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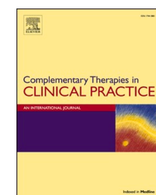

Haptotherapy for patients with cancer; experience of haptotherapists and reasons for consultation: A survey among haptotherapists

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ABSTRACT

Background and purpose: Haptotherapy is a type of mind-body therapy that makes use of affective touch. This study aims to provide insights in reasons for haptotherapy for patients with cancer, and in experiences of haptotherapists with these patients.

Materials and methods: In a cross-sectional study, a survey was conducted among 536 Dutch haptotherapists. Multiple-choice and open-ended questions were analyzed both quantitatively and qualitatively.

Results: Of 272 (50.7%) responding haptotherapists, 167 (61.5%) had experience with treating people with cancer. Most frequently, combinations of emotional problems and a disturbed body experience were reported as reasons for haptotherapy. Haptotherapists emphasized the need for affective touch to restore patients' body connection.

Conclusion: Two-thirds of the respondents treat patients with cancer, addressing the interaction of body and mind. Reasons for consultation cover a wide range of problems in multiple dimensions, in which a disturbed body experience in combination with emotional problems is mentioned most often.

1. Introduction

Haptotherapy is a relatively young discipline in health care, thus far mainly practiced in the Netherlands and France. In the 80's and 90's of the 20th century, it was developed in the Netherlands as a person-oriented mind-body therapy, based on the principles of Haptonomy [1].

Haptotherapy can be deployed in many situations throughout lifetime, from perinatal coaching through gerontology and palliative care. Although the therapy is basically person-oriented, each haptotherapist can focus on a specific group of clients, such as patients with cancer. Up to now, there are only a few studies, focusing on various aspects of haptotherapy [2–7]. Research related to patients with cancer is even more scarce [5–7].

Cancer and/or its treatment can cause bodily and mental damage - from minor to major - in many ways. As a result, patients with cancer often suffer from a variety of symptoms that have a negative impact on their quality of life [6]. They can experience changes in body image and body awareness, reduced body confidence, and mental detachment from the body (See Box 1) [8–11]. Additionally, they can have physical symptoms such as pain or fatigue, as well as psychological problems, like distress and cancer-related posttraumatic stress disorder (PTSD) [12–14], and/or spiritual needs [15,16].

Consequently, the treatment of patients with cancer requires a multidimensional and integrated interdisciplinary approach. However, in well-known psychological treatments in oncological patient care, such as Cognitive Behavioral Therapy (CBT), Mindfulness Based Cognitive Therapy (MBCT) and Acceptance and Commitment Therapy (ACT) [17], the impact and the psychological consequences of cancer-related body damage on (the processing of) the patient are largely overlooked. In the literature, these psychological consequences are either absent or mentioned obliquely [18]. For example, in a recent Dutch handbook for professionals in psycho-oncology, describing psychological treatments in oncological patient care, the term 'body experience' (see Box 1) occurs just once, in a chapter about person-oriented-experiential psychotherapy [17]. Haptotherapy has the potential to fill this gap by addressing patients' needs with respect to cancer-related body damage: because the treatment focusses on the integration of body, reason and emotions, the impact of physical damage on the psychological processing and coping by the patient with cancer is explicitly included from the start (see Box 2).

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Haptotherapy receives very positive evaluations from patients receiving care in psycho-oncology centers (for specialized psychological care in cancer) [5,7], but its possible effects on patients with cancer are mostly unexplored. Only two small studies involving individuals with cancer (N = 35 and 54 respectively) report that haptotherapy contributes to a reduction of pain, stress and other physical complaints, to a decrease of panic and anxiety, and to improvement of perceived social and cognitive functioning, well-being and quality of life [5,7].

The aim of the present study was to provide insight into the experience of haptotherapists in the Netherlands with patients with cancer, and in the reasons for which these patients turn to haptotherapy. Formulated in research questions:

1. What is the experience of Dutch haptotherapists in treating patients with cancer?
2. What are the reasons why patients with cancer wish to consult a haptotherapist?

This information was considered necessary before researching the effects of haptotherapy on this patient group.

2. Materials and methods

Ethical approval

This study among professionals was performed within the Dutch law and regulations, and Good Clinical Practice guidelines [26]. Based on criteria established by the Central Committee on Research involving Human Subjects (CCMO) in the Netherlands [27], the study was exempt from the Medical Research Involving Humans Act; no permission of the medical ethical committee was required. For that reason, haptotherapists were not required to sign an informed consent form in order to participate. However, in the preparatory phase, the three main Dutch professional associations of haptotherapists informed their members about the study and facilitated recruitment. Potential participants were informed that they could call or e-mail the researcher if they had questions. The participants were free to choose to participate. Choosing to fill in the questionnaire indicated their informed consent.

2.1. Study design

In a cross-sectional study, an online survey was conducted among Dutch haptotherapists, to investigate the experience of haptotherapists with patients with cancer, and the reasons for consultation.

2.2. Procedure and participants

The survey was built in Castor EDC, a cloud-based validated Electronic Data Capture platform [28]. In order to capture a comprehensive picture, the aim was to reach as many haptotherapists as possible. Consequently, no sampling strategy was used. The inclusion criterium was to be qualified as a haptotherapist; there were no exclusion criteria.

Each member of the Dutch Professional Association of Haptotherapists, Vereniging van Haptotherapeuten (VVH) (n = 524) received an e-mailed invitation to participate in the survey. The two other professional associations, the Dutch Federation for Health Care (Nederlandse Federatie Gezondheidszorg (NFG) (n = ± 100) and the Dutch Professional Association for Specialized Psychosocial Therapists (Nederlands Verbond van Psychosociaaltherapeuten en Agogen (NVPA) (n = ± 35), although supporting the present investigation, did not give permission to send an e-mailed invitation to their members. Instead, they were willing to mention the survey in their newsletters, so that their members themselves could take the initiative to subscribe to the survey. This led to 7 and 5 additional potential participants respectively. In this way, a total of 536 haptotherapists had the opportunity to participate. Participants were informed that their answers would be processed anonymously, and that the estimated time needed for filling in the questionnaire was 20–30 min. After three weeks, non-responders received a reminder. After six weeks, the Castor database was locked and exported to SPSS version 22.

2.3. Survey

The authors developed the survey's content in collaboration with two patients with cancer, who had been treated by a haptotherapist, and four haptotherapists. The same haptotherapists, a junior researcher (experienced in qualitative research in palliative care) and a lay person pilot-tested it in order to detect possible ambiguities and inaccuracies; this was considered important because it was a newly developed, non-validated survey. Based on their comments, the concept survey was adapted. This led to small improvements, basically in replacing indistinct phrases with clear and precise language, and to different response categories for two related questions (see Appendix 1, questions 4.3 and 4.5).

The survey consisted of two parts: a general part for all participants, and an additional part for haptotherapists with experience in treating patients with cancer (see Appendix 1 for the content of the questionnaire, including the number of questions and sub questions on each topic). The general part consisted of multiple-choice questions about demographics, education and training, and work settings, with some open text fields for further explanation. The second part, consisting of multiple-choice questions and four open-ended questions, focused on the haptotherapists' experience with treating people with cancer, like indications on referrals, reasons to start haptotherapy from the viewpoint of haptotherapists and patients respectively, and correspondingly, the terminology they use to describe patients' problems and needs. This was based on observations that each discipline has its own vocabulary, written referrals often have limited room for narrative description, and haptotherapists are trained in subtle language use, especially regarding all the nuances about body experience (See Box 1). This led to slightly different formulated response options for the two questions about the reasons for consultation (See Appendix 1, Questions 4.3 and 4.5).

Box 1
Body Experience.

Body damage, caused by cancer and/or its treatment, influences patients' body experience. Patients use a whole range of subtle nuances in their attempts to express how the disease, the treatment and the damage to their body affect them and their body experience.

In this article, the term '**body experience**' is used as a comprehensive term to convey all kinds of these subtle nuances, as patients and haptotherapists distinguish them in haptotherapy, including - among others - body image, body awareness, body perception, body connection, body dissociation, relationship with the body or attitude toward the body. Conversely, these and other terms concerning various body-related aspects, are considered to fall under the umbrella term 'body experience' and thus are used interchangeably throughout this text.

2.4. Data analysis

After data cleaning (i.e. removing an excluded respondent), descriptive statistics were performed with SPSS 22 [29]. The answers to each open question were analyzed using thematic content analysis [30]. For each question, the answers of those respondents who reported to have experience in treating patients with cancer were gathered in alphabetical order. Three members of the research team, at least two persons per question, read and reread the answers, and then categorized and coded them independently. In order to prevent researcher bias, for example due to narrowmindedness, they mutually questioned each other and discussed any differences in coding until consensus about themes and subthemes was reached. Overall the original differences were small, though.

3. Results

3.1. Quantitative data

Of the 536 invited haptotherapists, 273 (50.9%) completed the questionnaire. One of them was excluded because the participant didn't meet the inclusion criterion of having the full education, nor the registration as a haptotherapist. Of the remaining 272 respondents, the 167 haptotherapists who indicated to have experience in treating patients with cancer were asked to answer the questions in the second part of the survey, including open-ended questions.

Table 1 shows the characteristics of the 272 included haptotherapists. Respondents were from all regions of the country. Almost all of them (n = 263; 96.7%) worked in independent practices in primary care and all were currently active as a haptotherapist. Besides, 85 haptotherapists (31.3%) were also practicing in their initial profession, mostly physiotherapy, nursing, psychology, or social work. Almost two-thirds of the respondents (n = 167; 61.4%) reported to have experience as a haptotherapist in treating people with cancer.

Table 2 displays several aspects of haptotherapists' experiences. Of the 167 haptotherapists with experience, the majority (n = 125; 75%) stated that their patients with cancer usually came without referral, sometimes on their own initiative because they are already familiar with haptotherapy for other reasons, otherwise usually on advice of family or friends, a General Practitioner-assistant, or another professional. The remaining 25% (n = 41) reported that their patients with cancer were referred mostly by general practitioners, psychologists/psychotherapists, medical specialists in hospitals or oncology nurses. About 80% of the respondents (n = 123) usually needed between 6 and 15 sessions to treat a person with cancer (See Table 2 for more detailed information).

Table 3 shows the reasons for consultation on written referrals (n = 41), and in the terminology of haptotherapists, as reported by the respondents (n = 167, see also Table 2). Table 3 is based on two related questions (Appendix 1, questions 4.3 and 4.5), with partly different response options. For this reason, the table contains two columns, one with the terminology that is customary on written referrals and one with terminology that haptotherapists are used to.

3.2. Qualitative data

The qualitative data is based on the answers of respondents with experience in treating patients with cancer (n = 167). The reasons for initiating haptotherapy mentioned by the respondents, emerging from

Box 2
Haptotherapy.

Haptotherapy is a person-centered therapy, based on the insights of haptonomy, the science of affectivity [19–21]. It can be classified as a mind-body therapy [22], focusing on the integration of body, reason and emotions, by working with a combination of therapeutic conversation, affective touch and experiential exercises. Usually, a haptotherapy session will last about 1 h. Affective touch and experiential exercises may deepen the insights brought about in therapeutic conversation – which are mostly on a cognitive level - into a profoundly felt experience with, supposedly, a more lasting impact. Haptotherapy can be deployed as an independent therapy as well as an additional intervention to other therapies. Collaboration with professionals from other disciplines, for example psychologists, is not unusual.

'Haptonomy' stems from the Greek terms 'hapsis' ('touch, sense, tact') and 'nomos' ('law, rule). It is a philosophy of life that advocates contact: contact with ourselves, with others and with the world around us. And we have that contact by feeling, physically and emotionally, the haptonomy does not make that distinction. In contact with others, people develop and grow into persons with a matured emotional life, connected with their body, their feelings, their affective capacities in relation to others, and their ability to stay with themselves in contact with another person [19].

Haptotherapy does have common ground with some other - internationally well-known - therapeutic and healing interventions like (integrative) massage therapy and mindfulness. The most distinguishing characteristic, however, is that in haptotherapy, the body is considered as the bearer of emotions: emotions always have a physical component – they are felt somewhere in the body. This recognition has implications for the treatment: the affective touch of the haptotherapist is meant to help the patient to get into contact with their body and emotions, which is assumed to foster the emotional processing. Compared to the more objectifying touch in medical examination, affective touch has an affirmative and emotionally supportive effect. This can be particularly helpful in restoring the disruption of body connection and the emotional or psychological damage induced by cancer and/or its treatment [8,9,23,24].

In haptotherapy, the role of the body and its mutual influence on emotional and rational aspects are acknowledged. This way, the impact of the physical damage on the psychological processing and coping of the patient is explicitly included in the treatment from the start.

Psycho-oncology centers (for specialized psychological care in cancer) in the Netherlands - among others - offer haptotherapy to patients with cancer, often in addition to psychological treatments.

Haptotherapy is a four-year post-graduate education for professionals in relevant occupational categories, usually in health care. So, haptotherapists have an initial education and profession, for example physiotherapy, nursing, psychology or social work. They choose whether to confine themselves to haptotherapy or to continue clinical practicing in this original profession as well.

Besides, the Institute for Applied Haptonomy, one of the training institutes for haptotherapy in the Netherlands, offers a two-day course 'Dealing with cancer' for graduated haptotherapists [25]. Participants are haptotherapists, working in various settings, e.g. individual practices, hospitals, or health centers, who wish to improve their expertise, often because they observe an increasing number of patients with cancer visiting their practice.

Table 1
Characteristics of the responding haptotherapists (N = 272).

	N (%)	Mean (SD)
Sex (female)	229 (84.2)	
Age		55 (7.7)
Training Institute [b]		
Academie voor Haptonomie (Academy for Haptonomy)	190 (69.9)	
ITH/Instituut voor Toegepaste Haptonomie (Institute for Applied Haptonomy)	105 (38.6)	
Veldman Jr.	37 (13.6)	
Synergos	28 (10.3)	
Veldman Sr.	22 (8.1)	
Other	9 (3.3)	
Total	394	
Number of years of experience as a haptotherapist		15 (8.6)
Currently actively working as a haptotherapist	272 (100)	
(Also) active in original profession [a]	85 (31.3)	
Professional setting(s) [b]		
Independent practice	263 (96.7)	
Center for primary health care	67 (13.6)	
Physiotherapy practice	23 (8.5)	
Hospital	6 (2.2)	
Psycho-oncology center (for specialized psychological care in cancer)	5 (1.8)	
Other	30 (11.0)	
Experience		
Haptotherapists with experience in treating people with cancer	167 (61.4)	
Haptotherapists without experience in treating people with cancer	105 (38.5)	
Post-vocational training in 'Dealing with Cancer' [c]		
Haptotherapists with experience in treating people with cancer	28 (10.3)	
Haptotherapists without experience in treating people with cancer	7 (2.6)	

Abbreviation: SD, Standard Deviation.
[a] Haptotherapy is a post-graduate education for professionals in relevant occupational categories. So haptotherapists have an initial education and profession, for example physiotherapy, nursing, psychology or social work.
[b] Multiple answers possible.
[c] 35 of the 272 respondents attended the post-vocational training 'Dealing with Cancer'. Of them, 28 respondents had experience in treating people with cancer, 7 did not (yet) have this experience.

Table 2
Haptotherapists' experiences in treating people with cancer (N = 167).

	N (%)
Estimated number of treated patients in the last 5 years	
≤5	89 (53.3)
6–15	57 (34.1)
16–25	5 (3.0)
>25	16 (9.6)
Phase of the disease [a]	
Curative	114 (68.3)
Cured or chronic	137 (82.0)
Early palliative	73 (43.7)
Terminal	72 (43.1)
Average number of sessions [b]	
≤5	1 (0.6)
6–10	52 (33.5)
11–15	71 (45.8)
16–20	25 (16.1)
>20	6 (3.9)
Route to the haptotherapist [a]	
With referral	41 (24.6)
Without referral	125 (74.9)
Referral by [a]	
General Practitioner (GP)	33 (19.8)
Psychologist/psychotherapist	22 (13.2)
Medical specialist (hospital)	15 (9.0)
Oncology nurse	11 (6.6)
Other	37 (22.2)
Collaboration with other professionals [a]	
Psychologist/psychotherapist	105 (62.9)
GP	81 (48.5)
Colleague haptotherapist	64 (38.3)
Physiotherapist	56 (33.5)
Working solo	35 (21.0)
Other	137 (50.4)
Haptotherapist sends message/feedback to the referrer	
Yes	103 (61.7)
No	49 (29.3)
Missing	15 (9.0)
Referrer receives [a]	
Notification at the start	33 (19.8)
Copy of treatment contract to referrer	4 (2.4)
Progress report during course of treatment	33 (19.8)
Final report	83 (49.7)
Other	24 (14.4)

[a] Multiple answers possible.
[b] This percentage was calculated based on the total (N = 167) minus the missing data (N = 12).

the open-ended questions, can be divided in the following six themes, with decreasing frequency (no exact numbers can be given because of overlapping answers and the inevitable interpretation of answers to open-ended questions): reasons concerning 1. disturbed body experience (about 140x), 2. emotional problems (about 140x), 3. emotional processing and coping (about 70x), 4. dealing with the social environment (about 55x), 5. existential issues (about 40x), and 6. a variety of other areas of life (each ≤ 5x). See Box 3 for a few quotes per theme.

- ***Theme 1: Disturbed body experience.*** An often-mentioned reason for referral or choice for haptotherapy was a patient's disturbed body experience (see Box 1). Respondents reported that many patients seek help because they find it hard to accept and to relate to their body, as it is damaged, sometimes even mutilated, by (the treatment of) cancer. Respondents also stated that many of their patients suffer from a changed body awareness. Patients loose connection with and confidence in their own body and wish to recover their feeling for their body; they express their body has forsaken or betrayed them and develop an aversion to - or even rejection of - (part of) it. Often, patients are concerned about or ashamed of their appearance, dislike their body, feel deformed or - where it concerns women - not feminine anymore.

Many haptotherapists emphasized the need for affective and affirmative touch, for being touched in a non-objectifying, non-medical way, in order to restore the patient's connection with the body.

- ***Theme 2: Emotional problems.*** Next, also mentioned by almost all respondents as a reason for haptotherapy, were emotional problems, a need for emotion regulation, and acceptance problems. Most often reported emotions were fear (e.g. fear of recurrence of cancer, death, pain, fear of dependency or of really feeling what the disease brings about), depressive symptoms (e.g. sadness, grief and loneliness), and traumas (due to medical treatment or pre-existing, reactivated ones). In addition, respondents mentioned a broad spectrum of other emotions, often with an unprecedented intensity, e.g. anger, powerlessness, sorrow, hope, loneliness, tarnish of feelings of wholeness and safety, and the desire to be (re)connected with one's feelings. Haptotherapists reported that many patients speak of an emotional rollercoaster because of their disease. Respondents remarked that it is not uncommon for patients to try initially to ignore these intense emotions, but eventually patients perceive it is necessary to face them in order to sort them out and to deal with them. Respondents also referred to patients' struggle for acceptance of physical damage and mutilations such as scars, amputations,

Table 3
Reasons for consultation on written referrals, as reported by the respondents (N = 41), and in haptotherapeutical terminology (N = 167)[b].

	Terminology used on written referrals (N=41) [a]	Terminology used by haptotherapists (N=167) [a]
	N (%)	N (%)
Disturbance of body awareness / dissatisfaction with (parts of) the body	25 (60.8)	123 (73.7)
Emotional problems (sorrow/ sadness, anger, fear, etc.)		153 (91.6)
Fear	33 (80.5)	
Mood disorders / depressive mood	20 (48.8)	
Desperation / devastating confusion ('ontreddering')		85 (50.9)
Problems in emotional processing	29 (70.7)	128 (76.6)
Fatigue	33 (80.5)	113 (67.6)
Pain	27 (65.9)	85 (50.9)
Lack of vitality		113 (67.6)
Reduced resilience		98 (58.7)
Problems in dealing with the social environment		107 (64.1)
Relation problems, related to /due to the disease	12 (29.3)	
Sexual problems	11 (26.8)	56 (33.5)
Questions concerning the meaning of life / existential issues	17 (41.5)	105 (62.9)
Problems with return to work	10 (24.4)	55 (32.9)
Reduced quality of life	14 (34.1)	86 (51.5)
Not applicable (no indication / referral)	6 (14.6)	
Other	5 (12.2)	7 (4.2)

[a] Multiple answers possible.
[b] For further explanation: see Quantitative results, Table 3, in the text.

stoma's, and of the whole range of other consequences of cancer, including the possibility - or even probability - of approaching death.

The above-mentioned disturbed body experience and emotional problems were often mentioned in combination.

- o ***Theme 3: Emotional processing and coping.*** A third reason concerned patients' difficulties with coping and psychologically processing their disease. According to the respondents, this is an arduous process that requires time and effort. They reported that many patients with cancer find it difficult to adapt to and to accept the changed situation, physically as well as emotionally, and experience a loss of (self) confidence. Moreover, many respondents mentioned the complicating factor of persistent fatigue, loss of energy, vitality and resilience, leading to a disturbed balance between physical and psychological burden on the one hand, and bearing strength on the other hand. Many patients experience the necessity – and difficulty - to acknowledge new limitations and to set limits, which is necessary because of their decreased level of energy.
- o ***Theme 4: Dealing with the social environment.*** Another common reason to seek haptotherapeutical help were problems in dealing with the social environment. Many patients experience changes of roles and positions in their family. They express problems in daily life with their loved ones. They feel unheard, unseen, misunderstood, isolated, and insufficiently supported. At the same time, they are worried about their loved ones. Furthermore, respondents mentioned problems in the field of intimacy and sexuality, e.g. difficulty in restoring an equal relationship, and problems in enjoying physical and emotional closeness.
- o ***Theme 5: Existential issues.*** Many patients need help – and turn to a haptotherapist - to regain autonomy, to retrieve themselves, to recover their dignity. Respondents outlined patients' loss of grip on life and their estrangement, their loss of self-esteem, and their right to self-determination.
- o Moreover, respondents described existential issues as a ground for consultation: brought to a standstill and experiencing confusion about giving direction to life, loss of identity and of connection with others and with life, and a strong awareness of the finitude of life. Respondents told that palliative patients come with questions about how to deal with this changed perspective and how to maintain a decent quality of life.
- o ***Theme 6: Other areas of life.*** Finally, respondents described the impact of cancer on a variety of areas of life as indications for haptotherapy: quality of life, the desire to live fully instead of just surviving, finding a new balance in life, dealing with all kinds of changes. Although the differences are subtle, these items did not really fit in the previous themes. Yet, they are mentioned here in order to provide a more complete picture.

According to the respondents, several patients articulate their requests for help in phrases that are strongly related to 'haptotherapeutical terminology', e.g. reconnecting to the affected part(s) of the body, restoring the disrupted relation between 'head' and 'body', creating room for whatever is bothering them.

Box 3 shows a few quotes per theme. Because in one of the questions respondents were asked to use, as much as possible, the words of the patients, part of the quotes are in the first person.

4. Discussion

Over half of the haptotherapists registered in the Netherlands responded to our survey. Two-thirds of the responding 272 haptotherapists also treated patients with cancer, addressing the interaction of body and mind. As motivation for initiating haptotherapy, combinations of emotional problems and a disrupted relationship with one's body, such as an aversion to the body, and loss of contact with and trust in the own body were mentioned most frequently. Other reasons for haptotherapy concerned the physical, psychological, social and existential dimensions of health, and often a combination of problems.

Each of the above-mentioned reasons by itself is not specific for haptotherapy; after all, psychologists are specialized in psychological issues, and physiotherapists can help to relieve physical symptoms. However, as haptotherapy focuses on the integration of body, reason and emotion, precisely the combination of physical and emotional problems is a key indication for haptotherapy. Cancer by definition affects the body, which inevitably has an impact on the above-mentioned integration [24]. In haptotherapy, the role of the body and its mutual influence on emotional and rational aspects are acknowledged and included in the treatment from the start (see Box 2).

The available – limited – research on haptotherapy for patients with cancer shows that haptotherapy contributes to a reduction of pain, stress and other physical complaints, to a decrease of panic and anxiety, and to improvement of perceived social and cognitive functioning, well-being and quality of life [5,7]. The respondents mention most of these issues as reasons for initiating haptotherapy. Although this does not prove that the outcome of the therapy will be successful, it seems reasonable to expect positive outcomes based on the literature. In this sense the findings of the survey are broadly in line with the results from earlier research.

Respondents mentioned a need for affective touch. This goal in haptotherapy corresponds with the view that healing through physical contact can be necessary for people who have suffered bodily trauma - which often is the case in people with cancer [31,32]. Leijssen stated that it helps patients to re-own the disowned parts of the body or personality, and that psychological interventions will have a longer-lasting impact if they are experienced physically [31].

Besides acknowledging the impact of cancer on a patient's body

Box 3
Patients' (p) and haptotherapists' (h) quotes, as reported by responding haptotherapists.

Theme 1: Disturbed body experience.

- I have lost contact with my body and myself (p)
- I feel abandoned by this body, my body no longer feels like my own (p)
- I can no longer trust my body, I do not recognize myself in the changes in my body, I feel deformed (p)

Theme 2: Emotional problems.

- I want to regain my feelings, I don't want to be so anxious, help me process, deal with emotions, help me relax, I want to be less in my head (p)
- I am devastated inside (p)
- Dealing with fear, sadness and insecurity, powerlessness, despair (h)

Combination theme 1 and theme 2.

- I need more physical than a psychologist and more with feeling instead of physiotherapy (p)
- Bringing head and body together (h)
- To get back in touch with the feeling and the body (h)

Theme 3: Psychological processing and coping.

- I have lost confidence in myself (p)
- I want to become who I was again, but I can't (p)
- How do I give a place to what happened to me? (p)

Theme 4: Dealing with the social environment.

- I don't want my family to worry any more (p)
- My partner doesn't understand me (p)
- I am very tired, but my family is still asking so much of me (p)

Theme 5: Existential issues.

- How do I get lust for life again? (p)
- Life has no meaning anymore, but I must move on (p)
- Can no longer give direction to my own life (p)
- I want to be myself again and not a medical object (p)

Theme 6: Variety of areas of life.

- Because I have little energy, I must organize my life differently and I don't know how (p)
- How do I relate to the finiteness of life? (p)
- Lack of flexibility, too much control, lack of spontaneity (h)
- Having endured all treatments, but lost themselves in the process, or being exhausted from it, or often a little later, surviving, but having difficulty living, continuing to live, no longer having to fight, but what then? (h)

Haptotherapeutical terminology.

- Listening ear & healing hands; if everything may be there, and I may resign to my fate
- I want to feel the affected area again
- Finding balance between thinking and feeling

image in the sense of physical appearance, the responding haptotherapists added a specific component by describing the loss of contact and connection with the body and the need for affective touch to restore this. Several previous studies concerned body *image* [8,23,33,34]. This term mainly refers to the outward aspects of patients' experience of the body, such as being dissatisfied with their appearance, feeling less physically attractive or avoiding people because of their appearance. As described in Box 1, body image is one aspect of the bigger picture of body experience. Responding haptotherapists mentioned many other aspects and strongly emphasized the importance of body *connection*, which is necessary to gain access to inner bodily stimuli and to achieve a state of observational awareness of inner body experience. This involves presence in and acceptance of bodily experience - versus the avoidance or dissociation from bodily experience [35]. To achieve this, the haptotherapist makes use of a combination of therapeutic conversation, affective touch and experiential exercises (See also Box 2).

Finally, according to the respondents, a substantial part of their patients with cancer formulate their request for help in terms that are strongly related to the core of what haptotherapy pretends to offer. This could indicate that the support of the haptotherapist matches the needs of the patient. Further research is needed to examine this hypothesis.

4.1. Study strengths and limitations

This is the first study that explored experience with and indications for haptotherapy for patients with cancer, according to haptotherapists. The high response rate of haptotherapists within a short period of time might reflect a high level of commitment and led to a rich set of quantitative and qualitative data that will serve as a solid basis for further research.

However, this study also has some limitations. The information concerning patients is indirect and only from the perspective of haptotherapists. Nevertheless, this seems appropriate as a first step, before directly involving vulnerable patients themselves.

Another limitation is the use of a non-validated questionnaire, as no validated one existed. However, its content was based on the input of and pilot tested by several experienced haptotherapists. Nevertheless, some imperfections were found in hindsight; more specifically: the two different response categories for two related questions (see Appendix 1, Questions 4.3 and 4.5) made it more difficult to compare and to interpret. The underlying reason was a supposed difference in terminology between the healthcare professionals who are most likely to refer their patients for haptotherapy and haptotherapists themselves. Further research is recommended to develop common reference frameworks and languages.

A third limitation is that there was no opportunity to explore the exact meaning of the terminology, used by the responding haptotherapists. This will be addressed in a next, qualitative study.

Finally, the results cannot simply be generalized to other countries, because the survey included only Dutch haptotherapists. This is due to the fact that, at this moment, haptotherapy is just a relatively small professional area, mainly in the Netherlands.

4.2. Implications for clinical practice

Referral to haptotherapy deserves serious consideration for patients with cancer who suffer from symptoms in multiple domains. We would recommend professionals in (psychosocial) oncology, e.g. psychologists and psychotherapists, to investigate patients' relating to their body and the extent to which the loss of body connection may interfere with the emotional processing. In the experience of haptotherapists, the combination of conversation, affective touch and experiential exercises might contribute to restoring the integration of body, emotion and reason. This is especially important for patients who lost the connection with and trust in their body, due to the damage caused by the disease and medical treatments.

5. Conclusion

Two-thirds of the respondents treat patients with cancer. Reasons for consultation cover a wide range of problems in multiple dimensions, in which a disturbed body experience in combination with emotional problems often plays an important role. As a next step, based on these results, we recommend investigating thoroughly oncological patients' experiences with haptotherapy, and subsequently to measure objectively the effects of haptotherapy for patients with cancer.

Availability of data and materials

The data sets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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CRediT authorship contribution statement

Agnes van Swaay: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Writing – original draft. **Kris Vissers:** Conceptualization, Methodology, Supervision, Writing – review & editing. **Yvonne Engels:** Conceptualization, Data curation, Formal analysis, Methodology, Supervision, Writing – review & editing. **Marieke Groot:** Conceptualization, Data curation, Formal analysis, Methodology, Supervision, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no conflict of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ctcp.2021.101352.

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