Utilization and Communication of Qualitative Research Findings

Introduction

> 'As the words grow longer and the concepts more intricate and tedious, human sorrows and temptations disappear, loves move away, envies, jealousies, revenge and terror dissolve. Gone are strong, sensible words with good meaning and the flavor of the real'.

> (Coles 1961:110 cited in Halling 2002:29)

Although written over 40 years ago by a psychiatrist in relation to the technical language, which had come to dominate in his discourse, this statement still holds value for qualitative researchers today. Research reports are often couched in dense academic terms with the result that they are, 'tedious to read', (Halling 2002) and lose the voice of the research participant. The word limit imposed on articles published in peer-reviewed journals often results in the description of the findings being abbreviated, Dahlberg, (2006:445) argues for,

> 'enough room for all levels of the findings to be presented, that is the most abstract levels and concrete levels, including the voices of the informants' in order to 'show the unique lived, and often rich experiences from the people that are in focus'.

> (Dahlberg 2006:444)

The traditional scientific report excludes most audiences other than the academic, both in terms of understanding and accessibility, (Funk *et al* 1995, Sandelowski 1997, Sandelowski 1998). Tierney (1995:384, Tierney 2002:391) states that we have failed to acknowledge the diversity of our audiences and in doing so, 'we have ignored our audience and mistakenly assumed that "one size fits all", as if one writing style is sufficient for all audiences'. Richardson (2002:924, Richardson & St Pierre 2006:959) goes further critiquing the traditional academic style of writing as 'boring' and on 'coming out' to other

academics she, 'found a community of like-minded discontents'. She acknowledges the fact that,

> 'it seems foolish at best, and narcissistic and wholly self-absorbed at worst, to spend months or years doing research that ends up not being read and not making a difference to anything but the authors career'.

> Richardson (2002:924), Richardson & St Pierre (2006:960)

In our, 'legitimate desire for our work to be recognized, it makes sense for us to be creative in making our research more understandable and available', (Halling 2002:36). Holloway & Todres (2007:14), identify two challenges facing qualitative researchers; how to make dissemination activities more imaginative and engaging, and how to transform research findings in a way that will make them relevant and useful to readers and audiences.

Utilization of Qualitative Research Findings

In light of what has been described as a 'growth industry', (the exponential growth of qualitative research reports), there is a 'renewed imperative to make better use' of qualitative research findings, (Sandelowski 2004:1368), in order to address what has been termed the 'so what' factor, relating to the gap between what is known, and what is done, (Estabrooks 1998, Holloway & Todres 2007). Despite this 'renewed urgency' (Sandelowski 2004:1366), to utilize qualitative research findings, the implications of qualitative research appear to have little impact on practice, research, policy, or people who use services, (Keen & Todres 2006). Estabrooks (2001), indicates that research utilization is a complex and poorly understood field, despite the continually expanding and increasing field of qualitative research and, the imperative from decision makers and practitioners to get, usable "best" information.

Estabrooks (2001:283) identifies three classifications of research utilization instrumental (direct), conceptual (indirect) and symbolic (persuasive).

Instrumental utilization is the concrete application to practice of research findings that have been translated into material forms, such as clinical guidelines, care standards, appraisal tools, pathways and intervention protocols. Instrumental utilization emphasizes the visible, tangible, material and measurable outputs of research and is the ultimate goal of empirical/analytical research and the evidence-based paradigm, (Estabrooks 2001, Sandelowski 2004). Estabrooks (2001) suggests that qualitative research findings are more easily used conceptually than instrumentally. Conceptual utilization is the least tangible example of research utilization, it entails no observable action, but involves a change in the way users think about problems, persons or events. Engendering such a change however relies on the findings of the research being portrayed in a way that engages the user/reader. This calls for findings to be presented in a way that evokes vicarious experience by providing a vivid worldview that seeks to create empathic insight and understanding, (Kearney 2001b). In this way findings act as either a revealing window allowing previously unknown aspects of life to be revealed and viewed, or a reflecting mirror that allows personal experience to be reflected on and reframed, (Sandelowski 2004). Symbolic utilization is the use of research findings as a persuasive or political tool to legitimate a position or practice. Its action resides mainly in talk, but it may be a precursor to instrumental utilization as a change in practice, may result from this form of use, (Estabrooks 2001, Sandelowski 2004).

Sandelowski (2004:1373) cites conceptual and symbolic utilization as the most important objectives of qualitative research as the *persuasive* power of narratives, or stories contribute to *understanding*. Sandelowski (2004:1373) defines narrative utility, as: 'the readability, writability, and evocativeness of, and also the meaningfulness and transformative possibilities in, stories'. The phenomenon of understanding is not a methodological accomplishment, that can be captured in terms of procedure or method, (Schwandt 1999:462). Understanding is 'characteristic of our "being' in the world', (Schwandt 1999), it is not merely a prelude to or basis for action, but action itself as worlds are created with words, (Sandelowski 2004:1373). Lomas, (1997 cited in Estabrooks 2001:291-292) asserts, 'that research must be translated into

common knowledge by its purveyors before it will be taken up readily'. Therefore we need to find both a language and a vehicle for communicating our research findings in a way that will engage our audiences, allowing our research findings to become 'common knowledge' thereby enhancing their utility. To achieve this aim, we need a language that can express and communicate these understandings, that remains oriented to the experiential or lived sensibility of the lifeworld, (Van Manen 2007).

Communication of Qualitative Research Findings

Dissemination is the most frequently used word to describe the process that typically occurs at the end point of a linear research design, whereby the findings are moved beyond the confines of the research project to a wider audience. However as previously identified the dissemination of research findings does not necessarily result in their utilization, and qualitative researchers are under a renewed imperative to address the gap between what is known, and what is done, (Estabrooks 1998, Farkas *et al* 2003, Sandelowski 2004, Keen & Todres 2006, Holloway & Todres 2007).

Dissemination can therefore be seen as a somewhat passive activity and indeed some researchers see it as a process that occurs outside of the research project. In a study by Shaw *et al* (2004:13) in which principal applicants of ESRC funded research projects were asked about the dissemination and utilisation of project findings, the researchers saw dissemination as 'a function lying beyond the project' as evidenced by the response of one participant who said, 'We don't do dissemination'. There are exceptions to passive modes of dissemination, these include action research (see for example Hart & Bond 1995) and participatory inquiry (see for example Heron & Reason 1997) both of which involve cyclic processes to bring about change in which participants reflect on what they are learning, and the implications of this for any next steps, (Morton-Cooper 2000).

At this stage it might be helpful to define the word dissemination. The Oxford English Dictionary, defines disseminate and dissemination in the following way:

Disseminate

- To scatter abroad, as in sowing seed.
- To spread here and there.
- To disperse (things) so as to deposit them in all parts.

Dissemination

- The action of scattering or spreading abroad seed, or anything likened to it.
- The fact or condition of being thus diffused.
- Dispersion, diffusion, promulgation.

(http://dictionary.oed.com/)

This definition, has an analogy with the biblical parable of the sower, scattering seed, however some of his seed fell on stony ground, withered, and died. If we as qualitative researchers 'disseminate' our research findings how can we be sure that they will not share the same fate as the seed.

Walter *et al* (2003:13), in their cross sector review on research impact identified two forms of research dissemination: - **passive** that is dissemination that is, unplanned, untargeted, and includes ad hoc forms of communication, such as publication in academic journals, and **active** that is dissemination that tailors research findings to a target audience. Vincent (2006) defines **effective** dissemination as one that uses 'plain and clear' language, in a range of formats appropriately tailored to different audiences. The key features of successful dissemination strategies are:

- tailoring approaches to the audience, in terms of the content, message and medium.
- enabling active discussion of research findings.

Walter *et al* (2003:14)

Tailoring research findings to specific audiences and moving beyond a passive mode of dissemination, and in particular enabling active discussion of research findings, are suggested strategies for enhancing research impact. Therefore a better term to describe this activity might be communication. The Oxford English Dictionary defines, communication and communicate in the following way:

Communication
- The imparting, conveying, or exchange of ideas, knowledge, information, etc. (whether by speech, writing, or signs)

Communicate verb
- To hold intercourse or converse.

- To impart, transmit, or exchange thought or information (by speech, writing, or signs.

- To convey one's thoughts, feelings, etc., successfully; to gain understanding or sympathy.

(http://dictionary.oed.com/)

The word communication suggests an active and engaging process that goes beyond active dissemination, as defined by Walter *et al* (2003), in that it actively seeks to both exchange knowledge and elicit understanding. Mullen (2003:169) speaks of the 'ethic of engagement' and asks us to;

'go beyond creating insightful texts about the human condition to moving ourselves and others to action, with the effect of improving lives' (Mullen 2003:177).

However in order to 'move others to action' we need to attend to the 'communicative concern' (Holloway & Todres 2007:13), in order to create insightful texts that will 'engage the imagination of our readers and audiences'. de Marrias (2004:283), poses the following question, 'how do we communicate or convey our work to others in ways that evoke understanding in them'? Funk

et al (1995:402), propose that as academic researchers if we wish to present our work in a coherent, clear and graceful manner we 'must first unlearn' our training to write in the traditional academic format. Willis (2004:6) refers to this format as 'classic 'cooled out' and abstracted', one in which language tends to be abstracted and analytic thereby running the risk of being lifeless. He calls for broader genres of writing, which do not 'kill' the phenomenon in the process of describing it.

Gilgun (2005) asks us to consider the idea that definitions of science are pluralistic therefore scientific writing is not condemned to 'detached third person' writing. Rather as qualitative researchers we should write in styles that fit with our philosophies of science, allowing us to write, lively, first-person, multiple-voiced texts;

> 'Social scientists observe, interact with, transform, and are transformed by other human beings. Thus, we social scientists have the task of figuring out how to represent ourselves and other human beings in the most full and accurate way possible. So, if other human beings—and we as researchers—have thoughts, emotions, silences, histories, and multiple motivations, then our job is to represent them well ….'
>
> (Gilgun 2005:260)

In order to 'engage in 'elegant communication' with our audience, deMarrais (2004:283) proposes that we use clear and engaging prose that is 'pleasingly graceful and pleasingly ingenious and simple', to describe the complexity of human phenomena. Holloway (2005) describes this as 'writing people', making the thoughts and emotions of the research participant come alive in a way that goes beyond engaging the readers' intellect to inviting them into the text by speaking directly to their emotions, by engaging the "hearts" of readers in an invitational rather than an authoritarian manner, (Todres 2000:42). Todres (2007:5) proposes that in order to produce 'qualitative descriptions of human experience' that facilitate embodied understanding in our audience, we need to address issues about truth (validity) and beauty (aesthetics).

The claim of validity or other alternative terms such as trustworthiness, credibility and authenticity, which have become common in qualitative research should not become a 'turgid legitimization process' to appease readers from the quantitative tradition, (Holloway 2005). We should however claim that as researchers we have reported the experience and reality of our participants and our part in the research process accurately, (Holloway 2005), whilst acknowledging that 'truths are relative, multiple and subject to redefinition', (Charmaz 2004 cited in Holloway 2005). There is a well documented debate and a large volume of literature (see for example: Lincoln 1995, Schwandt 1996, Seale 1999, Meadows & Morse 2001, Morse *et al* 2002, Guba & Lincoln 2005) surrounding the use of criteria to establish validity in qualitative research findings, in what has been deemed an 'obsession with *criteriology*', (Garratt & Hodkinson 1998:515), leading Sparkes (2001), to title a paper, Myth 94: Qualitative Health Researchers Will Agree about Validity. In fact even the use of the term criteria, has been contested by Schwandt (1996:65), he states that, 'rather than use the term "criteria", ………. which connotes efforts to develop and test propositions …….he prefers, ' to speak of a "guiding ideal", that shapes the aim of practice and a set of "enabling conditions''. Sparkes (2001:550) argues that as 'the terrain' in which judgments are made are continually shifting, 'the qualitative health community must grapple with the criteria issue and learn to judge a variety of approaches in different but appropriate ways'. In seeking to find 'criteria' or 'guiding ideals' that shape practice, qualitative researchers are moving away from the empiricist foundations of science and closer to a critical interpretivist project that stresses the blending of aesthetics, (theories of beauty) ethics, (theories of ought and right) and epistemologies, (theories of knowing), (Denzin & Lincoln 2002, Lincoln & Denzin 2003). In this spirit van Manen (1994:18), states that:

> 'Human science research is rigorous when it is "strong" or "hard" in a moral and spirited sense'. A strong and rigorous human science text distinguishes itself by its courage and resolve to stand up for the uniqueness and significance of the notion to which it has dedicated itself – prepared to be "soft", "soulful", "subtle", and "sensitive" in it's effort to

bring the range of meanings of life's phenomena to our reflective awareness'

Ellis refers to 'evocative effectiveness' as a measure of 'validity':

'In evocative storytelling, the story's 'validity' can be judged by whether it evokes in you, the reader, a feeling that the experience described is authentic, that is believable and possible'

(Ellis cited in Willis 2002:14)

Richardson (2000), goes further offering five criteria for judging the literary and aesthetic dimensions of what Denzin (2003:253) terms the 'new writing', criteria, 'that move back and forth across the dimensions of interpretive sufficiency, representational adequacy and authentic adequacy', (Denzin 2003:255). Her first criterion is *substantive contribution*: does the piece of writing contribute to our understanding of social life? Does the writer demonstrate a grounded social scientific perspective? How does this perspective inform the construction of the text? Her second criterion is *aesthetic merit*: does the writing succeed aesthetically, is it artistically shaped, satisfying, complex and not boring, and does the text invite interpretive responses in the reader? The third criterion is *reflexivity*: she asks; if the author is cognizant of the epistemology of postmodernism, how the information for the text was gathered, if there are ethical issues, if the author's subjectivity is in the text, is there adequate self-awareness and self exposure on the part of the author to allow the reader to make judgments about the author's point of view and finally has the author held themselves accountable to the standards of knowing and telling about the people they have studied. Her fourth criterion is *impact*: she asks how the writing affects her, emotionally, intellectually and as a researcher. Finally her fifth criterion, *expression of reality*: asks if the text embodies a fleshed out, embodied sense of lived experience, does it seem "true" – a credible account of a cultural, social, individual, or communal sense of the "real"? (Richardson 2000:937).

In paying attention to the aesthetic demands of writing, Todres (1998:123,

2007:9), poses the question, 'What kind of descriptions produce a feeling of understanding in the reader?' In answer to this question he asks that we attend to both the, 'structural as well as textural dimensions when communicating our understandings of human experience', (Todres 2007:47). Structure refers to a level of description in which context-related themes are expressed to allow readers to gain a general understanding of the phenomenon, in order to achieve this level of description, the specific texture of individual experience is de-emphasized, (Todres 1998). Texture refers to the richness or "thickness" of experience, communicating this dimension grants readers access to the 'aliveness' of the phenomenon, so that it is present not just as theory or principles, but as an intuitive essence that can be related to holistically and is "more" than words can determine, co-create or say, (Todres 2000). The challenge then is to write in a language that attends to both texture and structure in order to provide a qualitative description of human experience that creates empathetic understanding in the reader by communicating a bodily sense of being there. A language that helps:

'to retain the participative and shared qualities of human experience and reveals humans not as outsiders, strangers, mechanisms, clusters of behaviours and chemicals, but as intentional beings that are not reducible to variables or causes and effects'.

(Todres 2003:197)

In order to move beyond the imitation of "scientistic" reports and look towards means of (re)presentation that embrace the humanness of social science pursuits, (Jones 2006), in what Denzin (2001), defines as the 'post-experimental moment of qualitative research', a moment which is defined by a performative sensibility, (Denzin 2001:25), qualitative researchers, are 'increasingly experimenting with compelling and ethically valid ways to re-present qualitative findings', (Sandelowski 1997:130).

Performative Research as a Mode of Communication

The tension between art and science in qualitative research generates creativity, (Holloway & Todres 2007), inviting researchers to engage the imagination of their audiences by communicating their research in an imaginative and engaging way. Expression of knowledge may be primarily propositional but may also involve stories, pictures and other ways of giving voice to aspects of experience, which cannot be captured in propositions, (Reason 1998:5). Reason & Hawkins (1998:81), see creative expression as a mode of inquiry, a form of meaning-making, and a way of knowing in which meaning can be created and communicated:

'through the languages of words which lead to stories and poetry; the languages of action which lead to mime, gesture, and drama; the languages of colour and shape that lead to painting and sculpture; the languages of silence and stillness which are part of meditation'.

(Reason & Hawkins 1998:81)

Presenting social science data in this way can create meaningful encounters with a wider audience enabling feedback that is constructive and dialogical, (Jones 2006). The viewing and interpretation of visual imagery provides people with a basis for speaking about others' experiences and their own personal experiences, (Harrison 2002). In this way art becomes a form of language, that is reflexive, inviting us to question; how we see, what we know, and how we know what we know, (Bochner & Ellis 2003).

The need for innovation in the dissemination of detailed and descriptive and interpretive information has until recently, been largely neglected in the social sciences, (Jones 2006:67). The transformation of qualitative research findings into 'an art form may effectively support the goal of making knowledge available to interested audiences' by combining scientific scrutiny with creativity in order to carry a message with dramatic impact, (Simhoni 2008:354). Combining the two lenses, science and creative arts into a "social science art form", allows us to, 'see more deeply', (Richardson 2000:937). Articulating research findings through the medium of artistic expression can be:

'representational, but it can also be evocative, embodied sensual, and emotional; art can be viewed as an object or product, but it is also an idea, a process, a way of knowing, a manner of speaking, an encounter with Other's ….',

<div align="right">(Bochner & Ellis 2003:508)</div>

In what has been referred as the 'performance turn' in qualitative research. Denzin & Lincoln (2003:612), qualitative researchers have engaged a variety of methods, approaches, techniques, and philosophical underpinnings to progress their studies in order to engage wider audiences and/or to include them in a participatory research process, (Haseman 2006). "Performative," in the widest sense of the word, has become a "working title" for the efforts of social science researchers exploring the use of tools from the arts, (Guiney Yallop *et al* 2008).

In response to the challenge to engage wider audiences in a more imaginative way, 'there has been a groundswell of response from a genre that is calling itself Performative Social Science', (Holloway & Todres 2007:14). Performative Social Science, uses arts-based research methods to move beyond the traditional approaches to data collection, analysis and the communication of research findings, in order to facilitate both the generation and dissemination of new knowledge, (Jones 2006, Jones 2007, Rapport 2008, Guiney Yallop *et al* 2008). In this way we are:

'invited into considering the entire range of communicative expression in the arts and entertainment world - graphic arts, video, drama, dance, magic, multimedia, and so on as forms of research and presentation. Again in moving towards performance the investigator avoids the mystifying claims of truth and simultaneously expands the range of communities in which the work can stimulate dialogue'.

<div align="right">(Gergen & Gergen 2003: 582—583)</div>

It is outside the scope of this review to discuss the use of arts-based research methods as a tool for the collection and analysis of qualitative research data, instead I intend to focus on 'performance' as a medium for the communication of qualitative research findings. In the way that Haseman (2006:5) uses the term 'performative research' to describe research findings that are expressed in a presentational form. When a presentational form is used to report research it can be argued that it is in fact a 'text' – in the way that any object or discourse whose function is communicative can be considered a text and should be understood as such within the qualitative tradition, (Norris 1997, Haseman 2006).

In communicating qualitative research findings, researchers have an array of presentational styles and formats to choose from that include both audio-visual formats and text; these include drama, dance, poetry, song, painting, evocative writing, narrative story, animation, websites, films, photographs, videos, CDs, DVD's and audio-tape recordings, (Keen & Todres 2006, Keen & Todres 2007). Alternative modes of representation and presentation have been used by social scientists across a number of academic disciplines, each of which has its own missions and distinctive signature, (Sandelowski *et al* 2006) for example in education as arts based educational research (ABER), (see for example, Eisner 1997, Norris 1997, Mullen 2003). In making decisions about the most appropriate mode of representation and presentation for qualitative research findings, Saldaña (2003:219) proposes that the key question to be asked is, through which medium or format will the participant's story be, 'credibly, vividly, and persuasively told for an audience'. In answer to Saldaña's question and in line with the aims of my research for the purpose of this review, I intend to focus on modes of representation and presentation of qualitative research relating to aspects of health and well-being which have been transformed into audio-visual 'performances' in order to actively communicate with audiences in a way that is 'thought provoking, engaging, and accessible', (Sparkes 2002:131).

<u>Ethnodrama</u>

Ethnodrama- 'seeks explanation and expression in a public form which opens its meanings to its informants as well as to wide audiences ……… in doing so it 'de-academises' its research report format by translating its data into scripted performances' (Mienczakowski 1997:170). Data consists of interview scripts, field notes, journal entries and other written artifacts. Ethnodrama employs traditional theatre techniques in order to engage live audiences and enhance their understanding of the participants' lives through visual representation and emotional engagement, (Saldaña 1998, Saldaña 2003). In this way ethnodramatic performance allows us to explore what it is like from the inside looking out in order to provide meaning, understanding, and perhaps catharsis, solace and instrumental change, (Mienczakowski, 1996). Post-performance 'dialogical interactions', (Mienczakowski 1995:361), provide forums for collective debate allowing the audience an opportunity to explore the meanings generated by the play. Ethnodrama has been used as a vehicle for health education and to give 'insight into the lives of those who have become marginalised and disempowered through their relationships with health', (Mienczakowski 1997:163) and society. Morgan *et al* (2001:164), see its potential as its:

> 'capacity to concurrently be a visible reflexive tool for informing the provision of informed health services; a mechanism for shaping and informing political and public will; and a vehicle for emancipatory practice'.

Mienczakowski (1995:372), refers to this as 'the public voice purpose of ethnodrama writing'.

'Synching Out Loud' and 'Busting' are two examples, of what, Mienczakowski (1997), defines as critical (emancipatory) ethnodrama. Critical ethnodrama uses elements of Boal's forum theater techniques, in which post performance discussions with audiences, the research team, actors, performance director, script constructors and informant representatives, are 'used to rework scenarios, reinterpret events, and thereby reconstruct and negotiate the individual's understandings of the play's outcomes', (Mienczakowski 1995:361).

Boal's theater, is a 'complex and self-conscious regime in which audience and participant boundaries become blurred', (Mienczakowski *et al* 1996:447), reducing the distance between audiences and players, allowing meanings to be reconstructed, negotiated, and communally shared a process in which the audience become '*spect-actors*', (Mienczakowski *et al* 1996:448). Consequently ethnographic performance texts are about *speaking with* informants and audiences rather than *speaking for* or *about* them, (Mienczakowski 2001:469). Mienczakowski (1995), states that the ethnographic construction of dramatic scripts, creates plausible accounts of the everyday world (vraisemblance) as effectively if not more effectively than traditional research reports. In this way it is able to meet the demands of both an academic and public audience, providing more accessible and clearer explanations than are achievable by words alone, (Mienczakowski 1996). Ethnodrama uses vraisemblance to describe its scripted content and messages as being 'of' or 'from truths' rather than 'similar to truths', (Mienczakowski 1996). Mienczakowski (1995), argues that the validity of the stories is reconfirmed and recontextualised by each successive audience through the continual process of renegotiating meaning and representations, 'so although the stories may be perceived as crafted, they do not lose authenticity or truthfulness', (Mienczakowski 1995:372).

'Synching Out Loud' is an example of critical ethnodrama intended to provide a mirror with which to 'reflect the personal and impersonal forces at play within the psychiatric environment particular to the experience of schizophrenia' (Morgan *et al* 1993:267). Its objectives were to:

- bring issues pertinent to mental health consumers into critical debate.

- 'enable' a discourse between mental health service consumers and providers.

- inform a broad audience about aspects of mental health.

- create an entertaining dramatic piece.

The impetus for this project was derived from critical theory, and the attempt to explicate the nature of power relations between mental health services and consumers of mental health services, (Morgan *et al* 1993, Rolfe *et al* 1995). The content of the play was therefore tailored to contain controversial material in order to engage 'critical' responses from the audience, (Morgan *et al* 1993). In Synching Out Loud, audience members were assigned 'roles' as either patients or psychiatrists, in order to allow them to 'step out', from themselves, slightly, and to be assisted to develop a different, jarring, and hopefully, more critical approach' to the play. (Morgan *et al* 1993).

The play was performed at a number of venues during Mental Health Week culminating in a performance at a psychiatric hospital where,

> 'residents, workers, and their respective families created an interactive performance, in which exits and entrances were as frequent for audience members as for cast'.
>
> (Rolfe *et al* 1995:225)

In this way the audience became a part of the show, demonstrating, shouting, laughing and singing, 'fulfilling their roles as impromptu critical theorists, voicing their concerns and cognitions to hospital staff,' (Morgan *et al* 1993:271). In addition to raising consciousness in the community about schizophrenia, the drama also provided an alternative experiential educational approach for nursing students, 'which was far more cogent than classroom teaching, literature review, or even clinical practice', (Rolfe *et al* 1995:225).

Busting is an alcohol related study which developed the methodology of the 'pilot project', ("Synching Out Loud"), in which validated, 'reworked and fictionalized informant experiences', were used (Mienczakowski 1995:362), to a methodology where verbatim narrative linked by fictionalized account work was used, in order to link plot, subplot and narrative, (Mienczakowski 1995, Mienczakowski 1996). This change occurred at the behest of the project informants who expressed strong opinions that unnecessary literary fabrication would, render the performance as 'fiction instead of being a truth',

(Mienczakowski 1996:248). Fictional links were based on informant accounts or anecdotes. Mienczakowski (1995:363) sees the use of verbatim narrative as an empowering act as to:

> 'recontextualize and reconstruct their words unnecessarily and artificially to appease the aesthetic conventions of academic and literary traditions would have been to reduce further the significance of the voices of the informants and thereby act to disempower them'.

In this way he privileges the informants voices rather than condoning authorial interpretations of meaning, seeing the ethnographer as the conduit through which the stories of the informants are channeled relying on participant validation to redress textual imbalance, (Mienczakowski 1995).

Busting was based upon research carried out in an urban detoxification unit, performed in a variety of settings, the play also involved community drug and alcohol agencies that engaged with audiences in health promotion activities, in particular targeting teenagers and juveniles. Its aim was to not only give voice to health consumers and health workers and to reflexively inform health service providers, health educators and nursing students but also to engage with schools to encourage understanding of the potential of ethnodrama to inform curriculum in teaching areas other than health, (Mienczakowski 1995).

In both Synching Out Loud and Busting the dramas are continually validated by informants throughout their construction, performances are then open to audience debate reflection and evaluation. Both of these performance projects sought and received wide press and television coverage, which in turn initiated dialogue between the media and health service agencies about the issues raised by the plays. In this way, the ethnodrama report process provokes response rather than passively awaiting it, (Mienczakowski 1995).

Autoethnography

Autoethnographic performance, is described as, 'the convergence of the

"autobiographic impulse" and the "ethnographic moment"', (Spry 2001:706). Autoethnography is an autobiographical genre of writing and research, that uses an 'ethnographic wide angle lens' to focus on outward social and cultural aspects of personal experience; then looks inward exposing a 'vulnerable self', in order to produce texts that feature concrete action, dialogue, emotion, embodiment, spirituality, and self-consciousness. Usually written in first-person voice, autoethnographic texts appear in a variety of forms—short stories, poetry, fiction, novels, photographic essays, personal essays, journals, fragmented and layered writing, and social science prose, (Ellis 1999:673). Spry (2001:713), describes 'effective' and 'good' autoethnography, as; 'well crafted writing, that is emotionally engaging, critically self-reflexive, that creates a purposeful dialogue between the audience and the author, through personal identification, and recognition of difference'. Autoethnographic texts create the possibility for a reclamation of voices that have been absent, or misrepresented by traditional social science texts by, confronting dominant forms of representation and power, in an attempt to reclaim, through a self reflexive response, representational spaces that have marginalized those who are on 'the borders', Tierney (1998). However critics of autoethnography, have described it as, 'non-evaluative, anything goes, self-therapizing, sans theory, reason or logic', (Spry 2001:713). Sandelowski, (2004:1378) critiques autoethnography for allowing researchers:

'to escape the disciplined, skilled, and risky work of interpretation; study no one but themselves; legitimate virtually anything in the name of reflexivity and representation; and draw solace from the belief that inquiry that is therapeutic for researchers must be therapeutic for participants'.

Holt (2003), however in defence of autoethnography, argues that although those who, 'produce autoethnography are at risk of being overly narcissistic and self indulgent', (Holt 2003:19), research that links the personal with the cultural encourages empathy and connection beyond the self of the author thereby contributing to sociological understandings.

Examples of autoethnographical performance include, Spry (2001), who

provides a description of an autobiographical performance text BEING THERE – "An Eating Outing: Spectacle, Desire, and Consumption, that focuses on her teenage experiences with anorexia nervosa. Her claim that performing autoethnography has allowed her to:

> 'position myself as active agent with narrative authority over many hegemonizing dominant cultural myths that restricted my social freedom and personal development, also causing me to realize how my Whiteness and class membership can restrict the social freedom and personal development of others'.
>
> (Spry 2001:711)

appears to reinforce the criticism leveled at autoethnography by Sandelowski. Spry (2001:711) however counters this criticism by arguing that autoethnography has the ability to inspire its audience to, "reflect critically upon their own life experience, their construction of self, and their interactions with others within sociohistorical contexts'. She sees this kind of transformative and efficacious potential as the primary goal of effective autoethnography in both print and performance, (Spry 2001). However she provides no evidence of audience evaluation of her performance.

Schneider, (2005) provides an example of performance that draws on her experience as the mother of an adult child with schizophrenia she used her 'autoethnographic observations' to shape a 'performance autoethnography'. Inspired by the work of Gray (2000), she chose to perform her autoethnography rather than present it in a textual form. Through performance she made her 'private story' into a 'public story', making the material more powerful and memorable, in order to engage with audiences in a more embodied way, (Schneider 2005:335). Although no formal evaluation of the performance has taken place, anecdotal evidence from mental health professionals seeing the performance suggests, that it could be used in a classroom context, offering the possibility to, enhance understanding and awareness of the experience of family members of people with schizophrenia amongst mental health

professionals.

Research-Based Theatre

Research based theatre represents an innovative approach to disseminating the results of qualitative studies. Gray *et al* (2000) provide two arguments for the support of research based theatre; the first is the imperative to move research findings beyond the often unread academic article to a mode of presentation, that helps to clarify and transform social understandings; where through audience engagement with dramatic material, the potential for positive individual change is heightened. The second argument is the advantages it has over textual reports in its ability to remain true to qualitative research data, and lived reality by sustaining connections to bodies, emotions, and the full range of sensory experiences present in the original data-gathering situation.

Handle with Care? Women Living with Metastatic Breast Cancer, (Gray 2000, Gray *et al* 2000, Gray *et al* 2001, Sinding *et al* 2002, Gray 2003,), *No Big Deal?*, (Gray 2003, Gray *et al* 2003) about the experiences of men with prostate cancer, and *Ladies in Waiting? Life After Breast Cancer*, (Sinding *et al* 2006), are three research based drama productions, based on research undertaken by a research team based at the Toronto Sunnybrook Regional Cancer Centre.

The scripts for each of the plays, were developed by the research team, in partnership with ACT II Studio, a theatre programme for older adults, their theatre director, and, cancer patients. The development process involved discussion of original research transcripts, followed by improvisation exercises conducted to explore major themes identified by the research team, eventually leading to the creation of a;

> 'large repertoire of both visual images from the improvisation exercises and of quotes selected from transcripts for their representativeness, clarity and visceral impact'.
>
> (Gray *et al* 2000:139, Gray *et al* 2003:224)

The resulting scripts were then subject to further 'tightening', (Gray *et al* 2000) through intensive rehearsals and audience evaluation.

Gray *et al* (2000), defend the use of moving beyond word-for-word excerpts from transcripts as they contend that it, allows for the clearer expression of thoughts articulated by study participants and produces compelling presentations that entertain and engage audiences. In addition they claim the inclusion of cancer patients in the script development team acts as a 'correcting influence', (Gray *et al* 2000:139) as they provide feedback when content or tone stray from the realties of their experiences, 'limiting excesses in the expression of artistic license, or departures into intriguing but unessential byways', (Gray *et al* 2000:140).

Each of the dramas has been performed live on numerous occasions, to audiences comprised of health professionals and the general public, for example, *Handle with Care,* has been performed over 200 times across Canada and the US and has also received media coverage, (Gray *et al* 2003). In addition each of the plays have been recorded and are available on video. Formal evaluation of each of the plays has been undertaken, (for a full discussion see Gray *et al* 2000, Gray *et al* 2003, Sinding *et al* 2006). Feedback from *Handle with Care,* highlighted the following; the research foundation of drama is critical for ensuring a sense of relevance, in particular for audiences orientated towards empiricism, (e.g. health professionals), and the inclusion of multiple voices and perspectives allows more points of recognition, helping audience members to normalize their experiences, and also extending the meanings that can be created and derived from illness, (Gray *et al* 2000).

Health professionals who provided feedback on *No Big Deal,* found this type of research communication more direct and effective than traditional academic papers or didactic talks, and commented on the intimate and emotional engagement with patients that was made possible through the vehicle of drama, the authors argue, that this, 'connexional dimension' is often overlooked in discussion about what constitutes good care, and in interventions designed to improve care, they argue that:

'going beyond the boundaries of one's "self" to join with an "other"- is critical for motivating health professionals to engage compassionately with patients in their care'.

<div align="right">(Gray et al 2003:228)</div>

Audience feedback from *Ladies in Waiting*, was gathered at both live performances of the drama and screening of the video, and revealed a 'cover up' aspect of survivorship suggesting that the ongoing emotional and physical fallout from cancer goes largely unspoken, suggesting that, drama has the potential to 'ease isolation' and 'normalize' the ongoing struggle with cancer, (Sinding *et al* 2005). In a few instances the drama was described as 'depressing or 'upsetting', Sinding *et al*, ask us to consider whether this evaluation necessarily constitutes, 'a negative evaluation', as they claim that:

'quite commonly the assertion that *Ladies in Waiting?* was depressing or upsetting was associated with an equally strong assertion that its portrayal of survivorship was accurate and valuable'.

<div align="right">(Sinding et al 2005:699)</div>

This does however raise ethical questions about the use of research based theatre to deal with potentially sensitive subjects, and it is interesting to note that members of the research and facilitation team have gone on to discuss whether and how to prepare cancer groups and organizations who are considering hosting a screening of the video, (Sinding *et al* 2005:699).

The following two examples of research-based theatre, *Expressions of Personhood in Alzheimer's* and *I'm Still Here,* have both explored different facets of dementia.

Expressions of Personhood in Alzheimer's (Kontos & Naglie 2006, Kontos & Naglie 2007), is a dramatic production based on vignettes written from the field notes of an ethnographic study on embodied selfhood in Alzheimer's disease. The aim of the production was to re-present embodied expressions of selfhood in persons with cognitive impairment, critically exposing the depersonalizing

tendencies of treatment contexts and caregiving relationships in nursing homes, that are a consequence of an assumed loss of selfhood, (Kontos & Naglie 2006). The development of the production was part of a larger research agenda to humanize the practice of dementia care in nursing homes, (Kontos & Naglie 2006).

The rationale for using drama to translate and disseminate the research findings was to:

- provide an accessible presentation to research audiences of diverse disciplinary backgrounds (nurses and ancillary healthcare staff).

- recover the experiential immediacy of the body present in the original data-gathering setting… permitting a powerful demonstration of how selfhood is manifested in gesture and action.

- create a space to engage in a form of social inquiry that resonates simultaneously with critique and the envisioning of new possibilities.

(Kontos & Naglie 2006:302)

The translation of the ethnographic research into a dramatic form involved a partnership with a theatre school, (Kontos & Naglie 2006, Kontos & Naglie 2007). The play features examples of selfhood that are rooted in a theoretical framework that is complex, therefore, Kontos & Naglie (2007), used drama as a pedagogical tool in preference to academic prose, in order to facilitate understanding in the focus group participants as:

'dramatic performance privileges the phenomenological complexity of every day life and recovers the experiential immediacy of the body that was present in the original data gathering situation… allowing us to "evoke" rather than "represent" experience'.

(Kontos & Naglie 2007:807)

The resulting production was shown to a series of focus groups comprised of health practitioners from various disciplines and clinical backgrounds, who were involved in providing hands on care to residents diagnosed with dementia, (Kontos & Naglie 2007). The interactive dynamic created by the focus groups facilitated collaborative learning, in relation to the use of nonverbal self-expression by persons with severe cognitive impairment, and how recognition and support of this self-expression, could enhance person-centered dementia care, (Kontos & Naglie 2007). In addition focus group participants were asked to complete questionnaires to evaluate the use of research-based theatre as a means of raising awareness of dementia care practices, and its potential to change practice, (Kontos & Naglie 2007).

In their evaluation of the process, Kontos & Naglie (2006, 2007), state, that using drama allows audiences to engage at both an effective and cognitive level by offering expressive, sensitive, and experience near performances, that have the potential to make empathic connections, foster awareness, and enhance understanding, thus providing a catalyst for changing caring practices.

I'm Still Here!, is a research-based drama about living with dementia. It is based, on four studies guided by human becoming theory, undertaken with persons living with dementia and, a further study about the lived experience of loss for daughters whose mothers were diagnosed with Alzheimer's disease, (Mitchell *et al* 2006). After experiencing a number of rejections for publication from, 'traditional research journals' and inspired by the work of Gray and his colleagues, Mitchell *et al* (2006:198), state they were:

> 'prompted to stretch beyond journals to present our research findings in order to connect with persons who might benefit from the understanding we had gathered and grown over the span of a decade'.

They too created a partnership with ACT II Studio, to create a script that would bring the research themes to life, weaving direct quotes from research participants, (in order to reflect both the research themes and the theoretical concepts that emerged from their findings), with the intentions, and personal contributions of the researchers, playwright and the actors. The play was

developed in three phases over a period of eighteen months, (for a full description of the play development see Mitchell *et al* 2006).

This initial phase, '*Immersing in the Research'*; involved group building and trust exercises, that led to the sharing of personal experiences of dementia, direct account experiences of dementia, and a visit to a residential dementia unit, the immersion phase prepared the group for the second phase, *Exploring the Research Through Improvisation*. This phase enhanced the group's sense of emotional connection with the research, and with their own experiences of core ideas. The actors kept journals throughout the process, in order, 'to record their inner journey', (Mitchell *et al* 2006:200) allowing them to express profound emotional responses which they may have found difficult to share with the rest of the group. The final phase of the play development, *Weaving the Script*, drew together transcripts of scenes, silent improvisations, highlighted sections of the research interviews, '*aha'* moments, that the group found powerful, and journals of personal experience, (Mitchell *et al* 2006). This process was tempered by the ethical concerns of the playwright, 'I don't know how to do this play without it hurting people', particularly because the intention behind the project was to alleviate unnecessary suffering, and not to be the potential cause of more suffering. This formulated a critical question, was there a way of presenting the research, that would, 'counteract the potential damage of an uninvited and exposed truth?', (Mitchell *et al* 2006:201). This mirrors the ethical concerns expressed by Sinding *et al*, and this concern is one, that I propose to discuss further in relation to my own study in a later chapter.

The play has been performed before live audiences, including people with dementia, family members of persons with dementia and health professionals. Formal evaluation of the play has taken place, using a questionnaire comprised of open and closed questions, (see Mitchell *et al* 2006:203-204). The evaluation has highlighted how, 'something very special happens when persons engage with the performance, … you *experience* the play', (Mitchell *et al* 2006:205). For both family members and professionals this '*experience'*, has made, a 'meaningful and lasting difference in their lives and relationships', and they see people with dementia differently. It is this seeing '*differently'*, that,

'gives rise to different ways of *being with*', giving people understanding of how they can be in relationship with persons living with dementia (Mitchell *et al* 2006:205-206).

The final example of research-based drama, *HIV-Related Stigma in Five Voices* Sandelowski *et al* (2006), is based on a qualitative research synthesis of findings from 93 qualitative studies, conducted with HIV positive women, on stigma. The aim of the project was to produce a DVD, which could be viewed by HIV positive women, whilst waiting for their clinic appointments.

This project posed two unique challenges; firstly its placement on the border between an educational DVD program, designed to relay information in a non-dramatized format, and a play created chiefly to engage the viewer through moment-by-moment emotional connections. Secondly, it diverged from other arts-based transformations of qualitative research, as the object of transformation was based on an, 'artistic transformation' of a research synthesis, not the recordings or transcripts of interview data or, indeed, any data obtained directly from participants, (Sandelowski 2006).

The authors highlight the tensions between them in relation to; 'ensuring the fidelity of the script to the findings', producing a script that, 'acknowledged the many complicated facets of stigma, addressed them in a pragmatic way, and did not offer pat solutions', and the scriptwriter wanted to, 'achieve the right aesthetic balance between science and art, between imparting information to women and conveying understanding of their experiences', (Sandelowski *et al* 2006:1354). After discussion they determined that to be effective, 'our product', had to:

> 'accurately convey the research synthesis; represent and embrace, in a direct and/or creative manner, the diversity of the HIV-positive women who took part in the 93 qualitative studies constituting the data for the research synthesis; emphasize the social rather than medical challenges of HIV infection, encouraging viewers to maintain close and regular contact with health care professionals; minimize social isolation and raise self-esteem

among the HIV positive women who would view the program'.

<div align="right">(Sandelowski <i>et al</i> 2006:1354-1355)</div>

To this end five composite fictional characters were created based on the demographic details of participants in the original studies, with each character relating a narrative based on one or two of the most significant research themes as determined by the research synthesis, in the form of a monologue to camera. A female narrator; provided an opening orientation, to inform viewers that the performers were not actual patients, but were presenting information generated from research interviews with HIV positive women, introduced each of the five characters by noting the one or two research findings to be enacted in their monologue, and provided a conclusion with information and advice the researchers and health care providers felt most vital as closing thoughts. In this way, Sandelowski <i>et al</i> (2006:1357), claim that, 'the narrator would serve as a virtual partner with health care providers to mentor viewers as they processed the DVD's information'.

The research team chose to record the DVD in a studio setting, as without the distraction of five separate settings, viewers could focus exclusively on each character's words and emotions along with the narrator's counsel. A general backdrop, lighting, and instrumental music were used to support the changing moods of each character's message. The research team chose this environment, to encourage those watching the program to suspend their disbelief and become lost in the characters' narratives.

In contrast to some of the other performances reviewed here, the script was based entirely on research findings, and the dialogue was not, reviewed by, or contributed to, by a live audience. The performers were invited to share their impressions of their particular character's language, story line, mood, and general message, and expanded the script's potential through their detailed analysis and acting abilities. The DVD was produced on a modest budget and recorded in a single day.

The aim of the project was to enhance the utility of qualitative research findings for practice. Sandelowski *et al* (2006:1368) conclude by posing the following question:

'whether artistic representations of such findings serve the imperatives of clinical practice as well as they do the qualitative research imperative for faithful and evocative representation and the human need to create has yet to be determined'.

They highlight the complexity of dramatizing research syntheses, which are themselves, several transformations removed from the experiences told to researchers in primary studies, cautioning that, 'such dramatizations can conceal as much as they reveal', whilst at the same time reminding qualitative researchers of the fault line between representation and reality, upon which all human subjects inquiry rests, (Sandelowski *et al* 2006:1368).

Performance challenges and disrupts the more text-based ways of knowing that have been the 'bread and butter' of most academics. As illustrated by this review, some social scientists concerned with performance as research, are mostly interested in accurate representation of research findings, whereas others are more focused on evoking meaning through the creation of 'messy' performance texts, (Gray 2003).   Whichever direction we take, Saldaña (2003:220), reminds us that we are responsible for creating an, 'entertainingly informative experience' that is, 'aesthetically sound, intellectually rich, and emotionally evocative'. As we experiment by developing a play, a prose poem, or a short story, we consistently should question the purpose for which we are writing… 'to be certain that our experiments are efforts at creating change rather than merely an exercise in intellectual narcissism', (Tierney 1995:383) and that we do not leave 'research audiences with a mess'… but show how these modes advance knowledge for the public good', (Sandelowski 2004:1379).

Conclusion

There is an identified need to communicate research findings in genres other than the peer-reviewed journal article, if we wish to reach wider audiences and enhance the utilization of qualitative research findings. In achieving this aim we need to move from writing exclusionist, 'scientistic' texts to writing texts that engage in 'elegant communication' that convey both the 'structure and texture' of the phenomenon that we are describing.

Increasingly social science researchers are exploring the use of 'tools from the arts' (e.g., drama, dance, poetry, song, painting, evocative writing, narrative story, animation, websites, films, photographs, videos, CDs, DVD's and audio-tape recordings) as a way of communicating their research findings. Theatre is becoming a popular forum for communicating with diverse audiences, including members of the public. As this review shows these performances are progressed on a continuum from 'messy' performance texts where the audience become '*spect-actors*', (Mienczakowski *et al* 1996) and performers co-create data as part of both the development of the 'script' and the communication process (see for example Busting (Mienczakowski 1995) and Handle With Care (Gray 2000)) to performances recorded on DVD (see for example HIV-Related Stigma in Five Voices (Sandelowski *et al* 2007) where the performance was based entirely on research findings, and the dialogue was not, reviewed by, or contributed to, by a live audience.

The authors of the studies reviewed in this chapter have all used 'dramatic productions' as a way of actively communicating and utilizing their research findings in a way that goes beyond the passive style of dissemination of research findings presented in peer reviewed academic journal articles. As Mitchell *et al* (2006) note, when audiences engage with performance they '*experience*' the play. This '*experiencing*' provides the 'space' for creating empathic connections, fostering awareness, and enhancing understanding, of the research findings being portrayed in the performance.

In Denzin & Lincoln's (2003) 'performance turn' it is likely that social science researchers will continue to experiment with new methods for communicating their research in aesthetic and evocative ways. As qualitative researchers we do an injustice to our research participants if we fail to move our research findings beyond academic text. The successful communication and utilization of research findings calls for innovative methods that engage our audiences. In seeking to engage with our audience we should be mindful that 'one size does not fit all' and therefore we should consider tailoring our method of communication to our target audience.

Direction this study will take

The aim of my study is to make the findings of qualitative health and social care research useful to a wider audience that includes lay members of the public. In an attempt to achieve this aim I intend to use research-based theatre in the form of a scripted play based on a descriptive synthesis of qualitative research findings. The result will be captured on film in order to reduce the 'alienating distance and hierarchical relationship' produced by traditional forms of representation, (Schneider 2005), for if we are 'to invite our audience in, we must offer texts (in whatever form) that are understandable', (Norris 1997:105).

I will now move to the final literature review that I undertook in this study, which relates to dementia.

Dementia

Introduction

Terry Pratchett, captures the way in which people with dementia are viewed by society in the following words:

> "When you've got cancer you are a, brave battler against the disease. When you've got Alzheimer's you're a boring old fart. That's how society seems to see it"
> (Video – Diagnosis Part1/4 www.alzheimers.org.uk/outoftheshadows accessed 6/11/2008)

Dementia has probably replaced cancer as the most feared of all modern diseases. In The Global Burden of Disease, the World Health Organisation defines Dementia as:

> 'A syndrome caused by a range of illnesses. Most are currently incurable, and cause progressive, irreversible brain damage. They include Alzheimer's disease (the most common cause), vascular disease, frontal lobe dementia and Lewy Body disease. Symptoms of dementia can include memory loss, difficulties with language, judgement, and insight, failure to recognise people, disorientation, mood changes, hallucinations, delusions, and the gradual loss of ability to perform all tasks of daily living'.
> (www.who.int/healthinfo/statistics/bod_dementia.pdf accessed 15/10/2008)

All types of dementia are progressive and culminate in the person's death, either directly or indirectly, (Alzheimer's Society 2008). Society's taken for granted assumptions about the impact of dementia are negative, and the stereotypes of the experience of the disease are exacerbated by the sometimes negative and alarmist reporting of the media and by the negative discourse of politicians and policy makers, (Bond & Corner 2001).

It is estimated that there are approximately 700,000 people in the UK with some form of dementia, (Alzheimer's Society 2008) this represents one person in

every 88 (1.1%) of the entire UK population Alzheimer's Society (2007). Ageing is the biggest risk factor for dementia, and it is estimated that because of our increasingly ageing population and increasing longevity the number of people with dementia will double to 1.4 million in the next 30 years, (Alzheimer's Society 2007, Alzheimer's Society 2008).

Dementia is one of the main causes of disability in later life, and although older people are particularly likely to have multiple health conditions, dementia has a disproportionate impact on capacity for independent living. It is now recognized that dementia is a health and social care priority in the same way as cancer and heart disease, however public funding for dementia research lags far behind that of other serious medical conditions, (Alzheimer's Society 2007, Alzheimer's Society 2008).

There is a long recognized need to improve public and professional awareness and understanding of dementia. The Audit Commissions report, Forget me Not, (2000), highlighted the need for a strategic and comprehensive approach to dementia diagnosis and management, with an emphasis on education and innovation. This report was followed by the National Service Framework (NSF) for Older People (DoH 2001), which accepted that specialist services should support the development of dementia care in general practice, (as advocated by the Audit Commission), and required the development of protocols for dementia diagnosis and management across service boundaries by April 2004, identifying that early diagnosis gives access to 'treatment . . . planning of future care and helps individuals and their families come to terms with the prognosis', (DoH 2001:98).

However despite the recommendations and requirements of these two reports, nearly a decade later there is still concern surrounding the public and professional awareness and understanding of dementia. The following recommendations made in the recent report, Dementia out of the Shadows (Alzheimer's Society 2008:xv), highlighted the need for the:

- improvement of public understanding of dementia.

- improvement of GP's understanding of dementia.

- development of better specialist diagnostic assessment services for dementia.

- provision of information, which is timely and accessible.

- development of stronger peer support networks to help people cope.

In addition, The Department of Health's consultation document, Transforming the Quality of Dementia Care: Consultation on a National Dementia Strategy, (DH 2007), identified the need to improve public and professional awareness as one of its three key themes:

'Public and professional awareness and understanding of dementia be improved and the stigma associated with it addressed…and social exclusion and discrimination should be minimised'.

(DH 2007:11)

In the final Strategy, Living well with dementia: A National Dementia Strategy (DH 2009), this became a stated objective. The strategy acknowledges, that:

'Currently, people with dementia and their carers are prevented from accessing diagnosis, and therefore support and treatment, by a counter-productive cycle of stigma and misapprehension, leading to inactivity. There is a generally low level of public and non-specialist professional understanding of dementia. The stigma of dementia creates a background where both the public and non-specialist professionals find it hard to talk about dementia, and seek to avoid addressing the possibility of an individual being affected. The stigma associated with dementia also acts within professional groups, resulting in low priority being accorded to the development of the skills needed to identify and care for people with dementia. Professional and vocational training are of major importance in

determining professional knowledge, attitudes and behaviour …… The second part of the cycle is a widespread misattribution of symptoms to 'old age', resulting in an unwillingness to seek or offer help. The final element is the false view that there is little or nothing that can be done to assist people with dementia and their carers. This again is a view shared by public and professionals alike.

(DH 2009:25)

These factors are presented in Figure 1 below:

Figure 1: Public and professional knowledge and attitudes are a barrier to diagnosis of dementia and the receipt of good-quality care
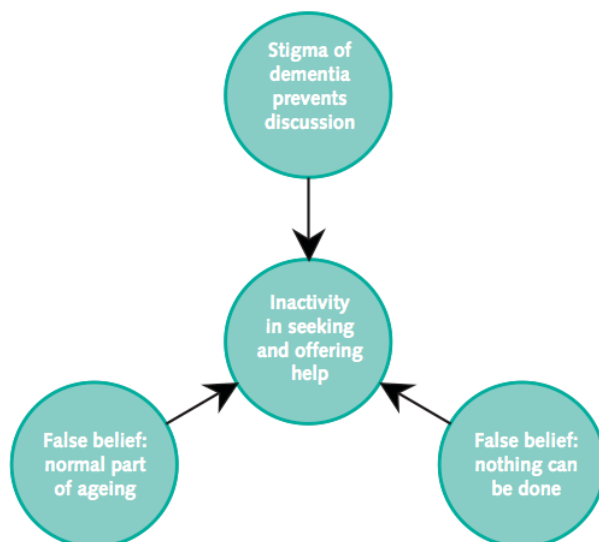
(DH 2009:26)

They intend to meet the acknowledged need to increase awareness and understanding, through a campaign, which they suggest:

'would need to be well planned, incorporating research evidence to build effective campaign messages, and crafted carefully to ensure that it is clear and honest. It should aim to reduce anxiety and promote understanding'.

(DH 2009:28)

In summary there is a continued and identified need for better education for health and social care professionals and members of the public, in order to, improve the understanding of dementia, and to reduce the stigma associated with it, in an attempt to reduce discrimination and prevent social exclusion.

Portrayal of dementia

There is recognition that the media could play a part in raising the profile of dementia and informing the wider public. However dementia is mainly portrayed in its most severe form in what one person with dementia described as a 'sad' picture of Alzheimer's of 'dribbling and nodding' or through announcements of 'wonder cures' that sink without trace, (Alzheimer's Society 2008:45). Portrayal of 'ordinary people' with dementia and their families would give a more 'holistic picture of the impact of dementia' by reflecting some of the 'coping strategies and mechanisms' that they use, showing that 'life after diagnosis' is often 'just about getting on with it', (Alzheimer's Society 2008).

Those who have analysed our current dementia care systems have stated clearly that there is a need for public information campaigns at a national and local level that make 'use of the personal narratives of people with dementia and their carers' in order to change awareness and understanding about dementia. (DH 2007:32).   In order to engender empathetic understanding in others there needs to be:

> 'More coverage of ordinary people saying what it is like for them to have dementia and for their carer/partner to say what it is like to be caring for them having dementia'.
>
> (Person with dementia quoted in Alzheimer's Society 2008:45)

People with dementia, carers, and health and social care professionals have supported the need for better information, (DH 2007:28). Transforming the Quality of Dementia Care: Consultation on a National Dementia Strategy, (DH 2007), and Living well with dementia: A National Dementia Strategy (DH 2009), propose that the key issues to be addressed in the provision of information are

that:

- the person with dementia is no less of a person simply because they have the illness.

- dementia is a common disease.

- dementia is not an inevitable consequence of ageing.

- people with dementia make, and can continue to make, a positive contribution to their communities.

- the social environment is important, and that quality of life is as related to the richness of interactions and relationships as it is to the extent of brain disease.

- dementia is not an immediate death sentence – there is life to be lived with the illness, and it can be of good quality.

- there are many positive things that we can do – as family members, friends and professionals – to improve the quality of life of people with dementia.

(Adapted from DH 2007:29, DH 2009:29)

This recent acknowledgement that the social environment and relationships are paramount in supporting the quality of life enjoyed by the person with dementia, is supported by Kitwood's (1990,1997), seminal work on personhood, which views dementia as a socially-embedded phenomenon. Kitwood's model of dementia challenges what he terms, 'malignant social psychology', that is social interactions, which can damage self-esteem and diminish personhood, the effects of which include feelings of treachery, disempowerment, infantilization, intimidation, labeling, stigmatization, invalidation, mockery, banishment and objectification, (Kitwood 1997). It is now recognized that the performance and behaviour of people with dementia is not exclusively determined by

neuropathology but is also influenced by their; personal histories, social interactions and social contexts, (Downs 1997, Steeman *et al* 2006, O'Connor *et al* 2007).

Dementia is a frightening disease for all of us, particularly as it reminds us of our own vulnerabilities. But by opening ourselves to their world, we create possibilities for relationships with people who are struggling with multiple losses and who feel they are being ignored, discarded, or left behind by the world around them, (Phinney 2002b). As Halling (2008:16), notes, 'any experience of coming to see the other "as if for the first time" is likely to be a milestone in one's relationship with that person'.

<u>Dementia Research</u>

Dementia has been viewed through the lens of many perspectives, but the biomedical and pathological model concentrating on the disease process and the use of medication, continues to dominate dementia research, providing little understanding of what it is like to live with dementia, (Steeman *et al* 2006, Cowdell 2006). Whilst the experience of caring for a partner with dementia is well documented in the literature, with the stress/burden model providing the dominant theoretical perspective it is not until the last decade that there has been a change in emphasis, with a move to a subjective/emotional/experiential understanding providing a broader view of the caring experience, (Hellström et al 2007). At the same time the number of studies that have actively engaged **with** people with dementia rather than carrying out research **on** them has begun to increase, (Cowdell 2006). Research into the experiences of people with dementia falls within three broad categories: information needs, the impact of diagnosis on self-identity, and coping strategies, (Gilmour & Huntington 2005) and more recently their experiences in hospital, (Norman 2006, Cowdell 2008). Downs (1997) acknowledges that when people with dementia are involved in research it tends to be those in the earlier stages of the disease process; this is partly due to issues of informed consent and the ability of researchers to find ways in which to communicate with those in the later stages of dementia.

A great deal of work has been done by researchers and clinicians to identify and describe the symptoms of memory loss, but these technological accounts of illness remain abstracted from the meaningful context of lived experience. We need a richer understanding that takes into consideration symptoms as they are *lived* and *articulated* by those who have the illness for if we exclude their accounts of the lived experience, the language for understanding such experiences will remain impoverished, (Phinney 2002b).

Within social gerontology a stress/burden model has provided the dominant theoretical perspective of family caregiving. Framing care relationships primarily in terms of stress and burden fails to capture the dynamics of couplehood in dementia, (Hellström et al 2007). They suggest that there, 'remains a great deal to understand about the experiences of couples living with dementia', (Helström et al 2007:387). Classic research and care traditions concerned with dementia (biological, psychological and sociological) have mainly focused on persons with dementia and their care giving partners as individuals living in parallel spaces, (Davies & Gregory 2007:481), Forbat (2003:68), notes that 'relationships seem to be missing from much of the theorizing around informal care research where relationships are centralized in the caregiving process'. To date very few studies have focussed on the relationship between the person with dementia and their carer, as experienced by both parties (Forbat 2003). The limited research in this area highlights the need to better understand how couples make sense of and adjust to a diagnosis of dementia, (Davies & Gregory 2007).

Conclusion

Dementia is recognized as one of the main causes of disability in later life coupled with our increasingly ageing population it is a cause for growing concern as evidenced by the recent publication of a National Dementia Strategy. In addition there is an acknowledged need to improve public and professional awareness and understanding of dementia at both national and local levels. It has been suggested the use of personal narratives from 'ordinary

people' with dementia and their 'family carers' would give a more 'holistic picture of the impact of dementia' and aid the reduction of the negative connotations and stigma currently associated with dementia.

Within health and social science research, dementia has been viewed through many lenses with the biomedical model dominating. With a few exceptions current research has treated the person with dementia and their care giving partners as individuals living in parallel spaces, in order to produce an 'holistic picture' of the impact of dementia we need to focus on their shared relationship.

Direction this study will take

In an attempt to illuminate the 'shared journey', of the person with dementia and their care partner, I will focus on existing literature that explores the experience 'of the dementia journey' from both the perspective of the partner with dementia and their care partner.

Overall Conclusion

In conclusion in Chapter 1, I have provided an overview of my study, followed by a three-part literature review, which has informed the direction my study will take. In the first part of my literature review, I both discuss and critique methods and approaches for the synthesis of qualitative research studies. I have chosen to take a phenomenological approach to synthesis in order to describe human experience from the 'point of view of the actor(s)', in this case from the point of view of a person with dementia and their care partner. In the second part of my literature review I both discuss and highlight the need for the better utilization and communication of qualitative research findings, and in particular address the language and mode of communication. My chosen method of communication is 'research-based theatre'. In the final part of my literature review I give on overview of the demographics of dementia, highlight the

increasing imperative to improve public and professional awareness and understanding of dementia and address the stigma associated with the disease, and, finally provide a brief overview of dementia research highlighting the limited understanding of the 'shared journey with dementia' and the need to explore this further.

This study moves away from the traditional ways of collecting data and communicating qualitative research findings, by seeking to develop a new approach for the utilization and communication of existing qualitative research findings, as such it may be considered to be on the 'edgelands'. Rapport *et al* (2004, 2005) have used the metaphor 'of the edgelands' to refer to a new interface within qualitative methodology, between established and new methods. They propose that the interface provides a space where new approaches can develop, and new way of asking and answering questions can be found. They argue for a:

> 'relaxation of the rigid frameworks we have built around the presentation of results and the interpretation of findings to allow room for the unexpected to happen fresh insights to be acquired, and theoretical perspectives to be developed', (Rapport *et al* 2005:38).

If we are to understand individual experience we need methodologies that can provide insights in ways that are illuminating and also ethically acceptable, and whose results may touch and enrich the lives of those who encounter them, (Rapport *et al* 2005).

The overarching aim of my research is to utilize existing research findings in a way that is useful to a target audience, and in particular to create empathic understanding, this aim is summed up by Opie (1993:9) who in a text on caregiving, argues that:

> 'a research outcome which offers those already within the situation... a means (of) gaining knowledge through credible representations, allowing

them to recognise the significant features of their own specific experiences, is as valuable in terms of its production of knowledge as the more systematic analytical text which produces knowledge in a form recognisable in a specific academic discipline'.

In order to achieve this aim in the next chapter I will move to the 'edgelands' in order to develop a framework for the synthesis and communication of qualitative research findings.

Chapter 2: Methodology

Introduction

The aim of my study is to develop a framework for the synthesis and communication of qualitative research findings. The development of this framework is motivated by the concern to better utilize the insights from qualitative research already in the public arena. The synthesis of such studies for use for various purposes pose particular challenges as one is not synthesizing primary data (as in conventional qualitative research) but is synthesizing both the findings and the secondary insights that are formulated from such studies. The strategy for synthesizing studies that is developed in this framework, nevertheless still draws on phenomenological and hermeneutic principles for synthesizing the essential meanings of these studies, and communicating them in accessible, coherent and evocative ways.

The stages of this framework proceed through the following four overarching stages:

Stage 1:   Identification of a Strategy for Searching for Relevant Qualitative Studies.

Stage 2:   Identification of Inclusion & Exclusion Criteria.

Stage 3:   Identification of a Strategy for Synthesizing the Identified Studies.

Stage 4:   Identification of a Communication Strategy.

Stage 1: Search Strategy

Introduction

The aim of literature searching is to identify relevant articles, and to exclude irrelevant articles for a defined research area, topic or question. There are a number of strategies available for searching for qualitative research, but little is

known about their effectiveness, and few have been formally evaluated, (Shaw *et al* 2004). Grant (2004), carried out a study to gain an overview of researchers experiences of searching for qualitative research studies, with a particular reference to the use of optimal search strategies, (complex search strategies used to optimize the way evidence is retrieved from electronic databases), she found that 67% of those interviewed supplemented their database searching, with other techniques, summed up by one respondent in the following words,

'searching databases is a very small part of what I call a literature search …. I would (also) rely on hand searching libraries ('pootling') and talking to colleagues'.

(Grant 2004:25)

Searching for Qualitative Studies

The results of searching electronic databases are measured in terms of yield, recall and precision, (Barroso *et al* 2003). Yield represents the number of 'hits' generated by the search terms, recall relates to the percentage of relevant documents in the database that have been retrieved, and precision is the percentage of retrieved documents that are relevant, (Barroso *et al* 2003, Flemming & Briggs 2006). A study by Shaw *et al* (2004), which involved searching six electronic bibliographic databases for studies on support for breastfeeding found that 96% ((7420-262)/7420) of the 'potentially relevant reports' retrieved were irrelevant, indicating that a high yield does not necessarily result in high precision rates. It is ironic that with the increase in information available the retrieval of relevant studies has become harder. A number of studies have highlighted the challenges of searching for qualitative studies, (Dixon-Woods & Fitzpatrick 2001, Dixon-Woods *et al* 2001, Barroso *et el* 2003, Fingfeld 2003, Walsh & Downe 2005, Dixon-Woods *et al* 2006, Walsh & Downe 2006, Bondas & Hall 2007a).

The task of screening records from electronic bibliographic databases is 'daunting' as the range of thesaurus terms that describe qualitative methodologies are limited and vary across databases, (Shaw *et al* 2004, Dixon-

Woods *et al* 2006, Bondas & Hall 2007a). Each database system also operates different and complex search strategies, including Boolean operators, MeSH headings, delimiters and expanders, and include 'minor idiosyncrasies' such as where commas should be placed in an authors name', which can be both irritating to the researcher and provide invalid search results, (Barroso *et al* 2003). Barroso *et al* (2003:167), highlight that a, ''no records found' message may not reflect the absence of records so much as the systems inability to map the search terms used. Electronic citation databases are also susceptible to human error, as indexers can make mistakes when entering the information onto the database, (Barroso *et al* 2003). In addition unlike much published quantitative research, qualitative papers appear more frequently in books and book chapters, both of which are underrepresented in databases, (Walsh & Downe 2006).

The process of sifting retrieved citations in order to determine relevance is a time consuming process, (Lloyd Jones 2004). One well-documented problem is the difficulty of determining relevance from a paper's title, (Barroso *et al* 2003, Lloyd Jones 2004, Flemming & Briggs 2006); this problem is further compounded by the absence of abstracts for many qualitative studies, (Dixon-Woods *et al* 2006). In addition locating published and unpublished reports, (e.g. Doctoral theses, Conference papers etc) can be both 'challenging', (Finfgeld 2003) and 'costly', (Paterson *et al* 2001, Barroso *et al* 2003). Dixon-Woods *et al* (2006), propose that the, precision of searching for qualitative studies could be enhanced through the improvement of electronic indexing systems, and by the qualitative research community making their study designs more explicit.

The question then becomes, how systematic does a literature review have to be?, (Walsh & Downe (2006). Barbour & Barbour (2003:184), caution that in our rush to comply with the imperatives of systematic review and synthesis of research it is important that 'we do not lose sight of the fertile ground traditionally visited and capitalized upon in wide-ranging scholarship'. Greenhalgh & Peacock (2005:1065), state that regardless of how many databases are searched, searches, 'cannot rely solely on predefined protocol

driven search strategies' but must look to strategies that might seem less efficient; 'such as browsing library shelves, asking colleagues, pursuing references that look interesting, and simply being alert to serendipitous discovery' as they 'are likely to identify important sources that would otherwise be missed'. Searchers must also be guided by the resources available to them at the time of their search, in terms of time, money, the number of people involved in the search, and the richness of their search environment, including the availability of expert librarian support, (Barroso *et al* 2003).

Therefore in this study I sought to identify a search strategy that would be able to be undertaken by a sole researcher, working without the support of a librarian, one that would attempt to overcome the barriers to searching that are identified above. A strategy, that would return to the 'fertile ground', suggested by Barbour & Barbour (2003), one which would more closely mirror, 'the real behaviour of information searchers', (Bates 1989:407), and move away from the 'pre-defined protocol searches' of databases with their potentially 'low precision rates'. The search strategy I identified for use in this framework, that best appears to overcome the identified difficulties associated with searching for qualitative research studies, is based on Bates (1989) "berrypicking" model and is shown below.

Framework- Search Strategy

This framework will use searching strategies identified in the "berrypicking" model (Bates 1989), which 'is much closer to the real behaviour of information searchers than the traditional model of information retrieval' (Bates 1989:407), whereby users:

> 'begin with just one feature of a broader topic, or just one relevant reference, and move through a variety of sources. Each new piece of information they encounter gives them new ideas and directions to follow and, consequently a new conception of the query'.
>
> (Bates 1989:409)

The search then becomes an iterative process where the question is treated as, 'a compass rather than an anchor', (Dixon-Woods *et al* 2006).

This framework will employ the following strategies:

- Footnote chasing (backward chaining) this involves following up footnotes found in books and articles of interest, moving backwards through reference lists.

- Citation searching (forward chaining) this involves following up citations of selected articles and their authors.

- Area scanning this involves browsing materials that are collocated with materials located earlier in a search.

- Journal searching this involves checking core journals in the subject area.

- Author searching this involves searching by author name to see if the author has other work on the same topic.

(adapted from Bates 1989)

Stage 2: Inclusion and Exclusion Criteria

Introduction

The increasing popularity of qualitative research has led to calls for it to be incorporated into the evidence base and to contribute to policy, (Barbour & Barbour 2003, Spencer *et al* 2003). As a result there are a large number of sets of guidelines, frameworks and checklists of criteria for assessing qualitative research in existence. A review by Spencer *et al* (2003), located 29 frameworks and checklists relating to assessment criteria for judging quality in qualitative research. Within the systematic review tradition there is a tendency to, 'vet' papers using a checklist of criteria. Jones (2004), argues that this rush to imitate quantitative procedures is producing 'a mission drift'. In particular some have

attempted to mirror the criteria used in the systematic review of quantitative studies by seeking to impose a 'hierarchy of evidence for practice' proposing that grounded theory studies provide the highest level of evidence and single case studies the lowest level of evidence, (Daly 2006). Dixon-Woods *et al* (2006), however point to the inappropriateness of specifying a hierarchy of evidence in qualitative research. Popay (2005), reflects that the act of floccinaucinihilipilification[1] is one that has been frequently directed at the product of qualitative enquiry and proposes that:

> 'just as debates about research paradigms have moved on-focusing now about issues of difference and complementarity rather than conflict and competition-debates about the role of different approaches to evidence synthesis need to focus on maximising the knowledge and insights generated by using a range of methods appropriate to the questions being asked'.

> (Popay 2005:1079)

It is important to recognize that "truth claims" are very different in the context of qualitative research, as they acknowledge the existence of multiple views, (Booth 2001, Popay 2005).

A scoping study by Walsh & Downe (2006), identified eight existing checklists and summary frameworks specifically for appraising qualitative research studies for inclusion in metasyntheses. Interestingly they then went on to add to this number by producing an eight stage checklist of their own, one which they claim should be 'applied reflexively and imaginatively', (Walsh & Downe 2006:118). Barbour, (2001:1115) however cautions that 'there is evidence that checklists are sometimes being used prescriptively' despite 'disclaimers by their authors' that they should be viewed as reflexive. There is a great deal of overlap between checklists, with some being more prescriptive than others, (see for example Campbell *et als* 2003, use of the Critical Appraisal Skills Programme (CASP) criteria). Koch (1996:178), proposes that researchers need to 'select or

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[1] The action or habit of estimating as worthless- (Oxford English Dictionary)

develop, the most appropriate criteria for their particular study'. In doing this it is not my intention to produce yet another prescriptive checklist for the appraisal of qualitative research, but instead to think of the appraisal of qualitative research, as an iterative process that calls on the reflexivity of the researcher, rather than as a rigid and dogmatic checklist with an "in/out" decision, (Barbour 2005:1080). Thus heeding the warning by Barbour and Barbour (2003), that whilst there exists such a thing as bad qualitative research, the over-rigorous application of checklists can be counter productive. In identifying the inclusion and exclusion criteria for this framework, I will in turn focus on the following; ethical considerations, quality criteria, data sources, sample size, epistemological considerations, and highlight how they inform the inclusion and exclusion criteria for the framework I am developing.

Ethical Considerations

Within qualitative research ethical considerations require that you obtain informed consent from those who participate in your research. This poses a particular question for those involved in the synthesis of qualitative research, as the participants in this case could be considered to be the studies that are included in the synthesis. In most cases these will be studies that are conducted by researchers other than the person undertaking the synthesis. Therefore do those carrying out the synthesis have an obligation to obtain consent from the authors of studies, in particular should they return their synthesis to the original author(s) for 'member validation'? Member validation or checking is a technique 'for establishing the validity of researchers' interpretations of data collected from research participants', (Sandelowski 1993:4), achieved by comparing the researcher's account with that of the participant to establish the level of correspondence between the two, (Mays & Pope 2000). It is claimed that a research report derived from this process both authenticates data and contributes to the rigour of the research process. Koch & Harrington (1998), however suggest that member checking has more problems than the literature reveals, cautioning that there are ethical and practical problems with the return of data to the participants, which are not often discussed.

In answering the first part of the question relating to consent, I propose that just as we acknowledge the influence of the work of others, in other forms of scholarly writing through the use of citations, that we apply this principle to the studies used in the synthesis. In this way by acknowledging the work of the original study authors through the use of citations we negate the obligation to seek their written consent to include their study in the synthesis. In relation to 'member validation', Britten *et al* (2002:215), propose that the authors of original studies be contacted, to test the extent to which interpretations are supported by the primary data indicating that 'discussions with the original authors could lead to constructive dialogue about the interpretation of findings'. They claim that such an exercise resembles member validation in primary research. Lloyd Jones (2004), however notes that although it might be theoretically appropriate to ask the original authors of the primary studies for clarification of key points, that in practice this would not be feasible, in terms of the ability to locate and contact the original researcher, and on their willingness to participate. In addition many argue against member checks, and in particular phenomenologists reject the notion of member checking as the researcher transforms the data in the process of analysis and writing, (Holloway 2005).

For these reasons in this framework it will not be necessary to seek either written consent from the author(s) of the original studies or to undertake member checks.

Quality Criteria

The issue of quality in qualitative social research remains an open conversation, (Mullen 2003:168). The search for criteria for assessing the validity of qualitative research is not a new preoccupation, (Popay *et al* 1998). There is a large body of literature in existence concerning quality or its substitute words, (see for example Lincoln & Guba 1985, Lincoln & Guba 1990, Erlandson *et al* 1993, Koch 1994, Koch 1996, Schwandt 1996, Emden & Sandelowski 1998a, Emden & Sandelowski 1998b, Sparkes 2001 Whittemore *et al* 2001, Morse *et al* 2002, Sandelowski & Barroso 2002, Dixon-Woods *et al*

2004b). A review by Dixon-Woods *et al* (2004a), identified more than 100 sets of proposals for quality in qualitative research.

The process of quality appraisal is a particularly contested issue in relation to qualitative synthesis. The epistemological 'positions' on criteria range from at one extreme a postmodernist relativist position which rejects the notion of criteria altogether, and for 'whom knowledge naming is like catching the wind', to, the other end of the spectrum, positivism which clings 'to the dogma of objective truth' and the retention of concepts common to the positivist traditions of quantitative research, (Spencer *et al* 2003, Walsh & Downe 2006). In between the two extremes there are those who propose alternative criteria that relate specifically to qualitative research such as the notion of guiding principles and ideals, (Spencer *et al* 2003).

There appears to be no final answer as to what constitutes 'quality' or substitute terms such as rigor, goodness, standards, guidelines, or principles in qualitative research, or to how such 'quality might' be gauged, (Emden & Sandelowski 1998b). Indeed Van Manen (2006:713), reminds us that if we are seriously committed to qualitative inquiry:

> 'we should resist the temptation to surrender to a view of method that hollows out our understandings and cuts us off from the deeper sources meaning'.

Sandelowski (1993:1), proposes that it is the ability of qualitative research to create 'evocative, true to life, and meaningful portraits, stories, and landscapes of human experience that constitute the best test of rigor'.

In considering Sandelowski's statement it may be helpful to reflect on the use of a 'signal score' to assess the relevance of publications, (Edwards *et al* 1998, Edwards *et al* 2000, Jones 2004). This technique does not eliminate research because, 'it is not at a certain level of evidence' or 'it has certain methodological weaknesses', (Jones 2004:99). Rather it advocates balancing an assessment of a studies methodological quality against the weight of its message, referred to

as 'signal to noise ratio'. Booth (2001), highlights that by excluding studies on the basis of design alone we incur the risk of denying valuable insights, which contribute to the interpretation of a phenomenon. In meeting the aims of my research to provide a descriptive synthesis that illuminates and explores the phenomenon of life world experiences from the perspective of the 'actors' it is the signal from the study that is of paramount importance. The selected studies should contain a strong 'signal', by which I mean the 'weight of the message' should retain the voice of the research participants. Indeed Jensen & Allen (1996:556), contend that the findings of a synthesis are 'internally validated through the quotes of the studies' participants and the metaphors used to describe these experiences'. Therefore the key question to be addressed is:

> 'does the research as reported, illuminate the subjective meaning, actions, and context of those being researched?.... the most important marker of the calibre of studies seeking to illuminate lay knowledge is the extent to which the research adopts a *verstehen* approach to knowledge, illuminating the meanings people attach to their behaviours and experiences…in studying the way in which actors act and employ their knowledge and experience, we can better understand the interaction between the experience of ill health, health action, and the use of services' .
>
> (Popay *et al* 1998:45)

In an attempt to address this question this framework will assess the quality of a study by the use of the following criteria, asking does the study show:

- Substantive contribution - does the piece of writing contribute to our understanding of social life?

- Aesthetic merit - is the writing artistically shaped, satisfying, complex and not boring, inviting interpretive responses in the reader?

- Reflexivity – has the author held themselves accountable to the standards of knowing and telling about the people they have studied?

- Impact – does the writing resonate emotionally and intellectually?

- Expression of reality – does the text embody a fleshed out sense of lived experience, does it provide a credible account of a cultural, social individual, or communal sense of the "real"?

<div align="right">(adapted from Richardson 2000)</div>

Data sources

Currently no consensus exists as to the best data sources for metasynthesis, (Finfgeld 2003). Some researchers exclude findings reported in 'grey literature', literature that is not found in peer reviewed journals and includes conference papers, books, government publications, public, private and voluntary sector reports, (Jones 2004), insisting on using only findings from peer reviewed journals, as they have been reviewed for quality, (Finfgeld 2003). However others have cautioned against the sole use of peer reviewed articles, Beck (2002a: 454), searched for unpublished reports in order to avoid "publication bias". However locating unpublished reports can be challenging and costly which may restrict the use of these types of data sources, (Finfgeld 2003). In making a decision about which sources to include in a synthesis it is important to heed Sandelowski *et al* (1997), caution, that valuable data can be excluded if unnecessary restrictions are imposed.

Jones (2004:99), highlights that 'grey literature is non-conventional, fugitive, and sometimes ephemeral but, by its nature often more inclusionary than standard peer-reviewed' work offering a greater voice to people who use health and social care services. Indeed one of the problems of relying solely on peer reviewed articles is that 'the extremely detailed description of method and analysis', (Chapple & Rogers 1998: 560), allows little space for the presentation of results, and as previously identified this particularly results in the loss of the 'voice of the informants'. Barbour & Barbour (2003:184), caution that in our 'scramble to climb aboard the evidence bandwagon' we are narrowing the scope of literature that we review, they suggest that we could 'reap enormous benefits' by examining more diverse literature, including first person accounts,

they cite the example of the DIPEx project hosted by the University of Oxford which links a video and audio database of patients experiences with evidence-based information, relating to illness and treatment options as an example of the use of first person accounts, (see Ziebland 2000 for more details). Van Manen (1994), points to the use of experiential descriptions in literature, poetry, or other story forms as a 'fountain of experience', which can increase practical insights into human experience, by:

- enabling us to experience life situations, feelings, emotions and events that we would not normally experience.

- broadening the horizons of our normal existential landscape by creating possible worlds.

- appealing to us in a personal way.

- evoking the quality of vividness in detailing unique particular aspects of life that could be my or your life.

(adapted from Van Manen 1994:70)

In particular biographies, autobiographies and personal life histories contain, 'the rich ore of lived-experience descriptions' (Van Manen 1994:72), providing rich potential for phenomenological analysis, or conversion into story or anecdote, (Van Manen 1994). This provides a possibility to gain evocative life-world descriptions of personal experiences that are sometimes missing from the classic 'cooled out' and abstracted' text of the peer reviewed journal article.

Therefore in order to produce a synthesis that is rich in life-world descriptions of personal experiences, this framework will include 'data' from a wide range of published sources, including peer reviewed journal articles, grey literature, and first person accounts in the form of autobiographies.

Sample size

Again there is no consensus regarding the optimal number of studies to be included in a synthesis. A review of studies identified by Finfgeld (2003), reported sample sizes ranging from 3 to 292. A particular consideration is whether the sample size relates to the number of studies included in the synthesis or the number of articles, as many studies are published in more than paper. Finfgeld (2003:899), suggests that if there are multiple papers resulting from one study that, 'it would appear prudent to purposively sample among studies to ensure a fair representation of findings' as 'this strategy will help prevent overvaluing findings on the number of times they appear in the literature'. However if the aim of the synthesis is to provide a descriptive analysis of a phenomenon the use of multiple papers may allow for the building of a more in-depth and comprehensive picture.

Sandelowski *et al* (1997), caution that overly large samples can impede deep analysis and threaten the interpretive validity of studies, however more recently in a 'Handbook for Synthesizing Qualitative Research', (Sandelowski & Barroso 2007:25), recommends that 'the validity of any research project rests in part on having retrieved all relevant reports of studies in a target domain'. The question here centres on the use of the word 'relevant', as the decision as to what is relevant is subjective and subject to different interpretations. Finfgeld (2003:898), 'recommends that the area of investigation should be broad enough to fully capture the phenomenon of interest but sufficiently focused to ensure that the findings are meaningful to health care providers, researchers, and policy makers'. The size of sample is likely to be governed by the focus of the study, the breadth of the study, the type of synthesis performed, and the amount and quality of data available. The aim of this framework is to produce a descriptive synthesis that provides a thick description of the phenomenon under study therefore 'the aim is not to count how many' but to 'understand a phenomenon more deeply through adequate exposure to qualities of the phenomena', (Todres 2005:109-110), therefore sample size is not prescriptive but will be guided by the depth and richness of the data available.

Epistemological Perspective

With regard to epistemological considerations, some researchers only synthesize studies from the same epistemological perspectives, (Estabrooks *et al* 1994, Jensen & Allen 1996), whilst others advocate combining findings generated from differing epistemological perspectives because of their complementary nature, (Finfgeld 2003), or because a metamethod analysis is carried out as part of the process as in metastudy, (Paterson *et al* 2001). Beck (2003:318), however indicates that a meta-synthesis profits from the assortment of methodological and theoretical contexts within the various studies included in it, combining such studies can contribute to the breadth and depth of the descriptions of the object of the study and may counterbalance the strength and limitations of individual methods, (Lloyd Jones 2004).

Holloway & Todres (2003), point to the fact that many elements of qualitative research are shared between the approaches; phenomenology, 'uses coherent narratives, and presentations of experience'; grounded theory, may focus on, 'the meaning and interpretation of experience' and ethnography relies strongly on the, 'naturally occurring language of the participants in the field'. This is of particular relevance when seeking to provide a synthesis of qualitative studies that communicates life world experiences in a way that seeks to resonate with an audience comprised of members of the public. This framework seeks to identify studies, from differing epistemological perspectives, which focus on the experiences of others expressed in their own language.

This represents the final consideration relating to inclusion and exclusion criteria. A summary of the criteria is given below.

Framework- Inclusion & Exclusion Criteria

This framework will use the following inclusion and exclusion criteria for the appraisal of qualitative studies identified during Stage 1 of this model:

Ethical Considerations

Not necessary to:

- Seek written consent from the author(s) of the original studies
- Undertake member checks.

Quality Criteria

To meet the quality criteria the following questions should be asked of the study: Does the writing show:

- Substantive contribution?
- Aesthetic merit?
- Reflexivity?
- Impact?
- Expression of reality?

Data sources

Data will be selected from a wide range of published sources including:

- Peer reviewed journal articles
- Grey literature
- First person accounts in the form of autobiographies

Sample size

The sample size will be guided by:

- The depth and richness of the data available.

Epistemological perspective

Studies will be drawn from:

- Differing epistemological perspectives, focusing on the experiences of others expressed in their own language.

Stage 3: Approach to Synthesis

Introduction

The world of human experience is a complex thing, (Dahlberg *et al* 2001:18) consequently the pivotal question is, what is the adequate research method to investigate this experience?, (Mortari 2008). Phenomenology is the name for the major movement in philosophy and the humanities in 20th century continental Europe. Initiated by Husserl, it has amongst its major contributors Heidegger, Sartre, Merleau Ponty, Ricoeur and Levinas, (Giorgi 2005:76). More recently it has been developed as a human science that is employed in diverse disciplines including clinical psychology and the health sciences, (Giorgi 2000, Adams & Van Manen 2008). Giorgi (2000:5) points to the difference between philosophical and scientific phenomenology thus:

> 'philosophical scholarship contains a certain style; the philosopher works alone and reflects upon others and the phenomena of the world based upon his own experiences and reflections. Scientific scholarship also has a certain style, one that turns to toward the world or others as the basis for its interrogations'.

The value of phenomenology is that it investigates how human beings experience the world, allowing every lived experience (phenomenon) to become a topic for phenomenological inquiry, enabling us to explore *directly* the originary or prereflective dimensions of human existence, (Adams & Van Manen 2008). The term "lived experience" derives from the German *Erlebnis*-experience as we live through it and recognize it as a particular type of experience, (Adams & Van Manen 2008). Ultimately phenomenology is not interested in explanation but is interested in the 'essential features of types of experience or consciousness', (Bentz & Shapiro 1998:98-99). In this way phenomenological enquiry is not unlike an artistic endeavor, a creative attempt to somehow capture a certain phenomenon of life in a linguistic description that is, both holistic and analytical, evocative and precise, unique and universal, powerful and sensitive, (Van-Manen 1994:39). 'It is not a case of our gaining a sort of detached awareness of the internal perspective of the other' but rather we place ourselves, 'in his or her world so that it compellingly unfolds for us', (Halling 1981:13). Phenomenology brings:

> 'researchers into contact with phenomena in a particularly direct and immediate way, allowing them to describe and make sense of issues that have not been so well understood before'.
>
> (Dahlberg & Halling 2001:12)

Phenomenological research is generally divided into two types: *descriptive* phenomenology and *interpretive* or *hermeneutic* phenomenology, (Todres & Holloway 2006:228). Descriptive or Husserlian phenomenology is based on three dominant notions: intentionality, essences and phenomenological reduction or bracketing, (Koch 1995). Husserl introduced the concept of the life world or lived experience, claiming that in order to access this life world we need to return to the taken-for-granted experiences and re-examine them bringing to light the ultimate structures of consciousness that is the 'essences' or 'essential structures', (Koch 1995, Bentz & Shapiro 1998, Todres & Holloway 2006). Essences refer to invariant structures that can be intuited within an experienced world of meaning, neither objective nor subjective they refer to an intelligible order that is intuited in the way that things are given to

consciousness, (Todres 2005). The essential structure is determined through the process of phenomenological reduction (epoché) or 'bracketing' whereby the researcher suspends 'belief in the outer world' neither confirming or denying its 'reality' in order to allow the phenomenon to appear in its ordinary givenness, (Koch 1995, Mortari 2008). Through the phenomenological reduction the researcher practices imaginative variation, by imaginatively varying the constituents of a phenomenon in order to consider its boundaries and internal relationships, until only the intransigent features remain, (Todres 2005, Rapport & Wainwright 2006). In short one asks at what stage does it imaginatively stop being what it is and become something else, (Todres 2005). In arriving at the essential characteristic of a phenomenon, one has arrived at an understanding of the way in which the object's essential state, is 'given to conciousness', (Rapport & Wainwright 2006). Giorgi (1997:240), contends that 'no work can be considered to be phenomenological if some sense of the reduction is not articulated and utilized'.

The work of interpretive or Heideggerian phenomenology, or following Gadamer hermeneutic phenomenology is to clarify the conditions in which understanding takes place, (Koch 1995), using 'interpretation and personal or theoretical sensitising to highlight important themes', (Todres & Holloway 2006:236). Heidegger criticizes the notion that meaning is totally neutral and unsullied by the interpreter's own view of the world and refutes Husserl's notion of bracketing, thus the researcher brings their own pre-understanding to the text, (Koch 1995). In this way every encounter entails an interpretation based on the researcher's background:

> 'we are self interpreting, self-defining, living always in a cultural environment, inside a web of signification we ourselves have spun. There is no outside, detached standpoint from which we gather and present brute data. When we try to understand the cultural world, we are dealing with interpretations and interpretations of interpretations'.
>
> (Taylor 1987 cited in Koch 1995:831)

In this way meaning is 'pointed out' in multiple ways, relying on personal insight and relevant theories. Gadamer used the term 'fusion of horizons' to mean how different understandings could come together, to achieve broad shared insights, that emphasise both uniqueness and diversity, (Todres & Holloway 2006).

A number of researchers (Dahlberg *et al* 2001, Rapport & Wainwright 2006, Todres & Holloway 2006), have argued that the differences between descriptivists and interpretivists have led to a 'false dichotomy'. Offering the view that the, 'distinctions between descriptive and hermeneutic phenomenology have been over emphasized' pointing to the fact that they share the following features: 'starting from 'lifeworld' descriptions, the use of 'bracketing or sensitising' as a reflective analytic method, and arriving at 'essences' or 'fusions of horizons' to characterize the experienced phenomena', Todres & Holloway (2006:228). Rapport & Wright (2006), contend that it is these similarities that are essential to our understanding of the nature of knowledge and the way phenomenologists pursue knowledge. Whether the analytic process is descriptive or interpretive, there is a sensitivity towards the phenomenon in focus that strives for openness: that is as researchers we make ourselves available to the world, to the phenomenon of interest as, it presents itself, 'in order to see the events or objects of the world in a new way', (Dahlberg *et al* 2001:97). Todres & Wheeler (2001), illustrate the complementarity of phenomenology and hermeneutics referring to them as 'natural bed-fellows':

> 'phenomenology *grounds* our research inquiries, turning us to the concrete happenings of living situations, the *what* of our reflections. Without this emphasis our explorations may be compromised by over-generality and theoretical abstraction. In acknowledging the positionality of knowledge, hermeneutics adds *reflexivity* to our research inquiries, turning us to meaningful questions and concerns that are culturally and historically relevant. Without this emphasis, our explorations may lack depth and significance in our current world…. Hermeneutics without phenomenology can become excessively relativistic. Phenomenology without hermeneutics can become shallow'.
>
> Todres & Wheeler (2001:6)

'However there is an indisputable difference. While a phenomenological analysis is a descriptive work, the hermeneutic analysis is an interpretive one', (Dahlberg *et al* 2001:182).

The aim of this framework is to provide a method or approach for the synthesis of qualitative research findings which will make available a description of others personal experiences:

> 'in such a way that the effect of the text is it at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience'.
>
> (Van Manen 1994:36)

Communicating human experience in this way calls for an approach to synthesis, that attends to both the structural and textural dimensions of the experience, in order to produce a synthesis that will allow the audience the, 'possibility of going through the experience in a more *enacted* way', (Todres 2007:57).

Approach for Synthesizing the Selected Studies

Introduction

This approach to synthesis draws on the logic of phenomenology and hermeneutics in order to create a structural-textural synthesis, that provides essential insights into a phenomenon. Moustakas, (1994) in his modification of the methods of analysis of phenomenological data suggested by Van Kaam, Stevick, Colaizzi, and Keen uses the term, 'textural-structural synthesis' (Moustakas 1994:144) to refer to a synthesis of the meanings and essences of an experience. In this study I have used the term structural-textural synthesis, to refer to a synthesis in, which 'structure' refers to the level of description used to express the context-related themes of a phenomenon in a way that provides general understanding, and 'texture' to refer to the richness or thickness of experience that, grants readers access to the 'aliveness' of the phenomenon.

However there is one important difference to consider: the 'data' on which the synthesis is based is drawn from a wide range of published sources, including peer reviewed journal articles and first person accounts in the form of autobiographies, and not from experiential narrative gained through interviews. Therefore the descriptions of lived experience do not come from the 'natural attitude', but from reflected insights based on lifeworld material incorporated in a summary of analysis. This framework aims to offer an approach to synthesis that will facilitate the carrying forward of 'understandings' distilled from qualitative research findings into a shared world through a structural-textural synthesis that is both evocative and structurally coherent. Through words this approach will offer essential insights, together with their components and sub-components in order to, 'show phenomena in both experientially evocative as well as structurally coherent ways', (Todres 2007:28-29). This approach to synthesis has four steps:

1. Data is Read for a Sense of the Whole.

2. Data is Read for a Sense of Meaning.

3. Essential Insights are Expressed.

4. Structural-Textural Synthesis is Expressed.

Reading for a Sense of the Whole

The phenomenological perspective is holistic, and the beginning of data analysis is a familiarizing one, where the whole of each text is read a number of times to obtain a global sense, (Dahlberg *et al* 2001, Giorgi 1997, Giorgi & Giorgo 2003). The reader adopts an empathic attitude that is attuned to the linguistic content, allowing them to immerse themselves, 'in the world of the description' by disciplining themselves to become 'open to such a world', (Todres 2005:112). This discipline requires the suspension or 'bracketing' of one's preconceptions as, 'the more one becomes involved and acquainted with the actual data, the less one's pre-understanding gets in the way', (Dahlberg *et*

al 2001). This initial reading gives a 'sense of the whole' providing 'an intuitive reference within which the specific details can become intelligible', (Todres 2005:112). At the end of this step the researcher should have achieved a sense of the overall theme of each text, this will support them to find their way through the data in the next stage, where they will engage more closely with each text in order to gain a deeper understanding.

Reading for a Sense of Meaning

In this stage the character of the reading changes, as the researcher aims to become more familiar with each text. The understanding of data is not a 'passive or distant act, but is characterized by an active and intensive dialogue with the text' where the text, 'moves from being an object for the researcher to becoming a subject that is ready for cross examination', (Dahlberg *et al* 2001:188). In this particular instance the text or data the researcher is 'dialoguing' with, is not drawn from interview transcripts rather it is drawn from a number of texts from a wide range of published sources, some of which contain an analysis. Therefore in order to gain a deeper understanding of each text, the researcher first needs to identify the parts of the text that contain the context related themes and/or findings that form the 'structure' and the parts of the text that contain the 'texture' recorded in the words of the participants which provide the richness of experience. The researcher then makes an initial transcription, from each study; of the parts of the text that contain the structure, (context-related themes), and the parts of text that contain the texture, (richness of experience), reported in direct narrative containing the participants' own words. The transcribed texts then become the 'data', and are ready for analysis.

 The researcher reads each initial transcript, and the parts of the text that refer to central aspects of a phenomenon or experience are noted, and during continued reading, similarities and differences in meaning are observed, allowing a pattern of understanding to emerge. To achieve this the researcher moves backwards and forwards in the text, grouping the emerging meanings, through a 'reflective and creative procedure' that 'has the potential of developing a meaningful pattern, like a beautiful and harmonic picture, as its

goal', (Dahlberg *et al* 2001:191). Throughout this process the researcher keeps their mind open to changes in meaning, new discoveries may influence previous descriptions; destroying patterns, involving changes, or minor adjustments. In this way themes are recovered; 'theme analysis' refers to the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work, (Van Manen 1994:78). In searching for themes in phenomenological research the researcher has to resist the tendency to leave the phenomenon behind in the reducing process, it is not a rule bound process but a free act of seeing meaning, (Van Manen 1994:79) and should not be confused with a 'conceptual exercise' as:

> 'the act of separating accidental elements from necessary or substantial ones in a recurrent *experience* is very different from looking for accidental or contingent elements, in contrast to substantial or necessary elements in an *idea*, which is characteristic of forms of conceptual analysis. The reducing or distilling process, applied as it is to such different entities, ends up quite different in its notion and its practice.
>
> (Willis 2001:11)

The researcher repeats this process, in order to 'empty' each text, of its meanings, (Dahlberg *et al* 2001). This results in a new transcript (secondary transcript), being written for each text, this secondary transcript contains the 'recovered' themes (structures) and the narrative (texture) that illustrates the themes. When this has been accomplished the researcher moves to the next step in the approach, in order to express the essential insights of the phenomenon.

Expressing the Essential Insights of the Phenomenon

When each text is 'emptied' of all meanings the researcher moves to the final step, (Dahlberg *et al* 2001), that is to express the essential insights, together with any subsequent components and sub-components that may be a part of the essential insight. When analyzing the data the researcher is at first seeking for the meaning of the unique experience, then at a certain point the researcher

seeks for the essential insights of the phenomenon. The entire analysis process is a 'whole-parts-whole movement' searching for both 'the unique' and 'the same', (Dahlberg *et al* 2001:194), moving from individuality to generality. The aim being to describe differences and similarities in how people experience something within their life-worlds:

'patterns of the lived world are at once consensual, portraying a commonly shared understanding that makes it possible for productive and meaningful co-existence with others, and simultaneously indicative of the uniqueness of the individuals to whom they refer'.

(Dahlberg *et al* 2001:194)

The process of uncovering the 'shared' and the 'unique' requires a dialectical going back and forth, between each of the texts produced in the secondary transcription, in order to do justice to the fullness and ambiguity of the experience. This process of coming to a fuller understanding has been described as 'the 'shuttlecock' movement of what has been called the 'hermeneutic circle'', (Todres 2007:10). This requires an open attitude that:

'allows for the discovery of meaning and it is not bound up with a priori structures…. This means that there is more spontaneity, a little bit more creativity, a little more making last-minute decisions and a bit more dwelling with things…. In some ways it's like not having to decide on anything until you really have to. It's as though one tries to be as patient as possible in order to dwell with the moment of the description as long as possible. One does not close off the phenomenon until one really has to'.

(Giorgi 1989:50-51)

This 'movement' involves a complex process of:

'rewriting (re-thinking, re-flecting, re-cognizing). The process of writing and rewriting (including revising or editing) is more reminiscent of the artistic creativity of creating an art object that has to be approached

again and again, now here and there, going back and forth between the parts and the whole in order to arrive at a finely crafted piece'.

(Van Manen 1994:131)

When this process is complete the researcher, reaches a new understanding, resulting in a phenomenologically oriented outcome, which articulates the essential insight or insights of the phenomenon, together with any subsequent components and sub-components, that are a part of the essential insight. The researcher then moves to the final step in this approach in order to produce a structural-textural synthesis.

Expressing the Structural-Textural Synthesis

Having articulated the essential insights and any subsequent components and sub-components, that are a part of the essential insight, the next step is to express them in such a way that they allow the reader to come to understand the phenomenon in 'a more intuitive way', (Todres 2007). In order to write the structural-textural synthesis in a way that cares for different audiences and purposes, there are two concerns: one scientific, which cares for the phenomenon and the other a communicative concern, which cares for the audience, (Todres & Holloway 2004). In attending to the scientific concern the aim of the phenomenological description is to move from 'specific individual experiences to a level of generality that rigorously expresses the phenomenon in a coherent way', (Todres & Holloway 2004:88).

The communicative concern relates to the expression of the structural-textural synthesis, and poses the question what language can we use to communicate with our chosen audience, in order to engage with them in an imaginative way that will engender empathic understanding. Phenomenological writings with their concern to 'name the un-nameable' can use language in ways that can over-sterilize or deaden the aliveness of the phenomena, easily becoming impenetrable and unreadable, (Willis 2002, Todres & Galvin 2008). This produces a tension in phenomenological writers seeking to write in a scientific way, as they attend to the task of presenting lived experience, (Willis 2002),

there is a danger that 'significant meanings can become imprisoned within a scientific notion of essences', (Todres & Galvin 2008:569). In transforming the phenomenological synthesis, the concern is how to harmonise the 'structure' (the level of description expressing context-related themes to provide a general understanding) and the 'texture' (the richness or thickness, of experience that grants readers access to the 'aliveness' of the phenomenon) in order to 'tell a story' in a way that would engage an audience, (Todres 2000). The danger as Todres (2000: 43), points out is that:

> 'One can err in either extreme: in attending excessively to the structural dimensions, one can over-generalise and become too distant and abstract, thus losing texture and intuitive presence; or in attending excessively to the textural dimensions, one can become overly poetic where the intuitive presence of the phenomena is palpable but where its meaning is left implicit, without reflection, far from answering relevant questions for a community of interested people.'

The challenge then is to find words that 'are faithful to the phenomenon in all its complexity, sense and texture', (Todres & Galvin 2008:569) that make the phenomenon, 'more present' so that it can live in ways that exceed any summary and produce knowledge that 'touches' the readers' own lives, (Todres & Galvin 2008). This calls for a more aesthetic approach to phenomenology that uses language in more evocative ways. Through the act of reading and writing insights emerge and knowledge is produced in the form of texts that not only, 'describe and analyze the phenomena of the lifeworld but also evoke understandings that otherwise lie beyond their reach', (Van Manen 2006:715). In this way narratives and stories have the power to promote empathetic, feeling, or visceral understanding moving listeners, or readers to act, (Sandelowski 2004)

In this framework in order to develop a 'story' or narrative that will communicate with, and produce empathic understanding in a wide audience, it may be helpful to consider the following signposts:

The 'story' or narrative will:

- be more than a definition or series of statements about the life-world experience.

- show (instead of tell) something that connects with universal human qualities to enable readers to bring their own reactions and meanings to the themes allowing them to imagine in a personal way.

- attempt to contribute to new understanding about the life-world experience being described.

- not attempt to exhaust the topic but attempt to allow it to be seen more clearly.

(adapted from Todres 2000:43, Todres 2007:49)

A narrative or 'story' created using the above signposts provides the opportunity to 'create meaningful encounters' with a wider audience, than the one reached by the traditional methods of reporting qualitative studies. In this way 'scientific scrutiny' is combined with 'creativity' in order to carry a message that allows us to see more clearly and deeply, inviting us to question; how we see, what we know, and how we know what we know, (Bochner & Ellis 2003, Simhoni 2008). This allows the, 'audience multiple places to stand in the story, multiple levels of emotionality and experience to which they can connect their own experiences in the world', (Berger 2001:508). For as Hirshfield so eloquently expresses:

'story is the spinning wheel on which continuity is spliced, source of our sense of self. Narrative's yarn is also the substance with which a culture addresses its questions…. By its place in the pattern, we learn which information is more significant, which less; though anything mentioned has meaning - as it must, in a universe in which each thing is tied to everything else'.

(Hirshfield 1998:112)

The creation of a structural-textural synthesis represents the final phase in Stage 3 of the framework. A summary of the approach is given below.

Framework- Approach to Synthesis

In order to produce a structural-textural synthesis this framework draws on the philosophy of phenomenology and hermeneutics in the following way:

- Reading for a Sense of the Whole: The texts from the studies are read for a sense of the whole, whilst the researcher's preconceptions are suspended or 'bracketed'.

- Reading for a Sense of Meaning: The researcher moves backwards and forwards in the text(s), and parts of the text that refer to central aspects of a phenomenon or experience are noted and during continued reading, similarities and differences in meaning are observed.

- Expressing the Essential Insights: The emerging meanings are grouped through a process of rewriting, rethinking, reflecting, recognizing in order to express the essential insights and their components and sub-components.

- Expressing the Structural-Textural Synthesis: The structural-textural synthesis or 'story' is then expressed in words that 'are faithful to the phenomenon in all its complexity', paying attention to both the structure and texture of the lifeworld experience.

Stage 4: Identification of a Communication Strategy

Introduction

'When we represent our research findings in elegant language or artistic representational forms, we seek to create the conditions under which the

truths within our newly acquired knowledge can resonate in an experiential manner with our intended audience'.

<div align="right">(Thorne 1997:127)</div>

The aim of this research is to find a way to communicate descriptions of life-world experiences that will support understanding in a wide range of audiences including members of the public. As Todres (2001), notes "understanding" is more than "explanation" it:

> 'involves an aesthetic dimension in which what is revealed has the possibility of being personally appropriated; that is, empathically understood as something that is within the realm of human participative experience'.

<div align="right">(Todres 2001:42, Todres 2007:47)</div>

In identifying a communication strategy there are three questions to be answered:

- Who is the intended audience(s)?
- How will you communicate with them?
- How will you care for them? (ethics of care)

Determining the Audience

The foremost question to consider is determining who the audience will be:

> 'Is it fellow phenomenologists, mainstream researchers, a broad range of readers from various disciplines, practitioners who are working with patients, educated lay persons interested in understanding some aspect of their own lives better or some combination of the above?'.

<div align="right">(Halling 2002: 30-1)</div>

As previously discussed the idea that, 'one size fits all', in relation to the traditional academic style of dissemination via peer reviewed articles, is one that is unnecessarily restrictive and exclusionary. Therefore if there is more

than one intended audience a key decision in choosing a format for communication will depend on whether the researcher wishes to find one style of communication that can be used to facilitate understanding in all their intended audiences or whether they wish to tailor their style of communication to meet the needs of individual audiences.

Mode of Communication

Reason & Hawkins (1988), indicate that in order to make meaning manifest through expression, we need to use a creative medium through which the meaning can take form.

> 'Expressive or arts-based research borrows from artistic and poetic forms to construct research presentations which aspire to generate emotions, feelings and conceptions which have a similarity to those many people experience when engaging with a work of art'.
>
> (Willis 2002:14).

The transformation of qualitative research findings into 'an art form' supports the goal of making knowledge available to wider audiences, in particular one comprised of members of the public. In choosing a format through which to communicate with your chosen audience the key question to consider is which medium will allow the 'story' to be, credibly, vividly, and persuasively told, (Saldaña 2003). Researchers have an array of presentational styles and formats to choose from when deciding how to present their narrative or 'story' to their chosen audience, including both audio-visual formats and text; such as drama, dance, poetry, song, painting, evocative writing, narrative story, animation, websites, films, photographs, videos, CDs, DVD's and audio-tape recordings, (Keen & Todres 2006, Keen & Todres 2007). The resources available may also guide the choice of format in terms of finances, time, equipment and expertise.

The choice will also be governed by the objective of the research; Sandelowski (2004), has highlighted the ability narratives and stories have for achieving

conceptual (involving a change in the way users think about problems, persons or event) and symbolic (a persuasive tool to legitimate a position or practice) utilization. Arts based communication strategies have been used in a number of ways:

- as a pedagogical tool in order to facilitate understanding in health and social care professionals, motivating them, to go beyond the boundaries of themselves in order to engage in compassionate care, (see for example Schneider 2005, Kontos & Naglie 2006, Kontos & Naglie 2007).

- as a vehicle for health promotion, (see for example Mienczakowski 1995, Sandelowski *et al* 2006).

- as a reflexive tool for informing the provision of health services and a mechanism for shaping and informing political will, (Morgan *et al* 2001).

- to enhance understanding and awareness of the experience of ill health both in the person with the illness and in their family members, (see for example Gray *et al* 2000, Gray *et al* 2001, Sinding *et al* 2002, Gray 2003, Gray *et al* 2003, Schneider 2005, Sinding *et al* 2006, Todres & Galvin 2008).

- to tackle stigma, (see for example Morgan *et al* 1993).

- to explicate the power relationships between health service consumers and providers, (see for example Morgan *et al* 1993).

Communicating research findings in more evocative ways through the use of arts based communication strategies contributes not only to propositional knowledge but also to experiential knowledge and its possibility for enhancing the emotional intelligence of audiences, (Todres & Galvin 2008). This produces the kind of knowledge that 'touches' an audience by making an experiential phenomenon more present allowing them to apply their understandings to their own individual circumstances and concerns, (Todres & Galvin 2008), unlike the

'distancing one may experience when reading a journal article in private', (Saldana 2003:230), it has the ability to provide 'meaning, understanding, prevention, and perhaps catharsis and solace', (Morgan *et al* 2001:164).

<u>Ethics of Care</u>

A number of authors (Morgan *et al* 2001, Morgan *et al* 2003, Mitchell *et al* 2006, Sandelowski *et al* 2006), have raised ethical questions about the effect of producing knowledge that 'touches' an audience, particularly when the research is dealing with a sensitive topic, that may offer the potential to; 'inadvertently unleash unanticipated emotional responses in audiences during or subsequent to a performance', (Morgan *et al* 2001:164). This concern led Mitchell and colleagues (2006), to posit the following question: is there a way of presenting research in a way that would 'counteract the potential damage of an uninvited and exposed truth?', (Mitchell *et al* 2006:201). Denzin (2003:258), in a text on reading and writing performance, acknowledges the diversity of audiences:

> 'audiences may or may not agree on what is caring, or kind, or reflexive, and some persons may not want their taken for granted understandings challenged'.

As yet there is little evidence in existence relating to the adverse impact that new forms of research representation may have on audiences, (Morgan *et al* 2001). A recent review by Rossiter *et al* (2008:145), highlights that to date few evaluation studies have been carried out, and 'with so few evaluation studies upon which to draw, important questions regarding theatre's use in health research remain', such as 'how we might measure theatre's efficacy, against its potential disadvantages'.

Morgan *et al* (2001:170), acknowledge that with this emergent tradition of research representation we encounter 'new and attendant ethical difficulties' causing them to, 'wave a cautionary flag indicating perilous waters ahead', for health and social science researchers, attempting to negotiate a 'safe performance mode'. The following two examples show that there may be some

circumstances in which, 'people may be damaged by exposure to some drama or ethnodrama', (Morgan *et al* 2001:171). *Tears in the Shadows*, an ethnodrama, which sought to express the experience of living with a psychotic mental illness, had, 'unexpected outcomes' in 'terms of possible imitative suicides associated with the performance', (Morgan *et al* 2001:175). In *Ladies in Waiting?,* a play about surviving breast cancer, (Sinding *et al* 2005), a small number of audience members described the message they took from the play as, 'depressing or 'upsetting', whilst the authors contend that this was not necessarily a 'negative evaluation', they have since discussed whether and how to prepare subsequent audiences.

As Morgan *et al* (2001:175), express, 'whilst in no way wishing to propose a censorship upon performance' as creators of evocative texts and arts based presentations we do have a duty to 'care' for our audiences. Research ethics in qualitative research are well established but as we continue to traverse 'the perilous waters' ethical guidelines relating to the concerns we may have about 'emotional dilemmas', which we may inadvertently create for our audiences, are as yet undeveloped. The subject matter, the intended audience, and the environment in which the presentation takes place will help to guide ethical considerations. As a minimum we can meet representational concerns by considering the following:

- pre-warning audiences.
- screening audience members.
- debriefing audiences.
- exercising self-awareness when creating the text or production.

The strategy for communicating the synthesis is summarized below.

Framework- Communication Strategy

This framework does not offer a prescriptive strategy for communicating the synthesis produced in Stage 3 of this Framework. Instead it proposes a series

of questions designed to support the choice of a strategy for communication that is tailored to the individual researchers aims.

Communicating to Diverse Audiences

In order to engage with wider audiences in a more imaginative way, there are several key questions to consider:

- Who will the audience be?

- Is there more than one audience?

- What is the appropriate style of communication for that audience?

- Does there need to be more than one style of communication?

- What resources are available to transform the narrative into the chosen medium (in terms of time, finances, equipment and expertise)?

- How do you care for your audience? (Ethics of care)

In Chapter 3, I address these questions in more depth in relation to my own research aims: in terms of audience, style of communication, available resources and ethics of care. This represents the final stage of the framework.

Conclusion

In this chapter I have developed a four-stage framework for the synthesis and communication of qualitative research findings:

Stage 1:   Strategy for Searching for Relevant Qualitative Studies

Stage 2:   Inclusion & Exclusion Criteria

Stage 3:   Approach for Synthesis

Stage 4:   Communication Strategy

(See Diagram 1 at the end of Chapter 2 for reference)

Stage 1: Strategy for Searching for Relevant Qualitative Studies

In Stage 1 of the framework I outlined a searching strategy based on the 'berrypicking' model, which involves:

- Footnote chasing
- Citation searching
- Area scanning
- Journal searching
- Author searching

Stage 2: Inclusion & Exclusion Criteria

In Stage 2 of the framework I identified the inclusion and exclusion criteria for studies, focusing, on the following:

Quality criteria:

The quality of a study will be assessed by its:
- Substantive contribution
- Aesthetic merit
- Reflexivity
- Impact
- Expression of reality

Data sources:

Data will drawn from a wide range of published sources including:
- Peer reviewed journal articles
- Grey literature
- First person accounts in the form of autobiographies

Sample size:

The sample size is not prescriptive but will be guided by the depth and richness of the data available.

Epistemological considerations:

Studies, included in the synthesis may be drawn from differing epistemological perspectives, which focus on the experiences of others expressed in their own language.

Stage 3: Approach for Synthesis

In Stage 3 of the framework, I identified a four-stage approach to synthesis based on the philosophical traditions of phenomenology and hermeneutics. This approach to synthesis draws on the logic of phenomenology and hermeneutics in order to create descriptive narrative structures that provide essential insights into a phenomenon. The approach follows four-stages:

1) Reading for a Sense of the Whole: Reading the study texts for a sense of the whole, whilst suspending or 'bracketing' preconceptions.

2) Reading for a Sense of Meaning: Moving backwards and forwards in the text(s), noting parts of the text that refer to central aspects of a phenomenon or experience and through continued reading, observing similarities and differences in meaning.

3) Expressing the Essential Insights: Grouping the emerging meanings through a process of rewriting, rethinking, reflecting, and recognizing in order to express a narrative structure of the phenomenon.

4) Expressing the Structural-Textural Synthesis: Expressing the structural-textural synthesis or 'story' in words that 'are faithful to the phenomenon in all its complexity', paying attention to both the structure and texture of the lifeworld experience.

<u>Stage 4: Communication Strategy</u>

In Stage 4 of the framework I proposed a series of questions to be answered when deciding on an appropriate communication strategy:

- Who is the intended audience(s)?
- How will you communicate with them?
- How will you care for them? (ethics of care)

In the next chapter I will apply the four stages of this framework to my own study.

Diagram No 1: Framework for the Synthesis and Communication of Qualitative Research Findings

Stage 1: Search Strategy

"Berrypicking" Approach:

- Footnote chasing
- Citation searching
- Area scanning
- Journal searching
- Author searching

Stage 2: Inclusion & Exclusion Criteria

Ethical Considerations: Not necessary to: -
- Seek written consent from the author(s) of the original studies
- Undertake member checks

Quality Criteria: Does the writing show:
- Substantive contribution?
- Aesthetic merit?
- Reflexivity?
- Impact?
- Expression of reality?

Data Sources:
- Peer reviewed journal articles
- Grey literature
- First person accounts in the form of autobiographies

Sample size:
- Guided by: The depth and richness of the data available

Epistemological perspective:
- Studies drawn from differing epistemological perspectives, focusing on the experiences of others expressed in their own language

Stage 3: Approach to Synthesis

Structural-Textural Synthesis: -

1. Data is read for a sense of the whole
2. Data is read for a sense of meaning
3. Essential Insights are expressed
4. Structural-Textural Synthesis is expressed

Stage 4: Communication Strategy

Will Be Determined by Answering the Following Questions:

- Who is the intended audience(s)?
- How will you communicate with them?
- How will you care for them (ethics of care)?

Chapter 3: Framework Application

<u>Introduction</u>

In this chapter I will apply the framework for synthesizing and communicating qualitative research findings that I developed in Chapter 2, to a worked example in order to demonstrate its use. In line with my aims as stated in Chapter I, the area that I have chosen to test the framework is the experience of living with dementia from both the perspective of the person with dementia and their care partner, (I use the term care partner throughout to mean spouse or significant other e.g. partner or adult child).

In focusing on my aim to produce a study that would be of communicative value to a wide audience including health and social care professionals and in particular to lay members of the public, the first question to answer was what 'story' from the many facets of dementia would I focus on? The second question was having found my 'story' what would be the most appropriate way of communicating it?

The answer to the first question could only be found by turning to the literature on dementia, and I provide a discussion of how I found the focus of my 'story' in Stage 1 of the application of the framework. In Stage 2 of the application of the framework I provide details of the studies together with their focus and theoretical perspective that I selected for inclusion in the synthesis. Stage 3 of the application of the framework describes, the process of synthesizing the studies into a 'whole' using the logic of phenomenology and hermeneutics to create a structural-textural synthesis. The resulting structural-textural synthesis presents essential insights into the phenomenon of 'Being Together'- the challenging shared journey with dementia. In Stage 4 of the application of the framework I attempt to answer my second question: what is the appropriate means for communicating my story. I do this by illustrating the decisions I made that led me to develop a script from the structural-textural synthesis produced in Stage 3 of the framework, the end product of which is a 'short film' recorded on DVD, telling the story of 'Being Together'- the challenging shared journey with dementia.

Stage 1: Locating Studies

At the start of this study I was not clear about which aspect or facet of dementia that I would focus on. The overarching aim was that the completed synthesis should be of use to the care partner, and health and social care professionals. With this in mind being guided by the berrypicking model, I first of all 'cast my net' widely in the literature on dementia in order to identify an area of interest. In doing this I attempted to answer the following questions:

- Would I select multiple reports/representations/articles relating to one single study?

- Would I select multiple reports/representations/articles relating to more than one study?

- What life-world experience of dementia did I want to capture?

- Should this life-world experience come from the perspective of the partner with dementia?

- Should this life-world experience come from the perspective of the care partner?

- Should the life-world experience attempt to show the perspective of both partners?

- What would be the focus of the life-world experience?

Would it be the:

  o experience of being diagnosed with dementia?
  o impact of early-on-set of dementia?
  o interface between the two partners and health and social care services?

- experience of caring for a partner with dementia?
- impact of the diagnosis on everyday life?

The process of searching was therefore an iterative one, as I immersed myself in the literature in an attempt to resolve these questions. I initially grouped the papers I identified using the berrypicking model, into loose themes based on the above concerns, prior to reading them for a second time. Throughout this process, I was guided by Dahlberg & Halling's (2001), discussion of 'openness': open-mindedness, open-heartedness, and dialogical openness. The first refers to the receptivity of the researcher to the subject matter, the second to self-disclosure by the researcher in relation to their thoughts or personal experiences, and the third to conversations with other researchers, which may help to place things in a new perspective. As Dahlberg & Halling, (2001:14) note in doing this:

> 'one is likely to experience disorientation and confusion along the way as one is caught up in initial impressions and vague hunches and tries to make sense of what is still unfamiliar'.

As I continued to read, recurring themes appeared in the literature; for example in literature relating to the experiences of people with dementia, there was a recurring theme of 'slow' or 'living life in the slow lane', (see for example Truscott 2003, Bryden 2005), similarly in the literature relating to the experiences of care partners there was a recurring theme of time pressures 'the ticking clock' experienced when they spend time away from the partner with dementia, (see for example, Svanström & Dahlberg 2004, Watts & Teitelmann 2005, Salmon 2006). In addition two studies made reference to the journey with dementia as, 'a dance' one study came from the perspective of the person with dementia, (Bryden 2005), and the other from the perspective of the care partner, (Salmon 2006). It was at this point I registered a potential 'gleam of light in the darkness' and made the key decision to look at the experience of living with dementia from the perspective of both the person with dementia and their care partner, in order to find a way to 'tell the story' of both of the partners engaged in the dance with dementia. In doing this I wanted to move away from

'burden of caring' (Hellström et al 2007) aspect, that has featured strongly in the literature relating to dementia, and explore whether there was another narrative in existence. A narrative, which would, acknowledge the joint experience of living with dementia, focusing on the experiences of both partners, in an attempt to simply tell what possibilities might exist for the two partners 'to be together'. Possibilities that might allow the partners to become fully present to seeing each other, in all their depth and complexity, allowing them to, 'grasp the point of view of the other in such a way as to understand', (Halling 2008:19-20). This decision was supported by the acknowledged 'gap in the literature' identified by Forbat (2003), and Davies & Gregory (2007), that to date few studies have focused on the joint experience of living with dementia.

The decision making process however was not in itself straightforward nor did it develop in a linear fashion, rather it happened through a process of 'openness' in which I was 'receptive' to the literature, 'receptive' to my thoughts and personal experiences of dementia, and 'receptive' to discussions with academic colleagues. Being receptive to my own thoughts and personal experiences of dementia called for reflexivity and self-disclosure on my part. I have previously been involved in research with people with dementia. (see Cash 2003, Cash 2005) and during the time I was 'exploring' the literature a close family member was diagnosed with Alzheimer's disease. Dialogical openness with colleagues led to me experimenting with a number of ideas for presenting and communicating my synthesis, and also helped me to clarify my thoughts. Having finally reached a decision on what 'story' to tell I narrowed my focus in the literature through the continued application of 'berrypicking'.

Stage 2: Studies Identified for Inclusion in the Structural-Textural Synthesis

Introduction

In order to answer my question 'What is the experience of living with dementia', in my application of Stage 2 of the framework I sought to identify studies from both peer reviewed and grey literature, which, contained rich descriptive narrative that would have communicative value and be of relevance to people with dementia and their care partners, and to health and social professionals. The studies represent a range of findings, from those that stay very close to lifeworld descriptions to those that offer analyses on the basis of the data. Synthesizing findings that offer insights by researchers and lifeworld descriptions, offers the possibility to use the insights in a way that allows the qualities and the textures of the lifeworlds on which they are based to shine through as much as possible.

In total I located eighteen studies that met the inclusion criteria identified in Stage 2 of the framework. The majority of the studies came from peer reviewed journal articles with the exception of two studies one of which was reported in a book chapter and the other was an autobiography written by a person with dementia. Of these eighteen studies, five studies reported on the experience of living with dementia from the perspective of the care partner, (see Table 1), eight studies reported on the experience of living with dementia from the perspective of the person with dementia, (see Table 2), three studies reported on the experience of living with dementia from the perspective of both partners, (see Table 3), and two were theoretical papers relating to personhood, (see Table 4). Some of the studies were reported in more than one paper or book chapter. Selecting studies that appear more than once in the literature, rather than overvaluing the findings offers a greater insight into the study allowing for the building of a more in-depth and comprehensive picture.

The studies came from differing epistemological perspectives; seven studies took a phenomenological approach to analysis, three used a form of grounded theory, two used constant comparative analysis, two were 'personal essays',

two were theoretical papers, one was an autoethnographic study and one was an autobiography. Five studies can be considered to be single case studies, four of these are written by and from the perspective of their individual authors, (see Study 3 in Table 1, and Studies 1, 5 and 8 in Table 2). The remaining case study is reported in one paper that is co-written by the research participant and the researchers and two papers that are written from the perspective of the researchers conducting the study, (see Study 1 in Table 1). Daly *et al* (2006:46), in their 'hierarchy of evidence', for decisions made in health practice and policy, contend that single case studies 'provide poor-evidence for practice', because of their lack of generalisability, whilst at the same time noting that they provide 'rich data on the views or experiences of one person':

> 'these individual accounts sometimes consist of moving, emotional accounts of personal experience that rouse sympathy, giving a rare insight into an uncommon experience'.
>
> (Daly *et al* 2006:46)

I would argue that it is these very qualities offering us empathic insights into the lifeworld of individuals that make single case studies a valuable resource for researchers synthesizing studies, because of the depth of information that they provide. The aim being not to produce a 'generalisable story' but to produce a 'story' in which '*meaning* rather than *measurement*' is the currency of understanding, (Todres 2007:65). A 'story' that tries to, 'reflect the particular in the general; the dance of the unique and the shared' to offer insights that have a communicative value, 'that are faithful to examples of unique occasions' but which have a 'potentially transferable meaning for others', (Todres 2007:66).

As discussed previously the traditional format of journal articles often results in abbreviation of the findings, in particular this often results in the loss of the voice of the informant. In an attempt to overcome this, the studies included in this synthesis were selected to balance the 'bare bones' or structure of an experience with its 'flesh and heart' or texture, (Todres 2007), that allow the thoughts and emotions of the research informant to come alive. To attend to this

concern I have included two theoretical papers that inform the structure, (see Table 4) and a number of studies that move away from the traditional method of reporting in the form of personal essays, (see Table 2 Studies 1 and 5) an autobiography, (See Table 2 Study 8), and an autoethnography, (see Table 1 Study 3) to add texture to the synthesis.

The details of the studies included in the synthesis, together with their epistemological perspective and focus and are shown in the following tables: -

Details of the Studies Included in the Structural-Textural Synthesis

Table 1 provides details of the studies that were selected for inclusion in the structural-textural synthesis that come from the perspective of the care partner.

Table 1: Studies from the Perspective of the Care Partner					
Study	**Authors &Year**	**Journal**	**Title of Paper**	**Epistemological Perspective**	**Focus**
No. 1 *Paper 1*	Galvin *et al* 2005	Scandinavian Journal Of Caring Sciences	The intimate mediator: a carer's experience of Alzheimer's	Hermeneutic Phenomenology	Series of interviews with male care partner exploring his experience of caring for a partner with Alzheimer's disease, in order to develop insight into his complex journey. Subsequent papers explore the potential of descriptive phenomenology, to produce in-depth lifeworld descriptions, which, contribute to a deeper understanding of caring for a partner with advancing memory loss.
Paper 2	Todres & Galvin 2005	International Journal of Qualitative Methods	Pursuing breadth and depth in qualitative research: Illustrated by a study of the experience of intimate caring for a loved one with Alzheimer's disease	Descriptive Phenomenology	
Paper 3	Todres & Galvin 2006	International Journal of Qualitative Studies on Health and Well-being	Caring for a partner with Alzheimer's disease: Intimacy, loss and the life that is possible	Descriptive Phenomenology	
No. 2	Watts & Teitelmann 2005	Australian Occupational Therapy Journal	Achieving a restorative mental break for family caregivers of person's with Alzheimer's disease	Phenomenology	Four in-depth interviews with 15 carers of people in the middle to late stages of Alzheimer's disease, exploring how carers achieve a mental break from caregiving concerns.
No. 3	Salmon 2006	Australian Occupational Therapy Journal	The Waiting Place: A caregiver's narrative	Autoethnography	This article combines the narrative analysis of personal diary entries with autobiographical excerpts to represent the last phase of caregiving at home.
No. 4 Data generated from 3 separate studies.	Perry & O'Connor 2002	Family Relations	Preserving Personhood: (Re)Membering the Spouse with Dementia	Secondary analysis- Constant comparative analysis	Interviews with both male and female carers exploring the experience of caring for a cognitively impaired spouse.
No. 5	de la Cuesta 2005	Qualitative Health Research	The Craft of Care: Family Care of Relatives with Advanced Dementia	Constant comparative analysis	Interviews with 18 carers of people with advanced dementia exploring caregiving strategies

Table 2 provides details of the studies selected for inclusion in the structural-textural synthesis that come from the perspective of the partner with dementia.

Study	Authors & Year	Journal	Title of Paper	Epistemological Perspective	Focus
Table 2: Studies from the Perspective of the Partner with Dementia					
No. 1	Sterin 2002	Dementia	Essay on a word A Lived Experience of Alzheimer's Disease	Personal Essay	Narrative description of the impact a dementia diagnosis has on social interactions and self-concept
No. 2	Harris & Sterin 1999	Journal of Mental Health and Aging	Defining and Preserving the Self of Dementia	Grounded Theory	In-depth interviews with people diagnosed with early stage Alzheimer's exploring the concept of self and personal identity in the early stages of the disease
No. 3 *Paper 1*	Clare 2002	Aging & Mental Health	We'll fight it as long as we can: coping with the onset of Alzheimer's Disease	IPA	Interviews with people in the early stages of Alzheimer's disease exploring coping strategies and awareness of memory problems
Paper 2	Clare 2003	Social Science & Medicine	Managing threats to self: awareness in early stage Alzheimer's disease	IPA	
Paper 3	Clare *et al* 2005	Dementia	Perceptions of change over time in early-stage Alzheimer's disease. Implications for understanding awareness and coping style.	IPA	Follow–up interviews after 12 months to evaluate changes in coping strategies and awareness of memory problems
No. 4	Pearce *et al* 2002	Dementia	Managing sense of self, Coping in the early stages of Alzheimer's disease,	IPA	Interviews with men diagnosed with early-stage Alzheimer's disease to explore their appraisal of their memory problems, strategies for coping and the resulting impact on their sense of self
No. 5	Truscott 2003	Alzheimer's Care Quarterly	Life in the Slow Lane	Personal Essay	Narrative description of the authors experience of early stage Alzheimer's disease
No. 6	Langdon *et al* 2006	Social Science & Medicine	Making Sense of Dementia in the Social World: A qualitative study	IPA	Semi-structured interviews with people with early stage dementia to elicit their views on the reactions of others to them.
No. 7 *Paper 1*	Phinney 2002	Dementia	Fluctuating awareness and the breakdown of the illness narrative in dementia	IPA	In-depth interviews and participant observation with people experiencing mild to moderate dementia revealing how dementia symptoms were experienced in and through the lived body
Paper 2	Phinney & Chesla 2003	Journal of Aging Studies	The lived body in dementia	IPA	
Paper 3 (Book Chapt-er)	Phinney 2002	In: The Person with Alzheimer's Disease Pathways to Understanding the Experience Harris (Ed)	Living with the Symptoms of Alzheimer's Disease	IPA	
No. 8	Bryden 2005	Publishers: Jessica Kingsley, London	Dancing with Dementia	Autobiography	Richly descriptive narrative of the author's experience of life with dementia

Table 3 provides details of the studies selected for inclusion in the structural-textural synthesis that come from the perspective of both partners.

Table 3: Studies from the Perspective of Both Partners					
Study	**Authors & Year**	**Journal**	**Title of Paper**	**Epistemological Perspective**	**Focus**
No. 1 Longitudinal Study *Paper 1*	Hellström *et al* 2005	Dementia	We do things together	Constructivist Grounded Theory	Eight interviews, (which were part of a larger constructivist grounded theory study) with an elderly married couple living with dementia, which explores their relationship. Presented as a single case study
Paper 2	Hellström *et al* 2005	Dementia	Awareness context theory and the dynamics of dementia- Improving understanding using emergent fit	Constructivist Grounded Theory	74 interviews with 20 spouse couples living with dementia exploring the impact of dementia on their relationship and everyday life
Paper 3	Hellström *et al* 2007	Dementia	Sustaining 'couplehood': Spouses' strategies for living positively with dementia	Constructivist Grounded Theory	152 interviews conducted with 20 couples over a period of 5 years exploring the strategies that spouses use in order to live positively when one partner has dementia
No. 2	Svanström & Dahlberg 2004	Western Journal Of Nursing Research	Living with Dementia Yields a Heteronomous and Lost Existence	Descriptive Phenomenology	Unstructured interviews with 5 couples exploring the lived experience of dementia
No. 3	Wuest *et al* 1994	Journal Of Advanced Nursing	Becoming strangers: the changing family caregiving relationships in Alzheimer's disease	Grounded theory	Interviews with 15 families exploring the reciprocal process of becoming strangers.

Table 4 provides details of the theoretical papers relating to personhood selected for inclusion in the structural-textural synthesis.

Table 4: Theoretical Papers				
Study	**Authors**	**Journal**	**Title of Paper**	**Epistemological Perspective**
No. 1	Whitlach 2001	Aging & Mental Health	Including the person with dementia in family care-giving research	Theoretical Paper
No. 2	Woods 2001	Aging & Mental Health	Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects	Theoretical Paper

Stage 3: Structural-Textural Synthesis of Identified Studies

Introduction

Unlike in an interview situation where you are asking people to describe a life-world experience, I was asking an open-ended phenomenological question; What is the experience of living with dementia from both the perspective of the partner with dementia and their care partner, from existing literature, in the form of published research findings. In this way I was seeking the story of the phenomenon, the where, when, with whom, the feelings, meanings, and all, of the narrative context that is the stream of experiencing from which a phenomenon stands out, (Todres & Holloway 2004). I was also allowing insights based on the analyses by the researchers and writers of the original texts. The constituent study texts were treated as the multi-vocal interpretation of a phenomenon, just as the voices of different participants might be in a single qualitative study, (Zimmer 2004), in order to be able to synthesize them into a whole, where, in Gadamerian terms I came to an understanding by 'exploring from within the hermeneutic circle where the parts (the constituent studies) illuminate(d) the whole (the phenomenon of interest)', (Zimmer 2006:316), following the four stage procedure identified in Stage 3 of the framework:

1. Data is Read for a Sense of the Whole.

2. Data is Read for a Sense of Meaning.

3. Essential Insights are Expressed.

4. Structural-Textural Synthesis is Expressed.

1: Reading for a Sense of the Whole

I read the text of each study freely and openly in order to obtain a global sense of the texts, keeping in mind that the essence of research on human experience is a:

> 'striving for openness, an ongoing concern for moving beyond initial assumptions and preconceptions so that the phenomenon and its meaning can show itself and hopefully, surprise us'.

(Dahlberg & Halling 2001:20)

Immersing myself in the texts I suspended my preconceptions in order to become 'open' to the data. The difference in this study was that the data was not in the form of a text composed of narrative resulting from the transcription of a recorded interview, rather it was the complete text of a study, theoretical paper, personal essay or autobiography, recorded in a journal article or book. When the studies became familiar the character of the reading changed and I moved to the second stage of the process.

2: Reading for a Sense of Meaning

The data I was reading was not gathered directly from lifeworld descriptions but from studies where some analysis had already taken place, resulting in the identification of themes, some of which were illustrated by direct narrative. After the initial reading to gain a sense of the whole I returned to each text and made an initial transcript of the parts of the text, that contained the structure, (context-related themes), to gain a general understanding, and the texture, (richness of experience), reported in direct narrative containing the participants' own words. The exception being the two theoretical papers shown in Table 4 which contain no direct narrative where only the structure was transcribed.

I provide an example of an initial transcript in Figure 2 below:

Figure 2. Example of an Initial Transcript: - This Transcript is from: The Lived Body in Dementia (see Table 2 Study No.7, Paper 2)

Figure 2: Phinney, A. & Chesla, C. A., (2003). The lived body in dementia, *Journal of Aging Studies*, 17, 283-299

Study interviewed 9 people with mild to moderate dementia.
Initial analysis used interpretive phenomenological methods.
Participants original words are shown in italics

Findings suggest that people experience dementia as the breakdown of bodily smooth flow at the loss of their taken-for-granted way of being-in-the-world.
Three distinct ways in which people in this study experienced this disruption of the skilled habitual body. **Being slow**, is about the lived body slowing down as activity becomes halting and tentative. **Being lost** is about people's difficulty finding their way in an unfamiliar world. **Being a blank** is about being in an empty world wherein people are unable to find the thoughts and words that make it possible for them to engage in a reflective act and meaningful habits fall by the wayside.

Being slow
People feel themselves slowing down. Words and thoughts seem slow to come and their bodies move with hesitation. Activities which were easy and smooth flowing now need careful attention and explicit effort, and as a result their everyday being-in-the-world seems fraught with difficulty.

Using equipment
Slowing down shows up in many ways, but in particular in people's use of everyday equipment.
The fluent skilled body is held back, being unable to engage in the easy habits of everyday living. Tasks like driving which employ embodied skills where the workings of the mind are deeply invisible become slower as the person needs to concentrate and consider each move as the familiar moves from a lifetime are no longer ready to hand.

have to scan everything in my car when I drive it. I have to look at everything and make sure I've got everything ready to start the car… otherwise I'll forget something'

The case for conversation
We normally are able to think and use language with little obvious effort, but for the pwd thoughts come more slowly and people often have to pause and consider how best to express themselves. This is most apparent in the practice of conversing with others. Conversations become slow and halting, no longer taken for granted because the person has to take time to think or to get words right. Conversations lose their smooth flow and become hard work and sometimes fail altogether.

'I'll be speaking to somebody, I'll get the wrong words, say the wrong thing. Sentences don't work very well'.

People suffer when they feel they are not taken seriously because they cannot make themselves understood.

Loss of smooth flowing conversation is not a private matter, it is perceived as the breakdown of a social practice that exists in public space. It reveals in a glaring way the extent to which someone is impaired. PWD may feel comfortable conversing at their own speed with old friends but in unfamiliar social situations they are careful to stay on track and say the 'right thing'.

Being Lost
In being lost people found themselves in a world that did not make sense- 'World' is used in the Heideggerian sense- that is, not solely as the physical space that surrounds us, but the meaningful whole constituted by our involvements in ready ready-to hand equipment and shared practices (Heidegger 1962:98). In our usual way of being-in-the-world, we are engaged in comfortable effortless and our coping and our involvements do not stand out for us. In the experience of being lost, people with dementia find the world to be unfamiliar and they are unable to cope as a result.

Lost in the world of space
This shows up most clearly in people's concern about getting lost when they are outside of their homes.

Lost in the world of equipment
People also experience being lost in the world of equipment whereby things simply do not show up as ready-to-hand or usable.

Lost in the world of activity
Our involvement in the world of practical activity is always directed towards a meaningful goal (Dreyfus 1991). In mild to moderate dementia, the body can lose this sense of mission even if it continues to be active and involved. In this case the activity becomes disorderly shifting focus suddenly without apparent accountability. It seems that the involved body is losing course, being unable to find its way though the activity. What must have been in the past a smooth flowing activity has become one requiring careful attention

'Ohhh, too much noise. Uh, somebody asking or telling me to do something. I don't get the directions for that in time to do what I have to do next. And then I … will be told to do 'A' and then before I can really think out 'A' I've got 'B' to do. And then I go back to 'A' and I can't remember what 'A' was.

Being blank

Is about the collapse of involvement, which shows itself in 2 distinct ways.
People are thrown out of a smooth flow only to find that it is no longer possible to reflect on a thematized world. They strain to bring a word, or an idea to mind but fail. In short, they forget. Second, they become disengaged from everyday habits and practices; they pass time sitting still, gazing absently into space. The result of this collapse is that people find themselves being in a world, that seems barren, devoid of meaning.

Forgetfulness

Each of the participants spoke about not being able to remember factual information. They lived with the uncomfortable sense they should know these simple things, but even with the greatest effort they could not bring the information to mind. They often found that when they tried to remember they were a blank.

It's almost like I'm a blank all the time. I mean really. It's kind of weird. I can't remember what I do from one next to the, from one day to the next. What did I do you know

Several explained it as if the information was not getting stored properly. This reflects a common background understanding in our modern society of memory as a kind of warehouse. There are facts that are filed away somewhere inside ourselves. People felt that in being a blank, those facts were no longer there. The information was not part of them.

Being a blank was often a frightening experience. In the breakdown of engaged activity people attempt a reflective stance but when this begins to fail and they find they cannot problem solve their way out of a situation they find themselves in total breakdown.

The body becoming silent

As dementia progresses the person becomes less involved in the world in a bodily way. They sit quietly, having nothing to do, nothing to say, and seemingly nothing to reflect upon. They stand apart as detached subjects just staring out a world of meaningless objects, not involved in the world through unreflective habits and practices, or through their thinking, languaging body.
Blankness is experienced as being empty without thoughts or words-

Well, (being a blank), it's kind of like just being a zombie. Not using your brain, you're maybe just looking at what's around. Don't think about, (pause) don't think about it. Don't (pause)
Don't think about it. Don't (pause) I don't talk to yourself about it.

This has been described as a kind of blankness wherein the world loses meaning- *'that kind of thing (is not pleasant) because it pushes you into the next world and the next world is always an empty place.*

In this sense being blank is about being disengaged from a meaningful world. The world is an empty place that can only be looked upon as an outsider and even in looking upon this world, there are times when it does not seem to make sense. The meanings of the world are hidden. Being absorbed in activity and adopting a reflective stance are part of meaningful engagement in the world. In being a blank people no longer embody this possibility.

Discussion

This study views dementia not as a disease of cognitive losses resulting in functional decline but rather as a breakdown of a deeply embodied sort. In dementia there are many instances when the smooth bodily flow of skilled know-how becomes slow, hesitant, halting and awkward. The everyday grace of engaged activity is lost. The taken-for-granted body, which normally recedes from direct perception, becomes obtrusive, drawing attention to itself when it does not do what it is supposed to do. What has in the past been transparent, seemingly 'thoughtless' activity is now revealed as a reflective act. One becomes aware of the attentive thoughtful work involved in carrying out activities, and the activity seems suddenly difficult and slow. Slowing down is about smooth bodily flow being interrupted by the obtrusive body. The body's implicit understanding of how to carry out an activity is failing and the person needs to think out each step explicitly.

The bodies implicit knowledge of what to do next falters, and in trying to work out in a conscious reflective way what to do, they discover that the explicit knowledge has gone as well. When thoughtful effort fails, involvement collapses completely and the person becomes increasingly silent as meaningful activities cease. The body becomes still and quiet as it withdraws from the world of practical involvements, and being in the world is constituted by a kind of blankness.

By seeing dementia in terms of the lived body, this study opens up the possibility of articulating a deeper and perhaps clearer understanding of people's experience of symptoms, an experience that has generally been overlooked by theorists and researchers alike.

What is needed is a new vocabulary that takes account of how the illness is experienced in everyday life, rather than how it is defined as a clinical entity with distinct, cognitive, functional and behavioural components.

Transcribing the text from each of the individual studies in this way, allowed me to prepare each text for its initial 'cross examination'. I treated the transcribed text from each study as though it was text from an individual interview. Keeping my mind open to changes in meaning I read each 'interview' text several times in order to allow a pattern of understanding to occur. Moving backwards and forwards in the text I grouped emerging meanings in order to recover the theme or themes that were embodied in the evolving meanings. This was not a linear process, in seeking to find meaning in the transcribed texts, I experienced 'alternating periods of darkness and light', (Dahlberg & Halling 2001:19), as I allowed rather than forced a sense of meaning to emerge, in order not to foreclose the 'emergence of a deeper level of understanding'. During this time I experienced, periods of 'chaos' as I strived for openness in order to let the meaning emerge, (Dahlberg & Halling 2001). When I had 'emptied' the initial transcript of its meanings, I made a secondary transcription (see Figure 3 for an example), containing the 'themes' (structures) and 'textures' (participant narratives) that I had identified. Throughout this procedure there was a tension to retain both dimensions - to keep the structure and the vividness of individual experience (texture).

Figure 3: Example of a Secondary Transcription: - This excerpt is taken from: The Waiting Place: A caregiver's narrative (see Table 1 Study No.3)

Figure 3: Salmon, N. (2006) The Waiting Place: A caregiver's narrative-, *Australian Occupational Therapy Journal*, 53, 181-187

Autoethnography- authors experience as a full time family caregiver awaiting her mothers nursing home placement- based on personal diary entries

Four themes (Structures)

- The waiting place
- Grieving
- Coping
- Cost of caring

Grieving
Grieving has no defined parameters
I grieved for her loss of friends, faces, history
I grieved mums loss of function
I grieved the end of caregiving

Texture
Diary entry 13th May-*Mum struggled with putting words together tonight. It is very sad to see this. At one point she said, 'I'm not a person'. That must be a desperate feeling.*

If our identity is socially constructed who do we become when the wrecking ball of dementia smashes holes into life stories?

When I had 'emptied' each of the initial transcribed study texts in this way and produced secondary transcripts for each one. I moved to stage 3 of the procedure, in order to express the essential insights of the phenomenon.

3: Expressing the Essential Insights of the Phenomenon

In order to express the essential insights I repeated the above process only this time I moved backwards and forwards between the transcribed texts (secondary) from each study, in order to discover both the central themes and the specific details. 'Leapfrogging' between the general themes (structure) and specific details (texture) identified in each of the individual studies I attempted to discover common themes in the data, in order to illustrate the essential insights of the phenomenon of living together with dementia. The danger here was that,

as some themes had already been established in the initial analysis by those undertaking the original studies, that I did 'not close off the phenomenon' prematurely but rather remained with the descriptions taken from each of the studies for, 'as long as possible' in order to be open to new possibilities, (Giorgi 1989). This involved a period of 'rewriting, re-thinking, re-flecting, re-cognizing', (Van Manen 1994:131), as I moved back and forth between the transcripts of the individual studies, in order to discover the essential insights and their component parts.

Through this process I identified two essential insights that describe 'Being Together'- the challenging shared journey with dementia, the first insight, 'Dementia the Disease of Society', describes the societal response to the person with dementia and the impact this has on their sense of identity. The second essential insight, 'Living with Dementia' describes the challenges faced by the partner with dementia and their care partner on their joint journey with dementia. I provide an example (see Figure 4 below), of how I 'discovered' the essential insights and their component parts, this illustration relates to the component Stigma & Labelling, which, is a component part of the first essential insight- 'Dementia the Disease of Society'.

Figure 4: Expression of the Component Stigma and Labelling

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Figure 4: Expression of Stigma and Labelling

Stigma
'*There is such a terrible stigma attached to this disease that no wants to talk about it or admit to a diagnosis, even seek one*'. (Table 2. Study No 8. - Bryden 2005:97)

Stigma
'*A person is a person through others*'. (Table 2. Study No 8. - Bryden 2005:12)

Stigma
There was a concern that others ---would react by prejudging and stereotyping them (Table 2. Study No. 6. - Langdon *et al* 2006:7)

Stigma/Labelling
'*Dementia implies a very derogatory and negative circumstance. Negative in the sense of implying something less than human; because demented really means mindless, or without a mind. And without a mind one is not really fully*

</div>

human…. In fact not human at all'. (Table 2. Study No. 1. - Sterin 2002:7)

Stigma/Labelling
Most participants were reluctant to use the word dementia or Alzheimer's disease, preferring more descriptive terms such as 'memory loss' or 'forgetfulness'. They felt that the medical terminology did not give the correct impression to others because of the negative connotations associated with the word demented. (Table 2. Study No. 6. - Langdon *et al* 2006:4)

Stigma/Labelling
The word dementia was linked to the word demented and felt that others might be inclined to so -participants used phrases such as 'short on top', 'a screw loose', 'a bit funny', gaga, crackers to describe what they thought others might understand by the word. (Table 2. Study No. 6. - Langdon *et al* 2006:4)

Stigma/Labelling
The use of the terms dementia and Alzheimer's disease seemed to evoke the strongest and most visceral emotional reactions in participants - In particular the word 'dementia' seemed to produce negative reactions (Table 2. Study No. 6. - Langdon *et al* 2006:4)

'*I don't like the word because it means mindlessness*' (Table 2. Study No. 6. - Langdon *et al* 2006:4)

Labelling
Dementia and Alzheimer's Disease- fancy words or dreadful names? (Table 2. Study No. 6. - Langdon *et al* 2006:4)

Labelling
'*Please don't call us 'dementing' we are still people separate from our disease… If I had cancer you would not refer to me as 'cancerous', would you*?' (Table 2. Study No 8. - Bryden 2005:143)

The two essential insights, "Dementia the Disease of Society' and 'Living with Dementia' and their component and sub-component parts, which make up the structural-textural synthesis, 'Being Together'- the challenging shared journey with dementia, are illustrated below. I first present a summary overview of the structural-textural synthesis followed by a more elaborate structural-textural synthesis (see page 134).

Summary Overview of the Structural-Textural Synthesis
'Being Together'- the challenging shared journey with dementia

'Dementia the Disease of Society'
The first essential insight, 'Dementia the Disease of Society', highlights the way in which relationships with others are pivotal in supporting a person's sense of

self. If society only recognizes people with dementia, in a negative and stigmatizing way, it fails to acknowledge them as a people seeing them only as their disease, so that in effect they become a non-person. This has negative consequences that impact not only on them but also on their care partner and the life they share together. As social relationships decline there is an increasing reliance on the care partner to support the partner with dementia to sustain a sense of self. The first essential insight, 'Dementia the Disease of Society', is characterized by the following components, *stigma and labelling'*, *'becoming a non-person'*, and *'supporting personhood'*, as illustrated in Diagram 2 below: -

Diagram 2 - Dementia the Disease of Society

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┌─────────────────────────────────┐
│       Stigma & Labelling        │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│      Becoming A Non-Person      │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│      Supporting Personhood      │
└─────────────────────────────────┘
```
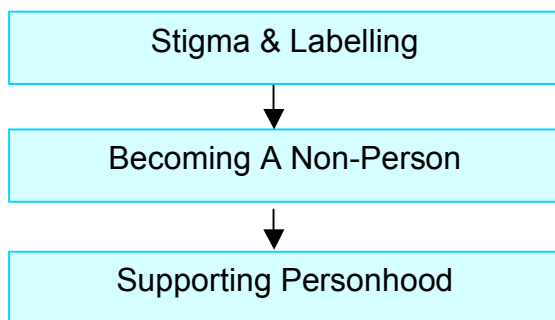
Although the components of 'Dementia the Disease', of society are presented in a linear fashion in the diagram, this does not represent any hierarchy they are all equal components of the essential insight.

Living with Dementia

In the second essential insight 'Living with Dementia', the process of 'living with dementia', follows the relationship between the care partner and the partner with dementia as it progresses along a continuum from intimacy to alienation, the relationship is characterized by the following components; 'Something is Wrong', 'Life that is Now Possible', and 'Letting Go', as illustrated in Diagram 3 below: -

Diagram 3 – 'Living with Dementia'

```
┌─────────────────────────────────┐
│        Something is Wrong        │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│      Life that is now Possible   │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│            Letting Go            │
└─────────────────────────────────┘
```
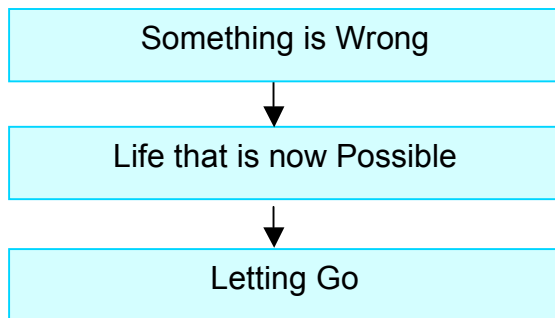
Something is Wrong

In the component, 'Something is Wrong' both partners recognize and begin to acknowledge the changes that are occurring in the partner with dementia, this is characterized by the sub-components of *explaining and normalising, masking and covering* and *holding on*, for both partners, illustrated in Diagram 4 below: -

Diagram 4 – Something is Wrong

```
            ┌──────────────────────────────┐
            │      Something is Wrong       │
            └──────────────────────────────┘
             /            │             \
            ▼             ▼              ▼
┌──────────────┐  ┌──────────────┐  ┌──────────────┐
│ Explaining & │  │  Masking &   │  │  Holding On  │
│  Normalising │  │   Covering   │  │              │
└──────────────┘  └──────────────┘  └──────────────┘
```
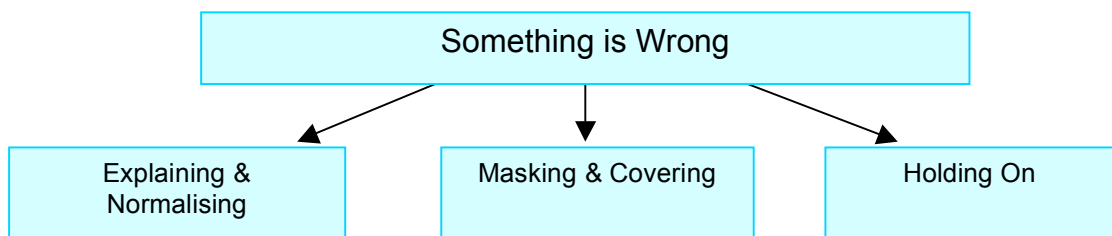
Explaining and normalizing, occurs in the context of speculating about causes and is used by both partners in an attempt to offer plausible reasons for the partner with dementia's behaviour. *Masking and covering* relates to the strategies used in an attempt to mask and cover the decline of cognitive abilities. *Holding on* relates to the attempts of the partner with dementia to hold onto their socially constructed identity as their inner sense of self, fragments, when they are no longer able to do this, the care partner is increasingly involved in "holding" for their partner with dementia.

Life that is Now Possible

The component, 'Life that is Now Possible', refers to the adjustments that both partners make, as they face up to a life with limited horizons. As they adjust to their new life, the way in which they re-define their roles in their changing relationship impacts on the life that is now possible. The 'Life that is Now Possible', is characterized by the sub-components of *'being together in simple ways'* which relates to both partners, the *'cost of caring,'* which relates to the care partner and *'life in the slow lane'*, and *'becoming a blank'* which relate to the partner with dementia, as illustrated in Diagram 5 below: -

Diagram 5 – Life that is Now Possible
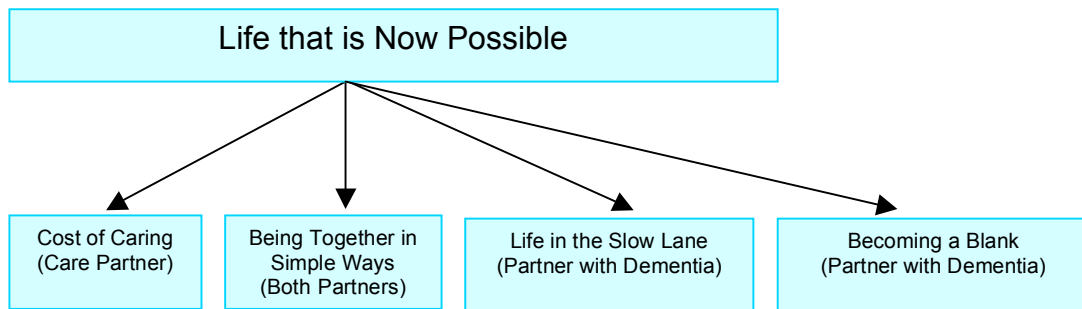
Being together in Simple Ways; in their 'joint journey' together with dementia, in both partners' value moments of time, of simply, 'being together', this is time, which exists outside of caring time. In addition 'Being Together in Simple Ways' is further characterized by '*carpe diem'*, which reflects the importance of making sure there is some joy experienced in each day, and for the caregiver '*carpe diem'*, is also used as a strategy for watching for unscheduled opportunities to engage in restorative activities and *'doing things together'*, which refers to the care partner's attempts to try to sustain a sense of agency in the partner with dementia, (see Diagram 5a below).

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          ┌─────────────────────────────┐
          │ Being Together in Simple Ways│
          └─────────────────────────────┘
                  ╱             ╲
                 ╱               ╲
   ┌──────────────────┐   ┌──────────────────────┐
   │   Carpe Diem     │   │ Doing Things Together │
   │ (Both Partners)  │   │   (Care Partner)      │
   └──────────────────┘   └──────────────────────┘
```
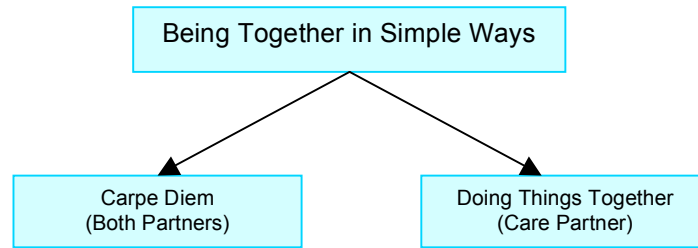
The *cost of caring,* relates to the care partner, as caring increasingly takes a position of priority in their life, they increasingly have to adjust to a life with more 'limited horizons'. *Life in the slow lane*, relates to the partner with dementia as they finds themselves, slowing down as 'mindful activity', takes more time, and what has in the past been 'thoughtless' activity, now seems suddenly difficult and slow. *Becoming a blank*, this signals, the beginning of the breakdown of meaningful and engaged activity, for the partner with dementia.

Letting Go

The component, 'Letting Go', signals the transition to living apart as the care partner detaches from the person the partner with dementia has become, as the cost of caring becomes too high. 'Letting Go', is characterized by the sub-components '*becoming strangers'* and '*a triggering event*', as illustrated in Diagram 6 below: -

Diagram 6 – Letting Go

```
          ┌─────────────────────────────┐
          │          Letting Go          │
          └─────────────────────────────┘
                  ╱             ╲
                 ╱               ╲
   ┌──────────────────┐   ┌──────────────────────┐
   │ Becoming Strangers│   │  A Triggering Event   │
   │                   │   │   (Care Partner)      │
   └──────────────────┘   └──────────────────────┘
```
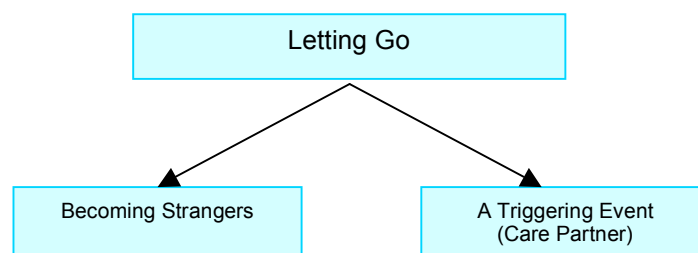
Becoming strangers, is influenced by the losses sustained by both partners. As reciprocity within the relationship diminishes, the care partner loses a major source of support for carrying on. *A triggering event*, the decision to '*step away'* from caring, is often preceded by a triggering event that results in the care partner being unable to continue to give care in the home.

A full expression of the essential insights and their component parts is given in the following structural-textural synthesis.

4: Expressing the Structural-Textural Synthesis

Introduction

Direct quotations from individual studies are used throughout the synthesis to illustrate both the essential insights and their components and sub-components because of their vividness and immediacy, as Halling (2002:30), notes:

> 'without well-chosen examples and quotes, the analyses of the phenomena and people, however insightful, will fail to bring the reader into a close relationship with the subject matter'.

In the following structural-textural synthesis direct quotations from the partner with dementia are shown in bold italics and direct quotations from the care partner are shown in italics in order to differentiate between the two.

Structural-Textural Synthesis

'Being together'- the challenging shared journey with dementia

This structural-textural synthesis presents the findings of 'Being together' – the challenging shared journey with dementia. From my analysis there are two essential insights that characterize the challenging shared journey of being together. The first essential insight; 'Dementia the disease of society', describes the societal response to the person of dementia and the resulting impact on their sense of identity. The second essential insight; 'Living with Dementia', describes the challenges and journey shared by the partner with dementia and their care partner.

"Dementia the disease of society"

The societal response to dementia and the labels that society bestow upon the person with the disease of dementia, impact on the persons sense of self and subsequently the relationships they share with others. Personhood is supported or diminished by the relationships the person with dementia shares with others. Within this context their care partner has a major role to play in supporting their partner with dementia, as together, they face the challenging journey that occurs within the essential insight of, 'Living with Dementia'.

The components of *'stigma and labelling'*, *'becoming a non-person'*, and *'supporting personhood'*, delineate the essential insight, "Dementia the disease of society".

Stigma and Labelling.

Living with dementia is not easy, because dementia is in many ways a disease of society where the person and their family are isolated by stigma

> *'Please don't call us 'dementing' we are still people separate from our disease... If I had cancer you would not refer to me as 'cancerous', would you?'.*

The world of the person with dementia can become circumscribed by the stigma of their illness and the labels that society attaches to them.

> ***'Dementia implies a very derogatory and negative circumstance. Negative in the sense of implying something less than human; because demented really means mindless, or without a mind. And without a mind one is not really fully human…. In fact not human at all'.***
>
> (Sterin 2002:7)

People are often reluctant to use the term dementia to describe their illness often preferring to use more descriptive terms such as 'memory loss' or 'forgetfulness'. Being labelled demented evokes 'strong and visceral emotional reactions' in people as they perceive that by being labelled in this way others would perceive them as 'being short on top', 'gaga', 'crackers' or having a 'screw loose', (Langdon *et al* 2006).

> ***'A person is a person through others'****.*
>
> (Bryden 2005:12)

The response of others has a significant impact on people's self evaluation and their ongoing attempts to preserve their sense of identity. As they struggle with their diagnosis people fear the 'loss of themselves' and face an identity crisis. Who are they and who will they become?

Becoming a non-person.

Diary entry 13th May: '*M… struggled with putting words together tonight. It is very sad to see this. At one point she said, 'I'm not a person'. That must be a desperate feeling'.*

(Salmon 2006:183)

No longer defined by their work, roles, and contribution to society, they are given a new identity as a person who is no longer valued and no longer able to make a contribution and they are assigned the role of 'non-person'.

> *'It's like a stigma, like carrying a sign that you are sort of demented, and you can't do this and you can't do that…………. I don't belong in society anymore. That is what they are telling me. The feeling that I get is that I am incompetent. I shouldn't be living'.*
>
> *(Harris & Sterin 1999:254)*

If people are categorised and labelled solely in the terms of their disease it fails to acknowledge their uniqueness as a person.   How others relate to the person with dementia can have an impact on their disease; as role changes, increased dependency and reduced control over their lives, result in negative effects on their perceptions of themselves and on their self-esteem.

Supporting personhood.

> *'You can restore our personhood, and give us a sense of being needed and valued. In our crisis of identity and our fragmentation value us for who we are now as it is very hard for us to be who we once were'.*
>
> *(Bryden 2005:127)*

Kitwood (1997:8), has defined personhood as "a standing or status that is bestowed upon on a human being by others, in the context of relationship and social being". This definition acknowledges the interdependence and interconnectedness of human beings, (Woods 2001).

There is a growing interest in the 'dynamics' of dementia, the types of relationships that are forged between the person with dementia (pwd) and their primary carer. Self and personhood are created within a relational context and as a person's sense of identity and sense of worth, diminish their care partner

makes a major contribution to the extent of personhood they enjoy, (Hellström *et al* 2005a).

Social relationships can create or diminish personhood and increasingly the care partner is called on to respond flexibly in supporting personhood as the person with dementia's capacities decline, (Woods 2001). As social relationships decline there is an increasing reliance on the care partner to support the person (partner) with dementia to sustain a sense of self, (Hellström *et al* 2005a). The care giver's relationship with the person with dementia becomes intrinsically linked, (Whitlach 2001), as they focus on both maintaining their relationship and preserving their partner's sense of self, whilst increasingly putting their own interests on hold, (Hellström *et al* 2005a). 'This poses the existential question of what kind of simple "being together" is possible in the light of limited horizons', (Todres & Galvin 2006:54).

"Living with Dementia".

This interactive process has been referred to as 'a dance with dementia' in which the two partners dance to the tune of dementia. Within this dance both the steps and the lead are constantly changing as the two partners adapt to the continually changing melody of dementia.

> *'But like all dances, there will be times when one partner is in charge, times when partners are separate, and times when the lead changes'.*
>
> (*Bryden 2005:165*)

For the two partners, the process of 'living with dementia', progresses along a continuum from intimacy to alienation in the relationship.

This study has identified the following components within the challenging shared journey with dementia: -

- Something is wrong
- Life that is now possible
- Letting go

The components together with their sub components are given in order to delineate the essential insight.

Something is wrong.

Something is wrong - both partners recognize and begin to acknowledge changes in the behaviour of the partner with dementia that cannot be explained as isolated occurrences as they begin to form a pattern. Complex processes are involved in the expression of awareness of memory problems. Clare (2003) suggests that responses are shaped by habitual coping styles and by relationships and interactions with partners.

The sub-components of *explaining and normalising, masking and covering, holding on,* characterize something is wrong for both partners.

Explaining and Normalising.

Explaining and normalising occurs in the context of speculating about causes and is used by both partners in an attempt to offer plausible reasons for the partner with dementia's behaviour, in order to diminish or to deny the gravity of the situation.

> *'you don't appreciate when you are starting on this dreadful journey because you think it is a bit of forgetfulness and you don't appreciate the gravity of what's coming until you have got to quite a bad stage'.*
>
> *(Galvin et al 2005:6)*

Both partners attempt to explain changes in terms of normal functioning. Attributing changed behaviours to plausible factors relating to life events such as aging, preoccupation, or concentration difficulties in order to maintain a

façade of normality and to preserve and protect their own relationship and their relationship with the wider world.

> *'Like leaves falling to the ground from a tree, old people lose their memories'.*
>
> *(Langdon 2006:9)*

In an attempt to maintain an intact sense of self the partner with dementia provides 'acceptable' explanations that do not challenge their self concept and attempt to normalize their memory loss. The explanation is often grounded in the normal cycle of physiological changes that occur with ageing.

> *'I think it happens to everybody when they get to my age…I've got a feeling that there's a limit to what the head can contain' I couldn't accept anything more drastic than that'.*
>
> *(Clare et al 2005:502)*

Explaining is affected by the individuals' beliefs about memory and ageing and is also used as a means of saving face or consolation.

> *'Well the way I think of it is… If I had a cine camera on top of my head, which looked at everything I looked at, and registered noises and conversations and I had done that for 70 years, how big do you think it would be? And it's supposed to be all in here. I mean there's no room'.*
>
> *(Clare et al 2005: 510)*

Presenting memory problems in this way is essentially self-protective and represents an attempt to maintain a sense of self and normality. In addition it also represents an attempt to shield their partner and families from their fears about their declining abilities, putting their assumed need ahead of honest expression.

> *'We don't talk about it, no… If I upset her it upsets me too you see'.*

(Clare et al 2005:507)

Attempts at explaining and normalizing are often socially reinforced by the reassurance of partners and friends. Partners also attempt to normalize problems both in conversations with others and in the presence of the partner with dementia by reinforcing and reflecting explanations.

'Oh yes! He has difficulty remembering. But no as far as that goes, my goodness, I can't remember sometimes what day it is either! You know. My memory's good but you have to get the paper to make sure'.

(Perry & O'Connor 2002:58)

By explaining in this way the care partner was able to support their partner with dementia to 'feel good about themselves', and also to attempt to present them as an intact person to the outside world. However this reflects a 'public presentation' of their partner's abilities. In private their views of the extent of their partner's memory loss was often markedly different. If both partners attempt to conceal their awareness of the problem and avoid frank discussion this reinforces the negative stereotype of dementia as a taboo and stigmatising subject.

Explaining and normalising is a strategy used to provide plausible explanations to explain and normalise memory loss, both internally to the self, and externally to the outside world.

Masking and Covering.

'Is that the word I want………in our head a string of pictures has formed, but the words for those pictures no longer make their way into our consciousness, let alone to our mouth. The words for those pictures seem as if they are on a loose spinning wheel………..and if the wheel spins too far, the wrong word comes out. It is as if my shelves of neatly filed words have been swept

onto the floor, and I have to search among untidy heaps to find the word I am looking for'.

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(Bryden 2005:118)

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We are normally able to think and use language with little obvious effort, but for people with dementia thoughts come more slowly and people often have to pause and consider how best to express themselves, (Phinney & Chesla 2003).

'I'll be speaking to somebody, I'll get the wrong words, say the wrong thing …sentences don't work very well'.

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(Phinney & Chesla 2003:289)

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This represents the breakdown of a social practice that exists in public space and affects the partner with dementia's sense of self worth and social standing. As the ability to communicate verbally declines they fear that others will no longer take them seriously, or value their company, (Chesla & Phinney 2003, Langdon *et al* 2006).

'The sense of being listened to, and of being heard will make us feel valued and in a relationship with you. This is what we need as we cope with shattered thoughts and fragmented selves'.

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(Bryden 2005:138)

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As they struggle to maintain an existing sense or prior sense of self, (Pearce *et al* 2002) they adopt strategies in an attempt to mask and cover the decline of their cognitive abilities, particularly in social situations. This allows them to maintain a façade of normality. Underneath their attempts at covering up, many people experience underlying fears that their difficulties can be seen reflecting their awareness of what is happening.

'You get rather cunning in dealing with people socially. Yes it's quite an art really. Making, trying to behave socially normally without letting on that you've forgotten a person's name…I try to hide the fact that I have memory problems'.

(Clare 2002:143)

By presenting themselves as being 'cognitively intact', to the wider world they attempt to avoid both the stigmatisation surrounding dementia and the negative social responses of others that they are 'hard to talk to', feel different from the way we do' and 'are unpredictable', and maintain their social identities, (Langdon *et al* 2006).

> **'People simply stop talking to you in the way that they used to. You are in a different category from the normal population'.**
>
> *(Sterin 2002:8)*

As strategies to 'cover up' and hide their difficulties fail, and it becomes harder to formulate and articulate their thoughts in conversation many withdraw from unfamiliar social situations and activities; as they do not want to risk embarrassing themselves or others.

> **'Sometimes when I've got into a mess, and I'm not making sense and can't dig it out, um I really crawl and fly away'.**
>
> *(Clare 2002:143)*

Partners also attempt to control the social environment in an attempt to isolate the partner with dementia from situations and people that may cause them feelings of inadequacy, by avoiding people who block their partners' attempts to communicate; by interrupting or showing impatience or talking across them.

> *'talk across people as though they don't exist… I resent them talking across my wife as though she is a non-person… This almost robs people of their dignity….' .*
>
> *(Perry & O'Connor 2002:59)*

However well-intentioned, attempts by the care partner to support the partner with dementia in social situations can result in them feeling 'side-lined'

'She did too much talking and didn't let me in…. How do I get the balance right so I'm seen to be, well alive?'.

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(Clare 2003:1024)

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Attempts by both partners to minimize or conceal the condition, often results in social awkwardness, as the condition becomes apparent, whilst attempts to be 'more open about it' leaves others uncomfortable as they seek a metaphorical and real distance from the realities of dementia, (Todres & Galvin 2006). The resulting withdrawal from social relationships increases isolation for both partners and reinforces the stigmatization of dementia*.*

'You cannot ignore that people are uncomfortable with you'.

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(Sterin 2002:9)

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<u>*Holding on.*</u>

'If our identity is socially constructed who do we become when the wrecking ball of dementia smashes holes into life stories?'.

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(Salmon 2006:183)

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The partner with dementia attempts to hold onto their socially constructed identity as their inner sense of self, fragments. In the early stages of dementia a persons' sense of self and identity fluctuates in the light of multiple losses caused by the effects of their memory problems. They struggle to maintain their sense of identity and to maintain their defining core values as they deal with the loss of significant roles, autonomy, self worth, and respect from others and their sense of competency, (Harris & Sterin 1999).

'Sometimes I'm me and sometimes I don't know who I am. I don't know it comes and goes; I never know. You're not you; you've got someone else kind in back of you'.

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(Harris & Sterin 1999:246)

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The central dynamic for the partner with dementia is the tension between attempts to protect the self from threat and attempts to engage with the potential threat and integrate the resulting experiences into the self, (Clare 2003). In an attempt to preserve their personal identity and maintain the core values that define who they are, the partner with dementia develops reaction patterns to the illness, (Harris & Sterin 1999). The coping style that they adopt is influenced by personality, and preferred coping strategies built up over the years in response to dealing with difficult situations, (Clare *et al* 2005).

> *'We need to create a new image of who we are and who we are becoming. How we do this depends very much on our personality, our life story, our health, or spirituality, and our social environment'.*
>
> *(Bryden 2005:158)*

Responses fall on a continuum between self-maintaining and self adjusting; some deny the diagnosis in order to maintain their 'old' sense of self, some fight the disease, others accept it and fit their new self-identity into their old one, for others the struggle is too hard and they accept a changed definition of self, (Clare 2002, Clare 2003, Harris & Sterin 1999).

> *'Those of us in the early stages of dementia undergo a constant adjustment and readjustment, a tug back and forth as we do this reconciliation, as we grieve our losses and try to accept the present reality'.*
>
> *(Truscott 2003:13)*

In order to hold on to, and maintain their sense of self the partner with dementia attempts to deal with the effects of memory problems by 'trying harder', (Clare 2002, Clare 2003, Pearce *et al* 2002), and using multiple coping strategies to enable them to maintain a sense that they are functioning normally.

'I need a system. We have to have something sort of regular to me. It's really important…So we're functioning because we have a system'.

(Clare 2002:142)

As 'trying harder' techniques begin to fail the partner with dementia begins to reappraise their abilities and downgrade their expectations of themselves and set lower aims for remembering things and completing tasks. This results in the redefinition of roles within the partnership.

The care partner is increasingly involved in "holding" for the partner with dementia, that which they cannot hold: the holding of continuity, (Todres & Galvin 2006). Our stories are told in and through dialogue with others, and for the partner with dementia, increasingly their story is told by family members and other care providers, (Phinney 2002a). Care partners attempt to maintain continuity of life stories for their partners with dementia by acting as 'custodians' and reporters' of their life histories. By 'telling the ways' (Perry & O'Connor 2002:57), of the partner with dementia the care partner is able to contextualise current reality, interpreting current behaviours based on previous history enabling them to separate the person from the disease process.

'So all of the time we went through the different changes that were occurring in my Bea (wife). There was a physical Bea that had things happening to her, but still underneath that- my Bea'.

(Perry & O'Connor 2002:57)

Separating the person from the disease in this way allows the essence of the partner with dementia to remain intact as it frames their behaviour as part of the disease process.

'You have to remember that's not John. That's his illness because he would never have done that NEVER!'.

(Wuest et al 1994:439)

Life that is now possible.

> *'The mental adjustment or reconciliation is very hard at times as I sometimes ache to have things the way they were before, and since that cannot be, I simply have to try to accept the changes in my life....'.*

> *(Truscott 2003:13)*

Adjusting to a 'life that is now possible' occurs in the face of increasing losses as both partners face up to a life with limited horizons. As both partners adjust to their new life, the way in which they re-define their roles in their changing relationship impacts on the life that is now possible. As the partner with dementia becomes more dependent the partners need to renegotiate their identities. The roles they assume in their changed relationship can either support (care-partners) or undermine (caregiver and caregiven) the identity and self-concept of the partner with dementia.

> *'We used to be on an equal footing with each other, a marriage of two accomplished people. Now he is a CAREGIVER and I am a CAREGIVEN'.*

> *(Harris & Sterin 1999:246)*

This reflects the loss of independence and self-worth experienced by the partner with dementia. Adopting the roles of caregiver and caregiven highlights the illness and results in a relationship that strips both partners of their other identities. The partner who adopts the sole identity of caregiven learns helplessness as they lose more roles, function and become more incapable.

> *'…being DEPENDENT- that's the pits. I feel like I might throw in the towel… I... I'm a has been'.*

> *(Harris & Sterin 1999:249)*

The partner who adopts the sole identity of caregiver becomes overwhelmed by the tasks they face and can quickly become exhausted and emotionally drained.

> *'We have become co-dependent needing each other to accept our labels as victim and sufferer'.*

<div align="right">(Bryden 2005:147)</div>

Forming a care-partnership removes the labels of 'victim' and 'sufferer' and allows both partners to adapt to new roles as they continue their journey into the life that is now possible. Forming a partnership allows the partner with dementia to become an active partner, and allows them to remain at the centre of the relationship, and supports their status as a person rather than a passive recipient of care.

> *'I love the imagery of a couple dancing with dementia. It's a couple, a care-partnership in which we move together. We sense each other's needs, and change and adapt according to the changing music of the journey with dementia …*
> *But like all dance partners... We both have to learn to listen to the music. What is happening to me, to us? What is the rhythm of our dance with dementia?'.*

<div align="right">(Bryden 2005:164-165)</div>

As both partners face a life with increasingly 'changing' and 'limited horizons' they have to 'attune' to living a life with dementia, as a 'future that was once wide becomes narrow', (Todres & Galvin 2006). As the disease progresses, the challenge is to find the 'shared life that is possible', this requires ongoing adjustment by both partners, (Galvin *et al* 2005).

> *'To live with the fear of 'ceasing to be' takes enormous courage. The precious string of pearls, of memories, that is our life, is breaking, the pearls are being lost. But by finding new pearls, those created in the struggle with dementia we can put together a new necklace of life, of hope in our future'.*

<div align="right">(Bryden 2005:170)</div>

The sub-components of '*being together in simple ways'* characterizes a life that is now possible for both partners. The sub-component of the '*cost of caring,'* characterize a life that is now possible for the care partner. The sub-components of '*life in the slow lane'*, and '*becoming a blank'* characterizes life that is now possible for the partner with dementia.

Being together ... the possibility of being together in simple ways.

> *'As we become less cognitive, it's the way you talk to us, not what you say that we will remember. Your smile, your laugh and your touch are what we will connect with. Empathy heals. Just love us as we are. Visit us and just be with us…. we don't need words as much as your presence, your sharing of feelings with us. We're still here, in emotion and spirit, if only you could find us'.*
>
> *(Bryden 2005:138)*

In their 'joint journey' together with dementia, both partners value moments of simply 'being together', "pockets" of simply "being" in which the flow of time becomes effortless, (Todres & Galvin 2006:56). Such time exists outside of 'care-giving time' which, is filled with instrumental tasks and strategies for everyday living, (Todres & Galvin 2006).

> *'I retain little information. But what I do retain is the feeling of pleasure or excitement …….the emotional response to the activity of the moment. And that is still precious'.*
>
> *(Truscott 2003:14)*

As cognitive impairment increases care partners replace and compensate for language losses, this new language is made up of gestures and tactile and tonal signals, (de la Cuesta 2005:888). This new language keeps the partner with dementia socially and emotionally alive by attributing them both an identity and social status, (de la Cuesta 2005).

'We can find new ways to enjoy each moment of our day. For me it is the beauty of the sunset, of seeing my daughters' joys and triumphs, of stroking cats and hugging my husband'.

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(Bryden 2005:166)

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Both partners share 'small joys' or 'small pleasures' *(Galvin et al 2005, Hellström et al 2007),* by focusing on rituals or routines that might have once been taken for granted, but which are now accorded far greater significance, as they search for the positives in their situation, (Hellström *et al* 2007).

'Then you have to find the positive things in life. You always search for the positive to be able to feel happy. You can't go and dig yourself in, but you have to find new angles which make it more positive'.

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(Hellström et al 2007:395)

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Partners value the intimacy of a loving relationship, and in particular occasions for connecting through physical touch, (Clare 2002, Todres & Galvin 2006).

'He gives my back a massage as soon as I ask him, and the same way when I shower he helps me to rub in oil'.

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(Hellström et al 2007:395)

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'Stroking is an important part of touch, and I find it lovely to touch and to stroke, and to be touched, to connect in this way'.

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(Bryden 2005:141)

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Moments of 'just being' can break through in silently sitting or walking or in listening to music together.

Diary entry- 20th May- 'M…. and I had a lovely walk. We both go along quietly- I lost in thought. M…. lost in a maze of thoughts'.

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(Salmon 2007:184)

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The sub-components of *'carpe diem'*, and *'doing things together''* characterize *'being together'*.

<u>Carpe Diem.</u>

> **'Carpe diem, let's seize the day- together. It doesn't really matter if I don't remember today or don't know what day of the week it is. As long as we all enjoyed it to the fullest together'.**
>
> *(Bryden 2005:122)*

Moments of being together are supported by *carpe diem.* The opportunity to seize the day exists at two levels. For the partner with dementia it reflects the importance of making sure that there is some joy experienced in each day, (Bryden 2005, Hellström *et* al 2007).

> **'You need to live today like it's your only day'.**
>
> *(Harris & Sterin 1999:247)*

Moments when the light shines through the darkness, allow the partner with dementia to appreciate the occasional 'good day' and to engage in enjoyable pastimes and activities, such as going for a walk, gardening or listening to music, (Clare 2002).

> **'To enjoy the brief activity in the moment, to enjoy the pleasant feelings'.**
>
> *(Truscott 2003:15)*

As memory, and the capacity to recall events deteriorate the immediacy of the event becomes paramount to the partner with dementia.

> **'Even if we never remember, surely the memory of the event is not what is important – it is our experience at the time that really matters'.**
>
> *(Bryden 2005:140)*

As temporal horizons shrink both partners adopt a strategy of living for the day, as the best way of maintaining a 'good life' together, (Hellström *et al* 2007).

> ***'We can find out how much music we can still make with what we have left. We can find new ways to enjoy each moment of our day'.***
>
> *(Bryden 2005:166)*

For the caregiver *'carpe diem'*, is also used as a strategy for watching for unscheduled opportunities to engage in restorative activities, allowing them to acknowledge their own needs, and to support them in their role as care partner, (Watts & Teitelmann 2005).

> *'If he's asleep (I would) sneak away from him or whatever, and pray and cry'.*
>
> *(Watts & Teitelmann 2005:287)*

Breaks achieved in this way afford the care partner time to 'refresh and re-energise', and provide a period of 'calmness, and mental clarity', (Watts & Teitelmann 2005).

> *'It just gives it a new lease on life'.*
>
> *(Watts & Teitelmann 2005:287)*

Doing things together………the care partner sustains a sense of agency.

'Doing things together' allows the care partner to provide help and support in a way that affirms their partner's sense of agency and helps them to maintain their self image, (Hellström *et al* 2005b). The care partner 'works' to create a 'nurturative relational context', such 'work' is a vital but essentially 'invisible' element in maintaining the partner with dementias involvement, (Hellström *et al* 2005a: 17). This involves the learning of patience and validating and valuing activities for their shared doing rather than on the basis of evaluating their outcome, (Todres & Galvin 2005:7). The care partner learns to 'hold back' from

the need to rush an outcome and to 'be with the process' of 'what movement is possible' valuing this for its own sake, (Todres & Galvin 2006:53).

Supporting existing competencies is a two-fold process achieved by identifying retained abilities and setting up situations that encourage the partner with dementia to do as much as they can.

> *'I'll do all the steps but the last step and say, "Would you put six teaspoons of coffee in here?" He can do that. But he can't go through all the steps'.*
>
> *(Perry & O'Connor 2002:57)*

As the dementia progresses the care partner has to increasingly 'work alone' to maintain the involvement of the partner with dementia. Initially, to protect their partner from being aware of how much support they need, thereby allowing them to perceive themselves as still playing an active role, and eventually because the partner with dementia is unable to contribute to the task, (Hellström *et al* 2005b).

> *'I can't manage without you, he tells me. He is incredibly thankful for whatever I do. I don't want him to feel like a burden for me. Instead I try to cover up [some of my caring]'.*
>
> *(Hellström et al 2007:394)*

Sustaining the partnership becomes an increasingly draining and difficult solo effort on the part of the care partner.

The cost of caring.

> *'M's dementia needed constant vigilance. Earlier today I felt overwhelmed by the vacuum she has become. She follows me aimlessly, understands almost nothing of what I say to her she has become my constant shadow'.*
>
> *(Salmon 2006:184-185)*

The phrase 'costs of caring' is typically connected to finances, yet there are other, less obvious costs that defy calculation, (Salmon 2006). Caring takes a position of priority in the care partners life, (Wuest *et al* 1993) and they increasingly have to adjust to more 'limited horizons', (Todres & Galvin 2005), as the needs of the partner with dementia increase and compete with demands outside of the home.

Respite from caring in the form of traditional respite, where the partner with dementia is with someone else, may provide a break from direct care responsibilities but it does not necessarily provide a mental or physical break, (Watts & Teitalman 2005, Salmon 2006). When they are away from their partner with dementia the care partner feels a compelling need to hurry back home, (Svanström & Dahlberg 2004) as the 'clock is always ticking', (Salmon 2006, Watts & Teitelmann 2005). Care partners experience a sense of urgency as they try to accomplish as many tasks as possible by 'playing beat the clock', (Watts & Teitalmann 2005), during respite opportunities.

> *'Even when I was away from the home doing something I enjoyed, I was constantly aware of the time... The clock always ticking'.*
>
> *(Salmon 2006:185)*

Relationships with others, outside of the caring partnership are also jeopardized, as caring takes a position of priority in the care partners' life, (Wuest *et al* 1994).

> *'Well looking after L… meant that I lost all social contact. It was a gradual process. I mean, my real one friend is an almost 82-year old on the floor below here and that is about it. Which is no social life'.*
>
> *(Galvin et al 2005:6)*

The care partners responsibility for the partner with dementia leaves them both 'metaphorically and literally bound to the home', (Svanström & Dahlberg 2004: 677).

Life in the slow lane.

> *'I used to be a race horse and master juggler, rushing from one activity to the next, and keeping many balls in the air at the same time... Now, I travel in the Slow Lane!'.*
>
> *(Truscott 2003:11)*

The partner with dementia find themselves, slowing down as 'mindful activity', takes more time and conscious effort as their world becomes more chaotic. What has in the past been transparent, seemingly 'thoughtless' activity, now seems suddenly difficult and slow, and the most simple of tasks come to require careful attention and consideration. They find it increasingly difficult to express themselves through words, and conversations become a challenge, (Phinney & Chesla 2003).

> *'The world goes much faster than we do, whizzing around, and we are being asked to do things, or to respond………. It is too fast, we want to say, 'go away, slow down, leave me alone' just go away'.*
>
> *(Bryden 2005:128)*

For the partner with dementia this requires a daily adjustment on both their expectations of themselves, and their expectations of life as they try to reconcile their 'old me' with the 'new me' and to accept that being slow, doing less, achieving less, experiencing less, is what it is like to live in the slow lane, (Truscott 2003). The complexity of daily living becomes a source of anguish and exhaustion.

> *'Each day, life is a struggle I'm like the swan, gliding above; paddling frantically beneath…It feels as if I am paddling faster and faster each day. It seems as if I'm going to sink soon, because I am getting to the point where I feel too exhausted to keep going like this'.*
>
> *(Bryden 2005:102)*

Becoming a blank.

> *'I suppose in a way it's like being in a fog and you can't find your way out of it… I mean, not knowing is frightening'.*
>
> *(Phinney 2002b: 55)*

Becoming a blank signals the beginning of the breakdown of meaningful and engaged activity. The partner with dementia increasingly finds them self in 'a world that does not make sense, "world" is used in the Heideggerian sense – that is, not solely as the physical space that surrounds us, but the meaningful whole', (Phinney & Chesla 2003:290). The fabric of their world changes and loses meaning.

> *'It feels as though there is cotton wool in my head, a sort of fog over my thoughts and feelings. I do not have enough energy to cope in the fog to find thoughts and get an idea or to work out what you are saying. I have lost my immediacy'.*
>
> *(Bryden 2005:106)*

As the bodies' implicit knowledge of what to do next falters, the partner with dementia's ability to consciously reflect on the next step, leads to a discovery that explicit knowledge is no longer available to call on, (Phinney 2002a, Phinney & Chesla 2003). The ensuing breakdown of activity leaves the partner with dementia in an increasingly 'lost and silent world' as they withdraw from the world of practical involvements.

> *'Everything I did in the past…. Everything I like to do has just gone now… I can't do any of it ... all the things I've lost, they're lost'.*
>
> *(Clare 2003:1024)*

Being a blank, results in the partner with dementia becoming a passive member of the care partnership as they detach from the world in a bodily way, they stand apart as detached subjects no longer able to engage meaningfully with the world, (Phinney & Chesla 2003).

'When my brain becomes overloaded and fatigued, it's like a short circuit and my brain cuts out. I get a blank brain-less look and withdraw from what is around me. I am not really there, my eyes cannot focus, and I can't say much. The fog thickens….'.

(Bryden 2005:116)

Letting go.

Letting go signals the transition to living apart as the care partner detaches from the person the partner with dementia has become, and the cost of caring becomes too high. Care partners find themselves 'working alone' despite their efforts to 'maintain involvement' and 'sustain couplehood'.

'Yes despite the fact we are living together, and we have lots of things in common, nevertheless we are lonely in a way… you live in two small worlds…'.

(Hellström et al 2007:402)

Detachment is at the foreground of the separation process.

'His personality went flat slowly. It lets you down very gradually so that it's a slow form of separation'.

(Wuest et al 1994:442)

The decision to hand over care by placing a partner in residential care invokes conflicting emotions as grief oscillates with relief in the care partner as they balance their needs with their partners and face up to their limitations as a carer, (Galvin *et al* 2005).

'All day today I have been saying this is the last time…. It broke my heart to say it was x last night in her own house. She could feel it but couldn't articulate it. And this is my last night as her primary caregiver. I know I am too tired to continue- I could feel that all day – the weight of her needs. Yet the battle with guilt surfaces every few hours…'.

Easing the physical burden of care by moving the partner with dementia into residential care does not necessarily result in reduction of stress for the care partner and the decision to 'sever the connection' may be more difficult than the decision 'to hold on', (Wuest *et al* 1994). The decision to hand over care is one of complexity. It involves the care partner facing and acknowledging their limitations in respect of the care they can provide.

> *'You feel this guilt for this person you don't want to put in a home, you don't want to put them away, and you think, I can look after them...'.*
>
> *(Wuest et al 1994:441)*

This inner resistance to relinquishing caring is challenged by the unrelenting demands of caring that drain the care partners physical and mental resources as they become more pervasive.

> *'I had no energy left to take care of myself: I am not taking very good care of myself these days'.*
>
> *(Salmon 2006:186)*

Whilst acknowledging their own limitations to provide care the care partner seeks reassurance that others can provide 'trusting' care, (Galvin *et al* 2005) and that they can 'trust loved one is safe', (Watts & Teitalmann 2005).

> *'Is x ok with intimate strangers'.*
>
> *(Salmon 2006:186)*

This is further complicated by the care partners' awareness of their partners need for constancy, sometimes expressed in articulate moments by the partner with dementia as gratitude for care, or a request for reassurance that the care partner will never leave them, (Wuest *et al* 1994).

Care partners begin to set limits upon caring and begin to establish criteria for when they will relinquish care such as 'when she doesn't know me' or when he gets violent, (Wuest *et al* 1994). The decision to relinquish care is an 'almost impossible decision to take alone', (Todres & Galvin 2006), and is more easily made if the care partner is supported in their decision making by external forces such as family or health and social care professionals.

> *(The hardest aspect) 'mostly the guilt…. I needed a person with good trained ears… I think I was pouring out my inner soul as it were'.*
>
> *(Galvin et al 2005:7)*

In relinquishing care to others the care partner has to negotiate a change in personal identity and role. If the care partner feels unable to 'maintain involvement' it becomes difficult to 'sustain couplehood', and 'we' becomes 'I', As the care partner moves towards a 'new beginning' they are faced with the task of finding new meaning in life, (Hellström *et al* 2007).

> *'Although the demands of caregiving were high, I knew the routine. Moving into unknown territory- life after caregiving- was terrifying'.*
>
> *(Salmon 2006:186)*

The sub-components of '*becoming strangers*' and '*a triggering event*' characterize letting go for the care partner.

Letting go… 'Through becoming strangers'.

Becoming strangers is influenced by the losses sustained by both partners. As cognitive impairment increases the partner with dementia and the care partner become 'increasingly lost and are strangers in their own world', (Svanström & Dahlberg 2004).

> *'I feel overwhelmed by the vacuum x has become. She follows me aimlessly, understands almost nothing of what I say to her'.*
>
> *(Salmon 2006:185)*

As the care partner becomes more focused on the practical tasks of caring the relationship becomes defined by the instrumental challenges of caring and the intimate partnership of couplehood recedes, (Todres & Galvin 2006) and the intimates become strangers, (Wuest 1994).

> *'Just two people... Putting up with each other'*.
>
> *(Todres & Galvin 2006:56)*

As reciprocity within the relationship diminishes, as the partner with dementia increasingly withdraws into a world of blankness, the care partner loses a major source of support for carrying on. Sustaining couplehood, becomes an increasingly difficult and solo effort on the part of the care partner. Increasingly, this 'working alone', results in feelings of becoming an 'I', rather than the 'we' which existed in the care partnership, (Hellström *et al* 2007). The burden of caring and the feeling of aloneness become too great balanced against the wish to continue to carry the burden, (Todres & Galvin 2006).

Letting go through... 'A triggering event'.

The decision to '*step away*' (Salmon 2006), from caring and place a partner with dementia in residential care is often preceded by a triggering event that results in the care partner being unable to continue to give care in the home.

> *'Well, the only thing I know is that I'll go on as long as I can manage. And then there will be no choice, he'll have to be taken to residential care'*.
>
> *(Svanström & Dahlberg 2004:680)*

The triggering event may be related to the failing physical health of either partner or a violent act committed by the partner with dementia, (Wuest 1994 *et al*). The event often results in the decision to relinquish care being taken out of the hands of the care partner and provides some 'kind of justification', (Todres & Galvin 2006), for the separation.

'He told me, "M… your good kind man is gone. It's another one now. Don't start crying when he has to go somewhere because it has to be done'.

<div align="right">

(Wuest et al 1994:442)

</div>

Having the decision to relinquish caring removed in this way, often through professional intervention may remove some of the feelings of guilt and self-questioning from the care partner.

Conclusion

This structural-textural synthesis offers the 'story' of 'Being together'- the challenging shared journey with dementia. Throughout the structural-textural synthesis the direct quotations from the partner with dementia and the care partner are differentiated by the use of different styles of text. This serves two purposes; it orients the reader to whose voice they are hearing, and it also highlights the interplay of the two voices in the journey or dance with dementia. Rather like a dance or a tune there are times when one partner's voice dominates over the other, and times when their voices are interwoven. In particular in the later stages of the journey, the partner with dementia loses their voice and remains silent. The fact that their voice is silenced may relate to their perceived inability to communicate with the world or equally it may be that we in the world lack the necessary skills, to be able to hear their voice, reflected in the lack of literature that one is able to draw on to illustrate the experiences of people in the later stages of dementia.

The 'story' is not offered as a 'final story' rather it is offered as a 'possible story' with transferable meanings. A 'story' that is 'open':

'enough to allow individuals to relate to it in personal ways that are unique, while also engaging with elements that may be shared. This play of the 'unique and the shared' characterizes the humanized essence of embodied understanding'.

(Todres 2007:183)

In particular it is offered as a 'story', that does not reduce human experience to numbers, arguments, and abstractions, (Pelias 2007).

Stage 4: Communication Strategy

Introduction

The choice of a communication strategy depends on the intended audience and the objective of the research. In this study my intended audience is a diverse one, which will include lay members of the public, in particular those caring for people with dementia, and health and social care professionals. The objectives are to; facilitate and enhance understanding and awareness of the experience of living with dementia from the perspectives of the partner with dementia and their care partner, and to attempt to tackle the stigma associated with dementia. In seeking a way to communicate the structural-textural synthesis produced in Stage 3 of the framework I was looking for a way of engaging audiences in:

'an ongoing conversation that seeks to share 'good words' and phrases that are evocative and 'carry understanding further'.

(Todres 2004:52)

It was not my intention to offer a definitive statement or determinate sets of ideas, essences or insights about the 'shared journey with dementia' with the implication that there is nothing more to be said, (Van Manen 2002), but rather to 'beckon empathy' by creating, 'a space', where others might 'see more clearly how they and others constitute and are constituted by the world', (Pelias 2007:419). Therefore I needed to find a way to communicate my 'story'; 'Being Together'- the challenging shared journey with dementia, which would have 'something to say to all people for all time', (Sandelowski *et al* 2006:1356). Richardson & St Pierre (2005), offer the suggestion that if you wish to experiment with evocative writing, a good place to start is to transform field notes into drama rules. Transforming data into a dramatic production is a way of

disseminating research findings to a diverse audience, in a thought provoking, engaging, accessible, and nuanced manner, producing an outcome, which transcends the limitations of text, and is:

'preferable to the fate of many manuscripts which lie unread, or at best skimmed over, on library shelves, or are commented on occasionally by other academics'.

Sparkes (2002:131)

In particular theatre has the potential to interpret, translate and disseminate research findings relating to health and the embodied human condition, in a way that inspires thought, critical reflection, emotional engagement and personal transformation in audiences including those outside of academic settings, (Rossiter *et al* 2008).

Writing the script

Following the 'rules' of Richardson & St Pierre, (2005:974), I developed my script paying attention to: 'fidelity - the speech of the participants, in the order of the speakers and events and literary rules – limiting how long a speaker speaks, keeping the plot moving along'. I was also guided by Pelias's, (2005), text on 'performative writing'. Performative writing does not just rely on its descriptive portrayal, but depends on its ability to create experience, offering both an, 'evocation of human experience and an enabling fiction', (Pelias 2005:418).

'Its power is in its ability to tell the story of human experience, a story that can be trusted and a story that can be used. It opens the doors to a place where the raw and the genuine find their articulation through form, through poetic expression, through art'.

(Pelias 2005:418)

Performative writing features lived experience, by telling, iconic moments that call forth the complexities of human life;

> 'it does not indiscriminately record experience, it does not simply duplicate a cinema verite experiment, but uses a 'highly selective camera, aimed carefully to capture the most arresting angles. Each frame is studied and felt; each shot is significant. Much is left on the editing floor'.
>
> (Pelias 2005:418)

As Pelias, suggests the creation of the script was therefore not a neutral action, it constantly involved choices about audience, language, density of analysis and the positioning of theory in the text, calling to attention the following questions:

> 'what is included and excluded? What is foregrounded, what is marginalised? Whose voices dominate? What constitutes a valid generalization?'
>
> Opie (1993:1)

A further concern was how to create a script that would 'touch' an audience by making an experiential phenomenon more present, but at the same time 'care' for them. Opie (1993) reflects on her experience of reading texts relating to caring for a family member with dementia, calling them 'inert', and critiquing them for failing to make an 'emotional impact' because, 'they were sanitised, there was a certain element of erasure of the personal and of the distressing', Opie (1993:5). She contrasts this with her experience of interviewing 'caregivers', where she, 'found much of what I heard extremely distressing', (Opie 1993:5). This highlights the ethical concerns, raised in Chapter 2, about the effect of producing knowledge that 'touches' an audience, particularly when the research is dealing with a sensitive topic, (Morgan *et al* 2001, Morgan *et al* 2003, Mitchell *et al* 2006, Sandelowski *et al* 2006). The question is how can we portray experience(s), in a way that 'cares' for audiences without sanitizing the experience by removing the 'distressing'? To date few evaluation studies have been carried out to 'measure theatre's efficacy, against its potential

disadvantages', (Rossiter *et al* 2008:145), and in particular to assess any negative impact it might have on audiences, (Morgan *et al* 2001). As a result there appears to be little guidance in the literature that specifically addresses the ethical issues relating to the care of audiences.

One response to 'caring' for audiences, would be to turn to the, 'common narrative' in our culture that attempts to give meaning and value to devastating illnesses, by dealing with the spiritual growth or heroism of those dealing with the illness, or by focusing on the finding the-silver-lining variation on that theme, (Mitchell *et al* 2006). This approach might make audiences 'feel better', by attending to their 'need' for a, story of heroism or silver lining to support them to deal with their '*dis-ease*', (Mitchell *et al* 2006), with dementia. However focusing on a 'silver-lining' theme, would offer a 'sanitized' representation of the experience, which would fail to stay true to the research findings. In particular it would offer a representation that would fail to honour the range of experience(s), faced by the partner with dementia and their care partner, in their joint journey or dance with dementia. My intention was to write a script that stayed grounded in my data, that would attempt to address people's *dis-ease* with dementia, which is reflected in the stigma surrounding the disease, and 'open' them to a greater understanding. In addition in considering the utility of the representation I was guided by Tierney's (1995:383) warning that our 'efforts at creating change' should not be 'merely an exercise in intellectual narcissism' therefore rather than view it merely as an artistic interpretation, I needed to present the resulting play in a way that would, facilitate and enhance understanding and awareness in its intended audience.

Taking all of the above into consideration, I created character monologues for both the partner with dementia and their care partner using direct narrative(s) drawn from the structural-textural synthesis to express the texture of the experience(s) of 'Being Together'. To ensure the play remained grounded in the research, the character monologues where interwoven by a narrator expressing parts of the descriptive analysis relating to the essential insights and their components and sub-components. This approach has considerable similarities

with hermeneutic phenomenology, which seeks to create alive accessible texts by the use of illustrative anecdotes, in which the essential meanings of a phenomenon are made evident, (Willis 2002).

Throughout the writing of the script choices had to be made about which parts of the structural-textural synthesis to choose, to illustrate the structure of 'Being Together', and which narratives to use to convey the texture. In some cases the character monologues are comprised of direct narratives from more than one research participant, that have been 'woven together' in such a way as to 'give life in artistic form', (Mitchell *et al* 2006), to the components and sub-components of the essential insights that they illustrate. Another key consideration was how to situate both the characters and the dialogue, in a way that would capture the attention of the audience, and in doing so achieve narrative probability and narrative fidelity, (Sandelowski *et al* 2006:1356). The most natural and believable setting in which to locate the characters was a 'homely' one, as this is where most day-to-day living takes place. In order to concentrate the audience on the two characters, I made the decision that the narrator would deliver their dialogue off camera. Some of the monologues delivered by the characters playing the partner with dementia and the care partner use the device of a 'talking head' where the dialogue is delivered directly to camera, using intonation and facial expression to convey the message in a way that will resonate with the audience. In others the dialogue is delivered as a 'voiceover' an image. The image of a 'couple dancing' reflects the 'dance with dementia' and is a recurrent theme that is used throughout the play, as a link between narratives.

The inclusion and situation decisions are shown in Table 5 below.

Table 5: Script Inclusion & Situation Decisions

Table 5: Script Inclusion & Situation Decisions	Setting-Lounge & Kitchen	

Script
Text: - Standard font = narrator
      Bold italics = partner with dementia
      Italics = care partner
	Situation	**Reason for inclusion**

"Being Together"- the challenging shared journey with dementia. This interactive process has been referred to as a dance with dementia, in which the two partners dance to the tune of dementia. Within this the two partners adapt to the continually changing melody, like all dances, there will be times when one partner is in charge, times when partners are separate, and times when the lead changes.	Narration over moving image of couple dancing	Portrays the complex journey with dementia as a dance in which the two partners in the caring relationship are directed/orchestrated by the tune of dementia.
Living with dementia is not easy, because dementia is in many ways a disease of society where the person with dementia is labelled and they and their family are isolated by stigma.	Narration over image	Used to introduce the component of stigma and labelling.
'Please don't call us 'demented' we are still people separate from our disease…. If I had cancer you wouldn't call me 'cancerous', would you?' It's like a stigma, like carrying a sign that you are sort of demented, and you can't do this and you can't do that…I don't belong in society anymore. That is what they are telling me. The feeling that I get is that I am incompetent. I shouldn't be living, demented really means mindless, or without a mind. And without a mind one is not really fully human…. In fact not human at all'.	Talking head of partner with dementia	Direct narrative from a number of participants that have been woven together to illustrate how the partner with dementia experiences stigma.
As they struggle with their diagnosis people fear the 'loss of themselves' and face an identity crisis. Who are they and who will they become?	Narration over images	Descriptive analysis chosen to ask the audience to consider what it feels like to be facing a loss of self
If people are categorised and labelled solely in the terms of their disease it fails to acknowledge their uniqueness as a person. How others relate to the person with dementia can have an impact on their disease.	Narration over images	Descriptive analysis chosen to portray the component supporting personhood
'You can restore our sense of self, and give us a sense of being needed and valued. In our crisis of identity and our fragmentation value us for who we are now as it is very hard for us to be who we once were'.	Talking head of partner with dementia	Direct narrative from a research participant with dementia chosen to illustrate how personhood can be supported
At the start of the journey both partners try to find explanations that normalise what is happening. Underneath this is an often unspoken realisation that something is wrong.	Narration over images	Descriptive analysis chosen to portray the component explaining and normalising
'You don't realise when you are starting out on this dreadful journey because you just think it is a bit of forgetfulness on their part and you don't appreciate the gravity of what's coming until they have got to quite a bad stage'.	Talking head of care partner	Direct narrative from a research participant. It has been chosen to illustrate how initially memory loss can be interpreted as forgetfulness. Additional wording has been added in order to identify the speaker as the care partner.
'Like leaves falling to the ground from a tree, old people lose their memories'.	Narration over images	Direct narrative from a research participant. It has been selected for its attempt to portray memory loss as part of the normal ageing process.
'I think it happens to everybody when they get to my age…I've got a feeling that there's a limit to what the head can contain' well the way I think of it is… If I had a cine camera on the top of my head, which looked at everything I looked at, and registered noises and conversations and I had done that for 65 years, how big do you think it would be? And it's supposed to be all in here. I mean there's no room'.	Talking head of partner with dementia	Direct narrative from a research participant chosen to show how the person with dementia attempts to provide an explanation for their memory loss in a way that is acceptable to them.

'Oh yes! Bob/Freda has difficulty remembering. But no as far as that goes, my goodness, I can't remember sometimes what day it is either! You know. My memory's good but you have to get the paper just to make sure'.	Talking head of care partner	Direct narrative from a research participant chosen to show how care partners attempt to normalise their partners' memory loss.
We don't talk about it, no… If I upset her/him it upsets me too you see'.	Talking head of partner with dementia	Direct narrative from a research participant chosen to illustrate how partners find it difficult to discuss what is happening.
As they struggle to maintain an existing sense of self, the partner with dementia adopts strategies to mask and cover the decline of their cognitive abilities, particularly in social situations. Allowing them to maintain a façade of normality. At the same time many experience, underlying fears that their difficulties can be seen reflecting their awareness of what is happening.	Narration over images	Descriptive analysis chosen to portray the sub component masking and covering
'Is that the word I want………in our head a string of pictures has formed, but the words for those pictures no longer make their way into our consciousness, let alone to our mouth. The words for those pictures seem as if they are on a loose spinning wheel………..and if the wheel spins too far, the wrong word comes out. It is as if my shelves of neatly filed words have been swept onto the floor, and I have to search among those untidy heaps to find the word I am looking for'.	Partner with dementia's voice over images	Direct narrative from a research participant chosen to portray how difficult it is for the partner with dementia to find the correct words to communicate.
'***You get rather cunning in dealing with people socially. Yes it's quite an art really. Trying to behave socially normally without letting on that you've forgotten a person's name…I try to hide the fact that I have memory problems, people simply stop talking to you in the way that they used to. You are in a different category from the normal population. I'll be speaking to somebody, I'll get the words wrong, say the wrong thing…………. sentences don't work very well. Sometimes when I've got into a mess, and I'm not making sense and can't dig it out, um I really crawl and fly away You cannot ignore that people are uncomfortable with you'.***	Talking head of partner with dementia	Direct narratives from research participants 'woven' together to illustrate the coping strategies, they use in an attempt to hold onto their socially constructed identity, whilst internally acknowledging, their memory problems.
'*They talk across (Bob/Freda) as though he/she doesn't exist… I resent them talking across him as though he's/she's a non-person… This almost robs him/her of his/her dignity'.*	Talking head of care partner	Direct narrative from a research participant illustrating how the reactions of others impact on them and their partner with dementia
'***She/He did too much talking and didn't let me in…. How do I get the balance right so I'm seen to be, well alive'.***	Partner with Dementia's voice over images	Direct narrative from a research participant chosen to reflect how well-intentioned attempts by their care partner to support them in social situations can leave them feeling sidelined.
The partner with dementia attempts to hold onto their socially constructed identity as their inner sense of self, fragments. They struggle to maintain their sense of identity and their defining core values as they deal with multiple losses; the loss of significant roles, independence, self worth, respect from others and their sense of competency.	Narration over images	Descriptive analysis chosen to portray the component 'Holding on'.
'If our identity is socially constructed who do we become when the wrecking ball of dementia smashes holes into life stories'?	Narration over image	Direct quote from research participant used as a reflective tool for the audience.
'Sometimes I'm me and sometimes I don't know who I am. I don't know it comes and goes; I never know. You're not you; you've got someone else kind in back of you. We need to create a new image of who we are and who we are becoming. How we do this depends very much on our personality, our life story, our health, or spirituality, and our social environment'. Those of us in the early stages of dementia undergo a constant adjustment and readjustment, a tug back and forth as we do this reconciliation, as we grieve our losses to try to accept the present reality'.	Talking head of partner with dementia Voice over images	Direct narratives from research participants, 'woven' together to illustrate how the partner with dementia attempts to preserve their personal identity.

The care partner is increasingly involved in "holding" for their partner with dementia that which they cannot hold themselves: the holding of continuity. Our stories are told in and through dialogue with others, and for the partner with dementia increasingly their story is told by their partner, who attempts to maintain the continuity of their life story. By acting as custodian and reporter of their life history, they are able to tell the ways of their partner. By 'telling the ways' of their partner. Interpreting their current behaviour, based on their previous history helps them to separate the person from the disease process.	Narration over images	Descriptive analysis chosen to illustrate the role the care partner plays in supporting identity by separating the person from the disease.
'So all of the time we went through the different changes that were occurring in my Bob/Freda). There was a physical (Bob/Freda) that had things happening to him/her, but still underneath all that- my (Bob/Freda). You see you have to remember that's not (Bob/Freda). That's his/her illness because he/she would never have done that NEVER'.	Talking head of care partner	Direct narrative from a research participant used to reinforce the message that the person with dementia is a person separate from the disease.
Adjusting to a 'life that is now possible' occurs in the face of increasing losses as both partners face up to a life with limited horizons. As both partners adjust to their new life, the way in which they re-define their roles in their changing relationship impacts on the life that is now possible.	Narration over images	Descriptive analysis chosen to portray the component, 'life that is now possible'.
'The mental adjustment or reconciliation is very hard at times and I sometimes ache to have things the way they were before, and since that cannot be; I simply have to try to accept the changes in my life…'	Voice of the partner with dementia over images	Direct narrative from a research participant used to illustrate how the partner with dementia attempts to face a future with limited horizons
The partner who adopts the sole identity of caregiver becomes overwhelmed by the tasks they face and can quickly become exhausted and emotionally drained. Adopting the roles of caregiver and caregiven highlights the illness and results in a relationship that strips both partners of their other identities.	Narration over images	Direct narrative from a research participant chosen to illustrate how the roles the two partners choose to adopt impact on their relationship and identities.
'We used to be on an equal footing with each other, a marriage of two accomplished people. Now she/he is a CAREGIVER and I am a CAREGIVEN. *We have become co-dependent needing each other to accept our labels as victim and sufferer. Being DEPENDENT- that's the pits. I feel like I might throw in the towel… I…I'm a has been'. Or alternatively we can become a partnership'.*	Talking head of partner with dementia	Direct narrative from a research participant. Chosen to illustrate the negative effects of adopting the roles of caregiver and caregiven.
'I love the imagery of a couple dancing with dementia. It's a couple, a care-partnership in which we move together. We sense each other's needs, and change and adapt according to the changing music of the journey with dementia But like all dance partners… We both have to learn to listen to the music. What is happening to me, to us? What is the rhythm of our dance with dementia'?	Voice of the partner with dementia over images	Direct narrative from a research participant chosen to illustrate how forming a care partnership can support the partner with dementia's status as a person rather than as a passive recipient of care.
'As we become less cognitive, it's the way you talk to us, not what you say that we will remember. Your smile, your laugh and your touch are what we will connect with. Empathy heals. Just love us as we are. Visit us and just be with us..we don't need words as much as your presence, your sharing of feelings with us. We're still here, in emotion and spirit, if only you could find us. I retain little information. But what I do retain is the feeling of pleasure or excitement …….the emotional response to the activity of the moment. And that is still precious'.	Voice of the partner with dementia over images	Direct narrative from two research participants used to illustrate the component of 'Being together in simple ways'.
'To live with the fear of 'ceasing to be' takes enormous courage. The precious string of pearls, of memories, that is our life, is breaking, the pearls are being lost. But by finding new pearls, those created in the struggle with dementia we can put together a new necklace of life, of hope in our future'.	Voice of the partner with dementia over images	Direct narrative from a research participant used to link the sub-component of 'life that is now possible' to the component of 'being together in simple ways'.

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For me it is the beauty of the sunset, of seeing my daughters' joys and triumphs, of stroking cats and hugging my wife/husband. Stroking is an important part of touch, and I find it lovely to touch and to stroke, and to be touched, to connect in this way.	Voice of the partner with dementia over images	Direct narratives from a research participant used to illustrate how rituals that might have once been taken for granted are accorded greater significance
'You have to find the positive things in life. You always search for the positive to be able to feel happy. You can't go and dig yourself in, but you have to find new angles which make it more positive'.	Talking head of care partner	Direct narrative from a research participant used to illustrate that the care partner also has to search for the positives in their situation
Moments of 'just being' can break through in silently sitting or walking or in listening to music together.	Narration over images	Descriptive analysis used to illustrate that moments of 'just being' can occur spontaneously
Bob/Freda… and I had a lovely walk. We both go along quietly- I lost in thought. Bob/Freda…. lost in a maze of thoughts	Talking head of care partner	Direct narrative from a research participant used to reinforce theme of 'just being'
'*Carpe diem, let's seize the day- together. It doesn't really matter if I don't remember today or don't know what day of the week it is. As long as we all enjoyed it to the fullest together'.*	Talking head of partner with dementia	Direct narrative from a research participant used to introduce the sub-component of 'carpe diem', which supports 'being together in simple ways'.
'*You need to live today like it's your only day. To enjoy the brief activity in the moment, to enjoy the pleasant feelings, even if we never remember, surely the memory of the event is not what is important – it is our experience at the time that really matters'.*	Talking head of partner with dementia	Direct narrative from a research participant used to illustrate the importance of 'being together in the moment'.
The care partner also watches for unscheduled opportunities to engage in restorative activities, allowing them to acknowledge their own needs, and to support them in their role as care partner.	Narration over images	Descriptive analysis used to support the sub-component of, 'carpe diem', for the care partner
'If Bob/Freda was asleep I would sneak away from him/her to 'refresh and re-energise', or whatever, and pray and cry to provide a period of calmness, and mental clarity. It just gives you a new lease of life'	Talking head of care partner	Direct narrative from a research participant used to illustrate that moments of 'carpe diem' are used by the care partner to take mental and physical breaks
The care partner works hard to maintain their partner's involvement in daily life. This 'work' is a vital but essentially 'invisible' element which involves the learning of patience and validating and valuing activities for their shared doing rather than on the basis of evaluating their outcome. They learn to 'hold back' from the need to rush an outcome and to 'be with the process' of what movement is possible' valuing this for its own sake.	Narration over images	Descriptive analysis chosen to introduce the sub-component 'Doing things together………the care partner sustains a sense of agency'.
'I'll do all the steps but the last step and say, "Would you put two tea bags in here?" Bob/Freda can do that. But he/she can't go through all the steps, I can't manage without you, he/she tells me. He/She is incredibly thankful for whatever I do. I don't want him/her to feel like a burden for me. Instead I try to cover up some of my caring'.	Care Partners voice over images	Direct narrative from a research participant used to illustrate the value of sustaining agency.
The care partners responsibility for the partner with dementia leaves them both 'metaphorically and literally bound to the home'	Narration over visual image	Descriptive analysis used to introduce the sub component, 'the cost of caring'.
Bob's/Freda's dementia needed constant vigilance. Even when I am away from the home doing something I enjoy, I am constantly aware of the time…the clock is always ticking. Earlier today I felt overwhelmed by the vacuum that Bob/Freda has become. He/She follows me aimlessly, understands nothing of what I say to him/her he/she has become my constant shadow. Looking after Bob/Freda has meant I have lost all social contact. It was a gradual process. I mean, my one true friend is almost an 82-year old on the floor below here and that is about it. Which is no social life.'	Talking head of care partner	Direct narratives from a number of research participants 'woven' together to convey the sub-component 'the cost of caring' in terms of the constraints and losses experienced by the care partner

For the partner with dementia the complexity of daily living becomes a source of anguish and exhaustion. Requiring a daily adjustment of their expectations of themselves, and their expectations of life as they try to reconcile their 'old me' with the 'new me' and to accept that being slow, doing less, achieving less, experiencing less, is what it is like to live in the slow lane.	Narration over images	Descriptive analysis used to convey the sub-component, 'Life in the slow lane'.
The world goes much faster than we do, whizzing around, and we are being asked to do things, or to respond………. It is too fast, we want to say, 'go away, slow down, leave me alone' just go away	Partner with dementia's voice over images	Direct narrative from a research participant used to illustrate the experience of the partner with dementia as they try to process and respond to daily life
Becoming a blank, results in the partner with dementia becoming a passive member of the care partnership as they detach from the world in a bodily way, they stand apart as detached subjects no longer able to engage meaningfully with the world.	Narration over visual image	Descriptive analysis used to introduce the sub-component of, 'becoming a blank'.
'*I suppose in a way it's like being in a fog and you can't find your way out … I mean, not knowing is frightening. It feels as though there is cotton wool in my head, a sort of fog over my thoughts and feelings. I do not have enough energy to cope in the fog to find thoughts and get an idea or to work out what you are saying. I have lost my immediacy. Everything I did in the past…. Everything I like to do has just gone now… I can't do any of it …. all the things I've lost, they're lost When my brain becomes overloaded and fatigued, it's like a short circuit and my brain cuts out. I get a blank brain-less look and withdraw from what is around me. I am not really there, my eyes cannot focus, and I can't say much. The fog thickens*'.	Voice of partner with dementia over images	Direct narratives from research participants 'woven' together' used to portray the sub-component 'becoming a blank'.
Letting go signals the transition to living apart as the care partner detaches from the person the partner with dementia has become, and the cost of caring becomes too high. Care partners find themselves 'working alone' despite their efforts to 'maintain involvement' and 'sustain couplehood'.	Narration over images	Descriptive analysis used to introduce the component 'Letting go'.
'*Yes despite the fact that we are living together, and we have lots of things in common, nevertheless we are lonely in a way………you live in two small worlds. Bob's/Freda's personality went flat slowly. It lets you down very gradually so that it's a slow form of separation*'.	Talking head of care partner	Direct narratives from research participants used to illustrate the beginning of the breakdown of 'couplehood'
Becoming strangers is influenced by the losses sustained by both partners. As the partner with dementia's cognitive impairment increases both partners are 'increasingly lost to each other and become strangers in their own world'.	Narration over images	Descriptive analysis used to illustrate how the losses sustained by both partners contribute to the breakdown of the partnership
'*Just two people putting up with each other. I feel overwhelmed by the vaccum that Bob/Freda has become. He/She follows me aimlessly, and understands almost nothing of what I say to him/her.*	Talking head of care partner	Direct narrative from a research participant used to illustrate the breakdown of the partnership
As the partner with dementia increasingly withdraws into a world of blankness, the relationship diminishes. The care partner loses a major source of support for carrying on. The burden of caring and the feeling of aloneness becomes too great balanced against the wish to continue to carry the burden.	Narration over images	Descriptive analysis used to illustrate how the loss of reciprocity in the relationship impacts on the decision to relinquish care
You feel this guilt for this person you don't want to put them in a home, you don't want to put them away, and you think, I can look after them but I have no energy to take care of myself: I am not taking very good care of myself these days	Talking head of care partner	Direct narrative from research participants chosen to illustrate the dilemma faced by the care partner as they begin to acknowledge their limitations.
Whilst acknowledging their own limitations to provide care the care partner seeks reassurance that others can provide 'trusting' care, and that they can 'trust their loved one is safe'.	Narration over images	Descriptive analysis together with direct narratives from research participants.

Carers begin to set limits upon caring and to establish criteria for when they will relinquish care such as 'when she doesn't know me' or when he gets violent, The decision to '*step away*' from caring is an 'almost impossible decision to take alone'. It is often preceded by a triggering event that results in them being unable to continue to give care in the home. This often results in the decision to relinquish care being taken out of their hands and provides some 'kind of justification' for the separation.	Narration over images	Descriptive analysis used to illustrate the complexity surrounding the decision to relinquish care.
Well, the only thing I know is that I'll, I'll go on as long as I can manage. And then there will be no choice; he'll/she'll have to be taken into residential care. My doctor told me your good kind Bob/Freda is gone. He's/She's another person now; don't start crying when he/she has to go somewhere because it has to be done. The hardest aspect is the guilt I need a person with good trained ears to pour my inner soul out to'.	Talking head of care partner	Direct narratives from research participants used to illustrate the impact professionals have on the decision to relinquish care.
The decision to hand over care by placing a partner in residential care invokes conflicting emotions. In relinquishing care to others the care partner has to negotiate a change in personal identity and role. As they move towards a 'new beginning' they are faced with the task of finding new meaning in life.	Narration over images	Descriptive analysis used to illustrate the changes faced by a care partner in relation to their personal identity and role, when they make the decision to relinquish care.
'All day today I have been saying this is the last time…. It broke my heart to say it was Bob's/Freda's last night in his/her own house. He/She could feel it but couldn't articulate it. And this is my last night as his/her primary carer. I know I am too tired to continue- I could feel that all day – the weight of his/her needs. Yet the battle with guilt surfaces every few hours… Will Bob/Freda be ok with intimate strangers. Although the demands of caring were very high, I knew the routine. Moving into unknown territory- life after caring- is terrifying'.	Voice of care partner over images	Direct narrative from a research participant used to illustrate the conflicting emotions felt by a care partner when they relinquish care.

From Script to Production

The final script is produced below, again the characters are delineated by the use of font, bold italics, and italics as before. The two characters in the script are named Freda and Bob, the roles of the partner with dementia and the care partner are written in a way that enables either of the characters to be played by a male or female actor.

Script: 'Being Together'- the challenging shared journey with dementia

Narrator: This interactive process has been referred to as a dance with dementia in which the two partners dance to the tune of dementia. Within this the two partners adapt to the continually changing melody, like all dances, there will be times when one partner is in charge, times when partners are separate, and times when the lead changes. Living with dementia is not easy, because dementia is in many ways a disease of society where the person with dementia is labelled and they and their family are isolated by stigma.

PWD: *Please don't call us demented we are still people separate from our disease… If I had cancer you wouldn't call me 'cancerous', would you?' It's like a stigma, like carrying a sign that you are sort of demented, and you can't do this and you can't do that…I don't belong in society anymore. That is what they are telling me. The feeling that I get is that I am incompetent. I shouldn't be living, demented really means mindless, or without a mind. And without a mind one is not really fully human…. In fact not human at all.*

Narrator: As they struggle with their diagnosis people fear the 'loss of themselves' and face an identity crisis. Who are they and who will they become? If people are categorised and labelled solely in the terms of their disease it fails to acknowledge their uniqueness as a person. How others relate to the person with dementia can have an impact on their disease.

PWD: *You can restore our sense of self, and give us a sense of being needed and valued. In our crisis of identity and our fragmentation value us for who, we are now, as it is very hard for us to be who we once were.*

Narrator: At the start of the journey both partners try to find explanations that normalise what is happening. Underneath this is an often unspoken realisation that something is wrong.

CP: *You don't realise when you are starting out on this dreadful journey because you just think it is a bit of forgetfulness on their part and you don't appreciate the gravity of what's coming until they have got to quite a bad stage.*

PWD: **Like leaves falling to the ground from a tree, old people lose their memories. I think it happens to everybody when they get to my age…I've got a feeling that there's a limit to what the head can contain' well the way I think of it is… If I had a cine camera on the top of my head, which looked at everything I looked at, and registered noises and conversations, and I had done that for 65 years, how big do you think it would be? And it's supposed to be all in here. I mean there's no room.**

CP: *Oh yes! Bob/Freda has difficulty remembering. But no as far as that goes, my goodness, I can't remember sometimes what day it is either! You know. My memory's good but you have to get the paper just to make sure.*

PWD: **We don't talk about it, no… If I upset her/him it upsets me too you see.**

Narrator: As they struggle to maintain an existing sense of self, the partner with dementia adopts strategies to mask and cover the decline of their cognitive abilities, particularly in social situations. Allowing them to maintain a façade of normality. At the same time many experience, underlying fears that their difficulties can be seen reflecting their awareness of what is happening.

PWD: *Is that the word I want………in my head a string of pictures has formed, but the words for those pictures no longer make their way into my consciousness, let alone to my mouth. The words for those pictures seem as if they are on a loose spinning wheel………..and if the wheel spins too far, the wrong word comes out. It is as if my shelves of neatly filed words have been swept onto the floor, and I have to search among those untidy heaps to find the word I am looking for.*

You get rather cunning in dealing with people socially. Yes it's quite an art really. Trying to behave normally without letting on that you've forgotten a person's name…I try to hide the fact that I have memory problems, people simply stop talking to you in the way that they used to. You are in a different category from the normal population. I'll be speaking to somebody, I'll get the words wrong, say the wrong thing…….…… sentences don't work very well. Sometimes when I've got into a mess, and I'm not making sense and can't dig it out, um I really crawl and fly away. You cannot ignore that people are uncomfortable with you.

CP: *They talk across Bob/Freda as though he/she doesn't exist… I resent them talking across him/her as though he/she is a non-person… This almost robs him/her of his/her dignity.*

PWD: *She/He did too much talking and didn't let me in…. How do I get the balance right so I'm seen to be, well alive*.

Narrator: The partner with dementia attempts to hold onto their socially constructed identity as their inner sense of self, fragments. They struggle to maintain their sense of identity and their defining core values as they deal with multiple losses; the loss of significant roles, independence, self worth, respect from others and their sense of competency.

If our identity is socially constructed who do we become when the wrecking ball of dementia smashes holes into our life stories?

PWD: *Sometimes I'm me and sometimes I don't know who I am. I don't know it comes and goes; I never know. You're not you; you've got someone else kind of in the back of you, we need to create a new image of who we are and who we are becoming. How we do this depends very much on our personality, our life story, our health, our spirituality, and our social environment. Those of us in the early stages of dementia undergo a constant adjustment and readjustment, a tug back and forth as we do this reconciliation, as we grieve our losses to try to accept the present reality*

Narrator: The care partner is increasingly involved in "holding" for their partner that which they cannot hold themselves: the holding of continuity. Our stories are told in and through dialogue with others, and for the partner with dementia, increasingly their story is told by their partner, who attempts to maintain the continuity of their life story. By acting as custodian and reporter of their life history, they are able to 'tell the ways' of their partner. Interpreting their current behaviour, based on their previous history helps them to separate the person from the disease process.

CP: *So all of the time we went through the different changes that were occurring in my Bob/Freda. There was a physical Bob/Freda that had things happening to him/her, but still underneath all that- my Bob/Freda. You see you have to remember that's not Bob/Freda. That's his/her illness because he/she would never have done that, NEVER.*

Narrator: Adjusting to a life that is now possible occurs in the face of increasing losses as both partners face up to a life with limited horizons. As both partners adjust to their new life, the way in

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which they re-define their roles in their changing relationship impacts on the life that is now possible.

PWD: *The mental adjustment or reconciliation is very hard at times and I sometimes ache to have things the way they were before, and since that cannot be; I simply have to try to accept the changes in my life…*

Narrator: The partner who adopts the sole identity of caregiver becomes overwhelmed by the tasks they face and can quickly become exhausted and emotionally drained. Adopting the roles of caregiver and caregiven highlights the illness and results in a relationship that strips both partners of their other identities.

PWD: *We used to be on an equal footing with each other, a marriage of two accomplished people. Now she/he is a CAREGIVER and I am a CAREGIVEN.*

We have become co-dependent needing each other to accept our labels as victim and sufferer. Being DEPENDENT- that's the pits. I feel like I might throw in the towel… I…I'm a has been. Or alternatively we can become a partnership-

I love the imagery of a couple dancing with dementia. It's a couple, a care-partnership in which we move together. We sense each other's needs, and change and adapt according to the changing music. But like all dance partners… we both have to learn to listen to the music. What is happening to me, to us? What is the rhythm of our dance with dementia?

As we become less cognitive, it's the way you talk to us, not what you say that we will remember. Your smile, your laugh and your touch are what we will connect with. Empathy heals. Just love us as we are. Visit us and just be with

us…we don't need words as much as your presence, your sharing of feelings with us. We're still here, in emotion and spirit, if only you could find us. I retain little information. But what I do retain is the feeling of pleasure or excitement …….the emotional response to the activity of the moment. And that is still precious.

To live with the fear of ceasing to be takes enormous courage. The precious string of pearls, of memories, that is our life, is breaking. The pearls are being lost. But by finding new pearls, those created in the struggle with dementia we can put together a new necklace of life, of hope in our future.

For me it is the beauty of the sunset, of seeing my daughters' joys and triumphs, of stroking cats and hugging my wife/husband. Stroking is an important part of touch, and I find it lovely to touch and to stroke, and to be touched, to connect in this way.

CP: *You have to find the positive things in life. You always search for the positive to be able to feel happy. You can't go and dig yourself in, but you have to find new angles, which make it more positive.*

Narrator: Moments of just being can break through in silently sitting or walking or in listening to music together.

CP: *Bob/Freda… and I had a lovely walk. We both go along quietly- I lost in thought. Bob/Freda…. lost in a maze of thoughts.*

PWD: *Carpe diem, let's seize the day - together. It doesn't really matter if I don't remember today, or don't know what day of the week it is. As long as we enjoyed it to the fullest together. You need to live today like it's your only day. To enjoy the*

brief activity in the moment, to enjoy the pleasant feelings. Even if we never remember, surely the memory of the event is not what is important – it is our experience at the time that really matters.

Narrator: The care partner also watches for unscheduled opportunities to engage in restorative activities, allowing them to acknowledge their own needs, and to support them in their role as care partner.

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Narrator: The care partner works hard to maintain their partner's involvement in daily life. This work is a vital but essentially 'invisible' element which involves the learning of patience, and validating and valuing activities for their shared doing rather than on the basis of evaluating their outcome. They learn to hold back from the need to rush an outcome and to 'be with the process' of what movement is possible valuing this for its own sake.

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Narrator: The care partner's responsibility for the partner with dementia leaves them both 'metaphorically and literally bound to the home'.

CP: *Bob's/Freda's dementia needs constant vigilance. Even when I am away from the home doing something I enjoy, I am constantly aware of the time…the clock is always ticking. Earlier today I felt overwhelmed by the vacuum that Bob/Freda has become. He/She follows me aimlessly, understands almost nothing of what I say to him/her, he/ she has become my constant shadow. Looking after Bob/Freda has meant I have lost all social contact. It was a gradual process. I mean, my one true friend is almost an 82-year old living next door and that is about it. Which is no social life.*

Narrator: For the partner with dementia the complexity of daily living becomes a source of anguish and exhaustion. Requiring a daily adjustment of their expectations of themselves, and their expectations of life as they try to reconcile their 'old me' with the 'new me' and to accept that being slow, doing less, achieving less, experiencing less, is what it is like to live in the slow lane.

PWD: **The world goes much faster than we do, whizzing around, and we are being asked to do things, or to respond………. It is too fast, we want to say, 'go away, slow down, leave me alone just go away'.**

Narrator: Becoming a blank, results in the partner with dementia becoming a passive member of the care partnership as they detach from the world in a bodily way, they stand apart as detached subjects no longer able to engage meaningfully with the world.

PWD: **I suppose in a way it's like being in a fog and you can't find your way out … I mean, not knowing is frightening. It feels as though there is cotton wool in my head, a sort of fog over my thoughts and feelings. I do not have enough energy to cope in the fog to find thoughts and get an idea or to work out what you are saying. I have lost my immediacy. Everything I**

did in the past…. Everything I like to do has just gone now… I can't do any of it…. all the things I've lost, they're lost. When my brain becomes overloaded and fatigued, it's like a short circuit and my brain cuts out. I get a blank brain-less look and withdraw from what is around me. I am not really there, my eyes cannot focus, and I can't say much. The fog thickens.

Narrator: Letting go signals the transition to living apart as the care partner detaches from the person the partner with dementia has become, and the cost of caring becomes too high. Care partners find themselves working alone despite their efforts to maintain involvement and sustain their partnership.

CP: *Yes despite the fact that we are living together, and we have lots of things in common, nevertheless we are lonely in a way………you live in two small worlds. Bob's/Freda's personality went flat slowly. It lets you down very gradually so that it's a slow form of separation.*

Narrator: Becoming strangers, is influenced by the losses sustained by both partners. As the partner with dementia's cognitive impairment increases both partners are 'increasingly lost' to each other and become strangers in their own world.

CP: *Just two people putting up with each other. I feel overwhelmed by the vacuum that Bob/Freda has become. He/She follows me aimlessly, and understands almost nothing of what I say to him/her.*

Narrator: As the partner with dementia increasingly withdraws into a world of blankness, the relationship diminishes. The care partner loses a major source of support for carrying on. The burden of caring and

the feeling of aloneness becomes too great balanced against the wish to continue to carry the burden.

CP: *You feel this guilt for this person you don't want to put them in a home, you don't want to put them away, and you think, I can look after them but I have no energy to take care of myself. I am not taking very good care of myself these days.*

Narrator: Whilst acknowledging their own limitations to provide care, the care partner seeks reassurance that others can provide trusting care, and that they can trust their loved one is safe.

Carers begin, to set limits upon caring and to establish criteria for when they will relinquish care such as, when she doesn't know me or when he gets violent, The decision to step away from caring is an almost impossible decision to take alone. It is often preceded by a triggering event that results in them being unable to continue to give care in the home. This often results in the decision to relinquish care being taken out of their hands and provides some kind of justification for the separation.

CP: *Well, the only thing I know is that I'll, I'll go on as long as I can manage. And then there will be no choice; he'll/she'll have to be taken into residential care. My doctor told me your good kind Bob/ Freda is gone. He's/she's another person now; don't start crying when he/she has to go somewhere because it has to be done. The hardest aspect is the guilt I need a person with good trained ears to pour my inner soul out to.*

Narrator: The decision to hand over care by placing a partner in residential care invokes conflicting emotions. In relinquishing care to others the care partner has to negotiate a change in personal identity and

role. As they move towards a 'new beginning' they are faced with the task of finding new meaning in life.

CP: *All day today I have been saying this is the last time…. It broke my heart to say it was Bob's/Freda's last night in his/her own house. He/She could feel it but couldn't articulate it. And this is my last night as his/her primary carer. I know I am too tired to continue- I could feel that all day – the weight of his/her needs. Yet the battle with guilt surfaces every few hours… Will Bob/Freda be ok with intimate strangers? Although the demands of caring were very high, I knew the routine. Moving into unknown territory- life after caring- is terrifying.*

The End

From Script to DVD

The final step now that the script was completed was to find a cast to perform it, and a person with expertise in media production to record the performance on camera. The three members of the cast were actors from the Wessex Actors Group, who were directed in rehearsals by the director of the company who also took the part of the narrator.

A meeting took place with the actors at the 1st rehearsal stage, when the script was given an initial 'read through' to allow the actors to share their impressions of the language of the play, to ensure that it was written in the language of the 'everyday', and not in the language of 'academia', and also to agree on the intonation of the dialogue. It was at this stage that roles were assigned and the male actor took the character of the partner with dementia and became 'Bob'. The scale of the budget and the time commitments of the actors dictated the number of rehearsals that took place before the DVD was shot.

A colleague with expertise in media production handled the technical design of the DVD recording session, directed the shoot and edited the final production. The DVD was produced on a modest budget, which resulted in a one-day shooting schedule.

Despite the limitations noted above the professionalism, commitment, enthusiasm and hard work of those involved are evident in the resulting production.

The resulting DVD is intended to communicate a structural-textural synthesis of qualitative research findings to a wide-ranging audience in an accessible, coherent and evocative way. Finally in returning to the ethics of caring for an audience, it is my intention that prior to the screening of 'Being Together'- the challenging shared journey with dementia, audiences should be made aware of the contents and their potential to evoke emotional responses.

A copy of the DVD 'Being Together'- the challenging shared journey with dementia can be found in a pocket in the inside back cover of this thesis.

Conclusion

In this chapter I have applied each of the stages of the framework that I devised in Chapter 2 to a practical example, the end product being a DVD that, portrays the story of 'Being Together'- the challenging shared journey with dementia.

In Stage 1 of the Framework - Locating Studies Using the Berrypicking Model: -

- I indicate how I located the studies and show the way I followed the berrypicking procedure to identify an area of interest.

In Stage 2 of the Framework - Studies Identified for Inclusion in the Structural-Textural Synthesis Using the Inclusion & Exclusion Criteria: -

- I identified the studies I selected for inclusion in the structural-textural synthesis, and provided the justification for their inclusion.

In Stage 3 of the Framework - Structural-Textural Synthesis of Studies Identified in Stages 1 & 2 of the Framework: -

- I provide an illustration of how I followed the four-stage procedure developed in Chapter 2 to produce a structural-textural synthesis.

In Stage 4 of the Framework - Communication Strategy Using the Principles Developed in Stage 4 of the Framework: -

- I describe how I developed a communication strategy for communicating the structural-textural synthesis.

In the next chapter I will provide a discussion and conclusion to my study.

Chapter 4: Discussion & Conclusion

Introduction

> 'A research outcome which offers those already within the situation… a means (of) gaining knowledge through credible representations, allowing them to recognise the significant features of their own specific experiences, is as valuable in terms of its production of knowledge as the more systematic analytical text which produces knowledge in a form recognisable in a specific academic discipline'.

> (Opie 1993:9)

In this final chapter I would like to return to the quotation by Opie (1993), as it captures the aims of my research question; that is how to make the findings of qualitative health and social care research useful to a wider audience, in particular to one audience that is often overlooked and excluded, that is lay members of the public.

In an attempt to answer the questions posed in my research aims: -

- How can the findings of research be appropriately contextualized?

- Who might be interested in the information?

- What is the appropriate vehicle for disseminating information to them?

> (adapted from Paterson *et al* 2001:128)

I have developed a framework for synthesizing and communicating qualitative research findings that are already in the public arena, which I have then applied to a worked example.

In the process of developing the framework, I have drawn on literature relating to the synthesis of qualitative research findings, and the utilization, and communication of qualitative research findings. The focus of the worked

example is drawn from qualitative research findings relating to the experience of living with dementia from the perspective of the person with dementia and their care partner.

In Chapter 1, I presented an overview of the study area, followed by a three-part literature review, and indicated how the literature has informed my study. In the first part of the literature review I discussed and critiqued methods and approaches for the synthesis of qualitative research findings, and indicated that I would take a phenomenological approach to synthesis. In the second part of the literature review, I discussed and highlighted the need for the better utilization and communication of qualitative research findings, and in particular the need for a language and mode of communication, which would both 'touch' and 'reach' audiences in a way that traditional methods of reporting research fail to do. In the final part of the literature review, I gave an overview of the demographics of dementia, highlighting the increasing imperative to improve public and professional awareness and understanding of dementia, and in particular to address the stigma associated with the disease. Finally I provided a brief overview of the development of dementia research, where methods have developed from **'doing'** research **on** people with dementia to **'actively engaging', with** people with dementia, in the research process.

 In Chapter 2, I developed a framework for the synthesis and communication of qualitative research findings. The framework consists of four stages; In Stage 1 of the framework I outlined a searching strategy based on the 'berrypicking' model, (Bates 1989). In Stage 2, I identified the inclusion and exclusion criteria for studies, focusing, on the following: quality criteria, data sources, sample size and epistemological considerations. In Stage 3, I identified a four-stage approach to synthesis based on the philosophical traditions of phenomenology and hermeneutics. In Stage 4, I proposed a series of questions to be answered when deciding on an appropriate communication strategy: Who is the intended audience(s)?, how will you communicate with them?, and how will you care for them? (ethics of care).

In Chapter 3, I applied the framework for the synthesis and communication of qualitative research findings, devised in Chapter 2, to a worked example. In Stage 1, using the 'berrypicking' approach to searching, I identified my area of interest: the experience of living with dementia from the perspective of both the person with dementia and their care partner. Through this process I identified a total of eighteen studies that met the inclusion and exclusion criteria determined in Stage 2 of the Framework. The studies came from both peer reviewed and grey literature. Of these eighteen studies, five studies, (8 articles), reported on the experience of living with dementia from the perspective of the care partner, eight studies (12 articles), reported on the experience of living with dementia from the perspective of the person with dementia, three studies (5 articles), reported on the experience of living with dementia from the perspective of both partners, and two were theoretical papers relating to personhood. Some of the studies were reported in more than one paper or book chapter. The chosen studies came from differing epistemological perspectives, and were chosen for their ability to provide both the 'bare bones' and the 'flesh and heart' of the experience. The studies were then synthesized into a whole to produce a structural-textural synthesis; 'Being together' – the challenging shared journey with dementia, using the four-stage approach indicated in Stage 3 of the framework, which draws on the philosophy of phenomenology and hermeneutics. In order to communicate the structural textural synthesis in a coherent and evocative way, that would be accessible to my identified audience of members of the public and health and social care professionals, I transformed the synthesis into a script, which was subsequently performed, and recorded on DVD.

In the remainder of this chapter I will reflect on the process of my study, the strengths and limitations of the study, and conclude by discussing how my research: contributes to knowledge, moves the field of qualitative research forward, and finally show future directions the study might take.

Reflection on the Process of my Study

> 'True innovation is the most difficult challenge in qualitative research as most researchers use well trodden paths and produce sound but non-innovative work (almost like the "McDonaldization" of research, when the product is similar where ever we go)'.
>
> (Holloway & Todres 2007:17)

One of the hardest parts of the research process was not having a 'well trodden path', to follow. In Chapter 1, I discussed how the development of the framework could be considered to be positioned at what Rapport *et al* (2004, 2005) have referred to as the 'edgelands', a space between established and new methods, that does not conform to our, 'preferred, neatly regulated landscape', (Rapport *et al* 2005:38). The process of developing this framework has been an iterative one, positioned in the 'space', between established and new methods, and as a result has been one of continual change through, experimentation, reflexivity, and theoretical development, rather than a process which, has followed a 'recipe' without deviation from established procedures, (Rapport *et al* 2005). This has required 'openness', to the research question, as I reviewed the literature that has supported the development of the framework and, 'openness' to my own experience, of disorientation, confusion and chaos along the way, as I became caught up in initial impressions and vague hunches whilst I was trying to make sense of what at first was unfamiliar, (Dahlberg & Halling 2001).

As I developed the framework I was keen not to succumb to 'mission drift', by adopting quantitative principles, but rather to keep in mind that the synthesis of qualitative research is best served by reliance upon qualitative methods, (Jones 2004). Unlike traditional qualitative research projects where data is generated through dialogue with research participants, the 'data', which has informed both, the development and execution of my framework, has been generated through extensive dialogue with a large amount of literature. As discussed in Chapter 2, the search for and the retrieval of qualitative research poses numerous problems, (Barroso *et al* 2003, Shaw *et al* 2004, Dixon-Woods *et al* 2006,

Bondas & Hall 2007a). I encountered several of the associated problems quite early on in the research process, in particular the high retrieval of 'irrelevant' reports linked to the 'idiosyncrasies', associated with electronic databases, (Barroso *et al* 2003), coupled together, with the time consuming process of sifting through the retrieved citations in order to determine relevance, (Lloyd Jones 2004). Bearing in mind Barbour & Barbour's (2003) caution relating to the rush to impose the criteria of systematic review on the synthesis of qualitative research, I asked myself the question how systematic does a literature search have to be, to be fruitful? I found the answer to my question through a 'serendipitous discovery' (Greenhalgh & Peacock 2005:1065), when I encountered the 'berrypicking' model (Bates 1989), which looks to strategies which, at first might seem less efficient; but which are in fact much closer to the real behaviour of information searchers, allowing the researcher to begin with one relevant reference which enables them to move through a variety of sources, including qualitative papers published in books and book chapters, and grey literature which is underrepresented in databases, (Walsh & Downe 2006).

In defining the inclusion and exclusion criteria for Stage 2 of the framework, I found myself entering a minefield particularly in the contested area of what constitutes 'quality' or substitute terms, in qualitative research. Where some of those undertaking the synthesis of qualitative research studies are adopting concepts common to the positivist traditions of quantitative research, with some researcher's going as far as to propose explicit criteria for a 'hierarchy of evidence', with which to evaluate qualitative studies. A number of authors (Sandelowski 1993, Jensen & Allen 1996, Edwards *et al* 1998, Popay *et al* 1998, Edwards *et al* 2000, Richardson 2000, Booth 2001, Jones 2004, Van Manen 2006), have however proposed that studies should not be excluded on the basis of their design alone, but rather be validated by their ability to create evocative stories, through the use of quotes and metaphors from research participants, which illuminate the subjective meaning, actions, and context of those being researched. With this in mind I have been guided by Richardson (2000) who proposes that the quality of a study should be assessed through the

use of the following criteria, asking does the study show:

- Substantive contribution - does the piece of writing contribute to our understanding of social life?

- Aesthetic merit - is the writing artistically shaped, satisfying, complex and not boring, inviting interpretive responses in the reader?

- Reflexivity – has the author held themselves accountable to the standards of knowing and telling about the people they have studied?

- Impact – does the writing resonate emotionally and intellectually?

- Expression of reality – does the text embody a fleshed out sense of lived experience, does it provide a credible account of a cultural, social individual, or communal sense of the "real"?

<div align="right">(adapted from Richardson 2000)</div>

I have not only asked these questions of the studies, I have included in the structural-textural synthesis, but whilst writing both the structural-textural synthesis, (see Chapter 3 page 133) and the subsequent script, (see Chapter 3 page 161), I have asked them of my own writing. It is only by answering these questions successfully that I will have achieved the aims of my research to communicate research findings in an accessible, coherent and evocative way to an audience that is larger than the traditional academic one.

The approach I have taken to synthesis has drawn upon the logic of both phenomenology and hermeneutics, following the work of philosophers and social scientists, (i.e. Husserl, Gadamer, Giorgi, Van Manen, and Moustakas). In taking this approach I am aware that once again I have situated myself on the 'edgelands'. However according to Todres & Wheeler (2001:4), the '*methodological status*' of phenomenological hermeneutic research, 'is progressive but always "on the way"'. In particular a number of authors

Dahlberg *et al* 2001, Todres & Wheeler 2001, Rapport & Wainwright 2006, Todres & Holloway 2006), have illustrated the complementarity of phenomenology and hermeneutics, arguing that the differences between descriptivists and interpretivists have led to a 'false dichotomy' between the two approaches. The approach I have developed for synthesizing qualitative research findings attempts to use language that is faithful to the phenomenon in all its complexity sense and texture, unlike traditional descriptive phenomenology, which has a tendency to use language in a summative way that can deaden the aliveness of the phenomenon, (Todres & Galvin 2008). The use of direct quotations from individual studies to illustrate, both the essential insights and their components and sub-components, is an attempt 'to write people' (Holloway 2005), in order to allow readers to, 'find personal meaning in the descriptions, and find themselves *in* the language', (Todres & Galvin 2008:570) for:

> 'often, the stories we hold about self and world are subliminal, wielding the power of the unexamined, and thus go unquestioned. But the shaping of art is also a way such hidden narratives are softened, made workable; it brings them into a kind of attention that reaches both conscious and unconscious minds.... narrative hunts out the seed-events that hold a useful knowledge for our lives. In its portable woven pouch, it places the moments that count and also carries the fact that there are moments that count'.

> (Hirshfield 1998:112-113)

In producing a structural-textural synthesis which attempts to be faithful to both the structure and texture of the phenomenon I hope that I have shaped a 'story' which will produce useful knowledge for readers, and in particular that I have 'softened the hidden narrative' in a way that will allow the reader to find 'moments that count'.

In answering Saldaña's (2003:219) key question, through which medium or format will the participant's story be, 'credibly, vividly, and persuasively told for an audience' I faced a unique challenge, given that the 'story' diverges from

other arts-based transformations of qualitative research, as the object of transformation is a second transformation (research synthesis) of a first transformation, (of qualitative study findings). The result is that my script is far removed from the 'messy' performance texts described by Mienczakowski *et al* (1996) where the audience become '*spect-actors*', and the actors co-create data as part of both the development of the 'script' and the communication process, as it remains grounded in the data. I chose to transform the structural-textural synthesis into a play, which was captured on DVD, in order to allow audiences to explore the experience of living with dementia, from the inside looking out, as a way of providing meaning, understanding and perhaps catharsis. In choosing this medium I hope I have heeded Jones (2005:8) warning not to follow too literally, 'Micky Rooney's excited exclamation to Judy Garland: "I know what we'll do! We'll put on a show', and produced an, 'embarrassing dramatisation'. By reaching across disciplines and collaborating with a theatre company, and a colleague with expertise in media production, I hope that the resulting production has the polish and ability to reach the intended audiences in an evocative, engaging and most importantly, an 'understandable' way. In particular I hope that my chosen method of communication is not regarded as an 'exercise in intellectual narcissism', (Tierney 1995) as it is not my intention to leave an audience with a 'mess', but rather to present the 'story': Being Together, the challenging shared journey with dementia, not only as an object or product, but also as an 'idea, a process, a way of knowing, a manner of speaking, an encounter with Other's …', (Bochner & Ellis 2003:508).

Finally in reflection, although my journey on the 'edgelands' has at times been full of tension, friction, and loneliness (particularly as my data collection has involved dialogue with the written word and not with people), it has generated creativity and innovation, (Rapport *et al* 2004). This has resulted in the conception of a framework for the synthesis and communication of qualitative research findings. Working on the 'edgelands' is messy and at times confusing, but if we are to understand the individual's experience we need methodologies that can provide insights in ways that are illuminating and also ethically acceptable. As Rapport and colleagues have warned in a climate where

practice and policy is driven by the randomised control trial and by systematic review, situating one's self at the 'edgelands', is not without danger, (Rapport *et al* 2004, Rapport *et al* 2005). However if we are to refocus the:

'understanding of what it is to be fully human; the reuniting of technical and humanistic knowledge and practice' the metaphorical edgelands is probably the place to do it'.

(Rapport *et al* 2004:6)

Therefore as qualitative researchers we should consider moving from the 'well trodden path' to the 'edgelands' in order to develop 'new methodologies' for both the interpretation and presentation of qualitative research findings. In doing so we may develop methodologies, which will allow, 'room for the unexpected to happen, fresh insights to be acquired, and theoretical perspectives to be developed', (Rapport *et al* 2005:38).

Strengths of the Study

The synthesis of qualitative research findings is being promoted by a number of agencies including the Evidence for Policy and Practice Information (EPPI) Centre and the Social Care Institute for Excellence (SCIE) in the United Kingdom. However in the quest for Evidence Based Medicine or Practice, there is a danger that the approaches for synthesizing quantitative studies may be applied to the synthesis of qualitative research studies, (Barbour & Barbour 2003, Grypdonck 2006). The danger here is that 'abstract, quantitative measures could forget the qualitative ground of what the numbers are about', Todres *et al* (2006:55). The framework that I propose is based on qualitative dimensions that provide a foundation for providing meaningful knowledge that is not concerned 'with goals and issues that measure quality in ways that are superficial', (Todres *et al* 2006:55). But rather, it provides knowledge that reflects lifeworld descriptions expressing peoples' experiences of health and illness, which are more detailed and informative than evaluations and

judgements, (Todres *et al* 2006).

Thorne *et al* (2004), propose that the measure of a product should be determined by criteria from both science and art. In evolving this framework I have drawn upon criteria from both spheres in an attempt to make the findings of qualitative health and social care research useful to a wider audience.

The phenomenological hermeneutic approach to synthesis that I have taken has made use of personal narratives to allow readers and audiences to gain a richer understanding of peoples' health experiences, as they are lived and articulated by those who have the illness. For as Phinney (2002), notes, if we exclude accounts of lived experience, the language for understanding such experiences will remain impoverished. This framework draws upon the phenomenological tradition by articulating an approach to understanding that allows others to suspend their own preconceptions by 'taking a walk in another person's shoes', (Galvin & Todres 2007:37) and in doing so it has the ability to engender 'empathic imagination':

> 'an interwoven fabric of thought, ethics and action in that an individual is fundamentally engaged in *being with* and, in some cases, *being for* another as a source of knowledge and action'.
>
> (Galvin & Todres 2007:37)

Experimental social science genres such as the short story or performance piece have a narrative nature that captures the unique voices and lives of individuals in a way that normal qualitative research texts cannot, (Tierney 2002). Image in particular:

> 'creates an intense compression of meaning; it carries into the mind the solidity, particularity and multifacetedness of actual objects. Such concreteness is a handle: it can be grasped. It must also be turned. That turning opens the reader (viewer) into a place of enlarged awareness, where different connotations may resonate together. Before the

slipperiness of unformed, thought, the image offers purchase; to the stolidity of things, it offers imagination's alchemical, stirring powers'.

(Hirshfield 1998:114) (word in brackets this author's own)

Communicating in this way creates a way of understanding that is lacking in traditional forms of understanding, it creates embodied understanding, a way of understanding that 'involves a living access to important feelings and insights that are carried and affirmed and are more than principles of just thought', (Galvin & Todres 2009:7).

Using the principles of both science and art I have attempted to present research findings in a way that will engage with audiences and change the way they think, (conceptual utilization) about problems, persons or events, by evoking vicarious experience and by providing a vivid worldview that seeks to create empathic insight and understanding. As Lomas, (1997 cited in Estabrooks 2001:291-292) asserts, 'research must be translated into common knowledge by its purveyors before it will be taken up readily'.

Limitations of the Study

This study has limitations that are common to all studies that are involved in the synthesis of qualitative research findings: -

- Locating qualitative research studies: As previously identified there are numerous problems that are encountered when attempting to locate qualitative research studies. Therefore it is possible that despite the most diligent searching, studies in the area of interest might be missed. However, unlike systematic review where the emphasis is on retrieving all the relevant studies in the target domain, the emphasis in this study was on '*meaning* rather than *measurement*', (Todres 2007:65), not to count how many but to come to understand a phenomenon through adequate exposure to qualities of the phenomena, (Todres 2005).

- Traditional methods of reporting studies in peer-reviewed journals often result in the description of the findings being abbreviated. This limits the voice of the participants and fails to 'show the unique lived, and often rich experiences, from the people that are in focus', (Dahlberg 2006:444). In an attempt to overcome this limitation the studies selected for inclusion in the synthesis include personal essays, an autoethnographic study, and an autobiography all of which are rich in personal experience.

In addition this study has limitations, which are particular to this individual study:

- The synthesis I have produced is based on my interpretations of the data; another researcher working with the same data might produce a synthesis with a different emphasis.

- The 'story' I have told is not offered as a definitive or generalisable 'story' on the experience of living with dementia; rather it is offered as a 'story' that tries to offer insights that have a communicative value, 'that are faithful to examples of unique occasions' but which have a 'potentially transferable meaning for others', (Todres 2007:66).

- Currently an audience consisting of members of the public has not engaged with and given their reaction to the DVD; 'Being Together', - the challenging shared journey with dementia. However the positive feedback from members of an audience attending an ERSC Festival of Science 08 event – Imagine this: Living with Dementia, (hosted by Bournemouth University's Centre for Qualitative Research), at which I presented and discussed insights from *I'm Still Here!*, (Mitchell *et al* 2006), has convinced me of the positive potential of communicating research findings in an audio-visual format. In particular for their ability to allow audiences, 'to grasp the point of view of the other in such a way as to understand', (Halling 2008:19-20).

Conclusion

Framework Contributions & Applications

This framework contributes to knowledge by evolving an innovative framework for synthesizing qualitative research findings from the arena of health and social care, 'that express peoples' experiences of health and illness, their shared and individual journeys, and their interactions with others', (Todres *et al* 2007:58).

Britten (2002), has cautioned that, in our attempts to find methods for synthesizing qualitative research findings, we should not be seeking to fit the round peg of qualitative research into the square hole of quantitative methods but rather we should develop separate methodologies. The framework that I have developed for the synthesis and communication of qualitative research findings draws on qualitative principles to communicate synthesized research findings to diverse audiences that include members of the public.

It differs from other approaches to synthesis, (i.e. grounded formal theory, meta-ethnography, meta study and systematic review), in a number of ways. It seeks to provide an experiential description of human behaviour, rather than to produce new interpretations and theories or to evaluate evidence against outcomes. It attempts to communicate in a way that exceeds any summary by producing knowledge that 'touches' the readers or audiences own lives, (Todres & Galvin 2008). By focusing on the insider perspective it offers a description, which has evocative impact and rich unique contextualization, rather than a premature abstraction of findings, (Todres *et al* 2009).

Research-based descriptions of people's lifeworld experiences are more detailed and informative than evaluations, judgements and theories, offering a narrative that supports others to understand. Therefore this approach to synthesis has the ability to inform both policy and caring practice in a more, 'humanizing' way than procedural, instrumental or technical knowledge', can, (Galvin & Todres 2009:2). Its emphasis on 'real experiences provides a kind of credibility that only human stories can give', by 'offering a humanly textured scene that communicates meaning and significance', (Todres *et al* 2007:60).

In addition to contributing to qualitative research methodology, this study also contributes to the field of knowledge in dementia. The structural-textural synthesis explores the experience of living with dementia from the perspective of the partner with dementia and their care partner. As previously identified there is limited research in this area, and there is an identified need to better understand how couples make sense of, and adjust to, a 'life with dementia'. Through the portrayal of a couple's journey with dementia, this study attempts to 'humanise' the experience of living with dementia. It seeks to offer audiences an insight into the journey or dance with dementia as it is experienced by the partner with dementia and their care partner, acting as both a revealing window allowing previously unknown aspects to be revealed and viewed, and as a reflecting mirror through which personal experience can be reflected on and reframed. This supports the audience to gain a sense of person, a sense of journey and a sense of place, by allowing them to enter into the world of the two partners, in a way that an academic text would not. Allowing audiences to enter into this world has the potential to offer them an understanding, which may address some of the stigma that is associated with dementia.

The aim of this framework therefore is not to produce theory or guidelines for practice, but to produce a 'story' that has the ability to engage with readers and audiences through its capacity to present evocative lifeworld experiences. In this way it attempts to overcome the barriers to communication that are inherent in traditional textual forms of dissemination, (e.g. academic text, practice guidelines, didactic talks and policy documents), by communicating in a way that adds to understanding in a meaningful way. Unlike the traditional approaches to disseminating research findings, which have been criticized for their lack of impact on anything other than their authors' career (Richardson 2002), communicating in this way gives research findings a 'life beyond the shelf'.

In particular this framework has applications for:

- Communicating research findings to audiences comprised of members of the public, (who are normally excluded access to findings as a direct

result of the traditional avenues of reporting qualitative research findings), supporting them to gain a deeper insight into lifeworld experiences, of health and illness. This may be of particular benefit to support groups led by people who use health and social care services and who may use the knowledge they gain; as a form of advocacy with health and social care service providers, as a mutual support system or to lobby for policy changes.

- Educational purposes, to deepen health and social care professionals understanding, by allowing them to 'be open' to the lifeworlds of their patients and clients, in order to 'listen to their stories, to touch and be touched', (Dahlberg *et al* 2007:5). Descriptions of experience are more detailed and informative than evaluations and judgements, and have the ability to produce knowledge, which supports empathic understanding of peoples' experiences. This represents a particular kind of 'knowledge for care' that has a humanizing emphasis, (Todres *et al* 2009:8). An emphasis that is not concerned with goals and issues that measure quality in superficial ways that are potentially dehumanizing, (Todres *et al* 2007), but an emphasis on providing 'life-world led care', (Dahlberg *et al* 2007, Todres *et al* 2007), that is a care that is:

  o humanizing in a way that moderates technological progress.

  o grounded in an understanding of others' worlds, in experiences of real people living through complex situations – the holistic context for understanding quality of life.

  o based on a framework for holistic human understanding.

  (adapted from Todres *et al* 2007:60)

- Influencing policy by creating a better understanding of health and social care experiences, supporting the development of policies that move beyond the consumerist/citizenship model on the one hand, with its

overemphasis on agency that can leave patients exposed and vulnerable and the 'medical model' on the other hand, with its overemphasis on illness and under-emphasis on agency, (Dahlberg *et al* 2007).

Moving the Field Forward

In developing the framework I have addressed the two challenges highlighted by Holloway & Todres (2007), that is: how to transform research findings in a way that will make them relevant and useful to readers and audiences, and how to make dissemination activities more imaginative and engaging, in the following ways by: -

- Offering an approach to synthesis that draws on the logic of phenomenology and hermeneutics to transform research findings into a structural-textural synthesis. This aesthetic approach to phenomenology uses language in a more evocative way; and is of value because of its 'distinctive emphasis on making human behavior and experience intelligible with reference to the point of view of the actor', (Halling 2002:19).

- Communicating research findings in a language that uses, strong sensible words with good meaning and flavour of the real, (Coles 1961 cited in Halling 2002), rather than academic language that is by its nature exclusionary in terms of both understanding and accessibility.

- Moving away from the more passive traditional approaches to disseminating research findings by communicating research findings in a way that actively seeks to exchange knowledge and elicit understanding through the medium of performance; privileging the phenomenological complexity of every day life by "evoking" rather than "representing" experience, (Kontos & Naglie 2007).

- Providing research based knowledge that is of value to members of the public, health and social care professionals, educators and policy makers. In particular, presenting knowledge in a way that evokes experience thereby creating a 'connexional dimension' with audiences, in a way that is not possible through traditional academic papers or didactic talks. This allows for a more intimate and emotional understanding in particular for those audiences orientated towards empiricism, as it allows them to go 'beyond the boundaries of one's "self" to join with an "other"', (Gray *et al* 2003:228).

- Offering insights into the experience of living with dementia from the perspective of the partner with dementia and their care partner, through their individual narratives and the related meaning in their lives. This has value for enhancing understanding of the lived experience, enabling others to feel with and to feel for the two partners. It also attempts to reduce the stigma associated with dementia by reducing the dis-ease that people experience when confronted with dementia.

- Addressing the need to improve public and professional awareness and understanding of dementia identified in Transforming the Quality of Dementia Care: Consultation on a National Dementia Strategy, (DH 2007) and in Living well with dementia: A National Dementia Strategy (DH 2009).

- Humanise healthcare practice by providing empathic knowledge supporting the objective of the High Quality Care for All, NHS Next Stage Final Report, (DH 2008) to improve the quality of NHS education', (DH 2008:14).

The next step is to assess the potential of this study to make a difference to the lives of people with dementia and their care partners. In order to do this it will be necessary to engage with audiences to assess their reactions after viewing the DVD. In particular to assess whether engaging with audiences in this way has the potential to: -

- enhance the understanding of the experience of living with dementia.

- tackle the stigma associated with dementia.

- act as a pedagogical tool to facilitate understanding in health and social care professionals.

- inform health and social care policy and practice.

and finally ……. for myself and for others who may be tempted into the 'world of synthesis' it is crucial that we heed Noblit's warning to be mindful of whose interests we are serving in order that synthesis does not become a 'method' for legitimizing policy and practice in a way that devalues and ignores the experience of the patient or client.

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