Exploring the perception of nurses and care volunteers towards aromatherapy in advanced cancer patients with symptom burden; a qualitative study.

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Name:	Nicky (N.) Verschuren
Student number:	3626415
Course:	Master Thesis
Status:	Final Version
Date:	23-08-2013
Number of words proposal:	3485
Number of Dutch abstract:	300
Number of English abstract:	293
Proposed Journal:	Journal of Hospice and Palliative Nursing
Reference style used:	Vancouver
Reference style journal:	American Medical Association
Number of words journal:	20 pages, including Annexes
Organization:	Academic Hospice Demeter, De Bilt
Accompanying instructors:	Dr. Saskia Teunissen Drs. Cathelijne Verboeket-Crul
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Reference number METC:	12-599/C

Key words: *Aromatherapy; experience; perception; nurses; care volunteers*

Samenvatting

Titel– “Het exploreren van de perceptie van verpleegkundigen en zorgvrijwilligers met betrekking tot het toepassen van aromatherapie bij uitbehandelde kankerpatiënten met symptoomlijden.”

Introductie- Uitbehandelde kankerpatiënten lijden vaak onder symptomen van fysieke, psychologische, sociale en spirituele aard. Steeds meer uitbehandelde kankerpatiënten doen een beroep op complementaire interventies, zoals aromatherapie, omdat conventionele zorg symptomen onvoldoende lijkt te verlichten. Voor verpleegkundigen en zorgvrijwilligers is het vaak een complexe taak om te voldoen aan de behoeften en het verlichten van symptomen van palliatieve patiënten. Aandacht voor het toepassen van aromatherapie ter symptoombestrijding lijkt toe te nemen, maar er is niet veel bekend over de ervaringen van zorgverleners met dit fenomeen.

Onderzoeksvraag- De hoofdvraag was: “Welke perceptie hebben verpleegkundigen en zorgvrijwilligers, die werken in Demeter, ten opzichte van het toepassen van aromatherapie bij uitbehandelde kankerpatiënten met symptoomlijden?" Het doel van het onderzoek was om inzicht te geven in de perceptie, ervaring en de visie van verpleegkundigen en zorgvrijwilligers met betrekking tot het toepassen van aromatherapie bij uitbehandelde kankerpatiënten met symptoomlijden.

Methode- Het onderzoek was explorerend en beschrijvend met een fenomenologische benadering. Gegevens werden verzameld door middel van semigestructureerde interviews en geanalyseerd op basis van de interpretatieve fenomenologische analyse methode.

Resultaten- Beschreven thema's zijn “sociaal-emotionele steun”, “machteloosheid”, “tevredenheid”, “symptomen”, “rituelen”, “visie op aromatherapie” en “aspecten bij het toepassen”. Intimiteit en emotionele steun zijn belangrijke aspecten van aromatherapie.

Aanbevelingen- Kwalitatief onderzoek wordt aanbevolen om ervaringen van zorgverleners verder te exploreren, kwantitatief effectonderzoek wordt aanbevolen om effecten aan te tonen en om integratie van aromatherapie in de zorg te bevorderen. Advies is om aromatherapie te integreren in het verpleegkundig onderwijs om holistische zorgvisie te bevorderen.

Conclusie- Aromatherapie wordt gezien als een nuttige, complementaire en holistische interventie voor zorgverleners en patiënten om het welzijn van patiënten te vergroten en symptoomlast in fysieke, sociale, psychologische en spirituele dimensies te verlichten.

Summary

Title – "Exploring the perception of nurses and care volunteers towards aromatherapy in advanced cancer patients with symptom burden: a qualitative study"

Introduction – Advanced cancer patients often experience various symptoms which include physical, psychological, social and spiritual pain and suffering. More advanced cancer patients reach out to Complementary and Alternative Medicine interventions, such as aromatherapy, since conventional care seems insufficient to relief symptoms and discomforts. Meeting the needs and alleviating symptoms of dying patients presents a complex and often difficult challenge to nurses and care volunteers. Attention towards applying aromatherapy for symptom alleviation in advanced cancer patients seems to increase, but there is not much known about experiences of caregivers with towards .

Research question Main research question was: "Which perception do nurses and care volunteers, who work in Demeter, have towards applying aromatherapy on advanced cancer patients with symptom burden?" This study aimed to explore and to provide insight into the perception, experience and vision of nurses and care volunteers about aromatherapy applied to advanced cancer patients with symptom burden.

Method- The study had an exploratory and descriptive design with phenomenological approach. Data was collected through semi-structured interviews and analyzed based on interpretative phenomenological analysis method.

Results- Described themes are "social and emotional support", "powerlessness", "satisfaction", "symptoms", "rituals", "vision towards aromatherapy" and "aspects of application". Intimacy and emotional support were identified as important aspects of aromatherapy.

Recommendations– Qualitative research is recommended to further explore experiences of caregivers, quantitative effect-studies are recommended to prove effects and to promote implementation of aromatherapy and aromatherapy should be integrated in nursing education to promote holistic care.

Conclusion- Aromatherapy is perceived as an helpful complementary and holistic intervention for both caregivers and patients. It increases patients' wellbeing and relieves symptom burden in physical, social, psychological and spiritual dimensions.

Introduction

Each year ten million people worldwide are diagnosed with cancer. In 80% of these cases cancer is incurable at the time of diagnosis and most patients die within one year (1). In 2011, approximately 43.139 Dutch people died of cancer (2).

Currently in healthcare, attention shifts from disease to health and focus shifts from cure towards achievement of wellbeing (3). Holistic approach becomes more important which emphasizes the human as a whole in which body and mind are seen as one. Sickness, treatment and cure are no longer separate processes, also subjective perception and experiences are essential parts (4). Body and mind are inseparable but do are distinguishable (5). The psychological component of sickness does not only arouse emotions. A sick body is a different body, which changes the person into another person (4). Holism involves identifying the interrelationships of the bio-psycho-social-spiritual dimensions of the person, recognizing the whole is greater than the sum of parts. It also involves understanding the individual as a unitary whole in mutual process with the environment (6).

For advanced cancer patients (ACP) cure is impossible. This changes the patient physically but also as a whole. Patients near the end-of-life often experience various symptoms which include physical, psychological, social and spiritual pain and suffering (7-9). Palliative care aims to prevent and manage these symptoms while optimizing the quality of life (QoL) throughout the dying process (9). Experience of pain for patients includes anxiety, depression, and fear (10). This concept is central to the assessment and diagnosis of pain and suffering (9). Most frequent symptoms are fatigue, pain, lack of energy, weakness, and appetite loss and occur in >50% of ACP (11). Treatment requires a holistic, multidisciplinary approach focusing on pain, symptom control and QoL (12).

More ACP reach out to Complementary and Alternative Medicine (CAM) interventions, since conventional care seems insufficient to relief symptoms and discomforts(13). Aromatherapy is the controlled use of essential oils to maintain and promote physical, psychological, spiritual and emotional wellbeing (14,15). Essential oils are scented, volatile, liquid components from aromatic plants retrieved from several parts of the plant (15). Different methods are used to deliver aromatherapy such as diffusers, massages, baths and compresses (16).

Nurses and patients increasingly using aromatherapy in oncology as part of the practice of holistic care. Research suggests the beneficial effects of aromatherapy are on symptom control and to promote health and a feeling of wellbeing (17). There is moderate evidence

that aromatherapy is effective in reducing psychological and physical symptoms such as anxiety and pain and improvement of QoL (18-25). In terminal care, creating pleasant environment sometimes is one of few things that can be done. Loved scents can support patients and family throughout the dying process (19).

Meeting the needs of terminally patients presents a complex and often difficult challenge to nurses(26). Related to the holistic approach, nurses' role is to take care of all needs of patients(4). Nurses and care volunteers (CV), which often work in hospices, sometimes experience feelings of guilt, helplessness or powerlessness towards patients (27,28). Studies, which examined experiences of nurses who give end-of-life care, suggest nurses feel confident about physical care but not quite as confident in meeting patients' psychosocial needs(29-32). There is moderate evidence an intervention such as aromatherapy might support caregivers in handling these problems (19).

Problem statement

Nurses and CV seem to struggle in handling symptom burden of ACP. Attention towards applying aromatherapy for symptom alleviation in ACP seems to increase, but there is not much known about experiences of caregivers with this phenomenon. However, it is unclear which perception, experience and vision nurses and CV have towards aromatherapy and which contribution aromatherapy has for both caregivers and ACP in relieving symptom burden.

Aim

This study aimed to explore and to provide insight into the perception, experience and vision of nurses and CV about aromatherapy applied to ACP with symptom burden. Clarifying the role of aromatherapy, in supporting nurses and CVs' in taking care of ACP with symptom burden, eventually may help to increase quality of care and QoL for ACP.

Research questions

Research question posed was: "Which perception do nurses and CV, who work in Demeter, have towards applying aromatherapy on advanced cancer patients with symptom burden?" This research question was divided into two sub-questions: "How do nurses and CV, who work in Demeter, experience applying aromatherapy on advanced cancer patients with symptom burden?" and "Which vision do nurses and CV, who work in Demeter, have towards applying aromatherapy on advanced cancer patients with symptom burden?"

Method

Design

The study had an exploratory and descriptive design with phenomenological approach. Phenomenological studies describe the meaning for several individuals of their lived experiences of a concept or a phenomenon (33). Conducting the study took eight months and was carried out in Demeter. Demeter is an academic hospice in Utrecht, in the Netherlands, with mostly advanced cancer patients. Aromatherapy is used for about two years, under supervision of a CAM-therapist. Aromatherapy is applied by vaporization (AV) through aromastone and by massaging (AM) hands or feet. Most used essential oils are lavender, wild rose and calendula.

Population

All nurses working in Demeter are educated to apply AM and AV, all CV are educated to apply AM and a couple to apply AV. Inclusion criteria to participate were: nurses (Dutch education level 3IG, 4 or 5) and CV who provide aromatherapy, working with advanced cancer patients and speaking Dutch fluently. To enlarge the diversity of the sample, no exclusion criteria were used.

Sampling

All nurses and CV working in Demeter were invited to participate in the study. Goal was 10-15 interviews to achieve saturation. In February 2013, information letters were distributed by e-mail among all nurses and CV who met the inclusion criteria. Due to the lack of response, a criterion sample based experience with application of aromatherapy was added. These selected nurses and CV were individually approached again by e-mail. Creswell (33) supports criterion sampling in a phenomenological study to get the most valuable information. After participants responded by e-mail, participants were contacted to schedule the interview. Participants received an email to confirm appointment date, time and place and were asked to fill in a form with background information and demographic details.

Parameters

Primary parameter was to explore and describe experiences of nurses and CV in applying aromatherapy on advanced cancer patients with symptom burden. Secondary parameter was to explore and describe visions of nurses and CV towards aromatherapy applied on advanced cancer patients with symptom burden.

Data collection

Data was collected from February till May 2013 through semi-structured interviews with written topic guide. Topics used included experience, feelings, thoughts & vision and were discussed with CAM-therapist and adjusted in-between interviews to aspire saturation. Interviews were recorded and supported by memo's. To ensure participants would not be interrupted, interviews were held during spare time. Interviews started with the question: "What is your definition of aromatherapy?".

Trustworthiness

To increase validity, the researcher followed an interview training embedded in the study program and a pilot interview was conducted. A convenience sample was used, complemented by a criterion sample with support of the CAM-therapist to obtain more variation (34). The researcher used bracketing to collect the data as objective as possible (35). To ensure reliability and validation of the data, triangulation and member checks were applied. Due to several (ethical) arguments, member checks were done during interviews (34,36-38). Method triangulation consisted of interviews and reading reports of aromatherapy in patients' nursing files. Researchers triangulation consisted of discussing preliminary and final results with the accompanying researchers until consensus was reached. Accompanying researchers reviewed the study procedure.

Data-analysis

The researcher summarized participants' answers to confirm accuracy of interpretations. Recorded interviews were uploaded in NVivo 10 (QSR International, Melbourne, Australia) qualitative software, transcribed literally, printed, read, re-read and analyzed based on Interpretative Phenomenological Analysis(39). To enlarge traceability all transcripts and other data were preserved accurately on an secured and encrypted USB-stick. During the study, the researcher was approachable for questions by e-mail.

Ethical aspects

The study was approved by the Medical ethical committee (METC) of University Medical Center Utrecht as not complicit to the Medical Research Involving Human Subjects Act (WMO) (No.12-599/C)(40). Informed consent was asked both verbally and written prior to the interview. Personal data was handled in compliance with the Dutch Personal Data Protection Act (Overheid, 2000).

Results

Total, 12 nurses and 46 CV were approached to participate in the study. Six nurses and seven CV, with different levels of aromatherapy experience, gave consent for an interview. Characteristics of participants can be found in table one and two. Interviews varied from 35 till 65 minutes and took place at participants' home or in a private room at the hospice. Identified themes with corresponding quotes can be found in table three.

Experienced effects for caregivers & patients

All participants mentioned several aspects of social, emotional and physical dimensions. Spiritual dimension was discussed minimal. Mentioned themes were "social and emotional support", "powerlessness", "satisfaction", "symptoms", "rituals", "vision" and "aspects of applying aromatherapy". Applying AM is mentioned as a very intense, warm and impressive experience for caregivers. Compared to other forms of patient-caregiver contact, it is said to create a very strong intimate connection between patient and caregiver in a relative short period of time.

Social and emotional support

Intimacy is a frequently mentioned theme by caregivers. Nurses and CV said it creates trust, calmness, deep, pleasant, warm feelings and intense feelings of connectedness with patients. This connection between caregiver and patient also seems to add another dimension in the relationship compared to regular care. It is said to create interaction, a flow of energy between caregiver and patient, by really having intense contact with each other. Some participants said it helps them to fulfill patients' needs towards restoring physical contact because patients sometimes have not been touched for a long time. For nurses and CV, AM is experienced as providing patients other sensations and an more intimate way of touching than regular care does. They also said patients frequently express their desire towards AM.

Due to the level of intimacy caregivers mentioned to sometimes experience it as difficult to apply AM. Gender and massaged body part seem influential factors on intimacy level. Both male and some female caregivers experienced giving AM to male patients as uncomfortable in the beginning. This feeling disappears as time expires. Male and female caregivers experienced no problems with female patients. Nurses and CV related these uncomfortable feelings towards cultural aspects. In general, hands are seen as more intimate to apply AM. Due to reduced physical distance the experience becomes more intense. All aspects,

specifically gender, were mentioned as little barriers which must be overcome by caregivers before applying AM.

Powerlessness

Some participants experienced aromatherapy as helpful in handling personal feelings of powerlessness and helplessness from caregivers towards patients, relatives towards patients and caregivers towards relatives. One nurse said to use aromatherapy as intervention to help relatives feel useful towards patients and show them how to apply AM or AV. But it is also mentioned to support caregivers' feelings of being useful or just "being there".

It was also mentioned that AM might help patients accepting or dealing with loss, letting go, help them resign oneself and support bereavement towards death. One CV mentioned the spiritual aspect of applying aromatherapy for her own coping with farewell and some sort of professional bereavement towards dying patients.

Satisfaction

Applying aromatherapy, especially AM, is experienced as satisfying for caregivers. Mentioned aspects that created this feeling were direct improved patients' wellbeing and relaxation of patients. Caregivers said an emotional connection between caregiver and patient is made during AM. Participants experienced it as very pleasant to really make personal connections with patients.

Caregivers mentioned it provides feelings of extreme happiness and gratification which they said is very valuable in their jobs. One CV noticed it is one of the most beautiful things experienced in life. However, sometimes this emotional connection cannot be achieved and some caregivers experienced reduced or absent relaxing effect on patients. Some CV, who experienced this, said they felt disappointed or imperfect when this happened. AM is not perceived as a duty but is said to be of enormous gratification for caregivers. CV mentioned to go home very satisfied after they gave aromatherapy.

Symptoms

Aromatherapy is also applied to alleviate symptoms in a direct or indirect way. Aromatherapy is mentioned as a form of distraction for patients which can lead to alleviation of symptoms and increased sense of wellbeing. It provides other sensations and associations to the body or helps patients' to cope with discomforts. AM is experienced as helpful for sleeping problems, nausea, restlessness, fear and pain. Relaxation is mentioned as influential factor

on wellbeing. To mask odors, from wounds or feces, AV with lemongrass is mentioned as useful intervention.

Rituals

Some participants use AM or AV as part of evening or bedtime rituals. Mentioned is, it helps patients to get into a certain mood or state of relaxation before going to sleep. Participants also said it is sometimes used as a ritual to mark the end of a work shift for caregivers or end of the day for patients.

Vision towards aromatherapy

Almost all participants mentioned they were still exploring which value and meaning aromatherapy had for them. Therefore participants found it difficult to formulate a clear vision towards aromatherapy when asked. Most participants said to be confused about rules and agreements made about aromatherapy, such as where to find equipment. Although they said this seemed improved lately. Some nurses thought aromatherapy should be applied mainly by CV, because it is part of their job tasks, while others thought it could be an intervention applied by both nurses and CV. Aromatherapy is said to complement something valuable which is not easily found in regular care. Some participants mentioned the interviews made them realize how valuable aromatherapy can be and that it should be applied in a more diverse way. Participants said they thought expansions should be made in frequency of application training and evaluation. They also plead for more diverse methods and oils for application.

Influencing Aspects

The workload and the lack of knowledge, experience and training are said to cause hesitations or absence of applying aromatherapy in participants. Due to workload and division, nurses regularly said to feel constrained to delegate aromatherapy to CV. Some thought this was disappointing others found it a satisfying idea of CV being able to do so. Some participants felt the lack of integration of aromatherapy into daily care has a share in this. Some CV said to be reluctant to apply due to insecure or dependent attitude. Experienced increased wellbeing of patients, positive experiences, discussing with colleagues about aromatherapy, open attitude, support of the hospice and feelings of satisfaction are mentioned as aspects which stimulate caregivers to use aromatherapy. Open attitude is said to be required from both the patient and the caregiver in order to be able to make an connection. If one does not surrender, effect is said to be reduced or absent. Some

CV emphasized the positive effect, undergoing AM themselves during a training, had on their conceptualization and motivation to use aromatherapy.

Discussion

Overall, nurses and CV share positive attitudes, experiences and vision towards aromatherapy but do sometimes feel insecure to use it due to the lack of knowledge and integration in care. This corresponds to findings of studies (41) which explored integration of other therapies. Remarkable is that nurses which attended aromatherapy at school, appeared to use it and more frequently and easier. Educational programs which provide information about use of CAM and underlying evidence most likely will increase appropriate use of it (41). Moreover, positive experiences seem to stimulate application.

Due to body-mind-spirit interaction, restoring patients' social, emotional, psychological or spiritual needs will also lead to alleviation of physical burden and vice versa(42). Like other study results support (18-25), nurses and CV experienced increased wellbeing, alleviation of pain, nausea, fear, and restlessness in patients. Moreover, results show aromatherapy can contribute in restoring patients' emotional and social values. Emotional support helps patients to feel more comfortable and supports their coping (43-46).

Especially on psychosocial level aromatherapy seems a valuable attribution to palliative care. It adds an extra dimension in caregiver-patient contact and creates high levels of intimacy in a short period of time. Dying is a lonely process and aromatherapy can contribute in making it less lonely by adding intimacy. Patients desire towards AM seems to confirm this. It seems an easy and accessible tool to restore patients' needs of physical contact and to relief physical symptoms. This need is also known as "skin hunger" (47). Meeting this need as a caregivers seems to create a different, more equal, patient-caregiver relationship. Therefore, male patients might be experienced as difficult for caregivers to apply AM. In times when technical care is developing quickly, human contact can be priceless (3).

Aromatherapy finds resemblances in "theory of presence" as explained by Baart (48) and Grypdonck (49). Building trust, dignity and recognizing patients as whole persons increases patients' wellbeing (48). Aromatherapy emphasizes the holistic nursing vision and seems to create awareness towards equivalency; helping a person or human being instead of just a body. According results, being able to let patients feel human again and being able to help them as a whole unique being instead of symptoms or sickness, appears of great satisfaction for caregivers. Also feeling useful and appreciated, seems of great importance for job satisfaction for caregivers (50). It seems to fulfill caregivers' feelings of being useful, being

there and being able to deal with their powerlessness towards symptom burden on all dimensions. Aromatherapy also seems very meaningful for CV, who said to go home very satisfied after applying aromatherapy that day. Especially experiencing improved patients' wellbeing, very directly due to caregivers own actions, seems of great impact.

Several studies describe how nurses distinct themselves from other professions by highlighting their holistic approach (51-55). Nearly all theoretical nursing models emphasize this holistic vision (56). Currently, healthcare is very much disease-oriented and behavior patterns in healthcare focus on physical wellbeing (3). Losing this holistic vision might give nurses feelings of powerlessness, aromatherapy seems to be able to restore this deficiency in end-of-life care. Especially in end-of-life care wellbeing is important just because so little other things can be done (19).

Moreover, AM seems to have great impact on both caregivers and patients. Intimacy through AM seems to appeal to the patients personality and uniqueness, it provides dignity and the opportunity to be human again. For patients intervention which provide personal attention, like aromatherapy, can feel very comforting (47). However touching is still surrounded by taboo (57), but AM seems to be able to overcome these negative aspects.

It is remarkable that aromatherapy not only seems to benefit the patient but also gives nurses and CV an intervention to handle psychosocial problems (7-9,19) patients are dealing with. Aromatherapy is not only used for symptom burden but also to restore contact between patients and loved ones by creating a pleasant environment. Thereby, masking odors by AV can also serve as a lure into patients' room to prevent patients ending up in social isolation due to relatives being repelled by unpleasant odors (17,58).

A limitation of this study is the lack of experience the researcher had with qualitative research. Also saturation was not achieved. It is difficult to generalize findings of the study due to possible subjectivity and the limited sample. However, literature did confirm multiple themes of this study. The strength of the study is the insight it provides in caregivers' personal experiences towards applying aromatherapy in palliative care. It clarified that aromatherapy benefits both patients and caregivers and it contributes in adding knowledge about this topic.

Recommendations

To further explore caregivers experiences about aromatherapy on ACP, future research should investigate these perceptions in a more detailed way and among caregivers in other

settings. Giving the results of the study, it is likely to promote integrating aromatherapy in nursing education to promote holistic care. Also quantitative research should be done to scientifically prove effects and to promote implementation of aromatherapy for ACP with symptom burden. Adequate attention should be given to integration of aromatherapy into care to optimize the use of this intervention profit most.

Conclusion

This study is the first providing insight into caregivers perceptions towards the application of aromatherapy on ACP with symptom burden. Participants perceive aromatherapy as a helpful and accessible intervention to increase patients' wellbeing. Aromatherapy benefits both patients and caregivers. It supports caregivers to handle symptom burden in ACP, but moreover it complements multiple holistic aspects in nursing care. It creates a high level of intimacy in a short period of time. Especially on psychosocial and emotional level, aromatherapy can be a valuable intervention and adds an extra dimension in caregiver-patient contact. Also intimacy seems an important aspect in applying aromatherapy. For nurses and CV, aromatherapy is of important value for satisfaction and gratification.

Table 1 – Participants' Characteristics

	Care volunteer	Nurse	total
Female	4	6	10
Male	3	0	3
Level of education			
MBO	1	2	3
HBO	3	3	6
WO	3	1	4
Age			
35-44	0	1	1
45-54	2	1	3
55-64	2	4	6
65-74	3	0	3
Total	7	6	13

HBO= Higher professional education,

MBO= Intermediate vocational education

WO= University

Table 2- Detailed participants' characteristics

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13
Female	F	F			F	F	F	F	F		F	F	F
Male			M	M						M			
Age 35-44					35-44								
Age 45-54				45-54				45-54		45-54			
Age 55-64	55-64	55-64				55-64	55-64		55-64		55-64		
Age 65-74			65-74									65-74	65-74
CV	CV	CV	CV	CV						CV		CV	CV
Nurse level 4						Nurse 4					Nurse 4		
Nurse level 5					Nurse 5		Nurse 5	Nurse 5	Nurse 5				
MBO						MBO					MBO	MBO	
HBO	HBO	HBO	HBO		HBO		HBO		HBO				
WO				WO				WO		WO			WO
Specialized education	–	–	–	Medicine, Homeo-pathics	Geriatric Nursing, Palliative care	Palliative care (post-HBO), CCU	CCU, Nurse antropo-sofics, Palliative care (post-HBO)	Oncology Nurse, Medical Antro-pology, Psycho-logy	Palliative care (post-HBO)	–	CCU	–	–
Followed courses	Hand & Feet Massage	VHC, KeK, Bereavement counseling, Bach remedies, Metamorphos is massage, Cranio sacral massage, Relaxation massage	KeK, Several courses for CV	–	Basic course aromathe-rapy	Breavement counseling, Training of CAM-therapist, Feet massage	Antropo-sofic courses; baths, rubbing, compresses, wrapping, herbal thea	Multiple courses in palliative care	Basic course comple-mentairy care	KeK	One confe-renceday palliative care, One day course palliative thinking	AT	AT
Years of experience in:													
Care	15	5	6	25	18	25	33	22	16	0,5	32	48	16
Palliative care	5	5	6	25	15	14	11	15	3,5	0,5	0,5	3	12
Hospice care	5	5	6	1	5,5	11	4	7	3,5	0,5	0,5	3	7
Hospice Demeter	5	5	6	1	5,5	5,5	4	7	1	0,5	1,5	3	5

AT= Aromatherapy, CCU = Critical Care Unit, HBO= Higher professional education, KeK= Education for care volunteers of high care hospices, MBO= Intermediate vocational education, VHC= Voluntary Home care, WO= University

Table 3 – Illustrating quotes

Experienced effects for caregivers & patients		
Social & emotional support	Intimacy Intensity Connecting Quality time Trust Physical contact	• **Participant 11:** "Maar je hebt ook écht letterlijk contact met iemand hè. Je, je.. de handen raken elkaar of de voeten en de handen raken elkaar. T contact is eh op dat moment even heel intens. Je komt aan iemand hè. D'r is... Ja t is anders dan een gesprekje bijvoorbeeld dus dat voelt eh ja.. ehm t geeft een extra dimensie, laat ik t zo zeggen, t geeft een extra dimensie ja." • **Participant 5:** "Maar wel heel vaak een vorm van contact is waar mensen behoefte aan hebben. Niet meer praten over hun ziek zijn, niet praten over dood gaan, niet praten over symptomen, gewoon lekker aangeraakt worden en gemasseerd worden." • **Participant 9:** "Het geeft iets weer van in mijn beleving van t er werkelijk mogen zijn van een patiënt." • **Participant 8:** "Soms heb je een moment dat t rustig is en dat t kan, of dat een collega van de volgende dienst al komt, en dan is dat wel even zo'n kwaliteitsmoment wat je hebt met de patiënt." • **Participant 10:** "En één van de dingen die we daar ook kregen was dus ook toen een klein mini cursusje handmassage van Cathelijne en dat moesten we ook op elkaar proberen en ik weet nog dat eh.. ik moest dat doen met een mevrouw die ook zorgvrijwilliger zou worden en ik weet nog dat ik eh dat ik echt ehm.. ja er half ondersteboven door werd geblazen van t effect wat dat had, verbazingwekkend." • **Participant 10:** "Hmmm een grote verbondenheid, een grote mate van verbondenheid en vertrouwen, heel veel vertrouwen en ook wel ja intimiteit zeg maar en...hmmm warmte, openheid, geen barrières tussen je in, ja zoiets." • **Participant 13:** "Eh ja dat is dan toch eh... ja toch net iets anders dan bij vrouwen. Dat ik denk goh nou ben ik toch bij een man zo bezig met z'n voeten.. ja ik kom er wel overheen hoor maar eh…." • **Participant 13:** "Nou dat ik eventjes toch iets moet eh.. uitschakelen van hé ik ben met een lichaam van.. Zelfde als met die massage, met wassen heb ik dat dan niet, dat je denkt hé nou ben ik toch vrij intiem bezig met t lichaam van een man." • **Participant 4:** "Dat is heel grappig want mannen en vrouwen zijn totaal anders om te masseren voor mij. Ja dat is echt eh.. groot verschil. Ehm van nature zou ik t bij een vrouw veel gemakkelijker kunnen doen dan bij een man." • **Participant 10:** "(…) normaal gesproken hou je bepaalde afstanden tot mensen, afhankelijk ook van hoe goed je ze kent, en dat doorbreek je bij dit dus heel erg. En sterker nog eh.. de afstand is dus heel dichtbij want je moet elkaars hand natuurlijk kunnen vasthouden, dus je zit duidelijk binnen de normale afstanden die je zou aanhouden (…)"

Powerlessness	Towards patients Towards relatives Being there Presence Bereavement and coping	• **Participant 5:** "Heel soms in de situatie bij een patiënt die stervende is en waar je het gevoel hebt dat je zelf niet meer zoveel kan toevoegen en ik daar wel wil zijn of in z'n aanwezigheid van familie.. dan doe ik t soms voor mezelf om gewoon daar te kunnen zijn, om in rust daar te kunnen zijn, en dan is een handmassage of soms een korte voetmassage fijn." • **Participant 5:**"Bij met name patiënten waarvan denk je ik kan eigenlijk niet zoveel meer toevoegen dan er alleen maar zijn en familie heb ik t gevoel dat ik daar niet bij weg kan lopen en je hebt toch t gevoel dat je íets wil toevoegen.. soms heb je dat en dan eh helpt t om een massage te geven en kan t een vorm zijn om aan je eigen onmacht vorm te geven en waarin t ook nog ondersteunend is naar de patiënt toe.. en ondersteunend naar familie toe is." • **Participant 1:**"Er is geen medicijn voor alle pijn. En dan kun je met rust, je kunt ook gaan zitten en rustig gaan ademhalen, maar je kunt het heerlijk ondersteunen met een massage." • **Participant 11:** "Zij zat ook in een fase.. in een bepaalde fase van haar ziekteproces, nou ja daar moet je dan toch.. zij moet daar toch doorheen. En dan kun je met massage of met olie kun je dan toch niet alles bereiken maar wél aanvullen." • **Participant 3:** "Dus kan ik me heel goed voorstellen dat bepaalde geuren voor deze mensen wel degelijk van invloed zijn. En dat dat dus kan helpen, kan ondersteunen bij eh.. een stukje eh.. rust of een stukje loslaten of een stukje eh.. prettig voelen ja.. en in die zin zie ik aromatherapie weldegelijk als een vorm van ondersteuning aan de patiënten in ons hospice." • **Participant 13:** "Want je kan niet alleen maar geven, dan houdt t op denk ik of zoiets. Dus dat eh... ja. En dat was bij die mevrouw dus duidelijk. Ik wilde voor mezelf zorgen een goed afscheid en haar natuurlijk ook dat nog even geven."
Satisfaction	Emotional connection Patients' wellbeing Gratification	• **Participant 13:** "Gewoon een goed gevoel en ook even eh... buiten het gewone verzorgende. Net een stapje meer. De andere dingen zijn verzorgend, moeten gedaan worden, en dit is nét iets meer. Dit is iets extra's ja. Zit even buiten de eh.. de ordinaire, gewone dingen in vind ik. (…) Maar ik vind t gewoon iets extra's toevoegen wat heel goed is." • **Participant 1:** "T is een, ja ik vind het altijd, het is geen belasting om zo iets te doen, het is eigenlijk ook mijn feestje zeg maar." • **Participant 1:** "Ehm stromen is ehm, ja t wordt letterlijk warm, je wordt écht warm. Van eh je voeten, je handen alles wordt warm. T is een t is comfortabel.. t is lekker. Een soort thuiskomen."
Symptoms	Relaxation Derivation Odors	• **Participant 1:** "Ik denk eh aan geur en ontspanning, dat is eigenlijk eh... het eerste en het belangrijkste eigenlijk want een ontspannen mens gaat anders om met zijn pijn en dat is heel belangrijk." • **Participant 9:** "Kijk bij pijn kan je ook aan denken zo'n geur waardoor je in een andere beleving komt waardoor dat lichamelijk ook anders ervaren wordt." • **Participant 7:** "Ja, of kan er weer even in wonen (lichaam), laat ik t zo zeggen. Als je pijn hebt dan.. ja of onrust dan.. dan ben je meer er buiten lijkt t hè dan dat je met overgave even kan liggen, ja.." • **Participant 5:** "(…) of waardoor t gewoon lekkerder op de kamer gaat ruiken waardoor t effect op familie ook is dat ze meer daar willen zijn.. dat patiënten t gewoon prettiger vinden om op die kamer te zijn."

Rituals	For patients For caregivers	• **Participant 5:** "nou vaak is t onderdeel van een ritueel. Nu hebben we een patiënt waarbij je van te voren voor dat iemand zich nacht klaarmaakt en zeg maar gemasseerd wordt, aromasteen aanzet met een geurtje. Ja dan is t onderdeel van het naar bed gaan. Geurtje aan, iemand wordt omgekleed, geurtje brandt dan al lekker en dan wordt gemasseerd en gaat daarna slapen. Dus dan is t voor startmoment van een ritueel waarin t gewend is geraakt." • **Participant 6:** "En juist voor de nacht is t weer een extra dimensie denk ik om die overgang te maken van de dag naar de nacht om rustig de nacht in te gaan." • **Participant 13:** "Omdat ik dus 's avonds werk is t toch gewoon bij mij de plaats van de avond afsluiten. ja. T sluit eh.. anders af bij een patiënt waarbij je massage hebt gegeven dan de gordijnen dicht dan t ligt uit enzovoorts dan waar ik t niet heb gegeven."
Vision towards aromatherapy		
Vision	Still exploring Developing Awareness Ambiguities	• **Participant 1**: "D'r is nog veel te weinig kennis, veel te weinig toepassing en als t hier gedocumenteerd wordt dan heb je er wel straks feiten." • **Participant 1**: "Het is een nieuw fenomeen en eh ja dat eh.. ja ik heb ook wel gesprek gehad met Cathelijne daarover dat dat ook zijn tijd moeten geven. Ik denk dat als we maar gewoon serieus genoeg hieraan werken dan krijgt t ook wel een plek, je moet er zelf ook in geloven." • **Participant 2**: "Ik denk dat in Demeter er vanuit de eh.. dat men daar positief tegenover staat. en ik denk dus dat t een groeiproces is met z'n allen om hier veel meer ruimte voor te maken." • **Participant 10:** "Ik vind zelf niet dat ik er al echt goed in ben. Ik begin pas half te begrijpen hoe t eigenlijk werkt, tot nu toe is t een beetje ja.. ehm.. Ik moet er gewoon nog wel meer van leren, beter in worden en beter gaan begrijpen." • **Participant 3:** "Eén van de mooie aspecten van dit interview is natuurlijk bewustwording. Bij mezelf ontstaat op dit moment een stukje bewustwording; je hebt nog die aromatherapie óók. Je hoeft niet altijd alleen maar af te wachten je kunt ook t initiatief nemen."
Influencing aspects	Workload Integration	• **Participant 10: "(…)** dat t er veelal op de ochtend meestal niet in zit omdat t te druk is. Hè dan ben je echt bezig met de mensen naar de.. met allerlei doe dingen; aankleden, onder de douche, naar de wc, eten, koffie nou dat is gewoon zo.. zoveel dingen zijn dat ja dat is gewoon écht werken zal ik maar zeggen en dan is er weinig tijd voor ehm.. voor ja voor dit soort.. voor aromatherapie." • **Participant 3:** "Het ligt ook t handigste bij onze zorgvrijwilligers. De verpleegkundige moet daar tijd voor vrijmaken, de zorgvrijwilliger is daar voor ingeroepen."

	Knowledge Attitude Support Positive experiences	• **Participant 4:** "Er zijn er die heel moeilijk kunnen ontspannen en dan is t eh... dan is t effect mij minder duidelijk. En t meest duidelijke is t bij mensen die zich eigenlijk gewoon durven over te geven en dat gaat een beetje gelijk op met hoe t contact is." • **Participant 10:** "(…) maar ook dus wel de eis die daar aan vast zit van je moet je er wel aan willen overgeven. Dat is wel de maar die er aan zit. want niet iedereen kan dat zo makkelijk en dat is ook iets tussen twee personen. Hmm of je.. dat is ook heel erg afhankelijk van de personen of je je daar aan wil overgeven." • **Participant 12:** "Eh ook overgave voor mij maar ook voor de patiënt de overgave." • **Participant 2**: "Ik zou dat voor me zien als ik zelf meer zou weten hoe we t hier doen dus ik denk dat er wat mij betreft dan meer ehh kennis over zou moeten zijn en ook over hoe je t kunt toepassen dan zou ik wel meer ruimte kunnen nemen in de ochtend als ik denk van nou dat zou goed zijn. Of als in de overdracht gezegd zou worden van hè dat zou heel goed zijn voor deze of die patiënt. Want daar hoor je eigenlijk ook niks over, in de overdracht komt dat eigenlijk niet naar voren dus dat vind ik wel een aandachtspunt." • **Participant 11:** "Dus positieve ervaringen die stimuleren mij toch om t vaker in te zetten. Dus hoe vaker ik een positieve ervaring heb gehad, hoe meer ik geneigd ben om aromatherapie in te zetten.

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