

That which goes unsaid:
Experiences of everyday life in residential care for residents
with limited communication ability.
A collective case study.

Dissertation submitted in partial fulfilment of the Master of Science (Nursing)

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This dissertation is submitted to the RCN Institute and the University of Manchester in part fulfilment of the **MSc in Nursing** and has been conducted and presented solely by myself. I have not made use of other people's work (published or otherwise) or presented it here without acknowledging the source of all such work.

Abstract

That which goes unsaid: Experiences of everyday life in residential care for residents with limited communication ability. A collective case study.

This research concerns the everyday experiences of people who have difficulties communicating and who live in a long term residential care setting. A collective case study methodology was used to illuminate the everyday experiences of four residents living in a residential care setting in the Netherlands.

Observation, interview and documentary data was gathered over a period of six weeks, with a total of 75 hours in the field. In order to enable participation for these four residents in this research, alternative strategies of communication were developed, to enable the co-creation of dialogue between participant and researcher. Among the alternative strategies was the use, by a participant who could not talk, of intentionally created artwork with which to share her ideas with the researcher.

Daily experiences for these participants were characterised by struggling against the constraints of the residential setting, which included having to wait, unmet needs, vulnerability and uncertainty. These constraints were made more challenging because of the communication difficulties they lived with. Their experience of struggling was sometimes ameliorated by significant social contact with family or particular staff members, and engaging in enjoyable activities. Occasionally the experiences of enjoying the here and now, and being 'seen' as a person by the other, would create beautiful moments in which, for a short time, truly person centred engagement would occur. These moments were neither articulated or recorded, and were thus invisible after they had occurred. In the same way, the experiences of struggling against the constraints were also unacknowledged and not recorded. Significant experiences in the lives of these four residents were therefore invisible to others. The unifying theme representing the daily experiences of participants in this study is: That which goes unsaid.

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Chapter 1: INTRODUCTORY OVERVIEW

“Do you see that man sitting by the TV? He can’t speak you know.
I think he’s a bit disturbed,”
(Volunteer in residential care setting)¹.

“What’s she called? What’s her name, that woman who shrieks all day?
I swear, sometimes I feel that noise in my marrow,”
(Resident in residential care setting).

The statements reproduced above were made by real people, in the residential care setting where I work. They made an impact on me when I heard them and I recorded them in my journal. These statements were made about particular residents; residents who have difficulties communicating. They suggested to me something of the experiences that people with communication difficulties might have. They might face being thought ‘a bit disturbed’ if they were unable to speak. Or perhaps be considered horrifying by other residents, who ‘feel’ the noises, perhaps made as the only possible alternative to speech, ‘in their marrow’. I wondered what was known about the lives and experiences of people in this situation. Was it as bleak as I imagined? It seemed an issue worthy of further investigation.

This research, therefore, concerns the everyday experiences of people who have difficulties communicating and who live in a long term residential care setting. In this introductory overview, I will highlight the issue and why it is significant for nursing and practice development. An explanation of the origins and relevance of this particular study are followed with a statement of the research aim. Finally, the structure of this dissertation is described.

1.1 The issue of interest

The same disabling conditions which lead to a need for assistance with personal or other nursing care may also result in communication disturbances. Multiple sclerosis, Parkinson’s disease or traumatic brain injury, for example, can negatively affect a person’s ability to communicate, and as Lemieux *et al.* (2001) point out, almost a third of all stroke survivors are affected by aphasia. Loss of language communication is the most common communication problem among people with disabilities (Harper and Bell, 2006). Communication can be negatively affected by both the sensorimotor and cognitive changes associated with aging (D’Wynter, 2006), including of course, dementia (Potkins *et al.*, 2003). People may find themselves, therefore, living in a residential setting, both dependent on others for physical care and unable to readily communicate.

Researchers interested in learning about the lives of people in these circumstances face difficulties. Recruiting participants with communication difficulties to research raises issues in terms of consent (Moore and Savage, 2002) and, as described by Harris and Dyson (2001), makes gathering data particularly challenging. Researchers in long term care settings have tended to focus on residents who are able to communicate their needs and opinions (e.g. Specchio, 2004; McGilton *et al.*, 2006). So despite a large body of research examining life in residential care, there is little work addressing specifically the situations of residents with limited communication abilities.

¹ For source information with respect to both these statements, see Appendix A, item 1.

There are two exceptions to this trend. The first is found in the literature relating to people with dementia, many of whom also have altered communication abilities. To try and understand something of their experiences or to discover meanings associated with particular behaviours, researchers in this field have often collected observational rather than, or as well as, interview data (e.g. Beck *et al.*, 2002; Buffum *et al.*, 2007). The viewpoints of proxies (staff or family members of the research participants) may also be relied upon (e.g. Edelman *et al.*, 2005; Winzelberg *et al.*, 2005). Authors such as Stalker *et al.* (1999), however, support eliciting the views of consumers (or residents) themselves if at all possible. Examples of the use of narrative methods, even in the presence of severe cognitive decline and language disturbance, can be found in the work of Normann *et al.* (2005) and Graneheim and Jansson (2006).

The second exception is in the field of learning disabilities where a history of user consultation exists, including among those who need support to communicate (e.g. Tuffrey-Wijne *et al.*, 2007). Although much can be learned that is perhaps applicable to residents with communication difficulties in other settings, as Stalker *et al.* (1999) point out, it would be incorrect to assume the conclusions are all transferable. In particular, people with learning disabilities have had to deal with communication difficulties all their lives, instead of acquiring them later in life.

Outside the areas of dementia or disability care, there is very little known about the experiences of people with communication difficulties living in residential settings. There is a gap in our knowledge with respect to the activities that make up their day, how much influence they have over the events of their daily life and the things that are important to them. Their 'voices' are indeed silent.

1.1.1 Significance of this topic for nursing and practice development

The current situation suggests that people with communication difficulties living in residential settings do not have their views taken into account in evaluation of services, and they may not be receiving the best possible person-centred care.

Investigation into the views of members of this group, in ways that value their perspective and enable the 'hearing' of their voices, would be significant for both nursing and practice development.

1.2 Origins of this study

This particular research project arose through the interaction of processes related to my dual role as both co-ordinator of the practice development unit in a residential nursing home for adults, and as a student enrolled in a Masters programme. Although the decision making processes within the organisation were happening concurrently with my own reflections, I will discuss them here separately for clarity.

1.2.1 An issue of concern: the organisation's perspective

This project grew out of a planned action research study which was to involve as many stakeholder groups as possible within the organisation where I worked, Riverside Care Nursing Home² (RC). The RC Management Team, Resident Council, Employee Council, and some individual family members of residents, had identified several issues of concern, a key step in the first stage of an action research project (Kemmis and McTaggart, 1988). The participants in this process noted that missing from the

² This is an assumed name, given for the purposes of this study.

'mix' of opinions and concerns were those of residents who were not well or able enough to participate in the Resident Council. It was agreed by all stakeholder groups that the views of residents who may have difficulty sharing their ideas in the existing forums needed to be sought.

1.2.2 An issue of concern: my perspective, as researcher

My office in RC was situated on one of the residential units. While working there I was easily visible to many of the residents as they left their rooms or approached the central lift bay. Soon after my arrival in RC, a number of residents started dropping in to say hi, or to let me know about events of the day or week just gone. Included in this group were three residents with severe dysphasia. To begin with they just 'rolled up' – all three of them used an electric wheelchair – sat for a minute or two after saying hallo, and then motored away again. In the end, I could count on these three residents to come by once a fortnight each for a chat, staying for 15 to 30 minutes at a time.

The time I spent with any one of this group of residents usually included long moments of silence while my visitor searched for a word, and a series of guesses from me. I had some spectacular misses as I worked to understand what my conversation partner was trying to say. I had no fixed topics with any of these residents and I rarely knew before we started talking what we would be discussing. We sometimes made use of diagrams, pictures, word lists, maps and diaries that were present in my office to enable our conversations. Once we got started, however, just talking together and watching each other were often enough to result in some surprising discussions. I looked forward to the visits from each of these residents.

I wondered, of course, what life was like for them outside the artificial calm of my office, in the daily swing of things on the unit. What happened during morning care, for example, when they wanted something different to their usual routine, or they wanted something done the same way but familiar nurses were not on duty? Before being hoisted into their electric wheelchairs each of my regular visitors was immobile without help. Two had difficulty saying more than one or two words after each other. The third spoke many words, every now and again, but invariably all in the wrong order. As well as being dysphasic, two of the three had limited problem solving skills as well as a tendency to perseveration. I imagined some fairly heated exchanges, and the idea of researching the issues faced by residents in this, in my view very vulnerable, situation, was born.

The identification of these issues, and the intention that my research design would create possibilities for some residents with communication difficulties to have their voices heard, lead to the formulation of my research aim.

1.3 Research aim

This research aims to illuminate the experiences of everyday life in a residential setting for residents who need nursing care and who have difficulties communicating.

As will be justified in Chapter 3, I chose collective case study methodology, as described by Stake (1995; 2005), to examine these experiences and meet the research aim. Stake (1995) states that it is important, when refining the conceptual structure of the research, to identify the key issues facing the researcher with respect to meeting the research aim. Issues that may be facing the 'case' should

also be identified. Posed in the form of statements or questions, their purpose is to facilitate the research work.

1.3.1 Issue statements about this collective case study

I wanted the perspectives of the participants to be the focus of the research. I formulated therefore, three questions designed to focus my attention on potential issues from the participants' perspectives.

- Are there aspects of the current situation, from the participants' perspectives, that are cause for concern?
- Are there aspects of the current situation, from the participants' perspectives, that demand prompt action towards change or practice development?
- Are there aspects of the current situation, from the participants' perspectives, that are worthy of continuation, or even celebration?

Finally, I identified the chief issue that I was facing, in terms of meeting the research aim. It was related to the lack of information known about including residents with communication difficulties in research. The issue was:

- How was it possible to illuminate participants' experiences of daily life, in order to come to some sort of understanding of their perspective?

1.4 Structure of the dissertation

This dissertation details the ways in which my Masters research was planned and implemented, and shares and discusses the findings. I begin, in Chapter 2, with a review of the relevant literature. This is followed by a discussion of my research paradigm assumptions, and their fit with collective case study methodology (Chapter 3). In Chapter 4, I present an account of the data collection and analysis methods, including a discussion of the ethical issues encountered in this study. The participants, or 'cases' are introduced in Chapter 5, along with a description of the context in which they live. The chapter concludes with the presentation of the themes that emerged from the analysis of the cases as a collective. Chapter 6 illustrates the interactions between the themes, compares and contrasts the findings with the relevant literature, and presents the limitations of the study. The main body of this dissertation concludes with Chapter 7, in which the findings are summarised and conclusions are drawn about the extent to which the research aim has been met. The contributions made by this research to practice and the literature are identified, and questions are raised for future research.

1.5 Concluding remarks

In this chapter I have introduced the research issue, and explained how I came to consider it worthy of investigation. I have presented the research aim, which is to illuminate the experiences of everyday life, in a residential setting, for residents who need nursing care and who have difficulties communicating. In order to establish the significance of the issue, I have presented a brief outline of the related literature. I will now present a more detailed review of the literature as it relates to the experiences of people living in residential care, with communication difficulties.

Chapter 2: LITERATURE REVIEW

Residential care settings are those in which groups of people, strangers to each other but all needing a certain level of assistance in their daily lives, live together to enable the clustering of care and service delivery. Such settings are not generally where we aspire to live out our days and certainly not where most of us expect to live for a long period of our lives (Specchio, 2004). In fact, most of us don't have to. Only one percent of people in the Netherlands, where this study takes place, live in long term residential care as a result of needing nursing care or help with activities of daily living (Actiz, 2006)³. This equates to a little over 166,500 people. In 2007, however, there were a further 64,000 people on waiting lists for residential care (Bijl *et al.*, 2007). Numbers of people needing such care are expected to continue to increase in the Netherlands (Singelenberg, 2003; Bijl *et al.*, 2007), and elsewhere (Royal College of Nursing, 2004).

Life in residential care has been examined from a number of perspectives in the nursing literature. There is information about how facilities are financed and run (e.g. Laing, 2002; Cohen-Mansfield and Bester, 2006), how they should be designed and built (e.g. Bakker, 2000; Torrington, 2006; Calkins and Cassella, 2007), what it is like for staff to work there (e.g. Chou *et al.*, 2002; Moyle *et al.*, 2003; e.g. Berkhout *et al.*, 2004; Morin and Leblanc, 2005), and what it is like for varying groups of people to live in residential care (e.g. Resnick, 1999; Chao and Roth, 2005). There are also articles regularly published about organisations that claim to have realised person-centred values or philosophies in practice, through implementation of a particular model of service delivery (e.g. Adleman, 2003; Keane and Shoesmith, 2005; Rauma and Vickery, 2005).

2.1 Themes related to life in residential care

Despite the diversity of countries, health care systems, and characteristics of residents and caregivers represented in the literature, there do emerge certain themes. These tend to concern the cultural and social-relational aspects of life, although one theme, that of unmet need, also affects physical health.

2.1.1 A culture not your own

Living in residential care involves making an important transition and readjustment into the residential situation (Lee *et al.*, 2002). This process is generally reported as traumatic and disempowering for the new resident (e.g. Nay, 1995; Efrainsson *et al.*, 2003; Braam, 2007). Relocation to residential care can also mean, however, getting the help one needs, as emerged in a grounded theory study conducted by Mandville-Anstey (2002). Furthermore, Walker *et al.* (2007) found evidence of coping, strength and personal efficacy among the sixteen new long term care residents in their study. They concluded that humour, life experience and common sense were used to cope, with what can also be viewed as just another of life's transitions (Walker *et al.*, 2007).

Whether the transition goes smoothly or not, living in residential care means learning to live in a particular culture, a culture that is not your own. It means, in fact, having to accept as normal what

³This figure is the number of people who have, through sickness, accident or age-related changes, become dependent on others for some form of care after living the majority of their lives independently. It includes those with dementia, but not those with psychiatric conditions or intellectual or physical disabilities present at birth or acquired in childhood. It does also not include the 430,000 people who receive home care or district nursing every year within the Netherlands, or the roughly 70,000 who live in sheltered housing.

you would have once considered strange. Examples given by Bosch (1998) in his rich descriptions of residential life, include having to dine in a group, among people you may not like; being surrounded by people (staff) who know your most intimate details, but for whom you may not even know their full name; and to know that a new 'vacancy', perhaps even the one you filled, comes as the result of another resident's death. These examples resonate with the findings in Fiveash's (1998) ethnography of nursing home life.

A particular frustration of residential settings is having to wait (e.g. Bourret *et al.*, 2002; Mitchell *et al.*, 2005; Tuckett, 2007). Waiting for care, or information, or simply waiting your turn. Needing help, and having to wait, emerged as an evocative symbol of limited independence in Driver's (1997) doctoral research. For the participants in her study the circumstance of 'waiting' was described as permeating their lives. Specchio (2004), too, named waiting as one of many interrelated variables that lead to constant tension for the working-age adults in her study, as they strove to 'make a life' for themselves while living in a nursing home.

2.1.2 Continuing importance of occupational or leisure activity

Occupational and leisure activities have been found to be important, not least in terms of the activity itself (e.g. Schreiner *et al.*, 2005; Bergland and Kirkevold, 2006). Activities also create opportunities for social contact (e.g. Mackenzie *et al.*, 2004) or the chance to be of service to others (e.g. Roelofs, 1999).

2.1.3 Continuing importance of social contact and engagement

Siveraman-Nair and Wade (2003) found that nurturing social ties were among the most important goals of the people with neurological disabilities in their study, and elderly people who continue to thrive into old age name social relationships and being needed by others as important contributors to wellness (e.g. Stanford, 2006). Such contacts do not become less significant for those living in residential care (Bergland and Kirkevold, 2006) and people continue to enjoy social contact into very old age (e.g. Washburn *et al.*, 2003). As Carpiac-Claver and Levy-Storms (2007) point out, residents in residential care risk experiencing a lack of meaningful contact, an area in which nurses and caregivers can play an important role. That nurses and caregivers vary in their abilities (e.g. Caris-Verhallen *et al.*, 1999) or desire (e.g. Tuckett, 2005) to address these needs is also evident in the literature.

2.1.4 Living with unmet need

A disturbing theme in the literature is the range of unmet need that residents in residential care either experience, or are at risk of experiencing. This can include poorly managed pain (e.g. Higgins *et al.*, 2004; Closs *et al.*, 2006), unnecessary incontinence (e.g. Mather and Bakas, 2002; Rodriguez *et al.*, 2007), unrecognised and untreated depression (e.g. Williams, 1999; Ayalon *et al.*, 2007), and untreated yet remediable sensory problems (e.g. Winter de *et al.*, 2004). Such issues, in turn, place residents at risk for reduced social interaction (e.g. Stabell *et al.*, 2004; Carpiac-Claver and Levy-Storms, 2007). A lack of meaningful contact with others is keenly felt by residents (Cook *et al.*, 2006; Brink and Stones, 2007).

2.1.5 Promoting flourishing is a difficult goal

In contrast to the above, a number of residential settings identify their goal of care as the recognition of residents as individuals, and promotion of their continued development, or even flourishing (e.g. Cohen-Mansfield and Bester, 2006; Hoban, 2007). It is recognised, however, that this is no easy goal and one which requires continuing vigilance and well co-ordinated action from management and employees (e.g. Glen Cove Center for Nursing and Rehabilitation, 2006; Crandall *et al.*, 2007).

2.1.6 Relationship with the nurse

Where person-centeredness is achieved, residents and staff enjoy mutually fulfilling contact (e.g. Adleman, 2003; Rauma and Vickery, 2005). But person-centred or not, contact with nurses and other caregivers has a big impact on how people experience life in a residential setting. At its worst, the contact between resident and nurse can be experienced as demeaning and infantilizing for the resident (e.g. Koch *et al.*, 1995; Nay, 1998). In general, residents are confronted with a variety of nurse-resident contact, requiring a corresponding range of responses from the resident (e.g. Irurita, 1999; Williams and Irurita, 2004). Spiers (2002) examined the range of negotiating behaviours that take place between resident and nurse in her doctoral research. She found that there were no 'formulas' in terms of the most effective reaction from the resident. The negotiating behaviours could not be usefully examined independently of the relationship the resident had with the nurse. In a similar vein, Brown (1995) found that nurses' soothing behaviours and residents' reactions to these were dependent on the relationship between the nurse and the resident.

2.2 Whose perspective is present and how has it been captured?

The vast majority of work referred to in Section 2.1 had elderly, or very elderly people, as the focus. There are two exceptions to this. Adleman (2003) describes a residential setting where care is provided for working-age adults, and where a person-centred approach is the aim. The study by Specchio (2004) was designed expressly to examine the experiences of working-age adults in nursing homes. Irrespective of residents' ages, in order to understand their experiences studies have focused, not unsurprisingly, on those residents who are readily able to give their opinion. This tends to mean those who are cognitively well and able to communicate. The noticeable exception to this is the situation of residents with dementia, as already outlined in Section 1.1. Many people without dementia also experience communication difficulties. There are a few studies which have explicitly sought to include members of this group.

Hemsley *et al.* (2001) investigated communication strategies between patients and nurses when the patients had severe communication difficulties. They found that while some nurses found effective ways of communicating, many did not achieve this. Once a breakdown in understanding occurred, usually as a result of having no readily interpretable communication system available, it led to considerable frustration for both parties. Lemieux *et al.* (2001) investigated the effect aphasia had on the experience of sexual dysfunction after stroke. Researchers in this study employed structured verbal questionnaires during interviews, supported with the use of gestures, and written and pictographic materials. Spouses also contributed, sometimes in their own interview, but also 'filling in the gaps' for the aphasic person. Although participants in this study lived at home after their stroke, it was relevant to my study because of the interview techniques used. Another study that appeared relevant to mine was that published by Philpin *et al.* (2005). Many of their participants had communication difficulties. In order to include these participants' views, researchers used pictures,

closed questions, shorter interviews and included carers in the interviews. These techniques were generally employed to find the answers to pre-determined questions. Lastly, Sundin and Jansson (2003) conducted an observational study of skilled nurses' interactions with patients who had aphasia. The patient participants were not asked for their opinions, but the observed interactions were richly described. A particular way some nurses had of being present with the patients lead to the '...co-creation of dialogue...' (Sundin and Jansson, 2003, p.115) between nurse and patient.

2.3 Concluding remarks

In general, communication is seen as being fundamental to the ways residents negotiate their world, both in terms of relationships with caregivers or others, and in terms of having their care needs met. Residents are recognised as vulnerable when the usual processes of communication are disturbed. Although a small number of studies have specifically attempted to include people with communication difficulties in research, this has not been with the intent to uncover their perspectives of their daily experiences as they live with those difficulties in a residential setting.

Chapter 3: METHODOLOGY AND METHODS

In order to illuminate the experiences of everyday life for residents with communication difficulties I have chosen to use a case study approach, as described by Stake (1995; 2005). I have located my research within the interpretive paradigm, although I have been influenced throughout the journey of this inquiry by elements of critical theory. In this chapter I will describe the assumptions underpinning my inquiry, the resulting research paradigm within which I have worked and the corresponding choices I have made with respect to methodology. Throughout this discussion of my methodological decisions, and while justifying the 'fit' of the methods to my approach, I will position myself as researcher.

3.1 Research paradigm and rationale

3.1.1 'Paradigm' defined

Weaver and Olsen (2006) compare four paradigms commonly used in nursing research: positivism, post-positivism, interpretive and critical social theory. They define *paradigm* as follows:

'Paradigms are sets of beliefs and practices, shared by communities of researchers, which regulate inquiry within disciplines. The various paradigms are characterized by ontological, epistemological and methodological differences in their approaches to conceptualizing and conducting research, and in their contribution towards disciplinary knowledge construction' (Weaver and Olson, 2006, p.459).

I found this definition useful, amongst others' ideas, and have used it to order my discussion of the paradigmatic frame of reference for this study.

3.1.2 Ontological assumptions

A researcher's ontological assumptions concern the nature of the world and the nature of our ways of being in the world. These assumptions address the nature of reality (cf. Maggs-Rapport, 2001). In this research I embrace the idea that truth is relative. That is, that there are multiple 'local and specific constructed and co-constructed' (Guba and Lincoln, 2005, p.193) perspectives of any situation. The alternative view, that 'truth' is universal and independent of human perception, is based on realism (cf. Guba and Lincoln, 2005). This idea, that there is one perspective of reality that can be considered 'right' in preference to others, is rejected within this project. Instead individual perspectives are valued and considered legitimate

3.1.3 Epistemological assumptions

A researcher's epistemological assumptions concern our ways of knowing (Weaver and Olson, 2006). What can we know and how can we know it? What counts as knowledge? Epistemologically, my inquiry is grounded in the assumption that we come to know through intersubjective engagement with the other (cf. Weaver and Olson, 2006). I, as the researcher, have an influence on the participants' lives and situations, and they in turn have an impact on my life. This process of interaction contributes to our co-creation of knowledge and understanding. In contrast to research conducted within the positivist or post-positivist tradition, where the researcher is concerned with

maintaining distance and objectivity, in the interpretive paradigm the researcher aims to *decrease* the distance between her or himself and the phenomenon being researched (Creswell, 2007).

3.1.4 Methodological assumptions

As Weaver and Olsen (2006) explain, the methodologies associated with each paradigm are a reflection of the ontological and epistemological choices already made. The following three characteristics of my research are typical of research conducted within the interpretive paradigm (cf. Guba and Lincoln, 2005; Weaver and Olson, 2006). Firstly, the overall goal of my inquiry was aimed at *understanding*, as opposed to control or prediction. Secondly, the type of theoretical knowledge I was seeking was *practical knowledge*; knowledge that would help me understand the social world of the participants in this study. Such knowledge is regarded as being co-constructed and continually revised. Lastly, the theoretical and practical knowledge in this inquiry *emerged inductively*, and I used established theory to explain the data. This research was not concerned with the deductive verification, falsification or replication of findings, as would be expected from research conducted within a positivist or post-positivist tradition. Neither was I specifically aiming to 'illuminate embedded barriers to autonomy and responsibility' (Weaver and Olson, 2006, p.462), as would be expected in an inquiry conducted within the tradition of critical social theory.

3.1.5 The influence of critical theory

Inspired by the writings of Marx, Habermas and Freire, critical theorists examine issues of power and alienation and assert that some versions of reality or truth are preferred over others (Weaver and Olson, 2006). This preferring of particular realities or ways of understanding the world is so effective that we often don't even know it is happening. Social injustice is thus perpetuated, even by those groups who are disempowered or negatively affected by the status quo (cf. Freire, 1970/1993; Spender, 1982; Carr and Kemmis, 1986). Critical theory demands an active agenda from research and researchers. It demands that research be conducted with the aim of taking action against inequalities and social injustice, or with the intent of making the hidden visible, beginning to raise consciousness and actively enabling the participation of less powerful groups within social institutions.

This call to social action has had far reaching consequences in the social sciences; it has influenced the way interpretivists view their paradigm (Denzin and Lincoln, 2005). Researchers that locate themselves in the interpretive paradigm have begun to incorporate elements of critical theory into their position, as Guba and Lincoln describe, using their own work as an example (Guba and Lincoln, 2005). Predicted by Carr (1989) and confirmed by Greenwood and Levin (2005), the influence of critical theory on research in the social sciences has become almost mainstream. Researchers in nursing and the health sciences also demonstrate valuing such a position. In a large and complex study, Binnie and Titchen (1999) describe being influenced by both the phenomenological and critical social science traditions, and eventually locating their action research study in both the interpretive and critical paradigms (Titchen, 1993).

The primary focus of my research was understanding and interpreting the everyday experiences of the study participants. This locates my research in the interpretive paradigm. The study did originate, however, from a recognition of a possible mis-match between espoused theory and theory-in-use (cf. Argyris and Schön, 1974) at an institutional level, making it likely that social inequalities were at work. The research also originated in a context of stakeholder consultation and with the intent to present the results of the study in such a way that they could be used to promote

local action to improve the circumstances of the participants in the study. Finally, my intention as researcher is to disseminate the findings in a wider context, thereby giving a voice (albeit small) to a group who are at this time largely absent from the literature. Therefore, although my research is conducted within the interpretive paradigm, the assumptions of the critical paradigm have also shaped the methodology.

3.2 Chosen methodology: collective case study

The issue I identified as my topic of inquiry, daily life in residential care as experienced by people who are dependent on others and who have difficulties communicating, is complex. It is also inextricably linked with its context because the place, systems and people of the residential care home are pertinent to the phenomenon under consideration. When a proposed investigation has these characteristics it is well suited to a case study methodology. In case study research, contextual conditions, because of their relevance to the phenomenon, are deliberately investigated (Stake, 1995; Yin, 2003b). The behaviours and events being studied are contemporary and not controlled or manipulated by the researcher (Yin, 2003b). As the name of the approach implies, the researcher focuses his or her attention on the particularities of one case, or a number of cases, within a bounded system (Creswell, 2007). A 'case' can refer to a single person, an organisation, or a system or circumstance.

Authors such as Lloyd-Jones (2003), Luck *et al.* (2006), and Creswell (2007) have discussed case study methodology and methods at some length, examining the suitability or not of this design for particular situations and including comparisons of the case study approach to other methodologies. With the exception of Graneheim *et al.* (2001) and Geering (2007), many recent sources on case study research draw heavily on Stake (1995; 2005) and Yin (2003b; 2003a). On occasion, the work of these two researchers is somewhat uncritically presented as a template for other case study research projects: see, for example, Tellis (1997), or Zucker (2001). Creswell (2007) and Lloyd-Jones (2003) are examples of authors who draw on the work of Stake and Yin while clearly contributing their own perspectives.

3.2.1 Characteristics of case study methodology

Although case study research can take different forms and vary in some points of design, there are certain characteristics that are common to all case study designs. I will describe these commonalities before focusing on Stake's (1995; 2005) approach. Case study research focuses on *one case* or a *small number of cases*. The case or cases are investigated through detailed, in-depth data collection from multiple sources of information in order to shed light on an issue or phenomenon of which the cases are recognised examples (Yin, 2003b; Creswell, 2007). Geering (2007), provides a useful metaphor in the opening chapter of his book:

'There are two ways to learn how to build a house. One might study the construction of many houses – perhaps a large subdivision or even hundreds of thousands of houses. Or one might study the construction of a particular house. The first approach is a cross-case method. The second is a within-case or *case study* method. While both are concerned with the same general subject – the building of houses – they follow different paths to this goal....Sometimes, in-depth knowledge of an individual example is more helpful than fleeting knowledge about a larger number of examples. We gain better understanding of the whole by focusing on a key part' (Geering, 2007, p.1) (original emphasis).

Common data collection methods within case study research include making observations, conducting interviews, and gathering artifacts or information from documentary sources. This triangulation of data collection methods, together with triangulation of data sources and engaging in member checking, are typical strategies of maintaining rigour in case study research (Stake, 1995). Investigator and/or theory triangulation can also be used, by either working in teams or asking peers and colleagues from other viewpoints to review aspects of the data (Stake, 1995). Additionally, case study researchers need to provide their audience with enough information for them to be able to judge the validity of the conclusions for themselves (Yin, 2003b; Creswell, 2007). Thick, rich description, meticulous audit trails and explication of the researcher's own views and influence throughout the research are therefore important.

3.2.2 Determining good fit between paradigm and methodology

As mentioned previously, the two main influences in this field have been Stake (1995; 2005) and Yin (2003b; 2003a). Yin's methodology was initially attractive to me, as a beginning case study researcher, because he offers a fairly prescriptive, step-by-step approach. But Yin's assumptions, although unstated, do not appear to match with mine: his approach seems not to value the viewpoint of the participants. Yin explicitly avoids a discussion of philosophy or paradigms, as is characteristic of research located in positivist or post-positivist traditions (cf. Guba and Lincoln, 2005). Furthermore, in his discussion of data collection, Yin warns about the inaccuracies inherent in interviewing people and the dangers of relying on one or a few informants who may exercise a subtle interpersonal influence over the researcher. I felt that Yin's methodology would encourage me to search for 'the one truth' about living in a nursing home as a person with communication deficits, while being careful not to let the opinion of my informants cloud my empirical, researcher's judgement. For these reasons I rejected case study methodology as presented by Yin (2003b) as a suitable approach to be guided by in my research.

Stake (1995; 2005), in contrast to Yin, gives less hard and fast rules. Stake discusses, however, epistemology and ontology, and the ongoing interpretive role of the researcher within case study research. He names subjectivity as an 'essential element of understanding' (Stake, 1995, p.45), and acknowledges the resulting need for reflexivity and intellectual effort in order to reduce the risk of misinterpretation or misrepresentation. I was attracted, moreover, by an imaginative element in his work. Stake refers not only to social scientists and researchers when supporting his arguments, but also to artists in the worlds of literature and music. When discussing data analysis and interpretation he accentuates that there are creative processes at work as a researcher tries to understand behaviour, issues and contexts, in the search for meaning. I felt that Stake's methodology fit well with my research paradigm assumptions. There was also a degree of resonance with the topic, my identified research issue. I anticipated having to be creative in my data collection strategies and to engage all my senses when working with people who were not easily able to communicate. Case study methodology as described by Stake (1995; 2005), would value these efforts to emphasize the particularity of the case, and the collaborative process of data generation.

3.3 Stake's conceptual approach

Stake (2005) describes three different forms of case study research. Firstly, if the primary goal of the research is to learn about the case itself, and not about other cases or some general problem, then the researcher conducts an *intrinsic case study*. In this form the case itself is the focus of learning. As he acknowledges, Stake (2005) is something of a lone voice in ascribing value to the intrinsic case study, but he considers the study of a single case, in order to learn about that case, to make a

worthwhile contribution to knowledge in its own right. The second type of case study described by Stake is the *instrumental case study*. Here, the goal is to learn something about an issue, a larger number of cases, or a general problem. It is hoped that by paying attention to the particular and ordinary features of a specific case, that some understanding will be gained about the wider issue. When 'there is even less interest in one particular case, a number of cases may be studied jointly in order to investigate a phenomenon, population, or general condition' (Stake, 2005, p.445). This is a *collective case study*. Here cases are chosen because it is believed that understanding them will lead to a better understanding, or perhaps a better theorizing, about a still larger collection of cases. In collective case study, the individual cases may or may not be known in advance to exhibit similar characteristics.

As the issue I was focussing on concerned a large 'collection of cases', and I was hoping to learn about a larger phenomenon through the investigation of several individual cases, my research project can be identified as a collective case study.

3.3.1 Issues

One of Stake's key devices for the conceptual structuring of case study research is the organisation around issues, or areas of concern, as mentioned in Section 1.3. Issues pull attention to both ordinary experience and disciplines of knowledge, and are usually complex, situational and involved with problems or constraints (Stake, 1995, 2005).

3.4 Concluding remarks

In this chapter I have introduced and discussed the research paradigm in which I have situated this research, and demonstrated that collective case study methodology is a good fit for both the research aim and the chosen paradigm. I have outlined the methods commonly used in case study research. Stake's three forms of case study research have been introduced, so too the important role he assigns to the identification of issues.

Chapter 4: DATA COLLECTION AND ANALYSIS

Textbox 4.1: Conditions of Ethical Approval

- I was permitted to make notes from resident dossiers and nursing handover sheets, but not to take photocopies or remove them from the relevant unit.
- I was explicitly refused permission to make video-recordings.
- If photos were taken of, or by, participating residents in the course of data collection, I could not include copies of the photographs in the final report, even if permission was granted by the resident.
- It had to be clear to both staff and residents in which role I was operating at any given time. I would be seen to be operating in my usual role unless I put up a notice on the unit (or in the room where I was observing) and wore a badge stating that I was present as a student researcher at that time.

This chapter is concerned with the ways in which I applied the theoretical principles presented in Chapter 3, during the course of my research. I begin by explaining how I gained access to the research site and participants. I then discuss the ethical challenges faced. While presenting the methods used to collect data in this study, I give special attention to the creative communication strategies used during interviews and conversations. My approach to data handling, and issues of rigour and reliability are also discussed.

4.1 Access to the site and participants

As explained in Chapter 1, I worked in RC as the co-ordinator of the practice development unit, and I was reasonably well known to many of the residents, as well as the staff. As mentioned in Section 1.2.1, stakeholder groups had expressed a wish to know more about the opinions of residents who were not well represented in existing forums. These forums were the Resident Council, work-groups or committees. Neither were the opinions of residents with communication difficulties gathered in satisfaction questionnaires, externally administered to comply with external audit requirements. When I suggested a small project focusing on the daily experiences of residents with communication difficulties, the idea was well received by members of the different stakeholder groups within RC.

Formal permission and ethical clearance (see also Section 4.2) was obtained by providing written and verbal information about the proposed project to the Resident Council, the Employee Council, the location manager and my colleagues in the Management Team. This included meeting with the various

groups and answering their questions. After stipulating certain conditions, permission was formally granted by the location manager and chairpersons of the two councils (see Appendix B, for an English translation of the written permission). The conditions under which the approval was given are listed in Textbox 4.1.

4.2 Ethical considerations

I complied with the conditions as listed. There were, however, other ethical aspects which needed my attention. These issues are discussed below.

4.2.1 Absence of ethics committee

Small qualitative research projects are not covered by the Research with Human Subjects legislation in the Netherlands (Ministerie van Volksgezondheid, 2006). The organisations in which research occurs, and the researchers themselves, must ensure they comply with ethical principles of research. The nature of the conditions imposed by the people within RC who reviewed my proposal indicated to me that they understood many of the ethical issues and potential problems that could arise.

4.2.2 Vulnerability of primary participants, the 'cases'

The participants formed a vulnerable group. They knew me, they were dependent on the organisation where I worked for care, and they were not used to standing up for themselves. I felt a strong sense of responsibility to make sure participants were treated well, came to no harm and that I represented their stories correctly. I had arranged with RC's counsellor, psychologist and spiritual support worker to be able to refer participants to them (via regular RC procedure) if this should be necessary and if the participant had given permission for this.

Participants who knew me may have consented because they didn't want to disappoint me. For this reason I specifically didn't invite the three residents with whom I had regular contact, to participate. Of the eight residents who were invited to participate, three declined.

Residents may also be vulnerable after the study has been completed, as their experiences may be recognised by other people in the setting. This recognition could lead to negative consequences for the resident. This danger has been addressed through disguising identifying details that have not changed the significant features of participants' experiences. In addition, it was not widely known throughout the organisation who precisely participated as a 'case', because I gathered data in many situations and not just in the company of the primary participants.

4.2.3 Vulnerability of secondary participants

Secondary participants also participated in interviews or were observed. The same consent procedures were therefore used with these participants as with primary participants (see Section 4.2.4.).

Other people in RC, who were not participants in the study but who could well be present in situations that I was observing, could also be vulnerable. I managed this ethical concern by well publicising the project and the conditions under which I had received consent. I ensured that members of all major stakeholder groups were represented in the ethical approval process. I gathered data openly, hung up a sign in the area and wore a badge saying that I was doing so. In addition, I announced it to those present when I arrived. I answered any questions that people asked and let them see what I was writing if it involved them (although very few people asked to see this.) If I observed a particular interaction which stood out, or had a conversation with someone, I explicitly asked their permission before using it.

4.2.4 Consent: written and process

I approached potential participants, both 'case' and 'non-case', and gave them information about the study in both written and verbal form. If they were interested I made a follow-up appointment,

with family members present if necessary. People who agreed to participate then signed a consent form.

I viewed the gaining of written consent as the start of the consent process during this study, not the end. As has been discussed by many authors (e.g. Gerrish, 1997; Harris and Dyson, 2001; Maijala *et al.*, 2002; Clarke, 2006) consent in such a study as this must be a process. The effects of participation on the participant cannot be fully anticipated. Participants may want certain aspects of their experience to be excluded from the research, and this may change over time. I dealt with this by checking, periodically, with participants, whether they were still happy about participation in general, and in relation to specific events. Two examples below illustrate my approach to process consent.

Marita, initially included as one of the cases, had severe receptive and expressive dysphasia. She was almost completely silent. I was not convinced that she understood the implications of participation and could not check this with her to my satisfaction. In such situations, in the Netherlands, it is usual to acquire consent from the next of kin (Ministerie van Volksgezondheid, 2006). I did this, but the conversation seemed very short, the relative had few questions, and I learned that this family member only visited once or twice a year. I was not convinced that the relative had Marita's best interests at heart, or even if they knew what she might have preferred. So I decided to err on the side of caution and stop her involvement in the study, explaining my reasoning to her.

The second example occurred during the course of the research. Anja changed the nature of her consent several times. To begin, she was happy for me to observe episodes of care involving her and the nurses. But before one of these episodes had taken place she had reconsidered and let me know (by pointing to my bag, indicating the A4 coloured cards with word lists, and looking for the list with the elements of consent on it) that she didn't want this to happen. She also withdrew consent for me to look at her dossier. At a later date, after some of our conversations had moved to a deeper level, she took her old medical history notes out of the safe in her room and gave them to me to read. After that she indicated that I could also look at the rest of her dossier. This illustrated to me that Anja both understood the nature of process consent, and was happy to tell me 'no' and to change her mind, trusting that I would honour her wishes.

4.2.5 Issues of representation

It was important to me that I represented the participants in ways that promoted and valued their contributions and their ways of contributing. I showed these values-in-action by creating ways for them to influence the conversation topics and direction and by discussing with them how they wanted to be represented in terms of their identity being disguised through the use of pseudonyms.

In Chapter 5, I will describe some of the particular communication difficulties experienced by the residents, and the challenges these presented, but I will generally represent their speech and our conversations without showing all of the halting and stopping. I made this decision because it is the message they are trying to get across that is important, not the assistance that they needed getting the message heard.

I checked frequently during data collection that I had understood a participant correctly, and that they were happy with the way in which I had written something down. Where possible, I also engaged in member-checking after I had begun aspects of the data analysis.

Finally, I have made an agreement to return and present a summary of the findings, in Dutch, to whichever participants are interested in hearing them.

4.2.6 Data handling and storage

Data storage was in password protected computer files. No real names were used anywhere. I took my field notes and journal home every night and took care not to leave them where someone could read them inappropriately. I generally wrote field notes and interview notes in Dutch. This enabled member checking, but was also important in relation to not making the respondent feel vulnerable. When writing in Dutch, the people I was writing about would have the opportunity to understand what I had written, if they so wished. Another issue related to translation from Dutch to English. I was doing this myself as I work and live in the Netherlands and speak Dutch. However, sometimes I wanted someone else to check that I was on the right track. I did this with native Dutch speakers who also spoke English fluently by showing them excerpts of data without any identifying features.

4.2.7 Uncovering dangerous practice or witnessing unethical behaviour

This ethical issue is one that every researcher in the field faces. It was essential to think about my possible responses if I was to witness dangerous or unethical practice or behaviour. I made it clear during my research that while I was not looking at reporting the ways individuals practiced, I would have to take action if I saw something dangerous or unethical. I was prepared to step out of researcher role and into nurse or coach role if necessary. I queried situations of questionable practice in the conversations I had with people, although I did not witness outright dangerous practice.

4.3 Identifying residents and inviting them to participate

4.3.1 Approaching participants

I needed to identify participants from whom I was able to learn, so I approached seven residents who were deemed by me and colleagues to be able to communicate in some kind of 'othered' way than language, for example with gestures and a spelling sheet. I also approached the family of one client who was not able to communicate at all, due to his very low level of consciousness, as I was interested in including him as a contrasting case. I concentrated my explanations and requests for participation on the residents themselves, as I believed I would be able to create a process consent method that would be participant centred. I recognised, however that some of their families needed to be cared for too, in relation to their concern for their relative. In these cases I asked for their consent too. It was not my intention to seek proxy consent, except in the one case described above. His family gave consent for me to include him in the study. Four other residents also agreed to participate. This made a total of five resident participants, or cases.

For reasons explained in Section 4.2.4, I only completed data collection for four of the participants. Thus, although all five participants are presented here, findings from only four cases will be presented in the next chapter.

4.3.1.1 Typical cases: Marita, Evelien and Jim

These participants had communication problems caused by stroke and accidental injury (thus acquired brain injury), among the most typical type of problems seen in long term care. All have a degree of receptive and expressive dysphasia.

4.3.1.2 Contrasting case 1: Anja

Anja's is a situation in which there are only problems of a physical nature disturbing communication. Anja's tracheostomy disturbs her speech, and a gross intentional tremor and spasticity disturb her use of alternative communication strategies.

4.3.1.3 Contrasting case 2: Martijn

Martijn's situation is one of someone unable to communicate with others at all. We have no indication that Martijn understands our attempts at communication. We are not able to adequately understand or interpret his 'communication' with us.

4.4 Data collection methods

In this study, I collected data via observation (generally participant, but sometimes almost non-participatory), interviews and conversations, and I collected documents that had been produced within the organisation, originally for another purpose. Over a period of seven weeks in 2007, I collected data from the residents participating as cases, and from other participants and documents. These last two sources provided information about the 'cases' and the context. Table 4.1 summarises the data collection methods used and shows how often, and in what circumstances, each method was used.

Table 4.1: Data collection methods

Data collection method and explanation	Situation in which data collection method was used	Number of episodes or items	Time spent
Non-participant observation <ul style="list-style-type: none"> I was overtly present, in the setting being observed, but I didn't interact with the people being observed except to introduce myself, explain the purpose of my presence or to answer questions. 	Reception area	2 episodes	1 ½ hours
	Recreation and meeting hall	2 episodes	2 hours
	Atrium West/ Atrium East (aspects of all three West- or Eastside units visible respectively)	2 episodes	2 hours
Participant observation <ul style="list-style-type: none"> The level of my participation varied from social interaction to full participation in, for example, an episode of nursing care. 	Participating residents (while they were alone or interacting with one or two other people)	27 episodes	11 hours
	Participating residents (while they were participating in a group activity)	7 episodes	5 hours
	Nursing-handover (on all units)	10 episodes	5 hours
	Dining room (on 3 units)	4 episodes	4 hours

(Table 4.1 is continued on next page)

Table 4.1: Data collection methods (continued)

Data collection method and explanation	Situation in which data collection method was used	Number of episodes or items	Time spent
Interviews or conversations <ul style="list-style-type: none"> Either scheduled (interviews) or opportunistic and more informal (conversations). 	<i>With</i> participating residents (the 'cases'), 1-to-1	25 episodes	15 hours
	<i>About</i> the participating residents (talking to staff or family members), 1-to-1	31 episodes	14 hours
	With staff, not specifically related to the participating residents	6 episodes (but talked to 10 staff members)	5 hours
Documents <ul style="list-style-type: none"> (The time noted is the time spent collecting data from the document, either making handwritten notes or, where permitted, making photocopies.) 	Documents produced for internal use, resident specific (eg, resident dossiers, written handover sheets)	10 items	8 hours
	Documents produced for internal use, non-resident specific (eg, organisational policies and procedures)	7 items	1 hour
	Documents produced for external use (eg, publicity, newsletters)	12 items	1 ½ hours
TOTAL:	Episodes of data collection	116 episodes	
	Items of documentation	28 items	
	Hours spent collecting data		75 hours

4.4.1 Collecting observational data

When making observations in which my level of participation was low, I took rich field notes, noting time, smells, sounds, environment as well as recording descriptions of interactions and dialogue. During participant observation I was usually less able to take detailed field notes at the time. I wrote them up as soon as possible afterwards, usually on the same day, and often reflected on my behaviour during the activity using my journal.

4.4.2 Collecting data through dialogue

I spent a lot of time talking to people. Some of this ‘talking to’ took the form of semi-structured interviews, where I had a list of questions already prepared in my mind. Sometimes a conversation grew out of a shared experience or episode of care, quite spontaneously. At other times I planned an interview or conversation to take place directly after an observation-of-care episode, or directly after attending an activity. I did this to enable me to ask questions about what I had just observed. At all times, I was aware of, and recorded, which mode of talking and asking questions I was using.

During planned interviews, I generally took notes during the interview, then wrote the interview up directly afterwards or at the end of the same day, fleshing out the notes, with my observations, for example, of body language. I often showed the person being interviewed what I was writing during the interview, asking them to alter or add to what I had written down. The special circumstances of co-creating dialogue (cf. Sundin and Jansson, 2003) are described in Section 4.4.2.1. These situations were usually active for me, limiting the amount of writing I could do at the time.

I did not tape-record the conversations. I had anticipated that even more of the interview or conversation than normal would be occurring in ways that would be not captured, or would be confusing if heard afterwards, on tape. I had applied to be able to video-record interactions, however, permission for this was denied.

4.4.2.1 Co-creating dialogue: development and use of alternative communication strategies

One of the biggest challenges in this study was that the participants, in general, could not easily respond to open questions. They tended to communicate, in everyday life, by responding to closed questions, or some variation of this in which they were given a choice between two answers. If I did this during the research I would be directing the answer by only giving two options. Together with my supervisor and peers, I developed a number of alternatives to improve the way I communicated with the resident participants in this study. This became a very special element of the research, justifying a more detailed handling of it here.

There were four main goals to the use of the alternative strategies:

- Making sure that I understood what the participants were trying to say
- Participants being able to get their message across
- Giving the participants a chance to decide what they would like to talk about
- Creating ways of making room in the conversation to by-pass my assumptions and existing trains of thought.

Two examples are given here of the use of special strategies in the study and they, together with the others, are summarised in Table 4.2.

The first example is of a simple modification to an existing technique. Instead of asking the usual two option question, I began asking a multiple choice question. So to the normal procedure of asking, “Do you want to do ‘a’ or ‘b’? Tap my right hand for ‘a’ and my left hand for ‘b’”, a third option was

added: "...or tap me on the head if it is, 'something else altogether.'" If the participant then chose 'something else altogether' I would have to think of a way to uncover this next answer.

Another example of an 'othered' way of communication was my invitation to participants to take photographs or do drawings/paintings of their experiences of living in RC. Only one participant took up this offer and her paintings are included in the findings (see Figure 5.1).

Although not all the strategies presented in Table 4.2 were used with all the participants, when one or two were used they had the effect of transforming the data collection, particularly when the strategy enabled the bypassing of some of my assumptions. Whichever of the strategies were used, an element of deduction or even guess work from me was still required. This was particularly true if the participant wanted to say something unexpected. Patience and adaptation were needed from both the participant and myself.

Table 4.2: Communication strategies used during data collection to enable co-creation of dialogue

Communication strategy	Anja	Jim	Evelien
Use strategies already familiar to and used by the resident in everyday life:			
<ul style="list-style-type: none"> Spelling sheet (resident spells out words by pointing to letters) 	✓	✓	
<ul style="list-style-type: none"> Speaking-computer pre-programmed with limited number of possible responses (resident chooses by pressing touch-screen) 		✓	
<ul style="list-style-type: none"> Ask closed questions (resident says 'yes' or 'no', or shakes or nods head) 	✓	✓	✓
<ul style="list-style-type: none"> Choice of two options (associate each option with something familiar and visible, resident indicates choice by pointing) 		✓	
<ul style="list-style-type: none"> Lip reading while resident 'mouths' words silently 	✓		
<ul style="list-style-type: none"> Resident uses gestures (hand signals, pointing) 	✓	✓	✓
<ul style="list-style-type: none"> Repeat back to resident what I have understood them to be saying, ask if this is correct or not. 	✓	✓	✓

(Table 4.2 is continued on next page)

Table 4.2: Communication strategies used during data collection to enable co-creation of dialogue (continued)

Communication strategy	Anja	Jim	Evelien
Modify existing strategy to decrease energy required from the resident during conversation: <ul style="list-style-type: none"> Use big A4 sized coloured cards with lists of words that can be pointed to (for example, lists of staff groups, family members, words indicating feelings, words indicating frequencies) 	✓		
	✓		
Modify existing strategy to increase resident control and create chances for resident to direct the conversation: <ul style="list-style-type: none"> Add a third option to the two option question. Third option is always “something other than ‘a’ or ‘b’” 		✓	
	✓	✓	✓
	✓	✓	✓
Introduce new strategy: invite use of other forms of expression to add depth or new direction to the conversation <ul style="list-style-type: none"> Ask resident to think about what they would like to discuss or share with me the next time I come, and to paint or draw a picture of this. (Other option is to take a photo.) Use this as basis for conversation. 			✓
Keep interviews or conversations short (often between 15 & 30 minutes) to reduce fatigue		✓	✓

4.4.3 Collection of documentary evidence

The documentary evidence, summarised in Table 4.3, was the easiest to collect. It was easy to identify and all participants gave permission for me to use information from the resident dossiers. In addition, being an insider to the organisation meant that I already had access to policy and procedure documents, as well as newsletters and copies of articles published externally concerning RC. I had received permission to use such documents for the research. The documents were an important source of information about how the organisation wished to be presented to the outside world.

Table 4.3: Summary of documentary sources and their original purpose

Document	Creator / author	Original purpose of the document and intended audience	Number of items
Resident dossier	Members of the multi-disciplinary team	<ul style="list-style-type: none"> To record and make available to staff all relevant resident-related assessment information and information about care/treatment decisions and progress, over time. Permanent and official record. 	5
Handover sheets	Nursing staff	<ul style="list-style-type: none"> Created daily, one central point where all the nursing staff make notes about what needs to be written in the dossier and handed over to the following shift. Discarded after use. 	5
Vision Statement	Management team	<ul style="list-style-type: none"> Statement of company vision. Copy given to all staff during orientation programme and remains accessible to all staff in their work environment. Available to residents or family if they ask for it. 	1 item
Behaviour Code	Management team	<ul style="list-style-type: none"> Statement of company values and expectations with respect to behaviour within the organisation. Principles apply to both staff and residents. Copy given to all staff during orientation programme and remains accessible to all staff in their work environment. Available to residents or family if they ask for it. 	1 item
Multi-Disciplinary Team Meeting Policy	Management team	<ul style="list-style-type: none"> Sets out expectations and agreements about the purpose of the multi-disciplinary team meetings, how they are supposed to function, and expectations about resident and family involvement. Available to all staff (and residents or family if they ask for it). 	1 item
Care- and Treatment Planning Policy	Management team	<ul style="list-style-type: none"> Sets out expectations and agreements about care- and treatment planning and evaluation within RC. Includes expectations about resident and family involvement. Available to all staff (and residents or family if they ask for it). 	1 item

(Table 4.3 is continued on next page)

Table 4.3: Summary of documentary sources and their original purpose (continued)

Document	Creator / author	Original purpose of the document and intended audience	Number of items
Complaints Commission Summary 2006	RC Complaints Commission	<ul style="list-style-type: none"> • Summary of complaints received and actions taken to resolve them in 2006 • Intended for internal use by management team, but must be made available for external audit. 	1 item
Adverse Incident Commission Summary 2006	Adverse Incident Commission	<ul style="list-style-type: none"> • Summary of adverse incidents and RC's actions in response in 2006 • Intended for internal use by management team, but must be made available for external audit. 	1 item
Staff and resident newsletter / internal magazine	Editorial Group, Location Manager is chairperson	<ul style="list-style-type: none"> • Printed monthly for staff, residents and volunteers. • Intended to be colourful medium to inform readers of events, policy and celebrations within RC, and to share information about staff and residents with each other. • Primarily intended for internal use, but other Citywide Care locations receive a copy, and family's take them home etc. 	6 items
Brochures and publicity material	Management team	<ul style="list-style-type: none"> • General information about RC with which to attract potential residents and volunteers • Intended for external distribution 	2 items
Interviews in external publications	Various	<ul style="list-style-type: none"> • Arranged by Location Manager, with positive publicity for RC as the aim. • Interviews with the location manager, the psychologist and an enrolled nurse have been published in 4 different publications • Copies of the articles distributed among RC staff, volunteers and residents 	4 items

4.4.4 Refining data collection methods and communication strategies

As Stake (1995) reminds us, we cannot understand everything about a case, and we have to be able to choose what we consider necessary to our gaining an understanding of the issues, or the case, during our research. This involves making judgements about what to collect and what, in fact, to ignore. Although I did become more focused over time, generally I struggled with this aspect of data collection. I made a lot of field notes, for example, that were never used during analysis. Finding conversations and dialogue interesting, I would record them, in quite some detail, 'just in case' it later proved to be relevant. This was not, in retrospect, good use of my time. I would have been better to have used my issue statements, or questions, to restrict the data I collected, instead of trying to see how everything that I observed or heard could somehow be made relevant to the issues.

Other aspects of data collection, however, were being continually refined. What worked well with one participant worked less well or was simply not possible with the others. Anja, for example, was not comfortable with being observed, so most data concerning her came from interviews/co-created dialogues. Table 4.4 presents a summary of the resident specific episodes of observation and interview, illustrating how the situations of each participant were investigated by relying more or less on particular methods of data collection.

Table 4.4: Summary of resident-specific episodes of observational and interview data collection

Data collection method	Anja	Martijn	Jim	Evelien	Marita
Observation of resident:		x 5	x 2	x 3	x 2
• while alone or not engaged in interaction	---	1hr 40m	1hr 10m	55m	40m
• during care moment or other one-to-one interaction	x 4 25m	x 5 2hr 40m	x 3 2hr 5m	x 3 1hr 45m	---
Observation of group situations (in which resident is taking part)	x 1 15m	---	x 3 2hr 45m	x 3 2hr 15m	---
Interview or conversation with the resident	x 8 6hr 45m	---	x 7 2hr 50m	x 9 5hr 5m	x 1 25m
Interview or conversation about the resident:	x 4 2hr 20m	x 3 1hr 30m	x 4 2hr 5m	x 8 3hr 10m	x 1 30m
• with staff-member					
• with family-member	---	x 3 1hr 20m	x 3 1hr 30m	x 3 1hr 35m	x 2 20m
Total per resident:					
• Episodes of data collection	x 17	x 16	x 22	x 29	x 6
• Time spent collecting data	9hr 45m	6hr 10m	12hr 25m	14hr 45m	1hr 55m

(Note that the information in each cell shows how many times a particular method of data collection was used with a resident, and how long this took. For instance, observational data was collected on five occasions, with Martijn, when he was alone or not engaged in any interaction. The total time spent collecting this observational data was 1 hour and 40 minutes.)

4.5 Data analysis and interpretation strategy

Guided by Stake (1995; 2005), my chief goal was to make each case understandable, firstly for myself, as researcher, and secondly, for others who will read my work. Therefore, as Stake suggests, and informed by Creswell's (2007) practical application of Stake's ideas, I looked for correspondence, patterns and contradictions among the various sources and types of data. I also followed Stake's advice of comparing ideas that were born from categorical aggregation with those that sprang out at me from the data (direct interpretation). He recommends using both where possible. The practical steps that I took during data analysis are presented in Textbox 4.2 .

Textbox 4.2: Steps Used in Data Analysis

1. **Collection of the raw data** (hand written, often using abbreviations, usually in Dutch)
2. **Typing up** each interview or episode of observation (documents now legible to another, in English)
3. **Preparing the data for analysis** (ordering and storing it, I used a software package, *Atlas.ti*)
4. **Immersing myself in the data**, getting a sense of it, scanning it. (Both on-screen via *Atlas.ti*, and printing it out to have it 'around me')
5. **Describing, classifying, beginning to interpret** (Assign memos, some coding, but not word-for-word in vivo coding. Identifying, grouping, classifying, marking.)
6. **Winnowing / deciding what to focus on** (remembering that I needed to make choices, what, about the case needs to be understood?)
7. **Identifying categories or aggregations of ideas**, also identifying **things that sprang out or seemed significant** (even if only occurring once).
8. **Look for contrasting ideas** and experiences, alternative explanations
9. **Collapsing the categories into themes**, lifting out the direct interpretations that were also supported by other evidence, into a theme or significant idea

Working through these steps, often in a much more cyclical fashion than is represented here, I tried to keep foremost in my mind, the following questions: What is the data telling me about the issues I have focused on as a researcher? What new issues, that I hadn't previously considered, are being presented by the data? What do they tell me about the 'case' (participant) and how she or he interacts with or struggles in the context?

4.6 Rigour and validity

The principle strategy for ensuring rigour in this study has been triangulation, both of sources of data and of data collection methods. This meant that the same event or issue could usually be examined from a number of different perspectives. The second strategy was member-checking. This was frequently employed during the seven weeks of data collection, and for the first five weeks after data collection was finished. Thirdly, I was supervised, and participated in peer and colleague debriefing, during this project. I was intentionally reflective and reflexive throughout all stages of the project, attempting to uncover assumptions and apply new learning, in a cyclical process. I was guided in this by my supervisor.

I feel that rigour may have been improved if I could have shared some examples of 'raw' data with my supervisor and peers, on video or audio tape recordings for example. This would have been particularly helpful when I was engaging in co-creation of dialogue with a participant, using alternative communication strategies.

4.7 Concluding remarks

In this chapter I have attempted to present the complex procedures of data collection in this project, in such a way that the reader can see what I did, and understand why I did it. I have discussed access to the site, approaching participants and the ethical issues which I have addressed in the study. The

particular methods of data collection have been described, with special attention given to the alternative communication strategies used in order for these participants to be enabled to contribute their own ideas and elements of their experiences. Finally, I have outlined the data analysis techniques I used, and how I worked to achieve rigour.

Chapter 5: FINDINGS

In this chapter I present the research findings. Firstly, the context and the individual participants, or cases, are introduced. I then present the themes that arose from analysis of the cases collectively. Four main themes came to represent the experiences of daily life for the participants in this study; constraining factors, ameliorating factors, beautiful moments, and the espoused theory (cf. Argyris and Schön, 1974) of RC. The interaction of these themes produced the fifth, overarching theme, of *that which goes unsaid*.

Particularly in the latter sections of this chapter, I will be referring to excerpts from the data in order to support my claims. Please see Textbox 5.1 for an explanation of how these data items are referenced.

Textbox 5.1: Referencing of data sources

For ease of presentation, all of the items of original data referred to in this dissertation have been given an item number. A list of all items referred to in this report appears in Appendix A, along with a brief description of how and when the specific data item was generated.

In the body of the dissertation, I refer to the data items in the following way. The item number is represented with 'Itemn'. This is prefixed by an abbreviation which tells the reader if the original data was generated through conversation or interview (Int), observation as recorded in my field notes (Fieldn) or comes from a document (Doc). I have also indicated if the data originates from a journal entry (Jour).

To illustrate, if 'Fieldn-Item4' is written in the text, then the reader knows that the data concerned was collected during observations in the field, and that this is item 4 in the list found in Appendix A. If an excerpt is given from the data item, then I will also include the page number(s) on which the excerpt can be found in the source item.

5.1 Context

The context of this collective case study is the residential care home that I have called Riverside Care (RC). Situated in the suburbs of a large city in the Netherlands, RC is surrounded by quiet residential streets, on the one side, and leafy well planted gardens with a pretty canal running through them, on the other. Within RC there are three wards, each located on a separate floor of the building. Each ward is divided into two units, which all have 22 one-person rooms, arranged in pairs on either side of a bathroom. The bedrooms look out over trees, and either the residential streets or the garden and canal. The assurance of a one-person room is often an important factor when potential residents make their choice for RC (Doc-Item2).

Riverside Care admits adults needing assessment and rehabilitation, or those needing long term residential care. Common reasons for admission include functional decline related to traumatic brain injury, stroke, multiple sclerosis, Parkinson's disease and other neurological conditions⁴. Eighty five percent of the 132 residents in RC are wheelchair dependent and over half experience some difficulties with respect to communication. Additionally, at the time of the research 20 residents

⁴ Potential residents are not accepted onto the waiting list if mental illness, or cognitive decline, are among their major problems.

were dependent on tube-feeding, and nine of these were referred to by the staff as 'coma residents'. Although these residents maintain their own vital functions, including a reasonable sleep-wake cycle, they are otherwise non-responsive, as far as it is possible to tell, to the people and events around them.

Nearly 200 people work in RC. The organisation's stated vision is to provide care that 'focuses on the person' (Doc-Items3-5). According to RC's policies, well co-ordinated medical, allied health and nursing care should occur against a background in which social, emotional, physical and spiritual wellness is actively supported and promoted (Doc-Items5-8).

5.2 The individual cases of four residents

In this section the four participating residents for whom data collection was completed are introduced. The communication challenges present during interviews and conversations will be described, together with any effective strategies the participants and I developed in terms of co-creation of dialogue.

5.2.1 Anja

Anja is a 50 year old woman, resident in RC for two years. She is sharp and alert, a keen observer of the things that go on around her. Anja describes her life before living in RC as 'never smooth' and typified by 'having to take care of myself, emotionally I mean' (Int-Item9, p.5). This pattern has tended to continue for Anja since moving to RC. She has only superficial social contact with other residents and rarely sees her children, of whom she is fiercely proud. She has no contact with her ex-husband.

Anja has an inherited progressive neurological disorder which causes gross muscular tremors. These are worse with purposive movement. She experiences frequent muscular spasms and her gait and balance are disturbed, necessitating a wheelchair. Anja has a permanent tracheostomy due to paralysis of her vocal cords. The combination of tracheostomy, Anja's extremely low tolerance for a 'speaking valve' (cf. Barnett, 2006), the muscle spasms which distort her facial expressions, and the tremors which disrupt gesturing and pointing, make communication an enormous effort for Anja. Communication with Anja is a very physical experience. She 'waves' and 'jerks' about. As Anja often reaches out to touch the person she is talking to, her uncontrolled movements can result in a nudge or even a hefty shove. She generally relies on the lip-reading abilities of her conversation partner, mouthing words and exaggerating their form with her lips. Her face often pulls into a spasm during these efforts to 'talk'. Pointing to letters on a letter-chart and spelling out words is her next preferred strategy, a technique also affected by her tremor and spasms. Sometimes, in frustration, she blocks the tracheostomy for a short time in order to speak in a hoarse, low voice; this invariably brings on a fit of coughing.

Despite these difficulties Anja enjoys contact and conversations with others. When talking with someone whom she trusts and likes she laughs readily, holds eye-contact and waits for the right moment to make a joke or her point, ask questions about the other or share a little information about herself. Anja spends, however, the greater part of her day alone, lying on her bed facing away from the door. Her TV is invariably on, although she pays it little attention. To someone walking past her room, Anja often appears to be sleeping. This is how I found her, in fact, on every occasion on which I had an appointment with her. Anja's description of her activity at these times was 'resting' (Int-Item10, p.3).

The periods of 'resting' in Anja's day were broken by contact with nurses who came to assist her. Once or twice a day she was visited for five to ten minutes by one or other of the nurses who knew her well. They would stop by to see how she was, have a little chat. Anja sometimes ate in the dining room with other residents from her unit, but she arrived as late as possible and left as soon as she could after the meal. 'Giving a nurse a shove is one thing, tipping my coffee on a table-companion quite another', (Int-Item11, p.10) was Anja's explanation for not wanting to spend time in the dining room.

Anja's daily experiences were typified by a routine in which her physical needs were met, and during contact with the people who delivered this care she snatched moments of social contact. Anja usually didn't know who would be coming to help her, or at what time they would arrive. It was not unheard of for the nurse to be called away halfway through helping Anja, leaving her to wait until they could return. Anja had considered her situation as a resident in RC, and had formed some conclusions about aspects of her life. These will be presented, as appropriate, in the discussion of themes.

5.2.2 Martijn

Martijn probably does not know that he has been the focus of my observations and intellectual deliberations for the last few months. Martijn has severe and permanent brain injury following cardiac resuscitation more than a year ago and is described in his medical notes as being in a persistent vegetative state (Doc-Item12). Although he can maintain his own vital functions and his eyes are open, the generally accepted assumption is that Martijn is not consciously aware of himself or of his environment (cf. Beaufort de, 2005). Consent for Martijn's inclusion in this study was given by his father and sister. They visit him frequently, and take him in his reclining wheelchair off the unit, out into the sun or into the recreation centre to be a part of the activities that are happening there.

Martijn's assumed lack of awareness, however, is difficult to establish with certainty because he vocalizes spontaneously. He calls out in a kind of wail or cry that builds in crescendo and then tapers off again. It typically sounds like he is saying 'nee, nee, nee, nee-oh, nee-oh' (Fieldn-Item13, p.2). To listeners in RC, this sounds like the Dutch for 'no, no, no-hoho'. Sometimes the sound of Martijn crying out can be heard on all six RC residential units at the same time. Martijn's vocalisations and other reactions appear random to those around him. Staff involved in his care indicates that he has completed a programme of structured sensory stimulation and observation. The goal was to look for patterns in his reactions, but none were found (Doc-Item12).

During my observations of Martijn and his daily experiences I saw him being washed, dressed, receiving his tube feeding and other nursing cares. This took about an hour and occurred at various times of the day, or even during the night. The remainder of the day, except for interruptions to change his incontinence pads or hang another bag of liquid food, was spent sitting alone, either in his room, or in a large atrium which forms the general corridor on the unit where he lives. The first time I saw him in the atrium, I nearly walked right past him (Jour-Item14). He was sat among a collection of wheelchairs, hoisting equipment and shower chairs. This equipment had been lined up in rows in front of a big window, at the side of the atrium, out of the way of people walking past. As I walked by, a feeding pump that seemed to be humming caught my attention. I looked more closely. Sure enough, the feeding pump was humming, because it was attached to Martijn's feeding tube and he was sitting there, in his wheelchair, amongst all the equipment.

Although Martijn was not able to communicate with me, and I have no evidence that he was able to understand anything of the time I spent sitting with him, the events of his daily life, as I saw them happening in RC, have added both confirming and contrasting perspectives to many of the themes presented in Section 5.4.

5.2.3 Jim

Jim is a short man. He is also thin. He says that this is ‘very handy’, seeing as he has ended up dependent on other people for almost every aspect of his physical functioning (Int-Item15, p.4). He noted, during the same conversation, that prior to the accident which left him so disabled he had always been frustrated by his small stature. This was typical of our interactions. Necessarily a man of few words, Jim could still get his point across.

Jim is 33 years old. When he was 25 he fell off his bicycle and hit his head. He can now move little more than his left hand independently. Sometimes his left leg moves of its own accord, which throws him off balance in his wheelchair. For this reason Jim sits with his legs fastened firmly to the wheelchair, and with a belt around his hips. He also has a Perspex table top fixed in front of him, on which he rests his right arm and to which he attaches a computerised symbol chart. This computer ‘speaks’ out a phrase after he taps on the chart with his finger. The chart gives a choice of 8 phrases. When communicating about other topics Jim uses a variety of strategies, as presented in Table 4.2.

When discussing participation in the research, Jim’s mother said that she and Jim felt it was an important topic. ‘My son has a lot to say, you know, but people have to be willing to help him say it’ (Int-Item16, p.2). Jim readily consented, although he indicated, ‘I don’t say much since the accident,’ pointing to his head (Int-Item16, p.5). Communicating with Jim was indeed a challenge throughout the project. He could make virtually no sounds at all, so every word that he ‘said’ was produced via a complicated process of me interpreting the clues and hints he gave through his gestures and spelling chart, and him pressing ‘yes’ or ‘no’ on his computer. This was tiring for me, but it was exhausting for him, and our conversations were often short. I had to be very careful not to project my own assumptions and interpretations of his experiences onto him. A breakthrough, of sorts, came when I added an ‘escape’ option; turning the double-choice question into a multiple-choice question. Jim could now tell me when I was on the wrong track. I was not always successful, however, at getting onto the right track. After a series of wrong guesses on my part, Jim would often push the button on his computer which said, ‘Go to the dining room’. This meant, I discovered, that the interview was over!

Jim was experiencing a period of transition during this research. He had lived in another residential setting for eight years. That home had recently closed down, necessitating a move for Jim to RC six weeks before data collection began. Jim was experiencing difficulties in getting to know new carers, and them getting to know him and his wishes.

Although I collected a lot of information about the things that happened to Jim in his day, and we were able to discuss many of these events to a certain extent, the depth and breadth of our conversations remained limited. I found out little of what Jim felt, or what he thought about his experiences. The things I did learn about Jim included his preference for a regular routine, and getting out of bed early. He liked to be helped in exactly the same way every day. He liked to tell people about his hobbies, which were watching football, listening to music, and playing quizzes that had to do with these two topics. He attended nearly all of the organised activities in RC, because his mother made sure his name was on the list for them. Jim wasn’t particularly enthusiastic about any of the activities, unless it had to do with one of his hobbies in some way. He did immediately

brighten up, however, if someone in one of the groups started talking with him. Going to the groups provided the best chance of this happening, and so his mother was very keen for him to keep attending. I was not able to find out what Jim thought of this rationale.

5.2.4 Evelien

Evelien is 73 years old and has lived in RC for four years, after having a left-sided stroke. This left her with aphasia and some memory problems, as well as a right-sided paralysis and neglect. Evelien needs assistance with activities of daily living in varying degrees, depending on the activity and her energy levels. Evelien's verbal answers to closed questions are not always reliable but her non-verbal cues and word emphasis usually make it possible to understand her meaning.

My early conversations with Evelien were somewhat limited. As with Jim, I felt I was influencing her options too heavily by only being able to ask closed questions. Evelien was unable to use either the multiple-choice question strategy or the spelling-chart. I found it helpful to accompany her to activities, using my observations to open up conversation topics later. While watching Evelien in an art group, I noticed that she appeared very certain of what she wanted to paint (Fieldn-Item17, p.2-3). She searched for a particular colour and examined her picture before adding new details. Although our conversations had left me with the feeling that life happened around Evelien, and that she perhaps didn't have much of an opinion about it, her actions in the art group made me reconsider.

Later, I shared with her that I had noticed how particular she was when creating her picture. She smiled, brightened, and nodded emphatically. She opened her wardrobe and poked around until she found a purple jacket. She grimaced, shook her head, said 'yes, yes, no, NO'. I asked if she meant that she didn't like the jacket. She wobbled her head a little from side to side and felt the fabric between her fingers, grimacing again. She then stroked the pale lavender jumper she was wearing and smiled, saying, 'yes yes'. When I asked if she was talking about the different colours, she nodded and smiled emphatically (Int-Item18, p.3). I smiled too. I had discovered something that interested Evelien, something that was important to her.

I told Evelien that I was very interested to learn about what she considered important in her daily life. I asked if she would be willing to paint or draw a picture of these important aspects, and then talk about them with me. She agreed to do this. What followed was exciting, particularly in terms of allowing our dialogue to bypass my assumptions. Evelien painted four pictures, in total, which we discussed during three conversations. The pictures are reproduced, with her permission, on the following page in Figure 5.1. Clockwise from top left the pictures are as follows: Bird on Grass, Tree seen from Window, Bokito the Gorilla, and Dog on Lead.

There are a number of important points to make about this development in my work with Evelien. For ease of discussion, I have presented them under separate headings.

5.2.4.1 The nature of our communication changed

Using these pictures as starting points made our conversations more animated and learnt the interaction a goal that was evident to us both. We were definitely engaged in the co-creation of a dialogue. Having the pictures to refer to did not solve all of our difficulties, of course. The Bird on the Grass and the Dog on the Lead were images that I easily identified. Recognising a tree in Tree seen

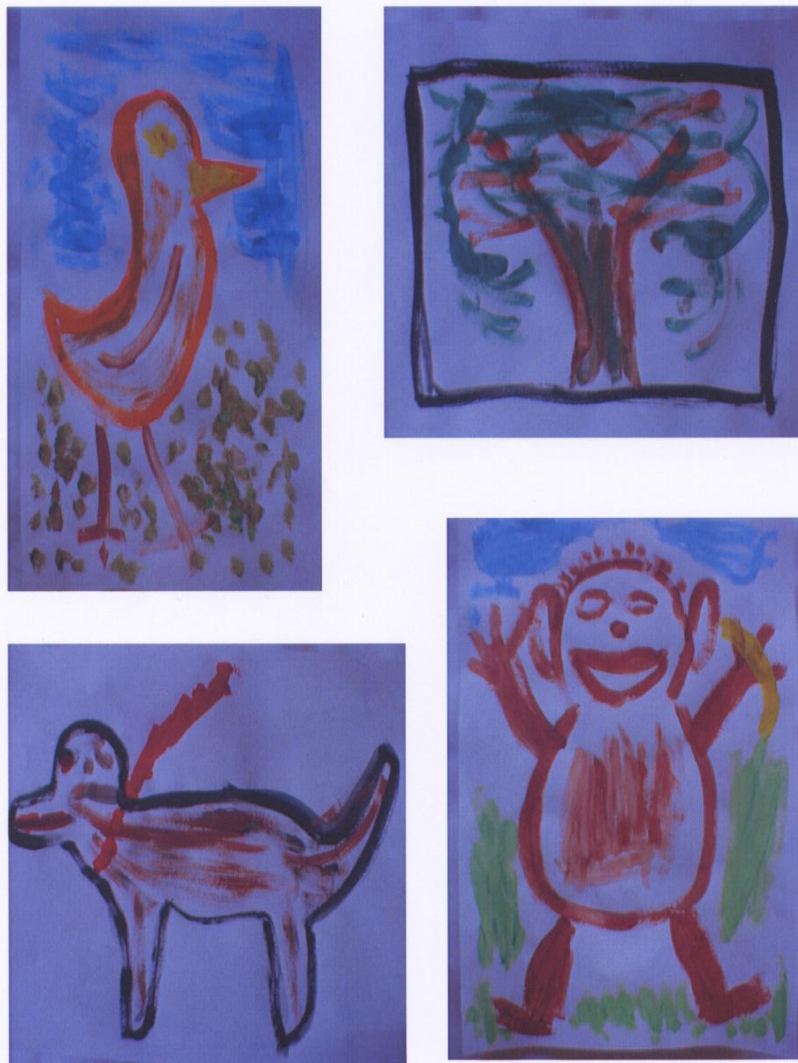


Figure 5.1 : Evelien's pictures

from Window, however, took me some time, and I only realised that the frame around it represented a window when Evelien pointed to a window frame in the room we were sitting in (Int-Item19). I thought, despite the banana in his hand, that the final painting was of a man, perhaps someone in her family. Evelien eventually used gestures, such as scratching under her arms and miming hitting herself on the chest, to help me understand her picture. I am glad she took such extreme measures. The story behind this picture challenged my thinking.

5.2.4.2 I had underestimated Evelien

Some weeks before our conversation, all the Dutch news channels ran a story about a gorilla that had escaped from his zoo enclosure and had injured a member of the public. The gorilla's name was Bokito and he became something of a 'celebrity'. Sometime later, Evelien went with other residents from RC on an outing to the zoo. Her point, in painting Bokito, was that she had seen him on the news and had hoped to get a glimpse of him at the zoo. This hadn't happened and she was disappointed. The entire story took Evelien and I a long time to get straight. But it was a wonderful

process, with both of us laughing, and it made very clear to me that I had been underestimating Evelien and, for example, her abilities to plan and anticipate (Int-Item20, pp.1-12 & Jour-Item21).

5.2.4.3 Evelien was enabled to share her perspective

The other three paintings were of things that Evelien could see in her RC environment. She emphasized that she enjoyed the colours, and she enjoyed the things themselves. I had frequently seen Evelien sitting, still and quiet, while she was waiting for staff or family to arrive. Based partly on my conversations with Anja, and her reaction to waiting, and my own ideas about how people may experience waiting, I had assumed that these periods were experienced negatively by Evelien. She had seemed bored, to me, with nothing to distract her. But Evelien, using her pictures, now described those periods as time she spent *watching* (Int-Item19, p.5). She watched the birds, she watched the dog that came in with a visitor, and she especially liked watching, or looking at, the trees. Without the use of the pictures, I would not have learnt about this activity that Evelien very much enjoyed, as I would not have thought to ask about it.

5.3 Themes arising from the collective case study

Stake (1995) says that identification of the issues facing a person, and observing how the issues are struggled with, is one of the most important ways in which we can learn about that person and their situation. How do the people, or the cases, do battle with constraints and cope with the problems present in their world? Most of the themes that emerged from the data in this study, could indeed be understood in this fashion.

The first main theme is the issue of struggling, as a resident with communication difficulties, against the *constraining factors* of the organisation. It is presented in section 5.3.1, and contains four sub-themes. The next main theme, called *ameliorating factors*, concerns elements which made coping with the constraints easier. This theme contains five sub-themes, presented in section 5.3.2. The third main theme was neither an issue nor a coping strategy. Instead it was a particular sort of interaction observed to occur. I've called these interactions the *beautiful moments* of the study, and they are described in section 5.3.3. The fourth main theme, that of RC's *espoused theory of person-centred care* emerged from the context, rather than from the cases themselves. The interaction of this theme, however, with the daily experience of the participants produces a sub-theme in this section. Finally, in Section 5.3.5, the major unifying theme, or essence of the experiences of daily life in RC as experienced by these residents, is presented. This essence is called, ***that which goes unsaid***.

5.3.1 Constraining factors (organisational norms and routines)

All four participants experienced four issues, or constraining factors, on a daily basis. These are *waiting*, *vulnerability*, *unmet need* and *uncertainty*. Outside the context of organisational norms and routines, none of these experiences would have been accepted or considered normal. But within this residential context, these issues, which were sometimes the defining elements of a resident's day, are seen as normal and acceptable.

5.3.1.1 Waiting

Waiting for care and receiving care, waiting for assistance and receiving assistance. Although often disjointed, this could almost be described as the rhythm present in the lives of the research participants. This theme was illustrated in many ways. In all my periods of general observation in RC, I observed at least one resident, and often whole groups of them, waiting. Jim, for example, before going swimming, was sent to his room to wait for help with his things. Then he was sent downstairs

to wait for the taxi, together with the other residents. After the taxi arrived, there was more waiting while everybody was 'loaded in' (Fieldn-Doc22, pp.11). This experience was very typical. My observations of the nursing handover also added to this theme. The call-bells invariably buzzed at least once or twice during handover, sometimes much more often. The most common response that I heard from a nurse was, 'You'll have to wait a wee minute. We'll be there soon'.

This theme was viewed by family, staff and residents alike, as an inevitable part of life in a communal setting.

'It's too bad, but there is nothing for it. I've only got one pair of hands. We can't physically manage to help everyone at the same time' (Int-Item23, p. 2).

Because it was seen as ordinary, it was rarely looked at critically. For the residents in my case studies, having to wait was more related to being dependent on others than to not being able to communicate. Nevertheless, it was a daily experience for them all.

5.3.1.2 Uncertainty

The theme of uncertainty was identified in the experiences of all four participants. Generally speaking, the residents never knew anything for certain. Even if the routines of RC become the routines of the residents, the residents never knew exactly (or even roughly) at what time a particular care event would happen, and they did not know which staff member would be helping them. This could even change during the care event itself. Group events, such as the music and art group, were less affected by uncertainty, but mealtimes were vulnerable to staffing problems and breakfast could be particularly chaotic if there were less staff than usual (Fieldn-Item24, pp.2-6).

Observations made of Martijn's care moments displayed the uncertainty, and a lack of regular routine, in the most extreme form. The time of his morning care varied from 04.30 am through to 11.30 am, or even after lunch. The routine during care changed too, according to who was giving the care. People often came in and out during the care episode, or the nurses might 'swap' halfway through (Fieldn-Item24, p.14).

When I asked Anja how she coped with the uncertainty, initially she had no answer for me. In a subsequent interview she indicated that she had been thinking about the question and had decided that 'not looking forward to anything' prevented her being disappointed. She explained that this left her free to enjoy social contact and conversations when they happened, but helped protect her emotionally from the aspects she felt she had no control over (Int-Item26, pp. 6-7).

5.3.1.3 Unmet need

The focus of care for these participants was their physical needs, although not all of these were consistently met. Evelien, for example, often got urinary tract infections that were noticed by her daughters before they were noticed by the staff (Doc-Item27; Int-Item28, p.4). Social, emotional, spiritual and occupational needs were not systematically identified within RC and therefore generally went unseen and unmet. This included, for all the participants, anything but the most rudimentary mention in their dossier about their communication difficulties. I found this so difficult to believe that I asked one of the nurses if they had a special folder anywhere, detailing the particular communication strategies which helped individual residents to communicate! There wasn't one (Jour-Item29).

Anja experienced unmet social and emotional needs on a daily basis. Furthermore, over the last six months she had experienced steady weight-loss related to worsening swallowing problems; worsening tremors had made independent mobility scooter use unsafe; and she no longer wanted to accompany staff on trips to the shops. The stated conclusion, however, of the last multidisciplinary

team meeting, was that 'Anja's condition is stable and she has adjusted well to life in RC' (Doc-Item30).

Having communication difficulties made it much less likely that unmet needs would become identified or dealt with, especially when the communication difficulties themselves numbered among the areas that were not adequately addressed in RC.

5.3.1.4 Vulnerability

Vulnerability refers to being at risk; at risk of having needs that remain unidentified, at risk of being misunderstood, at risk of being mistreated or ignored. Although this theme is similar to unmet needs, it is not quite the same. I classified experiences such as Jim's, when he was sitting by the reception desk for an hour, alone, with no one talking to him because the people around him assumed he was 'a vegetable' (Fieldn-Item31, pp.9), under vulnerability. Anja explained very clearly how vulnerable she felt when an unknown nurse came to help her in the shower, and she became scared that the person would not know how to keep the water out of her tracheostomy (Int-Doc9, p.6). For the residents in this study vulnerability was clearly exacerbated by not being able to easily communicate. They were easily misunderstood, even when the conversation partner had good intentions. If the nurse or visitor wasn't interested in finding out what the resident wanted, or didn't pay attention to non-verbal cues indicating anxiety, for example, then the participant could do little to remedy the situation.

5.3.2 Ameliorating factors

Almost as immediately apparent as the struggles or issues faced by the participating residents in their daily experiences, were a number of themes that I came to group together as ameliorating factors. These were the ways in which the residents coped, or the ways in which other contextual factors made the constraining issues more bearable.

5.3.2.1 Family

Family involvement was associated with positive experiences for the participants, in terms of meaningful social contact and also in terms of making sure the best care, under the circumstances, was achieved. Both Jim's and Evelien's busy activity programmes were co-ordinated by their family. Although recognised in theory, by the staff, that family involvement was beneficial, the actions of dedicated family members were often viewed by the staff as difficult and irritating. Evelien's routine, for example, was the most structured of all the residents participating in this research. Both staff and family attributed this to the efforts of her children. Staff expressed irritation at the level of influence her family exerted, and Evelien's family were aware of the tension too. One of her daughters said, however:

'That is the least of my concerns, what the staff think of me. My concern is my mother, and her quality of life. She needs regularity and a routine she can count on. What's more, without being ready on time she can't participate in the goings-on and the social occasions in RC. And isn't that the reason they run the activities? So that residents can enjoy them?' (Int-Doc32, pp. 3-4).

In contrast, Anja experienced the lack of family contact as a gap in her life. She missed family contact, longed for it in fact. When she began using the opportunities to direct the conversation, she always used photo's of her family and particularly her children, to begin the discussion.

The ameliorating effects of family involvement on the constraining elements of living in RC were evident with respect to decreasing the resident's feelings of unmet need, uncertainty and, to an extent, vulnerability.

5.3.2.2 Individual staff members

Each participant in this study was observed to enjoy the contact with particular staff members more than others. Some staff members were 'appreciated' by all the participants, but other positive interactions were seen with staff members who didn't seem to have a positive effect on all the residents. Often it seemed to have to do with a 'click' between resident and staff member. During interviews with Anja, she revealed her theory about this variation in the reactions of staff. She said that there were three different kinds of nurses: those who 'got it', those who would eventually learn to understand and those who would never understand what it was like for her (and other residents) (Int-Doc26, p.11). Staff members too, recognised that their relationships with various residents differed, but tended to discuss this from their point of view (who they liked nursing) rather than from the resident's perspective.

The ameliorating effects of individual nurse actions or attitudes, on the constraining factors of living in RC, were evident with respect to decreasing the resident's feelings of unmet need and vulnerability.

5.3.2.3 Organised social and leisure activities

The positive effect of organised social and leisure activities are an example of an experience that did not apply in all the cases; Martijn could not tolerate the stimulation of so many people or the noise, and Anja did not participate in any activities. This theme, however, seemed to 'spring out' of the data collected in the cases of the other three participants. Both group and 'solo' activities, like painting and drawing, created opportunities for meaningful social contact. Issues of communication were less important in this context, where the whole group was engaged in something together. Additionally, people who got to know Jim, for example, in the group, were less likely to assume that he couldn't comprehend what was going on. Evelien, too, participated in many activities within RC. In fact, she went to everything from the newspaper readings to bongo-drumming sessions in the recreation hall. She participated with enjoyment in every activity that I observed, and sought contact with other residents spontaneously. She also sought contact with animals, if the opportunity arose.

Enjoyment in the activities offered by RC was something that a majority of the residents in RC seemed to experience, not just those participating in the study. Stories contributed by residents to the in-house magazine (Doc-Items33-35) were usually written about enjoyable aspects of the activities. I suspected that participation in the activities, then, brought participants with communication difficulties onto a more even footing with the other residents. As an ameliorating factor it helped reduce the feelings of unmet need and being vulnerable.

5.3.2.4 Living in the here and now

This theme was initially far less visible to me than the three ameliorating factors presented above. When I look back at early field notes or interview data, it was present, but I had not recognised it. Living in the here and now was characterised by focusing on and enjoying the present. It was sometimes a necessary result of not remembering the recent past so easily (e.g. Jim), and sometimes a more conscious type of coping strategy (e.g. Anja and her strategy of not looking forward to things in order to avoid being disappointed). But whatever the motivation or reason for it, three of the residents in this study seemed to genuinely enjoy aspects of the here and now, for example, sitting under the shower, feeling the wind or sun, watching nature.

Humour played an important role in this theme. Jim tended to laugh at jokey looking hats, or funny haircuts, and Evelien would laugh at the antics of birds or dogs, for example. Anja, on the other hand, often made jokes about her situation, and the state-of-the-world, and could see the funny side in a broad range of situations. Regardless of the cause of the humour, laughing, especially with someone else, imparted a feeling of goodwill.

This theme helped the participants to cope with uncertainty and it helped decrease their unmet need of meaningful contact. It was also always a factor in the experience of beautiful moments (described in Section 5.3.3).

5.3.2.5 Being known by the other

This theme varied in extent, or depth. Sometimes it meant simply that the resident, and their routines, were familiar to the staff member. This removed the need to try and explain on the part of the resident, or for trial and error on the part of the staff member. Having likes and dislikes known, for example, decreased or even temporarily removed the experience of uncertainty for participants. Feelings of vulnerability and having unmet needs were also ameliorated when the staff member knew even small details about the participant, for example, where they liked to sit. It was important for Anja, most explicitly, in terms of tracheostomy care.

Although this theme was spoken of by family, staff and residents, much of the evidence I saw of its importance was when it was *not* present and I missed it. Jim was experiencing *not* being known, due to recently arriving in RC, and longed for the day when the nurses had 'got to know' him properly (Int-Item24, p.5). Anja had a particular (English) softdrink that she liked, but she could never make herself understood to nurses who didn't already know that spelling out 'E-L-D' meant a request for elderflower lemonade.

Being known by the other could also mean that the participant them self, and not a particular difficulty, could take centre stage. On these occasions, being know by the other described an interpersonal connection between resident and staff member, where the staff member seemed, without any effort at all, to 'see' the resident first and foremost as a person. In these situations, humour came into play much more quickly and more non-instrumental touch and eye-contact was used. Such a sphere was necessary in order for a beautiful moment to occur.

5.3.3 Beautiful moments

5.3.4

I did witness some beautiful interactions and moments. Although not occurring frequently, beautiful moments were characterised by the resident being 'seen' by the other as a person, not as a recipient of care. The interaction itself was of prime importance, even if this proceeded in relative silence. I got the idea of a dialogue – spoken or unspoken. The communication difficulty, or the care need being attended to, seemed to not be the focus, it seemed to be taken care of without much attention being paid to it. The focus was the two people enjoying each other's company. It was indeed a two-way exchange, although the focus was definitely the resident's perspective. When this happened, coping with the issues of daily life fell away. After such an exchange, the resident was always calm and relaxed, often smiling. But that was, unfortunately, the only 'evidence' of the beautiful moments. They were not documented or talked about. None of the participants in the study mentioned them, unless I asked a question about a beautiful moment which I had observed.

5.3.4 Espoused theory of person-centred care

This theme represents the collected group of ideas being ‘sold’ as typical of life in RC. Riverside Care espoused at institutional, professional and individual levels that the creation of an environment where ‘the person’ was the focus, was the aim of RC, so that both staff and residents could be all that they could be. This was espoused in a number of the internal policy documents (Doc-Items2,3,6,8). It was also stated explicitly in brochures intended to attract residents, staff and volunteers (Doc-Items5,38), and in externally published interviews with RC staff, (e.g. Doc-Item4). Staff also raised the person-centred vision in interviews with me, for example,

‘Residents in RC want the same things as people without disabilities. And so that is what we offer them’ (Int-Item39, p.2).

Finally, the monthly in-house magazine published regular interviews with staff, in which they spoke of their motivations for working in RC. These too, were consistent with the espoused theory of person-centred care.

‘We are here to help promote holistic wellness of the residents. That’s why we organise activities that help promote both physical and psychological health, and why we offer support that helps residents make connections and function in a social world, preferably a world bigger than RC’ (Doc-Item40, p.13)

In stark contrast to this, the resident participants in this study never talked about the espoused theory. In fact, the data for this theme arose entirely from documents or conversations with staff. Although actual implementation of the espoused theory was not evident in the experience of participants in this study, the opposite was: a tension existed, therefore, between the theories-in-use (cf. Argyris and Schön, 1974) in RC and the espoused theory.

5.3.4.1 Tension between espoused theory and theories-in-use

In Section 5.3.1.3, I presented the theme of unmet needs. Experiencing unmet need, or any of the themes related to organisational constraints, in the presence of the espoused theory described above, results in a tension. Although this tension was evident in the daily lives of all the participants in this study, it remained almost wholly unarticulated. I will illustrate it here with an example taken from the case of Martijn.

Martijn needed a regular routine, in a stable environment. The following data items were collected from his dossier (Doc-Item12) and during interviews with his family (Int-Item41) and staff (Int-Items42):

- Martijn’s care-plan states that
 - In RC a low-stimulus environment will be provided alternated with controlled periods of sensory stimulation,
 - Martijn’s reactions will be monitored and documented,
 - Martijn will receive structured, regular care that will reinforce a natural sleep-wake cycle and which aims to create a feeling of security.
- Martijn’s father stated that hospital staff and staff in RC told him that RC was specialised in the care of people in a persistent vegetative state, that there would be a controlled period of sensory stimulation but in general a low-stimulus environment, that the nursing care would be regular and structured.
- Interviews with nursing staff repeated the information shared by Martijn’s father.

If taken at face value, this information would give the impression that Martijn did, in fact, receive regular care in a stable environment. The reality, however, was revealed through my field observations and by critical reading of his daily progress notes. As related in Section 5.3.1.2, Martijn experienced very unpredictable care, and his reaction to this care went unmonitored.

Further illustrations can be taken from the theme of being known by the other (Section 5.3.2.5), which is something that people within RC *talked* about all the time. But people often *acted* like it was not important. For example, the nurses frequently sent someone who didn't know Anja to help her with her tracheostomy cares. Despite Jim's mother ensuring that his routines and preferences were clearly written in his care plan, each staff member appeared to be 'discovering' Jim for them self (Doc-Item37).

5.3.5 Unifying theme: That which goes unsaid

As revealed throughout the presentation of the themes, some of the most significant happenings in the lives of the participants in this study remained unsaid, in the usual course of events. Anja's experiences, for example, of increasing social isolation and declining physical health are virtually undocumented. In fact, the opposite is documented; that she is coping well with life in RC. In my initial analysis I had labelled such instances with 'invisibility of the truth' and 'distorted realities'. These are features recognised in the literature as elements which contribute to the perpetuation of theories-in-use (e.g. Senge, 1992).

It was not only the negative experiences, however, that remained unacknowledged in RC. Experiences that made residents' lives meaningful, brought pleasure or contributed to wellness were almost completely invisible in the written record of their care, and untold in things that other people said about them. This was true for the beautiful moments. But it was also true of much simpler things, like Evelien's enjoyment of animals. In an organisation where the espoused theory of person-centred care was truly a reality, such aspects of life would not only be recognised, they would be both articulated and actively facilitated (Crandall *et al.*, 2007). In RC these experiences remained unsaid.

Finally, the fact of living with communication difficulties meant that the participants in this study had to decide, every day, which things they would not say. This was true in their daily lives, but also with respect to the research. The processes of co-creation of dialogue that I engaged in with the participants, although valuable and rewarding, have merely whet my appetite for more. I have had a glimpse of the opinions and meanings of this group of residents. I know, however, that there is an awful lot that they would have liked to say, but which has remained unsaid.

5.4 Concluding remarks

In this chapter I have presented the themes and ideas that made up the findings in my research with four residents with communication difficulties living in residential care. The unifying theme, which related to both the fact of their communication difficulties, and the many unspoken and unarticulated realities present in RC, has emerged as that which goes unsaid.

Chapter 6: DISCUSSION OF FINDINGS

In this chapter, I share how the themes, presented in Chapter 5, interact with each other, enabling deeper understandings of daily life in residential care as experienced by the four 'case' participants. I also compare the findings of this collective case study to the literature. The limitations of the study are presented, before the concluding remarks.

6.1 A visual representation of the findings

While examining the themes in this research, I found a visual image helpful in considering their relationships to each other. The working out of this image, as a painting, has created a metaphor which I will use in this section. The painting is reproduced in Figure 6.1 below (and is described verbally in Textbox 6.1).



Figure 6.1 : Visual representation of themes

Textbox 6.1:
The landscape takes shape

I have painted a scene that begins, at the top, with a blue sky in which fluffy, inviting white clouds are floating. There is also a bright sun shining.

Under the sky is a dry looking landscape with a fair number of boulders and rocks scattered about. There are three green trees clustered together, almost in the middle of the landscape. They look like they would offer pleasant shade in this otherwise dry environment.

In between the land and the sky are some almost transparent wave-like forms coming in horizontally from the left side of the page. Initially two separate strands, they join together creating a more definite looking spiral shape above and mingling slightly with the upper branches of the trees. This spiral shape remains horizontal and

6.1.1 Landscape as metaphor of daily life in residential care

Firstly, the presentation of this painting takes up the challenge inherent in the unifying theme of 'that which goes unsaid'. The challenge for me, as researcher, is to present the findings in a way that articulates, or makes explicit, that which is usually left unsaid.

The inviting white clouds in the painting represent the espoused theory present in the context that is RC: that of person-centred care in which both staff and residents are nurtured to grow and thrive. Up here in the gently cloudy sky the air is moist and the sunshine diffuse. Moving to the foreground of the picture, the rocky hard ground represents the theories-in-use within RC. These theories-in-use were heavily influenced by institutional norms and routines, represented here by the horizon. The dry rocky landscape reflects that the actual focus of care was generally limited to the physical needs of residents, and these were attended to within a schedule in which the accommodation of individual wishes proved difficult to achieve. At its worst this kind of care was experienced as a daily grind of waiting for care and receiving care. Regular features of the daily experiences of participants, represented by the various rocks lying scattered about, are unmet needs, vulnerability and uncertainty. These rocks, or obstacles, are made all the sharper and more difficult to negotiate in the presence of communication difficulties. The rocks, however, are seen as an expected and ordinary feature in the landscape. Their presence is taken for granted and efforts are not made to remove them.

There are three trees in this picture, and they represent three of the ameliorating factors identified in this study as providing leafy, shady relief for residents negotiating this landscape. These aspects are the involvement of family, the positive influence that individual staff members can have despite the routines and prevailing culture, and the benefits of social activities. They are represented by a cluster of trees because they all have to do with social interaction, and they are all visible and widely acknowledged within RC as being important positive features.

The last element of the landscape is the wind. This represents, when it first appears on the left of the page, two separate ideas, both of which were not as solid or immediately obvious during the research as the ideas represented by the trees. The first of the 'winds' is the concept of being known by the other; the participant being 'seen' as a person (not as an object of care) and, in some cases, being able to 'see' the other. The second of the winds represents focussing on and enjoying the present, and the role that humour played in this area for the participants in this study. Both these

strands contributed to making life in this landscape more bearable, like a cool refreshing breeze bringing the promise of rain. Even when limited to 'knowing and respecting the resident's usual routine' and making simple jokes, these elements were both refreshing and reassuring. Sometimes, however, the interaction of being 'seen' by an individual staff member, and the use of humour or otherwise enjoying the present, seemed to take on a very special quality. In these 'beautiful moments' the participant and caregiver appeared, for a short while, to be lifted away from the rocky hard ground and to be gliding above it all, as if on the wind. In their interaction together they floated and danced and the communication difficulty or physical care need of the participant seemed no longer important, it was attended to but out of focus. The focus of the dance was the interaction itself. But, like the wind, these beautiful moments, once they were over, were invisible. Although beautiful, even profound at the time, they were characterised by being unseen. Not articulated and not recorded, they appeared to not be recognised as being of value at all.

6.2 Discussion of the findings with reference to the literature

Many of the themes presented and discussed above echo the themes already found in the literature and presented in Chapter 2.

6.2.1 Daily life constrained

In particular, the dry, stony form that daily life could take for participants in my study, has been found to be true for residents in residential care in studies spanning the last twenty years (e.g. Booth, 1985; Nay, 1998; McGilton, 2002; Bland, 2007). Similarly, the idea that the horizons of these experiences tend to be fixed by the prevailing routines and organisational culture of the residential setting has been pointed out by Jacelon (1995) and others (e.g. Fiveash, 1998; Chenoweth and Kilstoff, 2002).

Perhaps unsurprisingly, the findings of my study show that these issues are certainly relevant to people with communication difficulties living in residential care. The communication difficulties had the effect of sharpening the constraining issues, making them more challenging to avoid or overcome. Sometimes it was as if the unmet communication needs 'trumped' the others, as if being able to talk may have prevented or reduced the misunderstandings or uncertainties. This corresponds with the results of Lemieux *et al.* (2001), who describe participants with communication problems feeling that if they could only talk about it, then their problems (with sexuality after stroke) would be less severe. Whether being able to easily communicate *would* lessen these daily struggles is not, in fact, certain. Residents in Driver's (1997) and Specchio's (2004) studies, for example, could communicate well, yet 'waiting' was still a dominant theme in their lives.

6.2.2 Ameliorating factors

The relief and sometimes pleasure in this landscape were related to significant relationships, interaction with others, and having something enjoyable to do. These themes are also present in the literature as is discussed in Sections 2.1.2 and 2.1.3. Humour emerged as an important mediator, for participants in my study, in enjoying the here and now, but also in coping with difficult situations and feeling like they were being related to as 'people'. This resonates with descriptions of 'laughing together' (Titchen, 2000, p.91) in the context of a person-centred interaction, and confirms the

findings of Isola and Astedt-Kurki (1997) and Astedt-Kurki *et al.* (2001) in their studies into humour within the nurse-client relationship.

6.2.3 Beautiful moments

Special interpersonal moments occurring between nurses and their patients are well documented (e.g. Brown, 1995; Osterman, 2002; Armen and Rehnsfeldt, 2007). Such interactions, and the ways they can be facilitated, are the subject of much practice development literature (e.g. Titchen, 2000; Wright and Titchen, 2003). In general the focus has been about transforming cultures in order to create nursing environments in which person-centred care is the shared goal, and a not unrealistic outcome (e.g. Binnie and Titchen, 1999; Manley and McCormack, 2003). In my study, despite the context leading to tension and constraints, some caregivers were able to transcend this, in the context of their relationship with a resident, and engage in truly person-centred moments (cf. McCormack, 2008, personal communication). Characteristics of these moments were again similar to descriptions arising from Titchen's doctoral research, this time in relation to the concept of 'graceful care' (Titchen, 2000, p.89). They were also similar to moments of 'co-creation' as described by Sundin and Jansson (2003) in their observational study of nurses who were particularly successful at communicating with patients who had aphasia.

6.2.4 Tension between espoused theory and theory-in-use

A mis-match between espoused theories and theories-in-use (cf. Schön, 1987) was very evident in this study, and was in fact defining for the ways in which daily life was experienced. This finding is by no means unique. Braam (2007) recounts similar experiences in two residential settings in the Netherlands, suggesting that the situation may not have improved since Schrijvers (1997) pronounced his critique. Allen (2007) even asserts that such a mis-match is typical of the nursing profession in general. Authors such as Greenwood and Levin (1998) and Senge (1990; 2005), would argue that such a tension being present is not actually the important issue. It is what is *done* with it that is the crucial next step in taking effective action towards the espoused theory. The mis-match must be articulated and examined, it must not 'remain unsaid'.

6.2.5 That which goes unsaid

In some ways this seems a very predictable unifying theme to end with in a study about the experiences of people who cannot easily communicate. In fact, I had naively hoped to be able to conclude that a communicative floodgate had opened! However, in making a start towards enabling people in this situation to participate in research, it has become obvious what a long way there is to go before we can be sure that residents with communication difficulties can also be 'heard'. Furthermore, while the realities of daily life for these participants, and others like them, remain 'unsaid', there will be little chance of improving their situation.

6.3 Limitations of the study

During this study, the risk that I would impose my own ideas or assumptions on the participants and thus on the data remained high. Strategies employed to minimise this problem were reflection and reflexivity on my part, the use of creative communication techniques with participants in order to

by-pass my assumptions, and member-checking during data collection and the beginning stages of data analysis. The last stages of data analysis, however, have not been strengthened through member checking. Additionally, although I have shared my forming interpretations and the eventual results with my supervisor and peers, I feel the study would have been strengthened by enabling some joint analysis of data in the form of video- or audio recordings.

As with all case study research, it is not the intention that this study, involving four participants, be used to draw generalizations about all residents with communication difficulties living in residential care. My detailed description is intended to enable readers to judge for themselves in how far the findings from this research apply to other people and contexts known to them.

6.4 Concluding remarks

In this chapter, the findings of my research have been both visually presented and explained with the help of a metaphor. I have compared the main themes to the literature and the limitations of the study have also been presented.

Chapter 7: CONCLUSION

In this chapter I compare my findings to the stated aim of the research, and examine the issues raised at the start of the study (reproduced in Textbox 7.1). I identify the contributions this study makes to nursing and practice development, and mention possible future directions for research.

7.1 Addressing the research aim and issues

The aim of this study was to illuminate the experiences of everyday life in a residential setting for residents who need nursing care and who have difficulties communicating. This aim has been met with respect to the four participants in this study. As mentioned previously, however, it is but a beginning.

I consider the study to have successfully investigated the issues formulated at the beginning of the research. In terms of the first and second issues, this study not only identified areas of concern but also stimulated real change. Anja's deterioration, for example, silent and unnoticed before the holistic examination of her situation during this research, has been made explicit for her healthcare team and broader assessments are now underway. Additionally, the systematic observations of Martijn's experiences and reactions have led to a more critical appraisal of his care, by both the staff and his family.

Positive elements, mentioned in the third issue, also emerged. The beautiful moments, particularly, were worthy of articulation and celebration, although this is not yet realised outside of this research project. Also worthy of continuation, for Anja, Jim and Evelien, were the strategies of communication developed during the research. Evelien's family, for example, were very excited about using her pictures as beginning points of future conversations. This point also relates to the fourth research issue. It was indeed possible, with fairly simple communication strategies, to begin to discover these participants' perspectives.

Textbox 7.1:

Research issues as stated at the beginning of the research

1. Are there aspects of the current situation, from the participants' perspectives, that are cause for concern?
2. Are there aspects of the current situation, from the participants' perspectives, that demand prompt action towards change or practice development?
3. Are there aspects of the current situation, from the participants' perspectives, that are worthy of continuation, or even celebration?
4. How was it possible to illuminate their experiences of daily life, in order to come to some sort of understanding of their perspective?

7.2 Contributions of this research

Some of the contributions this project has made to the individual participants have been mentioned above. The project has also made a number of small, yet important, contributions to both nursing and practice development.

The constraints and ameliorating factors identified in this study were already present in the literature. They have thus been shown to be relevant to the care of the participants in this study, and perhaps to other residents who are in sufficiently similar circumstances. It also emerged, confirming my suspicions, that having communication difficulties increased the vulnerability of the participants to the 'stony ground', as illustrated in Chapter 6.

Importantly, it has been clearly demonstrated that it is possible to conduct ethical research with residents who have difficulties communicating, to use process consent effectively, and to involve these participants in co-creation of both dialogue and new practical knowledge. Moreover, although Wang and Burris (1994; 1997), for example, describe the use of photos taken by research participants to promote community development, I have not found other instances in the nursing literature where people with communication difficulties have used their artwork, intentionally created, to express and introduce their own ideas into a research project. This may be a unique contribution of this research.

7.3 Questions raised by this research

Designed as a collective, and thus instrumental, case study project (see Section 3.3), actually both the intrinsic and instrumental aspects of this research were significant. The intrinsic elements naturally had the most potential to illuminate the issues facing *individual* participants and bring change in their lives. This did not detract from the lessons learned through examination of the case studies collectively. This raised questions for me with respect to the methodological discussion around case study research. Is it, in fact, important, to choose either instrumental or intrinsic case study design? Could a project be explicitly designed to use the advantages of both forms? Might this be particularly suitable when social justice, for even a small number of people, is among the eventual goals of the project?

Other questions raised were in terms of the topic; residents with communication difficulties. These questions centred around broadening and refining the information already gathered. To what extent, for example, do the experiences of those with communication difficulties differ from residents in the same setting without communication difficulties? Can the experiences of this, arguably more vulnerable group, be used as a reliable indicator of the overall degree of person-centeredness of a particular setting? In what ways does reducing the communication difficulties actually improve the subjective experiences of daily life for this group of residents? And under what circumstances is it possible, for nurses and other staff members, to be facilitated to themselves engage in co-creation of dialogue with residents who have communication difficulties? How does this become a part of everyday, expected practice?

7.4 Concluding remarks

After addressing the research aims and issues, I considered the implications of my research findings for nursing and practice development, both now and in the future. If some of the questions posed above can be answered, perhaps the future of people with communication difficulties, living in residential settings, will contain more that is said, than that which is left unsaid.

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Appendix A

Numbered list of items of original data referred to in this report

Items described here are data that is one step removed from the actual raw data, which was invariably written in Dutch, and contained many abbreviations. This raw data was typed up, as soon as possible after the event, into Word files that were then used for all subsequent stages of data analysis. It is these Word files that are referenced here.

Item Number	Description of event, context, or focus of the data collection	Date of data collection
1	These remarks were overheard in the course of my ordinary work day, before the start of the research and were recorded in my journal.	12.11.06 25.02.07
2	Riverside Care's Year Report, 2006	
3	Riverside Care's Vision Statement	
4	Interview 2 with Riverside Care's Location Manager, published externally*	
5	Brochure: "Living in Riverside Care – Where We Focus on the Person"	
6	Riverside Care's Behaviour Code	
7	Riverside Care's Policy on Multi-Disciplinary Team Functioning	
8	Riverside Care's Policy on Care- and Treatment Planning	
9	Third interview with Anja, discussing life before RC, her reaction to moving to RC, things that bothered her.	26.08.07
10	Sixth interview with Anja, discussing among other things, my observations and beginning interpretations of her experiences.	02.09.07
11	Fourth interview with Anja, lots of discussion about choices that she makes in her day, her usual routine etc	28.08.07
12	Resident Dossiers, Martijn, handwritten notes made	26.08.07
13	Field notes made in the atrium, I was on the first floor but could see quite a bit of the second and third floor wards. Martijn was sitting in the atrium on this day, and his calling out was audible as I came up the stairs from the ground floor.	28.08.07
14	Journal entry made, before the data collection officially began, but it was the first time I remember seeing Martijn sitting in this spot, in this particular way. It made an impression on me and I had recorded it.	27.06.07
15	Third interview with Jim, discussing his life before the accident, and his move from the other nursing home to RC	01.09.07
16	Conversation with Jim's mum, after she approached me and asked if I still needed participants for the study. We went together, during our conversation, to see Jim and carried on talking with him as well. Discussion was about participation in the research.	27.08.07
17	Scheduled observations made of an art group. Reason for the observation was Evelien's involvement, so she was	06.09.06,

Item Number	Description of event, context, or focus of the data collection	Date of data collection
	my focus. It was the first time I saw her actively making decisions, or perhaps, it is the first time I <i>noticed</i> it.	
18	Fifth interview with Evelien, we discussed the observations I had made during the art group.	07.09.07
19	Eighth interview with Evelien, we discussed her picture of the window with the tree. This lead on to a discussion of waiting / watching	17.09.07
20	Seventh Interview, Evelien. Discussed Bokito!	14.09.07
21	Journal entry about Evelien and how our 'dialogue' is progressing. About how I had assumed that her memory / planning skills weren't that good because I hadn't seen her talking about the future / past. Here was evidence that she had seen and followed an event on TV, had hoped to see something of it for herself, was disappointed when it hadn't happened.	18.09.07
22	Observation and some conversation (little) with Jim. He had lunch and was supposed to go swimming. Theme I picked out at the time was how disjointed everything seemed, he was supposed to be doing one thing but ended up doing everything else but that. He started 'getting ready' to go swimming at 1.30 pm, but didn't get into the pool until 4.30 pm!	12.09.07
23	Interview with nurse, after handover.	23.08.07
24	Field notes made on 3 rd floor, breakfast time. Very different to previous observation of breakfast: today there is no ward assistant	04.09.07
25	Field notes made, non-participant observation of morning care for Martijn.	04.09.07
26	Fifth interview with Anja.	31.08.07
27	Resident Dossiers, Evelien, handwritten notes made	
28	Interview w Evelien's daughter. Focus was consent, but she also talked about things that made life difficult for E in RC	30.08.07
29	Journal entry made after not being able to find evidence of attention for communication problems in the dossiers of residents.	27.08.07
30	Anja's resident dossier, handwritten notes	08.09.07
31	Fieldnotes. Observed today, almost non-partic, in reception area and recreation centre. Also recorded some interesting dialogue, in which I had participated.	14.08.07
32	Interview with Evelien's daughter.	17.09.07
33	"Together for Each Other", Riverside Care's monthly newsletter for staff, residents and volunteers, issue number 6, 2007, eg article about Greek Restaurant night	
34	"Together for Each Other", Riverside Care's monthly newsletter for staff, residents and volunteers, issue number 7, 2007, eg article about making meatballs together with the cooks in the kitchen	
35	"Together for Each Other", Riverside Care's monthly	

Item Number	Description of event, context, or focus of the data collection	Date of data collection
	newsletter for staff, residents and volunteers, issue number 9, 2007, eg article about trip to zoo	
36	Last interview with Jim. Quite upset today, as is very frustrated that nurse's still don't follow his routine. Is all he wants to talk about.	23.09.07
37	Jim's resident dossier	
38	Brochure: "Volunteering in Riverside Care – Where We Focus on the Person"	
39	Interview with an activity co-ordinator, after observations had been made during a music group	10.09.07
40	"Together for Each Other", Riverside Care's monthly newsletter for staff, residents and volunteers, issue number 8, 2007	
41	Interview w Martijn's father.	28.08.09
42	Joint interview with enrolled nurse and health care assistant, focus of interview was Martijn and the goals of his care. Also, how it felt to nurse someone who was unable to respond.	27.08.09

Items marked with * are purposefully disguised in terms of title and omitting the source of publication, to protect the identity of Riverside Care and the people associated with it. For this reason these four articles do not appear in the reference list, but have been included here as primary document sources.

Appendix B

Permission to Proceed with Research

English translation of the text on the form granting permission to proceed with research, issued by the organisation known in this report as Riverside Care

To: [Name of researcher]
Date: [24 July 2007]
Category: [Research with vulnerable residents]
Project title: [Daily experiences of people with communication deficits]

We, the undersigned, have considered your request to conduct your research project, with which you hope to [fulfil the requirements of your Master's degree], in [name of the organisation].

We, the undersigned, grant you permission to conduct your research according to the written plan you submitted to us on [16 May 2007] and which you explained to us verbally on [15 June 2007].

Permission is granted as long as the conditions listed overleaf are complied with.

We, the undersigned, reserve the right to withdraw permission if it is noted that in the course of your research

- You deviate substantially from the plan you submitted to us, or
- You do not comply with the conditions we have stipulated, or
- There are unforeseen negative consequences for [name of organisation] or her clients or staff.

Signed:
Location manager [name of organisation]

Signed:
Chairperson Client Council [name of organisation]

Signed:
Chairperson Staff Council [name of organisation]

Conditions

- Client dossiers will not be removed from the units. No photocopies will be made of client dossiers. Handwritten notes are permitted to be made.
- No documentation containing client-specific information (e.g. end of shift reports) may be photocopied or removed from [name of organisation]. Handwritten notes are permitted to be made.
- Video-recordings may not be made.
- Photographs of clients or [name of the organisation] may not be used in final report or articles for publication. This even if client concerned has given permission.
- The roles of researcher and staff member must be clearly differentiated.

- Clients and other staff must be aware when research activities are taking place, that is, permission is not granted for covert observation.