Life-story Perspective on Caring within Cultural Contexts

Experiences of Severe Illness and of Caring

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Division of Nursing

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Vi bär redan en hel del av vår unika kommande ålderdom med oss, när vi går genom livet.

(We are already carrying a great deal of our unique coming old age with us when we are going through life.)

Tornstam, L. (1994, p.51)
Life-story perspective on caring in cultural contexts

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ABSTRACT


People are afflicted by severe illnesses and adversities in life and they practice care privately and professionally in different cultural contexts from the view of their own life-story perspective. Five studies with a qualitative approach were linked together with the overall aim of disclosing the experience of severe illness and caring with a life-story perspective in different cultural contexts. Audio-recorded, transcribed narrative and reflective interviews were analysed with a phenomenological hermeneutic approach. Data were from 34 people living with a stroke in Sweden and Vietnam, five Vietnamese relatives and 29 professional carers caring for people with a stroke in Vietnam, with dementia in Sweden and girls living on the streets in East Africa.

In this study, living with a stroke meant living with a sudden, adverse event that had interrupted the past of the life story from continuing in a similar fashion in the future. Apparently, some interviewees had not integrated the stroke event with their narrative identity and their life stories. They seemed to be confused about what had happened to them. The sensed feelings of living with a stroke in the study from Sweden were conveyed with the use of a metaphoric language. Living with a stroke in Vietnam meant feeling as a weakened thread in the family net. Caring professionally in this context meant collective narrative identity with a view of being assistants, advisers and supporters of a ‘family network’. Carers identified as good at achieving an understanding of people with dementia used maternal thinking emanating from personal experience together with knowledge about each resident’s life stories and the course of the disease. These carers used affect attunement and personal talents. The carers tuned into a resident’s affective state, noticed signs, put these into sentences and stories that corresponded with the narrative identity and the life story of the resident in the caring situation. Professional carers working among girls living on the streets in East Africa felt that they became committed to caring and had motherly feelings when they met with the girls. Caring for these girls meant fighting against the grip of street life, but also experience of satisfaction and hope. It meant experiencing powerlessness and frustration, and the carers felt squeezed between integrated values and the perceived demands from the girls in their meeting with them, whilst conveying visions to the girls of a better future.

Inspired by Ricoeur’s philosophy on language and personal identity, the findings from the five papers indicate that a life-story perspective can serve as a framework for bringing human experience in various cultural contexts and different ages into comprehensible language. This perspective should be useful in professional nursing when caring for people who encounter adversities in life as an afflicted person or relative. It is suggested that a life-story perspective can serve as a framework for professional nursing care that aims at a good quality of care.

Keywords: Caring, nursing, life story, experience, maternal thinking, narrative identity, metaphors, stroke, dementia, living on the streets, culture.
Experiences of severe illness and of caring.

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- Personal identity, severe illness and caring
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ORIGINAAL PAPERS

The dissertation is based on the following papers, which will be referred to in the text by their roman numerals.


INTRODUCTION

Care-receivers', relatives' and professional carers' views on care, relationships and families vary in different parts of the world as they are influenced by traditions and religions (Rarcharneeporn & Dale, 2000). Reasonably, integrated values and caring praxis in relation to family bonds and professional care will affect the understanding of meeting with adversity in life as an afflicted person, as a relative and as a professional carer.

Our world is rapidly becoming a global community with the trends in migration, travel and communication. Nursing has a history of attention to culture and nowadays this attention is demonstrated in the curricular content of nurse education programmes, and health care institutions are increasingly becoming aware of issues relating to language and culture. The efforts made, so far, to increase an understanding between people from different cultures mainly concentrate on the differences in various cultures rather than on the founding communalities shared by all us, for example personal change that takes place when people interact (Duffy, 2002). The subtle communalities in a human life, such as experience and feelings, can easily be shadowed by observable differences in behaviours and languages when people from different groups or countries meet in situations of professional caring.

As humans we are unique persons, steadily changing beings and related to ourselves and to others regardless of where we live our lives. All of us are also undergoing a maturation process that takes place from infancy to old age that changes our views on life and its meaning (Erikson, 1982; Erikson, 1988; Tornstam, 1994; 1999). This view contradicts a common perception of ageing after middle age as a state of deterioration or retrogression to developmental stages, passed earlier. At both ends of our lives, as newborn infants and as very old people we are fragile, vulnerable and dependent on others for our survival and well-being. However, the experiences gained and the maturation processes undergone constitute a significant difference between a very old person and an infant. During adulthood there is, for most people, a period of relative independence, even if we as adult,
autonomous people are fragile and vulnerable, although to a seemingly lesser extent (Bauman, 2000 p. xv). In addition, accidents, serious diseases, or other adverse circumstances can alter our relative independence.

Ricoeur’s (1992) philosophy on our identity and our understanding of ourselves and others has inspired my understanding of our human condition. He suggests that we are bound to live in relationships with others and advocates that we be sensitive toward others’ uniqueness with a responsibility towards ourselves and others. The sensitivity towards the uniqueness of a person makes it possible to respond to the perceived demand and at the same time ground our own uniqueness. It can be presumed that a care receiver, regardless of age and condition, conveys appeals to be understood as a unique person who needs assistance. Caring relatives or professional carers cannot experience their care-receivers’ experiences, but they can utilise their sensitivity towards the uniqueness of the person. The sensitivity guides a caring response to the perceived demands (Lögstrup, 1971; van Manen, 2002; Ruddick, 1989; Roach, 1997). The caring response is inseparable from our nature as human beings, but the sensitivity towards others can be desensitised and thus people can become non-caring (Gaylin, 1979; Roach, 1992).

Language is used for telling stories about the personal experiences we gain throughout our lifetime. This human ability makes it possible for us to understand ourselves and others and to share an understanding of the meaning of our experience with other people (Ricoeur, 1976). In professional caring situations the meaning of the care receiver’s experience should be shared with the care-receivers and their relatives. Such dialogues will both reflect and influence the understanding of the meaning of the experience of all involved. People, who are living with severe illness such as a stroke or Alzheimer’s disease, as well as children without caring parents, are subjected to other people’s willingness and ability to caring for and about them. As some of these people have various difficulties in using verbal language they also depend on other people’s ability and willingness to share the meaning of their experience with them. Assumedly there are family and professional carers who can sense subjective, tacit meanings of their care-receivers’ experience and share an understanding of these experiences as stories. Instead
of comprehensive language they may use figurative expressions that can assist them with tuning in to feelings and promote creative thinking (Gendron, 1994). Comprehensible stories can be developed, altered and mutually agreed upon as being relevant.

**Nursing as a caring profession**

Nursing as a caring profession is founded in a combination of art and human science. The art of nursing is practised when the carers are able to sense the meaning of the care-receivers’ and their relatives’ experience and skilfully perform care to the satisfaction of all involved (Johnson, 1994). Art as understood in everyday language can also be used in caring. For example, music and drama can be used in order to stimulate expressions of feelings (Aldridge, 1996), to achieve a dialogue in caring for people with dementia (Aldridge, 2000) and music can be used to convey and to develop our identity (Ruud, 1998).

Nursing has been described as performing within a relation with care-receivers and their relatives (Lövgren, 2000, pp. 26-29; Watson & Smith, 2002) and it has been suggested that it is undesirable to have one definition. In this thesis nursing care is understood from the perspective of the Swedish concept ‘omvårdnad’, which relates to the task aspects of caring as well as to the relational aspects (Sjöstedt, 1997) that is founded in our mode of being. Caring, as an expression of our humanity, is not unique to any profession, but can be seen as unique in nursing as it embodies qualities and essential characteristics of nursing (Roach, 1992). ‘Omvårdnad’ can be shown in caring episodes that satisfy the care receivers and their relatives. These episodes have an embedded meaning with regard to the quality of the caring performance (Asplund, 1994; Szebehely, 1996) and of the caring relationships (Roach, 1997). Good quality in caring involves a carer’s attitude towards the unique person as a care-receiver with her or his relatives, rather than an attitude towards generalised care-receivers. The carers’ attitude should support the personhood of the care-receiver, regardless of her or his ability to use verbal communication (Kitwood, 1997; Malmsten, 1999).
Education in nursing presupposes that students assimilate scientifically based knowledge, acquire practical skills, and integrate both with their personal experience. Personal experience and knowledge that is integrated with people's ways of reacting and acting in different situations has been referred as knowing more than we can tell, 'tacit knowing'. Such 'tacit knowing' emanates from experiences that give a sensed wordless meaning to similar situations later in life (Polanyi, 1983). Theoretical (knowing that) as well as practical knowledge (knowing how) are needed for developing a practical expert in caring (Benner, 1984). It can be assumed that it is possible to make some 'tacit' knowledge explicit through making professional carers reflect on what they have been observed doing.

Most professional carers are women (Evans, 1997; Ryan & Porter, 1993; Villeneuve, 1994), even if men for long have worked as nurses in asylums, military service and private associations (Macintosh, 1997). Men working as nurses in Sweden; Norway and Finland emphasise their task-orientated behaviour as opposed to women nurses who emphasise their people-orientated behaviour. This view is seen as influenced by the historically predominant social pattern of men as breadwinners, hardly participating in domestic work and in caring for children (Kauppinen-Toropainen & Lammi, 1993). It can be assumed that this reflects the prevailing situation in most countries, even if research indicates that men as fathers are in a process of involving themselves more in family life, including caring for children (Plantin, 2001).

The human caring

As humans we have experience of being cared for and about. Most people care for their children, beloved relatives, friends and acquaintances; and people in general possess a reflexive readiness to respond to helplessness. Viewing our capacity to care as our nature as human beings presupposes a relational way of being and it implies philosophical, ethical and epistemological concerns (Gaut, 1983; Gaylin, 1979; Roach, 1992; Ruddick, 1989; van Manen, 2002; Watson & Smith, 2002).
Caring for children has a special and familiar relationship to human dependency that can be relevant for other caring relationships where dependency on carers prevails. It includes emotional aspects and has historically in most societies been regarded as a private domain of women. However, it should be considered as denoting a broader meaning of ‘parenting’ and not as something limited to and exclusively inherited in the biology of women (Holm, 1993; Ruddick, 1989). In a broader meaning, mothering as described by Holm (1993) and maternal thinking and practice as described by Ruddick (1989) can be seen as actualising our inherent humanness.

Holm (1993) and Ruddick (1989) advocate that taking on the responsibility as a mother is basically a social practice, based on an uneven relation that should not be violated. The uneven relation has ethical implications that are applicable in other caring and uneven relations. The changes that take place when somebody is mothering cannot be explained with biology and can only be reflected upon in retrospect. ‘Mothering’ is to Holm (1993) “a condition one enters, a relation between two human beings, a social institution with norms, roles and expectations, and a traditionally transmitted practise with aims, demands, procedures, competences, virtues, vices and nowadays even so-called experts and professionals (ibid., p. 101, Holm’s italics in bold)”. Ruddick (1989, pp. 13-27) has an epistemological view. Maternal thinking is the intellectual activities that are different from, but not separated from emotions being practised. She suggests that the development of capacities to mother means developing lasting qualities that she names ‘maternal’. A similar development of desirable qualities in caring can take place when people care for relatives, for example, caring for a relative with Alzheimer’s disease (Bar-David, 1999). It can be presumed that being sensitive to the caring demands of people in vulnerable situations and adapting oneself to these situations forms thinking, knowing, and a preparedness to create reciprocal relationships.

Cultural aspects

Questions about quality of care are largely questions of values. Meeting with people and gaining knowledge steadily influence carers’ values and beliefs that are embedded within the story or the life experiences of a person (Heliker, 1999). This may or may not be
congruent with those of the professional discipline. Professional carers in institutions construct together a caring culture within each department, ward or group dwelling, which constitutes ‘a mini-world of being in here’ (Bauman, 2000, p. xxx). The culture in such ‘mini worlds’ also reflects the common values in the surrounding society, that may or may not support caring as being as part of our nature and as essential for human development throughout the lifespan. Whatever the prevailing values are in a ‘mini world’ or in a society regarding for example caring and gender, they cannot be used as an excuse for cruelty and violation of human rights (Okin, 1999).

Group dwellings for people with dementia in Sweden can be seen as ‘mini worlds’. A home like caring context can support residents and carers to identify themselves as ‘being in here’ (cf. Bauman, 2000). Professional carers in such units should ideally consider these homes as being more than their working places. If they share a meaning of caring for a home-like atmosphere with the residents’ relatives and each other, it should support their efforts to understand and support the residents’ meaning of being at home in a broader existential sense (Zingmark, 2000, pp. 30-31).

The education of professional carers in Sweden has been developed over years, has varied in content and length and is regulated by authorities. Most countries in East Africa are, like Vietnam, considered to be developing countries, with a comparatively short history of educating caring professions. The educational programmes are greatly influenced by Western ‘models’ and way of thinking, which does not always correspond with the prevailing values in these countries. The education of registered nurses (RN) and enrolled nurses (EN) in Zambia was almost a copy of the British model around the 1980s and many professionals in the health sector got their health education in the West before and after achieving independence around the 1960s. The influence from the West continues on several levels in East Africa, for example among other symbols of wealth in Kenya today are having one’s children in schools abroad and going on shopping tours to Europe (Kilbridge, Suda & Njeru, 2000, p. 78), which assumingly interfere with several traditional values.
Westerners have been involved in developing the nursing profession in most countries in East Africa and some places in Northern Vietnam. Until recently there was no professional concept used for nurses in Vietnam, regardless of the length of education. Instead an expression was used with a connotation to a general meaning of taking care of children, sick people, elderly etc. The Vietnamese traditions with Buddhism, Taoism and Confucianism and a ‘very foreign’ language to people from the west seem to have resisted most Western influence on values related to family life (my experience).

In spite of Western influence, the carers in these countries have to perform their care in the context of their culture. The society in East Africa is in rapid transition and young girls nowadays admire females starring in Western films and soap operas showing on television (Frederiksen, 2000). Big cities in Vietnam are also rapidly becoming ‘modern’ with regard to education and technical development, but the ‘traditional family’ that still has agricultural roots, seems to remain as the main institution for supporting its members throughout the entire life cycle (Johansson, 2000, p.16); even if higher-income households in Asian countries shift their service demand to more qualified providers, such as hospitals (Toan, 2001, p. 17).

In East Africa, the development is hampered by political instability, corruption and internal conflicts. The societies have few structures and hardly any resources to deal with refugees, droughts and poverty. In large cities such as Nairobi, the organisation reflects migration and a youthful population. The former traditional, extended family system, that took responsibility for all its children’s care, is breaking down as well as other supporting traditional systems (Gracey, 2002). No structures in the society have replaced their caring function for children when parents die or if they for social reasons cannot care for their children. In the increasing number of street children, girls are especially vulnerable. Unprotected, they are often sexually abused, often infected with various sexually transmitted diseases (STDs) and get pregnant (Kilbridge, et al., 2000). These authors (p. 3) claim that street children represent a worldwide phenomenon despite cultural differences and that the backgrounds of street children are remarkably similar.
There should be interesting meanings, of the experience of living with a severe illness and of caring in Vietnam, where the ‘traditional family’ still exists, and of professional caring in East Africa where the tradition of ‘extended family’ is disappearing.

The quality of professional caring in institutions depends on the carer’s knowledge and skills as well as on a culture that supports quality admits a variety of meanings to be expressed. The actions will be characterised by open rules and a development of practice, which is different from routine practice (Göranson, 1988). Excellence in caring can be seen as what the social group’s culture notifies as good. Professional carers should develop a shared meaning of good quality of care with care-receivers, their relatives and colleagues as a foundation for providing good care (Benner, 2000). Traditions, values and structures in a society may support or hinder professional carers from being caring.

Life story and personal identity

Each human has an inherited uniqueness as a person that remains throughout our lives. At the same time we are steadily growing older, developing and steadily influenced by living in relations with other people. This gives each person a steadily changing narrative identity that is constructed when we tell stories, that makes it possible to understand the meaning of our own and others’ experience (Ricoeur, 1992). The ability to tell stories about experience in life is universal and concerns meaning and coherence for a person within a specific culture (Cohler, 1991).

Memories of our experience of being understood, not being understood or being misunderstood are interrelated with feelings and connected with various contexts in our life stories. Professional carers should aim at achieving an understanding of the care-receivers and their relatives’ experience through shared narrative dialogues (Norberg, 1994), which is a different approach from care receivers and their relatives being given pre-set questions to answer (Skott, 2001). Narrative dialogues with a life-story perspective can enhance the professional carers’ options for achieving an understanding of the care receivers’ and their relatives’ experience of their situation as a basis for making appropriate care plans (Heliker, 1999), care-receivers with cognitive impairment included (Hansebo & Kihlgren, 2000).
Some people are disabled or, for various reasons, unable to tell stories about their experience. So are often people with a severe stroke, dementia (for example Alzheimer's disease) or children who might be restricted by social norms. Kitwood (1997) held that others can preserve a person's narrative identity and Thomasma (1984) argued that our responsibility toward the dependent young is to guide and to 'protect the future'. He saw that as different from our responsibility toward old people or people with chronic illness, whom we must honour and respect to protect the past.

**Living with severe illness and in adverse circumstances**

People with severe stroke or a dementia disease like Alzheimer's are vulnerable as they are living with severe illness. Young girls living on the streets are also vulnerable as they are living in adverse circumstances. These three different groups of people have in common that they, to various degrees, depend on others' care for survival and well-being and they are likely to face difficulties in conveying their experience and preferences.

Severe stroke and Alzheimer's disease are neurological and chronic illnesses that need to be managed by the afflicted person and the family, often together with professional carers (Wright, Hickey, Buckwalter & Clipp, 1995). Stroke as a disease (ischemic or haemorrhagic) is reasonably the same all over the world. It has an acute onset and is defined as rapidly developing clinical signs of focal (or global) disturbance of cerebral function lasting more than 24 hours with no apparent cause other than vascular origin (Asplund, Tuomilehto, Stegmayr, Wester & Tunstall-Pedoe, 1988). Living with the diagnosed disease is to be living with an illness as a subjective, often stressful experience and a desire to be understood (Toombs, 1992, 1995; Söderberg, Lundman & Norberg, 1999). A severe stroke attack will suddenly change the course of a person's life story as well as the story of the people involved in that life story. The severity differs. The most dramatic symptoms can subside within the first few weeks. The dimension, position and cause of the injury will influence the recovery. Researchers have found that people with a stroke include an existential dimension in their experience of stroke. They regarded their
experience as an extremely distressing struggle to manage in various situations in life (Nilsson, Jansson & Norberg, 1999).

Unlike the acute onset of stroke, Alzheimer’s disease, being the most common dementia disorder, is characterised by a progressive deterioration of the person’s memory and thinking. Relatives have expressed in retrospect that they had suspected for a long time that something was wrong and they were uncertain about the nature of the diagnosis. (Garwick, Detzner & Boss, 1994; Kirk & Swane, 1996). According to DSM-IV (APA = American Psychiatric Association, 1994 pp. 134-143) people with Alzheimer’s disease are gradually affected by cognitive deficits and impaired functions due to pathological changes that are slowly progressing in structures of the brain. The memory is prominently affected and the sufferers’ ability to learn new things becomes impaired, or they forget previously learned things. The inability to use language (aphasia), a steadily decreasing ability to accomplish motor activities (apraxia) and difficulties in recognising familiar things (agnosia) make it difficult to interact and communicate with others as well as manage daily caring matters. According to Norberg (2001) people with Alzheimer’s disease or other dementia in advanced stages do suffer. This suffering can be understood as not feeling at home in an existential meaning, but there is also the suffering of being degraded that can be inflicted by care.

Living with severe stroke or Alzheimer’s means living with various impairments in perception and cognition. The person afflicted by a stroke may find it difficult to understand what has happened (Anderson, 1992) and can experience sensations of ‘not being the same’ (Gustavsson, Nilsson, Mattsson, Åström & Bucht, 1995; Jacobsson, Axelsson, Österlind & Norberg, 2000). People who are afflicted by a stroke have not only difficulties in handling their physical disabilities, but they also experience that the stroke attack challenges their whole being as a person (Nilsson, Jansson and Norberg, 1997; 1999). This indicates that people living with severe stroke may need assistance to reconstruct their narrative identity as a person and to re-interpret their life stories.
The person with dementia experiences that the meaning of the life-world alters during the course of the disease (Nygård, 1996) and carers should make an effort to share an understanding with the afflicted people about how they experience their situation (Kitwood, 1997; Wogn- Henriksen, 1997). Such sharing may be extremely difficult if the afflicted person has severely impaired memory, cognitive functions and speech, influencing her or his capacity to express experiences and feelings in words (Arendt & Jones, 1992) and yet; the carers have to take over greater responsibility for decisions (Thomasma, 1984). Disturbed communication due to stroke also places special demands on the carers’ meeting with the care receivers (Sundin, 2001, pp. 47-61) and calls for attention to the long-term psychological problems of patients as well their relatives (Santos, Farrajota, Castro-Caldas & de Sousa, 1999).

Dementia is referred to as a ‘family illness’ as it involves family members’ support emotionally, socially and practically (Almberg, Jansson, Grafström & Winblad, 1998) and so does stroke (Anderson, 1992, p. 10). Relatives can be seen as significant parts of a person’s familiar, communicative context, when it comes to conversing and engaging in shared dialogues (Jansson, 2001). Professional carers should be aware of their task of seeing to the relatives’ need for information, counselling, and accessibility (Hertzberg, 2002, pp. 53-54; van der Smagt-Duijnstee, Hamers & Abu-Saad, 2000; van der Smagt-Duijnstee, Hamers, Abu-Saad & Zuidhof, 2001).

Miesen (1992, 1993) suggested that people with dementia function on two levels. On one level they are aware of their situation and on the other level this awareness is missing. He further suggested that attachment behaviour gains increasing importance between elderly people with Alzheimer’s disease and argues that it is attachment which links older people to their environment, and attachment is vital if human development is to continue. Attachment behaviour as described by Miesen (1992, 1993) can be seen as similar to infants’ attachment behaviour (Bowlby, 1973) and as a sign or code that carers who are sensitive see as a call for caring.
It is not only diseases that suddenly or gradually make us dependent on professional care. Almost half of today’s Third World population lives in conditions with extreme poverty. The governments cannot cope with the problems arising with rapid urbanization. Because of the breakdown of extended family structures and other supporting mechanisms the children in these areas can be trapped in cycles of homelessness, under-education, drug addiction and despair. Some children do voluntarily run away from the misery at such homes and others are left orphaned to live life on their own at the bottom of the status hierarchy. Girls living on the streets are living a life that is hazardous for their health. Establishing a caring relationship with these girls is a challenge. Most of them have lost the trust in adults; either they have no parents or they have run away from home and most of them have experienced that adults meet them as suspects in general (Kilbridge, et al., 2000). This can make it difficult for professional carers to get inside these girls’ network, and being left out may work counter to caring.

Children living on the streets may have difficulties with ‘solving’ developmental psychosocial conflicts. It can be difficult to find mothers, parents or other significant others that are essential for this process as described by J. and E. H Erikson as (1982, 1988). They may also lack opportunities to participate in constructive, story-telling activities in order to develop a personal, socially accepted identity as described by, for example, Ricoeur (1992) and Ruud (2001, pp. 51-54). It can also be assumed they have difficulties in thinking about the future of their life stories or that they have little concern about the future as they are preoccupied with getting hold of daily necessities.

Reasonably, integrated values and caring praxis in relation to family bonds and professional care influence our understanding of living with severe illness and meeting with adversity in life throughout the life span from the perspective of being an afflicted person, a relative or a professional carer.
Aims in the thesis

The overall aim of this thesis was to disclose the experience of severe illness and caring with a life-story perspective in different cultural contexts.

In Paper I the aim was to describe the stroke-affected person’s experience of living with stroke sequelae and their future expectations.

In Paper II the aim was to explore nurses’ and relatives’ experiences of caring for stroke patients and to illuminate stroke victims’ experience in Northern Vietnam.

In Paper III the aim was to illuminate the thinking of identified good dementia carers in an attempt to make explicit attitudes and means of communication embedded in a seemingly good caring atmosphere and in episodes narrated and interpreted as resulting in mutual understanding.

In Paper IV the aim was to illuminate individual skilled professional carers’ ways of achieving an understanding of people with moderate or severe Alzheimer’s disease.

In Paper V the aim was to elucidate the meaning of caring for girls of the street (GOS) as experienced by female staff members working in street children projects in Eastern Africa.
PHILOSOPHICAL AND THEORETICAL PERSPECTIVE

The five papers in this thesis are linked together on founding conditions, which I presume we share as healthy or seriously ill humans, regardless of age or where we live. My choices of philosophical and theoretical perspectives reflect four conditions. I have used them as pillar-stones for disclosing the meaning of the experience embedded in seemingly diverse studies: our narrative identity; caring as the human mode of being; sharing an understanding of the meaning of our experience; and our praxis constructs our culture.

Our narrative identity

My understanding of our identity as unique, speaking and acting persons is inspired by my understanding of Ricoeur’s philosophy on people’s identity (1992). Supported by the grammars of natural language he advocates that the term ‘identical’ has more than one meaning. The meaning of ‘identical to’ may be equivalent to ‘self’, but it may also mean ‘same [as]’. For example a person can be identified by her- or himself and by others as Mrs. Person, even if some time has elapsed since last meeting and her understanding of herself and others continuously changes throughout the course of life. As humans we cannot think or talk about ourselves without involving others. We use narratives to seek our identity and connectedness in life and to give sense and coherence to our lives. We compare us with ourselves and with others. There is dialectic between the ‘I’ as the same (idem=same) and ‘I’ as the self (ipse) in an existential meaning in which a narrative identity is disclosed. Through telling stories and through listening to others’ stories people develop both their individual and their collective identity.

Story-telling in narrative dialogues is a means to order and to allow details, events, meanings as well as history to be conveyed and reflected upon as whole stories (Cohler, 1991, p. 174; MacIntyre, 1993, p. 203; Polkinghorne, 1995; Ricoeur, 1992). Mrs. Person may tell: “They found me unconscious in the garden, and brought me to the hospital. That’s where I found myself...” Such a story will trigger off, or rather continue a re-interpretation of the story of Mrs. Person and the people involved.
We share stories in various relations. Living with others and being related has also to do with the comprehensible world and what transcends it in time and space and what people may believe transcends it (Buber, 1958; Roach, 1997). Relations beyond actual meeting might also influence us. Just thinking about someone may influence my mood and contribute to a sense of both of us as true beings [that are] lived in the present (cf. Buber, 1958, p. 13, Buber’s citation in italics).

Presumably, we have a great influence on each other’s narrative identity in relations where we are involved in each other’s life stories over longer periods of time. Members in a family and close friends have long-lasting, mutual emotional bonds and obligations throughout the 24 hours of a day. They are likely to continue their involvement in each other’s stories, continuously re-constructing the narrative identity of each person and the family or group when a person instantly or insidiously becomes seriously ill or cannot be cared for in ordinary homes (cf. Herzberg, Ekman & Axelsson, 2001). Professional carers can also influence care-receivers and their relatives by their participation in the care-receivers’ and their relatives’ life stories over a limited period of time.

Caring as the human mode of being

My understanding of caring as the human mode of being is inspired by Roach, (1992), who has a Judeo-Christian background against which she explores caring. Caring in her view can be actualised and manifested in caring activities. She does not subordinate spirit to matter, but advocates that caring is known through the spiritual nourishment of experience, expressed in art (ibid, 1997). My interpretation of ‘actualisation of caring as a mode of being’ connotes the Swedish expressions ‘bry sig om’ and van Manen’s (2002) ‘care-as-worry’. In this view the person of the carer affects and is affected by the care-receivers and their relatives (Watson, 1988). In the same way caring as manifested connotes the Swedish expressions ‘vårdar / ta hand om’. The view highlights that the desire to care is a human response to dependency and human values, not as something being valued by me, but as something that includes sacredness of human life and the preciousness of the human being.
A globally well-known and familiar actualisation and manifestation of caring as a human mode of being is caring for children as the maternal relationship can provide a model for other relationships (Grimshaw, 1986). Ruddick (1989), as a feminist philosopher, claims an epistemological view on maternal thinking and practice in that meeting the demands and adapting oneself to these demands in maternal practice is founded in reason that forms thinking, knowing, and a preparedness to create and retain reciprocal, trustful relationships. The practice forms a consciousness, which she names maternal thinking. This can be seen as embodied knowledge (Benner, 1994, p. 52; 104-105).

According to Ruddick (1989) maternal practice involves a universal, unspoken but perceived demand from infants who convey vulnerability and need of care and protection. She further states like Roach (1992) that there is ethics involved in responding to such demand. My understanding of this ethics is that it is a radical, silent, ethical demand, corresponding with Lögstrup’s (1971, p. 59) view on our human responsibility in general - the other has to be served through word and action. And we must make this decision on the basis of our own selfishness and our own understanding of life. Carers who are affirming caring and perform caring actions as a response to the ethical demand can in some respects be compared to mothers’ meeting with their infants.

The main responsibility for establishing relationships between carers and the care receivers lies with the carers. Professional carers as well as ‘mothers’, regardless of sex, are faced with immediate unspoken and radical, ethical demands, which need not correspond with what the care-receivers or their relatives express, if they are able to talk. The carers are supposed to determine what to do and say in caring situations as the care receivers’ lives and well-being are in their hands (cf. Lögstrup, 1971, pp. 46-47).

**Sharing an understanding of the meaning of our experience**

My understanding of how it is possible to share an understanding of the meaning of our experience through language is also mainly inspired by Ricoeur (1976; 1993). The experience as such cannot become the listener’s, but the narrative enables a sharing of the
meaning of our experience (Ricoeur, 1976, pp. 15-16). The sensation of understanding somebody or being understood in a conversation exceeds the words, expressions and language that are used. When we meet and talk with each other there are characteristics that are not present in written document, even if such documents convey a meaning that we interpret. We use sounds and actions, besides expressing words and sentences, and we influence the emotions of each other (Ricoeur, 1993). These will guide our intention to understand and to be understood as the use of spoken language can produce a mutual understanding of sameness of the shared sphere of meaning (Ricoeur, 1976, p. 73).

Ricoeur (1976; 1991) makes a distinction between language as a closed system providing codes and words for communication and language as an event when we are using the words for exchanging messages (Table 1). Language as system is composed of single letters, signs or words (= codes) that are neither true nor false, and they lack temporality. The function of this system is to provide people with codes to be combined in a communication. Language as discourse requires a synthesised connection of words in sentences to carry messages that are meant by someone and are organised as stories. The sense of the meaning proceeds from integration of the parts to larger wholes that always are about something (Ricoeur, 1976, p. 7).
Table 1. Language as system and as used in discourse (Ricoeur, 1976; 1991).

<table>
<thead>
<tr>
<th>Basic unit</th>
<th>Language as system</th>
<th>Language as used in discourse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function</td>
<td>Provides the codes for communication</td>
<td>Provides a world for exchanging messages</td>
</tr>
<tr>
<td>Relation to user</td>
<td>Lacks subject</td>
<td>Refers to a speaker</td>
</tr>
<tr>
<td></td>
<td>Collective</td>
<td>Individual</td>
</tr>
<tr>
<td></td>
<td>Anonymous and not intended</td>
<td>Intentional and meant by someone</td>
</tr>
<tr>
<td>Relation to time</td>
<td>Lacks temporality.</td>
<td>Realised temporarily in the present, but</td>
</tr>
<tr>
<td></td>
<td>Elements set in contemporaneous time (synchronic system)</td>
<td>presented as temporal events in succession =</td>
</tr>
<tr>
<td></td>
<td></td>
<td>a story over time (diachronic dimension)</td>
</tr>
<tr>
<td>Exists as</td>
<td>A compulsory, virtual system for a given speaking community</td>
<td>Personally decided opinions (= arbitrary) that depends on what is</td>
</tr>
<tr>
<td></td>
<td></td>
<td>happening or the circumstances at hand (= contingent)</td>
</tr>
<tr>
<td>Appearance in science</td>
<td>Finite signs and sets to be investigated and described as homogenous objects within semiotics</td>
<td>Descriptions that can fall under many sciences.</td>
</tr>
</tbody>
</table>

People’s meetings enable experiences to be shared, not only through verbal communication, but also as sensations of understanding each other’s experience (Buber, 1972, p. 3). Caring for infants may serve as an example. Stern (1985) suggested that there was ‘affect attunement’ between a mother and her infant in their communication with each other. Their understanding of each other’s experience through verbal language is not possible, but it can be understood as an influence of the oral discourse and the actions on emotions and affective attitudes (Ricoeur, 1976). Through use of imaginations in narratives about the child’s past and its future, the mother can anticipate suitable actions to be tried in order to satisfy the child and herself (cf. Ricoeur, 1991, pp. 168-181).

The meaning of our experience is often conveyed in a language of metaphors (Ricoeur, 1976, pp. 51-52). When using metaphoric language we compare our experience with concrete matters as our conceptual system of thinking and acting is fundamentally metaphorical in nature (Lakoff & Johnson 1980). Ricoeur (1976, pp 57-64) suggests that
symbols have a non-semantic side that resists transcriptions, whereas a metaphor (*ibid.*, 1993, pp. 38-39; 1976, chap. 3) is a semantic innovation. A metaphor conveys new meaning through productive imaginations, has emotive values and offers new information, but has no status in established language. It should be seen as having one of the emotive functions in a discourse as the words we use can have different meanings and functions in different contexts.

Beloved relatives and skilled professional carers are at times caring for people in vulnerable situations, who are disabled or unable to use language. It can be assumed that these carers are sensitive to signs shown and single words expressed by the care receivers. Productive imagination can assist them to put these signs and words (*cf.* Ricoeur, 1991, pp. 168-174) into integrated wholes of stories that are brought into comprehensive language as *meant* by the care receiver.

**Our praxis constructs our culture**

My understanding of culture as being constructed through our unending activities is inspired by Bauman (2000) and Ricoeur (1992). Together with others we create our identity that gives meaning to the ‘I’ as a unique being. Our social identity guarantees that meaning and gives meaning to the ‘we’ as being included and accepted within a face-to-face network. There is a context to which we belong and feel secure (Bauman, 2000, introd.; Ricoeur, 1992). Being ‘inside’ such a network is described by Bauman (2000, p. xxxiii) as *being at home*. Being ‘outside’ means being in a space that contains things one knows little about, one from which one does not expect much and for which one does not feel obliged to care (*ibid.*, xxxiii). The same author (2000, chap. 1) claims that in Western mentality ‘culture’ is often understood as a hierarchical concept i.e. a ‘cultured person’ is well educated, polished and above a ‘natural state’ contrasting with an ‘uncultured person’. It is also used with a meaning of difference between various groups of people and nations. He suggests a generic understanding of ‘culture’, connoting an ongoing process whereby people structure the world through their use of tools and
language. The structuring activities constitute human praxis; the human mode of being in
the world. Bauman’s (2000) view on culture as praxis seems to correspond with
Ricoeur’s (1992) view on people’s narrative identity and the development of practical
wisdom: *It is through public debate, friendly discussions, and shared convictions that
moral judgement in situation is formed* (ibid., p. 290). I also see it embracing mothering
as praxis (Holm, 1993) and caring as the human mode of being (Roach, 1992). The
required strength of our identity will not come by itself. It must be created in a culture
where there is education, teaching and training (Bauman, 2000). An epistemological view
(Ruddick, 1989) on maternal thinking and practice adds an important dimension to one
way of understanding how knowledge about care is achieved.
METHODOLOGY

The studies in the thesis had a qualitative approach with the intention of understanding more about the meaning of the experiences of severe illness and of caring. The choices of methods and the application of them, were discussed and agreed upon with the co-authors of the papers. Generally, the French philosopher Paul Ricoeur’s (1976; 1991; 1992; 1993; 1994) writings on the nature of language and meaning, of action, as well as on interpretation and subjectivity have been inspiring throughout the work.

Ricoeur (1993, pp. 114-115) advocates that meaning is an ontological, phenomenological question that presupposes hermeneutics as the meaning is concealed. People’s experiences are not objects that can be studied as such, neither can they be conveyed from one person to another, but the meaning of experience can be shared in narrative dialogues. Such dialogues with a sense of being together can make it possible to achieve a mutual understanding of sameness of the shared sphere of meaning of the experience in question (Ricoeur, 1976) for example of living with the experience of stroke and of caring.

Narrative dialogues can be established in narrative interviews as a means to collect data for investigating the meaning of peoples’ experience. Narrative is the form that people spontaneously use to formulate and to create meaning in their life experiences (Polkinghorne, 1988, p. 183). The interviewer as a researcher has to be aware of the mutual influence sounds, actions, words and sentences used during the interview have on emotions and the affective states (cf. Ricoeur, 1976, chap. 1). The awareness can assist the interviewer to use signs, gestures and words to stimulate the interviewee’s narration and to give further explanation. It is the responsibility of the researcher to change the direction of the discourse if focus is lost.

The transcribed text from audio-recorded, narrative interviews is seen as grounded in the objectivity of meaning of oral discourses (Ricoeur, 1976. p. 91). Also meaningful actions can be objects for science under the provision that they are fixed as discourse (Ricoeur, 1991, pp. 150-152), for example observed actions can be reflected on in narrative interviews at a later stage. The meaning that is present in the oral discourse and actions
can be understood in a dynamic reading of a text that is transcribed verbatim from audio recorded interviews. Every text will involve several potential horizons of meaning that can be actualised during the interpretation process. (Ricoeur, 1976).

The dynamic, interpretation process of a text should, according to Ricoeur (1976), follow a path of three stages in the dialectic of explanation and understanding. Initially, the meaning in the text is seen as something whole that can be grasped in a naive understanding and guesses about structures in the text can be made. The guessed structures are then looked for and thoroughly ‘mapped up’. If the guessed structures cannot be found or they contradict the meaning grasped in the naive reading, the latter has to be scrutinised and a new naive reading has to be performed. At this stage the text is like any object that can be looked at from several sides, but only one side at a time i.e. each structure must be looked at separately. The finalising stage is to comprehend the understanding in the naive reading and the explanations found in the structural analyses together in a comprehensive, critical understanding of the meaning as a whole. This is an appropriation of the meaning of the text itself as an existential matter that must not be mistaken for an understanding of the inner life of the informants or of the researchers. The whole process should instead provide a disclosure of a possible way of looking at things and a new mode of being.

The guesses made in the process cannot be validated through logic or empirical verification, but through presentation of good arguments for a most probable and qualitatively best-construed verbal meaning found in text. The guesses in the naive reading are not validated as logical verification through structural analyses, but as arguments in favour of the understanding that is presented. There is no validation of what the interviewees intended to tell, as the intention of the interpretation is to find the meaning that is embedded in the transcribed text. I suggest that this interpreted meaning in a text can be conveyed in a language of metaphors, as this language, according to the author is an integrated part of our conceptual system of thinking, talking and doing that goes to the depths of human experience.
The approach to analysing data as inspired by Ricoeur’s (1976) is under development for use in nursing research. It has been used for interpretation of transcribed interviews among others by researchers at the Department of Nursing, Umeå University, Sweden (e.g. Rasmussen, 1999, p. 46; Söderberg, A: 1999, pp. 18-20; Söderberg, S., Lundman & Norberg, 1999) and the Department of Nursing and Health, University of Tromsø, Norway (e.g. Talseth, Lindseth, Jacobsson & Norberg, 1999).

Pre-understanding

In order to hold some assumptions and suppositions at bay (van Manen, 1990, pp. 46-51; Öhrling, 2000, pp. 28-30) I have made an effort to make explicit some of the pre-understanding that may have influenced data collection, the findings in the five papers and the summary of them. I am aware that such knowledge is doomed to remain partial (cf. Ricoeur, 1993, p. 245).

My personal experience of caring emanates from being cared for in two foster homes as a 'Finnish child of the war' who has given an understanding of being involved in a family’s network as ‘being one of us’ at times, but also of not being fully involved, which the paradox ‘being just as one of us’ expresses. The experience also includes being cared for by beloved relatives and friends. As an adult I have been involved in a family with three boys and later on in their families with four grandchildren. I have also experience of caring for elderly relatives at the end of their lives. The years of practising care as RN, Public Health Nurse and of teaching nursing care as a Nurse Tutor on different levels as well as in different countries have contributed to my pre-understanding of caring in different cultural contexts. However, the main contributor for studying nursing research was my husband’s severe stroke attack.

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1 The concept pre-understanding is amongst others used by the phenomenological researcher van Manen (1990, pp. 46-51). He advocates making the researcher’s ‘common sense’ pre-understanding explicit. The concept is used by Ricoeur (1993, pp. 243-247) to denote that all objectifying knowledge is preceded by a relation of belonging on which we are unable to entirely reflect, but it can be constituted in relative autonomy through distanciation. It is always partial, fragmentary. The non-completeness is hermeneutically founded, and concerns the correct usage of the critique of ideology as a task that must be begun but can never be completed (Ricoeur’s italics).
I spent several months at his bedside as he underwent various, severe complications. During that time I often wondered what I should have done in many of the delicate situations that occurred, had I been a practising RN. I also questioned what my colleagues and I taught the RN-students and the EN-students in order to prepare them for these complex and difficult situations.

I got the impression that most carers just did their duty in a correct and polite manner; but there were some few who draw my attention in a positive way and they made me confide in them. It was their way of being, more than the uttered words, that made me feel that they shared an understanding of our situation. These nurses’ understanding, as I sensed it, constituted their platform for their performance of skilled care. Not only did we appreciate their presence; I admired their skills, including their handling of the sophisticated technical equipment. These carers significantly contributed to my understanding of good care. I presumed that these skills were anchored in their thinking, knowledge and experience and I assumed that their talents were experienced and appreciated by other patients, relatives and their colleagues.

These carers supported my involvement in the whole situation and they assisted me and us together to endure the several serious complications that came along. When I was mentioned as a ‘visitor’ by some other staff, I felt strong objections towards being regarded as a ‘visitor’. I felt inseparably involved in whatever happened to my husband. A frequent use of the concept ‘visitor’ contrasted sharply against the experience I and the family had from working in developing countries. Memories from four years in Zambia, where the extended family system worked at that time, had taught us lessons about relationships between people, family bonds, and of respecting elderly people as having acquired ‘life skills’. A student nurse asked me as lecturing tutor: “Who is teaching your children to live?” This question still remains, challenging that an answer be formulated, but I sense that it influences my understanding of the meaning of caring. Also, memories of a couple of years in Vietnam recalled scenes with at least one relative at the bedside in

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2 To give a more complete picture, there were also some few who for various reasons made me feel uneasy when they were on duty. I just tried my best to avoid them and made sure I was at hand for my husband during their shifts.
a hospital throughout the twenty-four hours of the day. I had been told that: “For us Vietnamese people it is more important to be alive socially than to die physically”. The saying seemingly conveys an important message about people’s living in relations.

My interest in language, in its broadest sense, may have been influenced by memories of arriving in Sweden and not being able to understand and to make myself understood. This situation was repeated fifteen years later when I met my biological mother and my sisters. I spent some days with a sister without having a verbal language in common, but I felt convinced that we shared a meaning of several experiences through use of gestures, signs and some expressions.

**Material and method**

The research settings for collecting data varied in cultural contexts (cf. Leininger, 1985, pp. 7-12 and 1991, chap. 1). Purposive samples of people with a stroke, relatives and professional carers were selected (Table 2) and the informants were approached with ethical considerations before, during and after collecting the data. A phenomenological hermeneutic method as described before was used for analysing the data.

**Research settings**

The choice of settings started with investigations of living with stroke sequelae in Northern Sweden, which was a familiar context (I). A hospital, built and supported by Sida during the 1980s and 90s in Northern Vietnam, was chosen as a suitable setting for further investigation of people’s experience of stroke. It was assumed that the prevailing traditional values with strong family bonds could influence the experience of stroke (II).

Six women and one man resided in the chosen group dwelling for people with dementia. Five selected professional carers’ interaction was studied with five of the residents, the man included. These residents were investigated and diagnosed with Alzheimer’s disease by a specialist prior to moving into the dwelling. Their mental ability as estimated by the primary carers with the help of a ‘Mini-Mental State’ test protocol ranged from 0 to 21
(Folstein, Folstein & MacHugh 1975) (III, IV). Ten enrolled nurses (EN) with varying educational backgrounds worked part-time in shifts during daytime and two nurse aids (NA) were on night duty between 9 PM and 7 AM. One additional EN supervised the staff at two similar group dwellings. All but one carer had worked in the dwelling since it was established four years prior to this study (III, IV).

East Africa was known to be a society in transition influencing family bonds, which was assumed to influence professional carers’ experience of caring for girls living on the streets, which was a comparatively new phenomenon in this area (V). The setting for these interviews was at the different non–governmental organisations’ (=NGO) project offices in Kenya, Uganda and Tanzania (Table 2) (V).

Table 2. The five papers’ geographical area, subjects, context and methods of data collection. Number of subjects, interviews and observations are given in brackets.

<table>
<thead>
<tr>
<th>Geographical area (Paper No)</th>
<th>Subjects (No)</th>
<th>Context of data collection (No)</th>
<th>Method of data collection (No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Sweden (I)</td>
<td>Post-stroke patients (29)</td>
<td>Private homes (27) Institutions (2)</td>
<td>Projective, individual interviews (29)</td>
</tr>
<tr>
<td>II Northern Vietnam (II)</td>
<td>Post-stroke patients (5) Relatives (5) Nurses (5)*</td>
<td>Hospital (3) Private homes (2) Private homes (2) Hospital (3) Hospital (5)</td>
<td>Individual interviews (15)</td>
</tr>
<tr>
<td>Northern Sweden (III, IV)</td>
<td>Carers (5)*</td>
<td>Group dwelling for people with dementia (all)</td>
<td>Individual interviews (5) Observations (25) Reflective, individual interviews after observation (25)</td>
</tr>
<tr>
<td>V East Africa</td>
<td>Female carers (13)</td>
<td>Offices of NGOs (5)</td>
<td>Individual interviews (7) Group interviews (2)</td>
</tr>
</tbody>
</table>

= Professional carers with various length of education
Informants

Totally 73 informants contributed in the studies with data; 34 people thereof had experience of living with a stroke, five of being caring relatives, and 29 informants had experience of professional care. In addition, five residents in the group dwelling contributed with contextual data as the professional carers’ interactions with them were observed. The focus for these observations was on the carers (Table 1).

Ten women and 19 men between 60 and 91 years of age participated in a follow-up study 18-22 months after a stroke attack. These informants had had eating problems during the acute stage. They also had remaining neurological sequelae at a 12-month medical check-up (Axelsson, 1988) (I). Two women and three men aged 28, 31, 54, 60 and 65 of age participated in Vietnam (II). Their caring relatives, identified at the time for the interview were: a younger brother (27 years), mother (60 years), younger sister (51 years), wife (48 years), and sister’s son in law (39 years) (II).

Five Vietnamese RNs between 27 and 35 years of age with three to four years of nursing education and seven to twelve years of nursing experience were included (II). Five professional carers in the selected group dwelling for people with dementia were identified by their colleagues and themselves as being good at understanding people with Alzheimer’s disease. They were married women with children, aged 29, 33, 41, 47, and 55 years respectively. Two had ten weeks of nursing education as nurse aides and three ENs had about two years of nursing education. Their caring experience ranged from ten to 27 years (Median = 14 years). Eleven of the totally 13 possible carers in the dwelling participated in a final group interview; one was on sick leave and one had been on night duty (III, IV).

Transcribed text from 13 female informants aged between 20 and 45 years was selected from interviews with a total of 17 females and 20 males. The selected text was identified as ‘saying’ something about female professional carers’ experience of working among girls living on the streets. Five of the selected carers worked in projects where the girls resided in institutions. Most of them had children, all of them had more than two years of
experience of working among girls and three of them had a formal education in social work.

Ethics

The benefits of collecting data for these studies were judged to be greater than the risks for the participants. All the participating informants were informed about the aim of the studies and the method for the data collection. They were also told that they could refuse participation and could withdraw at any time, as well as reassured that refusal or withdrawal would not affect their treatment, care or working conditions. They were assured of confidentiality and asked to give their informed consent to participation, and they were made aware of the applicability of the studies (WMA, 2002). The Ethical Committee, Umeå University, approved the written plans of the projects before the data collection began.

I participated in analysing the data without further information about the informants in order to keep the ensured confidentiality (I).

As the residents in the group dwelling for demented people were unable to give their informed consent to having the project carried out in their ‘home’, their relatives were approached and informed in writing (III, IV). They gave their informed consent by telephone. An effort was made to minimise the disturbance of my appearance on the homely atmosphere in the dwelling. I got advice from the carers that seemed to suit the described 'semi-participant' observations. The interviews with the carers were performed well out of the residents’ sight and hearing. I tried not to look as a newcomer each time I appeared; for example I wore the same clothing every time. I also adopted the carers’ way of not greeting each other on arrival, but rather meet with the residents. I was also told not to say goodbye on departure, as that was known to make residents wonder if they also were supposed to leave. During the observations I never entered the toilet with the subjects, but remained outside. During analyses and in the presentation of findings the participants appeared with given names and the only residing man was given a woman’s
name to ensure confidentiality. I saw it important to use given names instead of letters or figures as a means of preserving human dignity in data and findings.

Further ethical considerations had to be anticipated in approaching foreign cultures with an attempt to investigate the meaning of lived experience (II, V). As the ethical thinking in a foreign culture may differ from the researchers’, it was seen as essential to familiarise oneself in order to become aware about differences and to make researchers and the project, its aim, methods and applicability accepted (Leininger, 1985). Several discussions were held beforehand with various professionals in order to achieve agreements on these matters. I was aware of the risk that interviewees in Vietnam might expect some ‘expert’ advice or assistance and that my view on healing and curing illness had to be held at bay (Leininger, 1985). It was therefore important to give information about those issues when the interviewees were invited to participate (II, V), as well as informing them about the presence and the task of the male RN, one of the co-authors, who served as an interpreter (II). The information was given initially and repeated at the end of the interviews. I referred questions on health matters that were raised by interviewees to local professionals. When interviewees asked about my experience of stroke, as the RNs knew and some of the patients and relatives sensed that the questions and the dialogues seemed to emanate from personal experience, I asked for a continuation of the interview and promised to give a short answer before leaving (II).

Data collection

The data collection was carried out as projective interviews, narrative and reflective interviews individually and in groups, as well as in the form of observations. The audio-recorded interviews, scribbled observation notes (III; IV) and contextual comments (II, III, IV) were transcribed verbatim; laughs, giggles, stumbling, pauses and changes in volume of the voices were noted.
Projective interviews

The informants with stroke sequelae were shown two photos, one showed a caring situation of a person of the same sex as the interviewee, who was fed by a nurse in a hospital setting. The second photo showed the same person sitting on the hospital bed, eating independently. Each interviewee was asked to tell what the respective photo showed, what feelings and thoughts the watching of the photos evoked (I).

Narrative interviews

Narrative, individual interviews were carried out with 15 Vietnamese informants, five professional carers in the group dwelling in Sweden and 13 professional female carers in East Africa.

In Vietnam, where I had lived for two years, I interviewed five people with a stroke 10 days, 2 months, 2 months, 11 and 12 months after the attack. The co-author, a male Vietnamese RN, assisted with translations between the English and the Vietnamese language. The interviewees were first asked to tell about the event of the stroke attack, thereafter about what life was like before the attack and finally to tell about their future expectations. Relatives were asked similar questions, related to the affected person. The RNs were asked to remember a specific person with a stroke and then narrate in a similar way, question by question. The interviews lasted from 45 to 60 minutes. The recorded interviews were listened through and checked with regard to language errors by a second translator, without the Vietnamese co-authors’ presence. Corrective and clarifying comments were noted and transcribed into the English texts (II).

The selected five carers in the group dwelling were interviewed individually as a first initial phase of the project. They were asked to talk freely in a shared dialogue about their ‘professional history’, for example their views on becoming ‘skilled’ in this field and their thoughts about what had influenced the professional development and the view on the everyday work with the people in the dwelling. These interviews lasted 45-90 minutes (III; IV).
Transcribed data from female carers in East Africa were selected from interviews with carers caring for children living on the streets in East Africa. The first author and a female interviewer with a European background performed the interviews. Both of them had lived in Africa ten years prior to these interviews. They stayed with the staff members in the included project sites some days before conducting the interviews in order to familiarise themselves and to establish a context for the data (Leininger, 1985). Both individual and group interviews were held using open-ended questions that were related to health issues, community work and children’s participation in their rehabilitation (Mishler, 1986) (V).

**Narrative and reflective group-interviews**

The selected five carers in the group dwelling were also interviewed together with each other once. Before this interview, they were given a paper each with the names of the five included residents and told to write notes on their experience of what was ‘easy’ and what was ‘difficult’ with regard to achieving an understanding. They were then asked, one by one, to use their notes as a foundation for telling their experiences. The listeners were then asked, one by one, to reflect on what they had heard, before the next interviewee was invited to start her story using her own notes. The intention with using notes was to make all five contribute with the personal experience that first came into their minds, before being influenced by the others’ comments. The interview, after the notes were written, took one hour. A second group interview was performed with these selected five carers together with six of their colleagues at the end of the project as a means to get some data that could mirror the communicative atmosphere in the dwelling. The procedure was similar, but the interviewees were here asked to write notes on what they appreciated in their work and what they would rather see being changed. This interview took 90 minutes (III, IV).
Reflective, individual interviews

Reflective interviews were performed individually with the carers in the group dwelling after they had been observed in their interactions with residents (n=5/carer). They were asked to reflect on observed episodes that I had judged as successful. The interviews focused on caring actions that seemed incomprehensible to me. The questions were formulated from scribbled notes taken during the observations, as the following two examples can illustrate: You approached Mrs Anna singing, but you did nothing until she sang with you. Why? Mrs Dora appeared to be very anxious, but you did not say anything, nor did you touch her. You went round and tried to make her look at you, even if she seemed to avoid a glance at you. Why? These interviews lasted 15-45 minutes.

Observations

Each carer in the group dwelling was observed using observer-as-participant observations (Adler & Adler, 1994). During 2.5 hours one carer’s interaction with one of the included residents was followed according to a scheduled programme with a focus on the performance of a carer that seemingly satisfied both the resident and the carer but was incomprehensible to me. Trends, patterns and styles of interactions between the observed carer and the scheduled resident were discreetly scribbled on paper. These observed and noted ‘details’ were seen as a fixation of the discourse where the carer and a resident were the main actors in an effort to bring the carer’s tacit knowledge into language in the reflective interview that followed (cf. Nerheim, 1996, p. 398; Benner, 1994, p. 120). My role during five months of appearing and disappearing was known to the carers and the residents’ relatives, but not explained to the residents. I did not involve myself in caring procedures, but sat at the table when others did, took part in conversation if spoken to etc. Each observation with the reflective interview was finished up with my summarising audio-recorded comments, which took about 10-15 minutes (III, IV).
Analyses

The audio recorded, transcribed projective (I), narrative (II, III, IV, V) and reflective (III, IV) interviews were analysed and interpreted as text with a phenomenological hermeneutic method, inspired by Ricoeur (1976). This method is described on page 23. We made an effort to follow the three stages advocated by Ricoeur (1976). However, the process was not rectilinearly forward, but several movements of going back and forth in each paper. Initially, we read the whole texts with an effort to grasp and formulate the meaning as a ‘naive’ understanding and to make guesses about structures in the texts that could yield explanations through scrutinised analyses. In this stage, the text was divided in parts within which the guessed structures and codes were looked for. Finally, we made an effort to construe a text that could capture a critical, comprehensive understanding of the meaning that we had sensed in the naive reading and interpreted as well as verified as probable explanations to the meaning in question.
FINDINGS

The findings in papers are presented as the meaning found in the texts under the following headings; living with a stroke; being involved as a relative; and caring professionally for people who are in vulnerable situations.

Living with a stroke

The meaning of living with a stroke in the study from Sweden was found to be experiences of various feelings that were identified within four themes and related to actors and actions in the stories) (I).

A comparison between the stories emanating from the first and the second photo showed a progress in the story of these photos together and revealed that the interviewees had both positive and negative views on their present situation, the stroke attack and their future. The comprehensive understanding of the meaning of living with stroke sequelae was captured in four core stories, relating to the four themes and the progress in the stories. The sensed and interpreted concealed meaning was conveyed in a language of metaphors (Table 3) (I).
Table 3. Main findings in structural analyses and comprehensive understanding (I).

<table>
<thead>
<tr>
<th>/Themes</th>
<th>STRUCTURAL ANALYSIS</th>
<th>COMPREHENSIVE UNDERSTANDING</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Main actors</td>
<td>Actions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Core story; An actor living with stroke sequelae</td>
</tr>
<tr>
<td>Uncertainty and insecurity</td>
<td>Might be me</td>
<td>Being fed and eating. Do not know</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Married woman living at home. Cannot grasp what has happened, pities people who cannot</td>
</tr>
<tr>
<td></td>
<td></td>
<td>care for themselves</td>
</tr>
<tr>
<td>Sadness and mourning</td>
<td>I or he, she</td>
<td>Being fed and eating. Not able. Sympathising</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Marooned woman living at home. Does not want to be a burden to them or to reside in</td>
</tr>
<tr>
<td></td>
<td></td>
<td>institutions</td>
</tr>
<tr>
<td></td>
<td>She or he and I</td>
<td>Recovering</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A married man living at home, aware of what has happened, was helpless, but hopes for</td>
</tr>
<tr>
<td></td>
<td>Somebody; a nurse</td>
<td>He admires the pattern that is coming to an end with a few pushes and tugs remaining. He</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Single man who suddenly realises that he is old. Others are together with families, he</td>
</tr>
<tr>
<td></td>
<td></td>
<td>He is forced to look at a pattern that he cannot see. The piece can hardly hold together,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>uses his phone occasionally</td>
</tr>
</tbody>
</table>

Living with a stroke in the study from Vietnam implied sensations of an embodied, severe illness for example having experience of an unbearable headache and loss of physical abilities. There were worries about the economy of the family and one’s own ability to cope with the situation, in spite of being confident of relatives’ willingness to care. The interviewees used the pronoun ‘I’ for the main actor. The stories were detailed and dramatic about the stroke attack in the past, but the tense often changed to present tense when the informants narrated. This was seen as an indication of an ongoing re-
interpretation process of the stroke that had afflicted them. Various relatives were often mentioned, whereas nurses hardly occurred. (II).

**Being involved as a relative**

Being a relative to the person affected by stroke in the study from Vietnam meant being involved in the afflicted person’s life story in past, present and future tense, together with other family members. Dyads made of patients’ and relatives’ stories showed similar detailed and dramatic details about the situation when the stroke attack hit them. However, the relatives’ stories did not change tense and the subjective experiences told by the patients were hardly mentioned. These dyads also showed similar stories about life before the stroke attack and about future expectations, similar worries included. The pronoun ‘we’ was predominantly used with reference to various family members. It appeared to be self-evident to be present at the bedside, also during times when the afflicted person was unconscious. The presence of a relative at the bedside was regarded to be constitutional for supporting the affected person’s ‘will to survive’ and essential for assisting her or him according to well-known preferences for example position in bed, food and drinking as well as habits related to bodily care in all aspects (II).

**Caring professionally for people who are in vulnerable situations**

Professional carer in the study from Vietnam was found to indicate collective thinking, assisting the physicians, supervising the relatives’ and supporting the family net. The pronoun ‘we’ for the main actor, was seen as denoting the RNs as collective main actors and the actions were about carrying out the physicians’ orders, and supervising relatives. Triads of patients’, relatives and nurses’ stories showed that nurses’ stories were general, with limited content about the patients’ lives in the past tense and even less in the future tense with the exception of comments about the economy of the family (II).
The analyses showed that understanding people with dementia as identified ‘good carers’ was that the skills seemed to be connected to personal experience of maternal thinking. This was found through isolating maternal actors in the stories, putting these actors into the context of what the theme was about and then interpreting the meaning embedded in each theme (Table 4) (III).

Table 4. Maternal actors, what the themes were about and the interpreted meaning in stories about how skills were achieved in caring for people with dementia (III).

<table>
<thead>
<tr>
<th>Maternal actors</th>
<th>What the themes were about</th>
<th>Interpreted meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>My mummy</td>
<td>Was always around, was patient and was a model for being a good carer, but also a person who did not show physical love. Could be compensated for later for example by sharing hugs with the residents.</td>
<td>Influenced values and thinking and served as an ideal but also as lessons learnt by their ‘failure.</td>
</tr>
<tr>
<td>Myself as my children’s mum</td>
<td>Provided opportunities to develop caring skills for example exercising patience, interpreting unspoken messages, and preventing unwanted scenarios.</td>
<td>Provides useful skills in caring for people with dementia.</td>
</tr>
<tr>
<td>Being a mother to others</td>
<td>Residents’ “childish calls” called for attention but if colleagues behaved childishly it should be mastered.</td>
<td>“Childish calls” demands motherly behaviour. Residents’ calls approved, colleagues’ disapproved.</td>
</tr>
<tr>
<td>Demented people’s mothers</td>
<td>Carers interpreted the residents asking for their mothers as signs of anxiety, which needed specific attention.</td>
<td>Residents’ asking for their mothers seen as a caring demand for comfort.</td>
</tr>
<tr>
<td>Demented women as mothers</td>
<td>Assumed nagging conscience among the residents’ children about not visiting, especially the daughters. Understood as repelling; following the deterioration of the personality of a mother.</td>
<td>Feelings of sympathy with the residents’ daughters.</td>
</tr>
<tr>
<td>Residents in the role of a mother</td>
<td>Younger carers suspected that the demented women considered them their daughters.</td>
<td>Seen as being a resident’s daughter could create a close relationship.</td>
</tr>
<tr>
<td>“The original mother”</td>
<td>A description of a resident given by a carer, who was considered by her colleagues to be an ideal carer herself.</td>
<td>Admiration of a resident with character regarded as warm, loving and confident</td>
</tr>
</tbody>
</table>

Metaphors, personal and vernacular expressions conveyed important meaning for example about the carers’ attitudes toward the residents, trustful relationship between
residents and carers, how carers ‘registered’ that they were understood by the residents and the carers’ care about the atmosphere in the dwelling. Examples from the text are given, followed by the original text within parenthesis and some contextual information.

*It is a matter of maintaining her [socially] upright position.* (Det gäller att hon ska kunna ’hålla upp sig’). About a woman who, according to the carer, often showed signs that she interpreted as the resident ‘showed’ feelings of inferiority and guilt.

*We can [are allowed to] get right into their eyes.* (Vi kan gå ända in i ögonen på dem). About the residents’ trust in the carers, allowing the carers to come very close in several aspects.

*You can ‘see’ that it goes home.* (Man kan ’se’ att det går hem). About how a carer knew that an understanding of the situation was shared with a resident in a situation.

*Then, there will be a fire brigade action.* (Då blir det brandkårsuttryckning). About the need for quick, resolute and silent action if a resident had not defecated for some days, as a measure to prevent restlessness. Said to illustrate a contrast to the prevailing calm atmosphere, where most actions were performed very slowly.

The analyses showed that identified good carers used personal experience from childhood, motherhood, knowledge about each resident’s life story and knowledge about the nature of the disease as a means of achieving an understanding of the residents. The reflective interviews after observations revealed that the observed slow-acting carer’s ways of talking to the residents with few words and low voices had individual differences, which was interpreted through constructing tables of the text that facilitated comparisons between the carers’ caring actions with each of the five included residents (Table 5) (IV).
Table 5. Carer’s personal ways of achieving an understanding of the residents (IV).

<table>
<thead>
<tr>
<th>Resident</th>
<th>Mrs ANNA</th>
<th>Mrs BEDA</th>
<th>Mrs CILLA</th>
<th>Mrs DORA</th>
<th>Mrs ELLA</th>
<th>Interpreted summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lena</td>
<td>Connects words with context. Keeps ‘reality’ comprehensible for A. ‘Tuning in’ to A.</td>
<td>Verbalises actions. Uses knowledge and history to understand</td>
<td>Understands through emotional ‘togetherness’</td>
<td>Understands through connecting signs, actions and behaviour</td>
<td>Words, detailed descriptions. Understands through trying to sense and ‘value’ E’s mood</td>
<td>‘Tuning in’ and rational connections into comprehensible wholes</td>
</tr>
<tr>
<td>Maja</td>
<td>Prevents bad mood, satisfies needs through various means. ‘Tuning in’ to A</td>
<td>Actions and understanding based on her experience of B’s previous way of being</td>
<td>Emotional ‘togetherness’ and prevents C from feeling distressed</td>
<td>Connects words and statements to recent occasions based on mutuality experience</td>
<td>Connecting words with ‘noticeable’ feelings</td>
<td>‘Tuning in’ Connects signs and words into comprehensible wholes within the present time</td>
</tr>
<tr>
<td>Nora</td>
<td>Treats incomprehensible words as comprehensible sentences in a discussion</td>
<td>Visible and physical needs can be understood and met</td>
<td>Demonstrates respect and emotional ‘togetherness’</td>
<td>Registers signs that indicate the mood</td>
<td>Loving relationship</td>
<td>‘Tuning in’ based on her emotional ‘valuation’ of the resident</td>
</tr>
<tr>
<td>Olga</td>
<td>Finding togetherness in music and singing</td>
<td>Knowledge about B from being the primary carer. Expect responses</td>
<td>Respect. Two persons’ understanding of having fun with persons</td>
<td>Relying on some words and laughter to have mutual meaning</td>
<td>Understands through doing things together</td>
<td>Communicative cues and inducing good mood through singing and laughing</td>
</tr>
<tr>
<td>Pia</td>
<td>Togetherness a basis for understanding and actions</td>
<td>Togetherness a basis for understanding and actions</td>
<td>Respect, almost admiration</td>
<td>Togetherness a basis for understanding and actions</td>
<td>Knowledge about the history and shared laughter</td>
<td>Being close enough to make up for losses she feels the resident is experiencing in the actual situation</td>
</tr>
</tbody>
</table>

The caring atmosphere in the dwelling was interpreted and expressed in a language of metaphors. The dwelling, as a context for professional caring, was seen as a greenhouse for the residents, substituting an ordinary home, and was compared to an incubator as a substitution for a mother’s body in caring for premature babies (III, IV).
Working among girls living on the streets in East Africa as a female carer made the carers commit themselves to caring when they met with the girls and listened to their stories. This was connected to motherly feelings of wanting to protect the girls, to rescue them from the streets and to re-direct a girl’s story towards a brighter future. A trusting respectful relationship was seen as essential for getting through the defences most of the girls showed. In such relationships caring was often rewarding with feelings of satisfaction and hope. It also included struggling against the grip of street life and against colliding own integrated values when sensing the demands in the meetings with the girls. There were feelings of powerlessness and frustration when these carers struggled with counselling a girl in a present story of a girl as being useless and despised into a vision of a loveable respected regular girl in the future. These feelings were connected with the experience of not having personal experience and knowledge in professional caring for these girls as well as to their own integrated and prevailing traditional values in the society. These traditional values seemed to remain even if the surrounding society was in transition. The extended family system no longer worked and there were no supporting structures for these girls that had replaced this system. The findings showed that the carers felt that they and the girls on the streets were left on their own by the rest of the society. However, there was hope for a change connected to the carers’ positive experience of working on community empowerment and awareness (V).
REFLECTIONS

The overall aim of this thesis was to disclose the experiences of severe illness and caring with a life-story perspective in different cultural contexts. The transcribed data that were analysed as text with a phenomenological hermeneutic method were collected in Sweden with projective and narrative interviews as well as observations (I, III, IV) and with narrative interviews in Vietnam (II) and Eastern Africa (V).

The perspective on human beings and our lives in this thesis have four philosophical / theoretical presumptions (pp. 15-20) that I have used as pillar-stones for linking the papers together. The reflections start from the viewpoint of peoples’ experience i.e. the meaning found in the data from peoples’ experience of stroke as an afflicted person and as a relative as well as of being professional carers in the fields represented in the thesis. The reflections move on to professional caring and further to language as a means to share an understanding of peoples’ experience as carers. The final move is to reflections on culture seen as contexts of the various data and finding in this thesis. The reflections are sorted under the following headings: Personal identity and adversity in life; professional caring; understanding experience; and caring and culture.

Personal identity, severe illness and caring

...in many narratives the self seeks its identity on the scale of an entire life; between the brief actions – and the connectedness in life (Ricoeur, 1992, p. 115, Ricoeur’s italics in bold).

I consider Ricoeur’s (1992) concept ‘narrative identity’ as corresponding with our expression ‘the view of my self’, which is continuously brought into language by my ‘dialoguing’ with others and myself and thereby continuously undergoing re-interpretation along with the life story of the person. As it has been proposed that the ability to tell a life story that can be understood by both others and the speaking/acting person is universal I find it appropriate to apply this view on findings from data that are collected in different cultures, even if there are variations across cultures regarding what
constitutes an acceptable narrative of the course of life (cf. Cohler, 1991). A person constructs and re-constructs an understanding of themselves together with others as an actor in her or his life story that is brought to language (Cohler, 1991; Polkinghorne, 1995). Relatives and professional carers can support a person who is unable or disabled to use language. For example, the story of small child can be brought into language by the parents of that child until the child can be a narrating actor in her or his own story.

Narrative identity and the experience of stroke
The meaning of living with severe stroke was disclosed as living with an unexpected adverse event that can be seen as an interruption of the interviewee’s past course of their life stories from a continuation into a future (I, II) (cf. Cohler, 1991). This is in correspondence with Nilsson, Norberg and Jansson (1997) who advocate in their comprehensive understanding of ten peoples’ experience of a stroke attack that stroke means a break in the continuity of the identity and there is a risk of identity confusion. The findings in paper I showed that some interviewees experienced “uncertainty as well as insecurity” and “isolation”. They were confused regarding the actors pictured on the photos shown to them and what actions the photos showed. This indicates that the stroke as an event was not integrated with them as main actors in their life stories and their view of themselves did not correspond with their own narrative identity and their perceptions of their past, the event and the present situation. The theme ‘isolation’ can also be seen as indicating a lost connectedness in life (cf. Ricoeur, 1992, pp. chap. 5). In such situations it might be difficult to share an understanding of their experience with others. This interpretation is supported by Anderson’s (1992) result from interviews with 176 stroke survivors in England. Most of them were bewildered and confused (p. 49). After four weeks about every fourth patient did not know what had happened to them (p. 43). Over a half of the male and a quarter of the female survivors agreed with a statement: “I feel I am a burden to people” 18 months after the stroke attack (pp. 157-158).

Creating a story as a response to adversity in life, for example, having experienced a severe illness such as a stroke, can be a means of resilience (Cohler, 1991; Coleman,
1999). The theme “gratefulness, hope and satisfaction” showed that these interviewees clearly identified the actors on the photos and interpreted that recovery had taken place when they looked at the second photo. The interviewees compared their situation with the person on the photos and expressed gratitude. This indicates that the event of the stroke was integrated with their narrative identity at the time for the interviews. According to the findings these interviewees were confidently prepared to face their future i.e. they were prepared to continue their life stories as main actors in their stories.

The findings showed that the interviewed people with severe stroke in Vietnam knew what had happened. The text revealed embodied experiences of severe symptoms, for example severe headache, nausea and loss of functions. These were sparsely commented on by the other interviewees. However, the stories of the patients and the relatives were very similar, apart from the afflicted person's subjective symptoms. This indicates that these patients shared with their relatives some understanding of the meaning of the experience of stroke. The experience of these afflicted people showed that they felt like a weakened thread in a family net (II). This meaning was in the findings shared by the interviewed relatives and RNs (Fig. 1). The interpretation can be seen as conveying a message about these peoples’ narrative identity at the time of the interview.

![Figure 1. Illustrated meaning of the narrative identity of people with stroke in Vietnam.](image-url)
The interviewed relatives in Vietnam (II) saw themselves as involved in the life story of the afflicted person and they were prepared to encourage and support her or his ‘will to survive’ during the acute stage. They saw it as self-evidently their task, not the nurses’, to perform daily care to ensure that it was done according to the person’s preferences. They worried about the future, not only about the outcome of the disease, but explicitly mostly expressed as worries about the economy of the whole family. These worries were shared with the person with the stroke and expressed as concern by RNs. An afflicted person’s capacity to create a story as a means of resilience (Cohler, 1991; Coleman, 1999) might be enhanced by relatives’ presence during all stages of the disease. The presence of well-known relatives can metaphorically serve as plaster of Paris. They can temporarily keep a stable connection between the past and the future of the afflicted peoples’ life stories until the adverse experience is included in the person’s narrative identity and has anew become a main actor in her or his story. The findings can be seen as indicating that the Vietnamese relatives’ presence in all stages of stroke supported the process of re-interpretation of the afflicted person’s narrative identity.

As the relatives are involved in the afflicted person’s life story, they are also affected by the illness and the devastating consequences of the disease. They have their own special needs to be met. Van der Smagt-Duijnstee, Hamers, and Abu-Saad (2000) interviewed 17 relatives of stroke patients during the hospitalisation period in the Netherlands. They found that the interviewees’ experience changed over time and experienced needs of information, communication, support and accessibility to the affected person and to the staff. These findings were later supported by results from a questionnaire answered by 106 relatives of people living with a stroke (van der Smagt-Duijnstee, Hamers, Abu-Saad & Zuidhof, 2001). I suggest that carers’ meeting with the relatives as involved in the afflicted people’s life stories, (not as occasional visitors in the ward), would enhance the possibilities to meet the mentioned needs of the relatives. This suggestion is supported by Ciccarello’s (2003 p.218) view on the necessity to create a culture that supports end-of-life care: Clinicians, not the patients’ families, are “visitors”.
The findings from the group dwelling (III, IV) showed that the carers ‘knew’ that the residents view of themselves (their narrative identity) had changed over time and varied from time to time; for example residents could ask for their mummy, who was dead years ago, which the same resident talked about some minutes before. The interviewed cares in felt sympathy for the relatives. They viewed dementia as a disease that unavoidably also had changed the relatives’ view on their spouses, parents or siblings. The consequences of the disease had for long provoked anxiety about the situation and all involved were vulnerable and fragile (Jansson, 2001, p 74). The carers’ (III, IV) ways of talking about the relatives indicate that they considered the relatives to be involved in the residents’ life stories during the residents’ stay in the dwelling.

**Narrative identity and being a professional carer**

The findings showed that RNs in the Vietnamese hospital (II) had a collective identity that was disclosed in their use of ‘we’ when they were asked to give their personal view. There was hardly any personal experience involved in their stories.

In paper III, IV the intention was to identify carers who had a special, ‘positive’ professional, narrative identity. These carers confidently narrated about personal experience (III). They were also observed to demonstrate confidence in themselves when they performed caring actions and they willingly reflected in personal ways on what had been observed (IV). Seemingly, the narrative identity of these carers included both personal and professional experience (III, IV). I suggest that this finding indicates that personal experience is an important part of developing a professional narrative identity. The suggestion is supported by Gramling (1997, p. 96) who advocates that: *Personal caring images are created from individual experiences.*

The findings showed that being a professional female carer caring for girls living on the street meant having personal experience and integrated traditional values that were conflicting with the demands perceived when meeting with the girls and their stories. The personal experience rather contributed to feelings of powerlessness and frustration. The findings showed that these carers felt that they lacked professional, theoretical knowledge and support. Even if caring for the girls provided rewarding feelings of satisfaction as well
as hope, it was also connected to feelings of frustration and powerlessness (V). These findings indicate that personal experience of caring and being committed to care is not sufficient for developing an identity as a professional carer and feelings of being a good carer.

Professional carers and the narrative identity of people with dementia

The findings showed that the selected carers had gained various kinds of information about each resident’s past, which they steadily made use of as a means to achieve an understanding of vague communicative cues (IV). It can be understood as the carers regarded this information as knowledge of paramount importance for meeting with residents as main actors in their life stories. In a life-story perspective it can be presumed that the narrative identity of the residents had continuously been re-interpreted along with natural ageing and the progress of the disease. This view corresponds with Kitwood’s (1997) suggestion that carers who care for and about people with dementia should meet with them in a way that supports the afflicted peoples’ ‘personhood’, regardless of the progress of the disease. It is also in correspondence with Thomasma’s (1984) suggestion that we should protect, honour and respect the past of old, chronically ill people.

The carers seemingly knew that the residents’ awareness about their past and the present situation differed from time to time. They used their knowledge about the resident’s life story to make sure that they met with the person in the actual caring situation. For instance one carer said that she did not bother if a resident saw her as a daughter or a sister. This carer’s intention was to feel that she was on talking terms with the resident. This can be understood with Miesen’s (1992; 1993) suggestion that people with dementia may function on two levels; both being and not being aware about their situation.

The findings showed that each carer used her own personal ways to achieve an understanding of the residents in the dwelling (IV). For instance, the carer who used singing and laughing to induce a good mood in the residents (IV) can be seen as utilising her personal talents to support the resident’s narrative identity through music, as music
evokes memories that can be seen as connected to a person’s identity (Rolvsjord, 1998). Ruud (1998, p. 31) explains that listening to, performing and talking about music is not as much a reflection of identity as a way of performing our sense of ourselves, our identity (Ruud’s italics in bold).

**Professional caring**

*Caring, as the human mode of being, is caring from the heart; caring from the core of one’s being; caring as a response to one’s experience of connectedness* (Roach, 1997, p.16).

The intrinsic value of a human life can be honoured and respected through caring that is actualised in the meeting with the care-receivers and their relatives as well as with the colleagues. The professional caring is manifested in caring performances (Roach, 1992). Professional caring for RNs in Vietnam apparently meant carrying out the physicians’ orders, supporting the relatives and performing advanced, technical nursing procedures. These findings together with the interpreted collective narrative identity indicate that these RNs hardly considered personal responsibility for their caring for the people with stroke (II). This assumption should inspire further research on who is doing what for a person who is admitted to hospital.

In the findings from Swedish identified ‘good’ professional carers, caring seemingly meant putting a personally experienced and integrated ‘maternal thinking’ into practice when caring for people with dementia (III). This finding conveyed a positive dimension embedded in integrated personal, knowledge and experience of unconditional love, patience and always having someone around. In this context, the ‘maternal thinking’ can be seen as guiding these carers towards true human contact with the residents (*cf.* Holm, 1993; Ruddick, 1987). Several caring performances were observed and judged to satisfy both the residents who had lost most of their skills to use language (IV) (*cf.* Crimmens, 1995). The findings from the 25 reflective interviews that followed the observations,
revealed the carers’ positive attitudes towards the residents, each other and the atmosphere in the dwelling as well as satisfaction with their own performance.

A similar meaning of motherly care was also found in the data from the female carers’ caring for girls living on the streets. Expressions indicating maternal thinking and practice were used to describe the interviewees’ feelings towards the girls. Anyhow, in this context, the carers sensed demands that they found difficult to meet with. ‘Maternal thinking’ seemingly contributed to feelings of powerlessness and frustration when they were unable to find a means to care (V). It might be that maternal thinking and practice need some kind of home as a context for developing a care that satisfies care-receivers, their relatives and the carers. Further research is suggested. The findings indicate that these carers wanted to have access to supporting, knowledgeable people to share an understanding of their experience with. They seemingly hardly had any channels, outside their own group, to air their views on the unfairness they felt the girls were subjected to. Occasionally they did not even dare to speak up as advocates for the girls on unlawful matters these girls were subjected to, as they knew that powerful men were involved.

Maternal thinking and practice (Ruddick, 1989) can be seen as personal knowledge that contributes to having developed skills that enable carers to tune in to the care-receivers’ affective states (cf. Stern, 1985, pp. 139-148). The mother’s relationship with her child harbours the possibility of creating a communion if favourable circumstances prevail. The mother admires her child and recognises it with a kind of dignity in mankind (Norberg, 2001). The mothers’ care for and about their children can be applied in other caring contexts (Holm, 1993; Ruddick, 1989), which should be relevant when the care-receivers are in vulnerable situations. Like small children, who are depending on surrounding adults, these people are unable or disabled to satisfy their own caring needs and to use verbal communication for conveying their wishes, needs and preferences. To be depending on care as an adult person was by Strandberg (2002, p 43) understood as a struggle for reduced suffering and a struggle for the existence in a deeper meaning.

The studied carers (III, IV) appeared to connect and create a communion with the residents through using ‘affective attunement’ (IV) (cf. Stern, 1985, p. 139-148) before
performing the observed ‘successful’ caring actions (cf. Kitwood, 1997, chap. 8). In spite of the unevenness in the relation between the carer and the care-receiver, caring was seemingly the deep human and professional communion between them (cf. Eriksson, 1997). Similar findings are reported from researching conversations with a woman with severe dementia by Normann, Norberg and Asplund (2002) and for people with aphasia after stroke for example by Sundin, Jansson and Norberg (2000).

**Understanding experience**

_We individualise only if we have conceptualised. And we individualise with a view of describing more. It is because we think and speak in concepts that language has to repair, as it were, the loss caused by conceptualisation_ (Ricoeur, 1992, p. 28).

Ricoeur’s (1976; 1991; 1992) views on narratives, identity, actions and metaphors presuppose that human experience can be brought into language. One person’s experience can never become other people’s experience, but through actions and language in the broadest sense, we can share an understanding of the meaning of our human experience.

**Understanding the meaning in actions**

The findings showed that the carers in the group dwelling used ‘affect attunement’ as a foundation for achieving an understanding of the residents (IV). The seemingly connected the sensed mood of the resident within the actual situation with scattered sentences, single words, sounds, and signs (cf. Brody, 1994). The interpretation indicates that the carer and the resident mutually shared the meaning embedded in the caring situations that were judged to be ‘successful’. It seemed they considered the heard words and noticed signs as really meant by the resident and took seriously what they sensed in the actual situation. Two of the included residents did not use any words at all, but did at times perform actions that were incomprehensible to me as an observer. The
‘communication’ that took place within the caring situation can be seen as an event in the ongoing discourse.

Viewing ‘successful’ caring performance as a realised event in a discourse (cf. Ricoeur, 1976, chap. 1; 1991, pp. 145-146) can shed some light on how these carers achieved an understanding of the residents, which they apparently shared the meaning of with residents. The signs and words that seemed meaningless were brought into language as meaning sensed and put into meaningful sentences and larger wholes for example the actual context, recent occasions, and the resident’s life stories as well as knowledge about how the dementia disorder can affect a person. My suggestion that Ricoeur’s (1976) view on discourse can be used to understand the findings of these professional carer’s means of achieving an understanding of people with severe dementia is demonstrated in Table 7.

Table 7. Interpretation of the carer’s means of sensing the residents’ mood and bringing the sensed and interpreted meaning of experience into language

<table>
<thead>
<tr>
<th>Carers means of sensing the residents’ mood</th>
<th>Bringing the meaning of the sensed, interpreted residents’ experience into language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuning in</td>
<td><strong>Language as system</strong> (cf. Ricoeur, 1976)</td>
</tr>
<tr>
<td>What the carers perceived through their senses: Comprehensible and incomprehensible signs words and actions.</td>
<td><strong>Language as discourse</strong> (cf. Ricoeur, 1976)</td>
</tr>
<tr>
<td></td>
<td>The carers’ actualisation of the event became understood as meaning something through their connection of the noticed with the context of the situation, recent occasions or events in the life story of the resident</td>
</tr>
</tbody>
</table>

As human life can be understood and expressed in stories (Cohler, 1991; Hatch & Wisniewski, 1995; MacIntyre, 1993, p. 203; Polkinghorne, 1995; Ricoeur, 1992), these carers can be seen as demonstrating a narrative competence for example they were able to create, participate in, tell and understand the residents as stories (cf. Brody, 1994; Norberg, 1994; Ricoeur, 1992, chap. 7). I suggest that this narrative competence
contributed considerably to the included carers’ observed proficiency in caring for people with dementia.

Following Ricoeur’s (1992, p. 145), special attention to humans as acting and suffering, the identified ‘good’ cares’ intentions indicate willingness to support the residents’ well-being. This view corresponds with narrative ethics that never can be neutral and presupposes the carers understanding of human life as valuable (Brody; 1994; Norberg, 1994; Ricoeur, 1992, chap. 7). It is also in correspondence with Lögstrup’s (1971) view on the ethical demand we have towards ourselves and each other. The understanding of these carers’ means of bringing the experience of people with dementia into language in order to share an understanding of the resident’s experience of the situation, invites further research.

Meaning embedded in metaphoric language

The feelings that were sensed as being embedded in living with stroke sequelae were in the findings expressed in a language of metaphors in order to convey the meaning of the feelings that were felt as embedded (I). So was the interpreted narrative identity of people with stroke in Vietnam (II) as well as the atmosphere sensed, observed and understood as being prevailing in the group dwelling for people with dementia (III). This way of presenting findings is accordant with Gendron’s (1994) suggestion that the creative pattern of care could be conveyed in a language of metaphors. The finding that the carers used maternal thinking (III) can be seen both as having a literal meaning emanating from the carers’ personal experience, and as being a metaphoric expression. The words ‘mother’, maternal thinking and practice have literal sense, but in addition these expressions mediate a figurative sense without end that goes back to life itself (cf. Ricoeur, 1994, p. 188). Maternal thinking was an integrated part of these carers’ personal experience and knowledge, but these carers did in no way treat the residents as children. On the contrary, each resident was met respectfully as a unique, elderly being in need of care. In some aspects the caring needs of people with severe dementia and small children
are similar and go back to the value of every human life, regardless of age or abilities. Thus, the metaphoric meaning is also applicable.

The carers in the group dwelling used several metaphors as a means to convey their meaning of their experience (III, IV). The metaphors were either instantly created or known as being local ones. These findings are in accordance with Frogatt (1998), who found that nurses who worked in hospice used a metaphoric language to articulate their experience. The metaphors used and found in this thesis conveyed meaning of embedded feelings (I), narrative identity (II) and the carers’ attitude towards the residents and the dwelling as a home (III) as well as a means to describe experience of meeting with the girls living on the streets (V). The use of metaphorical language in the nursing discipline is supported by nursing scholars for example Chondon (1992) and Gendron (1994). However, even if metaphorical language is useful as a means to convey subtle matters, it can also be a source of misunderstanding if people understand such language literally.

Caring and culture

...although certain aspects of caring are culturally contextual, the phenomena themselves transcend cultures and societies (Meleis, 1997, p. 418).

When caring as a human mode of being is manifested in caring actions (Roach, 1992) the caring activities do influence people and the surrounding culture. According to Bauman (2000) culture is the continuous and unending structuring activity that constitutes the core of the human praxis, the human mode of being in the world.

The samples of living with stroke (I, II) were small and there was no intention to compare the meaning of living with stroke sequelae in Sweden and in Vietnam. However, some differences emerged (I, II). Living with stroke in Sweden was found in the texts from some interviewees to harbour insecurity and uncertainty about what had happened, which was not found in the Vietnamese context, where certain values on caring within the family prevail (cf. Johansson, 2000, p. 16). These values seemingly influenced the caring culture in the ‘mini world’ of the hospital. The
relatives were supposed to be responsible for daily caring of the patients, not the RNs. These findings should be related to the prevailing socio-economic situation. Most in-patients received their food supply from relatives and the infrastructure was not sufficient for keeping the relatives informed about the patient’s actual condition if they remained at home. Further research can show if the values of family members’ involvement in caring activities during hospitalisation and after makes any difference to the meaning of the experience of stroke for the people affected and their relatives.

In the interviewed carers’ view of themselves, there are experiences of being daughters and of being mothers within their society with enduring ties to integrated, local values in their stories (III, IV, and V). (cf. Usita, 2001). This was seemingly helpful experience to the carers caring for people with dementia, but contributed to feelings of frustration and powerlessness of caring for girls living on the streets (V). The ‘maternal thinking’ of the carers in the home-like dwelling could contribute to constructing a culture where caring as praxis prevailed, whereas the carers working on the streets had no such context for their caring. In a society in rapid transition these carers still had integrated values in relation to regular girls’ behaviour and the extended family’s responsibilities. The tradition of the extended family system in East Africa is no longer working and there are no structures in the society that supports caring for girls living on the streets. They are considered as not ‘belonging’ but as ‘being out there’ in several aspects (cf. Bauman, 2000, p. xxx). These female carers can in a broader context be seen as involuntarily participating in a societal discourse where street children serve both wealthy and working class people as stigmatised symbols in a structure of a well-established hierarchy (Kilbridge, et al., 2000, chap. 7).

In contrast, the group dwelling can be seen as a structure, supported by the society in Sweden. This provided a home-like atmosphere with respect for the residents’ sensitivity to the emotional environment (Zingmark, pp. 15-16; Norberg, 2001). Such context should be an ideal ‘mini-world’ for both the residents and the carers to ‘feel being in here’ and for practising ‘maternal thinking’ with confidence. In this context
the professional carers could continuously participate in constructing and re-constructing a culture that emanated from and supported caring and “at-homeness” towards the residents’ well-being and their own professional development and satisfaction (III, IV).

Leininger (1991) suggests a theory of culture care as suitable for the nursing discipline, and advocates that care is the essence of nursing (p. 39), which she believes is culturally constituted in every culture (p. 23). She defines culture as the learned, shared and transmitted values, beliefs, norms, and lifeways of a particular group that guides their thinking, decisions, and actions in patterned ways (p. 47). Viewing caring as the human mode of being (Roach, 1992), a praxis that contributes to continuously constructing cultures (cf. Bauman, 2000) emphasises in the nursing field that we are responsible for our caring activities that structures the culture in homes and institutions as well as in the society.

Theoretical and methodological considerations

What has to be appropriated is the meaning of the text itself-not as an inner life of another ego, but the disclosure of a possible way of looking at things (Ricoeur, 1976, p. 92).

The subject in this thesis was the meaning of the experience of a severe illness i.e. stroke (I II) and of caring for people in vulnerable situations (II, III, IV, and V). The transcultural approach gave a unique opportunity for investigating these meanings, which I consider reflect universal values (cf. Nussbaum, 2000, chap. 1). However, the difficulties in performing narrative interviews in a language, which was foreign to both the interviewer and the interviewees may have left some unnoticed misunderstandings and misinterpretations in data, which have influenced and twisted some findings. The findings were thoroughly discussed with Vietnamese colleagues individually and in a seminar at a later stage (cf. Leininger, 1991).
Foreign cultures (II, IV) might be too foreign to make any contributions to the understanding of living with severe illness and of caring in Sweden. However, this approach provided an opportunity to view similar human experience, so as to let ‘contrasts clear the sight’ about the meaning of these experiences. The interpreted meaning in the studies must be regarded as belonging to societies with values of which we as Swedish authors had some, but limited experience and our ‘Swedish minds’ have certainly influenced our sensitivity to the message in the texts in both ways.

The philosophies and theories chosen as pillar-stones are presented and used as parts of the vast, sometimes lifelong work of famous scholars, which continuously provides me with new understanding. It can be questioned whether the chosen pillar-stones can go together, for example Roach (1992) whose ideas originate from philosophy and theology and Bauman’s (2000) originating from sociology. There are philosophies and theories advocating different views even contradicting those that are chosen. To view caring as a mode of being might be too idealistic for professional caring as caring is often more evident by its absence than by its presence in the human affairs surrounding us (cf. Roach, 1992, p. xi). However, the human values in question are of paramount importance to the nursing discipline.

The interpretation and use of ‘maternal thinking’ and ‘mothering’ have a connotation to women in our everyday language. Anyhow, these concepts should not be seen as related to the body of a woman, but to the experience and knowledge gained from caring for children (Ruddick, 1989; Holm, 1993). This view might also be too idealistic in that reality shows that the mothers / fathers do not always meet their infants’ and children’s needs for love, protection and support. I consider such parents’ conduct to be non-caring. Further research is needed to mirror daily realities better with collection of data that also include carers and care-receivers in situations that can be judged as non-caring, for example oppression, neglect, abuse and degradation (cf. Nussbaum, pp. 242-245).

The projective interviews as alternative to straightforward questions were used (I) as it was presumed that peoples’ psychosocial reactions to diseases could be determined in projective tests (Keltikangas-Järvinen, 1986) Unnoticed, impaired vision may have
interfered with these interviewees' interpretation of the photos. Being one of the authors, my experience of stroke (p. 24) may have twisted and narrowed the findings, but it may also have contributed to our sensitivity to the messages in the texts (I, II). I trust that my scientifically skilled co-authors assisted sufficiently to overcome some of this intrinsic bias (cf. Patton, 1990, pp. 150-157).

Performing interviews can be seen as events in discourses where meaning is produced (cf. Ricoeur, 1976). I have had different relations to the meaning inherent in the texts that is analysed in this thesis. In the first paper, the first author presented the transcribed text to me, whereas in Papers II, III and IV I was part of the meaning produced in text. I have also been influenced during the 'fixation of the discourse' i.e. I was responsible for the recording procedure and I transcribed the data that were presented to the co-authors. Apart from being part of producing the meaning in text analysed in Papers II, III and IV I also had memories of the context for the data collection, which may have influenced the process of analysing data. In Paper V the transcribed data was presented to me and I was involved in the analysis with the co-author who was one of the two interviewers.

The application of a 'narrative identity' within a life-story perspective (I, II) can be questioned as data did not contain information about these peoples' cognitive status, social situation or other adverse events. The perspective is defended as a means of viewing severe stroke as living with a severe illness, an adverse event that interferes with a person’s and the relatives' narrative identities and life stories (Cohler, 1991), even if it may coincide with other adverse events or pre-stroke conditions and post-stroke cognition.

The observations in the group dwelling focused on performance that I judged as being 'successful'. Ordinary routines, clashes, and misunderstandings were therefore not noticed or discussed further. A different meaning might have emerged had these been included. The purposive selection of 'successful performances' was essential for achieving the aim of the project (III, IV). The observed 'successful' performances were not counted as singular events, which might have carried further valid information.
The data analysed in this thesis were texts. A text involves potential meanings that can be actualised in different ways and thus presents a limited field of various probable interpretations. Even if the intention was to find and actualise the *most probable interpretation* of the meaning in the text by means of arguing for and against the interpretation made, it might be possible to sense and actualise other constructs of the meaning in the analysed texts (*cf.* Ricoeur, 1976, chap. 4).
SUGGESTED IMPLICATIONS FOR NURSING CARE

'Being present' entails letting go of that obsession with doing which often damages care work, and having a greater capacity simply for being (Kitwood, 1997 p. 119, Kitwood's italics in bold).

The disclosed meaning of living with a stroke and of caring for people in vulnerable situations indicates that the life-story perspective can be useful as a founding context for professional caring for these people. The life-story perspective can provide a frame for providing care for 'the whole person', regardless of age, sex or cultural heritage, provided that the person in question together with her or his relatives presents the life story in narrative dialogues.

The life story may need 'repair' after severe stroke i.e. the affected people should be supported to integrate the attack and its consequences with their narrative identity and to connect the past of their life stories with the future, so as to become actors again in their own life stories. As people understand themselves and others through stories, care-receivers and their relatives should be encouraged to tell their stories several times. Professional carers should listen to the stories with special attention to positive and negative changes in the story about the past, present and future expectations. Beloved relatives and appreciated friends should be regarded as involved in the care-receivers’ life stories as ‘plaster of Paris’. As such they can support the ‘fractured’ life story of the afflicted person. The relatives’ presence during all stages of stroke enables them to tell and re-tell what they perceived happened.

People with dementia have usually had a long past that carers should gain knowledge about in order to be able to share an understanding of these care-receivers’ present narrative identity and experience in the caring situations. For people with Alzheimer’s disease the relatives and friends are essential for preserving the past of the care receiver’s life story in which they have been, and still are involved.

The view of a unique, integrated person within a life-story perspective can hardly encompass a commonly conveyed view that a ‘whole person’ is composed of separated
parts of physical, psychological, social and spiritual components. The former view rather conveys a holistic approach, which should benefit planning, implementation and evaluation of professional care. Dialoguing with people within their life stories ought to open up for meeting the unique, integrated person with a steadily changing narrative identity within a life story in order to share the meaning of their embodied illness and need of care. I suggest that the life-story perspective provides a realistic foundation for professional caring that can support the health and well-being of people and thus contribute towards satisfying the care-receivers and their relatives as well as the carers.

Viewings caring as the mode of being headlights the personal responsibility professional carers have for their attitudes, behaviour and performance. Professional care is not only a matter of carrying out the right actions. The caring performances should ideally demonstrate the carers’ preparedness to assist the care-receivers and their relatives with their health and well-being. Caring as the human mode of being is rooted in peoples’ experience of caring, regardless of sex. Thus, nurse students’ personal experience of caring should be a subject for students’ recurrent personal reflections on their personal experience of and view on caring together with skilled preceptors in the nursing field throughout their education. These reflections should be related to theoretical perspectives and to the students’ experience during the practical education (Öhrling, 2000 pp. 60-61). The reflections should also include reflections on metaphoric language, its usefulness and limitations. Such opportunities should also be offered as in-service education for employees in the field of nursing care with a focus on caring as a praxis that constructs the culture caring in private homes, wards, nursing homes etc.

The method used to collect data in Papers III and IV with observations followed by reflective interviews made it possible to make some practical knowledge explicit (cf. Benner, 1984). This research method should be further developed and used with ethical consideration for further research in order to gain useful knowledge for the nursing discipline.
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My warmest thanks go to the people with stroke sequelae, who participated in the projective interviews, to the carers and residents in the studied group dwelling for people with dementia for your kind co-operation and for accepting my presence in your ‘home’ over the months it took to collect the data. It also goes to Dr Nguyen Ngoc Ham for making the study in Uong bi possible; to the patients’ relatives’ and nurses’ in who conveyed their experiences of stroke and to my co-author Tran Quang Huy for guiding me with cultural sensitivity and being enduringly keen to explain differences in the meaning in the languages involved. The carers in East Africa, who conveyed their experiences of working among girls living on the streets are included in my appreciation and warm thanks.

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REFERENCES


GLOSSARY AND DEFINITIONS IN THE THESIS

Affect attunement: Intersubjective exchange of affective states, where a parent ‘reads’ the infant’s state of feeling and imitates or corresponds to the infant’s overt behaviour, so that the infant reads the parental response as something relating to its own original feeling response. The parent’s imitative behaviour expands into affect attunement, which expresses the quality of feeling, a shared affect state (cf. Stern, 1985 p. 139-148).


Caring: The human mode of being (Roach, 1992, p. 47), actualised in activities performed to care for oneself or others to satisfy fundamental needs (Hendersson & Nite, 1997). When caring for somebody both the carer and the care receiver contribute to the relation with affective response (cf. Noddings, 1984).

Carer: The person who performs care privately or professionally for a person who is unable to care for her or his daily care.

Culture: The continuous and unending structuring activity that constitutes the core of human praxis; the human mode of being in the world (Bauman, 2000, p.43).

Discourse: Reflects a meaning that we take part in and can reflect upon. People’s use of language is seen as an action; an event that can be understood as meaning and be fixed in writing (Ricoeur, 1992, 1976).


Gender: Refers to the dichotomy between the sexes and norms in a society ‘prescribing’ how women and men should naturally behave and what they should do. Compare ‘sex’, which refers to nature, for example, being a woman or a man, (Holm, 1993 pp. 63-78).

Good care: Refers in this thesis to performing care that satisfies care-receivers and their relatives when applicable, as well as the carers.
Maternal thinking: Thinking, knowledge and skills emanating from caring for children in general, not as limited to women (Ruddick, 1989).

Maternal practice: The experiences, knowledge and ethical values that are achieved through caring for children; can be applied in other caring situations (Ruddick, 1989).


Life story: The story we tell about our life (Hatch & Wisnewski, 1995), continuously refigured by truthful or fictive stories a person tells about him- or herself, making this life itself a cloth of stories told (Ricoeur, 1985, p. 246). It need not cover the entire life span in all its aspects.

Narrative identity: The constitution of a person’s identity in an endless spiral through narrative activities in the dialectic of selfhood (ipse) as the existential being and sameness (idem) through comparisons with self and others as being similar. Identity is thus not seen as something a person has, but as something that is constituted in relation with others (cf. Ricoeur, 1985, p. 247 & 1992, chap. 6; Kristensson Uggla, 1994, pp. 441-449). The concept can also be applied to a group of people or a community (Ricoeur, 1985, p. 247).

Praxis: A cooperation between and conversation between equals in which these steep themselves in fellow human beings (Holm, 1993, p. 303).

Social practice: A necessary or accidental human activity done for a purpose and on the authority of certain habits, traditions, norms and conventions that has developed among the practitioners (Holm, 1993, p. 303).

Successful caring performance: Refers in this thesis to caring actions in a given situation that are presumed to satisfy the care receiver, their relatives when applicable and the carer.

Tuning in: Denotes the process of affect attunement (Stern, 1985, pp. 139-148).
Twenty-nine persons 60 to 91 years old participated in a study concerning living with stroke sequelae. They narrated stories about two different photographs showing a person of the same age and gender as themselves being fed or eating independently. The stories were analyzed and interpreted by means of a phenomenological hermeneutic method. Some interviewees identified themselves with the actor and the action that took place in the photograph and others did not. Four themes were found: uncertainty; sadness and mourning; gratefulness, hope, and satisfaction; and isolation. The stories varied regarding completeness and expressed optimistic or pessimistic future expectations. The stories were condensed into four core stories. The emotional content of each core story was expressed by a metaphor. The tacit knowledge embedded in the interview texts, expressed through core stories and metaphors, is essential to nursing care.

Each individual has a subjective understanding of his or her own illness. Past experiences can be understood in an entirety, giving them a meaning. One carrier of meaning as a whole is a story (MacIntyre, 2002).

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1985). Every person is involved in several different stories at the same time: the story of the country, the family, and so on. A person will tell a story as well as he or she is told as a story. The story of the lived experience gives individuals their identities (Polkinghorne, 1988; Ricoeur, 1976; Sarbin, 1986). The interpretation of lived experience is an ongoing process.

Stroke is a life-threatening disorder with potentially devastating consequences. Among survivors, impaired life satisfaction, including long-standing depression, is common (Parikh, Lipsey, Robinson, & Price, 1987; Viitanen, Fugl-Meyer, Bernspång, & Fugl-Meyer, 1988). The stroke attack will threaten the identity of the diseased person as well as that of the close relatives because the individual is part of other people’s life stories. It may be necessary to find a radically new interpretation of life for both parties (Arendt, 1958).

Sarbin (1986) suggested that human beings think, perceive, imagine, and value in the form of narratives. He supported this view by referring to an investigation by Michotte (1963), which showed that if two photographs are presented to a person, he or she will connect them to form a story, an account relating the photographs in a patterned way. Interpretation of photographs has often been used as a projective method to disclose experiences that the interviewee may not be aware of. It presupposes that human beings tend to perceive the world around them according to certain subconscious patterns (Patton, 1991). To understand how individuals looked upon their lives after a stroke attack, a narrative approach was used to analyze stories told by interviewed persons looking at photographs. This approach made it possible to interpret this comprehension as an entirety (cf. Ricoeur, 1976).

PURPOSE

The purpose of this study was to describe the stroke-affected persons’ experience of living with stroke sequelae and their future expectations.
Table 1: Description of the Subjects

<table>
<thead>
<tr>
<th></th>
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<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 19</td>
<td>n = 10</td>
<td></td>
</tr>
<tr>
<td>Age, mean</td>
<td>73</td>
<td>76</td>
</tr>
<tr>
<td>Living at home with spouse</td>
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<td>6</td>
</tr>
<tr>
<td>Living at home, single</td>
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<td>3</td>
</tr>
<tr>
<td>Living in an institution</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Eating problems during the acute phase</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Cerebrovascular diagnoses</td>
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METHOD AND SUBJECTS

This article presents one part of a follow-up study of stroke patients with and without eating problems (Axelsson, 1988). A consecutive series of 104 stroke patients (one did not want to participate) during a 16-month period was studied regarding eating problems (Axelsson, 1988). The patients were treated at a nonintensive stroke unit in Umeå University Hospital in northern Sweden. A follow-up study of some of these patients was made 18-22 months (mean = 19) after the stroke attack.

Inclusion criteria were one or more of the following: eating problems while in the hospital during the acute stage, remaining neurological sequelae at a 12-month medical checkup, and living in an institution 12 months after the stroke attack.

After exclusion of patients with repetitive stroke attacks (n = 6), impaired vision (n = 2) or speech (n = 4), and unwillingness to participate (n = 2) there were 29 patients (19 men, 10 women) included in this study. The age ranged from 60 to 91 (means = 73 for men, 76 for women). Eighteen persons (62%) had been diagnosed as having various kinds of eating problems during the acute phase. Marital status, residence, eating problems, and cerebrovascular diagnoses are shown in Table 1. All subjects had various sequelae after their stroke attacks.

The present study was preceded by assessments of nutritional status, oral function, and the function of cranial nerves. Then a test meal, equally composed for all subjects, was served. The meal was studied by means of participant observation. Observation was followed by an interview with semistructured questions, focusing on the
subjects' experience of eating problems and on their general well-being. The interviewees were approached for their informed consent. Each interview took place in the person's residence (27 in their homes and 2 in institutions). The project was approved by the Ethics Committee at the Medical Faculty, Umeå University.

Interviews

Two photographs (Figures 1 and 2) showing a person of the same sex as the interviewee were shown one after the other. Photograph 1 showed a person being fed in a hospital bed by a nurse. Photograph 2 showed the same person eating at the bedside, with the tray on the bedside table. While looking at the photograph, the interviewee was asked to explain what it showed, what feelings it evoked, and if there were any specific thoughts that the photograph brought to mind.

The interviews were performed and tape-recorded by one person (KA), who knew the patients from the hospital stay. The material was transcribed later.

ANALYSIS AND FINDINGS

The analysis was performed mainly by the first author, who had experienced two relatives dying of subarachnoidal hemorrhage while young (26 and 37 years old) and a spouse who had survived the same condition despite severe complications. This was believed to make her more sensitive to the interviewees' messages. She was not familiar with the material and did not know the interviewees.

The method of analysis was inspired by Ricoeur (1976). Ricoeur's phenomenological hermeneutics implies that people disclose themselves through their verbal expressions, which can be fixed as texts, in which the utterer's meaning (the meaning intended by the utterer) and the utterance meaning (the meaning in the text) can be found. In this analysis, the utterance meaning was searched for. The research thus presupposed that interpretation could reveal meanings of which the interviewees were not consciously aware. Similar analyses have been performed by Brown, Tappan, Gilligan, Miller, and Argyris (1989), Tappan (1990), Viney and Bousfield (1991), and Udén, Norberg, Lindseth, and Marhaug (1992). They proceeded as follows.
Figure 1
Naive Reading

The interviewees’ comments on the photographs varied. Most of the texts were about “him” or “her,” and frequently about “one,” as the main actor. Some men seemed convinced that they were the person in the photograph. The actions were mainly recognized as feeding and eating, but three men saw a microphone of some sort. Two women saw actions other than feeding or eating (reading, writing, and taking medicine). Mention of the words “hospital,” “nurse,” or any phenomenon related to hospital was interpreted as showing that the interviewee interpreted the person in the photograph as a patient, even if the word “patient” was rarely used.

Uncertainty and insecurity were often expressed. The greatest differences between the stories told could be seen in the feelings revealed: from hopelessness and isolation to hope, gratitude, and expressed satisfaction with the present situation.

Structural Analysis

Coding in Categories. The first step was to find answers to the questions of whom and what these stories were about. This resulted in four nonexclusive categories.

In the first category, interviewees perceived that the photographs showed them, or might show them, being fed and eating. Some of the texts given by men stated that the interviewees were convinced that the photograph showed them, or they expressed uncertainty whether the photograph showed them or anyone else (Photograph 1, 8 men; Photograph 2; 5 men).

In the second category, interviewees perceived that the photographs showed somebody else being fed and eating. Texts in this category clearly identified another person who was fed (Photograph 1, 3 men and 3 women) or was eating (Photograph 2, 6 men and 2 women) as the patient in the photographs.

A third category of texts stated that the photographs showed somebody being fed and eating at his or her bedside, like the interviewee had done. Most texts identified another person who was fed (Photograph 1, 5 men and 7 women) or was eating (Photograph 2, 7 men and 7 women) and combined those comments with the interviewee’s own experience from the hospital. Some interviewees added comments about their own present situation.
In the fourth category, no feeding or eating was expressed in the text. Few interviewees failed to identify any eating or feeding activity (Photograph 1, 3 men and 2 women; Photograph 2, 1 man and 1 woman).

**Identification of Themes.** In a second step, repetitive reading of each story was performed with the question in mind of what feelings these stories revealed. The interviewees most often interpreted the photographs as showing the same person in both; they therefore continued the story when looking at the second photograph. The themes (main characteristics) presented were identified on the basis of these complete stories made up from both photographs. The following themes were identified as covering themes. The same text could present two equally important covering themes.

More than half of the texts showed uncertainty as the covering theme. The dramatic change in the life situation bound to follow a severe stroke attack will trigger many questions and result in an active effort to create a new interpretation of the life story (Sarbin, 1986). The reinterpretation procedure presupposes an identity and an active process to integrate the disaster that has occurred in order to be able to plan for the future. Uncertainty as the covering theme was interpreted as an ongoing process of reinterpretation (Erikson, 1982; Polkinghorne, 1988, p. 105).

Five men disclosed uncertainty as to the identity of the acting persons in the photographs; their stories were filled with questions or uncertain statements. Sometimes this uncertainty was explicitly stated insecurity about the interviewee’s own identity. It seemed to be difficult to start a new interpretation without knowing whose story needed interpretation (3 men).

One example is illustrative:

I do not know. It looks like me. . . . I am no longer able to recognize myself.

Nearly one third of the texts expressed confusion regarding what had happened, either to the main actor or to the interviewee (5 men and 4 women). It was evident that these persons’ internal control was lost, replaced by a feeling of being at the mercy of external forces. In one example, an interviewee said:

To become this ill, to need help in this way. . . . but yet I do not know. See this room, the photos . . . I do not know that I have experienced this. I simply do not know that.
Another third of the texts, proportionally more women, disclosed worries about the future (5 women and 4 men). It seemed that the most worrying thought about the future was a suspicion that it might include hospitalization in a long-term care unit. Such a future seemed to cause more worry than did death. Death was mentioned explicitly only twice, and those stories did not reveal anxiety about death as such. One interviewee expressed anxiety concerning placement in a long-term care unit:

That is the worst thing. They look horrible, those places. When they get in they will get nowhere... if one gets in one will remain there... one cannot go any further.

A second major theme was that of unpleasant feelings such as sadness and mourning. The majority of the texts relating to Photograph 1 revealed unpleasant feelings. Those were expressed as sympathy with the photographed person or were related to the interviewee’s own situation, mainly as mourning for lost abilities. The texts relating to Photograph 2 changed the feelings revealed for the better, but the whole story of the two photographs combined continued the course of unpleasant feelings in a quarter of the texts. These feelings of sadness and mourning were interpreted as being a result of the ongoing reinterpretation process (4 women and 3 men). One interviewee said:

I was trying to clean a ditch, but that was absolutely impossible. There wasn’t any water, but I felt so sad when I realized that I had no power. I had to take my saw and try to reach home.

A third theme was gratitude, hope, and satisfaction. Nearly one third of the texts showed these positive feelings, even if some of those were combined with worries about the future. Gratitude could be seen in the texts either as relating to the professional assistance offered during hospitalization or to the interviewee’s own fate. Also expressed were hope for recovery and satisfaction with the progress that had taken place between the two photographs or clearly related to the interviewee’s own recovery. These more positive expressions gave the impression that a process of reinterpretation after the stroke attack had taken place. As one interviewee stated,

Wonderful not to be there again! It’s nice to be at home. There isn’t much difference now compared to what it used to be like when I was still healthy.
Another interviewee expressed positive feelings about the person in his story:

He seems to be on his way to recovery. He looks tremendously filled with hope, happy and so . . .

A fourth theme was that of isolation. One fifth of texts did not relate to any feeding situation but instead to other actions that could take place in a hospital, such as speaking in a microphone, reading, writing, and taking medicine. These stories were fragmented and confused. The texts were interpreted as disclosing a feeling of isolation, both from the family and from a broader social network (3 men and 2 women). The reinterpretation procedure seemed to be disturbed by denial. In one example, an interviewee described the photographs showing

a man speaking in a microphone, a tray and a table. An old man in institution. He cannot care for himself.

Finding the Progress in the Whole Stories. In the third step, an effort was made to discover the progress in each whole story. The text was considered to contain a whole story, representing both photographs, when it named one or more actors, described an action taking place, and provided an endpoint. In this whole story, the interviewee disclosed himself or herself and described past experience, present situation, and future expectations. This resulted in an interpretation of three different views that the interviewees had of their futures.

Few texts connected to Photograph 1 talked about the future. Those that did contained thoughts such as “it will be like this sooner or later.” Only one interviewee, when looking at this photograph, expressed satisfaction with being able to feed himself. When the stories had been completed with texts from both photographs, they displayed negative future expectations, positive future expectations and acceptance, or an incomplete story.

The recovery observed when the interviewee compared the two photographs could evoke negative expectations regarding his or her own progress (5 men and 3 women):

The same person has become quite strong. She is able to use a knife and a fork. I will not be able to get that far myself.

Most texts compared the two photographs and commented on the improvement that the patient in the photograph had made, often
combined with sympathy or happiness for the patient (4 of each sex). One such story stated, "I am happy that she has become so much better."

Satisfaction with the interviewees’ own present situation was expressed. Old age, declining power, and stroke sequelae seemed accepted (5 men, 1 woman). In one example, an interviewee stated, "He looks quite well and so am I."

Those who expressed uncertainty concerning who the actor in the photograph was and confusion about what had happened could not present a whole story (5 men and 1 woman). The text was fragmentary, as in this example:

A nurse ... an old man speaking on the telephone ... a hospital bed.

**Interpreted Whole**

After the text had been analyzed, no particular differences could be seen between the persons who had been assessed as having eating problems during the hospital stay or at the time of interview and those who did not have eating problems. This suggests that the interviewees gave a general meaning to the story they told, despite the assessments preceding the interview, which focused on eating. The story told was seen as the person’s interpretation in order to see a meaning (Parry, 1991).

In the narrative analysis, the concept of core story was used to denote an interpretation of the meaning the interviewees were communicating by telling a story. This is the core or central aspect of the story (Viney & Bousfield 1991, Udén et al., 1992). First, the interviews were compared concerning the themes of the structural analyses and sorted on the basis of the covering (i.e., most important) themes: uncertainty, sadness, and mourning; gratitude, hope, and satisfaction; and isolation. Second, four core stories were created by narrating experiences of living with stroke sequelae, based on the covering themes in the interviewees’ narratives. To illustrate the complexity of human experience, each core story is dominated by one theme, but all four themes are present in each story. In the last story, the main actor was put into the third person to illustrate that he barely revealed himself as familiar with himself in the text that embedded the story.

Third, the interpretation process evoked feelings in the authors that were significant for each one of the core stories but could not be stated explicitly. These feelings were interpreted as an important part
of the stories that had been transmitted to the reader. A metaphor was therefore developed to communicate the emotional message of each core story. For each core story, an attempt was thus made to express the meaning of living with stroke sequelae that was implicitly embedded in the text. It was not possible to express these meanings in narrative language; they could be revealed through construction of a metaphor (cf. McGaughey, 1988).

Wearing a piece of tapestry was chosen as the metaphor for life. This concept highlights the idea that among several given possibilities, the person will create his or her own pattern, which is not completed until the end of life. Stroke was seen as a disturbance in the weaving procedure. The four metaphors are based on the dominant covering theme in the preceding core story and mediate different modes of living with stroke sequelae. After construction of these metaphors, it was realized that Erikson (1988) had described human life as a weaving. In fact, a web is commonly used as a root metaphor of life (Sarbin, 1986). The four core stories follow.

The Story of a Married Woman Living at Home With Stroke Sequelae. The covering theme of this story is uncertainty.

I don't understand. I just cannot grasp what has happened and what's going on. I think I used to care for the others and they appreciated it. I am missing something, but I can't get hold of what. Cooking and eating, the togetherness at the table?

I am the first to feel pity for people who can't care for themselves and others like they used to do. Maybe some sort of illness has put me or somebody else in this situation and left me here with the overwhelming question: What is left if you can't care for your family as you have done throughout life, not even care for yourself? I do not want anybody else to do my duties in my presence, just watching and reluctantly admitting that I am a person needing help from others now. That person can't be me! So, who is it—needing help with what?

This woman was making a piece of tapestry that was kept together quite well, and she had created a pattern she found distinguishable. Then an accident suddenly occurred. She could not help it. She lost control, and many pieces of string were broken. Nobody could assist to rescue the pattern. It seems to be impossible to find it again. She does not know where to continue and what she is able to do. Sometimes she suspects that she has somebody else's material, even if she believes that the warp and the material belong to her. She has little or
The Story of a Widow, Living With Stroke Sequelae. The covering theme of this story is sadness and grief.

I know I have always been quite preoccupied with being left alone with my two daughters. I think I did manage. I had to manage, anyway. They have left home (and me?) now and they are independent grown-ups. I should be grateful that they are behaving well.

I can hardly think that they will ever be forced to take care of me, as I have been caring for them. Should that happen I would rather die so that they could mourn in the ordinary way. It seems they will never realize what I have been through, and to experience that I am a burden to either of them is just an unbearable thought!

In this story, the metaphor is that part of the warp in her piece of tapestry was cut just when the weaver had learned to weave on her own. She tried her best to mend the string and made an effort to make a pattern again, even if she had never seen one. She had been forced to carry on with the weaving, hoping that it would hold together. Now, when she is close to the end, she feels very uneasy about the result. She worries about the moment when the piece has to be cut. It might be obvious that some string has been lost ever since the accident, even though she has tried so hard to make a beautiful piece of tapestry. She thought all along that her intention had been to give it to the children. Maybe it would be better to destroy it, set it on fire! That would avoid the risk that they would see her mistake.

The Story of a Married Man Living at Home With Stroke Sequelae. The covering theme of this story is hope, satisfaction, and gratitude.

I understand—it did happen, I became seriously ill in a stroke. I have seen so many others—relatives and friends—so I do understand it did happen to me. I am grateful that I have recovered so much.

You are quite helpless when you are confined to a bed and depending on others for everything. I was offered all the assistance I needed in a very friendly and professional way during my stay in the hospital.

I pity my fellow men left in the long-term care unit. I am happy that I am not one of them. I do realize that most of my lifetime has passed and my life will come to an end. Right now we are able to care for ourselves, my wife and myself, and every day adds length to our lives, which are filled with memories by now.
This man has understood that there are few pushes and tugs remaining. He is at the end of a pattern, which he can see clearly now. He realizes that close cooperation with others has given his piece of tapestry its specific pattern. The warp will soon be finished, and his piece is about to be cut down from the loom. He admires the pattern and feels satisfied with what he has created. He has managed to mend a few pieces of string, and the material will be sufficient for the remaining warp.

**The Story of a Single Man With Stroke Sequelae.** The covering theme for this final story is isolation.

He is suddenly realizing that he is growing old. He thought all along that he would have time enough to fulfill his dreams. Then this stroke attack hit him like a thunderstorm. He cannot understand how it happened. People in his neighborhood, but still far away, who are much older and less healthy, seem to make choices for their own future together with their families. The home aides visiting his home and assisting him are kind and quite helpful with most of the practical things that he cannot manage on his own.

Occasionally he makes use of the phone to have a chat with a distant relative or a friend. That gives him an opportunity to hear a familiar human voice and to make use of his own.

He has almost forgotten what he used to do and what he wanted to become. Something happened that interrupted his everyday life, and he does not know how to continue. He is waiting for somebody who can come and explain the mystery. There is an insight that he is trying to suppress, that can hardly be digested—a suspicion that this WAS his life!

This man has been forced by uncontrollable external circumstances to gaze at his piece of tapestry, what he has produced. He is almost forced to reflect on the pattern, which he can’t see. When he does so, he understands that he has lost some string in his warp a long time ago without being aware of it. The piece of tapestry can hardly hold together, but it is still in the loom. There is not much warp left, and there is not enough material to continue the pattern he thought he would be able to make but was unable to see.

**REFLECTIONS**

The interviews transcribed were regarded as texts (Ricoeur, 1971) that were interpreted by means of a method based on Ricoeur’s pheno-
menological hermeneutics (Ricoeur, 1976; Brown et al., 1989; Udén et al., 1992). In accordance with Arendt (1958), it was assumed that humans disclose themselves, showing who they are, even when they talk about objective matters.

The interviewee interpreted two photographs by telling stories about them in a communication with a researcher as one part of a follow-up study carried out after a stroke attack. The preceding parts of the investigation concerned eating problems.

The analysis of the text given as a reaction to the photographs showed that those who could identify a main actor and an action could also tell a story and relate themselves to that story. Interviewees seemed confident of their fates and could reveal their expectations even if those were unpleasant and sometimes explicitly included various stroke sequelae.

It is considered an important professional task for a caregiver to be a good listener in order to understand the persons under his or her care, thereby helping those persons to find their own voices and take charge of their own histories (Parry, 1991). It is suggested that professional nursing care should include a goal-oriented action regarding how the patient will be able to keep his or her own life history together after a stroke attack, as the stroke will most likely result in a need for a radically new reinterpretation before the patient is able to look ahead to an altered future.

The tacit knowledge embedded in nursing care needs a language different from enumerated facts. The latter is useful for some purposes and should be complementary to life stories and a metaphorical language in nursing education. The need to use narratives (Parry, 1991) and metaphors (McGaughey, 1988) to express “tacit knowing” has been addressed previously. Both have been reported as beneficial in everyday therapeutic communication (Larkin & Zahourek, 1988, p. 46). It can therefore be assumed that stories and metaphors would be a useful tool in the care of persons living with stroke sequelae.

Periods of unconsciousness make it important to encourage the presence of beloved relatives during the acute phase of stroke, to assist in “mending the warp” as part of the rehabilitation. If there are no relatives at hand, the nurse should consider it an important therapeutic role to become a story-listener in order to assist the patient to retell and reinterpret the story of his or her own life.

The use of metaphors may increase caregivers’ understanding of the patient’s life experience. Smith (1992) suggests that metaphors not only communicate meaning but also suggest paths for action. A
metaphor serves as "the shock to think more" (McGaughey, 1988, p. 415). Young persons may get a more realistic view of how an elderly person with a long life story may need assistance to carry on with the weaving of the piece of tapestry of her or his life.

REFERENCES


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Patients', Relatives', and Nurses' Experience of Stroke in Northern Vietnam

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Astrid Norberg, RN, PhD, Professor**
Tran Quang Huy, RN***

Transcriptions were made of interviews held in Vietnam with five nurses, five people affected by stroke (aged 28-60), and with one relative each. Their stories were analysed as texts by means of a phenomenological hermeneutic method. The role of the nurses in Vietnam appeared to differ from that usually ascribed to nurses in Western institutionalized care. In the former a relative was expected to carry out basic care during the acute stage and to assist socioeconomically thereafter. The interviewees spoke of family bonds in the past, present, and future tenses when narrating their experiences of stroke as nurses, patients, and relatives. This was interpreted as an indication of a consciousness of an essential relatedness. Nurses were aware of playing a temporary and secondary role mainly as assistants: firstly to the doctor by carrying out orders and reporting, secondly to the stroke patient and his or her family by carrying out advanced nursing procedures and giving support. The advantages and disadvantages of involving the family in nursing care can be revealed by obtaining views from a different culture, which can provide a contrast against which constructive criticism of the Western nursing tradition can be made.

If something acute and life threatening such as a stroke happens to an individual, it will affect the long-term quality of life, not only for the person affected, but also for his or her family since the individual is part of other peoples' lives (Evans, Griffith, Haselkorn, Hendrick, Baldwin, and Bishop, 1992). It may be necessary to find a radically new interpretation of life for both parties (Arendt, 1958).

The presence of an informal support network of kin, friends, and neighbors has been recognized as a predictor of well being and autonomy for older people in the United States (Brody, Poulschock, and Maschiocchi, 1978; Lopata, 1975; Wentowski, 1981). It seems reasonable to assume that such positive effects of the presence of an informal support network of kin are beneficial for people of all ages regardless of nationality. In Western countries the participation of close relatives often takes the form of visiting the institutions where their sick relative is a patient. They may or may not share in the care and treatment during the hospitalization, but they will remain ultimately responsible for the patient's welfare especially in long term-care situations (Evans et al., 1992).

In most places in the world care is generally carried out in homes by family members. In some cultures this continues when the sick person is admitted to hospital. Such generic care is generally rooted in the emotional bonds between the caregiver and the ill person. In this respect generic care is not always interchangeable with care from a health care professional. Therefore, the care and the designation of the caregiver for a sick individual depends on the culture of a society (Leininger, 1981, 1985, 1991). The role of the nurse may be different if the basic nursing care is carried out by the relatives, compared to the predominant practice in Western cultures where the relationship between a nurse and a patient is the basis for care, cure, and rehabilitation.

In Vietnam often two or more extended family generations live closely together. Collective obligations and decision making are emphasized in their everyday lives (Hickey, 1964). Despite a per capita income of less than 200 US dollars a year, 84% of the female population is literate, and the life expectancy exceeds 65 years (Kaufman and Sen, 1993). Health needs of Vietnamese people are best understood in terms of the family unit which is extended, collectivistic, and patriarchal (Gold, 1992). Thus, it is natural for family members to provide support and take responsibility for the basic generic care and rehabilitation of each other when a family member is suffering from a serious illness that needs treatment in an institution. These circumstances assume that a professional nurse will be given a role and undertake it. This is different from the most common practice in the West. Very little has been done to investigate and describe the roles of professional nurses and family members in the care and rehabilitation of stroke patients in cultures where the family units are the foundation of the total generic care and well being of the members.

Aim

The aim of this investigation was to explore nurses' and relatives' experiences of caring for stroke patients and to illum...
nate the stroke victim's experience in Northern Vietnam by means of a phenomenological hermeneutic interpretation of personal interviews. The findings will be contrasted with Western practices for reflections to benefit the nursing profession transculturally.

Method

Theoretical Framework

A phenomenological hermeneutic framework inspired by Ricoeur's philosophy (1976, 1992) was chosen. The leading idea of phenomenology is to "...go back to the things themselves" (Husserl, 1970/1990, p. 252). Phenomenology seeks to uncover the concealed meaning in lived experiences and hermeneutics interprets the meaning beginning with a naive approach to understanding the whole via an examination of parts and progressing to a comprehensive understanding of the interpreted whole. Ricoeur thus combines phenomenology and hermeneutics and sees them as interdependent with equal rights (1976, pp. 80-85).

Procedure

During a three-week stay in Uong Bi, in a Northern province of Vietnam, interviews were conducted by the first and the third authors. The latter is a Vietnamese nurse in a general hospital. The interviews were preceded by meetings with the hospital staff to give information about the background of the study, the philosophy, and ethics involved. The final preparation was a trial interview, which was carried out as a role-play, with a matron as informant and the Vietnamese author in the role of interpreter. Some minor amendments were made to the translations of the questions from English into Vietnamese and vice versa in all interviews.

The first author listened to the recorded tapes together with an experienced interpreter. This interpreter had not participated in the project. His few suggestions for alternative translations from Vietnamese into English were noted in written form. Copies of the tapes were taken to Sweden where they were transcribed verbatim by the investigator. The informants were asked for their signed consent prior to the tape-recorded interview. The project was approved by the Ethics Committee at the Medical Faculty, Umeå University.

Informants

Five nurses, who had worked in their profession 7-12 years were interviewed individually in the nursing office. The staff of the two medical wards were asked to find Vietnamese patients who were less than 60 years of age, had suffered a stroke attack during the past twelve months, and were able to talk. Three Vietnamese inpatients met the stated criteria together with two Vietnamese patients who had been discharged from the hospital and lived within the township. It was made known that if there was a family member present at the time of the interview, he or she would be asked to participate in an interview directly after the interview with the patient. All five patients had family members assisting them at the time of the interview. Characteristics of the informants are presented in Table 1.

Interviews

After the initial greeting and attempts to create a relaxed atmosphere, the informant was asked three questions requiring short, precise answers: How old are you?; Are you married?; and What is the size of your (extended) family? Apart from providing relevant background information, these questions were regarded as polite and appropriate to ask when two people meet for the first time in Vietnam. The interview with the nurses continued with questions concerning the kind of nursing education they had and how many years they had worked as nurses. The interviews with patients and relatives were made using the same method. Questions were asked regarding their occupation and the relationship between the stroke victim and the interviewed relative.

A narrative interview technique was used. In a narrative perspective, individuals understand their own illness in the entirety of a story (MacIntyre, 1983). One person is involved in several different stories: the story of the country, the family, and so on. According to Tappan (1989), a person will tell a story as well as be told a story. The story of lived experiences contributes to the identity of the individual, and the interpretation is an on-going process (Poikinhoorne, 1988, and Sarbin, 1986). Story telling as a part of making up the identity also presupposes a listener. For example, the presence of a you in order to identify an I (Burgh, 1970).

All informants were encouraged to share their lived experiences of stroke with the interviewers (Mishler, 1986). Guidance for the interview indicated that the story should include the informant's view of life at the present time, in the past, and as expectations for the future. These questions focused on one experienced stroke episode from the perspective of the victim, a relative, and a nurse. Follow-up questions were often asked such as: How did you feel then?; Can you explain a bit more? Clarifying questions were also asked. For example: Do I understand you correctly?; Do you mean to say—?” One interview was conducted with each informant and lasted 45 to 60 minutes.

Analyses and Findings

The project was influenced by the first author's previous experiences. Her experiences with a severely stroke-affected spouse had provided her with a lived experience of both being much needed at the bedside and having her own need to be present. Prior to the episode she had worked in Vietnam as a Swedish advisor in a primary health care project (Swedish International Development Aid). The remembered impressions included the involvement of the extended families which seemed to intensify if a family member became ill. The memories of family care in Vietnam were contrasted with the perceived view of family roles in Swedish hos-
Table 1
Characteristics of Interviewees

### Nurses

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</table>

*spouse, subject, & children included
**completed 2 years of nurse training & then worked as enrolled nurse for 6 years. Then completed 2 years RN education/training and has worked as RN for 2 years.

### Patients

<table>
<thead>
<tr>
<th>CODE #</th>
<th>AGE</th>
<th>GENDER</th>
<th>FAMILY SIZE*</th>
<th>TIME SINCE STROKE</th>
<th>OCCUPATION</th>
<th>SYMPTOMS <strong>/ SIGNS</strong>*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1**</td>
<td>31</td>
<td>M</td>
<td>4</td>
<td>2 mos.</td>
<td>ships mechanic</td>
<td>paralyzed L side looks worried***</td>
</tr>
<tr>
<td>2</td>
<td>28</td>
<td>F</td>
<td>3</td>
<td>2 mos.</td>
<td>farmer</td>
<td>paralyzed R side weak (interviewed in bed)</td>
</tr>
<tr>
<td>3</td>
<td>65</td>
<td>M</td>
<td>11</td>
<td>6 mos. (i) 10 days (ii)</td>
<td>colonel (retired)</td>
<td>paralyzed L side** impaired speech**</td>
</tr>
<tr>
<td>4</td>
<td>54</td>
<td>M</td>
<td>6</td>
<td>11 mos.</td>
<td>engineer</td>
<td>headache**</td>
</tr>
<tr>
<td>5</td>
<td>60</td>
<td>F</td>
<td>9</td>
<td>12 mos.</td>
<td>cleaner (retired)</td>
<td>paralyzed R side**</td>
</tr>
</tbody>
</table>

*spouse, subject, & children included
**observed
***patient’s complaints
(i) first episode (ii) second episode

### Relatives

<table>
<thead>
<tr>
<th>CODE #</th>
<th>AGE</th>
<th>GENDER</th>
<th>FAMILY SIZE*</th>
<th>OCCUPATION</th>
<th>RELATION TO PATIENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>27</td>
<td>M</td>
<td>single</td>
<td>farmer</td>
<td>younger bro.</td>
</tr>
<tr>
<td>2</td>
<td>60</td>
<td>F</td>
<td>6</td>
<td>farmer</td>
<td>mother</td>
</tr>
<tr>
<td>3</td>
<td>51</td>
<td>F</td>
<td>6</td>
<td>farmer</td>
<td>younger sis.</td>
</tr>
<tr>
<td>4</td>
<td>48</td>
<td>F</td>
<td>6</td>
<td>retailer</td>
<td>wife</td>
</tr>
<tr>
<td>5</td>
<td>39</td>
<td>M</td>
<td>4</td>
<td>factory worker</td>
<td>sister’s son-in-law</td>
</tr>
</tbody>
</table>

*spouse, subject, & children included
pitals. This is evident in the cheerful questions from hospital staff in Sweden such as, *Are you visiting today again?* As an employee in development programs in Zambia (1978-82) and in Vietnam (1984-85) the first author was invariably intrigued by the way health care workers solved difficult problems in spite of the serious lack of materials, facilities, and the type of knowledge that Western countries consider important. Care was rarely left to the hospital doctors and staff only, but was a matter in which the whole extended family participated.

The transcribed material was analysed by a method inspired by Ricoeur who states that people disclose themselves through their verbal expressions which can be fixed as texts in which the utterance's meaning (the meaning intended by the informant) and the utterance meaning (the meaning in the typed interview text) can be found (1976, pp. 12-13). In this analysis it was the utterance meaning that was sought. It was thus presupposed that interpretation could reveal meanings that the informants were not consciously aware of. Similar analyses have been performed for example by Viney and Bousfield (1991) and Åström, Jansson, Norberg, and Hallberg (1993).

**Naive Reading**

A naive reading started when the first author proceeded with the transcription. The aim of it was to get a sense of the interview text as a whole and to formulate guesses for the following structural analysis (Ricoeur 1976, p. 74). The process of naive reading led to formulated guesses about socioeconomics and the meaning implicit in the pronouns used by the informants.

The socioeconomic situation was mentioned in most interviews as being an important part of the history as well as having a crucial role for the future. As this was a specific statement made in several interviews it was interpreted as an important part of the social context and was not taken any further in the analysis. Examples from the interviews were:

**Nurse No. 2:** This disease is not caused by living conditions. The rich also get this disease—and the poor too.

**Patient No. 2:** Of course we lose the income, but we must accept any support we get from the family.

**Relative No. 2:** If I work hard, I will get more [=money].

The five female nurses were a homogeneous group in length of professional preparations, period of work, family size, and length of employment, whereas the patients as a group and their relatives as another group varied widely as to age, occupation, and the time that had elapsed since the stroke occurred. Nurses seemed to have a temporary role in the patients' and relatives' lives. They seemed to consider themselves the doctor's assistant first and the patient's or relative's nurse second. Nurses mostly used *we*, when they spoke about themselves. *I* was the most commonly used pronoun in the patients' stories and they related subjective symptoms and feelings. The relatives varied the pronouns, and their stories corresponded with the patients' stories quite well. As the three groups used different pronouns for the main actor in their stories, it was suggested that the choice of pronoun had a specific and implicit meaning (Åström, et al., 1993). It was further suggested that such meaning would possibly be visible if the chosen pronouns were related to the actions taken.

The patients, relatives, and nurses seemed to consider it as self-evident that there should be a relative involved at all times even if the patient was unconscious. A sense based on the naive reading was an idea of the family's history as a foundation for present and future care by family members. This led to the decision to analyse the informants' narratives of their lived experience of the stroke with regard to use of pronouns and the tenses: past, present, and future.

**Structural Analyses**

**Step No. 1 Identifying Actors, Actions and Tenses**

In each story the actor and the action were identified. The narrator often became the main actor in the story. In accordance with Åström, et al., (1993) the way the main informant talked about her/himself was noted. In addition, each statement was put into separate columns in three different sections that indicated the action in the past, present, and future tense. This step clarified three different types of stories. This analysis is exemplified in Table 2.

**Nurses' stories**

Nurses used *I* as a pronoun for the main actor in a few sentences like: *I think, I remember.* In their caring actions the main actor's pronoun was *we*. They used *he* or *she* for a stroke patient or a relative or a doctor. Their stories had few actions in the past tense and even fewer in the future. All stories included a family member besides a stroke patient in all three tenses. Various aspects of professionality were expressed in the actions, such as professional knowledge about stroke and nursing procedures carried out. Some examples were: "...and we always put the patient in the position we call 'functional position.'" and "There was always a relative close by the bed—a son."

**Patients' stories**

The main actor was mostly *I* in all three tenses in the patients' stories. These were often dramatic and very detailed in past tense as they included whereabouts, time, interrupted action, and the actor's subjective feelings. The most intense episodes in the past were told in the present tense, embedded as episodes in the past. Relatives as actors had taken part during the acute stage and were included in the future. The three older people were confident of their fate, whereas the two youngest combined *I* with expressions for insecurity and worries about the future. Two stories made no mention of the presence of nurses (the two youngest patients), whereas three mentioned nurses on a few occasions with the pronoun *they*. Their actions involved assisting and caring. One patient stated:

*You know, well, we had a party to say good-bye to one of my friends, so we drank some beer and after that we played cards and there was some tension for me while playing cards, yes, so suddenly I feel some very strange feeling, yes, and after that I see—I told my friend and recognized that my mouth is not normal! Yes, it is drawn to one side.*

Another patient stated, "Yes, my wife was to stay with me... She was there to take care of me and to prevent me from falling..."
Experience of Stroke in Northern Vietnam

down." Another said, "I have to depend on... I have to ask my husband to help me. I have to depend on him..."

**Relatives' stories**

The relatives' stories varied concerning the main actor. The pronouns I, we (referring to us relatives), he or she (mostly referring to the stroke affected person) were used. Their actions were also dramatic concerning the attack. Three of the stories were based on hearsay in the past tense, as the storyteller had not been present on the occasion. The storyteller was involved in the victim's life in all three tenses. For instance, one said, "I am sure he is worried about his future. But a relative has to be with him and encourage him."

**Step No. 2. Similarities and Differences in the Stories of Nurses, Relatives and Stroke Patients**

One of the nurses referred to stroke patients in general and two had a particular patient in mind who was not included in this study. The remaining two nurses spoke about two patients who were included in the study which provided an opportunity to compare the stories told about the same episode by a nurse, a relative, and the patient himself or herself. Nurses' individual stories could not be compared with patients' or relatives' stories, so the analysis for this group could not be taken any further than has been reported in step No. 1.

**The stroke patient and a relative = two dyad stories**

The patients' stories had mostly I as the main actor, whereas the relatives had he or she and I or we when they spoke about themselves. It was undoubtedly the same incident that was described as two stories, with several common details. The main differences were the subjective symptoms and feelings expressed in the patients' stories. These were repeated and verbally underlined by the patient but not mentioned by some of the relatives in the past or present tense. Their worries about the future had some similarities, but were expressed differently in the otherwise parallel stories. Three of the patients' stories had comments about nurses, whereas their relatives did not mention them. The opposite applied to the two remaining patients where the comments on nurses where missing but appeared in the relatives' stories.

**The stroke patient, a nurse, and a relative = two triads**

The nurses' stories had very few comments on the history or about the future expectations (comparing individual stories), whereas the patients' and the relatives' stories were detailed. The greatest differences were to be found when the patients expressed their subjective symptoms—headache, weakness, and difficulties in walking. The relatives related some of these symptoms in a few words but the nurses did not even mention them.

**Interpreted Whole**

Lastly the interviews were read through again. The entire text was interpreted as a whole taking the first author's horizon of expectations, the results of the naive reading, and the results of the structural analysis into account. The professional nurse seemed to be given and accepted the role of an important and professional assistant. She assisted the doctor by carrying out his or her orders and assisted the relatives by giving them advice and support. The finding that in the nurses' stories we was predominantly used as the pronoun for the main actor which was interpreted as a conscious reference to a collectivistic belonging. The nurses also used we, when they talked about actions they took as individuals. This was seen as indicating an awareness that some tasks had to be done by a certain trained nurse, but such tasks could be completed by any other trained nurse on duty.

The patients only used I to indicate the main actor. This was interpreted as a specific individually lived experience that could not be shared physically with anyone else, that is; suffering, pain, impairment, and dying. A next of kin may be willing to support but will not be able to share intense sensations, feelings, and experiences. As various relatives frequently were referred to in all three tenses in the patients' stories, it was seen as an awareness that these relatives had been part of the victim's life story, and there was an expectation for a continuation in the future.

An important finding was that occasionally the stroke victims and their relatives narrated detailed episodes in the present tense while embedded in the past tense. When they spoke about how it all happened in the present tense this indicated that such episodes were still in the process of being reinterpreted. This interpretation was made in the context of an uninterrupted sequence of telling a story. The informant suddenly switched tense and seemed to view the events of the story he or she was telling as if reporting an ongoing film or game. When this present tense episode was over and the informant switched back to the past tense, it was obvious that he or she was involved in the story. Such interpretation can be compared to Lakoff's and Johnson's statement: "Self-understanding requires unending negotiation and renegotiation of the meaning of your experience to yourself" (1980, p. 233). The switching of tense represented a negotiation process of whether to accept the stroke episode as an integrated part of the life story or not.

The presence of family members seemed to be of paramount importance for all three parties involved; the nurses, the patients, and their family members. It was interpreted as being implicit in the stories that a shared family history led to the expectation of support in various situations in life, right now and in the future.

The relatives often used I as the pronoun when they talked about themselves except when they expressed concern about the future. Then they used we which indicated that they included other relatives. This finding was interpreted as an expectation that the extended family would share the future burden. In the relatives' stories the victim often appeared as the main actor as he or she. The finding of a frequent change of main actors in the relatives' stories was interpreted as having a twofold significance—on the one hand an awareness about their personal involvement in the life story of the stroke patient and on the other hand a preparedness to continue to include this person in the family. This indicated a quality in the relationship between the patient and his or her relative, which included a continuation of the care that could not be handed over to someone else.

The interpretation of the relationship between the patient and his or her relative contrasted with the interpretation of the relationship between the nurse and the patient. A sense of helplessness in facing the future was seen in the relatives' stories. This alternated between hope and despair emanating from a hope of further recovery and a suspicion that the stroke victim could
Table 2
Illustration of the First Step in the Structural Analysis
NURSE #4

<table>
<thead>
<tr>
<th>PAST</th>
<th>some patients</th>
<th>a specific patient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>· had hypertension before</td>
<td>· had paralysis</td>
</tr>
<tr>
<td></td>
<td>· had another disease</td>
<td>· had speaking difficulties</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· had swallowing difficulties</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· was at first semiconscious or confused</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· (then) could walk by himself</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· (then) could speak normally</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· (then) became fully conscious</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· was very grateful on the day of discharge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· was widowed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· lived together with son and his wife</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PRESENT</th>
<th>patients generally</th>
<th>some patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>· are anxious, worried</td>
<td>· are slightly affected</td>
</tr>
<tr>
<td></td>
<td>· not only poor, but rich alike (are victims)</td>
<td>· are severely affected</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>most severely ill</th>
<th>paralyzed patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>· are unconscious or semiconscious</td>
<td>· may get pneumonia</td>
</tr>
<tr>
<td></td>
<td>· cannot communicate</td>
<td>· often have a lot of secretions</td>
</tr>
<tr>
<td></td>
<td>· are in coma or are paralyzed</td>
<td>· some poor patients</td>
</tr>
<tr>
<td></td>
<td>· are incontinent</td>
<td>· · get support from the hospital</td>
</tr>
<tr>
<td></td>
<td>· cannot eat</td>
<td>· · can take care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· a specific patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· looks after his grandchildren</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· a specific patient's relatives</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· are always close by the bed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· a specific patient's son</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· stayed there throughout</td>
</tr>
<tr>
<td></td>
<td>relatives generally</td>
<td>we</td>
</tr>
<tr>
<td></td>
<td>· are anxious, worried</td>
<td>· encourage relatives</td>
</tr>
<tr>
<td></td>
<td>· one is always at the bedside</td>
<td>· take care together with relatives (severe cases)</td>
</tr>
<tr>
<td></td>
<td>· together we feed</td>
<td>· work hard with patients' pressure sores</td>
</tr>
<tr>
<td></td>
<td>· if poor, cannot afford right diet</td>
<td>· change positions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· manage personal hygiene</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· clean the mouth</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· have to take observations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· report detected abnormalities to the doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· have to put in flat lateral position</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· suck (secretions)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· supervise food/feeding (type &amp; amount of food)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· report poor relatives to doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· have some poor patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· are happy, glad in discharge if patient recovers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>· prescribe tube feeding</td>
</tr>
</tbody>
</table>

|               | doctor | we |
|               | · prescribes tube feeding | · encourage relatives |
|               | · orders amount of food | · take care together with relatives (severe cases) |
|               | · reports poor patients to hospital board | · work hard with patients' pressure sores |

<table>
<thead>
<tr>
<th>FUTURE</th>
<th>a specific patient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>· cares for himself</td>
</tr>
<tr>
<td></td>
<td>· looks after his grandchildren</td>
</tr>
</tbody>
</table>
Experience of Stroke in Northern Vietnam

not recover any further. Most comments regarding the future seemed concentrated on the economy of the family. This was seen as another indication that it is not only the stroke victim who is affected but the total well being of the relatives in a broader socioeconomic way.

The experience from Vietnam that human phenomena in life can be understood in poetry and metaphors gave rise to the idea of creating a metaphor which could capture the lived experience of being a person affected by stroke in Vietnam (Viney and Bousfield, 1991; Häggström, Axelsson, and Norberg, 1994). The researcher reacts in some way to the metaphor with its symbols and achieves a new understanding (Lakoff and Johnson, 1980, p. 8). A metaphor manifests remarkable powers over the human mind as one of its powers is the ability to devise conceptual structures and project them onto reality (Turbayne, 1991). Biedermann states that the use of a net as a symbol (in metaphors, for instance) indicates catching (1991, p. 299). This symbolism is, for example, used in Luke 5:1-11 (The Holy Bible) in the story about the calling of the first disciples. Some fishermen were washing their nets after a night of no success by the Lake of Gennesareth. Jesus talked to the people and "...he said to Simon: 'Put out into deep water, and let down the nets for a catch.'" When the fishermen had caught a large number of fish, Jesus said to Simon, "'From now on you will catch men.'" After that the fishermen left everything and followed him.

In order to verbalize the subtle message of the interview texts as a whole, a metaphor of a net was created by the first author (Häggström, et al. 1994). It illuminates the embedded sense of relatedness to a family as a prerequisite for experiencing meaning in life for these patients. It further illustrates how one human (any of the interviewed stroke patients) is part of the stories of others (the family’s), and entangled in a network that will permit the meaning of life to be captured within such a network. A stroke patient is given the focus of the narrator:

My life was, is, and will continue to be a tiny bit of a living and growing fine thread, a thread that started with my birth (and will end with my death?). My life-thread is mine and is interwoven into a network with others’ threads. Together we are the creation that constitutes our family net, which made and makes us a meaningful, useful, and respected body in society. But lightning or something else incomprehensible, hit my thread and destroyed most of it. It is not completely cut, but very thin—a sudden and unexpected weakness, that I am painfully experiencing.

If my thread breaks it will leave a hole. The other threads give temporary release to the tension on my thread. My line in the net has been taken in for repair, so we are involved in some kind of mending work. For that we need professional assistance. This episode was beyond the common weaknesses in our net that are usually rapidly mended with some stitches by somebody more experienced. I feel I am expected to participate actively in this mending procedure, but I am too preoccupied with enduring my headache and sorting out my worries about the future.

I wonder if we will be able to keep our net together. Will it be possible to make it work as an efficient catching instrument again? Or will a valuable thing pass through my hole and make the tension on the rest of the strings unbearable. If I cannot be completely mended, I might need another string more or less tied to mine thus reducing our catching area.

Reflections

The main findings in this study of the role of nurses and family members in the care of stroke patients in Vietnam were that the interviewed informants expected members of the stroke victims’ families to take the responsibility for the basic care at all times of the day during the hospital stay. All informants seemed to consider the family as an entirety where the stroke affected the whole family. Thus the individual relative regarded him/herself as involved and found it natural to participate in the care and rehabilitation in order to make the unit function again. The nurses’ stories indicated an awareness that they were merely assisting the doctor and the family, a professional role that appeared to differ from that in Western cultures.

The credibility (believability) of the findings (utterance meaning) as well as the meaning-in-context were established by continuous discussions with the Vietnamese co-investigator and at a seminar with about 80 people representing the Ministry of Health, nurse educators, nursing staff, and physicians from Northern Vietnam. The participants agreed with the orally presented findings. No evaluation of the confirmability (direct evidence) of the findings (utterer’s meaning) was made. For a description of the criteria of credibility, meaning-in-context, and confirmability see Leininger (1990). For a description of the two concepts utterance meaning and utterer’s meaning, see Ricoeur (1976, pp. 12-13).

The results of this study are in agreement with what has been reported from Vietnamese families who have immigrated to the United States (Leininger, 1991; Gold, 1992). The accuracy of the interpretations carried out on a text that has been obtained with the assistance of a translator and interpreter and the ability to see and interpret phenomena in the context of a foreign culture may be questioned. The following factors may mitigate these concerns. The third author, a Vietnamese nurse, served as translator and interpreter and was accustomed to working with Swedish advisers. The language in the questions was thoroughly prepared beforehand, discussed in detail in relation to the aim, and checked in a trial interview. The tapes were checked thoroughly by an independent professional translator who had not until then been involved in this project. The first author had worked two years previously in an area close to Uong Bi in a primary health care programme in which the cultural relativism was emphasized. Efforts, including personal contacts, were made over a period of twelve years to learn and understand more about the values, norms, and lifeways of the people in this part of Vietnam.

Care of Stroke Patients Within a Vietnamese Context

According to Demaine (1992, p. 1042), 70% of the labor force in Vietnam is engaged in agriculture. The agricultural society serves as a part of the socioeconomic foundation for the family life in this part of Vietnam. Thus, a family member who is suffering from any inability or infirmity for a long period of time is a disaster to the economy of the whole family, as it reduces the work and income of two people—the infirmed and a relative who is the caregiver.

From a Western perspective on care it could be questioned whether the type of care provided by families in Northern Vietnam
during hospital stays may encourage (or tempt) Vietnamese nurses to take too much advantage of the presence of relatives. Such lack of professional responsibility could result in allowing or demanding relatives to act where professional skill is needed to carry out technical procedures safely. There could also be a risk that family members are left alone at the bedside of an unconscious patient in silent despair. Such wordless silence may be interpreted as everything is all right by the staff. If the presence of a relative is optional, it may create negative circumstances for the relationship as a sort of involuntarily exchange of roles; that is role reversals. Finally, when and if an optional presence also includes family members who do not get along with each other, it could be questioned whether it would reduce the quality of the life for the whole family.

The Vietnamese nurses’ use of the pronoun we for the main actor was seen as indicating experienced support from colleagues. This finding is analogous with Åström, et al. (1993), concerning Swedish nurses caring for cancer patients. The same use of we was seen in the relatives’ stories, but in their stories it was an indication of historically experienced support from the family. This involvement was also expected to continue as a prerequisite for future family life. On the basis of the fact that the ill person’s family is so essential for the basic care and the interpretation of the illuminated experiences of having suffered a stroke, it seems reasonable to assume that Vietnamese people find the feeling of sameness and relatedness essential for the meaning of life. Bel Habib suggested that the social communion gives the human existence a meaning beyond the individual

Care of Stroke Patients Within a Western Context

Scandinavian countries have highly specialized personnel resources available and a social security system. This should ensure the sick individual safe and professional care and care regardless of his/her economic situation. Åström, et al. (1992) concluded that, in spite of the available resources, major depression early after stroke, functional disability, and an impaired social network interact to reduce life satisfaction for long-term survivors in Sweden. It has proved to be difficult to keep the caring chain together in Sweden, resulting in numerous contacts for the patient from the acute stage until rehabilitation is completed (Pontén and Persson, 1990). It is reasonable to assume that encouraging the involvement of relatives from the acute stage and throughout the rehabilitation process would diminish the impairment of the patient’s social network and the effects of the lack of continuity in the professional caring chain. It has been demonstrated in England that the risk is high that a relative of a stroke victim becomes ill herself/himself in the first year after the patient has suffered the stroke attack (Brocklehurst, Morris, Andrews, Richards, and Laycock, 1981). An involuntary break in the interwoven life threads in such disastrous situations may create unsteadiness in the relations and decreased health for the relatives which in turn hampers the optimum outcome of the rehabilitation. At the same time it is well known that the amount of involvement of the family influences the rehabilitation initially.

These demonstrated effects on the family provide a reason for reflecting on the differences that can be perceived between the Vietnamese and the Swedish nursing care systems. After a crisis such as a stroke, a thorough reinterpretation of one’s life story will be necessary as the identity is threatened. Following the ideas in narrative theory (Polkinghorne, 1988), it will be necessary to support the affected person together with his/her family in finding a new meaningful shared life story and thus maintain and restore the concept of family (Ricoeur, 1992, p. 218). The relatives’ daily care during the acute stage means that these relatives continue to involve the sick person in their daily lives. Thus, their life threads are not separated but continue to be intermingled in spite of one person’s acute illness.

It might be that Swedish nurse teachers have concentrated their efforts on educating nurses in making them and their surroundings, relatives included, believe that the relationship between the nurse and the patient is so exclusive that there is hardly any place for care by relatives during the hospital stay. The room and the time are already filled with various aspects of important, life-saving professional care. In the future education of nurses it is suggested that the concept caring for the whole patient include a close relative when there is one available and willing to continue his or her involvement. This should be considered from the day the patient is admitted until discharge, which is a commitment much greater than just participation by the relative in a caring procedure during visiting hours.

Recommendations

This study should be followed with a study based on further systematic observations in order to note who is actually doing what for the patient. More comparisons of the Western and Eastern nursing philosophies and systems should be carried out in order to elucidate the positive and negative impacts on the nursing profession generally and on the total well being of the patient and his/her relatives particularly. The stroke victim will always need qualified, acute attention for survival, but he/she will also be depending on others’ patience and skilled assistance for a long period in order to reach an optimum outcome of the rehabilitation and adjustment to a new situation in life. As humans we are often completely dependent on others. It is not only the stroke patient who needs attention, but care is needed in various situations in life. It is assumed that the development of the caring roles is dependent on the culture in which the care is to be carried out. Thus, respectful transcultural studies should benefit the development of nursing as a profession. Leininger (1985, p. 10-11) listed a number of contrasts in research paradigms between the Western and non-Western philosophical worldviews, which should be considered. She described that the Western orientation has the focus primarily on individuals and small groups, who are to be studied and explained, while the non-Western orientations are focusing on families, institutions, corporate groups, history, civilization, and humanistic experience which are to be explained and understood. This study affirmed Leininger’s work and theoretical position.
Experience of Stroke in Northern Vietnam

References


WANTED: Transcultural Nursing Consultants

The Chinese Nurses Association and its branches welcome the willingness of American nurses prepared to teach various areas of nursing to share their expertise through continuing education courses and/or lectures and presentations.

Contact Madame Lu Bing, Chair, International Educational Exchange Committee, Shanghai Branch, Chinese Nurses Association, Superintendent of Nursing Science, Department of Nursing, Shanghai No. 6 Municipal Hospital 200233. Write your proposal (including area of expertise, dates available, etc.) and send to this address. You will be expected to pay your own expenses, including airfare.
Maternal thinking in dementia care

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INTRODUCTION

Human development was described by Erikson (1982) as a process of solving eight development crises during a lifetime. Maturation can be regarded as encapsulating the entire life experience and might reach a stage where approaching death can be anticipated. The various life crises are always present. Experiences in early childhood will therefore constitute the core of the adult personality and influence the pattern of interaction.

Demented people need assistance in satisfying their basic needs and someone who is able to interpret their communicational attempts. There is inversely parallel with infants in some respects (Asplund et al. 1991). The infants are at the beginning of their life development and learning, while the demented people are at the end of their life, steadily losing abilities. However, the demented person may exhibit episodes of psychological clarity (Norberg et al. 1986) that indicate that past experiences are not completely lost but locked in. Some of these ‘lost’ abilities can be released by integrity promoting care (Kihlgren 1992).

Group living has been found to be suitable for demented people in the stage between home and institutional care, and the quality of staff is the most important factor influencing the care (Annerstedt 1995). Reasonably, carers gain the opportunity to utilize their talents in a smaller group, where they can influence the emergence of a supportive and creative caring culture, i.e. a ‘homelike atmosphere’.
'Home' is a metaphor for a physical, psychological and spiritual space that constitutes a foundation for satisfying the inhabitants' needs in all respects (Zingmark et al. 1995). Neither the surroundings in an institution nor the staff have any representation in the life experience of the demented individual, who thus lacks interpretative tools for understanding the situation and feeling at home (Zingmark et al. 1993).

Communication
Carers often interpret meaning in the demented individual's communication, which is difficult to state explicitly (e.g. Jansson et al. 1993). This can be done in the same manner as mothers interpreting meanings in their infants' communicative behaviour (Stern 1977, 1990). Stern (1985) suggests that 'affect attunement' takes place in this intersubjective relatedness.

The noticed, subtle and complex communicative process between carers and demented people has proved to be difficult to verbalize in research findings as statements. It can, however, be presented as narratives created from the findings (Jansson et al. 1993). The interpreted findings concerning life experience and care are often emotionally loaded. One way of conveying such sensed and interpreted findings is to express the 'tacit findings' as a metaphor when literal equivalent expressions are lacking (Logstrup 1986, Haggstrom et al. 1994). Reasonably, stories and metaphors may be useful means of presenting the interpreted meaning of the interaction between demented people and good dementia carers.

THE STUDY
The aim of this study was to illuminate the thinking of identified good dementia carers in an attempt to make explicit attitudes and means of communication embedded in a seemingly good caring atmosphere and in episodes narrated and interpreted as resulting in mutual understanding.

Subjects
This study took place in a group dwelling for demented people situated in Northern Sweden, with a good reputation among caring authorities. One man and four women, with Alzheimer's disease, diagnosed more than 4 years earlier, were included in the study. Two inhabitants were excluded; one had just arrived and one suffered from vascular dementia.

Four enrolled nurses and one nurses' aid, out of a total 13 carers, all women, were selected for personal interviews and reflective talks following observations of their interaction with the selected demented people. The five carers were defined by themselves, the head of the department and their colleagues, as good at communicating with demented people. The carers were married, had children and were between 29 and 55 years old. Their nursing education ranged from 10 weeks to 2-5 years, and their working experience within the caring field from 10 to 27 years. Eleven carers, aged between 29 and 60 years, participated in a final group interview.

Data collection
During the interviews and reflective talks, such questions were asked as: 'How is it that you developed an interest in dementia care?' Questions were asked to make the interviewees reflect, such as: 'You mentioned your Mum took care of Granny. How has that influenced your professional views?' Lastly, clarifying questions were asked, such as: 'Do you mean to say that your child has increased your ability to understand demented people?' The types of interviews are shown in Table 1.

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Each carer was interviewed for about an hour. The questions were intended to stimulate narration concerning each nurse's professional history, views of her job, present job satisfaction, and her expectations for the future.

Each carer was observed for 2-5 hours in interaction with each one of the five demented people, in all 62-5 hours. The investigator followed the communication process in a deliberative balance between observing and participating, in an attempt to 'see and feel' whether there was a mutual understanding that was not tangible to the observer (Leininger 1985). Brief field notes were taken.

A reflective talk was carried out after each observation. The reflections were triggered off by questions that the observations had suggested to the investigator, such as: 'When V started to pour coffee into the sugar basin you quickly shifted the basin to a cup without comment...?' When one observation and the reflective talk were completed, the investigator took 5–15 min to tape-record a summary.

Group interview
The five carers participated together in a group interview. Once 25 observations with reflective talks had been completed, they were asked to write down short notes on what they considered to be easy and what difficulties they were facing in their efforts to communicate with the demented individuals. These demented people were then discussed one by one, starting from the notes. The interviewees were encouraged to reflect on each other's comments.

Staff interview
Finally, an interview was conducted with 11 carers in order to grasp the communicative context of the ward. The participants were asked to write down notes about the positive and the negative aspects of their work. This interview gave them an opportunity to share reflections on
Maternal thinking in dementia care

Table 1 The means of data collection

<table>
<thead>
<tr>
<th></th>
<th>Initial interview</th>
<th>Reflective talk*</th>
<th>Group interview</th>
<th>Staff interview</th>
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<tbody>
<tr>
<td>No. of participants</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>11</td>
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<td>Individual narration</td>
<td>Reflective comments</td>
<td>Reflective comments</td>
<td>Reflective comments</td>
</tr>
<tr>
<td>Types of questions asked</td>
<td>Narrative, clarifying follow-up</td>
<td>Observations asked about, reflected upon</td>
<td>Same initial questions reflected upon</td>
<td>Same initial questions reflected upon</td>
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<tr>
<td>Duration per session</td>
<td>45–90 min</td>
<td>15–45 min</td>
<td>60 min</td>
<td>90 min</td>
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* Preceded by systematic observations and followed by the investigator's summarizing notes. These two types of data are not discussed in this paper.

being observed, and on being a member of a staff whose domain and daily working place had been studied, although one was not personally involved.

The interviews and the summarizing notes were tape-recorded and transcribed verbatim. The transcriptions included words or letters for all uttered sounds, indications for pauses and the voice volume.

Ethics

Relatives of each demented patient were approached in writing and asked for their informed consent. An effort was made not to disturb the home-like atmosphere. During visits to the rest room the observer stayed outside and only noted the conversation. In order to become familiar, the observer wore the same clothing most of the time. The personnel gave their informed consent to their participation. They were asked to indicate to the researcher if any of the inhabitants showed signs of being distressed by the study. The carers were approached before finalizing the manuscript in order to gain approval of some passages that could identify individual carers. The project was approved by the Ethics Committee of the Medical Faculty, Umed University.

FINDINGS

All data were interpreted by using a phenomenological-hermeneutic method inspired by Ricoeur (1976) and previously used by, for example, Jansson (1993). First, there is a naive reading in order to grasp the main content and to get ideas for the structural analyses which follow. Finally an attempt is made to make explicit a comprehensive understanding. This report focuses on the interviews.

Naive reading

During the transcription it was felt that the interviewees searched for suitable words to describe the meaning of their lived experience. They made long, reflective pauses, which gave an impression of honesty and of having a realistic self-esteem, especially as they often touched on very personal experiences. They mentioned their present work, their colleagues and care receivers in positive terms. They felt chosen.

The carers seemed familiar with mothering and they mentioned a variety of roles for a mother. It was unanimously agreed that the role of mother is important for the care of the demented people. One interviewee did not mention the word ‘Mum’ or its synonyms, but she spoke once of one of the demented care receivers as ‘the original mother’ during the group interview. Her expressed opinion was shared by the others and the carer herself was mentioned as one of the ideal carers by other staff in the ward. The absence of males (apart from one single demented man) in their daily work was stressed as a negative thing when they compared the ward with a family unit, stressing the complementary role of the two sexes. In the group interviews the participants talked freely and objected to each others’ statements at times. One carer, who had come to the ward later, was more silent than the others in the final interview. She found it difficult to make comments and objections, as she was ‘not yet feeling at home’. The naive reading provided a reason for investigating further the frequent presence of the concept of mother in the text.

Structural analyses

The sentences that were concerned in any way with the concept of mother were gathered with their contexts into one document, in which the mother figure was mentioned in different roles and relations. The influence of a particular role of a mother became visible by combining relationship and role.

Roles and relations of mothers in the text

My mummy

The carer’s physical mother was mostly referred to in positive words, e.g. somebody who was always around, exer-
cised patience and was serving as a positive model. 'She patiently took care of Granny every day for several years.' Some less positive aspects of the concept 'my mummy' were also found, e.g. 'I did not have any physical affection from her'.

Myself as my children's mum
The carers saw their relations with their children as a source for such skills as exercising patience, interpreting unspoken messages, and preventing the occurrence of unwanted scenarios through diplomacy: 'As women we dare to care for our children and to exercise patience'.

Being a mother to others
The interviewees met and interpreted a 'childish call' from both the demented people and their colleagues, but responded differently. 'You have to be like a mother for them [the demented].' 'I could be a mother to most of them [the colleagues], but of course I refuse!'

Demented people's mothers
The care receivers were at times asking for their mothers. The carers saw this as signs of anxiety which needed specific attention: 'When they talk about mummy or going home, we have to comfort them and make them feel at home here.'

Demented women as mothers
The demented women were also mothers. Their children were talked about as varying in their interest in their mothers, and were assumed to have a nagging conscience about not visiting, especially the daughters. There was also an understanding of how repellent it must be to follow the deterioration of a mother's personality: 'When a mother does not recognise her own children!'

Demented women taking the role of mother
The younger carers suspected the demented women considered them their daughters, which gave a close relation: 'I feel they see me as their little girl at times'.

Themes in the stories including a mother
The next step in the structural analysis emanated from the question: 'What themes were brought into the stories by using the concept of a mother?' The meaning units in the previously mentioned 'texts about mother' were sorted into themes, which partly overlapped with the above groupings. The themes were as follows.

Mother-child relation in general
The mother was mentioned generally in meaning units that said something about what it should be reasonable to expect in a mother-child relation: 'And then they [infants] start to speak and strangely enough, mummy, she understands!'

My mother influencing my caring
The carers' mothers/grandmothers' influence on their views about caring were mentioned: 'I was influenced by my mum! She was a paid family carer. We [note the change to we!] took care of Granny every day.'

I am close to my children
The interviewees' own experiences of being a mother came in situations when the interviewees tried to explain the close relationship between themselves and the demented people: 'The youngest girl has taught me what love is all about.'

Filling in gaps in life experience
The oldest of the five carers (55 years old) used the expression 'mum' more than any other interviewee, but the context varied. There was nostalgia and some grief expressed, but also a willingness to care for the demented women as she had wanted to be cared for as a child, and had wanted to care for her mother: 'Some remind me of my mother, leaning forward and so... I hadn't the time to care for my own mum, that's maybe what I am lacking'.

Demented people asking for their mothers
The five demented individuals commonly asked for their mothers and/or wanted 'to go home'. This created a special caring demand, which could be difficult to meet: It's hard to hear every other minute: 'Where is my mummy?' and 'I want to go home!'

One demented woman as the original mother
There was one woman who was said to have a very specific quality. It was agreed upon that she was like 'the original mother': 'She radiates security. I like her!' That she exercised a sort of 'motherly care' in the ward was agreed upon, but how far it went was debated. Some claimed that she was taking on responsibility for the other demented people's situation in the absence of carers: 'She called for our attention when E fell out of the chair by turning on the water. She wanted us to come rushing to check what was going on.'

Metaphors used by the interviewees
Metaphors used to explain something about dementia care were extracted from the texts and an attempt was made to make the meaning explicit. Some were difficult to translate as they were in vernacular. Others were individually developed. The following examples illustrate the carers' views about their relations with the demented people. An effort is made to offer one possible interpretation, which
takes the investigator's pre-understanding, the observed context, and the text into consideration.

**Carers' attitudes towards the demented inhabitants**

Some metaphors were interpreted as carrying an imprint of the interviewee's view of demented people. 'She is like the original mother.' This was said in a group interview to explain the interviewee's view of one woman. There was a search for words prior to the utterance, which was delivered in a soft, low and tentative voice. It was interpreted to mean that the carer had a loving and admiring attitude towards the lady mentioned.

'It is a matter of maintaining her [socially] upright position.' This was about a woman who often showed signs interpreted to mean she suffered from feelings of inferiority and guilt. The metaphor was interpreted as a conscious attempt to prevent bad feelings by conveying a view of the actual situation in a positive and encouraging way.

'She prefers to be a bit “stuck-up”.' This was about a woman who had lost her ability to express her preferences to dress smartly and correct. It was interpreted to mean that the carer made use of her historical knowledge about this woman. The carer took for granted that the woman still retained her former preferences and she found it natural to assist her accordingly.

'We can get into their heads [eyes].' This indicated a very close face-to-face relationship (eyes are locally used as a synonym for face), where the demented individuals accepted that the carer entered into their personal territory. It was interpreted as an effort to make explicit the demented people's trust in the carer as the carer saw it. There was an embedded satisfaction of being involved in a close, important and satisfying relationship.

**Being understood by the demented**

There were metaphors expressing an awareness of the difficulties of communicating with demented people. It was necessary to use metaphors in order to convey the message. 'It is possible to make oneself understood without relying on the verbal answer from “the other” and still know that the understanding is shared.' This was seen as a communion.

'You can see that it goes home.' This indicated a confidence that there was a communicative relationship. A dynamic and mutual view was embedded in it. There was a confidence expressed that “the other” has the same understanding as I have. 'We share an understanding of a present existence of which we are both parts.'

'Need to getting it into them.' This was said about one woman. The same dynamic view as above was expressed, but there was a consciousness about a necessity to violate 'the other's' integrity in order to reach a situation where it was possible to share the understanding.

'It gets there.' This was used to signify the communication with the demented individuals and a confidence that 'I know when I make myself understood', but the mutuality differed. It indicated communication about the same situation rather than involvement and communion.

**Care about the atmosphere in the ward**

Finally, there were metaphors used to explain the calm and homelike atmosphere the carers wanted to create. 'This is their family.' The ward as a family expressed a relatedness between the people there; a foundation for security, nourishment, and a belonging to a historical place. It also illustrated the need for a reasonable number of people to enable a communicative context. Finally it was used to indicate that such a big family with only one man is 'anomalous' in a way.

'To have eyes in the back of the head.' The sight as a vital and acute sense illustrated, apart from closeness, a kind of alertness that the carers had to observe. The demented people could not be expected to ask for help or assistance. It was the carers' task to be constantly aware of the situation in the ward even if their attention was directed towards something else.

'Fire brigades action.' This illustrated the carers' worries if they realized that one of the demented people had had problems for some days that needed attention. The selection of metaphor was interpreted as a valid indicator of the calm, slow-motion atmosphere that the carers managed to create. It stated that the staff would hurry to assist, e.g. if they noticed that a demented individual had not defaecated for some days. It was interpreted to mean that such awareness would noticeably speed up the otherwise very slow tempo.

**Comprehensive understanding**

The carers were given a challenging opportunity when they were chosen to initiate group dwelling for demented people. Seemingly one woman, named 'the original mother', served as a model for a warm, loving person. The carer who originated the expression was mentioned as a model carer. This carer spoke little and expressed herself directed towards something else.

There were qualities in the atmosphere that made the carers co-operate well and feel comfortable in their work. This contributed to their positive attitudes towards the demented people. The texts gave hints about the conditions the interviewees considered important for their opportunity to utilize their caring abilities. Firstly, each person, staff and care receivers alike, was seen as a unique individual, e.g. 'She is very special', 'She always does it this way'. Secondly, everyone present was considered to
be valuable. This was an embedded attitude in the interviewees' way of talking about the demented people, each other, and the way they reflected on each other's comments in the group interviews. Thirdly, this group dwelling was seen as a home, e.g. 'She [about a severely demented woman] has to decide. It's her room!' 'We demonstrate that this is their home.'

McFague (1988) suggests that God can be thought of as a mother, who with an Agape love gives life itself and wants growth and fulfilment for all. Accepting this metaphorical view of maternal love, the meaning-in-context (Leininger 1990) was sought by asking the question: 'What was mentioned in the texts that was interpreted as a prerequisite for metaphorical maternal love and practice with a foundation in the three conclusions?'

The understanding of the atmosphere that constituted the communicative context illustrated only one part of the interpreted findings. There was also an interpreted confidence for the future in the midst of a reality filled with the deterioration of human competence in the demented people. This was hidden 'between the lines of the text' and carried meaning beyond ordinary language. As it might be possible to convey such meaning in poetic language, where the reader finds a meaning through hermeneutic imagination (Kristensson Uggla 1994), the understanding of the texts was finally worded in a metaphor.

Understanding of caring for and about demented people

In order to thrive human beings need a good, suitable climate just like plants need a suitable climate. Demented people and premature babies are like some delicate plants, who have difficulty surviving unless they are kept in a good greenhouse (group dwelling or incubator). However good a greenhouse is in itself, skilled and careful gardeners (carers) will be needed to make individual plants thrive, tending their invisible roots (the history of an individual) and supplying nutrients to the plants. Such a 'psychosocial greenhouse' for demented people can be seen as an incubator in a reversed parallel to the incubator needed by the premature infant, as a physical substitute for the mother. The device cannot replace her psychologically, socially or spiritually.

The 'greenhouse-incubator' as indicated above, may be a solution when a human being's condition is deteriorating as in the case of a dementia disease. The physical mother of an infant and a member of a demented person's family can provide the so-called 'kangaroo-method' (home care). This can be very demanding, especially if there are other family obligations that need attention and no-one to share a 24 hour commitment with. Therefore, a good greenhouse (group dwelling) with good and loving gardeners (carers) can serve as an alternative to the kangaroo-method (home care) for everyone involved. Such a greenhouse can preserve the dignity of an old demented individual until the Father Time cuts the life line in order to assist the body back to a non-material existence via the womb of Mother Earth.

REFLECTIONS

In this study the interpreted caring for and about the demented individual was seen as a good and loving care of demented people (Jecker & Self 1991). An effort was made to make explicit with a metaphor the demented individual's 'maturing process', which presumably takes place and should not be associated with measurable cognitive functions. It can rather be understood as 'gerotranscendence', a continuous process throughout the lifetime. Given opportunities to mature, a person is able to accept his or her lifetime as mostly passed and in a way faces mortality and death as a present reality (Thornstam 1994). Thus, the old person may have one foot in ongoing life and one foot in a universal eternity, where the importance of the present physical life is decreasing.

It should be stressed that this project was carried out in a group dwelling with a good reputation, including carers who were considered to be good at communicating with demented people, and aimed at identifying situations when a carer and a demented individual seemingly functioned well together. Thus this paper only concerns episodes of good care at the investigated ward. The carers' metaphorical use of the concept of mother means that there are multiple meanings conveyed (Ricoeur 1976). Therefore the presented interpretation is not the only credible one. However, nothing in the texts contradicted the presented interpretation. Furthermore the findings coincide with previous suggestions (e.g. Kihlgren 1992).

Anxiety

The included carers repeatedly stated the necessity of preventing anxiety and of comforting a person who showed signs of anxiety. It has previously been remarked that demented people often want to go home or ask for their mothers in situations of anxiety (Zingmark et al. 1993). The carers' ambition to create a home-like atmosphere therefore seems relevant. The staff seem to consider themselves as constituting a part of the atmosphere of being at home. Therefore, the ambition that was made explicit, to create and keep a 'home', can be seen as related to the concept 'mother', which should be seen metaphorically (McFague 1988). A mother signifies the home for a child. If the mother lacks clarity about her own self it will be transferred to the child, with negative consequences for the child's experience of the home (Csikszentmihalyi & Rochberg-Halton 1981). Seemingly the staff formed together a friendship relationship that bears an ethical
code of companionship (McFague 1988). This seems to correspond with the concept of interpersonal communion as described by Stern (1985).

Further studies
The reported findings indicate a need for further studies in dementia care in order to elucidate the use of the metaphor mother and the benefit of maternal thinking and practice in the everyday work. The importance of maternalism in dementia care has been addressed earlier by Åkerlund (1990) and Kihlgren (1992). Metaphorical use of the concept mother signifies unselfish love, but there are important differences between being a physical mother and being a carer of demented individuals. Firstly, in her relation to her own children the mother wants them to grow and behave in a way that can be appreciated by themselves and others. The carer in dementia care must be prepared for the opposite to growth, development and appreciated behaviour. Reasonably, the carers included in this project were aware of the limitations of the demented people’s future. They still seemed to be prepared to fulfil a meaning in the situation at hand. Secondly, the physical mother is not interchangeable as a person, even if some tasks can be done by somebody else occasionally, whereas the carer is only present during working hours. Lastly, there is the lifelong experience that the demented people have while the infant is just starting to build, which demands different types of respect and understanding for human dignity.

THE MOTHER METAPHOR
The comparison between mothers and carers of demented people should be seen as an effort to discuss a means to find a useful, meaningful and familiar metaphor for what can be regarded as a ‘pillar component’ in dementia care — ‘maternal love’ — in order to guide the thinking processes towards good caring for and about demented people (McFague 1988). The effort to find and defend such a metaphor must in no way be taken as omitting or excluding other types of knowledge about people and the individual suffering from dementia disease. The incubator may be a substitute for a mother’s body, but a spine from a father will still be a crucial foundation for parenthood. From a spiritual point of view Father Time will be needed before a return to Mother Earth is possible, but a period of greenhouse-incubator care might be needed before the material involvement in the universe can unify with a non-material eternity.

The findings that a mother metaphor has a bearing on a professional role within dementia care contradicts to some extent nursing education where autonomy and integrity for the patient are advocated. The mother metaphor tells something about a very close interrelationship where one part compensates for ‘the other’s’ lost abilities at any time, as it includes some kind of dependency. The interpretation of the metaphors the carers used indicated such a close relationship. This can be seen as analogous with Lévinas’ (1982) ethical reasoning, that the meeting with ‘the other’s’ face with defenceless eyes will preclude any conquest. The findings indicate that these carers knew how to act in various situations. They did not seem to reason about difficult communicative situations as if they were problems to be solved, but as challenging and hidden messages to be interpreted.

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References


Skilled Carers’ Ways of Understanding People With Alzheimer’s Disease

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Five carers in a group dwelling for people with dementia were observed and interviewed concerning their interactions with five residents with Alzheimer’s disease. The tape-recorded and transcribed data were analyzed as text. The carers’ personal ways of achieving understanding were defined as: affect attunement; affect attunement and completing a puzzle through explanatory connections of observation, knowledge about the residents’ life histories and behavior at the group dwelling; and affect attunement within the context of caring as an intrinsic end. Personal experience from childhood and motherhood, knowledge about the residents’ life history and the nature of the disease, and personal talent seemed to form these carers’ ways of achieving understanding.

People with Alzheimer’s disease (AD) are becoming increasingly dependent on carers for their well-being. The dependency is related to decreasing abilities and impaired function due to pathological changes that are slowly progressing in structures of the brain (American Psychiatric Association, 1994, pp. 134–143). Loss of memory, cognitive function and speech are symptoms that usually develop over several years and greatly influence the possibility of communicating experiences and feelings (for review see Arendt & Jones, 1992; Athlin & Norberg, 1987; Bayles & Tomoeda, 1991). Nonverbal communication may also be problematic (Apell, Kertesz, & Fisman, 1982; Asplund, Jansson, & Norberg, 1995, Athlin & Norberg, 1987, Bayles & Tomoeda, 1991; Obler & Albert 1984). Dementia causes reduced facial expressions (American Psychiatric Association, 1994, p. 134; Asplund, Jansson, & Norberg, 1995; Asplund, Norberg, Adolfsson, & Waxman, 1991) and the person’s gestures are less expressive (Critcley, 1964).
The communication problems make it difficult for carers to provide people with dementia with opportunities to act according to their will and preferences (Ekman & Norberg, 1988) and to meet their needs by helping with activities of daily living matters (Athlin, Norberg, Asplund, & Jansson, 1989; Borell, 1992, p. 16). This leads to carers feeling uncertain about how to treat people with dementia in an ethically acceptable way (Jansson & Norberg, 1992).

Magai, Cohen, Gomberg, Malatesta and Culver (1996) reported that people with AD expressed a range of affective signals and some of them showed an intact and functioning emotion system even during the last stages of the disease. This observation throws some light on previous findings that there are carers who understand people with severe dementia and can help them to achieve a state of well-being through creating calm situations with no heavy demands (Zingmark, Norberg, & Sandman, 1993). Nursing care based on promoting the experience of integrity in people with severe dementia has focused on improving the quality of nursing care also in a nursing home environment (Kihlgren, Hallgren, Norberg, & Karlsson, 1996). Ekman and Norberg (1993) suggested that understanding can be comprehended as a communion between a person with dementia and her or his carer that, among other things, is created by the music of the mother tongue (Ekman, 1993, pp. 41-42).

Previous research shows that there are moments when carers seem able to understand people with severe dementia who have almost no verbal and distorted nonverbal language. Research findings have suggested various explanations for how such understanding is achieved. Athlin, Norberg and Asplund (1990) suggested that carers of people with severe dementia impute meaning to seemingly incomprehensible communicative cues, thus creating a feeling of contact with the carer in the person cared for. They referred to Pawlby’s (1977) theory about imitative interaction between mothers and their infants. The theory states that mothers and infants imitate each other reciprocally and the mother imputes meaning into the infant’s cues. When the mother acts as if the infant’s cues were comprehensible, it creates a feeling in the infant that what he or she communicates has a meaning. This constitutes the beginning of a two-way communication. Hallberg and Norberg (1990) used the concepts, projective identification, transference, and counterference, to illuminate carers’ understanding of the message in vocally disruptive behavior of patients with moderate and severe dementia. The patient calls for attention without being aware of it and the carer’s reaction demonstrates that the patient’s noise has a communicative meaning. Jansson and associates (1993) suggested that people with severe dementia can be understood when their fragmented communicative cues are regarded within the framework of the whole of a narrative understanding of the care episode in question that gives the pieces their meaning. Several researchers have emphasized the need for knowledge about the patients’ past life histories and personalities as a means of creating this narrative whole that gives meaning to the pieces carers can
perceive and experience (Gibson, 1994; Harrison, 1993; Jenkins, 1996; Kitwood, 1997; Kitwood & Bredin, 1992).

This paper reports findings from a study based on observations of five carers' interactions with five residents in a group dwelling for people with moderate and severe AD. The observations were directly followed by reflective interviews based on the observations. Interviews with the same carers had previously been analyzed and the interpretation showed that these carers narrated their understanding of the residents by referring to their experiences of being cared for by a mother and caring for children as mothers. The ways of expressing maternal thinking differed among the investigated carers (Häggström & Norberg, 1996). This finding induced questions about whether and how these carers practiced their maternal thinking in achieving an understanding of the residents as a means to perform care to the residents' satisfaction. The purpose of this study was to illuminate individual skilled professional carers' ways of achieving an understanding of people with moderate or severe AD.

METHOD

A project entitled “Interaction Between People With Moderate and Severe AD and Their Carers,” was carried out with the aim of giving a penetrating description of this interaction phenomenon in a context of caring situations in a group dwelling. Data collection was based on observations of five selected carers' interactions with five of the residents and reflective individual and group interviews with the carers.

The Context for Data Collection

A group dwelling in a small town in northern Sweden with a good reputation was chosen as the location for this investigation. It was identified by asking professional carers familiar with the care facilities in the city: “If a relative of yours gets Alzheimer’s, where would you like that person to be cared for?” Each resident (one man and six women) had a bedroom with an en suite toilet. The kitchen and the two sitting rooms were equipped and furnished as in ordinary homes. Breakfast based on individual preferences, snacks, and “weekend extras” were prepared by the staff. At times the residents participated in everyday housework, such as washing up dishes and doing laundry.

One enrolled nurse (EN) was the team leader and in addition had a supervisory function over the staff at two group dwellings. These ENs had graduated from a 2-year Swedish education program for ENs at the senior high school level (now extended to 3 years). Six ENs and four nurse aides worked part-time in day shifts and two nurse aides worked nights. All but one member of the staff had worked in the dwelling since it was established 4 years prior to this study.
Participants

The five carers were selected by their coworkers, who perceived them as being good at achieving an understanding of the residents. The carers were married women age 29 to 55 years, and they all had children. Two carers were nurse aides and three were ENs. Their caring experience ranged from 10 to 27 years.

One man and four women (n = 5) with AD were selected from seven residents for observation of the five carers’ interaction with them. One resident could not meet the inclusion criteria “moderate or severe AD” and one resident was excluded due to a different diagnosis (vascular dementia). A geriatric specialist had made the diagnoses according to the DSM-III-R criteria (American Psychiatric Association, 1987) and the NINCDS ARDA criteria (McKhann et al., 1984) prior to the residents moving into the dwelling. The primary carers had performed a Mini-Mental State Examination (MMSE) (Folstein, Folstein, & MacHugh, 1975) 2 months prior to this study and the estimated MMSE score was 0 to 2 for three residents; for two others the scores were estimated as 11 and 21, respectively, 6 months prior to the study. Assessments were not repeated, as the latter residents had shown signs of increased confusion and anxiety at the previous assessment. Relatives and carers thought that the cognitive condition of these residents had deteriorated considerably since the first assessment. Narrative descriptions of the five residents are presented in Table 1.

Procedures

Observations Followed by Reflective Interviews, and Summarizing Notes. The first author made an effort to take on a role of “peripheral-member-researcher” in the selected dwelling during a period of 5 months in order to conduct observations in the mode of “observer-as-participant” (Adler & Adler, 1994, p. 379). Each carer was observed for 2 1/2 hours of interaction with each of the five residents, one at a time (5 per carer); these data provided material in a natural setting for reflective interviews with each carer. The observer (first author) did not involve herself in daily activities, but participated, for example, by responding if spoken to. She located the scheduled carer and resident when she entered and focused on caring performance that could be judged as satisfying to the resident as well as essential for the resident’s well-being. The resident’s communicative behavior and the carer’s way of responding to the observed behavior were discretely noted on paper as words/sentences. The paper was mostly kept in a pocket so as to be as unobtrusive as possible. The phenomena of interest could also be memorized, together with the context in which they occurred or were uttered.

Each observation was directly followed by an audio-recorded reflective interview focusing on the “ingredients” that the observer had interpreted as indicating the carer’s achievement of an understanding of the resident. The carer was asked to reflect on what she thought the resident had experienced in
the observed situations and on her ideas about observed communicative cues. In selecting caring sequences to be investigated, priority was given to those sequences that had seemingly satisfied the resident, especially when it had been difficult for the observer to comprehend how the carer could understand the resident or when the observed carer seemed unaware of what she had done. The reflective interviews lasted between 15 and 45 minutes (approximately 2.5 hours per carer, thus 12.5 hours in total).

An audio-recorded summary of notes and impressions from the observations and reflective interviews was made immediately after the reflective interview. This took between 5 and 15 minutes (about 4 hours in total).

**Group Interview.** A group interview of approximately 2 hours was performed with the five carers after the completion of all scheduled observations and interviews. Before the interviews started, the carers were asked to note in writing what they considered to be easy and difficult, respectively, about caring for the five residents. As the interview proceeded the interviewer asked one carer at a time for comments, and asked the others to reflect on these comments.

**Data Analysis**

The audio-recorded data were transcribed verbatim and analyzed in steps. In the first step the text was read in order to grasp what it was about. Thereafter the text was sorted to form a table that facilitated a view of each carer in relation to each of the five residents in order to find explanation in the parts of the text. Finally, a summarized interpretation of the lines and columns, regarded as a characterization of each carer’s personal way of achieving an understanding of the five residents, was constructed.

**Ethics**

Relatives of the residents gave their informed consent in writing to having their next of kin participate in the study. The researchers wished to minimize any negative influences on the participants’ integrity and the homey atmosphere in the dwelling (Adler & Adler, 1994, p. 387). To preserve anonymity, all residents (even the male resident) appear in the report under female pseudonyms. The Ethics Committee at the Medical Faculty, Umeå University (No. 93/039), approved the project.

**INTERPRETATION**

A first reading through the text indicated that the five carers had some caring behaviors in common. They acted in slow-motion, they seemed to have a period of “shared history” with the residents, and their caring for the residents seemed important and meaningful work in their eyes. The residents appeared
<table>
<thead>
<tr>
<th>Resident and her age</th>
<th>Brief description of the residents</th>
<th>MMSE score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs. Anna 73 years</td>
<td>Mrs. Anna is quite tall and slender. Talks in single words and short sentences. Wears ordinary, but severe clothing and hardly any makeup. Her gray hair is mostly well combed in a straight page boy style. Sits with a very straight back and gazes ahead of her as if ‘watching a film.’ Sometimes she suddenly makes strange high-pitched sounds, rises, and moves her right arm upwards with screwing movements. Sits attentively listening to all kinds of music as long as a tape lasts (30-60 minutes). When singing together with relatives and staff she fills in surprisingly long sequences of correct words and sings the melody in a lovely voice. Her facial expression is quite readable. Seems constantly hesitant to visit the rest room, gets a scared look on her face and tries to grab onto something in the doorway. Often meets the observer with a wordless smile.</td>
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<tr>
<td>Mrs. Beda 80 years</td>
<td>Mrs. Beda is tall and slender. Sits in an armchair most of the day with closed eyes. Wears ordinary clothing and uses no makeup. Her hair is cut very short. Hardly any ‘readable’ facial expression. Often scratching herself. Two carers cooperate when assisting her with hygiene, dressing, and elimination. At times she surprises people around her by suddenly uttering a word or two, occasionally in sentences that sound like Finnish, but cannot be understood by Finnish speaking people. The observer could not register any response to her presence.</td>
<td>0</td>
</tr>
<tr>
<td>Mrs. Cilla 80 years</td>
<td>Mrs. Cilla is quite heavy. Walks slowly with resolute steps, with feet apart. Her thick gray hair is naturally slightly curly and cut in a style that frames her face. Her clothing is reminiscent of older women from the countryside. Lies on a sofa for a while now and then. Utters few words, often something that sounds like the beginning of a sentence. An accompanying smile makes it seem as if she is asking for help to complete the sentence. Likes eating and steals available foodstuffs when the staff is absent. She apparently notices (without making any comment) and cares about things happening in the dwelling and somehow she seems to</td>
<td>2</td>
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</tbody>
</table>
know where the carers can be found. Stretched out her hands with a smile and rubbed the observer’s freezing hands when they first met, took the newcomer’s hands between hers: “Freezing?!”

Mrs. Dora  
80 years  
Mrs. Dora is ‘ordinary’ in build. Mostly moving in a hurried manner. Has permed, curly, gray hair, is ordinarily but smartly dressed with discreet makeup. Stays alone in her room for long periods. Speaks long sentences, but mixes words and changes the course of the topic, for instance, when she talked about her shoes she pointed to a car passing: “Look, there’s a black tomato cruising!” Seems to suffer from distress and anxiety quite often. Then she wants to go home or suggests/demands various actions be taken. These episodes come suddenly and seem to be related to money. Likes cakes and sweets, but stops eating if she becomes worried about the cost. Makes efforts to ask and comment on things to the observer who mostly fails to comprehend the verbal message.

Mrs. Ella  
75 years  
Mrs. Ella is short. Leans forward with her arms thrust out in front of her when she walks. Her quite short, white hair has permed curls. Strikingly smartly dressed and is usually heavily made up. Moves about aimlessly and swiftly with short stumbling steps until something catches her visual attention; a tablecloth that she starts rolling up, a stain on the table that she tries to scratch out, a newspaper that she folds over and over, etc. Makes sure she knows the staff’s whereabouts, peeps behind doors if they are out of sight, but changes direction once she has caught sight of any of them. Seems ‘moody’ and her almost incomprehensible language is mixed up with all sorts of expressions when she becomes upset. On these occasions she speaks fast to no one/does strange things, for instance, when she swiftly grabbed the watering can and poured water over the sofa and the pillows, ‘preached’ loudly when there was no staff around. Seems to pay no attention to the observer’s presence, continues to look for ‘other staff’ if she is alone with the observer, even if the latter tries to get in touch.
as persons with a great variety of personal traits. The carers seemed to respect these personal traits and were apparently mostly able to achieve an understanding of the residents when they performed care, even if the residents quite often appeared to be “somewhere else” and/or “in some other time.” When the carers were questioned about how they thought they could achieve understanding in situations that were observed, their explanations were not clearly expressed. The achievement was seen as related to: knowledge about the residents’ history and about recent events, a sensing of the resident’s present mood, and, metaphorically, as “having eyes at the back of the head.” The carers used personal approaches which made their caring performance look different when they made efforts to understand and satisfy the residents. Their explanations about their ways of achieving an understanding of the individual resident also seemed to be different. These carers made use of their personal talents and skills to achieve an understanding of the residents as persons.

**EACH CARER’S WAY OF ACHIEVING AN UNDERSTANDING OF THE RESIDENTS**

The first reading of the text guided a more systematic analysis. Abbreviated and summarized data were listed according to the text from which they originated from. The headings used to organize the text for each carer are presented in Table 2.

The analyses showed that the carers had some ‘caring behaviors’ in common. Interpreted summaries of lines and columns demonstrated that there were differences in their ways of achieving an understanding of the residents. Examples from the text as a table will be given for each carer, together with the interpreted summaries. Finally, each summarized interpretation will be exemplified with a narrative example from the data.

<table>
<thead>
<tr>
<th>TABLE 2. The ‘Headings’ Used to Organize the Text as a Table</th>
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<tbody>
<tr>
<td>Resident/Carer: (e.g., Lena)</td>
</tr>
<tr>
<td>Observation note</td>
</tr>
<tr>
<td>Reflective interview</td>
</tr>
<tr>
<td>Summary note</td>
</tr>
<tr>
<td>Interpreted way of understanding</td>
</tr>
</tbody>
</table>
Lena

Lena tried to understand/sense before she resolutely acted according to what she thought was the resident’s intention within the actual situation. She did not pay attention to what the resident actually said or did. She rather put the pieces of vague communicative cues into her own framework/context. She commented on her actions while performing caring activities and waited for responses from the resident. She did not change her tone of voice much and she used eye-contact/touch before she spoke.

In the reflective interviews Lena described how she understood the resident’s communicative cues by referring to her observations of the resident in various situations and to her knowledge about the resident’s previous life. Lena explained the resident’s observed “strange behavior” and most of her caring actions through various connections of her knowledge about the resident’s history and the context of the caring situation. Examples from the text and the summaries are presented in Table 3.

**Conclusion.** Lena achieves an understanding through ‘tuning in’ and making rational connections into comprehensible wholes of various events, significant people, and things in the actual situation or the resident’s life stories.

**Example.** Mrs. Anna was often laughing unexpectedly. She was also seen moving her right arm upwards in screwing movements. Lena was convinced that the laughter was triggered off by something that Mrs. Anna had misinterpreted and therefore it became funny to her. Lena thought that the screwing movements were some kind of reminiscence from childhood when Mrs. Anna and her sisters and brothers had to assist her father in his ropery. Mrs. Anna’s brother agreed; the movements reminded him also of their shared childhood task—to care for rope ends for several hours.

Maja

Maja worked slowly as if she were waiting for hints from the resident about how to continue. She listened attentively to residents when they talked and she tried to understand the words and sentences literally. She commented on most of her actions, waited for responses and underlined positive emotional aspects with words and tones of her voice. She tried to use eye contact during her caretaking. She appeared not to seek explanations. Rather, she responded to communicative cues that were embedded in warm feelings and she connected these conclusions to experiences from her family life.

Maja tried to find words and explanations from various experiences of being understood as a child and understanding as a parent. She explained that she patiently had to try various means to satisfy the residents. She seemed both happy and surprised by her own conclusions as she went on reflecting. Examples from the text and the summaries are presented in Table 4.
### TABLE 3. Examples From the Text and the Interpretation of Carer Lena's Way of Achieving Understanding of the Residents

<table>
<thead>
<tr>
<th>Resident/Carer: Lena</th>
<th>Mrs. Anna</th>
<th>Mrs. Beda</th>
<th>Mrs. Cilla</th>
<th>Mrs. Dora</th>
<th>Mrs. Ella</th>
<th>Interpreted summary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example from observation note</strong></td>
<td>A turns chair, looks at it. Talks incomprehensibly and laughs unexpectedly. L understands? L strives to meet A's eyes-makes a nice gesture 'sit here.'</td>
<td>B listens to piano music with open eyes (unusual). B applauds with one hand on the back of the other.</td>
<td>C lies on the sofa. L vanishes (to do her room?)</td>
<td>D looks anxious—talking fragments about something missing (lottery money?). L convinced there is something—goes away to ask colleagues.</td>
<td>L does a very thorough make-up job.</td>
<td>Uses few words when working with patients, but connects them to context, often with emotionally loaded tones. Gives words to actions.</td>
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<tr>
<td><strong>Example from reflective interview</strong></td>
<td>T: this laughter? L: she mostly smiles, but not if its bad. I think she has heard something that makes sense to her that we cannot register.</td>
<td>T: opened eyes? L: Her eyes are always open when we listen to music. I think, no I know, she likes music and enjoys it. She smiles when she listens to music. She used to sing.</td>
<td>T: You did her room without her? L: She used to participate. Now it seems distressing- She just looks so unhappy standing there with a cloth not knowing how to use it.</td>
<td>T: Convinced about her speech about missing a lottery prize? L: Sure! Usually there is. The trick is to find out, what it was that triggered it off. If you can it is easier to comfort her.</td>
<td>T: All details in the procedure of make-up? L: In her situation you need somebody who can think for you, and I am sure she wants to look like she used to.</td>
<td>Seems confident that there is a reason for the residents' actions and reactions.</td>
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</tbody>
</table>
**Example from summary note**

—they seemed to understand each other. When A laughs L smiles or laughs too seemingly sharing the same laughter. They talked about children and seemed to be involved in the same discussion. L explains that she can understand, but cannot bother with the words.

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<table>
<thead>
<tr>
<th>Interpreted summary of ways of understanding</th>
<th>Connects words with context.</th>
<th>Verbalizes actions she is doing. Understanding based on knowledge, uses history to understand.</th>
<th>Understands through emotional ‘togetherness’?</th>
<th>Understands through connecting signs, actions and behavior.</th>
<th>Details important? Many words, detailed descriptions. Understands through trying to sense and ‘value’ E’s mood.</th>
<th>Achieves an understanding through <em>tuning in</em> and rational connections into comprehensible wholes.</th>
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<tbody>
<tr>
<td>L is keen to position her wheelchair so that she can see the piano and the musician. When music finishes they all remain seated for some minutes.</td>
<td>—after breakfast L asked C if she wanted to lie down on the sofa that is occupied by a resident who was offered the opportunity to listen to music. C accepted and seemed happy. L went to do her room—explained her arrangement in the reflective interview.</td>
<td>—D looks anxious, walks around saying something: “pity to miss a lottery prize!” L went to find out what people had visited and what programs D had seen. L found out that it could have been on TV. L repeatedly explained; D seemingly believed and looked relieved.</td>
<td>—the morning procedure took a very long time. Whispering sessions in the toilet and application of a thorough make-up. L explained that she thought that this was the way E wanted it.</td>
<td>Seemingly strives to find an explanation in the past that she can connect with what happens in the actual situation. This makes her understand, so she can assist.</td>
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<tr>
<td>Resident/Carer:</td>
<td>Mrs. Anna</td>
<td>Mrs. Beda</td>
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<td><strong>Example from observation note</strong></td>
<td>M and A have eye contact. M smiles and shows a direction with the index finger. Both move, smilingly, toward the toilet. A points too. A: “This is dangerous,” M whispers.</td>
<td>On a wheelchair in the elevator B says: “She is alive! Where does M stay?” M gives information about her spouse.</td>
<td>C is rolling the tights down the legs. Suddenly starts rolling them up. M drops what she is doing (hanging clothes) and demonstrates direction with her hands on C’s hands.</td>
<td>D asks about school, dance and music without comprehensible context. M answers every question as if it had been reasonable and related to something that happened today.</td>
<td>E states that the plate with sour milk is a ‘heap of rats.’ M says that she is also afraid of rats and names the things that E has in front of her on the table.</td>
<td>Acts without words at times and with informative words and sentences at other times.</td>
</tr>
<tr>
<td><strong>Example from reflective interview</strong></td>
<td>T: Strategy for visiting the toilet? M: Important to avoid bad mood. She seems to be scared of the toilet. —It’s a T: Your interpretation of the two sentences? M: Very unusual with sentences now. Mostly “no” or “yes.” It used to be the T: Demonstration in stead of words? M: She becomes distressed when she doesn’t understand. She should be allowed to do T: What guided your answers? M: She is talking about all days as one day. Today there has been music, so I related to that - maybe? T: Why naming things on the table? M: I think she sees something different. She talks about rats and snakes in a terrifying</td>
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<tr>
<td>Example from summary note</td>
<td>Interpreted summary of ways of understanding</td>
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<tr>
<td>—M tries to figure out how to comfort A. The pointing, smiling and whispering seemed successful, as A appeared comforted.</td>
<td>Tries to prevent bad mood and satisfies needs through various means. Understands through 'tuning in' to A?</td>
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<tr>
<td>—M registers signs, and words. Interprets it with assistance of her previous experience of B in the dwelling.</td>
<td>Actions and understanding based on her experience of B’s previous way of being in the dwelling.</td>
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<td>—These two converse and seem to enjoy it, but the conversation is not sensible to the observer.</td>
<td>Understands through emotional ‘togetherness’ and prevents C from feeling distressed.</td>
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<tr>
<td>—M registers signs of distress. Experiences the feeling? and comforts verbally.</td>
<td>Understands through connecting words and statements to recent occasions based on mutuality?</td>
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Seemingly acting on what she registers in the actual situation, considering words and signs to be adequate messages.

Achieves an understanding through tuning in. Connects signs and words into comprehensible wholes within the present time.
Scholarly Inquiry for Nursing Practice

Conclusion. Maja achieves an understanding of the residents through ‘tuning in’ before she responds to more visible needs, e.g. putting shoes on, combing the hair. She connects signs and words into comprehensible wholes within the present time and relates to her experience in life.

Example. Maja approached Mrs. Cilla, who smilingly glanced at her from a distance as she walked toward Maja. Apparently, Maja thought that Mrs. Cilla wanted to share a hug. They approached each other and shared a long and smiling hug. Her reflection on this was:

You appreciate getting a hug now and then. You don’t have to talk all the time! Periods of silence are not distressing—that gives you an opportunity to understand that you are together. (She seemed astonished.) Yes!? That’s how you feel in your own home as well, where you can feel safe! Isn’t it? I have not thought about this before!

Nora

Nora showed considerate attention to residents for whom she had warm feelings and they got warm and loving care. She appeared to be sure about those residents’ feelings and intentions and the performance seemed to satisfy them. Her verbal communication changed considerably in different relationships and in different situations. The volume of her voice varied from something like a loudspeaker to a soft whisper and the intonation could sound strict and correct but also tender and loving. She hardly waited for a response.

Nora explained the resident’s actions through various connections of her knowledge about them. It seemed difficult for Nora to find explanations for her own actions. She often expressed her warm affection for some of the residents with emotionally loaded statements and underlined them with tone and volume in her voice. She also stated that she found it very difficult to understand a couple of the residents. She made connections to her own life experiences. Examples from the text and the summaries are presented in Table 5.

Conclusion. Nora achieves an understanding of a resident through ‘tuning in’ based on her emotional ‘valuation’ of the resident.

Example. Mrs. Ella indicated that she wanted to know the carers’ whereabouts by peeping into the resident’s room where the carers were. Mrs. Ella seemed satisfied once she had seen Nora. Nora’s reflection: “You know we like each other, that’s why we need to know where we are!—she just needs to know where we are and keep in touch.”

Olga

Olga moved slowly and she met the residents with different approaches. She appeared to maintain a steady good mood with a sense of humor, often accompanied by infectious laughter that she shared with the residents. She
communicated some kind of “good mood” before she talked or acted. With some residents she was talkative; with one she was silent for long periods or whispered; and with two she often sang her verbal messages. Apparently by inducing a good mood she thereafter ‘knew’/sensed means to satisfy the resident.

Olga frequently said that it was important for the residents to be in a good mood, otherwise nothing would work. She seemed uninterested in finding explanations of her caring actions but was quite amused when she did. She often considered experiences from her own present family within her reflections and expressed great satisfaction with having had the opportunity to have such interesting work and to choose working hours that suited her family life. She said, “The relief from the demands at home for a while makes the demands in the dwelling appear as a stimulating challenge.” Examples from the text and the summaries are presented in Table 6.

**Conclusion.** Olga achieves an understanding of the residents through **inducing good mood** and then connects communicative cues with her knowledge about the resident’s previous history through **singing and laughing**.

**Example.** Mrs. Anna apparently hesitated to enter the rest room. Olga started to sing and took Mrs. Anna by her hand and looked at her expectantly. When Mrs. Anna joined in singing the correct melody and some scattered words, a happy smile appeared on her face. They moved together toward the bathroom. Olga reflected, “She does not want to visit that room. But if we can sing together we can manage. Sometimes she clings on to the door frame. Even that can be overcome with singing. I think we sing ourselves onto the toilet! You have to calm down before going to bed, so sometimes a lullaby is nice. It is the same as with my children. I cannot ask them to come in and go straight to bed. You need to prepare them for it.”

**Pia**

Pia acted in slow motion even if her performances were resolutely carried out, seemingly to the resident’s satisfaction. She was keen to gain eye contact with the residents before she did or said anything. She used very few words. There was a soft tone in her voice that did not alter much. She often appeared to apprehend ‘a message from a resident’ that was neither said nor conveyed by signs or gestures. Her way of communicating seemed to be connected to her way of being in the situation.

Pia thought carefully before she spoke and appeared to have difficulty in finding words that expressed what she wanted to say. Her speech was interspersed with embarrassed giggles. She neither referred much to her previous experience, nor did she connect knowledge about the residents’ histories or the nature of AD. She rather searched for statements and words that suited her feelings best. Examples from the text and the summaries are presented in Table 7.
<table>
<thead>
<tr>
<th>Resident/Carer:</th>
<th>Mrs. Anna</th>
<th>Mrs. Beda</th>
<th>Mrs. Cilla</th>
<th>Mrs. Dora</th>
<th>Mrs. Ella</th>
<th>Interpreted summary</th>
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</thead>
<tbody>
<tr>
<td>Example from observation note</td>
<td>A jabbers incoherently. N answers as though these sounds were a part of a conversation. N holds the glass in front of B’s mouth and asks her to drink. She does so. N’s eyes never open during the process of drinking.</td>
<td>C and N talk to each other about life ‘as it used to be,’ apparently participating in the same conversation, even if N is producing most of the words. D is asked to assist N with folding the laundry. N swiftly puts away each folded towel. During the morning procedure N had mostly whispered. E is tip-toeing on high-heel shoes a step behind N on their way to having breakfast.</td>
<td>Has a great repertoire in her way of using her voice.</td>
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<tr>
<td>Example from reflective interview</td>
<td>T: Your comments to the sounds. N: She must be allowed to talk gibberish. Your way of answering can make her relax. T: You didn’t give her the glass to hold and drink. N: Sometimes she can eat, but drink? No, I don’t think she is able to do that. T: You talked about ‘the good old time?’ N: She is comforting others. Yes, one is somehow slowing down in her presence. Just introduce a subject that is familiar to her and there may come a lot that you can share. T: Why putting the folded towels away so quickly? N: That assists D to know when she can leave one and take the next. We cooperate, you know! T: She was tip-toeing behind you? N: Was she?! (Laughter). Eh, we thrive together! She didn’t want to disturb the cozy atmosphere.</td>
<td>Some residents’ behavior is judged to be sensible.</td>
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<tr>
<td>Example from summary note</td>
<td>—When A jabbers, N answers something like Eh, that’s what you are saying. N explains that ordinary speech comforts A.</td>
<td>—Other carers make B hold glass and cup? N admits that: ‘I do not dislike her... One has one’s own favorites! B is not one of those.’</td>
<td>—N demonstrates a great respect for C and they seem to share warmth and experience.</td>
<td>—N demonstrates patience together with C. Tries to comfort, sits very close and tries to distract her when she appears worried.</td>
<td>—These two have a special relationship. N states that E reminds her of her mother, whom she had wanted to care for when she was dying.</td>
<td>Seemingly valuing the emotional content in the relation with the residents as a prerequisite for understanding them.</td>
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<tr>
<td>Interpreted summary of ways of understanding</td>
<td>Treats incomprehensible words as comprehensible sentences in a discussion.</td>
<td>Visible and physical needs can be understood and met.</td>
<td>Understands through demonstrating respect and emotional ‘togetherness.’</td>
<td>Understands through registering signs that indicate the mood.</td>
<td>Loving relationship.</td>
<td>Achieves an understanding through tuning in based on her emotional valuation of the resident.</td>
</tr>
<tr>
<td>Resident/Carer: Olga</td>
<td>Mrs. Anna</td>
<td>Mrs. Beda</td>
<td>Mrs. Cilla</td>
<td>Mrs. Dora</td>
<td>Mrs. Ella</td>
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<tr>
<td>Example from observation note</td>
<td>O approaches A singing, waits until Mrs. A joins the singing and then they move together.</td>
<td>O talks with few words whilst assisting B, waits for: &quot;Yes,&quot; &quot;No,&quot; or an opening of the eyes. O translates signs and movements into words.</td>
<td>O converses with Mrs. C about her previous life. Mrs. C's contributions are very few words, but warm and encouraging smiles.</td>
<td>O reassures Mrs. D (who repeatedly wants to go home) over and over again, that she has a comfortable bed here, it's late, she needs some rest, etc. Often joking.</td>
<td>O makes the bed and Mrs. E participates by pushing and pulling here and there. O talks as if they are cooperating on an equal basis.</td>
<td>Reassuring, has an approach that demonstrates expected cooperation.</td>
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<td>Example from reflective interview</td>
<td>T: You often sing together with her before you act? O: Oh, yes, sometimes I think we sing ourselves into the restroom as a means to overcome her</td>
<td>T: You wait for her approval of what you intend to do? O: Errm. I think we know each other quite well. I feel convinced that she still can</td>
<td>T: You introduced a 'conversation' about her mentally retarded daughter? O: I think her children are still very important to</td>
<td>T: You repeated with great patience? O: Eh, ... I think if she cannot hear or understand all that I am saying, maybe some words can be verified by</td>
<td>T: You made her participate in making the bed? O: Oh, that is important, to make her participate, but when she is satisfied, you</td>
<td>Seems to induce cooperation through singing, laughing or actions.</td>
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<tr>
<td>Example from summary note</td>
<td>Interpreted summary of ways of understanding</td>
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<td>O noticed something and started to sing, offering Mrs. A her arm. Off they went singing together—</td>
<td>Finding togetherness in music and singing.</td>
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<td>—‘Makes’ B cooperate by “responding.”</td>
<td>Previous knowledge about B from being the primary carer. O continues to expect responses.</td>
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<td>—O seems to ‘converse’ about a handicapped daughter. C seems absorbed in the conversation.</td>
<td>Respect and two mothers’ understanding of having children with problems to care for themselves.</td>
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<td>—Repeats over and over again, that it is getting late, it would be a good thing to rest for a while, etc.</td>
<td>Relying on some words and laughter to have mutual meaning for the two of them.</td>
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<td>—They make the bed together, but leave it with the bedspread very creased.</td>
<td>Understands through doing things together.</td>
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<td>She relies on her own experience and good mood.</td>
<td>Achieves an understanding through communicative cues and inducing good mood cues through singing and laughing.</td>
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<td><strong>Example from</strong></td>
<td>A has a very appropriate manner at the table during party-like occasions. P and the other carer do hardly talk.</td>
<td>P dips a lump of sugar in a cup of coffee, then puts the lump into B's mouth; finally the cup is put into B's hand. B sucks the sugar, takes the cup and drinks.</td>
<td>P approaches C and whispers a question and gets a &quot;no.&quot; They continue to watch TV together with the other residents. A joke on TV makes C clap hands. The others follow.</td>
<td>A does not respond to signs of anxiety. She seeks eye contact without words before she starts talking to D.</td>
<td>E stands leaning forward. P steps in, bends down and seeks eye contact. When they look at each other, P slowly rises and so does E.</td>
<td>Uses few words, soft voice and moves in slow motion.</td>
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<td><strong>observation note</strong></td>
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<td><strong>Example from reflective interview</strong></td>
<td>T: You don't talk at the table? P: . . . well, I think the residents get an opportunity to talk to each other if we don't talk all the time.</td>
<td>T: The lump of sugar in the coffee? P: . . . I think she used to drink that way. Feeling the taste of sweet coffee before actually</td>
<td>T: You whispered? P: She doesn't know when she needs to go to the toilet, but the others need not know?</td>
<td>T: You seek eye contact, before you say anything or take her by the hand?—P: Eh, . . . I think I judge whether we have contact</td>
<td>T: The leaning forward? P: I think her back is hurting her. Maybe we can assist her body to a better position.</td>
<td>Seems to have difficulties in finding words, but appears very confident.</td>
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</table>
starting to drink. She gets coffee in the mornings while sitting in the bed in the same way.

or nor... if I take her hand...
I am leading somehow...

<table>
<thead>
<tr>
<th>Example from summary note</th>
<th>Very few words. The visit to the toilet was completely silent.</th>
<th>'Makes' B demonstrate social competence.</th>
<th>P seems to consider herself as a stand-in for lost functions.</th>
<th>Seeks contact before she acts or says anything, regardless of signs of anxiety.</th>
<th>—Interprets incomprehensible sentences. Interferences silently if anything goes wrong.</th>
<th>She relies on other means than language.</th>
</tr>
</thead>
</table>

Interpreted summary of ways of understanding | Togetherness as a basis for understanding and actions. | Togetherness as a basis for understanding and actions. | Respect, almost admiration. | Togetherness as a basis for understanding and actions. | Understands through knowledge about the history and shared laughter? | Achieves an understanding through being close enough to make up for some of the losses she feels the resident is experiencing in the actual situation. |
**Conclusion.** Pia achieves an understanding through being close enough to make up for some of the losses she feels the resident is experiencing in the actual situation.

**Example.** Pia was asked to elaborate on her statement that this dwelling was ‘more human’ than her former work place. She answered with several silent moments:

I think here I want the residents to feel well—spiritually, so to speak, not only physically!—they can not interpret their own cues and the situations so we have to work—as some kind of interpreters—if I can say that (giggles).—I think I get a better contact if I can look into their eyes.—I can see or feel?—if they follow, if it makes contact, if they understand.—If I take them by the hand, then it will be me leading somehow (giggles). I do not want that. I want them to feel that— they are doing things. . . .

**COMPREHENSIVE UNDERSTANDING AND REFLECTION**

This study shows that these five carers had personal ways of communicating with the residents which made the residents appear more like respected partners whom it was possible to understand than people who could not manage their activities of daily living. The carers’ caring performances were interpreted as being similar to mothers’ ways of caring for their small children, even if it must be stressed that these carers clearly demonstrated their respect for the residents’ personal life histories and treated them as adults (e.g., by not using “baby talk”).

The interpretation of the observations of the carers’ caring performance was that these carers performed their maternal thinking (Häggström & Norberg, 1996) in their caring performance in personal ways. Based on this metaphorical interpretation of carers’ understanding people with severe dementia as a kind of mothering, as previously discussed by Kihlgren (1992, pp. 42-47), it seemed reasonable to use theories founded on studies of mothers’ understanding of their babies to illuminate the understanding these carers had of the residents.

A disadvantage with Pawlby’s theory (mentioned above) about mothers’ imitative interaction with infants used by Athlin and colleagues (1990) is that it implies that the carer creates the meaning that is imputed; it is the carer’s perception of the patient’s wishes and feelings (Norberg, 1996). The carer’s perception may not correspond with the wishes and feelings that the person with AD has but cannot use common means to express.

**Affect Attunement and Other Elements in Achieving Understanding**

It seems that the theory about mothers’ interaction with infants by Stern (1985) emphasizes rather clearly that there is an objective basis for the mother’s understanding of the infant’s communicative cues. Stern (1985, pp. 139-147)
stated that mothers are intersubjectively related to their infants and share their affective states. He stated that intersubjective exchange of affective states is a process where a parent "reads the infant's feeling state from the infant's overt behavior" and performs in a way that "imitates or corresponds to the infant's overt behavior" (p. 139). Finally, the infant must be able to read the parental response as something that is related to its own original feeling response. The mother expands her behavior beyond imitation into affect attunement as the infant grows. This is embedded in other behaviors and expresses the quality of feeling, a shared affect state whereby the mother and the infant can create reciprocal behavior. Stern (1985, p. 148) called the performing of an affect attunement "interpersonal communion."

**Affect Attunement as a Way of Achieving Understanding.** The carers' way of performing in slow motion can be understood as affect attunement; i.e., their 'reading the residents' feeling state' took some time before they became attuned and could perform according to their interpretation of the residents' feelings, wishes etc. This gave an impression of quality in their care (Stern, 1985, p. 142).

The fact that the carers tuned into the residents' affects could be a factor behind the interpretation that the actual time and space could be transcended in personal ways by the carers in various situations to achieve an understanding of the residents. The residents appeared to dwell in a different place and time from the carer; i.e., the resident might act as if she were in her former working role and place. This, however, did not seem to bother the carer, who seemed to act according to the emotions expressed/sensed in the situation.

Maja's, Nora's and Olga's ways of achieving an understanding of the residents can be interpreted as affect attunement as described in Stern's theory. These carers did not seem to make efforts to achieve a cognitive understanding of the meaning of the residents' actions, but mainly joined them in their activities. There seemed, however, to be differences between the three carers.

Maja seemed to tune in to the residents' affects and act from a sharing of the affects. She apparently needed time for patiently 'reading the resident's feelings' before she acted and seemed to be constantly learning and happy about gaining new insights (Stern, 1985, p. 153). Nora appeared very dependent on her own feelings toward the residents. They appeared to be a condition for her affect attunement, and her vocal behavior was very intense and clearly conveyed an emotional message for those for whom she had warm feelings. Olga seemed to consider good mood to be a condition for achieving an understanding. She worked on transferring her positive affects to the residents. She shared laughter and singing as ways of inducing a good mood in them, which can be understood as initiating a social dialogue within the musical domain through the intensity in her vocal behavior (Stern, 1985, pp. 139, 153).

The findings suggest that these carers' personal ways of achieving an understanding can be understood as their ways of tuning in to the residents' affective states, which constituted a basis for a further sharing of an understanding of caring
to be performed. When the carers sensed that they were ‘tuned in’ to the residents’ affects, they relied on what they perceived and felt it was sensible to say and do in the situation.

The carers’ personal ways of achieving an understanding of the residents through affect attunement can be seen as a communion between the carer and the resident (cf. Stern, 1985, p. 148). A similar phenomenon was described by Ekman and Norberg (1993).

**Affect Attunement and Completing Puzzles as Ways of Achieving Understanding.** Lena had respect for the residents’ integrity. She had an understanding of wholeness and meaning of her caring performances as necessities for fulfilling the residents’ intentions in certain situations (Kihlgren, Hallgren, Norberg, & Karlsson, 1994). She also seemed convinced that the residents’ actions were meaningful and could be understood. She was resolute in her caring performance. Lena often underlined her actions vocally and sought explanatory connections that could be combined into comprehensive wholes. She seemed quite cognitive in her approach as she tried to find logical explanations for the residents’ actions. This way of achieving understanding is reminiscent of the way discussed by Jansson and associates (1993). They argued that the interpreter fills in gaps between fragmented pieces by imaging the pieces as belonging to a narrative whole. Lena combined affect attunement with a narrative approach of puzzling pieces together and filling gaps by imputation of meaning based on an imagination/intuition of a narrative whole.

The way of achieving an understanding of residents with moderate or severe AD also has similarities with Callery’s (1997) description of how mothers interpret their child’s behavior within the context of the child’s normal pattern of behavior. Maternal knowledge is acquired in close contact with the child whom the mother knows intimately, and therefore she can make intuitive judgments about the child’s feelings and well-being.

**Affect Attunement Within the Context of Caring as an Intrinsic End.** Pia seemed to act in a very confident way. She seemed attached to the residents and, in a way, lent them the help of her body at the same time as she seemed very eager not to threaten their integrity. She established eye contact before she spoke or acted, as if to attentively confirm the resident as a responsive being. What made Pia very special was her deep concern about the resident’s integrity. For Pia to care for and about a resident seemed to be valued as an intrinsic end (Norberg & Asplund, 1990).

**DISCUSSION**

**Limitations**

This study has added some further knowledge to the growing comprehension of how skilled carers can achieve an understanding of people with moderate or
severe AD. The way these five selected carers achieved an understanding of the residents was seen as being related to the carers’ openness and preparedness to interact with the residents in a reciprocal way and to support the residents’ remaining abilities, which enhanced the interactions between the carers and the residents. More studies are needed regarding this phenomenon. There are certainly aspects of achieving understanding that cannot be verbalized either by carers or by researchers (Polanyi & Prosch, 1975, pp. 40-41, 62). These aspects have to be understood through being lived.

This project was carried out in a selected group dwelling during a period when the staff situation was stable. The carers were identified and selected as skilled in interacting and communicating with the residents in order to enhance the occurrence of carer-resident understanding. A positive selection was a prerequisite for the whole project. Therefore, phenomena that were considered to be negative in the interactions and the caring culture were not registered and, consequently, not described. A false picture of a paradise for people with AD might emerge from the presentation of the findings from such a one-sided positive selection. The selection nevertheless seems defensible, as the intention was to collect data for further investigation of achieving an understanding of people with moderate and severe AD and caring performances that were judged to satisfy them. Comparisons with other institutions, homes, or dwellings for people with dementia cannot be made.

People with AD, as well as carers, are in a constant state of progress from birth to death and during a lifetime and will develop a strictly personal repertoire of actions and concepts in order to meet various situations. Considering these dynamics, the findings mentioned correspond with an expectancy that individuals will behave differently in different situations. This is especially significant, as the overt competence in people with severe dementia disease is reported to fluctuate markedly, even in very severe stages (Norberg, 1996).

Implications for Professional Care

There is a contradiction between the uniqueness of human beings as carers, residents in group dwellings, or patients in any institution and a seemingly prevalent idea of stereotyped caring procedures and manuals to be followed by all carers. Such manuals, obediently followed, may restrict the opportunities of dedicated carers to develop their own potential means of providing people with AD with good and loving care. The development of carers’ personal talents in ‘affect attunement’ and establishing mutual and reciprocal relationship should be given priority in developing personal communication strategies (Webb, McNatt Schreiner, & Asmuth, 1995). These five carers’ ways of achieving understanding suggest that maternal thinking and caring performance can be combined.
REFERENCES


Acknowledgment. Professional carers’ communication and relationships with people with moderate and severe dementia are ongoing studies conducted at the Department of Nursing, Umeå University, Sweden. This study is supported by grants from Umeå University, Medical Faculty; the Joint Committee of the Northern Sweden Health Region; the Federation of County Councils; the South Swedish Nurses’ Association, Lund. Our thanks to Patricia Shrimpton for revising the language.

Offprints. requests for offprints should be directed to Terttu Häggström, Department of Nursing, Umeå University, S-90187 Umeå, Sweden.
COUNSELLING FOR RE-DIRECTION OF LIFE STORIES

Narrated experiences of female professionals working among girls living on the streets in East Africa

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ABSTRACT

Background Children living on the streets is a global and escalating problem and girls are presumed to be especially vulnerable. In East Africa, the traditional extended family system is rapidly breaking down and traditional gender values seem to remain. This was the context for investigating female carers’ experience of caring for girls.

Aim The aim of this study was to elucidate the meaning of caring for girls of the street (GOS) as experienced by female staff members working in street children projects in Eastern Africa.

Method This study is one of two studies based on data from interviews conducted with 37 project staff members working with children living on the streets (COS) in the framework of non-governmental organisations (NGO) in Kenya, Uganda and Tanzania during 1997-1998. Transcribed text from female interviewees (n=13) working with GOS was analysed in this study. The data were analysed with a phenomenological-hermeneutic approach.

Findings The meaning of caring for GOS, for female professional carers in East Africa, was comprehensively understood as counselling the GOS to integrate the past of their adverse life stories with their present identity. On this foundation counselling meant conveying visions for a possible re-direction of the life stories, from being a GOS into being an accepted family girl. Caring in this context meant being squeezed between ethical demands and gender values. Experiencing frustration and powerlessness was related to gender structures in society, having to fight the grip of street culture and a lack of professional tools. Hope and satisfaction were related to having experienced success in changing the course of life stories of GOS and to seeing possibilities of contributing to the empowerment of GOS and community members.

Key words: Child Abuse, Caregiving, Counselling, Gender Issues, Life History, Psychosocial Nursing
COUNSELLING FOR RE-DIRECTION OF LIFE STORIES

Narrated experiences of female professionals working among girls living on the streets in East Africa

Key words: Child Abuse, Caregiving, Counselling, Gender Issues, Life History, Psychosocial Nursing

What is already known about this topic

- Children living on the streets, as a phenomenon, is a global and escalating problem. Girls living on the streets are specifically vulnerable.
- In East Africa all children have been traditionally cared for in an extended family system. This system and societies are now in transition, while the traditional gender values to a large extent remain.
- There are few structures in society and limited knowledge and experience of caring for girls living on the streets.

What this paper adds

- An overall understanding of the meaning of caring for girls living on the street from the perspective of female carers.
- Gender aspects of caring for girls living on the streets.
- The experience of lacking “professional tools” when caring for girls living on the streets.
INTRODUCTION

The ability to care can be seen as inseparable from our nature as human beings and mothering can be seen as a symbol of care. Care in this sense is not tied to any particular activities of the female bodies, but can be performed by both women and men (Ruddick 1989, pp. 46-47). Roach (1992 Chap. 3) suggests that care is the human way of being that can be developed and affirmed in professional care as a response to values like dignity of life and the preciousness of the human being.

Carers and care receivers, regardless of their age, understand themselves and others through stories that they tell about their lives (Hatch & Wisniewski 1995). The stories are continuously refigured by truthful or fictive stories that make life itself a cloth of stories told (Ricoeur 1985, p. 246), which need not cover the entire life span in all its aspects (Bertaux 1981, pp. 9-10). The carers’ responsibility toward the dependent young, in a life story perspective, can be seen as a responsibility to provide guidance and protection of the future life story (Thomasma 1984). A mother’s stories can be beneficial for the mother and her children, as story-telling can increase a mother’s self-confidence, can connect the mother’s and the children’s understandings of shared experience, and can assist the children to tell their own life stories (Ruddick 1989, pp. 97-102).

The work carried out by women to maintain the personal, familial and reproductive side of life is crucial to the survival of humankind. Domestic arrangements provide a major focus for women in most contemporary cultures (Gilligan 1982, Okin 1999, pp. 12-24, Waerness 1996). Informal care is supposed to provide love as well as work in a private setting (Abel & Nelson 1990) in which a safe shelter for caring for children and others can be maintained. Formal care is mostly performed in institutions, private homes (Waerness 1996) or special homelike care units like orphanages for children. Women who provide formal care for street children are usually not surrounded by any of the above-mentioned contexts in their daily work.
The street children phenomenon is global and their situation has been described by authors such as Boyden (1991). In East Africa this problem is comparatively new and rapidly escalating, and most societies in this area have no or little preparedness to deal with the problem (Deininger, Garcia & Subbarao 2003). The extended family traditions are now changing and some children are raised in poorly functioning extended families where the fathers are often absent (Kilbride, Suda & Njeru 2000). The rapidly increasing number of AIDS orphans (Foster & Williamson 2000, Deininger, Garcia & Subbarao 2003) is contributing to the increasing number of street children. Additionally, many children have run away from home because of abuses (Boyd, 1991, Matchinda 1999). The violence experienced by East African street children in their families is closely connected to parental abuse (Mdoe 1997, Ranji & Kudrati 1994), especially among girls (Kilbride et al. 2000, p. 62). A well-defined group of homeless children is "children of the streets" (COS), denoting children who live and work on the street full-time (Glasser 1994). "Girls of the streets" (GOS) will be used similarly.

Streetism in Africa has mainly been associated with boys and their lives on the streets. However, reports indicate that there are an increasing number of GOS in East Africa (UNICEF 1993) and their lives on the streets are often connected with sexual abuse (Lalor 1999). On the whole, GOS regularly practice prostitution, even if they do not identify themselves as prostitutes, and are not identified as prostitutes by members of society (Kilbride et al. 2000, p. 111). In the traditional East African society boys have greater freedom than girls have, as the girls are mostly controlled within their homes (Weisner 1997). Research reports focusing on GOS are few and so are specific caring programmes for GOS. It is a difficult process which requires commitment and strength on the part of the involved staff and the GOS, as well as support from the community (Warburton & Camacho de la Cruz 1996).
During the process of collecting data to study health problems among COS in East Africa (Sävenstedt, Sävenstedt & Häggström 2000), the authors sensed that female staff members' stories about GOS had an embedded special meaning.

THE STUDY

Aim

The aim of the study was to elucidate the meaning of caring for GOS as experienced by female staff members working in street children projects in Eastern Africa.

Method

A qualitative approach was used to analyse transcribed data that were collected through narrative interviews with female carers caring for GOS. The text was analysed with a phenomenological-hermeneutic approach, inspired by Ricoeur (1976). The method provided an opportunity to combine the philosophy of the meaning in a text with a hermeneutic interpretation of the text from tape-recorded interviews. The transcription was seen as a fixation of the meaning of the carers' experience in the discourse during the interviews (cf. Ricoeur 1976, pp. 26-28).

Research context and participants

This study is one of two studies based on data from interviews conducted with project staff members working with COS in the framework of non-governmental organisations (NGO) in Kenya, Uganda and Tanzania from 1997-1998. The first study focused on staff members' experiences of working with health problems among COS (Sävenstedt et al. 2000). In this second study, texts from interviews with 13 of a total of 37 carers were selected on the basis of the criteria that they were females and exclusively worked with GOS. These carers were employed as formal carers in four different projects that were
mainly funded by external donors. The carers were employed to care for the GOS with the aim of supporting their integration into society. The actual tasks were to take care of the psycho-social needs of the GOS, e.g. to comfort abused girls and to give advice on health issues such as hygiene and common infectious diseases. Eight of the interviewees were working both with the GOS, who lived on the streets, and girls who lived in different rehabilitation centres. Five of them only had experience of working with the GOS in rehabilitation centres. They had various kinds of professional education, some of them in social work. None of them had had any specific training to care for GOS. All, except one, of the interviewees were local professionals (Table 1). The exception was an expatriate who had worked 15 years in the same project.

**Table 1. Characteristics of selected interviewees**

<table>
<thead>
<tr>
<th>Interviewees</th>
<th>Work experience</th>
<th>Education*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>No. 2-4 years</td>
<td>&gt;5 years</td>
</tr>
<tr>
<td>20-25</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>26-30</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>31-</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
<td>7</td>
</tr>
</tbody>
</table>

* “Degree” refers to a completed university degree, "diploma" refers to other post-high school training of medium length and "certificate" refers to short-term training courses or high school education.

The interviewees gave their informed consent to participation before the interview and were promised anonymity in the coming reports. A special promise was given not to exploit the interviewees or their projects in any way. The interviewers made themselves open to objections and available for answering questions after the interviews. The Ethical Research Committee of the Medical Faculty, Umeå University, Sweden, approved the study (No. 97/257).

**Data collection**

The first author and a female assistant of European background conducted the interviews. In order to understand the context of the carers’ work, the interviewers visited the project sites and spent an average of 3-4 days with the staff members of each project. Seven
individual and two group interviews were performed. Five interviewees from the individual interviews participated in one of the two group interviews, held with one group of six and one group of five participants. The interviews were conducted with a narrative approach, and focused on the meaning of caring for COS. The individual interviews preceded the group interviews. As the participants appeared to share some experience, topics that the interviewers felt could be further reflected on and elaborated were brought up in the group interviews in order to capture the range of experience (cf. Mishler 1986).

Broad questions were used, for example: "Please, would you tell us about your experience of working with health issues among the girls?" The tape-recorded interviews took an average time of one to one and a half hours.

**Analysis**

The approach of analysing transcribed text followed a process developed at the Department of Nursing, Umeå University, Sweden (e.g. Benzein, Saveman & Norberg & 2000; Häggström & Norberg 1998) and the Department of Nursing and Health, the University of Tromsø, Norway (e.g. Talseth, Lindseth, Jacobsson & Norberg 1999). This process was inspired by Ricoeur's (1976) interpretation theory suggesting that analyses of texts should encompass three phases in the dialectic of understanding and explanation. In the first stage the whole text was read in an attempt to grasp a sense of the meaning in the text (naive reading). In the next stage, the text was approached stepwise. Meanings and patterns in the text were identified in order to find explanations for the sensed naive understanding (structural analysis). Thereafter the identified units were condensed and grouped together and the content was compared with the original text. Finally, the two previous stages were combined into a critical interpretation that was seen as conveying the most probable meaning of caring for GOS as a female carer in the text as a whole (critical comprehensive understanding). The process of analysis did not follow a linear structure. Rather, it was performed as a movement of going back and forth between the stages.
FINDINGS

The presentation of the findings follows the three stages of analysing: naive reading, structural analysis and critical comprehensive understanding.

Naive reading

The first reading of the identified text as a whole gave a sense that care in this context meant that the encounters between the carers and individual GOS created awareness and indignation at the unfair past life stories and present situation of the GOS. This contributed to carers’ commitment to care and to struggling to change the seemingly bleak future destiny of the GOS. Being able to create trustful relationships with the GOS seemed a central and sensitive issue and was often related to the carers’ personal experience of motherly care and protection. The struggle for a better future involved fighting against the grip of street culture and against one’s own and others’ values, as the behaviour of GOS collided with traditional values concerning how average family girls should behave. Carers’ personal relations with GOS seemed also to create feelings alternating between hope and frustration, as well as between satisfaction and powerlessness. This sensed understanding provided a base for further analyses of the meaning of care.

Structural analysis

The identified units of text about the meaning of care were grouped together into nine sub-themes that finally could be formed into three themes: encountering the life world through stories, struggling with the grip of street life, and being the voice of GOS. Themes and sub-themes are described and examples from the text are given in Italics.
Table 2. Overview of sub-themes and themes

<table>
<thead>
<tr>
<th>Sub-themes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meeting a girl commits</td>
<td>Encountering the life world through stories</td>
</tr>
<tr>
<td>Trusting through sharing of meanings</td>
<td></td>
</tr>
<tr>
<td>Getting through and being involved</td>
<td></td>
</tr>
<tr>
<td>Lacking a means to support change</td>
<td></td>
</tr>
<tr>
<td>Struggling with drug abuse</td>
<td>Struggling with the grip of street life</td>
</tr>
<tr>
<td>Struggling with colliding values</td>
<td></td>
</tr>
<tr>
<td>Conveying positive visions</td>
<td></td>
</tr>
<tr>
<td>Being frightened and powerless</td>
<td>Being the voice of GOS</td>
</tr>
<tr>
<td>Supporting empowerment</td>
<td></td>
</tr>
</tbody>
</table>

Encountering the life world through stories

Through listening to the stories of GOS, the carers opened their minds and became touched by encountering the life world of GOS. This, together with an increased awareness of sharing an understanding with the GOS of their experience of the prevailing tough and non-caring street life, made the carers commit themselves and spend time creating trustful relationships. The carers felt that they became involved in the life stories of the GOS. The theme consisted of four sub-themes: meeting a girl commits, trusting through sharing of meanings, getting through and being involved, lacking a means to support change.

Meeting a girl commits

Commitment to caring for GOS as a mother was expressed as a strong conviction that emanated from the encounter with an individual girl. The commitment seemed closely connected to an understanding of the young girls’ vulnerability when listening to their stories about being ostracised and their experience of the brutality of street life: *Their behaviour is opposite to what people think is right and that is why they ostracise them. It is like they were from Mars.* The strong commitment was connected to motherly feelings of protection and a will to rescue the girls from street life: *Somebody has to help these girls since their situation is not their fault. I feel at this moment as a mother to them.*

Trusting through sharing of meanings

Caring for GOS was in the text closely connected to the ability to create trust in the
relationship with the individual GOS. Without trust a good caring relationship could not exist. GOS were used to being rejected and despised on the one hand, and on the other hand they had developed an attitude of showing independence and using smartness as a response to being rejected. Mutual trust meant respecting the girls in their vulnerability and having an ability to transfer the feelings that they were accepted, loveable and worth listening to. It could also mean sharing feelings and thoughts with the girls as friends: *Most of the time they are defensive and they think you are going to accuse them of doing bad things. When I told them that I accepted them, they started to trust me and told me all the things.*

*Getting through and being involved*

Getting through and being involved meant having experienced that it could be possible to break through the thick wall of defence surrounding the emotional life of GOS and being accepted as a provider of care who could share their emotional problems, as well as providing counselling and comfort. The experience of getting through contributed to feelings of being involved as a friend and gave rewarding feelings of satisfaction, e.g. when receiving evidence that the caring efforts had helped a girl to overcome some of her problems. The satisfaction contributed to further commitment to care: *It has given me a lot of satisfaction that when they realise that you have become friends, they come close and they have somebody to talk to. Whether you can solve their problems or not, the fact that I am a friend seems enough.* For the carers, getting through often meant sharing love and providing care for girls whose stories contained painful experiences: *Through love and care we have been able to help the girl whose mother was an alcoholic and sold her daughter to get money for her drinking, even if it is still a pain for her.*

*Lacking a means to support change*

Lacking a means to support change meant having experience of failure to care and feelings of not knowing how to support the girls. The carers’ awareness of lacking knowledge and a means to care for GOS created feelings of frustration and confusion: *I need more education on the problems [related to caring for GOS] and there is nothing there.* They [UNICEF officers employed as advisors in the country] *talk about Latin America, but you can’t apply*
those experiences here. This frustration was also connected to the experience of working hard to get a girl reintegrated into the community and still failing to make it work: *We are doing a lot of things for these girls and then you find that you have done nothing. I need to go back to school and learn more on how to deal with them.*

**Struggling against the grip of street life**

Struggling against the strong forces that reigned over the GOS and the prevailing drug abuse and prostitution among GOS made the carers realise that it was difficult for GOS to re-direct their life stories whilst they still were in the grip of street life. The girls had to be rescued from the street life. There were three sub-themes: struggling with drug abuse, struggling with colliding values, and conveying positive visions.

**Struggling with drug abuse**

Struggling with drug abuse meant encountering drug abuse as an integrated part of street life. Drug abuse affected the caring process negatively, was difficult to handle, and sometimes became too overwhelming. Caring for the individual GOS and being able to support a change of their destiny meant convincing them to give up drug abuse. This was perceived to be one of the major hurdles. Knowledge of the conditions of street life made the carers understand and accept that drug abuse could help the GOS to endure hunger, coldness and abuse. *When they are hungry they will be sniffing and they are always hungry so they will be sniffing aviation fuel most of the time. You have to consider the reasons why they take it before you remove it.* The drug abuse made the GOS aggressive and difficult to deal with. It also made the GOS do things that they never would have done if they had not been high on drugs. This became an unequal struggle, not only against the girls’ drug addiction, but also against the powerful interests that could be involved: *It is very hard for us to fight the drug abuse on our level since we are just grass root workers and drugs are connected to big people.*

**Struggling with colliding values**

Struggling with colliding values meant fighting against prostitution and sexual abuse. These problems were value-laden and frustrating. A strong motivating factor for fighting
the grip of prostitution was the frustrating insight that prostitution and sexual abuse among the GOS included the risk of getting infected with HIV/AIDS and having to live with the consequences: *It is very difficult to see them dying of AIDS after all the work you done...especially when you know that they got it through abuse.* Struggling against prostitution meant dealing with the carers' own integrated gender values concerning how normal girls and young women should behave. It also meant dealing with society's ignorance and rejection of the girls. It meant both convincing the girls that there was an alternative way of living and going against the values of street boys, pimps and other street girls who felt that they had an ownership of the GOS.

*Conveying positive visions*

Conveying positive visions meant conveying hope and providing GOS with the vision that it was possible for them to become loveable ordinary family girls, who could attend schools and form a family of their own. It also meant convincing the girls to accept and integrate prevailing gender values related to family girls. GOS were used to the relative independence of street life and to making most of their own decisions without interference from adults. Instilling attitudes and values corresponding to the life of family girls was a process that had to be accomplished with a participatory approach. *We found that when the girls stayed on the streets for a couple of months, it was more difficult to convince them to change their lives. You could not just tell them what to do and you had to spend a lot of time with them.* The process of conveying positive visions was in the text often described as being a mother for the GOS. Signs showing that GOS struggled towards actualising positive visions created feelings of hope and further commitment: *I really love work with them.... I feel good when a child who was useless has changed and I feel I can do more helping them than those who have everything.*

*Being the voice of GOS*

Being the voice of GOS often meant an experience of being alone and without power in the struggle against gender values in society and powerful men. However, it was also connected to supporting empowerment among GOS and people in the community in the
struggle for GOS. There were two sub-themes, being powerless and supporting empowerment.

*Being frightened and powerless*

Being frightened and powerless meant having experience of being an advocate for the GOS, fighting against the sexual abusers and experiencing feelings of fear, frustration and powerlessness. It also meant facing the difficulty of convincing the abused GOS of the necessity of sharing their painful experiences so that the carers might be able to act as advocates for them. [You] have to go about it in a very sensitive way so that you don't endanger the girl's life or your own. Caring for GOS evoked strong negative feelings about the sexual abuse of young girls. A way of dealing with the problems and their own frustration seemed to be through contributing to public awareness: *I really feel bad about these men who are abusing girls. I don't like them........ I have even become a member of a local awareness group.*

*Supporting empowerment*

Supporting empowerment meant becoming increasingly aware of the magnitude of the problems facing young girls in poor communities and contributing to girls leaving their homes to live on the streets. The carers' own awareness resulted in eagerness and a will to work with members in the communities. *We feel we need to sensitisise the communities about child abuse because many in the communities are not aware of what is wrong about child abuse.* Hopes for a better future for GOS were attached to empowering them through education, even if girls were traditionally seen as more useful for generating income in a family: *It is a big sacrifice for the slum family to send the girl to school, but if she is not empowered by education they are just used and abused by everybody. An educated girl will also give hope to their mothers.*

*Comprehensive critical understanding*
The meaning of caring for GOS, being a female professional carer in East Africa, was comprehensively understood as counselling the GOS to integrate the past of their adverse life stories with a view that they were valuable. On this foundation counselling meant conveying visions for a possible re-direction of the girls’ life stories, from being a GOS into being an accepted family girl. Caring in this context meant being squeezed between ethical demands and gender values.

The phenomenon of care started as a process when the carers listened to the life stories of the individual GOS. Encountering a GOS meant that as professional carers they committed themselves to caring for her as a mother. When the carers were committed, they had to create trustful relationships that enabled them to get through the personal defences of the GOS and share with the GOS the meaning of her experience. Sharing with the girl the meaning of her experience made the carer feel involved in the story of the GOS. In this involvement the carers often felt that they lacked the means to support a change in the life of the GOS. They also had to struggle with the grip of street life and colliding traditional and gender values when they were trying to convey positive visions for a change in the future life of the GOS. Conveying hope for a better future for the GOS also meant being a voice for the GOS, acting as an advocate for their rights in society. This process of counselling and caring for the GOS was connected to feelings of frustration and powerlessness, as well as feelings of satisfaction and hope. Their involvement in the life story of the GOS could invite them to be a counselling carer empowering the GOS to integrate a vision of a future life story similar to the life story of a family girl.
DISCUSSION

The aim of the present study was to elucidate the meaning of caring for GOS as experienced by female staff members working in street children projects in Eastern Africa.

The meaning of care is in this paper investigated within a society in rapid transition (cf. Foster & Williamson 2000). In this context the meaning of care seemingly started as a process where the carers committed themselves to caring for GOS in their encounter with a girl and through listening to her story. This commitment to care can be understood in the light of Løgrup's philosophy (1971, p. 59), maintaining that in our meeting with people, we perceive radical, ethical, silent demands to make a decision on the basis of our own selfishness and our own understanding of life. The carers’ lived experience served as a base for sensing that the girls lacked motherly support and guidance. Ruddick (1989) suggests that mothering as an activity is governed by commitment that perseveres through feelings and activities that can be carried out by both men and women. This maternal work gives rise to a distinctive kind of thinking called forth by the demands of the children (p. 61). The interviewed carers seemingly developed an enduring commitment to caring for GOS and to defending them against rejection and abuse in society.

Being committed to care also meant that the carers had experienced that they had to create a trustful relationship with the girls that could break through their personal defences and enable the carers to share with the GOS the meaning of their experience. Sharing the meaning of experience is possible through telling and listening to stories about experiences in life (cf. Hatch & Wisniewski 1995). The carers aimed at supporting a change of the life story of a GOS in spite of her behaviour against traditional and gender values. Viewing care as a support of a care-receiver’s life story that can be accepted by herself or himself and others can be understood as corresponding with what Davies (1995, p. 142) describes as a means to ruminate about the past and motivate training and planning for a future. Foreseeing the future can be seen as an essential task for these carers, as GOS usually have
little concern about their future. Their daily life is filled with concern about daily survival (cf. Epstein 1996).

The commitment to care as mothers can be seen as relating to the interviewees’ experiences of having and being mothers. The relationship between mothers and daughters is specific. Girls play an important role in assisting the East African mother in managing domestic duties, and the home is essential for learning appropriate behaviour according to age and gender (Weisner 1997). A young girl who is outside this system will still be judged according to traditions, and children tend to retain close bonds with their mothers or other female caregivers, as well as with siblings who have functioned as caregivers (Kilbride et al. 2000). Motherhood, in general, is connected with caring for one’s children in one’s home, and caring is generally associated with women and mothers in most parts of the world (Condon 1992, Unger & Crawford 1992).

The carers had to struggle against their own integrated gender values and traditional gender values. These are issues of power (Dahle 1998). Power relations between mothers and daughters in the average East African family differ from the interviewed carers’ relationships with GOS, as GOS are socialised through the influence of peers. The interviewed carers had limited power over the GOS. GOS often act independently as adults and manifest adult behaviour (Setel 1996). Parker Lewis (1998) gives a glimpse of having experienced the life world of COS: Besides being difficult to assist and resistant to help offered, street children are also difficult to understand. They will put up with really sordid living conditions, deprivations and inconvenience, if they feel secure. Above all else, they value the freedom to make their own decisions. A homelike institutional setting as a context for the interviewed carers’ maternal, counselling care might increase the carers’ possibilities of exercising “maternal” control over the GOS, in comparison with the street setting. Sandvin, Söder, Lichtwarck, and Magnusson (1998) claim that understanding the level of power between a caregiver and a care receiver is important for understanding the professional role. The carers’ experience of power relations on the streets and in the families seemed to contribute to creating frustration when the carers responded to perceived
ethical demands to care (cf. Lögstrup 1971, Ruddick 1989), even if care also provided feelings of satisfaction and hope.

The carers seemed aware of the girls’ rights (cf. Hammarberg 1990). Speaking on behalf of the GOS, especially regarding sexual abuse, became an unequal struggle against powerful forces in this East African society, where GOS have the lowest status (cf. Kilbride et al. 2000). The carers’ maternal power seemingly had to submit to the paternal authority in society (cf. Ruddick 1989, pp. 109-113).

Hope for a change in the future, as an aspect of the meaning of care, was in the findings connected to experience of community empowerment and awareness. Elsworthy (1996) argued that power is created through working together in a spirit of responsibility for one’s fellow community members and through cooperation among women and men, and not through competition. This could be a suitable way for female carers caring for GOS in Eastern Africa to overcome feelings of powerlessness.

Transcribed data from 13 female carers caring for GOS, who were chosen from a total of 37 interviewed carers of both sexes caring for COS, were selected for further analysis in this study. Men’s views on caring for GOS are thus excluded, which gives a one-sided view of a gender perspective. The authors have a European background with ten and four years’ experience of living and working in Africa. These circumstances may have made us more sensitive to some messages as well as more insensitive to other messages. Since the aim of the paper was to elucidate meaning, we found it appropriate to use a phenomenological-hermeneutic method for analysing the transcribed text. Our intention has been to actualise the most probable interpretation of the meaning in the text through critically reviewing our interpretations in our relations to the text. Our use of narrative theory, i.e. a life story perspective, as a means to elucidate the meaning of care might have overshadowed other important aspects of the meaning of care which might have emerged if other perspectives had been included.
The findings indicate that caring for vulnerable girls such as GOS is a delicate matter. Gender issues are involved to a great extent and the interviewed carers felt that they lacked relevant knowledge and support. Ethical aspects and gender issues in relation to professional care for vulnerable girls ought to be addressed in education and practice, not only for developing countries, but as a matter of global interest. This study proves the need for further research on the topic of caring for vulnerable girls in general and in different cultural contexts in particular.

Acknowledgements

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