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BEING IN SAFE HANDS

Berit Seiger Cronfalk

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The experiences of soft tissue massage as a complement in palliative care. Intervention studies concerning patients, relatives and nursing staff



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ABSTRACT

The overall aim of this thesis was to explore how patients, relatives and nursing staff experienced soft tissue massage in palliative care.

In order to explicate the experiences of soft tissue massage two methodological approaches were used. To retrieve information of how soft tissue massage was experienced among patients and relatives, in-depth interviews (59) were used. In order to learn of nursing staffs attitudes towards a one-day course in soft tissue massage, focus group discussions (six discussion groups/ 30 participants) were conducted. Analysis was performed using hermeneutics (22 patients) or content analysis (37 relatives and 30 nursing staff).

In studies I and II patients and relatives in palliative home care were introduced to nine sessions of soft tissue massage over a period of two weeks. The offer of hand or foot massage in their private homes was perceived as luxurious. The experience of receiving soft tissue massage was however, dominated by feelings of retrieving a respite from illness and worrying concerns. The massage sessions were also perceived as generating a sense of own time as well as personal attention, physical nearness and existential meaning in daily life.

In study III soft tissue massage was introduced as an early intervention to bereaved relatives in palliative care. Here, hand and foot massage was offered once a week for eight consecutive weeks following the death of a family member. The main results show that the massage was experienced to facilitate feelings of consolation and help in learning to re-structure their every day life. The results also show that relatives indeed sought early support when offered, as fourteen of eighteen relatives contacted the researcher directly after their loss.

In study IV nursing staff (135) from three large palliative care units were introduced to a one-day introduction course in soft tissue massage involving theory and hands on practise (hand-, foot and back). Following the course 30 nursing staff participated in focus group discussions concerning attitudes and opinions about the actual course. Most staff was overall positive. The teacher's skills and ability to provide relevant information were emphasised as important for learning. Still, some had doubts about the appropriateness of introducing the massage in palliative care.

The result of this thesis illuminates the complexity and power of what physical touch comprises. Even so, a relatively short and simple hand or foot massage proved to be immensely important within a palliative care context.

LIST OF PUBLICATIONS

- I. **Seiger Cronfalk B., Ternestedt B-M., Strang P., Friedrichsen M.** The existential impact of soft tissue massage in palliative home care. An intervention study. *Submitted*

- II. **Seiger Cronfalk B., Strang P., Ternestedt B-M.** Inner power, physical strength and existential well-being in daily life; relatives' experiences of receiving soft tissue massage in palliative home care. *Journal of Clinical Nursing*, (2008. in press)

- III. **Seiger Cronfalk B., Strang P., Ternestedt B-M.** Soft tissue massage- an early intervention to bereaved relatives in palliative cancer care. *Submitted*

- IV. **Seiger Cronfalk B., Friedrichsen M., Milberg A., Strang P.** A one-day education in soft tissue massage: Experiences and opinions as evaluated by nursing staff in palliative care. *Supportive and Palliative Care*, 2008. **6**, 141-148.

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LIST OF ABBREVIATIONS

| | |
|------|--|
| SPA | Salus per aqua, health or healing through water |
| ISPA | International SPA new definition “Your time for recreation, relaxation, renewal, reflection and joy” |
| STM | Soft tissue massage, gentle, firm and structured massage of the skin |
| TT | Therapeutic touch, energy medicine working with energy fields over the body |
| CAM | Complementary or alternative medicine |

1 SAMMANFATTNING PÅ SVENSKA

Det övergripande syftet med denna avhandling var att undersöka och beskriva patienters och närståendes upplevelser av att få mjuk massage i palliativ vård samt att tydliggöra omvårdnadspersonalens attityder och uppfattning av en riktad introduktionskurs i massagemetoden.

Avhandlingen innefattar fyra delarbeten baserade på kvalitativa data där upplevelserna av att få mjukmassage har varit i fokus. Patienter, närstående och efterlevande har i djupintervjuer beskrivit sina upplevelser emedan omvårdnadspersonalen deltog i fokusgruppsdiskussioner. Intervjuerna skrevs ut ord för ord innan de analyserades med hermeneutisk analys eller innehålls analys.

I delstudie I deltog totalt 22 patienter med avancerad cancer sjukdom och som var inskrivna i palliativ hemsjukvård. Patienterna erbjöds mjukmassage under en period av två veckor med totalt nio behandlingstillfällen (fyra gånger den första veckan och fem den andra). Massagen gavs i hemmet som hand eller fotmassage under 25 minuter av utbildad massageterapeut (BSC). Patienten valde själv tidpunkt på dagen när massagen skulle ges. Ungefär en vecka efter avslutad massagebehandling genomfördes djupintervjuer (BMT). Denna studie analyserades med tolkande hermeneutisk analysmetod med syfte att nå en djupare förståelse för mjukmassages betydelse i livets slutskede. Resultatet visar att svårt cancersjuka och döende patienter i hemsjukvård upplevde att massagen skapade en stunds existentiell respekt som upplevdes motverkade känslan av utsatthet, ensamhet och meningslöshet. Patienterna upplevde även känslor av tillfredsställelse av att känna sig bekräftade och fria från sjukdomskänslan under massagestunden såväl som omedelbart efteråt.

I delstudie II deltog 19 närstående till de patienter som deltog i studie I, studierna gick parallellt och hade samma design. Dessa intervjuer analyserades med innehållsanalys då syftet var att beskriva de närståendes upplevelser av att få mjukmassage i den utsatta situation de befann sig i. Resultaten visar att mjukmassagen gav de närstående inre styrka och kraft men även energi att orka med den många gånger tunga och orosfyllda vardagen. Massagen erbjöd personlig uppmärksamhet, närhet och omsorg. Inledningsvis var det dock några få som kände en viss osäkerhet inför massagen och den fysiska beröringen.

I delstudie III erbjöds efterlevande till patienter i palliativ vård mjuk massage som ett tidigt stöd i sorgearbetet. Arton efterlevande deltog i studien varav de första fyra inledningsvis utgjorde en pilotstudie. Tre efterlevande hade tidigare deltagit i studie II. I denna studie erbjöds de efterlevande massage en gång i veckan under åtta veckor. De erbjöds hand eller fot massage vid den tidpunkt och plats som bäst passade. Efter avslutad massagebehandling genomfördes djupintervjuer. När intervjuerna skrivits ut ord för ord analyserades dessa med både beskrivande(manifest) och tolkande (latent) innehållsanalys. Resultatet visar att mjuk massage upplevdes som ett stöd och tröst i sorgen och en hjälp i att finna ny livsstruktur. Dessutom beskrevs upplevelsen av att få massage generera tillåtande stunder att sörja privat och att få släppa oro och ångslan för en kortare eller längre stund. Massagen upplevdes även ge mänsklig närhet och värme. Utav de arton som deltog i studien ringde fjorton efterlevande spontant själva upp forskargruppen med en önskan om att få delta. Vidare visar resultaten att erbjudandet om mjuk massage upplevdes ge stöd och efterlängtat kontakt med sjukhuset. De flesta fick massage i hemmet men några valde att få massage på annan plats (sjukhuset eller arbetet).

I delstudie IV utbildades 135 omvårdnadspersonal från tre palliativa enheter i mellan- Sverige. Personalen fick vid en obligatorisk utvecklingslag teoretisk och praktisk introduktion till mjuk massage (hand, fot och ryggmassage). Ungefär en månad efter avslutad kurstillfälle genomfördes sex fokusgruppsdiskussioner med 30 personal. Personalen valdes utifrån att de var i tjänst den speciella dagen för diskussionen. Intervjuerna skrevs ut ord för ord innan de analyserades med innehålls analys. Syfte med metoden var att fånga personalens attityder

och åsikter om kursen. Resultatet visar att en kort endags introduktion i mjuk massage togs emot väl. Kursens innehåll beskrevs vara väl avvägt till förutsättningarna. De praktiska övningarna uppskattades liksom lärarens engagemang och kunnighet. Detta sågs som väsentligt för inlärnings-processen. Det framkom även negativa aspekter under intervjuerna såsom, bristande tid, genans inför andra, känslor av otillräcklighet och oro för sexuella närmanden eller misstolkningar. Det framkom även synpunkter om att mjuk massage inte är en omvårdnadsåtgärd samt att patienter troligtvis inte uppskattar massagen.

1.1 KLINISKA IMPLIKATIONER

Mjuk massage är en relativt enkel och tidseffektiv omvårdnadsmetod som kan erbjuda patienter, närstående och efterlevande i palliativ vård respit i svåra livssituationer. Mjuk massage kan även erbjuda personalen ett komplement i den dagliga vården av döende patienter. Idag är de kurser som erbjuds generella och kostsamma i tid och pengar. Det vore därför mer motiverat att erbjuda korta och riktade introduktionskurser i metoden inledningsvis.

2 INTRODUCTION

I was introduced to soft tissue massage eleven years ago, a method offering gentle and structured massage of the skin.

Following a course in hand, foot and back massage I was contacted by a patient. It was a reasonably young woman who specifically asked to be physically touched as that kind of contact was missing in her life since she became ill. This first introduction led to many more encounters and as I heard and saw patients' reactions I realised that the gentle touch presented by soft tissue massage could be a potential asset in the clinical care of seriously ill and dying patients. The patients' spontaneous feedback encouraged my curiosity to further understand what actually happened during the massage sessions.

In order to expand my understanding I included eleven patients in palliative phase to a single case study of foot massage. The study was carried out as a single-case study with a quantitative approach measuring physiological parameters before and after each session (in all nine treatments). The findings showed physiological effects in form of decrease in blood pressure, heart rate, pain and nausea directly after receiving the massage (published as a Master's degree essay).

Still, the pilot study gave me some answers but I had more questions. I wanted to find out and explore further how soft tissue massage was perceived and experienced on a deeper level among patients in palliative care but also to find out whether relatives in palliative care would be a suitable target group for the massage. And if so, would they benefit from it?

As a result you are holding the consequence of my curiosity in your hand, a thesis with focus on how patients, relatives, bereaved relatives and nursing staff experienced physical touch and in particular soft tissue massage in palliative care settings.

This research has brought me a deeper understanding for the complexity of physical touch and its existential implications at the end of life or during a life threatening situation among patients and relatives but also among the nursing staff. I have also gained an opportunity to extend my understanding for how nursing staff as professional care givers perceive conscious and structured touch in caring situations.

3 BACKGROUND

International studies indicate a growing interest among patients with cancer for complementary therapies in addition to traditional medical treatments (1, 7, 27, 34, 36, 39, 73, 77, 84, 86, 100-102, 106, 111, 112, 118, 132, 141, 152, 157)

However, in Sweden the law *SFS 1998:531 (1960:409) on administrating complementary or alternative treatments outside the health care system (Kvacksalverilagen)* rigorously restricts complementary treatments. Certified or licensed staff (doctors, nurses, physiotherapists and occupational therapists) are allowed to carry out certain complementary therapies within the Swedish health care system but the law prohibits therapists from treating patients with cancer outside the official health care system.

3.1 THE HUMAN NEED OF PHYSICAL TOUCH

This section will illuminate some general aspects of physical touch.

3.1.1 Touch and human development

Barnett (8) has described that in all cultures touching another individual is evidence of affection and kindness constituting the basic desire of physical and emotional warmth and comfort in humans. The opposite, avoidance of touch may indicate social rejection and withdrawal of affection. According to Barnett (8) the predominant aspect in human communication is developed through physical encounters and relationships with others. The consequences of inadequate skin contact have been described as retarded development of areas such as speech, cognition, symbolic recognition and mature sensitivity in early infancy (8).

The importance of receiving physical touch when seriously ill and dying has been emphasised as a valuable asset as the gentle touch of the skin activates the touch receptors to release the neuropeptide oxytocin (9, 58, 142, 156). The positive effects of oxytocin relates to relaxation, improved sleep and well-being but also as affirmative on stress and the social behaviour of bonding and trust (9, 58, 142, 156). The gentle touch of another individual may provide a means of non-verbal communication (124, 128, 142). This becomes especially valuable when words for different reasons are hard or difficult to utter. The spoken word has been described as constituting boundaries (46) in sensitive situations as a hindrance or burden.

3.1.2 Three modes of touch

The feelings of nearness, acknowledgement and acceptance by others are described as basic human desires (85) in order to survive emotionally as well as physically. Leder and Krucoff (85) describes touch (reciprocal) as enhancing the awareness of body and self in all individuals even those with a frail and by illness marked body (85).

The characteristics of touch have been described as comprising three modes; gestural, impactful and reciprocal (85). (1) The gestural touch implies activity and expressiveness as an ongoing process of meaningful intensions (conscious or unconscious) while (2) impactful touch is associated with the impact of touch (contact) through the seeing and hearing but also through emotional and cognitive perception and expressions. This explains the cultural significance attached to the social codes of touch such as loving and consoling touch, sexual touch or hostile touch. The impact of gestural touch has been described as constituting metaphors such as, "I was moved by that". (3) The third mode, reciprocal touch, emphasises that touching another individual means also to get touched in reverse. Another aspect of reciprocal touch is that it is the creator of intimacy, of inner and outer dimensions on or near the physical body. The

intimacy between partners or spouses such as frequent hugs have been described to release oxytocin; a neuropeptide known for its effects on well-being touch (76, 87, 142). Oxytocin release has also been associated with lowering the risks of cardiovascular disease and early mortality (76, 87, 142).

3.1.3 Alternative touch

However, in Sweden today there are options of receiving physical touch without emotional attachment. The development of the SPA (*salus per aqua*) culture consists of various alternatives of physical treatments such as massage, skin treatments, manicure and pedicure as examples of how the modern Swede can achieve a sense of well-being through sensory stimuli from professionals without any emotional affection. In the care of elderly or seriously ill other means of physical nearness, contact and comfort have been presented through introducing domesticated pets (10, 43) in the care as a possible source of nearness.

3.1.4 Nursing care and caring touch

This section will expand the view on physical touch in nursing care in general and later specifically to palliative nursing care.

The tentative definition of physical touch in nursing care is that it comprehends a behavioural process of endorsing both physical and emotional comfort, social meaning as well as relationships based on human values with the intention to facilitate the interaction, communication and intimacy between patient and carer (8, 14, 16, 19, 90).

As healthy individuals we perform most of our own bodily care automatically and without reflecting or discussing it. Bodily care has been described (94) as having a low and ignored position often taken for granted and thereby made invisible. However, as illness imposes on the individual, the body and its care is handed over to the health care providers. According to Chang (19) nurses have the unique status of being endowed a special stance allowing to physically touch patients while caring for their most private and intimate parts. Even though, there is an understanding in nursing for the bodily care it has rarely been acknowledged as being significant or important but rather cause for embarrassment and therefore devalued (94).

Caring is generally described to be a basic value in human life, guided by ethical principals of performing human concerns (103). In nursing care this incorporates attention to physical, emotional and psychological needs but also by providing nurturance to heal as the intention is to reduce the patients suffering and thereby facilitate a sense of well-being (25, 26). The underpinning perception of nursing care is therefore that each individual has a right to a balanced life as a whole person with body and mind.

3.1.4.1 Palliative care and touch

In the sixties Dame Cicely Saunders emphasised the need to improve the care for dying patients and thereby provided foundation for the first hospice to open in London (1967) acknowledging the patients as individuals. Saunders (127) used the concept of “total pain”, a holistic description of dying and death enhancing relief from physical, social, spiritual and existential symptoms (2). The patients and their families were seen as a unit as the families too were encouraged to be involved in making decisions concerning the process of the patients dying and death as well as their bereavement. The hospice philosophy became the basis for the World Health Organisations definition of palliative cancer care (107-109) as it today is defined as an approach to improve quality of life for patients and their relatives when life is endangered by a life-threatening illness. The core of palliative care aims to provide relief of symptoms but also to assist the whole family with spiritual and psychosocial problems and to offer bereavement support following death (109).

In some studies in palliative nursing care the concept of “closeness” has been defined as the essence of the nurse-patient relationship primarily founded on trust during the act of caring (90, 94, 128).

Still, to physically touch or be touched is a matter of delicacy (123) as it is imperative to understand that not all individuals are partial to physical touch. In health care each individual case must be judged separately as it could stir feelings of insecurity, discomfort, loss of integrity or sexual concerns (123). Even though physical touch is an essential part for the human development (8), the negative aspects (123) may influence the individuals’ emotional as well as social development. These negative experiences could contribute to disturbed contacts or alienation from physical touch (123).

3.1.5 Previous studies on soft tissue massage

The previous studies on soft tissue massage have mainly focused on the symptom effects of receiving the massage in cancer or palliative care. The studies show dissimilarities and variations in design, duration (3- 45 minutes), intervals of massage (1-8 times) and areas of the body as well as the milieu where the massage was performed. Positive effects have been reported on: anxiety (18, 27, 38, 120, 130), pain (17, 18, 38, 51, 81), nausea (18, 38, 51), better bowel function (116), decrease in fatigue (18), mood (81), improved sleep (131) decreased blood pressure and heart rate (98).

Following the exclusion 65 studies remained divided into three groups, (1) ten studies that met with inclusion criteria (patients with cancer), (2) twenty two that did not meet the inclusion criterion (e.g. did not utilize a control group, no baseline data, qualitative data or given to others than patients) and lastly three studies could not present an abstract with sufficient information.

In all eight RCT (randomly controlled trials) studies were eligible as two were presented in the same trials, all met with the inclusion criterion (3, 24, 51, 130, 146, 149).

The great number of published papers in this area of complementary therapies and the variation of how data were collected and presented does indeed present a problem when seeking evidence. The review by Cochran Collaboration (38) suggests replications of previous studies (using the same scales for measuring outcomes) as it would reinforce the evidence base. Few if any studies present negative aspects of the massage. I have found one paper concerning Aromatherapy where the negative consequences are described as not being able to receive enough aromatherapy (times) (28).

As a conclusion one needs to consider the choice of design when conducting research in this field of care. It is imperative that the research continue in the search of evidence for therapies such as soft tissue massage.

Table 1 Overview of massage methods used in palliative care. All but the Swedish massage illustrate methods of gentle skin massage.

| <i>Massage method</i> | <i>Described by</i> |
|------------------------|--|
| Swedish massage | Zottele, 1999 |
| Touch | Kelly et al., 2004, Bottorff, 1993 |
| Aromatherapy | Kohara, 2004, Wolcock 2004 Fellowes et al., 2006 |
| Therapeutic touch (TT) | Field, et al. Robinson et al. 2006 |
| Therapeutic massage | Ejindu, 2007, Smith et al. 2002 |
| Tactile touch | Bergsten et al. 2005 |
| Effleurage | Billhult et al. 2007 |
| Massage | Lafferty et al. 2006, Cassileth & Vickers, 2004, Fellowes & Barnes, 2006, Russell et al. 2008 |

3.2 PALLIATIVE CARE – PATIENTS, RELATIVES AND NURSING STAFF

3.2.1 Patients

Palliative cancer care of patients is divided and concurs as two phases, early and late phase describing the severity and progress of illness. In the early phase tumour specific treatment is given to control growth with the intent to facilitate relief of symptoms in order to sustain as good quality of life as possible(20, 21). This phase could reach over a period of several years depending on diagnosis as well as the severity of the disease when first diagnosed.

In the late palliative phase focus of treatment changes (40) as the process of the progressing illness often incorporates various symptoms and problems. Here, the main purpose of care is symptom control or relief to facilitate the patients' life situation. The patient in this phase often experiences dependency of others (family members or health care workers) that could generate feelings of existential anxiety (18, 27, 88, 120, 126). According to Winterling et al., (151) psychological distress depends on how the individual perceives life. In a sample of 67 patients with newly diagnosed gastro- intestinal (GI) cancer two aspects of life philosophy was described as their circumstances in life dramatically changed. In all 72% thought about reasons (meaning) why the cancer had occurred while 28% had not thought about it occurring. The main reason given for not contemplating was that they would not get a reasonable answer anyway (no meaning). Central aspects such as being healthy, having good relationships, having a good life and living a long life with a partner were described as the most important values in life. The main result implies that being able to incorporate a positive life philosophy lessens the burden of psychological distress in a group of severely ill patients with cancer (151).

3.2.2 Relatives

In all palliative care settings relatives play an important role especially when caring for a dying family member at home. The role as the primary caregiver involves exposure for stress and immense pressure(4, 31, 72) as it requires both being the main provider and the source of continuity in the daily care and life of the ill family member (45, 72, 133)

The process of caring at home alters the family structure, with changes in daily routines as well as in the interplay between the family-members (13, 31, 110, 148). This transition has been described to be both burdensome and stressful; it creates feelings of anxiety, vulnerability and depression and contributes to a relative health risk (68, 78, 115, 143) among the relatives. The situation causes a sense of private and social isolation (13, 44, 75, 80, 117).

Even though most literature regarding relatives have focused on the negative aspects, positive effects have also been described(50, 126) such as the important awareness of the purpose of being a family. The common death threat, facilitates a sense of social belonging that creates feelings of trust and comfort. The family is bonding together and experiencing a time of opportunities to share love and compassion (31, 50). Other positive aspects include becoming a stronger person, experiencing hope and gaining insight to limitations of life (15, 31, 64, 66, 72, 117). As the relatives are confronted with dying and death their understanding of the existential values of life are formulated. This insight and understanding has been described by Yalom (155) as the apprehension between becoming conscious about the inevitable death and the individual's wish for eternity, the core existential conflict (155). Still, the relatives' existential needs are sparsely acknowledged or focused upon in palliative care (31, 117).

3.2.3 Bereaved

In our society the view on death, grief and mourning has changed during the past century. Birth like death used to be a natural part of life, performed in the private homes during the end of the nineteenth century (62, 145). These procedures were surrounded by rites and rituals giving the individuals structure as well as confirming their behaviour during the process of mourning. This

was followed by a period when grief was seen upon as something that needed to be dealt with by using medicine. Grief was seen upon as a disease best treated in hospitals by specialised professionals (62, 145). In this way the relative's grief became marginalised as their emotional feelings were treated as a disease rather than being part of a natural process of grieving.

During the 50's and onwards, theories on death, bereavement and grief developed (79). These were characterised by describing death and bereavement as possessing separate phases, alienating the individual from the process of grieving (6). However, these theories have become scrutinised and criticised for being too normative (145) and today, the death of a family member or close friend is described to be one the most stressful and inconsolable moments of emotional and existential despair (97, 99, 135).

In the literature grief is described (70, 71, 136) as being a natural but complex phenomenon including different stances (for instance an active, dynamic, unique and dual process) in order to handle the loss. According to Stroebe & Shut (136) and Jacob, (70, 71) the grieving process oscillates between what is described as private grief or loss orientation (privately suffering pain related to the loss) and restoration orientation, to socially get on with life. Stroebe and Shut (136) stress that the grieving period consists of both private suffering and the urge to proceed with life. Both stances facilitate the relatives' transition towards accepting and acknowledging the loss and their changed life situation (70, 71, 136).

Today, support is offered to bereaved family members and close friends within the palliative care settings (52, 53, 67, 70, 71, 74, 96, 99, 109, 134, 136). The focus on bereavement support (often starting six to twelve months after) serves to facilitate the grieving process through actively confronting, expressing and reinterpreting the intense emotions following the loss (99). Previous studies also indicate that bereavement support could serve as alleviating or prohibiting an increased risk for poor health and morbidity among bereaved relatives (115, 137, 138, 143, 148).

Still, as most relatives are advised to wait six to twelve months before starting in any bereavement support, few options of early assistance are available (139).

3.2.4 Nursing staff

In palliative nursing the confrontation with severe illness and death has been identified as a source of stress (83, 114, 147). The nurses are witnessing the existential and physical suffering of patients and relatives at the same time as they are involved and engaged in the actual clinical care (114, 128, 147). However, Källström et al., (83) were able to describe a small sample of five nurses that over time (eleven years) had changed their attitude to working with dying and death. These findings were associated with their own personal as well as professional growth. The attitude to death on a personal as well as professional level was acknowledged to be a natural part of life rather than being a threat.

Other aspects of positive basics in nursing care have been described by Edvardsson et al., (30, 31) who found the specific atmosphere of the care setting (hospice, geriatric ward and an acute ward) to be of importance for the experience of personal satisfaction. At three different care settings Edvardsson et al., (30) identified five categories of importance for how the environmental atmosphere influenced staff, patients and relatives: (1) experiencing a welcoming environment, (2) acknowledging oneself in the environment, (3) establishing and withholding social relationships within the environment, (4) experiencing a keenness to serve the environment and lastly to (5) experience a secure environment. As the experience of the environment was exceeded it facilitated a sense of atmosphere at ease (30). In the specific environment of palliative care Edvardsson et al (119) described the atmosphere to hold hospitality, safety and everydayness as senses of facilitating the individual needs and expectations generating feelings of "at-homeness" or "homeless" (119). These findings are exiting as it suggests that an accepting environment may provide possibilities for healing

(emerging from within the individual). In the context of this thesis it is of particular interest as the experiences of soft tissue massage has been described as a tool of communication but also of facilitating the own worth among staff in a caring context (29, 48).

3.3 THEORETICAL BACKGROUND

During the process of analysing the empirical research data in papers I-III different stances of what constitutes the experiences of soft tissue massage emerged, such as existential implications of being physically touched. Assisting me during this process was the theoretical understanding of life and death as described by Yalom (1955). According to Yalom (1955) who has adopted and modified Martin Heidegger's ontological view, the ordinary every day life is lived in a mode of *forgetfulness of being*. In healthy individuals this state of being is described as a mode where the individual seldom is contemplating on his or her own being. But as life is threatened by serious illness and impending death, the individual awareness of being shifts as he or she enters a mode of consciousness, *mindfulness of being*. This view is referred to as the ontological mode of constant awareness.

The basis for understanding the theoretical facets of receiving soft tissue massage implies that physical touch of the body may be linked to the core of existence when life is threatened and death awaits (1955, 155). Two existential challenges of special concern are described as *isolation and meaningfulness versus meaninglessness*. The existential isolation refers to the own human existence, being essentially described as a persisting feeling of isolation despite engagement and integration with others. The mode of isolation is described by Yalom (1955) as a separation from other individuals as well as from the world as (1) interpersonal (social loneliness), (2) intrapersonal "when you don't know yourself" anymore or (3) existential.

According to Yalom (1955), all individuals are lonely in life with own responsibility. In other words each individual has to take charge and authorship of their own life. Our feeling was that isolation and loneliness were predominant feelings creating a void of anxiety due to the participants' circumstances in life. They had experiences and feelings, some of which were impossible to fully share (existential isolation) as the patient's own body had become unfamiliar (intrapersonal isolation) and their social contacts had been reduced (interpersonal isolation).

4 OVERALL AIM

The overarching aim of this thesis was to explore how patients, relatives and nursing staff experienced soft tissue massage in palliative care.

4.1 SPECIFIC AIMS

4.1.1 Paper I

The purpose of this study was to explore how patients in palliative home care with a cancer disease at the end of life, experienced soft tissue massage.

4.1.2 Paper II

The aim of this study was to explore relatives' experiences of receiving soft tissue massage as a support supplement while caring for a dying family member in the home.

4.1.3 Paper III

The aim of this study was to explore how an early intervention with soft tissue massage was experienced by bereaved relatives during the first four months following the death of a family member in palliative cancer care.

4.1.4 Paper IV

The purpose of the study was to clarify through focus-group discussions the nurses' experiences and opinions of a one-day introductory course in soft tissue massage (STM) and to shed light on the nurses' motivations to employ STM in the care of dying patients.

5 MATERIAL AND METHOD

The methodological section will explicate the context of the participants and how the studies were planned and performed but first a description of the preconception in this field of research.

5.1 PRECONCEPTION

The authors' preconceptions adhere to their comprehensive clinical experiences and research experiences in palliative care and medicine. The first author was also trained as a massage therapist with broad knowledge and long experience in the field of soft tissue massage. The co-authors' preconception of soft tissue massage varied as some were distantly familiar with the method while for others it was a well-known massage method even though they had no actual skills. During the ongoing studies two of the co-authors received hand massage to further their own understanding of what receiving soft tissue massage entailed.

An assumption was to get a balanced picture of what soft tissue massage encompasses, as previous findings in quantitative studies had been presented with overall positive results (17, 18, 27, 38, 51, 98, 116, 120, 130, 131). These needed to be challenged in qualitative studies as they might voice other more profound (both positive and negative) views of the massage.

5.2 SETTINGS AND PARTICIPANTS

5.2.1 Papers I-III

The studies were conducted in Sweden at a large palliative care unit set in a hospital in the Stockholm area. The palliative unit incorporated advanced palliative home care with 24 hrs service and two specialist wards with in all 40 beds. Patients and relatives were predominantly seen at their private homes while participating in the studies. On few occasions both patients and relatives received massage at the hospital.

5.2.2 Paper IV

This study included nursing staff from three large palliative units in Sweden. All had extensive home care services as well as hospital beds on specialist wards. The introduction courses in soft tissue massage were mainly set in the own clinical environment. Still, two occasions (one unit) the course was carried out in a conference centre.

Table 2. Context and participants

| Paper | Aim | Setting | Participants | Data collection | Method of analysis |
|--|---|---|---|----------------------------|--|
| I. The existential impact of soft tissue massage in palliative home care. An intervention study | To explore how patients in palliative home care with a cancer disease at the end of life, experienced soft tissue massage | One palliative home care unit in the Stockholm area | 22 patients with advanced cancer admitted to palliative home care | Semi-structured interviews | Hermeneutics |
| II. Inner power, physical strength and existential well-being in daily life: relatives' experiences of receiving soft tissue massage on palliative home care | To explore relatives' experiences of receiving soft tissue massage as a support supplement while caring for a dying family member in the home | One palliative home care unit in the Stockholm area | 19 relatives to the patients' in study I | Semi-structured interviews | Content analysis (manifest) |
| III. Soft tissue massage- an early intervention to bereaved relatives in palliative cancer care | To explore how an early intervention of soft tissue massage was experienced by bereaved relatives during the first four months following the death of a family member in palliative cancer care | One palliative unit (one ward and home care unit) in the Stockholm area | 18 bereaved relatives | Semi-structured interviews | Content analysis (manifest and latent) |
| IV. A one-day education in soft tissue massage: experiences and opinions as evaluated by nursing staff in palliative care | To clarify the nurses experiences and opinions of a one-day introductory course in soft tissue massage and to shed light on their motivation to employ the method in the care of dying patients | Three large palliative units in three counties in Sweden | 30 nursing staff (135 participated in the one -day course) | Focus-group discussions | Content analysis (manifest) |

5.3 RECRUITMENT, INCLUSION CRITERIA AND SETTING

5.3.1 Inclusion criteria

In papers I-III we employed criterion sampling (113). The purpose of criterion sampling is to study cases that meet with predetermined criteria. The predetermined criteria in papers I-III were patients, relatives, bereaved relatives (criterion one), within a palliative care setting (criterion two), criterion three encompassed the participants understanding the Swedish language in reading and writing.

In paper IV all nursing staff working at the three predetermined units was included (purposeful sampling). However, in the focus group discussions the informants (30) were randomly selected from the nursing staff on duty the particular day of the discussions and were asked to participate. The purpose was to receive a versatile picture of their views and opinions on the education day in soft tissue massage.

5.3.2 Paper I

The study was carried out over a period of ten months (2004-2005) recruiting 25 patients with incurable cancer admitted to palliative home care. The patients retrieved written information about the study from a coordinating nurse at the home care team. If accepting participation they were contacted by telephone by the first author who arranged a first visit where baseline data was retrieved (gender, age, diagnosis, previous experience of massage).

During the ongoing study three patients deteriorated resulting in death shortly after the massage intervention was finished. The remaining 22 completed the interviews, fourteen women and eight men, between the age of 41 and 76 years. All patients lived at home and were cared for by a relative (husband, wife or adult child) as well as being assisted by the palliative home care team. Most patients were severely ill during the intervention and all suffered from and were treated for multiple symptoms related to the progress of their illness (insomnia, anorexia, anxiety, worries, pain, nausea, infections, fatigue etc.). Fourteen of the patients died within three months after participating in the study.

5.3.3 Paper II

This study was carried out in parallel with and at the same time as study I. As the patients were contacted by the coordinating nurse about participation they were also offered information about the possibility for their relatives to receive soft tissue massage in a similar study. If the relatives accepted participation they were contacted by the first author before arranging a first visit. Most visits were performed at the same time as study I but with the specific wish from the first author to inform each individual separately. Still, nine couples wanted to get the information together mainly due to the severity of the patient's illness. Baseline data were retrieved at the first preparatory visit (gender, age, social status, relation to patient and previous experience of massage).

In total 21 relatives between the age of 27 and 77 years were included. Two relatives did not finish participation due to the early death of the family member or lack of time. In all nineteen relatives concluded participation in the study.

5.3.4 Paper III

The study was carried out over a period of eight months (2005-2006) recruiting bereaved relatives from one large palliative unit (one ward and one home care team). The bereaved relatives received a leaflet containing information (ongoing study regarding relatives/bereaved at the unit) concerning grief and the mourning period as they left the ward following the death of their family member, or as the home care team left the private home of the deceased. The leaflet also contained information about study III informing the relatives that they would be contacted by the first author four to six weeks following their loss about participation in the intervention study.

After accepting participation a first preparatory visit was set up by the first author. The visit was pre- dominantly performed in the homes of the relatives, still five opted to get the information about the study at the hospital. This was followed by the two nurses (massage therapists) setting up a visit, in order to retrieve baseline data (gender, age, social status, relation to the deceased and previous experiences of massage) and to arrange a time schedule for the massage sessions.

In total twenty five bereaved were approached about participation. Seven declined part-taking due to insufficient time or moving away from the area. In all eighteen accepted and finished participation. The participants were between the ages of 34 and 78 years. Three had previous experience of soft tissue massage as they had participated in study II. Fourteen of eighteen were women and most were in employment (11). Three of the four men were retired.

5.3.5 Paper IV

This study was carried out during late autumn and early spring 2004 -2005. Nursing staff from three large palliative care units in Sweden were recruited. Each head nurse (HN) was first asked whether they wanted their staff to participate in the study. All (four) accepted and chose to inform the staff themselves about the study. They also chose to introduce the course on a compulsory education day (i.e. no voluntary participation). Each HN received written information sheets about the study to forward to their staff before the course.

In total 135 assistant nurses and specialist nurses participated in a one-day introduction course to soft tissue massage. The units were comparable as they all provided advanced palliative care in the homes of patients with twenty four hours service accompanied by hospital beds on specialist wards (varying between 12 and 40 beds). Following the one-day course, 30 nursing staff members were randomly (on duty the particular day of interview) chosen to participate in the focus group interviews. All nurses had extensive experience of palliative care.

5.4 DATA COLLECTION

In this section the reader will get an overview of the procedure of inclusion and collection of data, see also tables 3 and 4.

Table 3. Demographic data for papers I-III

| <i>Paper</i> | <i>Inclusion n</i> | <i>Age</i> | <i>F/M*</i> | <i>Co- habit</i> | <i>W/R/SL/O**</i> | <i>H/F***</i> | <i>Pervious exp</i> | <i>Home/ hospital/ work****</i> | <i>Times</i> |
|--------------|------------------------|------------|-------------|----------------------|-------------------|---------------|-------------------------|---|--------------|
| I | 22 | 45-76 | 14/8 | 18 | - | 6/16 | 4 | 22/2/- | 7-9 |
| II | 19 | 37-76 | 9/10 | 17 | 8/8/2/- | 8/11 | 8 | 19/2/- | 7-9 |
| III | 18 | 34-78 | 14/4 | 2 | 6/6/4/2 | 9/9 | 3 | 11/5/2 | 6-8 |

*F-female/M-male, **W-working/R-retired/SL-sick leave /O-others, ***H-hand/F-foot massage

**** The place for receiving the massage

Table 4. Collection of data, papers I-IV

| <i>Paper</i> | <i>Interviews</i> | <i>Method of interview</i> | <i>Individuals</i> | <i>Couples</i> | <i>Groups</i> |
|--------------|-------------------|----------------------------|--------------------|----------------|---------------|
| I | 22 | In-depth interviews | 15 (7) | 7 | |
| II | 19 | In-depth interviews | 12 (7) | 7 | |
| III | 18 | In-depth interviews | 18 | - | |
| IV | 30 | Focus groups (6)* | - | - | 2/4/5/6/6/7 |

*In all six focus groups

5.4.1 Papers I - III

One to two weeks following the massage intervention, tape-recorded in-depth interviews were conducted with the patients and the relatives in papers I-III. In paper I the interviews lasted between 35 and 75 minutes. Even though most of the patients were severely ill they wanted to contribute and to express their views and experience of receiving soft tissue massage. In paper II the interviews lasted between 60-120 minutes as they too were keen to tell about their experiences. As the interviews were carried out in at their homes it allowed the relatives to get involved in the interview without the stress of leaving the patient on his or her own.

In paper III tape-recorded in –depth interviews were carried out approximately one week following the massage intervention. Here, the interviews lasted between 60-135 minutes mainly due to the bereaved relatives wish to described their current situation in relation to the first visit prior to the massage sessions.

In papers I and II nine couples interviews were carried out while the remaining thirteen (patients) and ten (relatives) were interviewed separately.

All participants were invited to narrate freely about their experiences of soft tissue massage. In order to retrieve detailed information the interviewer posed questions such as “Would you like to tell me more?” and “Would you like to explain how you felt then?” with follow-up questions based on the participants descriptions. The interviewer used dialogical validation when posing the questions, this meant using different phraseology to make sure that the relatives’ responses were understood correctly (95).

Follow-up telephone calls were conducted six to eight months after the interviews. The main reason for this was to find out if the patients, still alive, had the opportunity to receive soft tissue massage. Of the initial twenty-two patients five were still alive. Three patients received soft tissue massage on a regular basis from the home care team, the other two received the occasional massage from the physiotherapist.

As most patients had died a great number of relatives were in a period of grieving. The main question to the relatives was how they were coping following their loss. In all seven relatives in study II answered the phone calls. Four widows were living on their own while two of the widowers had new partners, the third was about to enter into a new relationship. One relative had died shortly after the death of the family member.

The main query when phoning the bereaved relatives in study III was how they had progressed with their lives.

5.4.2 Paper IV

Approximately four weeks after the introductory course tape- recorded focus – group discussions were conducted. To minimise the possibility of bias the group discussions were carried out by the co-authors as they had, had no previous contact with the nursing staff. In total, 30 nursing staff took part in six focus- group discussions. Each interview (45 minutes) were conducted with one facilitator and one observed according to focus – group guidelines (32, 57, 69). In the interview- guide, focus was on questions concerning relevance, content and pedagogical issues concerning the introductory course, typical questions posed were: “Would you like to tell me about the theoretical session?”, “What concerns do you have regarding planning of the theoretical part?” and “Where you satisfied with the content of the course?” The observer had the role of making observations, taking notes but also asking follow-up questions and ending the interviews by summarising the content of the discussions.

5.5 PROCEDURE OF SOFT TISSUE MASSAGE

5.5.1 Papers I - III

5.5.1.1 The soft tissue massage procedure

In studies I-II soft tissue massage was introduced and carried out by the first author as hand or foot massage. In study III the first author carried out the follow-up interviews where as two nurses administrated the massage (hand and foot).

The massage was carried according to a structured method of slow strokes, light pressure and circling hand movements using a lightly scented vegetable oil (Citrus or Hawthorne by Weleda®). Towels were used to keep the part (hand or foot) of the body that was not exposed to the massage covered to keep warm. Each session lasted for approximately 25 minutes. The massage was mostly performed in the private homes of the participants however in some instances the massage was carried out in the hospital or at the relatives' place of work (paper III).

A preparatory visit to retrieve baseline data was carried out by the first author in all three studies. The purpose was to gain information as well as giving extended information about the studies but also a possibility to get the participants to ask questions concerning the studies.

In studies I-II the first visit (approximately 60 minutes) included an individual planning schedule of the massage sessions as well as choice of location and scent of the oil (first author). In study III the two nurses conducted a separate visit to establish the individual planning schedule with each bereaved relative. Pre-arranged sessions were scheduled between 7 am and 8 pm depending on the participant's daily routines and activities in all three studies.

Prior to the sessions the participants were told that the massage therapist would not deliberately engage in conversation during the massage. Following the sessions they were encouraged to rest for thirty minutes to prolong the moment of rest.

In studies I and II soft tissue massage was introduced as an activity for nine days during a two week period (four days the first week and five the second). In study III soft tissue massage was introduced to bereaved relatives as a weekly activity for eight weeks.

All were informed that their participation was voluntary and could at any time be postponed without it affecting them in any way.

5.5.2 Paper IV

The introductory courses (8 hrs) were performed during office hours. The nursing staff was divided into two groups participating at different days to cover for each other and thereby save costs. The course was divided into a theoretical part and a practical hands-on session. The course included theoretical and practical aspects of touch in general and specifically soft tissue massage in palliative care, current research and hands-on practice.

Table 5. Content of introductory course in soft tissue massage (STM)

| <u>Theoretical session (4 hrs)</u> | <u>Hands-on session (4 hrs)</u> |
|--|---|
| An introduction to: <ul style="list-style-type: none">- basic physiology- psychological/existential awareness- physiological effects of STM- relevant research in the area- aspects of STM in clinical care- positive and negative examples of clinical cases | An introduction to: <ul style="list-style-type: none">- hand- foot- and back STM.- practical issues of importance such as informing the patient about the procedure- clinical assessment of the patient during STM (skin colour, breathing)- having the right height on the bed/massage table- choice of oils- introducing blankets, towels and pillows for comfort- written manual |

5.6 ANALYSIS OF STUDIES

5.6.1 Paper I

5.6.1.1 *Hermeneutic analysis*

The interviews in paper I were analyzed using qualitative method employing a hermeneutic approach with focus on interpretation.

The hermeneutic tradition of interpretation constitutes from reading and understanding texts. In modern research one purpose for using hermeneutics is to explain the individuals' experiences and perceptions of social and cultural contexts. Historically, philosophers such as Heidegger, Gadamer and Ricoeur, have described the purpose of hermeneutics. According to Heidegger, the existential meaning of understanding develops through the principles of comprehending the structure of existential meaning of existing in the world. To reach the understanding of existing in the world Heidegger used interpretations of texts. The purpose was to understand the content of the texts through interpretation to increase the knowledge about being in the world (125). In modern times, Gadamer (41) developed Heidegger's existential hermeneutics by focusing on the human existence as it is communicated and understood through the language. He suggests that only through the understanding of another individuals' word one can fully understand their situation and in that, comprehend their existence (158).

In this process of analysing the experiences of receiving soft tissue massage Kvale's main principle of gaining a well-founded and deep understanding of the phenomenon through qualitative interviews was used. The choice of Kvale (82) was based on his views on how to use qualitative interviews in order to gain an extended understanding of the world through the individuals (subjects). As their standpoint unfolded the meaning of their experiences revealing their lived world (before the scientific descriptions).

Each interview was transcribed word-by-word by the first author. The text was then read through (naïve reading) to obtain a first impression (making notes while reading) by the authors. This was followed by a structured analysis of the parts (meaning units) in relation to the whole (the continuous process of back and forth between the parts and the whole text). Finally, an interpretation was performed to attain understanding of the text and to reach a "good gestalt" i.e. when the interpretation of text goes beyond the obvious and already recognised presenting a differentiated insight as it broadens the meaning of the phenomena (82). In the analysis of data in paper I Kvale's (82) principles of the hermeneutic circle was used.

5.6.1.2 *The seven principles of the hermeneutic circle are:*

- a) The continuous back and forth process between the parts and the whole (starting with a vague and intuitive understanding of the text) the hermeneutic circle or spiral.
- b) The interpretation of meaning ends when one has reached a "good gestalt" an inner unity of the text free from logical contradictions.
- c) Testing the parts of interpretation against the global meaning of the text.
- d) The autonomy of the text; the text should be understood on basis of its own frame of reference by explicating what the text itself states about a theme.
- e) An extensive knowledge about the theme of the text.
- f) An interpretation of a text is not without presupposition: e.g. the interpreter of the text may attempt to make the pre-understanding explicit and try to become conscious about the certain formulations of a question in order to be aware of and to clarify one's own pre-understanding when evaluating the text.
- g) A sense of innovation and creativity needs to be present in the interpretation of the text i.e. to go beyond the immediately given, in order to enrich the understanding by bringing forth new differentiations and interrelations in the text (Kvale, 1996).

5.6.2 Papers II, III and IV

5.6.2.1 Content analysis

The interviews were analysed by all authors employing a qualitative approach using content analysis (49). Content analysis incorporates different levels of interpretation and abstraction; a descriptive (manifest) part and/or an interpretive (latent) part. In paper II and IV content analysis with manifest focus was used on descriptions while in study III both manifest and latent focus were used when analysis data.

According to Graneheim and Lundman (49) content analysis did initially deal with objective, systematic descriptions (manifest) but has over time experienced a development to now also include interpretations (latent) of communications such as interviews.

Both manifest and latent content analysis deals with interpretations but on different levels (depth and abstraction). The units of analysis are described as meaning units (sentences or sections of words) that can be understood as holding aspects that are related to each other through its context. Following the meaning units is the process of condensation of the meaning units i.e. shortening the text but still preserving its meaning. This is followed by abstraction, highlighting the descriptions and interpretations on a higher and logical level to create codes, categories and themes.

The following principles were applied in the analysis of the interviews in papers II-IV:

- a) The interviews were read through to obtain a first impression (or a sense of the whole)
- b) The interviews were read again, thoroughly to identify significant text segments (meaning units)
- c) The meaning-units were abstracted into codes (descriptions close to the text)
- d) The codes were then compared and based on their similarities were sorted into categories (paper IV)
- e) The categories were then interpreted and compared in order to find central components, ending in an overall theme only applicable on latent content analysis (manifest and latent) (papers II-III)

5.7 ASPECTS OF TRUSTWORTHINESS

Following the transcription of the interviews in paper I-III, all were read through and analysed independently by the authors before they were compared. In case of inconsistency these were discussed until common images were formed. The process of analysing the patients, the relatives and the bereaved relatives experiences of receiving soft tissue massage was carried out in accordance with Kale's (82) main principle of gaining a well-substantiated and profound understanding of the phenomena (soft tissue massage). To gain further understanding the reader is encouraged to follow the procedure of interpretation through understanding the content of the citations.

In study IV the first author was not involved in the initial process of analysing as it could be judged as bias due to being responsible for the education day. However, following the initial analysis all four authors were involved in the evaluation and analysis as to broaden the perspective.

In the papers I-IV dialogical validation was used to ensure an authentic perception of the participant's experiences (32, 63). Dialogical validation may also be employed by sending the transcribed interviews back to each participant for comments, if the analysis aims at descriptions as in this e.g. the case of phenomenography. However, when applying interpretation, especially hermeneutics, the method of allowing informants to comment on the results is not applicable, as the interpretation is made from the researcher's perspective and not from the informant's perspective.

Paper IV was excluded from this kind of dialogical validation as the comments from each participant during the focus group discussion would be difficult to identify in the text. It would also endanger the anonymity and integrity of the participants (32, 63).

6 ETHICAL CONSIDERATION

This section will argue in favour of research in palliative care but also contemplating against it.

Is it ethical to occupy the time of dying patients and their relatives in order to carry out research? or is it ethically defensible to impose on grieving relatives? These questions are central when applying research in palliative care. However, recent studies on ethical dilemmas of research in palliative care have described positive responses from both patients and relatives (8, 33, 54, 55). Still, there is cause for concern when entering into research in palliative care such as the intrusion of the patients and relatives integrity and privacy.

These studies were mainly carried out in the private homes of the patients and relatives. The private home has been described as a sanctuary of security (5) still, as serious illness or impending death appears the security of the home may be threatened. A major concern in studies I-III was therefore the threat of intrusion (integrity and privacy) during a period when death was predictable and existential crises was apparent. In studies I-III a specialist nurse (working clinically at the home care team) was therefore the first person contacting the participants to minimise the experience of intrusion. This could however be seen as placing the patients and the relatives' in a situation of dependency and loyalty towards the nurse but on the other hand it could be seen as the building of a trustful relationship.

When planning for the studies (I-III) there was an uncertainty about the reactions from patients, relatives and bereaved. Still, during the process of inclusion in studies I-II all within the palliative facilities were asked and as the question was posed all were positive to participate. In study III all bereaved relatives received information about the study as a leaflet was included in the general information handed out at the ward or by the staff at the home care unit. Most patients and relatives had no previous experience of soft tissue massage still, they accepted participation even if some initially, were hesitant towards receiving physical touch. Even so, following the first massage session all wanted to continue.

Their experiences of receiving massage facilitated a feeling that they were contributing to the development of soft tissue massage in palliative care. This view on participating is in good agreement with recent studies (33, 54, 59, 122).

The ethical considerations concerning paper IV has to do with the involuntary aspect of introducing the massage at a compulsory education day rather than it being introduced on voluntary basis. Still, it could be that the HN's made a conscious decision to introduce all nurses to soft tissue massage as they appreciated the course to be a meaningful contribution in caring.

These studies received ethical approval by the Human Ethics Committee at Karolinska Institutet, Stockholm, Sweden (03-513) (amendment 2005).

7 RESULTS

“We are like tiny snowflakes swirling through the air still some of us fall to the ground and smelts sooner than others. We are all the same but still we are different somehow.” (patient)

The overall results from the studies show that soft tissue massage was experienced as an important contribution in palliative care. It became especially clear in studies I-III, but also in study IV as the nursing staff was predominantly positive towards the massage.

The patients and relatives found the massage sessions as moments of being acknowledged as individuals during an overwhelming and existentially exposed life situation. Soft tissue massage was described to generate a sense of respite from different worries. The massage was also experienced as a sense of timelessness and of transcendence as the sessions constituted a structure that facilitated feelings of meaning in to their relatively chaotic life.

7.1 PAPER I

The main results were that soft tissue massage stimulated peacefulness, relaxation and energy in daily life during a vulnerable life situation. By means of warm hands, soft tissue massage facilitated feelings of rest and respite and consolation from daily concerns among the patients. The massage was experienced to enhance a sense of bodily well-being as they felt free and liberated from illness. The massage also created a sense of mental relaxation, being at peace and in a mode of timelessness, here expressed as a meditative- like moment of “floating on clouds”. The patients experiences of time consisted of three dimensions; (1) to halt for a while (to stop a process), (2) to reach a mode of respite (a breathing space or interlude) and (3) being here and now (in the moment). These dimensions were emphasised as creating a prolonged sense of peacefulness, signifying the body and mind as intertwined.

The patients’ preconceptions of massage and physical touch varied but most had a clear picture of the experience as well as their expectations of what soft tissue massage would entail. *“I believe that physical touch make a difference. For example if I rub someone’s back it says so much more than just that I like you, it could be a whole story that are being told. I really believe that physical touch has an impact but not the kind that don’t have a purpose. I believe that it is good for me but also for the one who is giving it.”*

The preconceptions were also influenced by the current state of illness and the actual environment. The familiar and secure environment of the home was valuable to all and became even more so as the patients’ health deteriorated. Some did however experience stress related to being at home as it reminded them of their previous life situation in relation to the present with progress of illness and loss of functions. Still, as they received soft tissue massage they were able to experience a sense of luxury of getting the massage at their own home.

In this study we found the above mentioned dimensions as synthesised into two categories; “an experience of thoughtful attention” and “a sensation of complete tranquillity.”

7.1.1 An experience of thoughtful attention

The experience of receiving soft tissue massage in the own home as well as achieving personal attention was important to the patients. The close and sometimes intimate encounters during the massage left feelings of being exposed as the patients could not conceal or withhold their physical appearances. *“It was a big thing for me, to let someone touch me for that long (25 minutes).”* The interplay with the therapist was important during the massage sessions as the attentiveness by the therapist confirmed and acknowledged the patients existence. The physical closeness and dedication to each situation was experienced to create a bond of trust between the

patient and the therapist, the experiences of retrieving someone's complete attention created feelings of being special.

7.1.2 A sensation of complete tranquillity

Soft tissue massage resulted in total relaxation of both body and mind related to the temporary absence of symptoms and discomfort. The relaxation of the physical body during soft tissue massage enhanced feelings of comfort as the aching and stiff body was relieved of soreness. In a patient with severe and recurrent pain and death anxiety the massage reduced these symptoms every time soft tissue massage was provided. Soft tissue massage facilitated the mood of regaining control of the physical body as no symptoms ruled during and immediately after the sessions. This generated feelings of being liberated from illness and the impending death as they for a short time and became a breathing space.

Other positive experiences of the massage where joy and satisfaction dissolving worries and concerns to an atmosphere of peacefulness and fulfilment.

7.1.3 Existential respite

As a whole, soft tissue massage increased a sense of existential respite, counteracting feelings of loneliness and meaninglessness. The feelings of meaninglessness were defused at least during and immediately after the massage. The patients seemed to reach a feeling of transcendence i.e. they were in a space away and beyond their current situation, beyond their actual suffering. During that transcendent mode, anxiety was absent.

7.2 PAPER II

The findings show that when soft tissue massage was introduced to relatives caring for a seriously ill family member at home, it was perceived as facilitating inner power, strength and existential well-being.

Despite a burdensome situation soft tissue massage was experienced to facilitate feelings of physical and existential powers momentarily or for a longer period of time. The theme "inner power, strength and existential well-being in daily life" derived from three categories "being cared for", "bodily vitality" and "peace of mind". The categories reflects on the relatives' need to feel acknowledged, consoled and in a way cared for, their need to feel bodily vitality, strength and peace of mind. The sessions created an increased sense of well-being during a difficult time in life.

Mixed feelings were however initially described concerning exposure of the body (hand and feet). The interplay between the relatives and the therapist was implied as being significant for how the massage was perceived. The findings will be presented through descriptions of the three categories.

7.2.1 Being cared for

Soft tissue massage was emphasised as means of thoughtful consideration. The relatives experienced feelings of being cared for, as they were put on a pedestal during the massage. These feelings helped to facilitate a sense of trust and comfort among the relatives. The category derived from two sub-categories, feeling acknowledged and feeling trust.

7.2.1.1 Feeling acknowledged

The feeling of being acknowledged contributed positively to the feeling of being recognised as both an individual and career. *"At first I could not believe it (the offer of massage) but it felt so good that someone actually cared about me... I needed that feeling, of being cared for, it did me good."*

7.2.1.2 *Feeling trust*

The mutual and silent interplay between the relatives and the therapist was emphasised as important during the massage sessions. A trustful and secure relationship was imperative to feel safe. The possibility of receiving massage at home without having to leave the ill family member was also seen as reassuring as it encouraged feelings of comfort and trust. No one expressed doubts about receiving massage at home, rather the opposite. Still, in the initial phases of the study some relatives expressed ambivalence concerning being physically touched by an unknown as the body was experienced as notably private. This uncertainty did not discourage them from exploring soft tissue massage further.

7.2.2 **Bodily vitality**

The experience of bodily well-being was related to the actual massage. Soft tissue massage was described to facilitate feelings of bodily vitality which was predominantly experienced after the sessions. The massage also enhanced feelings of nearness and sensuality. The category bodily vitality derived from two sub-categories; bodily relaxation and energy and feelings of nearness and sensuality.

7.2.2.1 *Bodily relaxation and energy*

A complete bodily rest was experienced during soft tissue massage, described as lingering on for hours or even the rest of the day. The sensation of being completely relaxed was followed by a sense of powerful energy “*I could go out there and win a tennis match.*” Other responses to being physically touched, were experienced such as tingling sensations in the head or the whole body, feeling heavy or weightless.

7.2.2.2 *Feelings of nearness and sensuality*

Soft tissue massage was described to generate feelings of nearness towards the ill family member. They shared the special moment of receiving the massage. During the session most would lay side- by- side in their beds or just being close by. This intensified the sense of nearness towards each other. Feelings of sensuality was described as unexpected in this context still, it was experienced as a sensuous pleasure of intimacy. However, there was a clear distinction between intimacy, sensuality and sexuality.

Soft tissue massage was also described to generate feelings of luxury in a vulnerable life-situation.

7.2.3 **Peace of mind**

Soft tissue massage was described to facilitate moments of peacefulness of mind, a feeling of self-transcendence, a possibility to achieve a moment of tranquillity. The category peace of mind derived from two sub-category “a sense of floating away” and “peacefulness”.

7.2.3.1 *A sense of floating away*

The experience of floating away was described as going beyond or standing aside of oneself in a process of transcendence.

7.2.3.2 *Peacefulness*

Worries and tiredness somehow dissolved for a while as a sense of inner tranquillity and timelessness emerged during the massage. This was described as reaching meditative sensations and peacefulness but also a sense of “emptying the mind” of worries and concerns.

The existential experiences of receiving soft tissue massage could be described as generating positive moments of completeness.

In papers I and II follow-up phone calls were made six to eight months following the interventions. All claimed to be coping reasonably well emphasising the massage as being a valuable asset during a stressful time.

In conclusion, soft tissue massage was perceived to generate inner power, physical strength and existential well-being among these relatives.

7.3 PAPER III

The findings show that the offer of soft tissue massage offered as an early intervention was experienced to be a help at the right time. *"It has been great to have something to focus on and sometimes it has been my own private moment of luxury it has given me an enormous sense of well-being."*

Even though the bereaved relatives experienced intense grief they were able to find meaning and structure in life as soft tissue massage was offered. The main findings have been conceptualised in the theme "feelings of consolation and help in learning to re-structure every day life. The findings will be presented going through the four categories that emerged during analysis: (1)"a helping hand in the right time, (2) "something to rely on", (3) "moments of rest" and (4) "moments of retaining energy".

7.3.1 A helping hand in the right time

Even though most relatives had no previous experience of soft tissue massage, it was described to satisfy their need of early comfort and to a certain extent hope during a time when it was difficult to fully comprehend the content of their loss.

The feeling of loss of a family member was described as a pendulum between feelings of helplessness, despair and uncertainty. The human attention of receiving soft tissue massage facilitated feelings of being confirmed and acknowledged, described as a relief and for some a "life-saver".

7.3.2 Something to rely on

The weekly massage sessions and visits from the massage therapists were perceived as a gentle start towards forming new routines in life. The continuity of the repeated sessions created a sense of stability as they felt connected to the health care that previously had played such a significant role of importance in their lives. Some chose to receive massage at the hospital as they found it a comforting and secure place implying that even if they had been through a difficult time they were able to identify positive experiences connected to the hospital and thereby a link to the now dead family member.

7.3.2.1 Moments of rest

Grief was initially an overpowering and energy consuming experience of constantly being emotionally drained and tired. Some even experienced that they became physically and emotionally paralysed with grief. However, the massage sessions were described as permitting a respite from the emotional pain and anxiety. During the moment of receiving soft tissue massage private and intense grief was allowed, described as a source of personal development. The massage seemed to facilitate a turning point of re-discovering their own life-situation.

The experience of rest was described as having diverse meaning such as an imaginative retreat from daily worries and a moment of complete relaxation when they were detached from the worldly concerns. Other important aspects of rest was being in the quiet as it facilitated a sense of peace with the own thoughts, permitting a private sphere of grieving without interruption. Three relatives had previous experiences of soft tissue massage and made comparisons. All

three found the massage to be more relaxing. This was due to the fact that they were able to fully concentrate on themselves when they were no longer in the caregiver position.

7.3.2.2 Moments of retrieving energy

The massage was experienced as a contributor of physical energy but also as a source of reinforcing inner strength. This was welcome as the relatives had a persistent feeling of being drained of energy. Soft tissue massage was described to generate inner strength, energy and positive feelings that helped in the every day life.

Soft tissue massage was found to generate energy in dealing with their new life situation. Some expressed the sessions to be “a miracle medicine” creating feelings of completeness.

7.3.3 Feelings of consolation and help in learning to re-structure every day life (overarching theme)

Soft tissue massage promoted feelings of consolation as it was prominent in all categories. It was also apparent that the relatives experienced their body and mind as a unit during the massage session. The experience of receiving physical touch and human closeness emphasised their need to feel accepted and notable as individuals. The weekly routine helped to diminish the sense of empty space as well as social and existential loneliness connected to their loss, bringing to mind a sense of consolation.

As a whole soft tissue massage was helpful in the relatives’ learning to re-structure every day life during the first four months of bereavement, balancing between the need to grieve and the need to proceed in the process of creating a new self.

In study III all but one claimed to be coping well even if some at times described themselves as inconsolable. Everyone made a point of expressing gratitude towards the hospital for taking so good care of them as well as their deceased family member. Some uttered appreciation towards being part of the study and of receiving the massage. Most described that they had entered a new phase in life and one had joined into a new relationship.

7.4 PAPER IV

In general the one day introduction of soft tissue massage was experienced by most nursing staff as a positive and appreciated potential complement in the care of dying patients. Still, negative views on its credibility were also expressed. The findings reflect on focus group discussion with 30 nursing staff of the 135 participants.

In this study background data was retrieved in order to establish the interest as well as motivation to learn and implement soft tissue massage in the care of the patients. In the pre-scoring of the nursing staff 81% scored that they were very interested in learning the method while 19% was not sure. Following the course and the post scoring 95% were very positive and 5% expressed that they were negative.

The information about the one-day course was perceived differently. The majority of the participating nursing staff was positive towards the opportunity of getting an introduction to soft tissue massage. Their positive outlook was mainly due to previous experiences and effects of the massage. The course was perceived to be an inspiration to most and for some it became encouragement to develop a strategy of how to implement the massage into daily nursing care.

However, some clearly expressed an unwillingness to participate. The negative attitudes were focused on feelings of being uninformed as well as being submitted to a compulsory education day.

During the analysis of the focus group discussions, three categories were identified.

7.4.1 Experiences of and attitudes towards the education

7.4.1.1 Positive aspects

Different positive aspects of the course were uttered. The theoretical part was appreciated as being informative and easy to follow. It was also considered to contain relevant information. The nursing staff also acknowledged the importance of establishing significant evidence of the method as it would contribute to a stronger position when offering complementary alternatives.

Another aspect of importance was the teacher as a person was perceived to be enthusiastic and possessing sufficient skills in the field. The teacher's pedagogical skills were also emphasised as she was able to explain the method from a clinical point of view and thereby make it more applicable. This utilization enhanced the interplay and communication between the teacher and the nursing staff. The nursing staff also emphasised the importance of the teacher bringing up negative aspects as this utilized a sense of balance.

The majority of nursing staff had previous insight to what soft tissue massage encompass and expressed a positive attitude and motivation during the course. The practical session was the most wanted part, as it was experienced to be the starting point towards implementing soft tissue massage in the care of the patients.

The demonstration as well as a variety of clinical cases and hands-on instructions was appreciated. The opportunity for group and individual support as well as the warm atmosphere and environment was also seen as an important aspect for learning, as it encouraged the nursing staff to feel comfortable and to overcome shyness and bodily discomfort.

7.4.1.2 Negative aspects

For some participants the theoretical part was found to be lengthy and tedious while others found it too basic. Only a small number experienced the scientific articles too hard to comprehend. Other negative aspects of concern were the perceived lack of information about what the education day would entail.

As the course was introduced during a compulsory education day and in some informants minds, an unwanted replacement for a regular education day. Being part of a scientific study was also experienced as negative by some. They experienced that it had an adverse shimmer that overshadowed the whole day. This attitude was partly directed to the inability to opt out but also to how the course was introduced by the HN. There was some criticism pointing towards the health organisation as the approval of participating in the study was made at a superior level. Even so, nurses who had criticised the poor or sparse information were satisfied with the actual teaching.

Some nursing staff expressed a sense of self-assumed stress as they compared their own ability and skills to that of others.

7.4.2 Experiences of implementing the skills in every-day care situations

Soft tissue massage was perceived to be a positive complement in palliative care even if not all favoured the practical hands-on exercise themselves. There was a shared opinion that time was a limitation and obstacle to give the massage on a routine basis. Even so, for most nurses time was not experienced to be a problem as the massage was perceived to generate time in dealing with suffering patients.

The organisation and routines of work was experienced as possible obstacles. A few believed soft tissue massage to put further strain to the already burdened situation. There were also doubts about the method as an appropriate nursing intervention as it would take valuable time away from other nursing activities.

Some expressed that the limited time of hands-on training made them feel insecure and not ready for own responsibility while for others it was natural to practice at home in order to gain more training. However, for some it became evident that they had sustained enough training during the course to feel secure in offering soft tissue massage to the patients.

A small number of nurses emphasised the sexual aspect of touch as a cause for concern. It became apparent that physical touch was considered as a threat of getting too close to the patient and thereby losing the professional distance. Bodily taboos were also emphasised as uncomfortable and distressing. Even to physically touch a colleague created feelings of uneasiness. A small number of nurses articulated the opinion that patients in general would be hesitant to receive soft tissue massage.

7.4.3 Attitudes to the physical body in nursing care

The nurses' attitudes towards their own as well as the patients' bodies varied. The majority of nurses emphasized that bodily touch form one of the most important and self-evident aspects in nursing care. The majority of nurses expressed enjoyment from receiving the massage themselves as they became relaxed and were able to unwind.

To physically touch a patient was perceived to comprise different aspects in caring, as means of communicating and of getting closer to the patient. Some expressed that physical touch in general was important more so than offering a structured method such as soft tissue massage. This opinion was however not shared by everyone. A small number of nurses expressed their doubts about soft tissue massage as they were not convinced that the method should be used in nursing care at all.

8 DISCUSSION

Previous studies in the field of research concerning soft tissue massage have predominantly focused on studies with a quantitative approach describing the effects on symptoms (11, 17, 18, 23, 38, 81) rather than the personal experiences of receiving the massage (12, 42). We also performed a literature search concerning relatives in palliative care (II-III) and found sparsely any literature that focused on forms of massage (48, 92) as support to this group of individuals.

The aim of this thesis was therefore, to attain knowledge about the experiences of receiving soft tissue massage in palliative care by patients and relatives and to get an understanding for how nursing staff perceived a short introduction course in the method. The exploration was sought through 59 in-depth interviews (I-III) and (IV) six focus group discussions (n =30) with the intention to get a versatile description of what it means to receive soft tissue massage in palliative care. The results from all four studies (I-IV) show an overall positive attitude towards soft tissue massage even though there were some negative aspects of concern.

The main result in studies I-III should be formulated as comprehending feelings of gaining emotional and physical consolation and a respite from illness, impending death, anxiety, worries, loss and loneliness. We were however, surprised to find that in all three studies concerning patients and relatives there was an overwhelmingly positive response towards taking part. The compliance to participate in such open manners even when in stressful and burdensome circumstances where not expected.

The positive attitudes towards soft tissue massage could of course be interpreted in different ways. Still, it was evident that all even though they had no previous experience of massage had some idea of that it would entail something that they might benefit from. Still, with this overall positive attitude towards participating one has to consider, if there was a situation of dependency towards the health care staff in the moment of acceptance. It could be argued that the patients and relatives undoubtedly were in a sensitive situation of dependency and thereby wanted to please. However, this scenario seems somewhat unlikely to occur among all individuals. The most likely explanation might be that they really needed something to focus on (a structure of daily routines) or something that distracted them in their sometimes unbearable situation.

In study III yet another unexpected outcome was found as the main part of the bereaved contacted the researcher themselves immediately after or shortly after their loss. A common attitude is to wait until the funeral (22) we too, took this view and were therefore surprised by the early turn out. This suggests that the relatives had a substantial need for an early contact following their loss. This should be seen in contrast to Milberg et al (99) and Worden (154) who suggest that early bereavement support one to three months following the relatives' loss may constitute a risk of burden. This attitude is common even if studies indicate the need for early support in order to decrease the risk for morbidity and poor health among relatives (115, 143).

In palliative care time is of essence. Therefore the unforeseen generosity of all patients and relatives to give of their valuable time must be considered as an unexpected result. It might however be explained by the sense of luxury all experienced during the massage sessions i.e. it was worth while. According to Schuster (128) touching another individual's skin includes a sense of carefulness and sensitivity. In the care of dying patients this adds a special stance as their bodies are frail and marked by illness. In this situation Schuster describes the body as becoming the meaning-unit of life (128) as the touching of a severely ill patient also emphasizes the own (nurses) mortality. These are strong words but still need to be considered when reflecting on the results in study IV as it exemplify the negative aspects of soft tissue massage.

The negative concerns of soft tissue massage were according to a few nurses revealed as feelings of hesitance when engaging in physical contact. There were suggestions that the physical nearness would affect the relationship between patient and nurse as the massage might stir unwanted feelings of intimacy and sexuality. This must be considered a problem in nursing, not only in study IV but overall, as nurses shy away from the fact that patients too have intimate needs even in palliative phase of their disease (60, 129, 153).

Another negative aspect of concern was that soft tissue massage could present a conflicting interest among the nurses. This was mainly due to the serious issues concerning time and changes in work routines and structure. This might adhere to the organisational principles at each unit as it might undermine the nursing staffs' ability and motivation to introduce massage in daily nursing care. Some nursing staff was also concerns about whether the patients indeed wanted the massage. These aspect needs be argued further and in another context as it may reflect on the staffs overall attitude towards physical and bodily care (94) rather than the massage and more so, the actual concern for the patient well-being i.e. gate-keeping (65). The results indicate that the nurse's attitudes, positive versus negative of the course may have effects on their motivation to implement soft tissue massage in regular nursing care.

8.1 SOFT TISSUE MASSAGE

In order to understand the implications for offering soft tissue massage within the context of palliative care one has to understand what the method implies. Soft tissue massage is delivered by gentle but firm movements of the skin such as strokes, light pressure and circling movements. The concept also includes the choice of environment as the atmosphere of the room might affect the individuals' experience of the massage. The context of soft tissue massage therefore implies other means of equipment to improve the patients comfort such as extra pillows and blankets. Most educational programs that are available today also introduce candles and music in order to improve the atmosphere. As the purpose of this thesis was to explicate the experiences of soft tissue massage, candle light and music was excluded as music is already known for its positive effects on relaxation (61, 121).

In studies I-III the massage was predominantly performed in the individuals' private homes which meant that the environment and atmosphere already was set. This may have contributed to the positive results of these studies. It became evident that to patients and relatives in studies I and II the offer of receiving massage at the own home was their opportunity to take part. As the majority of patients could or would not have been able to leave their home on a daily basis. Whereas the healthy relatives could theoretically have left their homes to receive massage at the hospital. Still as they did not want to leave the ill family member it was not really an option. It was also apparent in the interviews that the carried out at home contributed to the relatives experienced of decreased stress. Another aspect that should not be overlooked was the individuals opportunity to share memories of togetherness in their own environment. They also experienced the massage to facilitate a sense of taking time out from illness and worries. It could be argued that the massage thereby a source of consolation in the daily lives of the individuals especially in studies I and II. A question that should be considered in this context is if the choice of body location was of relevance to the individuals as they accepted participation.

I would therefore, like to take this opportunity to explicate the choices of body location (hand or foot) in all four studies. The main principles for choosing hand or foot massage as appropriate locations were to limit the sense of intrusion as regards to integrity and intimacy. There were also concerns of unnecessary exposure of the body and in this respect the hand and foot massage was appropriate choices. Other influencing factors were previous experiences of touch such methods of massage, pedicure or manicure. Lastly, insufficient or decreased (due to illness) blood circulation was also considered as principles for offering hand or foot massage. There is to my knowledge no previous research addressing the choice of location in this manner.

This thesis exemplifies how four different categories of participants experienced soft tissue massage within the palliative care context. Bearing in mind the difficult life situation and that the main part of the participants had no previous experience of the massage, it was exiting and unexpected to find the overall positive attitude towards participating in the studies. Some (I-III) expressed curiosity as their main reason for taking part. Still the majority saw an opportunity to retrieve something extra that generated a sense of structure in their every day life. Most participants emphasised that it was important to join research studies as it gave them an opportunity to share their experiences.

8.2 PERSONAL ATTENTION

The experience of gaining personal attention was a common description in all four studies. In studies I-III all described the feelings of being acknowledged and special as positive (14, 83, 147). Feelings of being acknowledged were described as their relationship with the therapist developed. This was especially apparent in the initial phase of the intervention and special concerns were therefore taken to develop a structure or routine according to each individuals own wishes. This meant in some cases that the therapist in study I and II visited the home twice daily i.e. the relative was working. This was emphasised and acknowledged by all as respecting the participants' lives and their self-worth.

As the therapists entered the private homes of the patients and the relatives (I-III) an initial moment of conversation was encouraged. The main purpose was to let the individual talk about their own situation and emotions but also to inquire about how they had perceived the prior massage session. This was followed by the arrangement concerning the massage such as warming the massage oil and putting out towels to cover the hand or foot that was not exposed for massage in order to keep warm. It was also considered important to make sure that each individual was had comfortable position in bed. This included a blanket to warm them if they became cold. Some preferred to sit in their favourite armchair. As each individual became familiar with the routines they themselves had prepared each session i.e. prepared the bed with the towels. In some cases the patients were waiting in bed as the therapist arrived. The massage was mainly performed in silence. This was encouraged by the therapists as was the thirty minutes of rest following the massage. The purpose was to give each individual an opportunity to get a daily moment of rest. Following the sessions there was an agreement that the therapists would let themselves out. If the patients and relatives had queries or doubts they were encouraged to seek contact with the therapist by telephone.

The relatively short (25 minutes) massage in studies I-III was considered to encourage feelings of humanly concern. This was understood to generate feelings of getting personal attention. The experience of gaining own attention became specifically significant among the relatives (II-III) as they emphasised the most, their own situation as being lonely, burdensome, vulnerable and stressful.

According to Yalom (155) feelings of existential loneliness and isolation are activated during severe illness or crisis and is something that everyone has to deal with. Still, Yalom (155) confer that the "aleness" can be shared during an act of compassion. According to Joan Erikson (35) the physical touch from hands of professionals' can "creating miracles" as it facilitates the communication of recognition and of important powers for existing. The provision of soft tissue massage to patients and relatives could therefore be viewed as an act of shared compassion or as moments of gaining unreserved attention.

According to Norberg et al (104) and Talseth et al (140) the experience of interaction and deeper bonding consolidate means of consolation. This gives reason to query the individuals' need for consolation and support. The question that need to be asked may be if the health care organisations should employ a more vigilant and generous view when offering support in this context of care? The results presented in this thesis indicate that soft tissue massage may be such an option of support.

The nurses in study IV experienced that they had gained attention from the head nurse as their wish to learn soft tissue massage was acknowledged. This was expressed as one valuable aspect of retrieving attention the other was when they, themselves, received the massage during the hands-on sessions. This made them aware of how the massage may be perceived by the patients. One could therefore argue that their own experience would motivate them to introduce soft tissue massage in the care of the patients.

Other aspects of importance were the feeling of being acknowledged by the teacher as this too, generated positive feelings of gaining personal attention. It was described as important in the process of learning. These results are in agreement with what Mackey, et al. (93) and Edvardsson et al. (29) found in their studies. They found that the skills of learning soft tissue massage had reinforced a sense of own development among nurses and assistant nurses in palliative home care and in the care of elderly.

Even if most participants experienced the personal attention as positive some nursing staff (IV) experienced negative confounders attached to the hands-on practice during the introduction course. This was predominantly due to comparisons with colleagues who had previous experiences of massage.

8.3 BODY AND MIND- INTERTWINED

Why is it so difficult to explain or express the experience of completeness of being? When describing the experiences of receiving soft tissue massage (I-III) it became difficult to fully comprehend the meaning of body and mind. This may be due to the dualistic view of the human being as the common view is that each individual consists of body (objective) and mind (subjective) however inconceivably intertwined. According to Sand et al., (126) the body becomes an altering device when it is occupied by illness and becomes the inevitable meaning unit of life as the body constitute the existential core of existence (126).

Another description is that of Lundgren and Bolund (91) in a study of ten women with breast cancer. The authors imply that time is a predictor for how the body is perceived in ten women with breast cancer. According to Lundgren and Bolund (91) a prolonged disease may cause bodily awareness as it is affecting the physical functions as well as the physical appearance evoking feelings of anger and uncertainty. It is however possible to live with cancer and to have a positive and confident attitude towards the own body when the disease is in a stable phase (91). This might imply that patients in late palliative phase and suffering from multiple symptoms may be apposed by exposing their bodies.

A question would be raised why soft tissue massage was perceived in such a positive manner among the patients in study I. It could be that they found themselves being focused upon, not as patients but as human beings or it could be the environment of the home that made them feel secure. One important aspect when considering the results in study I would be the context as the patients were confronted with the inevitable progression of illness and their impending death. Still they were able to identify experiences of feeling free from illness for at least a short time. These results may seem remarkable considering that most patients were in a late palliative phase and died within weeks following the massage.

However, the experience of bodily well-being when living with advanced cancer has previously also been described by Lindqvist et al., (88). As they were able to show that in a group of men with advanced prostate cancer health was experienced to be lost when affected by physical discomfort and symptoms. However, at occasions when the patients experienced no symptoms they perceived themselves as possessing health. This finding could be considered as a valuable contribution to palliative care as it offers a broader understand of the complexity of how patients with severe illness perceive their own body as well as health. The results show that none of the patients with severe cancer hesitated to accept soft tissue massage in study I.

In study II only few relatives uttered some kind of hesitation concerning soft tissue massage. This was described as part of their own inexperience or shyness concerning exposing their feet. Even though they were alarmed by exposing their feet they still chose foot massage. This was indeed surprising and could possibly be explained by an uncertainty towards receiving hand massage.

An interpretation of this might be that they acknowledged their hands to be more sensitive, intimate or personal. However, the first uncertainty of gaining massage was overcome after the first session. All relatives in studies II and III emphasised that they lived under considerable stress and strain which made them appreciate soft tissue massage as it offered moments to be on their own (during the period of rest following the massage). The massage was also described to facilitate a sense of completeness of feeling whole as they gained physical energy and inner power. One may suggest that soft tissue massage offered human compassion and consolation when it was most needed.

8.4 SHIFT IN PERSPECTIVE

In all four studies the participants (I-IV) experienced a change or shift of perspective during the massage. This shift of perspective may be difficult to comprehend but in studies II and III it became apparent that something happened during the process of receiving massage that became important experiences in the relatives' lives (70, 71, 136, 148). The recurring massage sessions introduced possibilities to create a structure in the relatives' daily lives. In studies II and III the life changing situation that the relatives encountered generated a need to find a way of re-building a life and a new identity. This was an important change and process that occurred over time and was necessary by all to endure. This process could be described as a transition. However focus had not been on studying the process of transition but rather to describe the experiences of receiving soft tissue massage. Still, the results imply a change or shift that could be understood as a transition among the relatives but in this thesis describe in this thesis as a shift of perspective. This shift of perspective was found to be temporary in study II while in study III there was a more profound shift mainly due to the relatives change of social status as bereaved. According to Stroebe & Shut (136) the bereaved relatives new life situation demands to socially get on with life (restoration orientation) but also allowing a time for own grief (loss orientation). An unexpected and interesting result was that the bereaved relatives experienced the massage to allowing time for own grief. The sessions encompassed special qualities that allowed the bereaved to grieve unconditionally during the process of receiving the massage.

Patients and relatives in studies I -III experienced the massage as an emotional sensation of vacuum from illness and worries and a respite from meaninglessness. This mode of respite introduced the individuals to a frame of timelessness enhanced by feelings of rising above or going beyond themselves (floating away). This was described as promoting the participants sense of existential well-being.

The experiences of receiving soft tissue massage in late palliative phase might imply that controlled and structured touch by professionals could help in the process of dying. Some severely ill patients expressed few words but as they received the massage they uttered feelings of pleasure of being at ease this was understood as constituting a shift.

According to Nygren et al (105) the term inner power is considered a useful concept in nursing research as it describes means of human resources. The term has been explicated into four different characteristics; (1) having capacity, (2) a sense of control and self determination, (3) a sense of mastery of challenging life experiences and (4) psychological well-being (105). In the results of studies II and III these characteristics were found as the relatives were in the process shifting of perspective.

In study IV most nurses shared the view that their role was to create feelings of trust in their relationship with patients and relatives. According to Garnett (42) the behavioural aspect of nurses should be viewed as a combination between a sense of integrity, confidence and appropriate manner. Garnett (42) argues that in order to reach a good relationship between individuals their behavioural attitude is of special importance.

In all soft tissue massage created strong feelings of emotional and physical well-being. The massage sessions have been described to provide a structure in the lives of patients and relatives resulting in a sense of being at ease and at peace, existential peacefulness. Complementary therapies such as soft tissue massage could be considered as worthy and important tool in the care of dying and their relatives. The “cocoon” of emotional support that the massage offers during vulnerable time should not be overlooked by the health care.

8.5 A MESSAGE THERAPISTS REFLECTIONS

The purpose of this thesis has been to describe patients and relatives experiences of receiving soft tissue massage as well as the nursing staffs' attitudes to an educational intervention. However, the massage therapists' views on giving soft tissue massage have not been focused upon nor describe. Still, this information should also be considered as important when attempting to understand what motivates nurses to give massage.

One aspect of importance is the purpose for giving massage. Therefore, one has to distinguish between the professional or personal act as there is a significant distinction between the two that needs to be clarified. Initially, it may be difficult to distinguish between the two. However, one of the main principles described by the participants in this thesis was that the therapists had to be professional. It was a frequent comment among patients and relatives as no one was prepared to receive from massage from "just anyone". They expected professionalism. As a therapist the main purpose is therefore to ensure feelings of security, trust and confidence. In order to reach that, one has to be confident in performing the procedure.

The massage sessions encourage the therapist to meet each individual at "their point in time" with an open mind and with no preconceptions. Each massage session is individually arranged by the therapist in accordance with the participant's needs and wishes. The actual time of giving massage generates feelings of basic human concern but also of reassurance that sometimes the simplest thing could have unimaginable impact on life.

9 METHODOLOGICAL DISCUSSION

In this thesis and especially in studies I and II the design of the studies need to be considered as it involved in all nine massage sessions over a short period of two weeks. A relevant question would be, why choose such an intense design when dealing with patients and relatives in late palliative phases? We were guided by the results from eleven single-cases in a Master's essay with patients in palliative care when planning for studies I and II, as the results showed positive attitudes towards daily massage sessions. The same results were found in studies I-II even though their life situations were intense, vulnerable and life-changing they experienced the massage as a valuable source of support. When they were asked about the duration of sessions no one found the intensity of the sessions to be burdensome or inappropriate. According to Wennman-Larsen and Tishelman (148), relatives in palliative home care expect to receive certain support from the health care (care-related tasks) but also hope for support in other areas such as help in the transition towards a new life situation. The results of this thesis imply that soft tissue massage was experienced to facilitate a shift of perspective. The patients and relatives in studies I and II were satisfied by receiving soft tissue massage as it was presented in the study design. All expressed a wish to continue with the massage on a regular basis, daily or every other day.

In study III the massage was introduced on a weekly basis for eight consecutive weeks. This was considered appropriate after studying four pilot cases. The intervention was also found to be helpful as it was introduced in an early phase of the grieving process (four to six weeks after death).

Previous studies on massage have predominantly been concerned with the utilization of massage as a possible recourse of symptom relief, mainly employing quantitative designs (12, 18, 36-38, 47, 56, 89, 120, 150). The primary goal in this thesis was however to deepen the understanding of how patients and relatives experienced soft tissue massage in a difficult life situation from a humanistic point of view. A qualitative approach was therefore appropriate.

The purpose of papers I-III was to extricate patients, relatives' and bereaved relatives' experiences of receiving soft tissue massage in palliative care. In all we attained 59 in-depth interviews. The intention was to retrieve wide-ranging descriptions of the experiences of receiving soft tissue massage during a burdensome and vulnerable period in time for patients as well as for their relatives. Special consideration was taken to each individual needs and circumstances and the interaction between the interviewer and participant was emphasised as important. This meant that initially some time was spent discussing other subjects of concern to the participants' e.g. worries and their stressful situations. This information was acknowledged by the interviewer as important to further understand each individuals' life situation. By using in-depth interviews we encouraged the participants to express their own total experiences rather than merely focusing on i.e. the patients' symptoms as this would have been a source of limitation.

In all studies the aspects of trustworthiness and credibility have been supported through applied dialogical validation during the interviews as well as in the analysis (95). During the analytic process all interviews were listened to several times before being transcribed word-by-word by the first author. They were then read through and analysed separately before all authors compared their analysis. In case of inconsistency among the authors these were discussed. The purpose of these discussions was to test any alternative interpretation rather than to reach consensus. The results initiates the reader to understand the process of building categories and theme through the different text segments (49, 82).

In all, seven couples-interviews were carried out in studies I and II mainly due to the patients severity of illness but also due to their wish. This implies that the participants most likely influenced each other when describing their experiences of receiving the massage. This means

that their descriptions of how they perceived the massage might have been told differently in individual interviews. The present thesis has not engaged in this aspect.

In study I a hermeneutic approach with focus on interpretation (82) was applied. Thus, the authors pre-understanding is emphasised as hermeneutics explicates the understanding of the interpretation in order to attain a deeper understanding for the phenomena of receiving soft tissue massage while seriously ill and dying. The choice of analysis made it possible to use pre-understanding as well as deliberate from it in order to reach deeper understanding i.e. when the interpretation of the text (interviews) goes beyond the obvious and already known as to present a broader meaning what soft tissue massage entail.

In studies II-IV content analysis was used as described by Graneheim and Lundman (49). The analysis has been described to encompass different levels: a manifest (descriptive) and a latent (an interpretative level). A descriptive, manifest part with the intent to describe the content of what was said in the interviews was applied in studies II-IV. However, in study III both manifest and latent (interpretive) analysis was carried out allowing levels of abstraction of the overall theme. Another option of analysing the interviews would have been a phenomenographic approach. Still, as one source of validity in phenomenography is often to return the transcribed interviews to the participants they are seen as the expert of their experiences (a second-order perspective) it was decided against mainly due to the ethical consideration of burdening the relatives further. Moreover the phenomenography, is a descriptive method and only allows interpretation to a limited degree. When using latent content analysis interpretation was possible.

In study IV the purpose was to explicate nursing staff's experiences of an educational intervention. Initially we had planned for individual in-depth interviews however, as we wanted to explore both positive and negative aspects of the intervention we decided to choose focus group discussions as they are more dynamic and have become a useful approach in qualitative research.. They provide essential quality data by using the spontaneous openness created by in the atmosphere of a dynamic group interaction (32, 63, 69).

10 LIMITATIONS

A limitation of this thesis is that all participants in studies I-III were recruited from one palliative care unit within a limited area in the greater Stockholm district. The area is considered to inhabit mainly affluent individuals... This might have influenced the participants' attitude towards participating in the studies even though all were in difficult and life changing situations. It would be interesting to conduct similar studies but in areas with greater variety of ethnicities and cultures.

An obvious limitation in study IV was that the nurses were unable to choose whether if they wanted to participate in the one-day course or not. This caused feelings of apprehension among some nursing staff. It implies that this kind of education should be on a voluntary basis, in order to receive good results i.e. motivated nursing staff.

11 CLINICAL IMPLICATIONS

Even though this thesis illuminates the complexity of what physical touch comprises soft tissue massage should be considered as a valuable complement in palliative nursing care. Soft tissue massage proves to be a useful source of support to dying patients and relatives in palliative care. The experience of retrieving a respite from illness and anxiety as well as gaining structure during immense stress should be judged as an important contributor when discussing quality of life in palliative care.

The aspect of cost effectiveness might also be considered as many of the courses available today are expensive. Many participants in our study saw the potential of introducing soft tissue massage into the daily care routines. Their desire to further their own education and at the same time offer their knowledge to the palliative organisations should be considered at its full value of commitment. As the relatively short (25 minutes) and simple method is easy to comprehend it should initially be offered as a specialised one-day introduction course. However, more studies are needed in this field research.

12 WHAT THIS THESIS ADDS

Previous studies are of importance for understanding the value of massage as constituting a tool for symptom relief. Still, to fully comprehend the complexity of structured and professional massage in palliative care one has to understand that each individual hold their own experience. In previous studies the focal point has been on symptom relief while in this thesis focus have been on the global experience of receiving a structured and comparatively short massage treatment (25 minutes). The insight to what and how patients and relatives experience soft tissue massage in palliative care has not been described in this manner before.

This thesis recognises that there is a need among relatives in palliative care for early bereavement support. According to these results, soft tissue massage could very well present such an option of support. Early interventions may contribute to the relatives' process of regaining meaning and structure in life and thereby reducing their risk for poor health (53, 143).

The nurses in study IV found the content of the one-day introduction to soft tissue massage adequate and sufficient. The results could therefore encourage hospital organisations to introduce short and pointed courses in soft tissue massage, in order to improve the nursing staffs' attitude, understanding and motivation to implement soft tissue massage in palliative care.

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