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The Experienced Body, When Taken-for-Grantedness Falters: A Phenomenological Study of Living with Breast Cancer

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The Experienced Body, when Taken-for-Grantedness Falters:
A Phenomeonological Study of Living with Breast Cancer

Annemarie Kesselring

Dedication

To my mother, Hedi Kesselring and the memory of my father, Fritz Kesselring, who died shortly before the completion of this dissertation. They taught and encouraged me to search beyond the obvious.

ACKNOWLEDGEMENTS

This dissertation would never have been written if Anne Davis and Margaretta Styles had not strongly supported my being accepted into University of California San Francisco's School of Nursing's articulated BS/MS program in 1981. I shall always be very grateful to them, not only for having opened the doors towards graduate education for me, but also for their benevolent interest in my progression through eight years of exciting learning in this fascinating university and city.

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Marylin Dodd strongly encouraged me to continue my education in the doctoral program and maintained her amicable support throughout the years. She advised me during the first half of my doctoral education (making sure my education would not fall short on bio-chemical and statistical insights!). As research assistant in her large nursing study, I met the women whose stories are told on the following pages. Marylin Dodd allowed and encouraged me to use the interviews for analysis and read the interpretations from the perspective of someone familiar with many patients and most of the larger study's interviews. Her valuable comments helped me while going back, re-reading and thinking over again, questioning where her impressions differed from mine. I am very thankful for her interest in and guidance through my education at UCSF.

All three, Dr. Benner, Dr. Strauss, and Dr. Dodd generously suggested improvements and were patient in editing and re-editing many drafts. Especially Dr. Strauss' recommendations both clarified and polished sentences, paragraphs and whole sections. Thank you for making this work readable.

Special thanks go to the women and their families who so generously shared their experiences with us. They taught me much about embodied experiences in illness. I hope to have given a faithful account of what their experiences were like and what mattered to them.

Deep gratitude goes to my Swiss mentor and friend, Ruth Quenzer. She was the one who, years ago, considered me capable of pursuing studies at UCSF. She continued to believe when I doubted and has never stopped encouraging me. This dissertation has been inspired by her conviction that nursing care can be improved through better understanding of patients' situations.

Several of my Swiss friends and colleagues trusted throughout the years that my American academic endeavors are important and worthwhile to be pursued. I am indebted to Madeleine Bircher, Emmi Cassani, Vreni Fiechter, Erna Grell, Martha Meier and Hildegard Steuri for their belief and encouragement.

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mutual experiences, and much pleasure.

Fusaye Kato transcribed the interviews. I am indebted to her for weeks of excellent transcription. The study from which the data came was funded by the National Center for Nursing Research (RO 1 NR01441-03).

Finally, I am especially grateful to my family in Switzerland for years of sustained moral and emotional support. Their confidence in the importance of what I learned here made these studies and my life in San Francisco all the more meaningful.

San Francisco, October 25. 1990 Annemarie Kesselring

THE EXPERIENCED BODY, WHEN TAKEN-FOR-GRANTEDNESS FALTERS:
A PHENOMENOLOGICAL STUDY OF LIVING WITH BREAST CANCER

Abstract

Phenomenological in its premise and utilizing grounded theory methodology for a secondary analysis, this study describes the experienced body as it was alluded to in 48 interviews with 18 women who underwent chemotherapy for breast cancer. Embodied experiences and the experienced body are described on three closely interrelated levels: 1) as the shaper of self and the world as it is known to the person; 2) in its identity creating role when subjugated to medical interventions; and 3) as it was conceptually understood or known about. These three levels of analysis are used to illustrate how the experienced body appeared in patients' lives by creating six paradigmatic sketches. Wavering or breakdown of usually spontaneous "I can" capabilities were at the core of patients' illness experience. As "I can" faltered, reality appeared in unfamiliar "I cannot" modes. The women vacillated between both modes of being. Feeling comfortable and in control characterized a self-understanding out of the "I can". "I cannot" elicited much suffering as it made visible patients' vulnerability and powerlessness in many of daily life's previously taken for granted dimensions such as eating, drinking, as well as their senses of time and space. Relations to self, others and the life-world were reflected in vacillations between "I can" and "I cannot". Frequently, the body appeared as ambiguous and/or paradoxical; but it always constituted a woman's reality as self-in-the-world. Different levels of abstraction characterized patients' formal knowledge about illness related bodily features. Yet, like a sieve with which one aims to capture water, formal knowledge appeared as illusive and inadequate if sought to mitigate embodied, existential concerns. By focusing on physical deficiencies and psycho-social problems medical and nursing diagnostics tend to gloss over the body's pervasive, reality constituting perceptibility. Re-endowing the body with a soul or anima, and acknowledging its power of being connected beyond self might complement nursing's conceptual models of an objectified anatomico-physiological organism and theories of self-as-separate from or against its body, others, and the world. This study's findings may enhance nursing's growing interest in phenomenological approaches towards caring and contribute to a beginning professional understanding of embodied illness experiences.

Patricia Benner

CHAPTER

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CHAPTER 1

KNOWLEDGE ABOUT THE BODY IN NURSING

Why Knowledge About the Body?

> We have to recall Max Scheler's findings that in any culture the highest rank is accorded to one of the three types of knowledge distinguished by him - knowledge for the sake of domination (Beherrschungswissen), knowledge for the sake of knowing (Bildungswissen) - knowledge for the sake of salvation (Heilswissen) - and therewith to one of the three types of men of knowledge: the scientist-technician, the sage, the saint (Schutz, 1964, p.242).

In its pursuit of happiness, contemporary American self-understanding encourages the individual to strive for personal independence, self-reliance, and self-authenticity. To achieve these ends, freedom to choose life-style and goals, engagement in upwardly mobile job opportunities, and readiness to move great distances are highly valued (Bellah, Madsen, Sullivan, Swindler, and Tipton, 1985). Yet, there is no self without a body. An attractive, able, agile, healthy body is widely taken for granted and expected to contribute to the accomplishment of these cherished goals. Cosmetics and fashion are big business to keep bodies attractive. Body building, physical training towards fitness and mastery in competitive and leisure sports strengthen the body. They have become cultural endeavors to which much time and money are devoted (Glassner, 1989).

A lot of what is known about the body serves to master, preserve, mend, and control the organism and its performance. Knowledge easily serves towards enhancing bodily functions and competence in the quests of achieving life's cherished goals.

Macintyre (1984) suggested that managers and therapists are paradigmatic characters of contemporary Western cultures. Frequently, they are looked upon as experts in their fields. Acquisition of knowledge serves managerial and therapeutic purposes. Managerial zest is described as being driven by faith in continuous "progress" and achievement, the belief that problems can be solved strategically, that natural and human resources can be mobilized and efficiently exploited, and that things can be controlled. Similarly, contemporary therapeutic attitudes are depicted as activating an individual's inner resources in order to enhance "life-effectiveness" (Bellah et al. 1985, p.44-48).

Characteristic of both attitudes is a utilitarian stance. This means that ends are understood as given and great zeal is invested into maximizing the procedures that lead towards achievement of those aims. Knowledge about the body is readily employed as means to mobilize the body's potentials and to maximize its fitness and usefulness in the pursuit of every day life's goals.

However, illness, such as cancer, is apt to bring to consciousness the body's - the person's - vulnerability and thus imposes unforeseen limits to the quest of life's aspirations. Suddenly, the body ceases to appear as an unending source of energy or regeneration. For the first time it may become recognized as embodiment, the foundation and source of one's life, rather than as a tool or resource to be exploited.

In the United States, one out of four people, during their life time, will be diagnosed with cancer. In 1986 the incidence of breast cancer in the USA was 139,816 and 40,534 women died from it. The frequency of breast cancer is still increasing (MMWR, 1989). Treatment modalities for breast cancer are usually aggressive and invasive; they include mutilating operations, systemically active chemotherapies (CTX) and in depth radiation (RTX).

Nurses actively participate in the treatment of, and care for cancer patients. They are part of a team with therapeutic and managerial goals. These goals are affected by nurses' knowledge of physiological functions and views of the human body. Indirectly, knowledge about and interpretation of the body is expressed in their work with patients. Professional perspectives also appear in pertinent literature. One needs to be cautious, however, in that actual attitudes are not necessarily congruent with what appears in print.

As follows from the introductory quote, knowledge is neither neutral, nor impartial in its application. In this chapter I attempt to outline nurses' conceptual knowledge about, and images of the human body as reflected in professional literature, both of nursing and medical origin. Against this background, I shall argue for the need of more knowledge for the sake of knowing. Such knowledge may enhance nurses' understanding of patients' experiences as they live with breast cancer and its treatments.

The Body as Depicted in Nursing Literature

Nurse Theorists' Views

Obviously, the body does not appear in a conceptual vacuum. Various nurse theorists defined their view of the patient/person thereby implying their ideas of the body. They attempted to explicate the goals of nursing activities and interventions. The following list contains definitions of "person" by five widely used nurse theorists (Fitzpatrick & Whall, 1983, p.340):

Henderson:	Biological beings with inseparable mind and body
King:	An open system exhibiting permeable boundaries permit-

	ting exchange of matter, energy, and information with the environment.
Orem:	Man is an integrated whole, functioning biologically, symbolically, and socially.
Rogers:	A four-dimensional, negentropic energy field identified by pattern and organization and manifesting characteristics and behaviors that are different from those of the parts which cannot be predicted from knowledge of the parts.
Roy:	A biopsychosocial being in constant interaction with a changing environment. The person is an open, adaptive system.

Henderson's view contains a mind-body unit which implies to be different from and probably more than its biological basis. In all of the other definitions the body must be insinuated, be it through a system's permeable boundaries, biological functions, and to some extent, interactions with the environment.

It is through the aims of nursing, as conceptualized by these theorists, that we indirectly learn more about the persons who are expected to benefit from nursing care.

Henderson (1969, p.4) held that nurses

> assist the individual...in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge. And to do this in such a way as to help him gain independence as rapidly as possible.

In King's (1981) view, nurses aim to attain, maintain, and restore health. Orem (1980, p.18) envisioned nurses to be able to "prescribe, design, manage, and maintain systems of therapeutic self-care for individuals" until their clients are themselves able to do so. Rogers (1981) conceived nurses to assist people in "achieving their maximum health potential" (p.86), while Roy's goal of nursing is the promotion of the client's adaptation in the realms of 1) physiological needs, 2) self-concept, 3) role function, and 4) interdependence (Roy, 1980).

Congruent with the culture's strivings, these ideologies emphasize nurses' zeal to assist patients in their attempt to maintain or regain health understood mainly as functioning in self-reliance. In all, but Henderson's conceptualizations, concerns about a self-evident, living, not just bio-physiological body, are undermined by an overriding preoccupation with achieving as much health for/with a person as possible. Self-care is proposed as means to achieve the maximum of one's health potential, and thus, hopefully, to strengthen individual independence. Nursing actions include training to (re)gain (lost) strength and capabilities, to elicit missing will in the patient which is assumed to be there as a potential, and to educate with the goal of augmenting patients pertinent knowledge and skills towards taking care of self.

In Henderson's more traditional understanding nurses use their own bodies and skills to do for, and assist patients in what they cannot do for themselves. Orem's nurse takes on a similar task, but hers is a different outlook. She is a professional with the power and authority to diagnose and to temporarily prescribe, design, and manage strategies of substitution or treatment of deficient self-care in her clients. In Orem's view,

> self-care and care of dependents are forms of human activity referred to as <u>deliberate action</u>. This means that it is purposive goal- or result-seeking activity. It also implies that the meaning of the result sought is identified before the action is taken....Deliberate action is distinguished from physiologically and psychologically "programmed mechanisms" for responding to internal and external conditions. These are reflex activity...instinctual urge.., emotional reaction.., and feelings of pleasantness and unpleasantness (p.68).

If the body is implied in this passage, it can be seen as both the tool for performing self-care and the focus of such care. As a tool of the mind or self the body is actively used in deliberate actions and, as the focus of self- or dependent care, it is reduced to programmed, physiological mechanisms which react to internal and external stimuli.

One may argue that it is unfair to imply such limiting views on the body into a passage which does not even talk about the body. Yet, as I will try to show, this view is not atypical in nursing literature. The body, in mental awareness, is usually conceptualized as body-image in its relation to the psychological concept of self, and thus, as part of what is understood to be a person. Knowledge about biological and (patho)physiological processes of the body, on the other hand, is widely shared in nursing literature.

King (1981) conceptualized body-image and self as part of "personal systems". She assumed that body-image influences the concept of self (p.19-34). Bonham and Cheney (1983) contributed the only theoretical framework for nursing in which the concept of body-image is somewhat explicated. "Personal identity", in their view, is composed of "self-concept, body-image, and self-esteem". Body-image is a "learned concept formed from our responses to the environment". It is a composite of four dimensions: 1) body percept which establishes the postural model of the body; 2) body concept which comprises beliefs and feelings about the body which arise from interacting with others; 3) body ego which is the receiving or viewing aspect of the body; and 4) body ideal which provides a kind of mental measuring stick against which to judge the actual body (p.175). The authors' assessment of patients' body-image includes three components: 1) derived from self-image: "how I see my body"; 2) self-esteem: "how I feel about my body (values)"; and 3) self in action:

"how I use my body".

Body-image, in this conceptualization, is limited to a visual/mental (seeing) representation to a narcissistic (assigning values to feelings) individual with a utilitaristic (use) understanding of the body. It depicts the body as a mute appendix to a cognizant, self-conscious, intentional self which in turn creates, believes, feels, scrutinizes, measures, evaluates, and uses it. Without much connection to the surrounding world this self carries a mental image of its body, a picture which reflects the input of others, notions of a "real" body as compared to an ideal, cultural body. Yet, any assault on that "real" body potentially impacts on its mental image and may thus have repercussions on the self. Body-image seems to be paradigmatic for a modern notion of the Cartesian body: An object-like extension into the world represented to the self by the mind.

Body-Image: Its Conceptual Use

Without giving much reference to the psychoanalytic roots of the concept (e.g. Schilder, 1935/1950[1]), body-image has been used in several nursing studies and as a theory against which illness impact can be assessed. Woods, Laffrey, Duffy, Lentz, and Michel (1988) asked 528 women what being healthy meant to them. Content analysis yielded an eudaemonistic understanding which included: Clinical absence of illness, role performance, adaptability, actualizing self, practicing healthy life-style, self-concept, body-image (which meant feeling good about one's body and appearance), social involvement, fitness, cognitive functioning, positive mood, harmony, and feeling spiritually whole.

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[1] For theoretical synopsis of the concept see pp.60-64.

In this explicit, almost disembodied conceptualization of health body-image appears with self-conscious, hedonistic connotations. The body as health's physical foundation seems non-existent. Implicitly, however, it is the body's fitness and spontaneous reliability which is praised. Neither skills nor performances are conceivable without body, nor can mood or spirituality be experienced detached from a finely tuned organism endowed with a central nervous system (Brothers, 1989).

Body-Image and Alopecia. Wagner and Bay (1979) studied the impact of alopecia on body-image and social activities. They linked hair to physical appearance and thus to body-image which, in turn, "provides a base for identity" (p.365). In their study they compared perceived body-image and social/non-social activities in 77 patients, 43 of whom had experienced chemotherapy (CTX)induced alopecia, and 34 had undergone CTX without losing their hair. To assess patients' perceived body-image, they used Secord and Jourard's (1953) Body Cathexis Scale (cathexis = degree of dis-/satisfaction with various body parts). This scale measures "feelings about 46 body parts and functions" on a five point scale ranging from 5 "consider myself fortunate" to 1 "have strong negative feelings and wish change could somehow be made". A social activities' questionnaire was developed by the authors. An ANOVA was performed on group by performance level (few or no versus moderate to severe physical limitations) and by gender. Results showed lower "body-image scores" for the group with physical limitations as compared to the group with normal performance ($F1,76 = 6.347$, $p<0.05$). The author's hypothesis that subjects with alopecia would have lower mean body-image scores was not confirmed. They redid ANOVA with only the results of those subjects who had scored their hair as fairly to very important and found lower mean scores for the alopecia group in this sub-sample ($F_{1,34} = 5.050$ $p<0.05$). No statistically significant differences were found in social activities between the groups. The authors' concluded that their hypothesis "that alopecia would negatively affect body-image and social activities was not confirmed" because body-image might be too complex a concept and that "adaptive mechanisms" may have mitigated alopecia's impact on body-image over time (p.368).

The authors' narrow conceptualization of the body as object of display, or image of appearance for the self impeded them to further reflect on meanings which could be associated with the body in its performing capacities. It makes sense to score low (wishing for change if possible), when e.g. one's "health, breathing, energy level, digestion, appetite etc." (Secord et al. 1953) become troublesome due to cancer. But do such functions, scored by cancer patients, really reflect "body-image" on a tool that was designed to test aspects of "personality theory" like anxiety, undue autistic concerns, and self-insecurity (Secord et al. 1953, p.343)?

Baxley, Erdman, Henry and Root (1984) replicated in part Wagner et al's study. To them, body image is the "mental picture of (one's) own body" which is "determined by interpersonal, environmental, and cultural factors" (p.499). They measured body-cathexis versus self-cathexis by using Secord et al's (1953) scale. This scale included 40 parts or functions and 40 variations of conceptual aspects of the self out of 46 in the original scale. Answering options were the same as described above. The sample consisted of 40 cancer patients who were treated with

CTX, of whom 20 had experienced alopecia. Independent t-test results of the group means showed statistically significant (p. <0.0001) differences: The alopecia group was more dissatisfied with self and body than was the group which had not experienced hair loss. Men scored lower in "self-image" than did women. The authors admonish nurses to be aware of alopecia's potential to devalue body- and self-image and to counsel patients to wear wigs or conceal baldness with a cover.

Conceptually, Wagner et al's and Baxley et al's studies fully embrace body-image as a mental representation of body parts to self and display of self to others. Hair and its opposite, baldness, are viewed as central to physical appearance. Thus, it was hypothesized that alopecia would be a "threat to body-image" (Wagner et al. 1979) or impact "self-concept" (Baxley et al. 1984). Congruent with body-image's mental conceptualization is the choice of an instrument which relies on cognitive appraisal: It elicits from the person likes/dislikes about distinct body parts or functions and self. However, if there is such a thing as a whole body-image, validity may be threatened by scoring a decomposed body. The use of alopecia vs. hair as independent variable assumes a causal relationship between hairdo and body/self-cathexis and social activities as dependent variables. Although reductionistic, this assumption may fit the decontextualized concept of a self-conscious body/self-image from which any allusions to meanings (elated to a soliciting life-world) have been excluded.

The fact that Wagner et al. (1979) found statistically non-significant differences between their two groups' mean scores (which they had separately analyzed for full and reduced performance status) is interesting, mainly if compared to Baxley et al's (1984) statistically significant findings. Sample differences may play a role, but more importantly, there may be an "interaction effect" between assessing two dependent variables "body-cathexis" and "social activities" (1979) versus "body- and self-cathexis" (1984) at the same time. If satisfaction with body is measured in conjunction with social activities, (which questionnaire was first administered is not reported) respondents' attention is steered towards body and the social world. In such a perspective, alopecia may lose its "threat to body-image". If however, the respondent is induced into other-exclusive self-contemplation by questions pertaining to satisfaction with one's body and self, alopecia may become more problematic.

Since their conceptualizations around body-image are doubtful, both studies and their inconclusive findings remain questionable. This is why the authors' collegial admonitions to inform, support, or counsel patients before and while they lose their hair, sound trivial. It appears as if there is a belief behind this advice that the value of self can be restored if its body-image is retouched. Probably, this is a wrong conclusion. The use of abstract, reductionistic, "scientific" concepts to causally link very complex phenomena treat the body as a thing to be managed by a separate self.

Body-Image and Development. In a preliminary report, Beardslee and Neff (1982) shared their analysis of results from 18 out of 60 children aged 8-13 years whom they had tested. Three groups were distinguished: 30 healthy children, 15 with cancer, and 15 with orthopedic conditions. The study's aim was to find out what bodily related concerns children with fatal illness have, if these concerns change over time, and if such children express greater concern about body integrity and function than their healthy peers. Body knowledge was measured by a modified Gellert (1962) Index (e.g. what is the purpose of blood, skin, bones), feelings of vulnerability by a Sentence Completion instrument created by the authors, and a free-hand drawing of a house served to yield data "regarding the relative strength or weakness of body boundaries". Data collection occurred twice, the second time 3-4 months after time one. Results show more children in the sick groups with "relatively low body function scores" and a higher number of answers on the sentence test which indicate "injury, misfortune, and need for protection" (p.131). Even though these trends seem to have held up over time within the groups, individual children changed in their responses during the time interval. Findings from the two verbal tests conflicted with interpretations of the house drawings. No statistical analyses were reported. The authors so far found no support for the "common assumption" that fatal illness makes children feel more vulnerable and augment their "concern about threat to body integrity and normal body functioning" when compared to healthy peers (p.132).

The use of one cognitive (Gellert) and two projective tools to measure these children's concerns seems adequate for their age group. However, these tools imply the researchers' assumption that children's embodied, experience is mental to the extent that it can either be expressed as knowledge, projected into a drawing or associated with concepts such as pet, play, or other people, when elicited by the Sentence Completion Test. The inconclusive preliminary results may reflect problems with conceptualization and testing.

A combined physician-psychologists team (Zeltzer, Kellerman, Ellenberg, and Rigler, 1980) studied the psychologic effects of illness in adolescence. The study's purpose was to "relate the adolescent's perception of the influence of illness upon body-image, (only these results will be reported) autonomy, relations with others, family interaction, sexuality, future orientation and education". A healthy group of 345 was compared with 168 adolescents suffering from diverse chronic illnesses, among others, cancer. A self administered "illness-impact questionnaire" was constructed by the researchers. Chi-square analyses were performed for 1) each ill group versus the healthy control group, and 2) each ill group against the other ill groups. The oncology group reported treatment impacts which differed from all other groups. They felt that treatment heavily affected body-image ($p < 0.0001$ relative to healthy and $p < 0.01$ relative to other ill adolescents) and felt it to be worse than the illness. Body-image was associated with physical change and social acceptance. Girls in this study were more affected by such changes than were boys.

The tool's wording of body-image related issues remained unclear in the report. The fact that treatment related body-image impairment showed up more strongly in the oncology group may point to augmented physical awareness due to invasive procedures.

Beside these inconclusive studies, the concept of body-image has inspired health care workers' concerns about cancer and treatment effects on adolescent development (Valentine, 1978; Van Eys, 1977). Brown and Bjelic (1977) applied a developmental framework which included body-image related issues in their report on two adolescents of which they had taken care. These children dealt with leg amputation (osteogenic sarcoma), alopecia and fear of paralysis (medulloblastoma). Morrow (1978) described the impact of CTX on adolescent development. CTX side effects were assumed to threaten the "confirmation of body normality" and seen as "a blow to an already fragile body-image and integrity" (p.324). Cancer and treatment effects may interfere with body-image concerns, intellectual growth, separation-individuation process, and ego ideal formation (p.330). Carr-Gregg and White (1987) too, used a developmental model to show cancer experience's diverse threats to the healthy emergence of identity in adolescents. "In order to find one's identity, one must have an intact image of one's own body" and this unimpaired image evolves from the fusion of the "idealized and real body-image".

Any of these positions might be challenged by Frank's (1986) phenomenological case study of the quite "normal" human development and life, experienced by an American woman born with quadrilateral limb deficiencies. For example, she taught her younger sister to dance, because she "felt" her sister's movements since "part of her body (the part I lacked on the exterior) was mine too" (p.191). She called herself lucky because having no arms and legs is "the only thing that's wrong with me" (p.195). "I always liked my body when I had nothing (prostheses) connected with it" (p.206). The woman had a "positive self-image", was married, later divorced, and performed "culturally prescribed activities...and present(ed) herself as a member of the mainstream society" (p.214).

The difference between Frank's case history and the literature on cancer's impact on adolescents' development of body- and self-image lies not only between non-malignancy and malignancy, or congenital versus "acquired" body-image alterations. Rather, the theories of body-image and self resemble inversely used binoculars which narrowly focus on the cultural stereotype of a beautifully presenting body as basis for the development of a psychologically healthy person. This myopic perspective excludes the view on a broader, meaningful world and ignores existential meanings. Frank's phenomenological case study allowed for life and world to show up as perceived through the eyes and life-experiences of the reporting woman.

It is interesting to note that there is a paucity of literature about the developmental impact of cancer on the body-image of adults or older people. Nevertheless, theoretical linkages between self, body-image, and sexuality are a widely applied grid for the assessment of adults and older people with cancer.

Body-Image and Sexuality. Links between body-image and sexuality appear frequently in the (breast)cancer literature. One study which alludes to such a link was done by a surgeon and psychologists.

Goldberg, Stolzman and Goldberg's (1984) study pointed to relationships between mastectomy, breast reconstruction, and self-concept, body-image, primary relationships, sexuality, and life goals to be quite complex. The authors developed a 28-item questionnaire concerning the above five realms. It was given twice within approximately six months to post-mastectomy women. One group (N=15) had chosen breast reconstruction (R), the other (N=15) had not (NR). The subjects were matched for age, educational level, employment status, length of time since mastectomy, and marital status. With the exception of younger average age in the R-group, both groups were comparable. Both groups also reported a "satisfactory sex life" prior to mastectomy. At the time of the second testing the R-group had their reconstruction done. The findings in the NR-group stayed stable over the six months. For the R-group however, the findings "suggested that improved self-concept and body-image were the most remarkable changes" (p.40). The authors do not present any statistical analyses of their findings, but show differences among groups in percentages. They found major differences in the attitudes of these women in all realms (but life goals) addressed in the questionnaire. Attitudes in the "Body Image Items" were as follows:

	% NR-Group	% R-Group
reluctant to buy revealing clothes	58	100
difficult to look at self undressed	10	55
feeling less physically attractive since mastectomy	75	93

The authors concluded that the R-group experienced the mastectomy as a "more serious blow to their self-esteem" than the NR-group. Generally, the R-women felt less happy, more depressed and pessimistic and perceived to be less supported by their partners than their counterparts. The R-group women perceived their breasts as more important in regard to their sexuality than did women in the NR-group, thus their intimate relationships had suffered more from the loss of a breast, compared with the other women.

Body-image was conceptualized as physical presentation of self tied to the complex relations between self and others. We do not learn how these women felt about clothes, looking at, and finding themselves attractive before the mastectomy. Given the considerable lower post-mastectomy self-esteem in the R-group, breast reconstruction may have reassured these respondents of their bodily respectability, not of an abstract body-image.

Within the nursing literature, Fisher (1983), pointed to the repercussions that a lowered body-image may have on sexual relationships and thus on relationship satisfaction. Krumm (1982) linked real and feared threats to the body-image with patients' sexuality. Alopecia, facial edema, lymphedema, skin changes, burns, disfigurement and sterility comprise the list of such threats. She held that the most common problem following mastectomy is "interference with the perception of their role as a mate and with sexual behavior". Lamb and Woods (1981) associated sexuality with the meaning of being human and alive. They argued that for cancer patients physical closeness with the partner may allay fears, and that feeling accepted may be grounded in "sexual validation" by the partner.

The tenor is clear throughout these writings: Nurses should provide anticipatory guidance to patients, educate, and counsel them in the sexual realm of their lives. It is assumed that body-image is a suitable conceptual framework to guide such interventions.

Maguire (1985) associated a sense of failure in which the "body lets them down" with "body-image problems" like breast cancer and colostomy. He referred to affective disorders, sexual problems, illness behavior, and cognitive dysfunctions which have been observed in cancer patients and recommended that such deficits ought to be assessed carefully before interventions are started. He proposed therapeutic options ranging from technical (e.g. adjustment of a prosthesis) and relaxation methods, to couple therapy.

Two social workers, Wood and Tombrink (1983) described an educational program for patients and their partners which aimed at providing 1) "understanding of self and body" post cancer diagnosis; 2) "information on altered body-image and its effects on sexuality and emotions"; 3) information about the impact of cancer therapies on "self-image and sexuality"; and 4) to assist participants in feeling comfortable talking about self-image and sexual concerns.

This literature on body-image and sexuality shows conceptualizations in which physical presentation of self and satisfaction in sexual relationships appear to be closely linked. Thus, an almost causal chain of events is suggested: Cancer impacts the body-image through which the self presents, and is seen by the partner and others. Changes in this image have reverberations on the self and its relationships with others as well as on others' relationships to that person. This is quite a visual, mental model of human relationships and therefore, professional interventions tend to be geared towards improving the looks of the body, and/or enhancing insights about oneself and one's relationships.

Hence the need for plastic surgery, education, counseling or psychotherapy. The presupposed goal of such interventions is to protect, restore, or support a self which is threatened or has been damaged, failed or forsaken by a non-compliant body, or by the resulting alterations of its image. Rutherford (1988) stated that "a body-image disturbance relates more to an individual's perception of oneself than it does to actual facts" (p.248). Because body-image issues are thought to be problems of mental self-perception psychological interventions are expected to tap into, and mobilize hidden psychological resources which, in turn, are supposed to enhance patients' insights into and acceptance of their situation. Psychological interventions are designed to enable patients to feeling better about themselves. Moreover, improved self-esteem ought to enhance intimate relationships. The inclusion of partners in therapeutic approaches such as delineated above (Wood et al. 1983) underscores conceptual body-image-self-sexuality-other links.

Yet, the lived reality of a mutilated or ailing, embodied human being in a complex world hardly penetrates these conceptualizations. Perhaps more than in all other of the reviewed writings, Goldberg et al's (1984) study alludes to a variety of meanings within the same cultural background: The mutilated body need not exclusively be understood as a person's primary and exclusive image projected to self and others. The tendency to focus so strongly on body-image and its psychological impact on (intimate) relationships easily distracts from the existential and practical quests which show up in daily life, once people are faced with a potentially fatal illness such as cancer.

As long as humans are understood to be just a bio-psycho-social entity endowed with a developing self actively striving for life quality, Foltz's (1987) categorization of nursing research may make sense. She reviewed 78 studies which investigated the effects of cancer on self-concept and life-quality. Foltz reported their major findings under headings stemming from her own conceptualization of person/patient. She differentiated two "body compartments", comprised of a "functional self" and "body-image"; an "interpersonal compartment" composed of a psychological and sexual self; and distinguished "achievement" as well as "identification" as further components of the self.

The studies thus far reviewed may be subsumed under one aspect of Foltz' idea of body compartment, namely body-image, and allude to the psychological and sexual self of the interpersonal compartment. In the following sections, literature contributing to the concept of a functional self, as well as opinions underscoring the achievement and identification components will be discussed.

The Functional Self: Bodily Systems and Functions

Acknowledgements of cancer and its therapies' effects on body systems are abundant in nursing literature. Local impacts are differentiated from systemic ones and immediate consequences distinguished from late effects.

Discovery of local changes in the breast and women's responses to such detection were studied by Lierman (1988). Through a semi-structured interview guide she elicited information from 20 women. Content analysis provided behavior categories which then were correlated with demographics and assessed for group differences through ANOVA testing. She found a strong tendency ($p = 0.033$) among older (age 65 and above) women to delay early seeking of professional help. Lierman pushed nurses to develop strategies which would make women change their appraisal of discovered breast changes towards urgency and thus, allow for early detection and enhanced chance of survival.

Benedict (1989) found "physical aspects" besides psychological and interactional ones in 30 patients' experiencing lung cancer. Physical pain, disability, changes in appearance, nausea and vomiting, bowel problems, coughing and weakness/fatigue caused "very much" suffering in 50% and "a lot" in 10% of a sample of 30 patients. No suffering was reported by 17%. Physical suffering contrasted with 27% who suffered "very much" in the psychological and 3% in the interactional realms, in which 39% and 73% respectively had not experienced any suffering.

In their study of "patients' descriptions of the influence of tiredness and weakness on self-care abilities" Rhodes, Watson, and Hanson (1988) found that patients experienced a host of 16 "symptoms" which interfered with their ability for self-care. All of these symptoms had physical roots or were related to the body's ability to move and act.

Padilla and Grant (1985) developed a tool for self-assessment of strength, appetite, work, eating, sexual satisfaction, sleep, fun, satisfaction in life, and feeling of being useful. These items are scored on a Likert continuum from "none" to "normal for me". Pain, nausea, vomiting, general quality of life and medical costs are similarly assessed between "none" and "excruciating". In this questionnaire a "me" replaces the abstract self and the body is implicitly, although fractioned, present. Of course, Likert-scales limit variation and patients' experiential accounts, but the questionnaire contains allusions to how an embodied me might live.

In these reports, the body, parts or functions of it, are brought in relationship with seeking medical attention, suffering, self-care, and living every day life. Basically, cancer related bodily symptoms are assessed in their varying influence on certain aspects of daily life. Implicitly, these articles present the body's pervasive impact on all dimensions of human activities and relationships.

There is, however, a difference in what Lierman (1988) wanted to achieve through nurses' intervention and what nursing care ought to attain in the view of the other authors. In order for women to seek early professional advice, after having detected a change in their breast, they must intentionally attend to their body and breast and assign them with specific meaning in order to initiate the action (early professional help seeking) nurses expect of them. This asks for a switch in consciousness, from a pre-cognitive state of having/being a taken-for-granted body, to rationally grasping the fact that this body may be vulnerable. It is essentially this mental switch which takes place in the passage between health and illness. Without doubt, this is a difficult transition to live through for any person. On the other hand, reducing suffering, enhancing self-care, and improving quality of daily life are all goals in which, for their attainment, the body once again needs to become absent from patients' mental consciousness. It would have to resume its previously held oblivious, taken for granted existence.

Present day nursing concepts of mind/self-body relationships fall short in acknowledging the paradoxical mystery of living bodies: Their existence in, and simultaneously being basis for several changing levels of self- and world-awareness. Perhaps, some inadequacies of nursing interventions result from the pervasive underlying assumptions that education can influence the mind-body interplay through empowerment of the mind. If only the body, like other objects, could get the mind's attention if warranted, and then be easily pushed out of mind when its needs are taken care of!

Attending to physiological needs has long been one of the major tasks in nursing. Physiological late effects of cancer treatments are recognized by, and concern nurses. Ruccione and Weinberg (1989) gave an extended overview on "body systems", cardio-vascular, musco-skeletal, gastro-intestinal, respiratory, kidney-urinary, hematopoietic, vision, and hearing, which suffer from biologic late effects of cancer treatments. Late effects on the endocrine system were described by Hobbie and Schwartz (1989), on the central nervous system by Kramer and Moore (1989), on the immune system by Mulvihill and Byrne (1989). Fraser and Tucker (1989) described second malignancies from cancer treatments. There cannot remain any doubt about cancer treatments' potentially totalizing effect on the human body and through it, on every day activities and life quality. As possible interventions these authors proposed education, monitoring, counseling, prevention through vaccination and hydration in certain cases. Furthermore, the removal of damaged body parts and their replacement through transplantation, prosthesis, or aids were considered. After having been diagnosed with cancer and subjected to therapies which alter cellular biochemical life-processes, the body is ascribed with machine-like characteristics: Periodically it has to be checked, some of its parts have to be reinforced, others replaced.

So far, cancer and its therapies' impact on the person have been shown to affect what reductionistically is called "body-image" and on body parts and functions. Or, in Foltz' (1984) terms, on "body compartment" and the "psychosocial" and "sexual" self of the "interpersonal compartment". We have yet to trace how cancer illness may affect "achievement" and "identification". Both these psychological notions are conceptually linked to the self and are assumed to contribute to quality and mastery of life. Therapeutic movements such as Simonton (1978) and Siegel's (1986) have been reported to assist patients in mobilizing hope and promoting feelings of achieving some control over lives which seemed out of control. These therapies are geared towards the mind-body interface. Among nurses such therapeutic approaches have generally been well received and are used in certain circumstances.

At the Interface Between Body and Mind

In the minutes of a 1922 meeting of the French association "Lutte contre le cancer"[2] the following statement was recorded:

> Science does not know any remedy which could bring back to obedience the cancerous cell spread by this mysterious ill of anarchic proliferation (Pinell & Brosset, 1988, p.598).

This image of cancer as a disease of non-compliant cells is still with us today, but it became enriched with psycho-emotional attributions such as cancer being "despair experienced at the cellular level" (Hutschnekker, 1951). Carter (1989, p.200) drew strongly from the psychological tradition when she imputed cancer with the meaning of an "embodied form of protest" in the lives of breast cancer survivors.

Siegel (1986) underscored that very psychological approach by holding that early "psychological shaping" plays a determining role in, when, and where (organ, system) a serious illness will hit (p.85-99).

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[2] fight/battle against cancer

Additionally, he alluded to other generating or contributing factors by emphasizing that not all of cancer's complex causes are in the mind, but that genes and carcinogens play important roles as well (p.103).

Nevertheless, the mind appears as central in Siegel's work, while the body seems to put into life what a convincing mind asks it to do. He persuaded his readers that cancer is not a death sentence if there is a will to live. Cousins (1985) called this will a "physiologic reality with therapeutic characteristics" (p.44) and Jung (1955) attested such will to be much more than just conscious: It needs to be of the dimension of a "life-instinct". To Siegel, hope is not a statistical, but a physiological phenomenon. In his therapeutic approach, Siegel (1986) asks his cancer patients four questions: 1) Do you want to live to be a hundred? 2) What happened to you in the year or two before your illness? 3) What does the illness mean to you? and 4) Why did you need the illness?

Simonton (1978) claimed that we develop "disease" for "honorable reasons" and that blaming the victim is a wrong stance to hold. Through disease our body tells us not only our physiological, but also our emotional needs. Siegel and Simonton share the view that there is a continuous, unconscious dialogue between mind and body and that this dialogue more often than not, evades conscious or verbal capture.

The languages of the unconscious are dreams, imageries and drawings. In cancer therapy, these phenomena are used to gain insight into the illness process and prognosis. Simonton (1978) introduced guided imagery and visualization as therapeutics for cancer patients especially while undergoing RTX and CTX. Siegel's (1986) therapy groups work on "embodying the mind" through meditation, "effective belief", nutrition, exercise, play and laughter. Relaxation, meditation, visualization, and hypnosis are meant to "focus the mind for healing". He attributed to faith strong powers: Cancer treatments chosen and believed in by the patient have high healing potentials. Three fourths of the time, CTX and RTX side effects, in Siegel's view, result from "patients' negative beliefs, fostered by a destructive kind of hypnosis on the part of the physician" (p.132). (This stance underestimates or ignores the chemical and physical destructivity of these agents.)

Siegel understood death to be a form of healing. "When patients whose bodies are tired and sore are at peace with themselves and their loved ones, they can choose death as their next treatment". He held that they are "choosing to leave their bodies because they can't use them for loving anymore" (p.207/208). Death thus means no longer failure, but a "natural option".

Both, Simonton and Siegel attributed to certain patients the power to view their illness in a positive light, to assume their own responsibility and thus, to mobilize their dormant resources for gaining recovery and restoring health. Clearly, they portrayed a dualistic picture of mind and body. However, they conceived of the body as a mindful, wise partner and resource to a mind who does not really know, out of itself, what is good for the whole being. Emphasis is given to non-conscious embodiment of the will to live and a clear, but not always readily understood dialogue between an asking mind and an answering body. Yet, the final "decisions" seem to be made by the mind; perhaps, but not explicitly, in conjunction with the unconscious, embodied "life-instinct"? Implied is that, once the body cannot any longer be <u>used</u> for loving, time for dying has come.

There are strong notions of achievement and self-identification (spiritual and religious dimensions of the self (Foltz, 1984)) in this approach. The message of these authors' psychological position is ambiguous. Are body and mind, even though separate units, at least equals? No. The body is afflicted with cancer because the mind (self) did not pay enough attention to its whole existence. The mind uses the body to learn from its wisdom as it uses it for loving, working, and achieving any other of life's goals. Indeed, if the mind takes into account the body's wisdom, it in turn can help ridding it from cancer. Such healing can be accomplished through life changes, "effective" believing, enhanced internal dialogue in dreams, meditation and imagery. The mind thus complies with the body's demands for the sake of achieving conflict resolutions, healing, and a better, longer life. But once, when on life's balance sheet, "the cost of living" overrides "the rewards of life" (Siegel, 1986, p.206), the body is not used any more and can be left behind.

Simonton and Siegel's stances paradoxically inspire hope, faith, courage, satisfaction, and even pride if self-healing is "achieved"; self-doubt, guilt, and possibly despair if the illness fails to respond to the mind's endeavors. Their approaches are among the most powerful that modern psycho-therapeutic and self-help movements can offer.

However, transpiring assumptions of the feasibility of cancer cures (by using the right techniques such as attitude, will, relationships, diet, exercise in addition to medical treatment) mirror a psychotechnological understanding of disease as if it was a problem to be solved. Furthermore, philosophically, we are left with an utilitarian view of the body and profound problems of guilt.

The mind-self (because of implied mental deliberation, I shall use mind and self interchangeably here) comes across as a calculating, goal oriented, efficient strategist, e.g. belief has to be "effective". Of course, the self's life is dependent on the body. As long as the mind wants to live it must accommodate self with the body. This implies an adversarial relationship between self and its body. Through illness, the self had learned that something needs to be changed if life ought to go on. Therefore, it turns to a previously neglected source of wisdom: The body. The body is at the disposition of the mind: Its messages, subtle in dreams and images, but quite out of control, or despairing in form of malignant growth, will be heard if the mind is willing to listen. Self-healing is assumed possible, if the internal dialogue between mind and body improves to the point at which the body responds (obeys?) to the mind's changed attitudes towards self, body and life. Bodily wisdom thus serves the mind to learn about self and living.

In short and overstated, the position holds that the way the mind uses this knowledge will determine its own fate: Living longer and with high satisfaction is possible if love is lived through the body. Alternatively, death will occur sooner to end an unhappy life in which love was not lived.

Knowledge about the body: To what ends? Answering this question may help to summarize the diverse body conceptualizations thus far discussed, and their influence on the care of cancer patients.

Knowledge of Domination

Through the major thrust of its professional literature, nursing portrays itself as serving patients and clients, in times of breakdown, to regain strength, knowledge and will to achieve their individual goals. In this regard, professional nursing follows the culture's zest for personal independence, self-reliance, self-authenticity and -actualization, freedom to choose, and achieve one's aspirations. Knowledge generated by and for nurses thus must enable them to provide the therapeutic and managerial care which patients cannot provide for themselves. Since the self, in this culture, is the main individual actor, nurses are concerned about the self in its bio-psycho-sociological dimensions.

Throughout the reviewed literature, nurses' concern about the psychological well being of the persons under care shines through. Besides cancer's impact on self's psycho-social dimensions, "physical aspects" (Benedict, 1989) were acknowledged to cause "suffering". Not in one of the articles, however, was the body explicitly pivotal, nor was it ever depicted as a whole. With the exception of the body's role as a source of wisdom for the mind in Simonton (1978) and Siegel's (1986) works, the body has to be searched and glued together from fragmented pieces and functions, or from the pathologies of its systems.

A paradoxical feature, the body comes across as a mute addendum of the self and, at the same time, seems to present self, image-like, to others. The body seemingly contains an independent self which uses it deliberately for its purposes. Largely independent from the world around, the self relates to others and self as a psychological entity. The body's part in reciprocal, interdependent and dependent relationships to the world remains elusive in these conceptualizations. Nowhere does the body appear as constitutive of a person's life-world.

Of course, acknowledgement of the body's fundamental significance can be inferred. The shattering impact of a spoiled body-image on the self, its appearance and mainly its sexual relations to others is of concern to the writers. Further, if body parts are missing or bodily functions deteriorating, a mental body-image is assumed to become deficient and therefore the self's integrity threatened or thwarted.

Nursing interventions are geared towards empowering the self to become, or stay as independent from others as possible. Nursing knowledge is generated and used for this purpose. Nursing knowledge and concepts about the body, derived from psychology and (patho)physiology, serve the purpose, it seems, to conserve notions of the body as something like a functional appendix to the self at worst, or a wise servant of the mind at best. In either case, the body is viewed as an object of domination by the mind-self and knowledge is generated to reinforce this relationship.

If there is knowledge for the sake of educating and understanding (Bildung) and to gain wisdom, knowledge of the sage, what might such knowledge look like, if its subject is the body? What understandings of the body can we learn from patients and from nurses who are interested in the body's role in human life?

Knowledge for the Sake of Knowing

> I thought you could tell me if our bodies are given to us as counter-irritants to the soul. I thought you'd know why when our bodies ought to bring surcease from our tortured minds, they fail and collapse; and why, when we are tormented in our bodies, does our soul desert us as a refuge?...Why do we spend years using up our bodies to nurture our minds with

> experience and find our minds turning then to our exhausted bodies for solace? (Milford, 1970, p.245)

In her own way, Rosenblum (1988) reflected on these very questions. She underwent CTX for advanced, inoperable breast cancer. Illness and treatment impacted on her breast, lowered blood counts, made her bleed from the nose and rectum. She experienced extreme fatigue and breathlessness, loss of hair, and the onset of premature menopause. Prior to CTX she had experienced her relationship to the body as "simple, direct, uncomplicated...warm and pleasurable" (p.45). From the drugs, the "sexual language" of her body grew mute. New to her was the body's "language of symptoms", which she learned to monitor. Constantly she was confronted with searching new ways of living in her steadily changing body. Before, she had relied on her body as "the ultimate arbiter of truth", but now felt "thrown into a crisis of meaning". Sensations without anchor in meaning hit her from within (p.49). Her suffering was enhanced through language's limits to communicate what goes on in her body. Rosenblum felt being thrown out of what life had meant to her prior to the illness.

Rosenblum had fallen into a strange reality which defied familiar concepts and language. Body, meanings, behavior patterns, and self-understanding seemed so intricately linked into the whole of being that it appears impossible to clearly differentiate one from the other. Rosenblum never mentioned a body-image in her differentiated experiential account. Medical "symptoms", in lived experience devoid of scientific concepts, became bodily signs of meaning in her search of finding new understandings of self and life.

Gadow (1984) pointed to the difference between viewing bodily difficulties as "symptoms of failure" or "symbols of needs". Symptoms of failure become easily assessed as problems of an adversial body, warranting intervention with the goal to remedy or control them. Symbols of need, on the other hand, allow the body to appear more like "a friend fallen upon hard times". Symbols of need elicit empathy and solicit care in others. Acting out of caring may allow for "touching the self of the patient", thus preventing the self from being driven into alienating isolation from what s/he dependents upon. "Dignity and dependence need not conflict. Dependence upon another for care of the body constitutes an indignity only when the person cared for becomes an object for the care giver" (Gadow, 1984, p.67-68).

Consequences of these two different ways of perceiving the body and dignity in dependence are explicated in a concrete nursing action by Schilder (1986). She studied the use of restraints in acute care.

> When the body is considered separate from the self and the mind, then only an "object" body is being restrained. However, if personhood is considered inseparable from the body and the body is viewed as knower, then restraint of the body as a person becomes less plausible (p.33).

Both nurses, Gadow and Schilder, are concerned about the understanding dimension in nursing which finally is decisive for the attitudes through which all professional knowledge is applied. But, do we know enough about the experienced, knowing body as to gauge nursing actions towards its needs?

Search for Expanded Understandings of the Body

In a study in which they explored "the mundane complaint and the physical self" Olesen, Schatzman, Oroes, Hatton and Chico (1988) found that their respondents did "not reflect views on images of their bodies" and they wondered, if people, e.g. with ostomies, ever experience their body as an image.

Doolittle (1990) who studied patients' experiences in the recovery from stroke did not report one single quote in which people referred to their body as image. One of the big impacts of the stroke was that the paralyzed body side, after having lost its previous nonreflective spontaneity in movements, appeared as needing constant mental guidance. In the words of one patient (p.79): "You always have to think, 'pick it up', 'pick it up', 'bend that knee'". Doolittle heard patients alluding to their affected limbs "in a very detached manner". Yet, she also observed a few incidents in which the whole body (inclusively the paralyzed parts) responded in habitual, flowing movements to a soliciting, meaningful task or environment.

Both Olesen et al's and Doolittle's studies raise questions about lived (not theoretical) self-body relationships in illness and the body's pivotal position in a world which is shared with others. The quest that the phenomenology of self-body-world relations be given intensive considerations in human and social sciences is a recent, but promising development in diverse academic disciplines.

Csordas (1988) demanded that anthropologists take the

> embodied experience [as] the starting point for analyzing human creation of and participation in a world appreciated as already cultural prior to distinction between subject and object (p.2).

Turner, (1984) attributed the triviality of much work by social scientists to their neglecting "the most obvious 'fact' about human beings, namely that they have bodies and they are embodied". Sociobiology, he held, (and psycho-biology might be added), are "blind alleys" as long as they ignore that "biological presence is socially constructed and constituted by communal practices" (p. 227). Strauss (1990) works on describing how shape, functions and capabilities of the human body create(d) and influence the world in which we live.

The Need for Better Understanding of the Body in Nursing

The paucity of phenomenological understandings of the body's involvement in health and illness within nursing reflects the discipline's traditional, close reliance on other academic-scientific traditions such as medicine, physiology, psychology etc. Received views on self-body-world relationships from such disciplines seem inadequate and knowledge derived from theorizing appears easily as trivial or even misleading when gaining some understanding of patients' illness experience is at stake. A practice which takes care of embodied patients not only needs knowledge of physiological processes, but also of the body's pervasive role in creating and guaranteeing the world of daily living.

With the exception of Rosenblum's autobiographical account (1988), breast cancer illness has thus far not been approached on the level of embodied experiences. No studies exist to date in which bodily changes due to breast cancer and therapies are traced as they influence patients' perceptions of their every day reality.

So far, nurses have no other languages to talk about, and to understand the living body than the ones borrowed from psychology/ psychiatry and/or (patho)physiology. Neither of these languages is suitable for gaining an understanding of meanings surrounding the body and embodied life. Phenomenological accounts of embodied breast cancer experiences may add possibilities for nurses to share women's experiences otherwise hardly alluded to.

Summary and Outlook

This chapter explored two major sources of knowledge about the body in professional nursing literature. The psychological concept of body-image is widely used when the impact of physical alterations on the self are pointed out. Bio-(patho)physiological knowledge, on the other hand, is pervasive and utilized for description, explanation, prediction and the treatment of body parts and functions. Assumed relationships between mind/self and body, propagated in contemporary therapeutic movements (e.g. Siegel and Simonton), are made critically explicit. Finally, the claim for a better understanding of embodied living with breast cancer and its treatments is substantiated with an autobiographical patient account, as well as philosophical and humanistic critiques of current reductionistic, predominantly scientifistic body-theories.

The next chapter will give a more in depth picture from whence nursing's current conceptions of the body come and what a more phenomenological understanding of embodiment might look like.

CHAPTER 2

CONCEPTIONS OF THE BODY: A REVIEW OF LITERATURE

The Sisyphean Task of Conceptually Grasping the Body: The Review's Aim

In much of the professional nursing literature, the body is either understood as being mentally represented as an image to a cognizant self, or as a bio-physiological object, often in need of care. Where do these conceptualizations come from? What other understandings of the body may be gained from a literature search?

Reviewing literature with the aim to gain knowledge or understanding of the body is a paradoxical endeavor. Characteristic of the body is its ubiquitous presence and intimate closeness in all of human ventures, yet, it escapes rational consciousness most of the time. Embodied life may be understood as involvement in a present, concrete and specific situation through the living body. Individual history is embodied and so is every day reality. Through our bodies we relate to, and are solicited by, the world in which we live.

Embodiment is both ambiguous and informal. Nonetheless, there have always been conceptual images of the body and ideas about its features, functions, and essence. Such notions have been verbally passed on from one generation to another, as experiential anecdotes and in many forms of art. Basically, any artifact of human industry from prehistoric African sites to modern cities, any tool, machine, piece of art or music, every practice ever enacted by humans, bear witness to those embodied, skilled people who expressed themselves through their creations.

Only recently, by comparison with narrative traditions, have ideas been passed on in written form. One may argue that literature carries the most disembodied, abstract testimonies of all forms of cultural transmissions: Ideas are symbolically represented to the eye and mind. While writing itself is an embodied act, written concepts are bound to contain the most cognitive, abstract notions of embodiment. Therefore, literature must be considered an incongruent medium to reveal what embodiment might be. Why then, should one look into literature for ideas and conceptions about body and embodiment, if it is a comparatively recent, abstract, alienated, and probably misguiding source for understanding the body?

Humans differ from animals by their linguistic capacities. Whereas animals communicate with each other primarily through their bodies, people can use words to talk to each other <u>about</u> the body, much as ideas about other things or objects are exchanged. Written narratives and thoughts serve as pervasive, often implicit records of different ages' embodied, cultural self-understandings. Whatever the subject of a document's discussion, allusions to contemporary or disciplinary ideas of embodied reality can be inferred from it.

Literature is comprehensive. It includes the whole gamut from vernacular speech, "the embodiment of verbal thought" (Csordas, 1988, p.37), to abstract mathematical conceptions of perceived reality. Texts talk to the reader <u>about</u> feelings, thoughts, concepts, behaviors etc. as they appeared to writers in different times and diverse places.

Needless to say, it is a presumptuous, impossible task to review exhaustively, "pertinent" literature in the field of body and embodiment. Since there is virtually no non-pertinent literature to the subject, this literature review must remain wanting. Positively seen, it resembles a few randomly found fir-needles transported by one ant to an anthill. Or, to use the introductory metaphor with its allusion to futility, this review will pour more water into a bottomless barrel.

Yet, it is my aim in this review to paint, in broad strokes, a picture of major intellectual themes that contributed to shaping modern Western notions of the body. Included are ideas about mind-body relationships, body-image, and embodiment. For this purpose I shall trace anthropological, philosophical-religious, historical and scientific schools of thought which contributed to contemporary bodily self-understandings.

The Body and Society: Anthropological Views

Anthropology was early among social sciences to show that the body is culturally shaped. "Physical experience of the body, always modified by the social categories through which it is known, sustains a particular view of society" (Douglas, 1970, p.93). The body has inspired both people's understanding of the world they live in and cultural conceptions of what it means to be member of a certain society.

The body has served as symbol and matrix for understanding the cosmos, geographic environment (Bastien, 1978), and social order. Certain societies built their homes or villages to represent the main features of the human body (Griaule 1965).

Modern English retains symbolic bodily allusions such as "head of state", "head-nurse/master", "mother-tongue", "heart of the city/nation", "arm of law", "arm of the sea", or "blood of the or bleeding nation", to refer to organization, or national, institutional, and geographic features. Metaphorically, head symbolizes a hierarchical top, heart implies center, both in terms of geography as well as activity and center of life; arm alludes to mobility and intervention, as in arms as weapons and branching as in extensions from a center. Blood refers to life essence and existence, and tongue to speech.

Not only does the body shape social structures, but social practices and language in turn shape, from very early on, the individual body and its relationships with the surrounding social world. Caudill and Weinstein (1972) found in their study that, as early as at the age of six months, children behaved culturally, as either Japanese or Americans. Testimonies are countless to show how an individual's place in society becomes symbolically defined by body paintings, ornaments, garments, perfumes, and other accessories. Information about a person's social and marital status, age, gender, his/her participation in secular or sacred work, as well as group or caste membership is displayed by the body's "social skin" (Turner, 1980; Strathern & Strathern, 1971). Although the "social skin's" message may be ambiguous, it is powerful and usually weighs heavier than words in social interactions. Yet, social impact on the individual body does not stop at the skin.

Bodily decency is largely defined by social norms. Rules convey, mostly non-verbally, when, where, for whom, and under what circumstances laughing, crying, whistling, singing, moaning, groaning, sneezing, sniffing, coughing, breathing noises, spitting, sipping, smacking, belching, eliminating, or showing one's nakedness is allowed, tolerated, or forbidden (Elias, 1939/1976; 1939/1978; Vigarello, 1988). Douglas

(1970) proposed conceptualizing social climates as ranging from dimensions of weak to strong pressure with "strong social control demand[ing] strong bodily control". Further, she held that social systems which strongly control the individual body tend to "disembody or etherealize the [body's] forms of expression" (p.100). There may indeed be no bodily expressions, nor secretions which are not, in one form or another, culturally interpreted or judged. In other words, bodily features such as discharges, sounds etc. "exist" only in their cultural interpretation.

Scheper-Hughes and Lock (1987) viewed the body as both, a "physical and cultural artifact" and conceived boundaries between these two conceptions as blurred (p.19). On the side of the "physical artifact", the body's biological processes are accepted to be universal and understood to follow nature's laws. Weinberg (1974, p.43) described these laws "as impersonal and free of human values as the rules of arithmetic". Yet, in its presence as "cultural artifact", conceptions of physiological universality and the "normal nature" of bodily appearance or functions get easily muddled.

For example, until their valley became accessible through the railway around the turn of the century, the inhabitants of the Loetschental (Switzerland) thought that goiters featured a normal, healthy body. They pitied people "without throats". Similarly, in an African population where schistosoma was endemic, normal urine looked red and people whose urine was yellow were considered sick.

Indeed, as soon as physiology is interpreted in its relevance in every day life, the grey boundaries between nature's neutral, universal laws and culture's assigned (non)significance and specificity are crossed. A culture's given, taken for granted concepts of body and embodied life are usually reinforced as "being natural" (or God-given), thus implying their being "true" and unchangeable.

"Natural", social roles of embodied genders, for example, have been derived from anatomico-physiological differences. Keller Fox (1985; 1989) challenged the scientific community by charging that it was this (Western) scientific culture's invention to "make" phenomena like the body "natural". Once "naturalness" was scientifically supported, it could be enforced as irrevocable, neutral truth and thus became a powerful tool for maintaining a social order of gender inequalities. Scheper-Hughes and Lock's (1987) conceptualization allow for the body to be seen as the pivotal point on which universal, lawful physiology, cultural "nature", and social order meet, and/or clash.

For Western health care providers and patients alike, the taken for granted body is easily conceived of as "natural", rather than culturally endowed. Cultural messages on its being "natural" are pervasive and conveyed so early in life, that they may remain non-conceptual. Moreover, universal anatomical and physiological concepts or parameters enhance people's understanding of the body as being a "natural" given.

In the forthcoming sections of this chapter I intend to show how Western culture's "natural" concepts of the body grew out of changing philosophical, social, and scientific ways of thinking. It is of interest to look at some Western philosophical premises which influenced the social constructions of the modern human being.

The Western Philosophical-Religious Heritage

"Questions about the body are tied to questions about life, death, and soul..." (Kass, 1985). Not only appears the body both as culture and nature, it also exists simultaneously as experienced immediacy without reflected self-division and consciously, in various degrees, as separated from self. In its position somewhere between lived self-evidence and theoretical confusion, the body has been either ignored or assigned certain relationships to soul, spirit, mind and/or self, as well as to its surrounding world in Western religious-philosophical thinking. Mainstream philosophical traditions emphasized the elucidation of rational approaches to knowing truth and life. Other movements maintained, in Pascal's words, that "the heart has its reasons that reason does not know", or

> that in matters of perception, everyday knowledge, and action, finite human beings had no access to basic elements and rational first principles (Dreyfus and Dreyfus, 1986).

Both strands of thought, sometimes intertwined, are part of the following review.

Religious Theories of Bodily Relationships

Genesis (2,7) holds that the body, analogous to dust and earth, became alive and ensouled alone through the Creator's breath. Genesis 3 further reports that the body's nakedness was recognized by Adam and Eve after they had lost their innocence of being integrated into a larger creation previously beyond their own reflection. It was through their capacity to <u>think</u> and to <u>know</u> the difference between good and bad, that their body suddenly appeared as wanting and in need to be covered.

Two interrelated messages concerning the body are entailed in these accounts: One, thinking and cognitively knowing thwarts the paradise-like immediacy of embodied self-other-world relations; and two, once that immanence is broken, the body may appear to the cognizant mind as incomplete, thus requiring heedful interventions. In innocent embodied, ensouled immanence, self and world appeared as perfect and whole, yet controlled (animated) by a power beyond self. By conceptually dismantling the body from its intuitive, existential relationships to self and the surrounding world, much of the body's decisive power (and God's omnipotence) could henceforth be assigned to a knowing mind, which consequently gained the ability to deliberately control and utilize both its own body and the world.

Paul's (1. Corinthians 6,12-20) dual concept of the body reflects clearly, on one hand, an expected, bridling spiritual supremacy over sinful "flesh" (fornication). On the other hand, he conceived of the "body" as a "temple of the Holy Spirit", a gift from God. In this body-spirit dichotomy the body falls short twice: 1. Bodily power, "the flesh", appears in no other capacity than as debauchery and therefore, in need of mental/spiritual control. 2. The "body" becomes reduced to serve as a vessel to the spirit. Through the spirit's sanctity, however, the body may be purified to become holy as well. Yet, both notions retain the idea that the body is animated and ensouled with the capacity for both evil and good.

From its Judeo-Christian roots Western philosophy inherited a strong tendency, from a spiritual mind's perspective, to look down on an ensouled body with ambiguous potential. If left alone, the body appeared as impure, inferior, and in need of mind/spirit-full interventions for its improvement and purification.

<u>Philosophical Theories About Mind-Body Relationships</u>

In the Greek-Occidental traditions which based their endeavors on Socrates' preoccupation with understanding reality rationally through analytical and theoretical deduction, the body became devalued and mute because it defied the very rules by which reality seemingly operates. Dreyfus (1979; 1987) reiterated five essential characteristics of theories: Explicitness, universality, abstractedness, discreteness, and systematicity. Involved bodily intuition and spontaneity can never be made fully explicit. Embodied culture, tied to place and time, defies universality. Embodied meanings, constituted by specific contexts, evade abstraction and cannot be captured by discrete, "isolable elements". To the extent that the lived body resisted sysmatization into one neat theory, it provoked philosophers to neglect it as a non-mental, material appendix to a powerful mind.

Descartes (1641/1986) worked Socrates' position out by explicating his ideas of the body-mind relationship. He wrote in his Sixth Meditation:

> On the one hand I have a clear and distinct idea of myself, in so far as I am simply a thinking, non-extended thing; and on the other hand I have a distinct idea of body (corpus), in so far as this is simply an extended, non-thinking thing. And accordingly, it is certain that I (my soul, by which I am what I am - added French version) am really distinct from my body, and can exist without it (p.54).

By separating the thinking soul/mind from a non-thinking, material body he intended to verify that "the decay of the body does not imply the destruction of the mind" (p.10).

In Descartes' interpretation the mind became fused with the "noetic" part of the (antique) soul (Mauss, 1938/1985) to become the immortal dimension of human beings. Descartes still alluded to the "vegetative and sensory" dimensions of the soul, which animate the body and die with it (see p.17,18,30).

Kant's assumption that ultimately an universal "categorical imperative" guides, willfully and morally, all human actions, leaves out any consideration of the body's paramount role in human activities. By assigning the individual mind and will the exclusive responsibility for (moral) action, embodied, situated relationships must either be neglected or appear as thwarting the very intentional purity of willful action.

It seems as if, starting with Descartes, a mind was created in which thinking and knowing became disembodied and segregated from believing through a loss of valuing the body as being's ensouled, intuitive foundation. This rational, knowing mind stands against a non-thinking, therefore not knowing, dull, material body, deprived from its mind-soul component. From now on, this body could be studied, judged, and if needed, repaired, dominated, exploited and made docile (Foucault, 1975). Furthermore, in the explicitness, universality, abstractedness, discreteness and systematicity of biological sciences the organism became easily objectified by removing it from its lived relationships. At the same time and independently, once it too became object for scientific studies, a disembodied, etherealized mind/psyche gained credence as a construction with normal and/or pathological traits (Foucault, 1962/1987). These scientific divisions and the loss of ensouled wholeness would be extremely difficult to reconcile.

The development of biological sciences and industries for the sake of maximizing bodily potentials was further influenced by utilitarian intentionality promoted by thinkers such as Hume, Bentham or Mill. Concerned with the value of things and their potential benefit to those interested, utilitarian thinking enhanced the production of any good, bodily assets not excluded. Viewed through utilitarian glasses, the body presented itself as yet another resource for enhancement or exploitation, be it, on the individual level, as a source for magnified pleasure or wealth, or, in Marx' sense, for the benefit of a larger society, as a tool for work.

Much in contrast to the "philosophical uniqueness of Eastern thought", namely the conviction that

> true knowledge cannot be obtained simply by means of theoretical thinking, but only through bodily recognition or realization,...that is, through the utilization of one's total mind and body (Yuasa, 1987, p.25),

most Western philosophical theories inflated the mind's relevance in processes of knowing and acting by disembodying it. In Taylor's words (1989, p.145):

> Coming to a full realization of one's being as immaterial involves perceiving distinctly the ontological cleft between the two, and this involves grasping the material world as mere extension. The material world here includes the body, and coming to see the real distinction requires that we disengage from our usual embodied perspective...We have to objectify the world, including our own bodies, and that means to come to see them mechanistically and functionally, in the same way that an uninvolved external observer would.

It was Kierkegaard who pointed to the impossibility of trying to live a fully deliberate, explicitly planned, and chosen life (1843/1959). In his notion of world-defining, committed involvements he alluded to that embodied, never fully explicit, yet meaningful reality which makes up much of daily life (1843/1974).

Central in Heidegger's reflections (1926/1984) on "Dasein" (literally: being there) were phenomena which constitute "being-in-the-world", e.g. attunement (Befindlichkeit) or care. Despite the fact that the body is at once source and condition for "being-in-the-world" through the qualities of its attunement or care towards the world, it remained largely unacknowledged in Heidegger's thinking.

Merleau-Ponty (1962/1986) challenged disembodying and body-neglecting philosophical approaches likewise by conceptually endowing the body with "intentional tissues". Where Kierkegaard and Heidegger implied a perceptive, constitutive and knowing body, Merleau-Ponty explicated its relevance in embodied involvement with one's situation[3].
In a similar vein, Buytendijk's phenomenological studies were concerned with qualitative distinctions in the embodied realm where mind and world become one. He wondered if perception ought not already be interpreted as a form of encounter (1958, p.67/68). He thereby implied embodied reciprocity between self and world as already being there (not separateness to be overcome) between a lived situation and self. Moreover, in his reflections on "grace" (Anmut) in movements (1956, p.358) Buytendijk pointed to "ease" (Ungezwungenheit) as a mind-body relationship in which neither the spirit (Geist) coerces the body, nor the body constrains the mind. Bodily grace, it seems, has some similarities with Mauss' (1938/1985) three-dimensional soul which had been lost in the pursuit of a rational mind.

Judeo-Christian conceptions of the body were ambiguous. Holy and

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[3] Merleau-Ponty's work is reviewed in more depth at the end of this chapter (see pp.86-91).

profane, powerful and in need of spiritual bridling, ensouled with the capacity to be pure and sinful, the body appeared as a force to be reckoned with. Under the influence of rationalism and idealism the body slowly vanished into intellectual obliviousness.

The phenomenological body's mere absence in Western philosophy led to a dangerous narrowing in the understanding of lived reality's complexities. As if mirrored in an individual's (Daniel P. Schreber) schizophrenic experiences (Sass, 1987), philosophy tended to conceive mental representations as identical with reality (Kirmayer, 1988) and amputated bodily presence from the realm of acknowledged (mental-psychological) experiences. In the case of Schreber, a strange reversal of mind-soul-body relationships had seemingly happened:

> ...Physical inhibition due to intense self-consciousness is a concrete illustration of one of Foucault's generalizations about the modern, panoptical age: for here, quite literally, "the soul is the prison of the body" (Sass, 1987, p.145).

Western religious-philosophical traditions vacillate on a conceptual continuum between mutually contradicting notions of relationships among body, soul, and mind: The ensouled body containing a spiritual mind stands against a material appendix captivated by a psyche-soul-mind.

Contemporary explicit acknowledgement of bodily relations to its "life-world" (Schutz, 1964) broadened the scope again and gave impulses to overcome rational impasses. Furthermore, recent popular and therapeutic movements re-introduced mystic Western, as well as Eastern philosophical notions, such as native Americans' traditional understanding of an animated, shared life space which cannot be abused without harm to the exploiter (Seattle, 1951), or the principles of Yin and Yang. The life principle of Yin (feminine, dark, flowing, weak, etc.) and Yang (masculine, bright, concrete, strong, etc.) entail, enrich, complete and encompass each other to build a whole rather, than opposing or excluding one another as is the tendency in Western thinking (Capra, 1975; 1980). While divergent in their world-views, these trends have one common feature: They attempt to bridge dichotomies and value integrative, systemic over analytic thought.

Our philosophical heritage leaves us with dichotomies, paradoxes and contradictions: Conceptions of an embodied mind and the mind's independence from a body and ideas of an animated body as well as an organism to be objectified through scientific inquiry live alongside each other, often in the same person. The mind's power over the body is widely assumed, yet in instances of illness, the body's impact on the mind easily puzzles that mind. The body's soul-less nature is as confusing and counter-intuitive as the mind's sublime body-lessness and either's detachment from its life-world must appear as eery to a cultural outsider.

Interestingly, these incongruous puzzlements did not impede the social construction of a modern body and person. Rather, they may have inspired and enhanced it, since they are integral parts of modern self-understanding. In the next section I shall deal with the social construction of the modern body and thereafter introduce a few concepts of mind-body relationships as suggested by the psychoanalytic school of thought.

The Social Construction of the Body

From the above outlined philosophical background flows a reality with minimal to no explicit credit as to the body's presence in everyday life. Berger and Luckmann (1967) recognized exclusively the "common intentional character of all consciousness" (p.21) as the shaper of everyday reality.

> The world of everyday life is not only taken for granted as reality by the ordinary members of society in the subjectively meaningful conduct of their lives. It is a world that originates in their thoughts and actions, and is maintained as real by these (p.20-21).

Part of this taken for granted reality is, of course, the body. If interpreted literally, the body would be nothing but a product of thought and actions. Paradoxically, the body is both: In public and individual consciousness it is the (social) product of feelings, actions, and thought and, phenomenologically, it is the producer of feelings, actions, and thoughts through its responsive relation with the world (Collins, 1985). The social creation of the modern body evolved slowly, following changing social practices rather than philosophical thought. The next paragraphs will introduce notions of the pre-industrial, the industrial, and the medicalized body.

The Pre-Industrial Body

The creation of the modern body cannot be understood apart from changing socio-economic circumstances of the time, nor can these political circumstances be appreciated without a notion of changes in perceived embodiment. The body in the predominantly rural world of pre-industrial Europe was conceived to be open towards and communicating with the world. "Such a body, composed of fertile depths and procreative convexities is never clearly differentiated from the world but is transferred, merged, and fused with it" (Bakhtin 1965/1984, p.339).

Duden (1987), a 20th century historian, tried to re-perceive a pre-modern body through the study of historical sources, by immersing herself in the "body-interior of women" who lived in Germany around 1730. She relied on a physician's 1816 case stories with verbatim recording of complaints from 1650 different women whom he had counselled or treated between 1719-40. She experienced this submerging task as an almost impossible undertaking since she had to give up the majority of her basic, taken for granted, modern assumptions of bodily features. Without her effort to give up contemporary self-understanding she would not have been able to make convincing sense of that time's very different, and to moderns quite strange, medical practices, such as the spatially distant relationship between the suffering women and Dr. Storch. He often did not see his patients in person and almost never saw or touched the ailing parts of their "flowing" bodies.

As a representative of his time, anatomical knowledge served the physician exclusively for the dissection of corpses. In contrast, the living body was known by him and his "complaining women" as internally and externally flowing. Through the body's external flows, inferences could be drawn about the internal flow. Illness always meant some stagnation, sluggishness or even petrification of the internal flow. Thus, blood letting or purging were remedies which could "entice", through external flow, the interior flow to flow again. The women's complaints did not contain "categories of health or life, sexuality or reproduction" nor did they refer to their body as a possession (Duden, 1985).

Disembodied abstractions of an economic or scientific body had not yet touched these women's perceived lived embodiment. Interestingly, the physician shared the women's notion of that lived, flowing body. He used his scientific knowledge only in post-mortem research on the corpse. The living body, to him, was still a "barrier to knowledge" (Sullivan, 1986), which could hardly be looked at, or touched, let alone dissected. The body and its flows contained meanings of deep ambiguity. Further, the body was powerful to expel fluids or growths including children which could only be identified with certainty once they saw the light of the day. The "monthly flow" for example was neither clearly nor exclusively associated with women's menstrual cycles. Men could bleed regularly through hemorrhoids (the "gold vessel") as well, and the "monthly" could flow in form of pus or hemorrhage from body openings other than the vagina. Thus, menses were not perceived to necessarily stop during pregnancies or in old age (Duden, 1987).

The body's openness and communicative capacity with the surrounding world, the ambiguous, often paradoxical or grotesque qualities of its parts, excretions, or functions were characteristic of life, but needed not necessarily cease at death. Death and life were not yet mutually exclusive dichotomies. Bodily relics from saints, e.g. a drop of milk or sweat, a finger, tooth, head, or hair could be venerated for their capacity to help the faithful (Bakhtin, 1965/1984 p.349-52). Dead bodies were covertly dissected "in great fear of the dead" in the shadow of the night (Foucault, 1975). How could this boundary-less, ambiguous, mysterious body ever become a discrete, normative, highly predictable, orderly organism, structurally congruent with the corpse?

The Industrial Body

With the advent of industrialization around the 1780's and, somewhat later, with mass production, bodies worked machines in factories and at home. A new human nature had to be created in which an organism could be timed and task-oriented rather, than to follow the seasons' flow and needs in agriculture. Work and life separated and, since time had become money, the "secular currency" (Helman, 1987; Lakoff, 1989), organisms had to be used efficiently (Thompson, 1967). Similar to machines, organisms had to produce and reproduce. Also, they became easily interchangeable.

The close proximity of organisms in factories and urban dwellings begged for sanitation and the creation of the modern concept of health. In order to be economically productive, healthy organisms needed protection from a host of penetrating impurities and others' ill-making bodily products. Of course, those who offered protective and curative services asked for monetary remuneration.

In an environment now perceived as full of potential pathogenic influences, organisms required protective boundaries. Discrete one from another and from the world, closed and contained, the healthy individual was expected to develop perceptually clear body-boundaries (Bakhtin, 1965/1984)). As separate units they could be better controlled for punctuality, efficiency, and cleanliness. Depending on industrial needs, organisms, like other tools, could quickly be dislocated by transportation without use of their own energy resources. Enough bodies in good health, available wherever needed for cheap and efficient labor guarantee(d) production and lucrative incomes to the entrepreneurs

(Callagher, 1986; Ong, 1988). "'Homo economicus' was endowed with a biologic body which reflected the economic division of labor" (Duden, 1987, p.43).

However, in order for these biologic organisms to function well, they had to be properly maintained and kept fit (Illich, 1986). Knowledge of how to accomplish this came from

> physiology [as] the technology of healthy achievements: of wholesome feeding, good digestion, effective locomotion, sharp perception, fertile copulation etc. (Polanyi, 1962, p.334).

Services sold by people knowledgeable in medical sciences became salient in the endeavor to maintain (re-/productive) populations' good health.

The Medicalized Body

Medicalization of the body is an ongoing process which started parallel to the industrialization of work in the late 18th century. Health had become a new category in life. Organisms needed to be healthy or restored to health. In scientific objectification the body could be scrutinized, its previously concealed interior opened and its contents revealed to the "medical gaze". A conception of "visible invisible" anatomical-(patho)physiological bodily organizations grew (Foucault, 1975, p.170) and with it, normative standards were established, against which bodies could be checked, surveilled, and monitored.

Along with changing conceptions of work and production went a redefinition of male and female roles. The man earned money by working away from home and the woman cared for house and children. With such gender polarization, a new concept of sexuality emerged, having at least two distinct characteristics: The first one being that male and female bodies were no longer seen as similar, namely, the female as having "underdeveloped homologues of male organs". Instead, they became understood as opposites by "nature": With the female organism endowed with a reproductive apparatus, built for reproduction and bare of sexual feelings. In contrast, nature accorded the male body with sexual sensations (Laqueur, 1985).

The second characteristic was that sexuality, above all female sexuality, now became a medical category. Similar to the health of those who engaged in productive work, reproduction needed to be monitored and controlled. Female organisms could not be fully trusted to produce the needed offspring. Soon male physicians began to view the female body as potentially pathologic and in need of professional surveillance. Sexuality became a social and medical category through which mainly children, women, and deviants could be distinctly identified, their character and behaviors explained and, if found sick or aberrant, treatment or correction was ready to be implemented against remuneration (Foucault, 1980).

Today, organisms resemble machines in one more aspect: Medical treatment for malfunction has been supplemented by the possibility to repair breakdown with movable "spare parts". Artificial or "harvested" replacements are available to succeed failing organs or body parts. New is the generation of people whose organisms are "partially artificial" (Helman, 1988) and who wait in desperation for the accidental death of a healthy, anonymous heart, kidney, liver, cornea, or pancreas "donor" (Codoni, 1989). At the core of innumerable medical-ethical dilemmas appears the incommensurable abyss between utilitarian conceptions of a machine-body and notions that bodily ailments are related to life style and the world in which a person lives (Bernstein, 1986).

Descartes' and the Enlightment philosophers' thoughts did not directly lead to those profound changes in body conception that separate the pre- from the industrial body. Alterations in every day working patterns and practices were needed to transform the social and the embodied world. In turn, these changing cultural perceptions of productive life impacted on the emerging bio-sciences with constantly higher demands for managing physical failures.

In a highly structured work environment, bodily structures became more contained, physiological functions perceived to be efficient, purposeful, clear cut, and logical. Anatomical pictures crept into peoples self-perception and images of body mechanics entered education, institutional organizations, and every day life (Foucault 1979). Nonetheless, the body's symbolic and metaphorical power was difficult to eliminate from scientific conceptions. So implied physiology texts into the 1980's that the female body wasted or aborted pregnancies through menstruation - in an utilitarian world waste is negatively valued - while the fact that billions of sperms are produced to fertilize one egg was lauded, not as waste, but as one of nature's marvelous creations (Martin, 1987; p.27-54). Perhaps it was not accidental that female physiology was judged as destructive in sharp contrast to male organs as creating abundance.

Industrial and "naturally" physiological, medicalized organisms fused quite well to become yet another layer on an older whole, open, ambiguous, but theoretically de-souled and mind-less body. Scientific studies of the human mind or psyche became inspired by the wealth of knowledge gained in physio- and pathophysiology. The relationship between mind and body was given increased attention. Out of the psychoanalytic school of thought came major impulses for the creation of that pervasive modern ego or self-understanding, which evolves from a struggle against both nature and culture.

Psychoanalysis and the Mind/Body Problem

Freud (1938/1986) conceptualized the "psychic apparatus" as a structure composed of three "powers": the id, ego, and super-ego. The id, closely linked to the body through its un- and pre-conscious contents represents uncivilized, natural forces (drives) which the ego constantly confronts. The super-ego, on the other side, enacts cultural (parental) values, norms, and orders which impinge strongly onto the ego. Somewhere squeezed in between these two powers, the ego must develop by gaining territory from each side. This development is a tedious struggle, more comparable to war, than to peaceful developmental growth. The healthy ego is meant to represent the unique self as it emerges from this fight, having gained waste territories formerly held by either the id or the super-ego. The ego's ultimate health or self-actualization is its satisfaction in a (socially) acceptable way. Theoretically overstated, ego-health could mean radical independence and detachment from its (bodily) nature and cultural (familial) heritage.

However, life does not allow for complete ego-detachment. Physical facts and their constituting relationship on the ego have been psychoanalytic concerns from the beginning. The body is, in Freud's view, the primary and foremost shaper of the ego. Early sensory-motor experiences are viewed as fundamental for the subsequent development of the ego and for the ego's learning of its object and subject relationships to the world (Torras de Beà, 1987). Further, a close bond between mind (ego) and body is reflected in fantasies and dreams (Laufer, 1982). Goldenberg (1990) argued that "Triebe" (drives, instincts) link mind and body in Freud's theory and that, in contrast to Jungian "archetypal thinking", the (male) body is dominantly present in Freudian psychoanalysis.

Without doubt, bodily parts are basic to Freud's theory on sexuality (1938/1986). The names for all four phases of sexual development give credit to organs through which sexual feelings may be elicited: Oral, anal, phallic in early, and genital in adult life. Sexuality and life sustaining (bodily) drives like hunger, thirst etc., are assumed to be life's urging forces with which the ego has to hassle endlessly. Freud sought the organic basis of ego-psychology in sexual functions rather than in neurophysiology. Mind/body relationships to him were _intentional_ and clearly not determined by neurologic and brain functions (Silverstein, 1985). What role does the mind play in ego's life-long conflict between the bodily id and its own emerging or detaching endeavors?

In Gaddini's (1987) view, which seems incongruent with Freud's notion of the ego's bio-sexual foundations, mental activity is the "most highly differentiated function of the body" and "body and mind are a functional continuum" (p.315) whereby the mind, similar to the nervous system, is extant throughout the body. He suggested that early learning in life is physiological, implying that there is physiological memory, e.g. touch through which bodily boundaries will be remembered. Memory with its two dimensions, physiological and mental, therefore provides the essential link between physiological and mental learning. Physiologically remembered functions, when learned by the mind, acquire a new, mental quality of significance, not present in the physiological. This position seems close to Piaget's (1968) who held that sensor-motor learning falls short once cognitive learning takes over. Yorke (1985) held, again closer to Freud, that "somatic remembering" is rendered redundant when it gives way to verbal recall[4].

Following these views, the more mental, verbal, intentional, thus "mature" the ego grows, the more mute and obsolete the body becomes. This silent body may enhance the ego's illusion of conquering id's drives and come closer to the conscious, "ethereal world" of being it aims for (Binswanger, 1944/1953). In this endeavor of growing out of bodily constraints, the analytic mind is key in doing the fantasy- and dream-work which allows for mental integration of bodily rooted contents. Through analytic work, "what was id, shall become ego". This means that content from fantasies and dreams is mentally comprehended and channeled towards expression, but becomes simultaneously conceptually disembodied. Psychoanalytic therapy, understood in these terms, aims towards transforming embodied contents into rational, disembodied understanding.

Schneemann (1987) held a less traditional psychoanalytic position, namely, that the mind cannot think of something that is totally body- or

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[4] see also cellular model of learning p.77; and Merleau-Ponty's concepts of memory p.87; and habit p.88.

gestalt-less. Spirit (Geist) must incarnate, if it is to become manifest (p.148). Thus, human imagination, thought and memory are gestalt-dependent. The dove symbolizes the Holy Spirit; the flag the nation; the portrait the loved or mourned person; the relic the power of the dead saint. Only through their symbolic embodiment can abstract concepts elicit emotional, embodied responses in the beholder. The mind's inaptness of conceiving pure abstraction may somehow reflect its own body-boundness. Not only is the mind supposed to transmute pre-cognitive id contents into rational thought without being able to think other than in gestalt terms, it is also assumed to be the (exclusive?) keeper of the image of its own incarnation.

The Body-Image

Congruent with psychoanalytic theory is the idea that the mind keeps an image of the body. Schilder (1935/1950) pioneered the concept of body-image. He differentiated the image's three major parts as 1) the outer surface, 2) the openings, and 3) the heavy mass of the body. Through its surface, temperature is vaguely felt and the surface itself feels more or less warm, smooth, and straight. However, its outline is blurred and there are no sharp borders between the outside and the body (p.85). Openings are the body's most important parts. Schilder claimed that psychologically, physical sensitivity is greater at about two centimeters inside the openings than on the surface (e.g. sexual desire is felt close to the opening of the urethra). He proposed that an individual's character can be expressed in the body-image and that it "is almost possible to discern from the body-image how strong the anal complexes of a person are" (p.89). Schilder held that the body's inside is felt as a "heavy mass", a kind of inner emptiness. Further, many neurotic and pathological changes are perceived as alterations "concerning the substance filling the body" (p.93).

The process of body-image development, proposed by Schilder, is complex. First, pain, motor control, and sensations lay the foundation from which body-image evolves. Through sensations (perceptions) and underscored by "intentions, strivings and desires" the ego becomes involved in the creation of its body-image (p.104). Schilder suggested a strong libidinous involvement in this developmental process, but admitted that details of this involvement are yet unknown (p.195). Gymnastics, dance and expressive movements, clothes, body decoration, and postural features contribute to the conscious image, although Schilder wondered which postural reflexes and non-conscious movements enter, and which are excluded (p.207). Second, the body-image can be projected into space: A stick or hat may become part of it. Moreover, voice, breath, odor, faeces, menstrual blood, urine, and semen are still supposed to be part of body-image, even if they have been separated from the body (p.213). Lastly, a crucial component for the creation of the body-image are social relations: Distances to and encirclements by "the body-images of others" influence an ego's body-image. Schilder held that "body-images are on principle social" (p.241).

Several features stand out in Schilder's work. Body-image is a theoretical construct with its foundations in psychoanalysis. Ultimately, the body is mentally constructed and represented in many, complex layers, like threads of a loose web. Those parts of the body and those relationships which are psychoanalytically relevant are retained in the mental image, while pre- or unconscious features, the diffuse "heavy mass" of the body's interior, sensations such as hunger, or bodily reactions to strong emotions (other than sexually elicited) are either neglected or non-existent.

His view of body-image seems to be singular, with a capacity to change over the course of a life. This psychological body-image is contained by boundaries which are only slightly blurred, but when lost or broken, indicate psychotic disturbances.

Still, as in the pre-industrial body, body openings are essential. Their functions, however, have changed. While before, their meaning was to be an exit (Duden, 1987, p.140) for diverse bodily fluids, they now hold erogenic zones to be stimulated for sexual arousal. Indeed, they still discharge substances, but those excretions continue to be part of the body-image. They appear to be a possession of, and symbolically inseparable from the ego. The pre-industrial body-flows went from the inside to the outside, bearing a message to the outside of the body's interior flows. These, in turn, strongly reacted to externally provoked emotional happenings in a person's life. The openings associated with body-image serve two purposes: One, to be stimulated, with a flow towards the inside, and two, to release substances or tones to the outside which psychologically are still thought of as part of the bodily self. It seems as if both these purposes assist the ego's self-centeredness and distinction from the external world.

The concept of body-image vividly reflects the epistemiological confusion around the body and its relationship to "psyche", "mind" or "self". Were its cognitive and psychoanalytic pretense not so dominant, its patchy vagueness and complexity might even reflect some puzzling paradoxes of body/mind ambiguities.

Van der Velde (1985) presented a new concept of body-image. He attempted to clarify the "intolerable chaos" surrounding the construct by proposing that: 1) "innumerable body-images" compose our notion of the body as an entity; 2) body-images are constitutive in the formation of personality characteristics and, 3) that they are "our mental blueprints" for social behavior. Further, "extraneous body-images" serve as the basis of our "concepts of others" allowing for the interpretations of their physical and emotional situation. Body-images are mental representations of prior sensory experiences which include the wide array of "nociceptive, thermal, proprioceptive, visceral, and tactile stimuli that are internally conducted from peripheral nerve endings to corresponding layers in the parietal sensory cortex" (p.528).

Van der Velde corrected Schilder's concept for a multiplicity of changing body-images and recognized sensory stimuli of diverse qualities as important for the creation of body-images. Unfortunately, he did not address philosophical issues surrounding the question if living people indeed do experience, and are aware of changing body-images.

The ego/mind's interplay with body and culture is central to psychoanalytic theory. The mental ego's governance over a less and less driven, but increasingly silent and docile body goes along with the ego's growing sense of control over cultural norms previously perceived as overpowering and restricting. The mentally integrated images of the body enhance the ego's perceived grasp over the body and through its projected body-image, the modern self/ego makes itself known to others.

Both analytic self-cognition and a progressively mental image of an ego-serving and ego-projecting body assist modern persons in gaining supposed control over the ambiguities and paradoxes of their physical condition, life, and the world. Concepts of industrial, "natural", and/or medicalized bodies of multiple, contradicting layers become enriched with a powerful mind over or against a mute, yet utterly useful organism. In theory, the modern, autonomous self is assumed to struggle for and finally to possess as much independence as possible from both its body and culture.

What evidences can be found for the mind's partial independence and superiority over the body? In the next section I shall point to several puzzling mind/body phenomena, considered to occur within the wider range of "normal" or "marginal" psycho-physical relationships, excluding those mind/body problems which occur in a psychotic breakdown. The following phenomena tend to underscore a mind/soul/self over body dichotomy.

Special Mind/Body Relationships

Dissociation phenomena such as autoscopy, out of body experiences, hypnosis, multiple personalities and, on an other, more intentional level, self-starvation or body-overweight-consciousness are all assembled in the gray area of the mind/body juncture. The following is a short introduction into these phenomena.

Autoscopy: In his literature review on the topic, Grotstein (1983) called autoscopy "the idiosyncratic quintessence of self-consciousness". It is an uncanny experience of observing, often around dusk, one's own phantom-self, mostly as a torso or a bust. Grayishmisty in texture, the double may occur transparent, "jelly-like", or solid, without casting shadows. This double repeats exactly, but "in mirror writing", the movements of the beholder who often feels cold. Emotionally, autoscopy may be accompanied by anxiety, discomfort, sadness or amazement. "Autoscopy primarily involves splitting of consciousness and a projective identification (externalization) of one's body-image" (p.295).

The experience can be elicited by hallucination, illusion, fantasy, and has been reported after guided imagery. It need not indicative of pathologies, but has been described in cases of migraines, temporal lobe epilepsy, degenerative states, and tumors of the brain.

In autoscopy, Grotstein held, the "I" is confronted with its "self". This strange self seems to be a partial, elusive image of embodiment. Interestingly, the phantom torso or bust mirrors I's movements; but its texture is life-less and decontextualized or, in pre-Cartesian terms, anima-, soul-, or mindless. I propose that it is this very characteristic of the phantom which invokes uncanny emotions in the beholder. Emotionally very different from this experience are the accounts of out-of-body experiences.

Out-of-Body Experiences (OBE): Perceptions where the "I" is separated from or above the body have been reported, among others, by people who had near death experiences. Gabbard, Twemlow & Jones (1982) reported that 339 (77%) out of 420 people with a history of experienced dissociative states described OBE. To 81% of them OBE were pleasant, eliciting feelings of calm, peace, or joy; some reported additionally or exclusively fear (31%) and concerns of going crazy (3%). Self and body were perceived to be in the same environment by 58%. To 93% OBE were more real than dreams, to over half it was a religious experience which changed their life and for 66% it altered their belief in life after death. The experience was so outstanding that 81% would like to live through it again, 40% considered it to be the greatest thing that ever happened to them.

Experiencing detachment from a (life-less, de-animated?) body was an overwhelmingly positive, outstanding happening in the lives of those who talked about it in a Swiss TV series. What was interpreted to be their immortal dimension seemed to have been freed and simultaneously, this liberating experience shattered many of their previously held conventional values and judgements. Many people reported profound changes which enabled them to live with more satisfaction post OBE (Hampe, 1972; conversation with OBE-patient).

Implicit in these descriptions are notions of a mind/soul encasing body; a body from which the real essence of who one is henceforth looks forward to be liberated from. Death is understood to be this ultimate liberation.

Hypnosis: But, while still alive, impressive bodily changes and healing have been observed as sequelae of hypnosis. Hypnosis, a form of concentrated and narrowly focused awareness, acts on the complex junctures of mind and body. Physiological changes of body chemistry impact the mind, and vice versa. In hypnotic trance changes in mental states occur which bear upon the body's physiological condition (Spiegel, 1983). Hypnosis has been used as a method to promote healing in ailments such as pain, "psychosomatic" (asthma, ulcerative colitis) or dermatological disorders (warts, psoriasis), "psychogenic" paralysis, and allergies.

Auto-hypnosis, autogenic training, other forms of self-suggestion, and meditation can all be seen as attempts to further an intra-individual mind-body or body-mind dialogue. In some of the methods the mind's dominance or intentionality over the body is assumed (Levin & Coreil, 1986; Simonton, 1978; Schulz & Luthe, 1969), in others the body is supposed to talk to and teach a listening, open mind (Feldenkrais, 1949; 1986; Gendlin, 1982; Siegel, 1986; see also Herbert, 1989/1990), and in bio-feedback, body and mind seem to undergo mutual conditioning.

Multiple Personality: A special form of the mind's determination over the body is the "disorder" of multiple personality. Braun and Braun's (1979) description of the phenomenon follows:

> ...one human being demonstrating two or more personalities with identifiable, distinctive, and consistently ongoing characteristics, each of which has a relatively separate memory of its life history...There must also be a demonstration of the transfer of the executive control of the body from one personality to another (switching). However, the total individual is never out of touch with reality. The host personality (the one who has executive control of the body the greatest percentage of the time during a given time period) often experiences periods of amnesia, time loss, or blackouts. Other personalities may or may not experience this (quoted in Braun, 1983, p.124).

Fascinating are the characteristic psycho-physiological changes which occur in the body of the "host personality" under the reign of diverse personalities. Described changes are e.g. "handedness, rate and ability to heal, response to a given medication, allergic responses" (p.125) such as an itching skin rash as reaction to citrus fruit under one personality and its disappearance, which compares to cessation induced by antihistamines, under another.

Assumed explanations, documented in diverse, often contradicting studies cited by Braun (1983) reveal some of puzzlingly many, complex psycho-physiological interfaces. Mentioned are the immune system's sensitivity to mental influences. Memory and suggestive impact on the skin may be elicited by vascular changes which follow certain emotional states. This model suggests neurophysiological links between emotional states and the autonomic nervous system. Similar interactions come to play in the mental activation of the endorphin system in pain states and the suggested blockage of bradykinin release in burns or other wounds. Braun speculated about two overriding, common denominators present in multiple personality disorder and hypnotic effects: The person's ease of being immersed in meditative states and the concept of human state dependent learning, which assumes that "information which is encoded under one psychophysiologic condition is best retrieved under the same psychophysiologic condition" (Braun, 1983).

Less physiological than psychological are the aspects reported by Krippner (1987) who studied spiritualistic treatments of multiple personality disorders in Brazil. Distinct, but very different personalities who had lived once, e.g in past centuries, or speak their original language unknown to the host personality (p.283), are assumed to possess the host individual through temporary reincarnation. The goal of hypnotic therapy is to merge the diverse personalities into one, more complex, mentally healthier, and enriched personality.

These examples describe multiple personalities in one body. What about one personality in two bodies? In his movie Dead Ringers David Cronenberg approached the theme of "two bodies, two minds, one soul" by showing a pair of identical twin brothers' mutual self-destruction. The movie implied the hardship of one soul's life in two distinct bodies. Cronenberg's subtitle suggests a trichotomy which ties minds and bodies into separate units, but assigns the soul simultaneous, bi-corporal dimensions.

In the Brazilian interpretation, the souls of multiple, once "real" personalities possess one body until they, together with the host, find harmony. Into Braun's more scientific account one may read that the diverse souls (personalities) in the host body manifest themselves in the pragmatics of bodily changes. Does such a reading not remind us of the pre-Cartesian, three dimensional soul with its "noetic" or mind part and its "vegetative" and "sensory" components which, through their being inextinguishably tied to the body, reveal their essence through it[5]?

<u>Self-Starvation and Body-Overweight-Consciousness</u>: A more visible form of quite conscious and intentional mind over body domination is the group of phenomena that center around self-starvation and body overweight-consciousness. Self induced anorexia has been associated with a need to establish a sense of oneself, contesting wills, quest for autonomy, and struggle for self-mastery. Also, it has been comprehended as freeing the body from its hunger, sexual, and other urges, as well as liberating the soul from its imprisonment. Disembodied from its flesh, the soul/self can then devote its being to ethereal or spiritual endeavors (Bell, 1985). In various times and circumstances anorexia has been

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[5] Notions of the soul's ability to leave one body and to incarnate in another are very old and at home in some form or another in most cultures.

read differently: As an attribute to one's holiness, or a tool to influence familial or political decisions. The afflicted person may, depending on contemporary social interpretation, be a leader, saint, or deeply disturbed neurotic.

Gandhi's celibacy and repeated threats to destroy himself through starvation were enormously powerful in his nonviolent struggle for India's independence. His mind's victories over the body made the latter "the extension of his mind", a political tool (Nichtern, 1985, p.19). Gandhi is not alone, but he stands out for his austerities' successful messages to his 20th century contemporaries. Similar to Gandhi in their fasting, but different from him by gender and their not explicitly political lives, are anorectic women.

Bell (1985) reviewed the life histories of medieval and renaissance Italian female saints. Among 42 thirteenth century saints he found 17 who were known for their compulsive fasting and other extreme abstentions. These women lived a female piety, expressed through their emaciated bodies. They fascinated, but also raised suspicion in their male confessors and the guardians of the dominantly male religious practices of pre-Reformation Catholicism. Anoretic female saints disappeared after the 16th century as reformatory dogma ostracized "autonomous female piety..[as] insane, demonical, and heretical" (p.178).

The modern anoretic girl/woman (and sometimes her family) is frequently subjected to intense psychiatric, family therapeutic, and/or medical interest. Again, the woman's embodied statement is interpreted as protest against a perceived repressive world. In his fascinating, extensive case study of Ellen West, Binswanger (1944/1953) cited the patient saying: "I wanted to get to know the unknown urges which were stronger than my reason and which forced me to shape my entire life in accordance with a guiding point of view...to be thin" (p.257). Ellen West's life pursuit was her reason's struggle against a body which she perceived as being too fat. Were the mind so powerful and the body as silent and docile as assumed by certain theoretical positions, West's life might not have ended in suicide. West's struggle, in Binswanger's existential analysis, alludes to the power of the embodied being's continuous striving for acceptance by, and integration with, a sublime mind who searches, against all odds, to shed its material earthliness.

On first thought, overeating and/or consciousness of an obese body seem to mark an opposite position, one in which the body clearly reigns over the mind. Millman's (1980) study of obese women contains quotes which can support the inclination of seeing the problem as one of a weak will against a mighty body. Many citations can also be interpreted as narrations about an ongoing war between an alienated, enemy-body's attempts to destroy the self/mind.

Yet, Spitzack (1987) offered a contrary view. She held that willpower, understood as mind over matter, is pivotal in the perpetuation of an obese population (p.358). Wide spread weight consciousness, in her view, is maintained through countless cultural, social and individual every day impulses (e.g. fashion, advertisements) and behaviors (e.g. food, sedentary life styles). Thus, development of a self-evident bodily awareness, neither obsessive nor negligent, becomes difficult. The paradoxical situation of many obese people, she claimed, is one in which the body is lived in alienation, while simultaneously, the illusion of a culturally ideal (slim) body is constantly present in the mind. Again, as in anorexia, the mind appears to end up as dominating an unaccepted body.

Starving bodies always raise concern in others. Messages underscored by anorexia (or cachexia due to illness, marasmus or kwashiorkor) are difficult to ignore. They call for resolute re/actions, since a substantially vanishing body is symbol of life in jeopardy. Fat or obese bodies carry messages of wealth and beauty in certain cultures, of female self-indulgence or moral weakness, and male strength in ours (Millman, 1980). Interestingly, both anorectic and obese bodies tend to evoke stronger moral appeals or judgement in others than do average bodies. More forcefully than other bodies, they seem to symbolize the incarnation of a special mind.

Indeed, mind and body of anoretic or overweight people are judged to be different even among the genders. Gandhi was a revered leader. He symbolized strength and empowerment. He was judged as a man of politics, and favorably compared to other political leaders. For the analysis of anoretic women's lives however, a screen of normalcy will not do. These women are not comparable with their average peers: To interpret them, either religious or psychopathological explanations are warranted. Similarly, a man can be very overweight and still be considered strong, good looking and masculine. By contrast, the overweight female body, in contemporary culture, carries no valued stereotypes of its own gender. Worse even, it is easily attributed with being the incarnation of a weak will.

The Poverty of Cultural Models to Explain Bodily Phenomena

So far, this review attested to two major contemporary Western models on how to look at issues around the body. On one hand, a wealth of psycho-dynamic theories propose insights into the mind/self's relations to the body. In the previous section, the mind's power over, or possibilities of dissociation from the body becomes apparent. The body is an addendum to the self, a part to be mastered. Once under voluntary control, the mind/self through its conceptual independence from the body is free and able to achieve its own liberation from many of the life-world's constraints. This model is perhaps overstated, but it may shed some light on imputations such as missing willpower or moral weakness in instances of female overweight or "variable mobility" in patients who suffer from neurological diseases (Deegan, 1989). On the other hand, anatomical models as well as biochemical and physiological theories allow for insights, explanations, and predictions of a pure, physical body in details, never before attained. Yet, this body is essentially mind-less, dull and dependent from the mind. It's cellular processes have been compared to chemical factories, the brain's work to computerized information processing, the body's vigor to the cylinders of an automobile, and its functions and features to those of machines. None of these metaphors leave any doubt about the body's dependence on a mastermind or another source of external energy upon which it, by the logic of the allegory, is dependent.

In between these two poles of cultural understanding, mind over body and/or machine body, gapes a conceptual vacuum. Accounts of a body which relates to its socio-cultural world are sparse. Notions of a living, intelligent body are equally rare and concepts of embodiment virtually absent. Thus, it seems almost impossible for contemporary, affluent Americans to favorably associate a fat woman with wealth and high status of her family. In societies of scarcity, a well-fed body tends to be symbolic of abundance of food. In a folk tune from the Emmental[6] (Switzerland) a boy prizes his mother for being overshapely as women normally are in his valley. Implied in his compliment are notions of a good mother and wife, able to do hard physical work.

In either example, the body is seen in its connection to the social and life-world to which it belongs and of which it is part. There are no allusions to a split mind/self-body relationship in these understandings. Rather, the embodied person's dependence upon, and potential influence on the world is implied.

Concepts of a living, socio-cultural body or of embodied being-in-the-world could open up altered, perhaps neglected, ways of understanding self and others in this culture, which, for decades so heavily relied on scientific knowledge only. The remainder of this chapter will trace scientific, experiential and phenomenological reflections on uniting dimensions within the world-body-mind universe.

From a neurophysiological perspective mind and body relations appear reversed. The mind appears as a product, as an extension of anatomico-physiological structures, not as the body's master. Implicit in this view is the world in which the organism lives. Through its

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[6] From Trueber-Lied: "Mi Mueter isch e feschti, si isch vom Saeltebach, im Saeltebach isch saelte-n-es Meitschi bring u schwach..." (My mother is heavy, she comes from Saeltebach; in Saeltebach girls are rarely small and weak (Transl. AK)).

sensory organs, the organism picks up the world's messages and through its motor responses it reacts to and interacts with the world. However, it is difficult to find the body as a macro concept in the vast volume of physiological or biochemical literature. Too huge an universe is the body to the eye used to the electron-microscopic landscape of a cell.

The Body/Mind Question in Neuro-Physiological Terms

Kupfermann (1985) wrote:

> the mind is not an entity of any kind, but rather a set of functions carried out by the brain. Mind is what the brain does, just as walking is one of the things that legs do (p.797).

This statement implies the brain's nervous linking to all body parts and beyond, its being situated in the world through sensory afferences and motor efferences. It allows for a philosophical conception of a mindful body which, at least biologically, meaningfully relates to the world.

Sperry's (1982) work suggests that

> the two halves of the brain, when connected, work closely together as a functional unit with the leading control being in one or the other.

When one side is lesioned, both hemispheres function with

> impairment. However, after commissurotomy each hemisphere ...appeared to be using its own percepts, mental images, associations, ideas...Unlike other aspects of cognitive function, emotions have never been readily confinable to one hemisphere.

Emotional messages seem to cross from one hemisphere to the other through crossed fiber systems in the brain stem. It was through "subtle shades of emotions that the left disconnected hemisphere could guess a stimulus known only to the right hemisphere" (p.1223).

Brain areas such as the hypothalamus, prefrontal cortex, cingulate gyrus, and the limbic system have been identified as carrying out functions of emotional quality. With the exception of the prefrontal cortex, these brain structures are evolutionarily older than the cortex. Contrary to many of the cortex' split functions, which include separated sensory and motor innervation of two body halves, its emotional tuning represents the whole body's reaction to its being in the world. This subcortical, emotional awareness seems to "know" more about the whole of the body than does either disconnected hemisphere. It seems as if the subcortical emotional centers have a uniting function, since they can carry "knowledge" impulses from one cortical hemisphere to the other.

In order to survive in a group, higher organisms have been endowed with the ability to emotionally communicate. One affective mode of attunement to others is empathy. Brothers (1989) traced the biological roots of empathy to brain structures such as the temporoparietal parts of the cortex and the limbic system, specifically the amygdala. Observations of infantile autism, where an innate defect of empathy is assumed, and studies with monkeys, upon which bilateral lesions of the amygdala had been inflicted, point to profound, isolatory consequences for the individual in the group, who is unable to communicate emotionally. The survival of the individual in the group depends on its ability to emotionally communicate, to "know" about the others attunement and likewise, let them "know" of one's mode of being-in-the-world.

But, is the mind composed of just cognition and emotions? Not all awareness is necessarily cognitive or emotional. Central nervous functions such as proprioception, balance, or smooth motor coordination for example, enter cognitive awareness only if targeted by intentionality, or, if they are lost (Sacks, 1987, p.43-54). In either case these functions tend to deteriorate in their situational adequacy of flow or smoothness, as soon as they are subjected to rational intentionality. These functions are essential to guarantee the body's taken-for-grantedness.

Cognition and awareness of different qualities depend on the nervous-endocrine interplay between cognitive, emotional and bodily centers, between sensory in- and motor output. They are guaranteed through simultaneous synaptic exchange on countless levels of the central and peripheral nervous system.

In this interpretation, the mind is not just a function of the brain, but rather one of the whole system. Thus, the mind understood as encompassing more than cognitive and emotional qualities, is the result of constant exchange between the organism and its environment. One can therefore argue that the mind emerges as a result of the organism's relation to itself and to its surrounding world: A deeply embodied mind, flexible and able to grow, learn, and adapt throughout life.

Recent work in neuro-biochemistry proposes a cellular model of learning in primitive animals. Learning is, following these studies, a result of synaptic modification. Kandel (1985, p.831) summarized three stages of overlaying ontogenetic synaptic modification: 1) the stage of formation of the synapse (primarily in the developing animal) is under genetic and developmental control; 2) the stage of validation and fine tuning of newly developed synapses: This occurs during critical early periods of development and requires appropriated patterns of environmental stimulation; and 3) the regulatory stage of transient and long term effectiveness of synapses occurs throughout later life and is determined by day-to-day experiences. Thus, concluded Kandel (1985), "every-thing that occurs in the brain --from the most private thoughts to commands of motor acts-- represent organic, or biological processes".

The jump from cellular processes of learning in primitive animals to the suggestion that the human mind may expand through learning in a similar manner is immense and probably extremely reductionistic. But there is evidence from every day experiences and from studies of diseases affecting selective structures of the central and peripheral nervous system to remind us undoubtedly that the body's un-severed central nervous system is able to recall, remember, recognize, transform, combine, learn, relearn, and store, for life time, a multitude of taken-for-granted behaviors and experiences. Some of these activities are elicited and registered by full consciousness, a majority of activities, meaningful for survival, rely on a subliminal bodily awareness which gives them a quality of trusted self-evidence. In between these two extremes of mind-states lie further possibilities of more or less conscious learning and re/acting (Merleau-Ponty, 1962/1979).

When illness hits any of the body's physiological dimensions, both its taken-for-granted relationship to self and its interactional capacities to relate to others and the world change. We shall now proceed to a review of body-mind-other relationships in "physical" illness.

Body/Mind Relationships in Illness

Illness manifestations in the body and its limitations on performance of daily living activities provoke life reviews, value re-appraisals, and life changes in people. Corbin and Strauss (1988) pointed to the disruption of "self-image" through a failing body. "Body failure" refers to: "1) the body's inability to perform an activity, 2) the body's appearance, and 3) the body's physiological functioning at the cellular level" (p.50). Needless to say, these three dimensions are inclusive of the self: Mobility and independence, self-projection and self-understanding, moods, emotions, feelings, and thought; none of them may remain untouched by illness. Furthermore, as soon as alterations in body appearance and mobility occur, taken for granted interactive abilities get jeopardized and may become changed.

Kaufman (1988) found that patients with stroke experienced no mind/body separation in their lived reality. Yet, the cultural mind/body split was mirrored in patients' threatened conceptions of an "intact and autonomous self" once bodily functions were impaired and restricted. Contrary to epistemiological conviction, the survival of self's autonomy seems thwarted in bodily breakdown.

Through a serious collagen disease, Cousin (1985) learned that "your mind can cure your body". This statement, on the cover of a bestseller, may have been part of the marketing force that propelled the message of <u>Anatomy of an Illness</u> into the minds of countless contemporaries. Less radical than the sound of "mind cures the body" is Cousin's insight: If the body responds to "bad", stressful emotions with "adrenal exhaustion" and reduced immune resistance, would it not have the capacity to respond with regeneration to "good" emotions and "healthy" food? He discovered his body's wisdom and response by strengthening the pathways which link mind and physiological functions through laughter, emotional loosening, hope, optimism, and faith in his body's abilities, as well as high doses of vitamin C. Recovery followed his changed attitude and self-treatment.

Cousin's account, although compelling in his deep insights into the body-mind unit, is dichotomous in its essence. The attitude of the mind towards the body changed once the body's "failure" was such that he could hardly move, chew, sleep. Cousin's relationship towards his body became one of appreciative, gentle awareness and gratitude in contrast to his previous reliance on a body ever at the disposition of the mind's needs. He realized his taken for granted body as transformed into a needy, and later, into an appreciated body.

In his autobiographical essay Frank (1983) described how the sequelae of a brain abscess sobered him from his "delusions of invulnerability". Invulnerability, in his understanding, is a fundamental "feeling that affects attitudes, moods, and thoughts". It includes connotations of invincibility, independence, and safety (p.1269). "..Oppressed by the obtrusiveness of [his] body" he not only realized, but lived his vulnerability as dependency on others.

For Cousins the body became a newly discovered source of wisdom, for Frank the reminder of his human vulnerability. Illness experience brought into day-to-day life the awareness of their ultimate dependence upon bodily integrity. Loss of bodily integrity was equivalent to loss of the assumed freedom to depend on one's physical strength, coordination of movement, sense of direction, will, plans, and purposeful actions.

Weiner (1986) took up Descartes' assessment that sick people lose their freedom because of constant involvement with their body (p. 366). Since freedom is such a facet-rich concept, it may lend itself to some speculation. Isn't the body's taken-for-grantedness freedom from having to think about it at all times? Invulnerability of course, is freedom too, as is the ability to get around, to be active and able of showing one's "social skin" without fearing adverse reactions from others. Freedom in Descartes' sense may include undisturbed mental activities of which the focus may be anything but the body. Yet, the ailing body has a strong tendency to curtail any freedom of such understanding: It seems to force its existence into conscious self-awareness, thus limiting the self's illusions or delusions of any freedom which is based on ignoring the mind's embodiment.

Gadow (1980), in an attempt to reconcile mind and body, proposed that aging and illness have an integrating function:

> the body in illness and aging insists, not that the aims of the self be surrendered, but that its own reality, complexity, and values be supported. The acceptance of that insistence as valid is the recognition of the subject body. That is, when the body is experienced as subject, it is considered a part of the self with the same intrinsically valid claims as any other part of the self (emotional, intellectual etc.) (p.180).

Inherent in Gadow's position is a dualistic conception of mind and body. Her idea that the self accepts or even integrates the body as subject rather, than possessing it as an object in a master-slave relationship, still assumes a hierarchical connection: The mind-self as finally accepting a refractory, begging body-self. This new quasi unit is one that grows from acknowledgement to acceptance into slow integration of a widely unknown part of one's identity. Gadow did not explicate the forces which drive this process of consolidation. Pain is pivotal in bringing to consciousness that mind and body are inseparable.

Pain is a phenomenon which both unites and shatters mind and body, as well as inter-human relationships. Pain can make a person speechless, but cries in its own bodily voice. Scarry (1987) differentiated pain from any other "interior state" (emotional, perceptual, somatic). She held that we have always feelings about someone or something exterior to self: for example, love of someone, fear of something, feeling hungry for, etc.

> Physical pain - unlike any other state of consciousness - has no referential content. It is not of or for anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language (p.5).

Physical pain is about self, about the body (even if it is causally connected to, for example, a burned finger, giving birth, or passing a kidney stone). It speaks the body's ambiguous, un-objectifiable language. Its message makes itself heard and listened to by the self's mental capacity. Pain can be interpreted as that "interior state" which melts down the boundaries between dichotomies such as body-mind-self-world to encompass them with a new, smaller unit of a totalizing self-world. This oneness may feel separate from the surrounding world since pain, in its essence, can neither be rationally understood, nor physically shared (Illich, 1975).

Literary reflections on people's self-perceptions during cancer illness, alluded to in the first chapter, showed loss of sense of direction in life and the feeling of being thrown into nothingness, once the body's familiar language grows mute. The core of illness experience in life may be its bringing to painful awareness the vulnerability of human embodiment.

Before introducing Merleau-Ponty's phenomenological concept of embodiment, I shall draw a summary picture with the numerous notions of body and self so far presented.

The Conceptual Plurality of Bodies

In his paintings, Cezanne said, he searched to attain a synthesis between the unique and the general, between the whole and its parts. He aimed to unite the motif so tightly that there would be "no hole through which truth could escape" (Bocola, 1989). Embodiment might be the master work containing the whole truth graspable by humans. The theories or cultural constructions discussed earlier are, at best, comparable to outlines. Outlines, by definition, stand out because of the emptiness around them. They allow, in Cezanne's terms, plenty of space for the truth to escape.

Contemporary notions of the body are multiple, overlapping, contradicting, and/or complementing each other. Our knowledge of the body is nurtured from four sources: 1) it is self-evident, unreflected, culturally shaped; 2) reflects beliefs shaped by philosophical and psycho-social theories; 3) is founded on convictions of "natural" anatomico-physiological understanding; and 4) sustained by bio-chemical and -physical insights into life-processes.

In between these diverse cognitive representations and influenced by them is the lived, experienced, taken for granted body of embodied human beings. Theories and mental images serve to make the world explicit or visible, they give structure and explanation to life experience. The body, this life carrying enigma, cannot be comprehended without words or pictures, yet, certain dimensions of its life escape verbal or pictorial abstraction. The truth of lived bodily experience which escapes through the holes of theories, concepts, or mental representations might be closer to music than to words or images.

How is the self-evident body constituted in our cultural understanding? It carries the "social skin" through which the person learns to know self and is known by others. Not surprisingly, Keller (1986) noted ambiguous cultural understandings of skin: It may symbolize self-protective boundaries for individuation and/or stands for connecting self to others. Through this skin and its openings exit audible sounds, secretions and eliminations all endowed with cultural meanings. Meaning and value hierarchies as well as contextual definitions regulate all bodily movements, sounds, secretions and excretions.

The psychoanalytic concept of body-image assigns these social dimensions of the body to an owning self. In this understanding the body is the mind's vehicle for self-projection to the surrounding world. As such it has to be taken care of and cared for. Bodily needs are fundamental in Maslow's (1970) hierarchical thinking. These needs warrant satisfaction and mastery before self-actualization can be achieved.

Basically, the body known as body-image is constituted by and dependent on individual-social interaction. Hence, the eminent importance of skin, body openings and their ex- and secretions as basis for social self-understanding, both in the pre-industrial and the modern views. Bodily movements, the conditio sine qua non for life, are basic to the image of self and revealing to others. Modern self-understanding as a sexual being enhances the body's importance as an object to be tamed or desired.

Concepts such as self, ego, mind, and soul are easily understood as paradoxical in their relationship to the body: As independent or disembodied, but simultaneously in possession of, and dominating the body. In contrast to the concreteness of the body's touchable features and visible Gestalt, concepts like self, ego, mind or soul are ill defined and elusive.

Inherent in bodily self-understanding is a strong purpose orientation. It may have its roots in the idea of the mind's dominating power over the body. Bodies are useful and can be timed to work, sit, walk, or stand in deliberate sequences. Bodies can learn to perform activities and skills of highest perfection; they can provide the power and energy needed to move objects and transport self.

Changes in the body's capacities to behave as expected often elicit dramatic repercussions in self-identity (Chamaz, 1987) and evoke more or less strong reactions from others (Corbin & Strauss, 1988). Changes from a predictable body to an uncertain one are likely to raise existential questions around individual freedom, independence, control, invulnerability, or mobility (Wiener, 1989). Habitual notions of time and being timed, as well as moving in and through space are transformed through physical limitations.

Anatomical, physiological, and biochemical theories of understanding the body contain concepts of a complete organism composed of many organ-systems and tissues, all of them specialized by constantly active and interactive cells. Cells and bodily liquids, in turn, are composed of yet smaller units like molecules or atoms. This understanding is more fragmented, specialized, and abstract than psycho-social or philosophical notions. It has lost the Gestalt quality, but also some of the vagueness of the latter.

The knowledge about the body explicated in this literature review is called "savoir" in French or "veta" in Swedish. These verbs connote explicit, abstracted, circumscribed knowledge. On the level of the lived experience however, savoir merges with "connaître" and veta with "kånna". Both verbs allude to knowing qualitatively, through sensory perception, or intuitive, emotional awareness. In Swedish, "kånna" still means touching, or feeling with one's senses, as well as knowing. One connais or kånner a face, person, landscape, or one-self.

Merleau-Ponty (1962/1986) attempted to capture and describe some of those lived bodily experiences in which mind and body are one in their acting and reacting with the world. To use a paraphrase of Blaise Pascal's famous statement, Merleau-Ponty aimed to show que le corps connaît des raisons que la raison ne sait pas[7].

Merleau-Ponty on Embodiment

> ..I have no means of knowing the human body other than that of living it, which means taking up on my own account the drama which is being played out in it, and losing myself in it. I am my body, at least wholly to the extent that I possess experience, and yet at the same time my body is as it were a 'natural' subject, a provisional sketch of my total being. Thus experience of one's own body runs counter to the reflective procedure which detaches subject and object from each other, and which gives us only the thought about the body, or the body as an idea, and not the experience of the body or the body in reality (Merleau-Ponty, 1962/ 1986, p.198/99).

Throughout Phenomenology of Perception (1962/1986) Merleau-Ponty critiqued empiricist and rationalist positions on the objectified body in philosophy, (patho)physiology and psychology. He pointed to changes in

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[7] The body knows reasons which the (rational) mind does not know.

interpretation which occurred through analytic work in these traditions: Experience became emptied from mysticism by assigning it possession of diverse qualities. Reason and cause as driving forces for behavior thrust aside motivation understood as one phenomenon eliciting a chain of others to merge into a flow, a never quite explicit raison d' etre (p.49/50). He held, for example, that nervous lesions are followed by loss of differentiation in function rather, than just a loss of sensual qualities or certain sensory data. Active differentiation of stimuli becomes unreliable (p.73/74) and thus, severs the relationship of the body with its world.

Merleau-Ponty approached phenomena of the lived body from diverse angles. He compared the "gearing into each other" of physiological conditions with psychological determination (memories, emotions, beliefs) in phenomena such as phantom limb and anosognosia (having the limb but neither sensing nor knowing, thus not using it any more[8]. Phantom limb experiences arise because the body, through its sensory awareness, experiences its situation in the world as eliciting movements of whole body involvement. The missing limb is still part of the nervous patterns out of which behavior arises. Unless behavior is understood as

> directed at tasks and guided by a subtle awareness of the situation, though without consideration of alternatives, knowledge of determinate features or things, and deliberate choice,

the phenomenon of phantom limb is not comprehensible (Dreyfus, 1988). Once innervation is severed, as in anosognosia, the body's intuitive

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[8] See Sacks (1984) for an excellent description and for comparison with phantom limb p.170-72.

ability to propel towards a task or to move towards the world is hampered.

Merleau-Ponty thought of world-body relationships as paradoxical. Consciousness of the body is gained through the world, but the body is the being's pivot in the world. Through bodily impairment, the eliciting character of things or aspects of the world change from meaning that they can be handled by me, to things/aspects which can be handled (p.80-85).

Very different from both Schilder and Van der Velde's body-images, but congruent with his view of the body's purposefulness in the world, is Merleau-Ponty's concept of body-image. It is dynamic and arises out of "an attitude directed towards a certain existing or possible task" (p.100), like the knowledgeable hands projecting towards the keyboard in full integration with the whole body's flow towards the piano. Spatiality in this image is not one of position, but one of situation. Bodily space and external space form one practical system which is inhabited through bodily movement (p.102).

Merleau-Ponty used grasping/touching and pointing to exemplify two basic categories of movements: Concrete and abstract. Concrete movements are projective, flowing out of the body's involvement with the world, elicited, engaged through existential purposefulness, but escaping rational intentionality. Abstract movements in contrast, depend on mental intentionality. They are abstract in the sense that they are unrelated to a situation's immediacy (p.103-5). Similarly, legs are not moved as "things in space, but as a power of locomotion" allowing the body to project into the world (p.146).

Through bodily habits we understand the world; habits anchor our being in the world (p.144). Habits are understood as both motor and perceptual and as lying between "explicit perception and actual movement". Habits, therefore, set boundaries to both the field of vision and the field of action. Since Schilder's body-image revolves around a psyche to which a body is attached, body boundaries are more or less defined by the skin. Thus, boundaries detach the body from and oppose it to its environment. Merleau-Ponty's ever changing boundaries of the situational body-in-the-world unit resemble the pre-industrial notion of body-world exchanges through the body's openings.

The phenomenon of sexuality inspired Merleau-Ponty to expand on the concept of existential ambiguity. Sexuality connotes the body's constant being tuned towards the world or attuned toward another person. Similar to many bodily activities and movements, sexuality is not

> object of any intended act of consciousness...As an ambiguous atmosphere, sexuality is co-extensive with life...Ambiguity is of the essence of human existence, and everything we live or think has always several meanings" (p. 169).

Sexuality is paradigmatic for Merleau-Ponty's existential body-situation unit. This unit defines and holds all possible contingencies, of which one only is lived out as necessity through bodily involvement (p.170-71). Ambiguity lies in the unit's possibilities, whereas "conditioned freedom" (p.454) comes to life, if lived necessity is congruent with existential purposefulness. Freedom is situated; it is the "meeting of the inner and the outer" and its magnitude depends upon the acceptance of both bodily and situational components.

Sexuality in Freud's school of thought is fundamental to ego development and thus, pivotal in the ego's relations to others and the world. A driving force, sexuality is situated in the id (body) and the ego evolves by struggling against and/or accommodating the id. As the ego is envisioned as master over id (embodied drives) and super-ego (culture, world), the phenomenological body gets neglected on two levels. 1) Through the ego's rational dominance the body becomes objectified. Hence its non explicit ambiguity has been called "the hidden form of being our-self" (Binswanger, 1935). 2) Through its boundaries the body becomes segregated and even alienated from the world. Yet, as an object it merges into a world of objects to be manipulated. The body's resistance to explicit rational consciousness may be the major cause for both its taken-for-grantedness and its neglect in scientific discourse.

Merleau-Ponty's sexuality is intrinsic in the body-world relationship, and is simultaneously both, embodied and elicited by the situation. Sexuality, in its paradigmatic quality, is synonymous to embodied or existential purposefulness. Merleau-Ponty's emphasis lies not on a hierarchy of separate, fighting psychological dimensions (id, ego, super-ego), but on an embodied world relation of reciprocal elicitation and mutual response. Rationality is not the focus of his contemplation, but ambiguity. Rational attempts to understand mind-body-world relations are aimed towards reducing or ignoring ambiguities.

In many instances, clarification of the situation is important and helpful, and allows conscious strategic choices to be made. Our culture's fondness for rational problem solving has contributed to its wealth of explanatory models and technical advancement. However, it has also blinded us to the existential ambiguity of always being involved, through the body, with the life-world's ever changing situations. Often, it is the body's inability to respond in its taken-for-granted way which brings to awareness this hidden form of being ourself and the intricate ambiguities of its situatedness.

In Freudian terms, freedom is reached through cognitive distance from the body's drives (and from cultural mores). Freedom means independence from being forced or restrained by any power. Freedom in Merleau-Ponty's (1962/1986) sense is simultaneously anchored in, and dependent on, embodiment and the situation's possibilities. It comes to life in the existential purposefulness of the (inter)actions which arise between the embodied being and the situation. Involvement and commitment are sources of this situated freedom <u>to</u> satisfaction, while detachment and distancing lead to freedom <u>from</u> limitations.

Merleau-Ponty's phenomenological approach complements rational notions of the body and calls to attention the embodied foundations of clarity and ambiguity, freedom and restriction, elicitation by and projection into the world. Embodied life includes narrow boundaries and boundary-less communication within situations, as well as impulses which flow from the rational mind to the body and from bodily purposefulness to the mind.

Consequently, with this view, Merleau-Ponty loosened up Western culture's narrow, rational models of bodily understanding. He reintroduced the perceiving body as a never quite explicit nor rational shaper of reality. A faint notion of body-world wholeness shows up in his work. The body is given back some of the wisdom and anima, of which it had been disowned, at least theoretically, for centuries.

Summary and Outlook

This chapter offered an overview of the development of contemporary Western concepts of the body, and various body-mind-world relationships. The review includes philosophical, psychosocial, and biophysiological approaches to the enigma of the human body. The notions presented fuse to an utterly complex, conceptually confusing, contradicting and paradoxical cultural picture of what is understood to be human embodiment, the lived body, or just, the human body. This review underscores the necessity to broaden the scope of viewing the human body in nursing. The of question how phenomena like the experienced body or embodiment might be researched will be addressed in the next chapter.

CHAPTER 3

THE RESEARCH APPROACH

Perplexities of Knowing and Researching the Body

> Thinking...returns us to that mystery of mysteries which is its own ground: the being of an embodied mind or a thoughtful body. This is not a problem to be solved, but a perplexity to be faced, I suspect, permanently. We can here do little more than acknowledge it (Kass, 1985, p.28).

Much of our knowledge about the body comes from research done within an "objective", scientific tradition. The fallacy of objectivity becomes very clear in the realm of body-research. As Herbert (1989/1990) wrote: "'Objectivity' splits knowledge apart from the one who knows. And the mind that knows is split off from the body that the mind _is_". The body thwarts conceptions of a world separated in "objective" and "subjective" parts and aspects (Collins, 1985).

Today, much of the body's physiology and bio-chemistry is quite well known. Usually, this knowledge separates body from mind and details from the whole. Through it we have gained global and detailed knowledge on how the body works. Yet, in nursing, we remained largely in the dark about the experiencing body's constitutive involvement in people's self-understanding and life-world.

This study's focus is the experienced body, its influence on women's embodied self-understanding in illness. Embodiment is conceptualized as constant interplay of many bodily dimensions. Von Blankenburg (1982, p.14-15), trying to conceptualize the living body (Leib), identified eight bodily dimensions:

1) the organism (Koerper) as condition for psychological and (patho)physiological processes;
2) the body as the subject's center of orientation towards its life-world;

3) the body as "object" of embodied perception and proprioception;
4) the body as organ of spontaneity and precondition for the "I" can;
5) the body as focus of attunement, suffering, anguish and dying;
6) the body as organ of expression and presentation of self;
7) the body as pivot between self and world constructed inter-subjectively and simultaneously the condition for interpersonal relationships; and
8) the body as partner.

This study aims to problematize the experienced body. It describes how women with breast cancer who underwent CTX experienced themselves through their changing bodies:

- how bodily changes impacted on their embodied self-understanding (chapter four);
- how bodily subjection to medical treatments illuminated professional and self's relationships to the body (chapter five) and;
- what kind of knowledge about the body these women used in order to deal with their illness (chapter six).

Different levels and qualities of awareness and knowing made up women's embodied understanding of self and their situation. Included were implicit awareness, skilled know-how, recognition (connaître or kånna), as well as more or less explicit knowing "that" or "about" the body and its functions. In other words, women understood situations as meaningful wholes, recognized similarities with previous experiences and, at the same time, could reflect explicitly on specific details. The body cannot be experienced other than in its simultaneous multidimensionality, for example as knower, the one one knows as self and knows about as a functioning whole, as well as through some outstanding features.

The topic of this study, the body as major source and shaper of self-understanding, is both ambiguous and rarely fully explicit. For example, the perplexity of studying the living body resembles our inability to see our own eyes in action by natural means. If we fix our eyes to look at them in the mirror, they lose their spontaneous gazing motion and their self-evident quality of looking. Mental awareness takes over: The eyes react to it at the price of losing, temporally, their ability to grasp the clues of a soliciting, surrounding world. During the mind's absorption with looking at the eyes and the eye's inability to relate to the world, the body's spontaneous relations to its world become interrupted as well. The eyes and, to the extent it is observed, the body present themselves to the examining mind in a different than life-world related mode. Both modes, however, are constitutive of reality and important for analysis.

How then can embodied (changed) self-understanding be studied? Meanings appear both implicitly in practices and behaviors as well as more or less explicitly, in language. Observation of changing self-understandings seemed inadequate, since present illness experiences stood out against past states of being and arose from patients' life histories. Having them draw their bodies seemed too limiting because the drawn body tends to lose its meaningful relations to the past and its life-world. Similarly, direct questioning would put the person in a position comparable to observing one's eyes in the mirror. It might invite second order constructs (Schutz, 1962) developed by respondents who, up to the point of being asked, may never have deliberately thought about the issue under question.

Problem-oriented interviews (description follows) seemed closest to patient-nurse interaction and rich in daily life accounts. Still, interviews depend on language, while notions of embodiment easily evade explicit cognition (Dreyfus, 1986a, pp.8-11).

Most bodily experiences are flowing, pervasive, multi-layered, non-verbal, neither articulated nor cognitively reflected, but they are understood and real. Taken for granted like the air we breathe, embodied self-in-the-world-understanding is both background to and foundation of what is perceived as reality. It is evident that approaching embodied non-linguistic reality through language can only be an approximation to what the body's mysterious perplexity might be (Kass, 1985). After all, one cannot make a fish climb a tree, nor a squirrel swim in the ocean.

Although language is inadequate, it is yet the most familiar, every day medium through which, what ever can be made explicit of embodied experiences, are shared. Taylor, (1985a, p.76) underscored the necessity of language in self-interpretation (and, of course, other-interpretation as well). Mead, (1934/1962, p.79,97) emphasized language's constitutive role in the building of shared and individual consciousness. Words simultaneously serve towards constituting, explicating and sharing meanings, as much as they are themselves constituted, through interpretation, by culture's implicit, shared meanings.

Language entails the translation of implicit, lived dimensions into the abstraction of sentences. To the extent to which embodied realities can be shared verbally, they need to be interpreted by an embodied listener. The closer experientially (culturally) narrator and listener are to each other, the better the chance that one's sharing leads to the other's understanding.

As a researcher I came to listen to, and interpret patients' accounts with "prejudgments and prejudices" characterized by Bernstein (1988, p.141):

> ...they are handed down to us through tradition, they are constitutive of what we are now (and are in the process of becoming), and they are anticipatory - always open to future testing and transformation.

For example, I am an embodied woman and a nurse, but without own experience of breast cancer. Yet, bodily feelings of vigor and weakness are familiar from experience. I have witnessed the impact of invasive treatments, progressive illness and death in patients I cared for. I am not a native English speaker, but am a member of a Western (Swiss-German) culture. Thus, I could compare English ways of talking about bodily issues with those of other European languages. On the other hand, I fell short of understanding things which any American child would "know". I was (am) ignorant of certain cultural self-evidences (so important for the understanding of the body) unless they were pointed out to me. For example, I did not know that the words "itsy-bitsy" are related to a children's song and that children do specific hand movements while singing "Itsy bitsy spider". Only the image of these hand movements made clear why a woman felt them to be so futile (see p.256).

My own situation as a listener and interpreter might be seen both as enhancing and diminishing the "evidence" of the findings. In many instances, my "ear" was not subtle enough to "hear" unspoken background meanings. Yet, one can argue that this lack of cultural sensitivity upgrades the very stories because, what was told was so pervasive and "loud" that I could hear it.

This phenomenological study's interpretations and descriptions are influenced and limited by all of these issues. Furthermore, any insights revealed by one interpretation, at the same time, conceal interpretations from other view points. Understandings gained in this study are neither ahistorical nor universal, but are closely linked to the lives of these women and appear in my situated interpretation. But, as Dunlop reflected:

> a well-developed hermeneutical understanding provides the basis for ongoing understanding, for further interpretative development and redevelopment, as further events unfold or past events show up in new ways (1990, p.138).

All of the above considerations included, it is the aim of this work to help reduce some of the "helplessness (Ratlosigkeit) we experience when confronted with the self-evident [body]" (Pluegge,1957, p.340) and thus, to contribute some insights towards a better understanding of breast cancer illness' embodied realities, as they appeared in these women's lives. By describing "the lived-through quality of lived experience" and interpreting "meaning(s) of the expressions of lived experience" (Van Maanen, 1990, p.25) I hope to explicate some aspects of these women's reality.

Specifics of this Study

The Larger Study

The women whose interviews served for the secondary analysis on which this study's interpretations are based, had consented to participate in Dodd, Lindsey, Larson and Musci's (1986-1990) study Coping and Self-Care of Cancer Families: Nurse Prospectus. This larger study used a prospective longitudinal design. One hundred patients with diverse cancers and their families participated. Data collection occurred five times over six months of patients' CTX experience. Three times, at the beginning, after one to two months, and at the end of the study period, family interviews were conducted. Data collection and the interviews were done mainly by doctoral nursing students. I was one of them. (For results of the larger study see: Wiener, 1989; Dodd, 1990; Larson & Dodd, 1990; Musci & Dodd, 1990; Dibble & Dodd, 1990; Schumacher, Wallhagen & Dodd, 1990; Halliburton, Dibble & Dodd, 1990; Dodd, Thomas & Dibble, 1990; Jansen, Halliburton, Dibble & Dodd, 1990; Larson & Dodd, 1990; Larson & Dodd, 1990).

The Interpretative Study's Sample

Out of the hundred, 48 women (48%) had a diagnosis of breast cancer. Eighteen among them were interviewed by me (or I was present at their interviews as a recorder). Although the study's interpretation relies heavily on 48 interviews from these 18 women, I used all (N=135, inclusive the 48) interviews from patients with breast cancer for "theoretical sampling" and to improve the density of description (Strauss & Corbin, 1990).

The following two tables (demographics and disease characteristics) show the smaller sample (N=18) as quite comparable to the larger group (N=48) with one exception: Almost 90% of the 18 women in the study sample had undergone invasive treatments in addition to CTX (RTX and surgery), while the same is true for 65% in the larger group.

The sample statistics seem to reflect two trends over the six months of CTX: 1) Patients' mean ratings on the Karnofsky-scale suggest that they tended to feel weakened by CTX when they initially started it, then recovered somewhat (fourth month), but later felt weaker again. The Karnofsky performance status is rated on a numerical scale from 0 - 100, assessing a person's ability for normal activities and work as well as his/her need for assistance (Karnofsky & Burchenal, 1948; Schrag, Heinrich & Ganz, 1984).

2) The mean number of experienced side-effects almost doubled over time in the study sample. To assess the number of side-effects patients used an extended, inclusive list of 44 potential side effects of CTX (Dodd, 1982) on which they indicated which of the listed symptoms they had experienced (see Appendix A).

From these numeric perspectives, as a whole, the sample fluctuated in the energy needed for dealing with daily life; but patients became sicker over time and a majority had to deal with more side effects from the therapies.

Table 1. Demographics a)

Variable	N=18		N=48	
	Number	Percent	Number	Percent
Marital status:				
married	9	50	25	52.1
si.wi.di.sep.	9	50	23	47.9
Living:				
with spouse	8	44.4	24	50
with family	6	33.3	11	22.9
alone	1	5.6	6	12.5
other	3	16.7	7	14.6
Ethnicity:				
caucasian	17	94.4	38*	80.9
asian	1	5.6	3	6.4
black	-	-	2	4.3
other	-	-	4	8.5
Employment:				
full/part time	7	38.9	21	43.8
not employed	8	44.4	15	31.2
disability	1	5.5	5	10.4
other	2	11.1	7	14.6
	Mean Years	SD	Mean Years	SD
Age:	47.3	11.2	47.2	10.4
range	31-65		25-68	
Education:	13.1	1.5	13.96	2.3
range	12-16		9-20	

*   = missing data
si. = single
wi. = widowed
di. = divorced
sep.= separated

a) Acknowledgement: Dr. S. Dibble provided the descriptive statistics.

Table 2. Disease characteristics a)

Variable	N = 18		N = 48	
	Number	Percent	Number	Percent
Diagnosis:				
initial	10	55.6	30*	63.8
recurrent	8	44.4	17	36.2
Purpose of CTX:				
cure	14	77.8	28*	65.1
not cure	4	22.2	15	34.9
CTX-Treatment:				
first	13	72.2	35*	76.1
repeated	5	27.8	11	23.9
Other Treatment:				
none	2	11.1	16*	34.8
surgery	9	50	19	41.3
CTX+surgery	1	5.6	4	8.7
RTX+surgery	4	22.2	5	10.9
CTX+RTX+surgery	2	11.1	2	4.3
	Mean	SD	Mean	SD
Time since dx:				
in months	24.7	35.4	21.8*	36.2
range	1-120		1-144	
Karnofsky: in points 1-100				
1. month	82.1*	16.1	82.5*	13.9
range	39.5-100		39.5-100	
4. month	87.6	9.2	85.2	12.9
range	70-100		50-100	
6. month	81.6	13.5	82.0	14.0
range	39.5-100		39.5-100	
Side effects: number of				
1. month	6.8*	8.8	7.8*	6.9
range	0-30		0-30	
6. month	12.8	9.8	12.3	8.3
range	2-36		1-36	

* = missing data
dx = diagnosis

a) Acknowledgement: Dr. S. Dibble provided the descriptive statistics.

The Interview

The Problem-Centered Family Coping Interview (PCFCI) is a semi-structured interview guide developed by Lewis (1986). Conceptually derived from both family systems and coping theories, it was designed to yield information about family coping strategies in the management of daily life and illness problems. First, the family is encouraged to brain-storm for "problems, issues, or challenges" of the past month and then to pick the most important topic for elaboration throughout the interview. Then, the family is asked what effect the problem had on them, what they did or tried to do about it, who participated in the doing, if their actions had an impact on the problem and how the family felt about their actions. They were questioned whom they let know about the problem and what their goals were for the future (see Appendix B). Despite its rigid structure (which was not always fully adhered to by the interviewers), some families used the opportunity to share much more than was asked for. (The instrument's use in Dodd et al's study has been evaluated and critiqued by Mapes, Price, Kesselring, & Dodd 1990).

None of the PCFCI's questions addresses the body or perception of physical issues. In the interviews however, awareness of bodily presence was high and seemed of paramount importance, once illness related "problems" were addressed. (Only two families, one in the small (N=18) and one in the larger sample (N=48) never talked about any illness or body related issues throughout the three interviews. I excluded their interviews from the analysis).

The weakness of these interviews is the interviewers' inattention to bodily experiences. More body-focussed probing would have enriched the interviews with subtleties and qualitative distinctions. Yet, the data gain robustness through the unsolicited, un-self-body-conscious description of bodily awareness and embodied experiences as manifested in daily life activities. Their richness lies in the "banality" of every-day talk. Bodily awareness sneaked into the discourse, but was not consciously constructed to satisfy interviewer questions. In other words, the experienced body was so powerful that it permeated the interviews despite body-insensitive questions.

Technical Aspects: Most of the interviews were done in patients' homes or in a place of their convenience (e.g. restaurant, room in the clinic or at the university) by two graduate nursing students. One did the interview, the other jotted down expressed ideas and contents in addition to taping of the session. All tapes (except a few technical failures) were transcribed verbatim or, in cases of failure, reconstructed from notes. All transcriptions were done in Ethnograph format.

Interview Analysis

This secondary analysis centers on patients' contributions to the interviews and takes family members' parts into account only when they added to specific patient experiences or their impact on others. Interpretation of embodied experiences was the aim of this analysis and interviews were used as textual analogues of lived experience (Taylor, 1985a). The following report is an ex post facto reconstruction (Dunlop, 1990) rather, than an analytical plan which was implemented.

Primarily, questions on how bodily experiences and meanings may be connected were stimulated by Merleau-Ponty's phenomenological conception of a body-world unit. Additionally, and throughout the analysis, questions concerning experienced situations and their existential meanings arose from the study of the data.

At their core, and most of the time, embodied meanings are subliminal, intuitive and thus, a-theoretical. Meanings inhere the words used and the things done by people, as well as their relationships with the surrounding world. Although a-theoretical in Dreyfus' definition of theory (1979) (explicit, universal, abstract, discrete and systematic), most meanings are shared, coherent within a larger understanding of what the body is all about, and minimally idiosyncratic. Therefore, meanings can be interpreted in their different qualities and connected to other dimensions of cultural self-understandings, for example how to know about, negotiate with, or control the body.

For the analysis of the interviews (not for the data collection process) I relied heavily on Strauss et al's methodological approach (Glaser & Strauss 1967; Glaser, 1978; Strauss, 1987; Strauss & Corbin, - 1990). Grounded theory, by definition, is "inductively derived from the study of the phenomenon it represents" (Strauss & Corbin, 1990, p.23). A theory's applicability to the phenomenon is judged by "fit, understanding, generality, and control" (ibid).

This combination of approaching mainly phenomenological questions with grounded theory techniques raises two major questions: 1) Can meanings be interpreted and theoretically explicated by using grounded theory methodology, and 2) How limited application of the methodology jeopardizes both the derivation of theory and the findings' credibility. The second questions makes only sense if the first one is answered affirmatively.

1) Every day understandings - they are webs of meanings - share

Strauss' and Corbin's (1990) definition of applied grounded theory. They fit (to a larger or lesser extent) and entail the meanings that make sense out of a situation. To the extent that meanings are shared in <u>similar situations</u>, every day understandings are general and allow for some control within situated circumstances. I understood experiences of lost taken-for-grantedness to be widely shared understandings which arose from experiencing a similar situation, but also as influenced and colored by the different conditions under which patients lived.

In contrast to every day understandings, grounded theory methodology leads to a <u>systematic</u> inquiry of situated, complex phenomena. Grounded theory, if it "fits" the phenomenon, <u>explicates</u> in detail what was intuitively known, but not fully and clearly understood. As a fitting <u>interpretation</u>, grounded theory makes explicit the details and relationships which, in (more superficial) every day understanding, remain hidden. Through its generality it allows for a more cognitive grasp of similar situations' complexities and also for more influence (control) on, or within such situations. The denser the theory, the better can the situation be understood. Evidently, <u>all theory is interpretation</u> (Rabinow & Sullivan, 1987). Strauss and Corbin (1990, p.27) emphasize the role of creativity in the break through from old understandings into new interpretations as a "vital component" of grounded theory.

In this study, experiences such as "I can" or "I cannot" (chapter four) were situations of immense complexity. They depended on bodily (and other) conditions, shared certain characteristics and varied within a multitude of dimensions. Bodily experiences provoked various self-body relationships (chapter five) and activities ("musts" or "have tos") such as gaining knowledge about what is happening (chapter six).

I understand this study to be *theoretical* in the sense that it attempts to shed light on some interrelated aspects in situations of bodily breakdown ("I cannot") as compared to the body's obliviousness in awareness during the "I can" mode. Breakdown situations *invite* analysis of their components. Analytical breakdown of complex situations is paramount for the building of a grounded theory. Theoretical intelligibility in this study captures what was pervasive and makes explicit, to some extent, the meanings inherent in the situation of lost taken-for-grantedness. Because of limited specificity and depth in interviewing, theoretical density, in this analysis, remains limited. While this study aims to contribute to a more sophisticated theoretical understanding of the experienced body, it is not a comprehensive grounded theory.

2) Even if my non-adherence to grounded theory's reciprocal data collection and analysis methodology were disregarded, there remains the philosophical problem of developing a theory out of, or within the realm of embodied, existential, never fully explicable meanings. For example, I cannot explain, but describe to some degree only why, how, or when women switched from one "I"-body relationship to another, or "surrendered" to a dying body's power (chapter seven). Indeed, these phenomena are core to what the experienced body *is*, but they can, if at all, only be alluded to in narrative form. Narrative, by definition, is *interpretative*.

Chapter seven contains the stories of six women. To the extent they seemed salient for the understanding of their experiences as existence (in a broken down situation), the narratives contain theoretical perspectives. In addition, I attempted to explicitly interpret some of these experiences as suffering by linking them, in part through the use of literature, to broader cultural understandings. In this (partially deductive) endeavor I deviated from grounded theory's mainly inductive) approach in which firmly specified linkages are unusual. Instead of enhancing the understanding of complex situations, these interpretations attempt to evidence glimpses of the suffering which inhered in breakdown experiences. These interpretations aim to give voice to what Taussig (1987) called the "mysterious side of the mysterious", but also, to link threads of individual suffering to broader cultural understandings. These intentions contain both, the risk for misinterpretations and a chance to humbly take part in these patients' suffering.

Using elements from both grounded theory and hermeneutic phenomenology seems adequate and appropriate for this study, because the experienced body is simultaneously foundation for situative and existential experiences. I approached the interviews with grounded theory techniques and the paradigmatic narratives by looking for concerns which appeared in many interviews, but were specifically salient in a woman's experience throughout the interviews.

In first time readings I used "open coding" and subsequently, "axial coding" (Strauss, 1987, p.27-34, 55-81) to find, describe, and conceptualize major themes. The "coding paradigm" (ibid p.27/28) (conditions, interactions among the actors, strategies and tactics, consequences) served with some modifications. For example, in many instances, the women were the only cognizant "actors" in these stories. Much of what happened for them occurred because their bodies appeared as different, their relationships to the body vacillated and their world appeared as changing as well. I therefore changed the meaning of "actor" to self, body and world and tried to grasp relationships within this unit. Furthermore, much of what these women did was not intentionally planned as would be implied by "strategies and tactics". Thus, I substituted "activities" or "happenings" to detect in the passages nonrational, often sub- or pre-conscious qualities of embodied reality.

The analysis moves by interpreting embodied experience from implied awareness to explicit knowledge about the body. Implicit aspects of changing person-world relationships (chapter four) are followed by more intentional endeavors, as bodily subjection to treatments impacts on "I"-body relationships (chapter five), and women's mostly explicit knowledge about the body (chapter six).

In theoretical terms, the three chapters are linked in the following way: With a changing body, a woman's world and self-understanding changes too. As one major consequence to their identity, self-body relationships appear as more conscious and, under conditions of perceived "I"-body separation, often as vacillating. Knowledge serves to deal with difficult embodied situations. The level of analysis in these chapters is predominantly descriptive; theoretical reflections are added in the form of summaries.

Chapter seven contains the interpretations of paradigmatic case studies. Paradigm cases (Benner 1985) are strong instances of particular self-body-world relationships. Certain "family resemblances"

(Kuhn, 1970, p.44) identify a paradigm "without agreeing on, or even attempting to produce a full interpretation or rationalization of it". Chesla (1988, p.53) pointed to the importance of paradigmatic case recognition, "complete with their saliences and nuances" by expert nurses for skillful and specific patient care. Likewise, paradigmatic approaches to a changing body illustrate specific cultural notions on how self, body, and world are related. Such notions were common in the self-understanding of many, but appeared with less salience than in the paradigmatic cases.

Issues Around the Study's Credibility

Credibility (Glaser & Strauss, 1967; Sandelowski, 1986; Strauss & Corbin, 1990; Corbin & Strauss, 1990) or truth value in interpretative work is achieved if descriptions (theories) are dense, substantive, easily understandable and make sense to the respondents, as well as to lay and professional readers. "Truth value" refers to the "answers" this study proposes to the "meaning questions" asked in this phenomenological study (Van Maanen, 1990). As I pointed out earlier, by offering one interpretation, other possible interpretations remained concealed (e.g. through my own situation), thus excluded from this analysis: There can be no claim to "truth" in an absolute sense. Nonetheless, findings can ring "true", or "right" to people whose experiences are recorded here or who had similar experiences.

After completion of chapter one I reported a synopsis of the findings, namely that the body shapes both the world and self's relationship to that world to Anne (paradigm case pp.265-280). She agreed by adding, that throughout most of her life she had tried to impose her mind and will on things and relationships until she learned, in the late stages of her illness, that her body was paramount in, and to all endeavors.

Jane's attitude towards cancer (paradigm case pp.230-243; 272-280) had challenged me because it was rather atypical of the sample. In order to not misinterpret her self-understanding, I asked her to talk more about her life and the illness' meanings to her. My understanding of her attitudes grew from these additional talks.

One reader who herself had had breast cancer found many of her experiences represented in chapter one. She pointed out, however, that not enough emphasis has been given to strategies of presenting themselves to others (e.g. through make up, careful grooming, constant concern on how they may be perceived by looking into the mirror). I went back to the data, but found minimal allusions to this very concern. Additional follow up interviews may have served towards adding more density to "musts concerning the visible body" and no doubt to other parts of the analysis.

Such deficiency in density indicates the extent to which this study does not fully meet the standards for rigor of grounded theory (Strauss & Corbin, 1990, p.249-258). Its methodological shortcomings affect the study's theoretical sophistication as a grounded theory where such refinement could have enhanced the elucidation of complexities in bodily breakdown.

Another strategy for improving credibility of qualitative work is triangulation, the use of perspectives from diverse angles, or different methodologies. The larger study (Dodd et al. 1986-1990) used 12 questionnaires to assess patients' and families' coping, among them the

"Profile of Mood States (POMS) (McNair, Lorr & Droppleman 1971). This 65 item instrument measures "six independent mood or affective states" (1. tension-anxiety, 2. depression-dejection, 3) anger-hostility, 4) vigor activity, 5. fatigue-inertia, and 6) confusion-bewilderment). Patients in the interpretative study spoke to all of these dimensions, but in ways which were related to specifics, or as pervasive background colorings in their lives. The instrument's decontextualized questions and ratings (0-4) did not capture the embeddedness of moods and emotions which invigorated or concerned patients in this study. Therefore, I did not attempt to use it in support of the study's credibility.

The consistent use of the active voice (rather than a delusionary "neutral" or "objective" passive voice) in the following reports is meant to remind the reader of this interpretation's situatedness and my responsibility for misinterpretations.

Summary and Outlook

In this post hoc presentation of methodological issues I first alluded to some epistemiological and methodological problems of studying the body as the source of embodied reality. Descriptions of the sample, the interview, techniques of data collection and analysis, as well as concerns about the study's credibility followed.

The next three chapters contain descriptions of three different dimensions on how the body appeared in the self-understanding of the interviewed women: 1) The body as foundation and source of life and shaper of one's world; 2) the body in subjection: "I"-body-other relationships; and 3) the body as it is known to and by the woman.

CHAPTER 4

THE BODY AS FOUNDATION AND SOURCE OF LIFE: SHAPER OF THE WOMEN'S WORLD

Introduction

The body as foundation and source of life and shaper of women's world, the body in medical subjection and "I"-body-other relations which follow, as well as the body as it is known to the patient, all are intricately intertwined dimensions of self-understanding. Any shift in one dimension has repercussions throughout, impacting the others.

These dimensions are not really distinct, except analytically. Like facets of one whole they overlap, constitute and contain each other, holding paradoxes and contradictions. Embodied life is multidimensional at any given time. Could we assign a voice to every one of its components, a multi-vocal symphony would sound unremittingly.

Viewed from the perspective of embodied human life, analytic differentiation of three dimensions and subdimensions thereof violates the very integrity of life's constantly changing, sometimes ambiguous, polymorphous quality. Taken for granted as background to and source for every day life, these dimensions may only infrequently and fleetingly enter full conscious contemplation. Yet, analytically they provide us an entry into furthering our understanding of life's complexity.

One of the striking features in cancer illness experience were the changes on different awareness levels of what the women had previously taken for granted. Suddenly, certain dimensions of embodied life showed up as more powerful, significant, and salient than before, while others lost their former importance.

Accounts of their daily life pertaining to illness and treatment mirrored accentuated awareness of bodily capabilities, realization of what the patients could or could not do, and how they felt. They gave considerable reflection to what needed to be done to the body to reverse, or improve bodily processes in order to "get back to normal". Like red threads these concerns will be seen to weave through this and the next two chapters. In this chapter I shall attempt to describe some of the foundations on which taken for granted life usually relies and how this basis became shaken.

Embodied Spontaneity: "I Can" or "I Am Able to"

Von Blankenburg (1982) called the body "organ of spontaneity as presupposition of the 'I can'" (p.18). In healthy days, abilities such as for example breathing, eating, moving, communicating, thinking, willing, or working are so pervasive and self-evident, that they elude full consciousness most of the time. Self-understanding is largely based on one's capabilities for participating in what is customarily done and what one self is able and used to do. The body provides the capacity to perceive horizons both interior and exterior.

Although "I can" may connote a more active, deliberate self-understanding as compared to "I am able to", which implies allusions to being and readiness for engagement of any sort, these notions will be used synonymously throughout this text. "I can" and "I am able to" always imply intertwined, self-recognized and assumed capabilities of physical, emotional, mental, moral, aesthetic, social and spiritual qualities. In its variations, reports on "I can" may include all qualities, or refer to mainly one capability (e.g. physical fitness).

Notions of "I can" capabilities include: Competence, mastery, expertise, ability, aptitude, faculty, skills, a certain kind of ease, and encompass allusions of such generative powers as energy, strength, will, or faith. "I can" appeared in the interviews either as a matter of oblivious self-evidence, or, after regaining their abilities following temporal loss, women mentioned capabilities with pride and other sentiments of satisfaction.

Abilities of unobserved, taken for granted quality varied widely. There were every day endeavors such as walking, climbing stairs, taking care of self, others, and things, working in various capacities, speaking and breathing, all of which rely on highly complex physiological processes. Physiological integrity allows for coordination, qualitative sensations, perceptions of vigor, self-reliance, and constitutes "I can's" foundation for consciously engaging in activities or to let things happen. "I am able to" indicated a woman's chosen, accepted, or just obvious involvement with her situation. It implied both options and possibilities to influence what happens to her, and impact on her world. It also signified being tuned affirmatively and confidently towards the world.

The more taken for granted and unchallenged that "I cans" were, the more oblivious were the women of them. But, certain competencies were developed for the sake of illness management: Changing diet composition and schedules, learning relaxation skills, or taking rest periods in order to adapt to the exigencies of illness and treatment. These new activities implied reliance on bodily signs, willingness and a hopeful conviction that the course of illness could be positively influenced through novel competencies.

Further, abilities included mental or spiritual aspects such as confidence into one's capability (e.g. of enduring side effects from CTX or pain). This reliance was founded, for three women, on their embodied memories of having undergone previous CTX or having been pregnant. Embodied memories of previous recoveries allowed them to hope that once again, things would turn out well.

Optimism regarding one's capabilities included the ability to anticipate treatment side effects and to be ready to take care of them; or the conviction that cancer "can be beaten". In this regard, abilities to alter previous attitudinal dispositions by "thinking positively", "straight", or "to accept what comes" opened up possibilities for intellectual, emotional, social and spiritual work that needed to be done. One woman felt good about having been able to convert her haunting thoughts from "I'm doomed" to a more hopeful and accepting "I am probably going to die" which freed her up to live for reconciliation with her disrupted family.

After a period of laborious or even lost capabilities, every day activities such as walking, taking a shower, enjoying food, breathing, or reading and thinking clearly, became events of deep satisfaction. Regaining them meant improvement and recovered self-confidence. Further, it meant that in patients' awareness, these abilities once again had grown mute by eluding full consciousness; again, they happened with ease. They were experienced in contrast to a past when engaging into these basic activities had become difficult or impossible. For example, the ability to return to work or previous activities after interruptions due to CTX was accompanied by satisfaction, joy, or relief. The ability to sleep after CTX, made one woman feel better and rested; meeting with friends banished another's loneliness; or "feeling strong, energetic and better" allowed one patient with advanced disease to "take charge of myself" again.

Through the "I am able to" the person is linked to her world. In healthy days, this linkage may go unnoticed, be buried in habitual routines. One woman welcomed the end of her CTX as "being able to start doing what comes easy and natural", indicating she was "back to normal". In these words "I can's" existential core seems to be captured: In the body reside those aptitudes which allow one simultaneously to be actively and receptively involved with what ever happens. "Normally" or "naturally" such involvement flows easily with only subliminal attention paid to it. Lived time and space are perceived through involvement. For this woman, her "normal" past appears again in the ease of present involvement. Yet, this very ease reminded her of the immediate past, when involvement had been un-easy and laborious.

The impact of advanced illness on the other hand, demanded full concentration and coordination of all of another woman's capabilities, in order to attend her father-in-law's 80th birthday: "I was determined that I was not going to look droopy and sick so I must have banked my energy somehow". Between the ability to do what comes easily and naturally and knowing that "I can" bank all energy with full determination, there lie variations from strenuous to effortless involvement.

The notion of "I can" is founded on wisdom that flows from past experiences. Simultaneously, it embodies present and future possibilities. This meant that having lived through several cycles of CTX, some women felt confident that they could "get through one more time", or "know that after four days I feel better".

"I am able to" is basic to self-understanding. From it emanates that sense of embodied knowing, which is experienced as predictability, security, and certainty, and which allows one to take self for granted and expect what comes to be manageable. Inherent in this embodied self-world relationship are senses as diverse as satisfaction, relief, happiness, energy and/or perceptions of mastery, power, or control. Closely associated with the "I can" is the notion of "making (it)", with its inherent meaning of achievement.

"I can" is carried by a sense of importance or salience since it connotes the ability to bring to life or actuality one out of several possibilities. Although the perception of possibilities within one's competency varies greatly among healthy people, awareness of limited possibilities seem to be both pervasive and at the core of illness experience.

"I am able to" transcends lost and limited possibilities by actualizing what is important and still, or again, within one's capacity. "I can read again", to one woman, released profound relief and was indicative of big improvements after death seemed imminent. To another woman, ability to slow down and pace herself meant that she could soothe the impact that fatigue from CTX had on her physical rigidness from Parkinson's disease.

It is the "I can" which transforms significant possibilities into the web of lived experience with its notions of reality and satisfaction. In brief, "I can" or "I am able to" embodies people's self-understanding, their involvement with and relationship to their world. "I can" is composed of physical, emotional and mental dimensions, all founded in physiological integrity. Rooted in "I can's" inherent sense of mastery, power and control are notions of self, autonomy and independence. "I can" grounds present activity in past experience and allows for the future to show up with some predictability. Through "I can", what is salient and meaningful can be lived. "I can's" notions of reality and certainty seem woven with threads of a more or less oblivious ease in the flow of activities. The world's possibilities are actualized into reality through embodied spontaneity lived as "I can" and "I am able to".

Yet, in the accounts of these women, "I can" was often thwarted or even muted by opposing forces expressed as "I cannot", and its correlates "I must" or "I have to". Just as yin and yang cannot be conceived of separately, "I cannot" is inherent in the "I can". Happiness, a sense of independence, or control can only be experienced when contrasting experiences of unhappiness, dependence or powerlessness also exist. It is through the "I am able to" that the body as foundation of life can be forgotten or neglected. Breast cancer illness however, with its life threatening potential, impacted these woman's self-understanding by bringing to awareness multiple "I cannots", "have tos", or "musts", inflicted upon them by either treatments and/or the progression of disease. In the following sections I shall outline dimensions, antecedents and consequences of the "cannots", "have tos" and "musts".

"I Cannot"

Cannots are part of human limitations. Human physiology limits the spectrum of what can be perceived and the range of possible activities. Unlike bats, humans cannot fly, nor have they a radar like organ to detect very high frequency waves. From elephant seals we differ in that we cannot swim as they can, nor can we survive several months in abstinence of food and liquid, while we give birth, lactate, and mate.

Limitations have been major motivators for finding or inventing ways to overcome them. Collaboration with others and the use of technical aids made human enterprise powerful and world transforming. Major bodily limitations have been overcome, compensated for, or placated with medical-technical assistance.

Cannots reported in these interviews were not always founded on bodily un-easiness. As many as six families (33%) reported more or less severe financial limitations which they perceived as overriding all other concerns. Financial and social wealth or hardships impacted patients' possibilities to deal with bodily promoted cannots and these in turn hampered their prospects to earn livelihood and forced them to rely on others for help.

This analysis focuses on cannots which have their primary source in the body. Financial and social resources enter the analysis marginally as they impact upon patients' prospects. Prior to their cancer diagnosis, 14 (78%) women considered themselves as healthy and able-bodied. (However, two patients suffered more from the limitations of their Parkinson's disease than they did from cancer, one woman had diabetes mellitus, and one had previously had a malignant thyroid tumor).

Bodily Sources or Components of the "I Cannot"

Cannot is sensed, felt, or known through lacks or losses of different qualities. By their absence in the cannots, "I cans" foundations showed up. For example, erosions on energy, strength and faculties manifested themselves in weakened or faltering skills, aptitudes and expertise. Consequently, the certainty of one's competence wavered and so did, often times, trust both in self and faith beyond self.

The following paragraphs will describe how distinctions within the existential experience of "I cannot" showed up as decline in energy or strength, in changes of the ease or difficulty with which activities could be done. Further, I shall point to how emotions and moods shifted, how senses of time, space, knowing and certainty changed, and how patients' possibilities of being involved with and in their world became altered. From these changes emerged different or new saliences in what was important. Patients also yearned to regain lost possibilities.

Cannot may be brought forth through weakened, lower or lost energy or strength which impacts the capability to be active. Patients associated their weakness, usually in causal relationships, with any one or combinations of their losses of appetite, feeling nauseous, bad, fatigued, or indisposed from CTX. In cases of advanced disease, pain and dyspnea contributed to, and exacerbated these combinations. Cannot and its imperative sequelae "have to" and "must" had repercussions not only for the patient, but well beyond her.

Because the source of cannots was in the bodily impact of illness and/or CTX, cannots manifested themselves in all facets of daily activities, physical, emotional, mental and social. Cannots varied from all encompassing incapacity to minor discomfort in just one dimension, like increased fatigue. Strong emotions colored highs and lows as women vacillated between "I can" and "I cannot" and experienced cannot's dimensions over time.

It is in the breakdown that "I can's" constituents entered awareness and became pervasive in a woman's life. Intricately intertwined and complex, different dimensions of "I can's" breakdown became more or less prominent, and varied in acuity over time. Prevalent throughout the interviews were notions of lacking energy, difficulties with eating and almost constant fatigue. Pain and soreness appeared in cyclic episodes in some women who were newly diagnosed and underwent treatments for the first time, while pain became a theme in late stage disease. Changing in their prominence and varying in their mitigating or exacerbating cause-effect relationships, energy and strength, tiredness and fatigue, eating and drinking, as well as pain were associated as generative forces for the "I cannots". I shall now expand upon these bodily phenomena.

<u>Energy and Strength</u>. Energy and strength showed up in awareness as they departed from previous availability. Energy was referred to either as (lost) possession like "I didn't have any energy", or as an attribute and quality of being like "I feel strong and energetic again". Energy as possession I shall call reservoir-energy in contrast to energy-of-being.

The possession of <u>reservoir-energy</u> signified a kind of fuel or charge, which could be saved, retained, or replenished. Analogous to one woman's concept of banked energy, possessed energy was frequently talked about in quantitative terms. As if women indeed owned an account with a constant balance of more or less energy over time, depending on their expenditures or savings. Congruent with this conceptualization are strategies to save or replenish energy, or to wonder how long energy would "hold out".

Energy saving or retaining strategies included purposeful expenditure of energy for fewer but more important or warranting activities; relying on others to help or take over; and pacing the activities to be done. Replenishing endeavors were mostly concerned with food intake such as eating more, adding special ingredients, or changing from "junk" to "healthier" food. Energy regeneration was complemented through sleeping or frequent rests.

Inherent in the notion of energy-of-being were qualitative distinctions such as feeling weak, strong, tired, sick, good, better, or great. In contrast to the understanding of energy as reservoir for activities, strength and energy-of-being connoted health, wholeness, alacrity, vigor, or life. Yet, like reservoir-energy, notions of weakness or strength were used comparatively. They contained implicit references to previously lived experiences. Reflecting on weeks of severe illness exacerbation one woman said:

> The two months previous to that [onset of using experimental chemotherapy drugs] just everything seemed to be going to pieces. I couldn't remember anything, I didn't have any energy, I couldn't read. That was one of the real frustrations that my mind couldn't even concentrate on TV. We all figured this was it. It just did not look good at all.

She alluded to both aspects of energy in this passage. She had known herself to be whole. Utter devitalization showed up as "everything... going to pieces". Even minimal links between her and the world (reading and watching TV) had fallen apart. Extreme depletion of reservoir-energy impeded her to take in and get involved with what came from the world around her. Further, her world had closed in upon her as she had lost the possibility of taking showers, or walking three steps to the elevator. It was the loss of her vital ability to engage in basic daily activities which indicated a turn for the worst.

In cases of such energy exhaustion, taking care of self through saving, retaining or replenishing reservoir-energy was either problematic or impossible, because anorexia, the inability to regenerate through sleep, or the loss of energy for willing, had profoundly devitalizing effects. At such times, hopes were thrust upon medical interventions for either reversing energy depleting processes in the body, or for relief from the suffering that inheres in such loss of strength.

Energy, in both modes, was experienced through its fluctuations. If at all, it rose to awareness or recall through one's involvement. It was through daily skilled performances or their breakdown that energy and strength got acknowledged and thus interpreted. Closely linked to the ups and downs of energy and sometimes almost synonymously used for description of how they felt was the experience of fatigue or tiredness with its urge for rest or sleep.

Tiredness and Fatigue. Energy and fatigue related inversely to each other: As energy diminished, fatigue increased and so did the urge to rest. The reverse is true as well. Some women with other than mainstream cultural awareness (Chinese or Greek people or women of low or marginal socio-economic status) spoke of fluctuations in fatigue rather than perceived changes in their energy levels. Language limits associations of fatigue and tiredness to the being mode. There is no possessive use of the concept. No one says "I have tiredness or fatigue". However, "I am tired [for x time] after chemotherapy" or "I feel fatigued all the time" were frequent comments. Feeling or being tired was thus synonymously used as diminished energy-of-being, while a relating concept to reservoir-energy was absent. Feeling strong, good, healthy etc. were fatigues' yang-associates.

Sleep represented hope for regaining strength, as well as for relief and escape from nausea and weakness. People developed new patterns of sleeping or resting during day time and many at night as well. Sleep allowed for a welcome, regenerative withdrawal from the world. "I sleep all the time after treatments. I come home and sleep. About five hours after that it'll be okay".

But the sanctuary of sleep was not always undisturbed. Prescribed high liquid intake interrupted sleep through the urge for frequent urination; nausea, pain and feeling bad impacted upon sleep as well. A strong craving for sleep caused women to always consider a place's suitability with respect to retiring for a nap. Considerable arrangements were made to allow for resting periods during the day: Women quit working temporarily, one boss arranged for a cot to be brought in for the employee, children were sent to grandmother's house in order to reduce disturbance during day time naps. For many, in a sea of countless cannots, the ability to sleep stood out as an isle of comfort. This ability was, if necessary, enhanced with medication.

Quite different in quality from tiredness and sleep were experiences with appetite and eating. Fatigue appeared as appetite disappeared; while sleep remained within the possible "I cans" for most women, the ability to eat vanished into the realm of perceived cannots.

Eating and Drinking. Familiar embodied activators like appetite and thirst vacillated between different qualities; sometimes they disappeared temporarily, or for good. At times, eating grew erratic through anorexia, dislike for certain foods, or sudden unpredictable taste changes. Eating developed easily into an instrumental strategy for goal attainment, with the goal being the maintenance of energy or prevention of its depletion. Eating, following CTX and in advanced illness had lost its joyful, satisfying and social qualities. Foods showed up as tasting differently. The certainty of previous preferences or dislikes disappeared. While in the cannot mode, none of the women talked about eating as enjoyable. One month after the end of adjuvant CTX one woman reflected:

> Food does not interest me at all right now...There is no nausea. It's not that. Food is just not interesting to me. And I eat because I have to, not because I like it. And a lot of things I can't stand the smell of, like fish, for example. It just turns me off - and lettuce taste like metal to me. There are a lot of things that still taste metallic after all this time.

Prescription of large quantities of liquid to prevent possible kidney damage from CTX made drinking a "must", to be monitored cognitively as thirst and desire to drink had disappeared. Drinking was usually perceived as one more "have to" rather, than a satisfying pleasure.

> I'm a great water drinker. Now I can hardly get it down even though I know I'm supposed to drink...[The] biggest problem is getting water down...Right now, water makes me vomit...I could not get the water down. The last couple of chemos were rough.

Eating and drinking thus became a major struggle for patients and the families who tried to make them eat. Often, these efforts were aggravated by mouth sores, stomach aches, or digestive troubles from CTX. There was widespread strain around food preparation for the family or for self: "I'm not interested in getting dinner ready when I'm on drugs. I don't feel like eating, but don't want to go out either...". Some patients forced themselves to overcome their aversion against eating and for the most part, family members took over food preparation. They took great pains over enticing the patient to eat, often imploring her to counteract loss of strength through eating.

Effort-laden eating is expressed in the image "I could not hold anything down". Keeping food down is no longer a spontaneous act to be forgotten as soon as the piece of food is swallowed. Rather, it is a consuming endeavor, and a constant reminder of food's presence in the stomach. The effort to keep food down became augmented and simultaneously thwarted in the struggle to contain eruptions of vomiting. In the experience of a Greek woman who experienced progressing disease:

> There was to me the feeling of wanting to throw up all the time. You know how it feels to feel like you can't even feel like you can do it (throwing up) all the time? It wears me out, it takes my strength away whatever I have left. I can't eat.

Changes of taste, perceived nausea and the urge to vomit are all bodily, as of course is smooth unnoticed digestion. Not only did these symptoms dramatically deprive a woman of her ability to enjoy eating, but they contributed to the spiralling effect of simultaneous, paradoxical energy expenditure and energy depletion. Trying to keep food down, or the physical effort of throwing up, taxed their already sapped energy. Under the influence of CTX and in advanced disease, eating thus became a problematic source of energy renewal. Worse yet, in cases of advanced disease, weakness and anorexia were accompanied by considerable wasting away of body mass.

If people are - as the proverb suggests - what they eat, then being unable to eat added to weakness a pervasive sense of powerlessness. In the words of the woman with recurrent disease who had experienced a severe, temporary exacerbation during which "half a bowl of rice was a big meal":

> I just can't believe this, that I just cannot make myself feel better. It was one of the most frustrating feelings in the world because throughout these ten, twelve years [of cancer] I've been able to just grit myself into doing better and [this time] I really couldn't. I lost 18 pounds in 10 days. I had no energy at all.

Her wasting was the embodied witness of pervading, spiralling powerlessness: Inability to "make" herself feel better was based in, and exacerbated by, the body's repulsion of food and sprawling weakness.

<u>Pain</u>. Abilities to eat or sleep were often associated with the presence or absence of pain. The web of "I can's" bodily limitations contained pain as yet another thread. Manifold were the qualities of distinct pain mentioned. Mouth soreness, stomach "trouble", "problems", "hurt" or "pain", painful, limited movement in the arm after mastectomy or excision of lymph nodes, pain from the implantation of a porto-catheter, and pain from bone metastases each limited the sufferer. Cannots resulting from pain hampered or restricted: Eating customary food, chewing, sleeping, bending over, movements in general, and using one arm specifically. Of course, pain medication was available. But it forced patients into decisions of balancing the drugs' unappreciated side

effects against its benefits. An unsettling back pain has:

> limited what I can do. I've been taking Tylenol #3 which takes care of the pain - but makes me dopey, less sprightly, less energetic, euphoric.

In many cases, either pain and/or analgesics were added into the vicious cycle of energy depleting experiences, and thus intensified limitations of bodily abilities.

Patients and families, however, employed with more or less success an array of measures to prevent, soothe, or heal ailments, pain and indisposition. Ultimately, all of these endeavors aimed at maintaining current, or restoring lost, "I am able to" possibilities.

Deeply embodied strength, tiredness, pain, and feeling "wiped out" were sources of (temporarily) curtailed possibilities in these women's lives. Their vacillating experiences between "I can" and "I cannot" had infiltrated such existential sources of regeneration as eating and sleeping. Yet, repercussions of switches between being able to and not (any more) being able showed up in people's understanding of their changed reality.

Reality is an almost fleeting, yet persistent composition of activities, a sense of time, space, trust or certainty, as well as of moods and emotions. Self-understanding, or one's involvement with reality, is what emanates from activities which either are "I cans" or "I cannots". In the following section I shall describe the impact of "I can's" breakdown on patients' sense of reality. Reality was reflected through issues around activities such as eating, resting, mental work and the ability to move. Actively embodied are the senses of time, space, and certainty.

Reality as Shaped by the Embodied "Can" and "Cannot"

"I can" is always enacted. From the wealth of past activities and involvements flows today's and tomorrow's taken for granted confidence that the world is open, accessible, manageable and events can be anticipated. Activities are the substance of knowing oneself (and others of course). There are no human activities without extensive, complex bodily involvement.

Reality Mirrored Through Activities

Intellectual work like thinking, concentrating, memorizing depend on neurophysiological integrity. For the women interviewed, as CTX went on over months, certain declines in their mental capacities like remembering things, or concentrating on administrative work worried them, their family members, and co-workers. For example, what used to be easily retained by memory needed now to be written up in long lists. As mentioned before, one employer provided a day bed at work for the patient to rest when her attention failed and exhaustion took over.

Another boss, a lawyer, went to court once on a wrong date because the patient had "screwed up" his scheduling. A mother of two young children felt satisfied with her administrative work. Exhaustion and failing concentration forced her to seek sick leave. She commented:

> The problem with me is stay at home - I just can't do that. I'm not a housewife....I'm not a cleaning person or a stay around the house. I gotta get out. I just go crazy in here.

and six months later, after she had returned to work:

> I had a rush job to do yesterday by 12 o'clock. I did it, after that I was sweating, and then I had a headache....I just want my energy and my mind back and my hair!

Energy, mind (and hair) constituted who she was through her work.

Soliciting empty walls and cleaning tasks at home, however, pressed her hard into being what she "just cannot do". Here, "cannot" strangely, but logically, refers to what she is _able_ to do, had she understood herself differently - namely as a housewife - through doing these very chores. Unfortunately, decorating walls and cleaning house were exactly those persisting reminders of what had vanished: Her energy and mind, the powers which permit her to do well at what she loves to do. At home, lacking energy for and elusive concentration towards household chores hardly disturbed her. Yet, they deprived her of understanding self as a competent, successful member of a law office team. Constantly there, inherent in house work, lurked the reminder of who she is _not_. She fled home as soon and as often she could and relied, even more heavily than before the onset of illness, on her husband and parents for child care, food preparation, and keeping the home afloat.

Fluctuations in mental capacities occurred over time or suddenly. Sudden spells of deterioration in close association with recent CTX treatments were reported as dizziness, "almost at the edge of fainting", or as fainting by three patients. One woman said: "I went crazy...got kind of violent". Her family described her as "delirious" and having "hallucinations". She continued: "I was not sick, but for four days I was just in another world...everything was blurring...". Seeing such mental deteriorations happening scared the families and elicited supportive, protective or help seeking actions from them, while the patients were temporarily "in another world". Reality, for a short time, might have lost its grasp on these women.[9]

Reality, projected from the world of one's involvement is authoritatively, but by no way exclusively constituted by mental capabilities. The ability to move, from simple to complex motions, powerfully anchors involvement with the world in the body.

Arms link people to their world. An abundance of activities are generated by the incredibly skillful use of the human arm and hand. Lymphedema in the arm of the afflicted side hampered its use in the whole range of its motions:

> I think the main problem for [patient] and for me has been the edema in her right arm which is not seeming to be relieved...it's becoming a real concern because the longer this goes on the more permanent the damage is going to become.

Moreover, the arm's awkwardness potentiated its already augmented vulnerability:

> I cut my finger on a rod that was sitting in the middle of the hallway...I have been panicked about this for two days. Any other time I could nick myself on this hand and not even think about it. My doctor said the key thing now is infection - I do not cut anything - cuticles, fingernails, do not cut anything. Then I get this and watch it.

Loss of agility, altered sense of configuration and its constant, subliminal reminding presence in daily activities let lymph edematous arms infiltrate awareness in ways that at once impeded their previously taken for granted use, but also made it a maladroit bodily part. Vacillation between care-full use of the arm and over using it had consequences in both modes. Repercussions involved more dependence on others to carry or move heavy objects, heavily relying on the healthy side (with the

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[9] Buytendijk (1967) pointed to fainting as a specifically human capability unknown to animals.

potential to over extend it) and to jeopardize the edematous arm's future mobility and integrity.

Two patients alluded to their inability to bend. Yet, bending, widely integrated in movements, is a major way of locating oneself in the world. It is central in an abundance of motions which, in the daily flow of practices, constitute reality. In one instance, this elementary movement harbored the possibilities of caring for self by dressing, bathing, or grooming self. For another woman, bending had allowed her to relate to, and create her world through gardening. As pain from bone metastases or pleural effusion inhibited bending, taking care of self grew into an effort-full, tedious process. The loss of capability to bend in association with garden work, became a world constricting force to another woman:

> The neighborhood changes so often I really don't get to know too many people...because I don't go out and garden like I used to. I used to love gardening, but I can't even bend down to do that anymore.

Bending allowed for satisfaction with gardening, which in turn meant meeting new people and keeping up with the changes in the neighborhood. Inability to bend removed her from a fulfilling activity and from the space in which she used to meet others.

Sense of Space. Intrinsic to activities is a sense of space. Space, as experienced by these women, was not made up of abstract distances, depths, plains, or heights. Rather, it was coherent through its sensory appeal, by what it looked and smelled like; the noises that emanated from it; by the textures of space and the movements it elicited. Place was shaped by the intensity and meaning of involvement with people and objects. It appeared in sequences of movements, positions and as occupational flows. Further, bodily mobility made space show up in transient qualities. Activities were both grounded in spatial coherence and transition, and at the same time, were constitutive of these spatial qualities.

Certain components of eating had become problematic for most patients. Under the influence of chemotherapy distinct food smells changed in quality from unobtrusive or attractive to repulsive. The kitchen, the place for food preparation with its abundant smells, repelled the women with disgust for two to five days following treatments. Locations with food dominance such as restaurants or grocery stores were shunned during times of nausea. Family members had frequently no choice but to take over shopping and meal preparation, or to go out for meals. Relieved, one woman said: "The godsend is, I appreciate his [husband's] going out to eat because last time, odors were a real potential problem". In addition, her social place in shared meals remained empty at times, when she fled odors, or just the sight of food.

The urge to vomit exerted a force that both limited and rushed movement through rooms in the endeavor to find a safe place for the eruption to happen. How successful activities such as reaching a place or a basin, protecting the area and self, cleaning up if necessary, rinsing the mouth, or returning to a previous room or position could be, depended decisively on the woman's strength.

Sleeping's close association to place and space is appreciated throughout life. Although bedroom and space in bed seemed unchallenged for many of the patients, at times couples slept in different rooms or separate beds. One patient had moved across the continent to live with her grown children for the duration of CTX treatments. Often she found herself without a place of her own into which she could withdraw. Another patient's bed had been moved into the center of the living room in which the family gathered. There she was constantly surrounded by, but also exposed to her daughter and small grandchildren. For both women and their families, crowded space contributed to tense relationships.

Lethargic thoughts, difficulties in concentration and recall, a blurred grasp of content while reading or watching television, tended to transform the mental realm into a barren world. Depleted of excitement, fascination and the ability to get involved in and connected to cognitive endeavors, mental activities narrowed both in scope and depth. Describing her second and third day post CTX, a professional woman implied the shrunken radius of her world by mentioning her only two activities: "I can watch some TV. That's my distraction, or badly [worse], the desire to go back to sleep...I try to sleep as much as - if I sleep, I love it." Two spatial possibilities were left: Either sit in front of the TV-apparatus which predetermines one room, or to retreat into bed, that minimal space needed by a stretched out, sleeping person.

The more that an office or garden had been places of fulfilling identification, the stronger were feelings of frustration or loss. In their own homes the women felt enclosed and excluded from their worlds of work or neighborhood. Space and activities are so closely fused, that a patient who had come out West for treatments was unable to assess if she was able to work or not:

> It's hard to evaluate because I'm still down, not as bad as last week. Back home I know at what level I can function. I really feel I need to get back what I lost. I don't feel like I belong anywhere. I'm doing day by day. I need struc-

ture and routine.

Her inability to evaluate her "level of function" implies the broken down cohesion and consistency of previous active involvement with the space of her habitual world. Belonging implies a spatial relationship of ease and satisfaction: Neither was she really part of her grown children's lives, nor did her cyclical treatment activities elicit that sense of routine which would help her feel as belonging.

All women, without exception, received pervasive, ambiguous cues about themselves from activities in clinical settings. In chapter five I shall describe these experiences in more detail.

Cycles of CTX challenged or broke down the coherence of spatial attraction as sensual qualities, like smell and taste, changed. Also, experiences of transient space became fewer, as nausea worsened, or mobility weakened. Breakdown may be partial, as when certain kitchen odors repel. After airing and cleaning, it may again be a tolerable place to be. Disintegration of space was all encompassing in spells of dizziness or fainting. Breakdown of spatial possibilities may happen suddenly, (as when throwing up forces the woman into one place above all others), or gradually, (as declining energy to propel self into space narrows her reachable radius). Intricately associated with and inseparable from activities and space, are senses of time.

Sense of Time. Time was a pervasive theme in these interviews. It was alluded to in different dimensions: As calculated in units, as patterns of activities and happenings which allow comparison from one time to another, as a "container" (Helman, 1987) to be filled or emptied, as a resource to be used, as a flow that links present to past and future. Features of all these dimensions made up a highly complex embodied sense of time. In a couple's description of CTX, different aspects of time were mingled to join into a picture of pervasive time awareness:

> But the pattern 's a little bit different each time. The last time I went through chemotherapy, it was only two days of kind of being sick. One night and all the next day. I'll be a little slow getting my energy back. I had more energy problems the last time than I had this time. I mean, I'm out four days and it's really bad, and then on the 5th day...I try to take a little easy on the 5th day, but by the 6th I'm running again, and the last time as the treatments progressed, I really lost energy...

Her husband added his impression about her second and third days:

> You are well enough that you get real bored and real impatient, but you [are] still not in any real situation to read...you just don't have that kind of concentration.

On one hand, "I cannot", provoked by CTX, became a calendar of reoccurring progressions e.g. from sleeping to watching TV to reading. On the other hand, the very activities through which time was lived served as constant reminder of the body's paramount involvement in all things done.

Ordinarily, for healthy people, it is highly unusual to talk about units of time spent urinating or having a bowel movement. Taking care of these urges is rarely accounted for, either by time spent per activity, or by their frequency. Vomiting shares with the above their involuntary, urgent quality, while nausea has an all encompassing pervasive presence. For these ill women, nausea and vomiting became demarcations of time through which hours, "whole afternoons", days or nights appeared and were counted. CTX stood out as decisive force, forcing time management in an ebb and flow pattern: There was the "before", often filled with a whole spectrum of work, business and enjoyment. Any activities that relied on "feeling energetic" were squeezed into the two to three weeks before. The week or two after CTX, however, "was just not a good time", a time, in which patients "felt wiped out", "consumed", "bad", etc. This time had, to many patients, a taste of emptiness in which boredom lingered and "needs and wants" predominated in their capability to get involved.

The body's memory of "déjà vécu[10]" allowed for comparisons between familiar and foreign experiences throughout time. At times when patterns of nausea, low energy, and elusive concentration were similar from cycle to cycle, patients felt confident to anticipate their level of possible engagement in "the time after". This was not true when reactions to treatments were erratic from one time to the other, or in periods of illness exacerbation.

Time was understood as both a resource to be used and as a chance:

> I'd like to spend more time with the kids because now I see that we ought to spend time as a family, going out here and there and taking time out. We're always doing something separately - taking more time out with the kids, cause I've been in a spot and there's a chance that I may not be able to...So I see that I'm not spending time as a family as I really should. That's what I feel.

Another young woman who "was depressed constantly before I got sick" "stopped feeling depressed because I didn't know how much longer I was gonna be around". In such instances, present bodily strength and its relative integrity opened up dramatic new possibilities in a future which suddenly appeared as finite rather, than endless.

Future possibilities did not always appear as chance. Within the

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[10] Lived before

body's yin and yang capacities, future prospects also lurked as fears of doom, thwarting hopes to be fulfilled, plans to be executed, confronting the sufferers with the time ahead when the "body gives up". Further, future time appeared as a measured, but unknown entity calling to be filled:

> I have the impression that I have no more time for what I should do...in another way I had the impression that my life was really empty and that I was filling it with that type of things [diet, therapy, support group] just to make it more full.

The enigma of future actuality, however, could only be assessed as it became experienced and certainty grew, as experiences were compared over time to past embodied memories. After a severe exacerbation, it took a month for one woman to assess her newly regained possibilities: "...Just to be sure that this was not just a fluke - that it really was a real remission as it were".

At the same time the future showed up as chance within possible doom, the past gained status as a safe and secure rock of taken for granted life. Yearnings included "getting back" to times and places, as well as regaining lost embodied capabilities in the realms of mentation, energy, mobility, appearance, and feeling at ease. The past stood out as harboring all of those temporarily or permanently lost possibilities, of which the present was depleted. For many women who were recently diagnosed and underwent CTX for the first time, the months of treatment shrank to merely a time of "getting through". Getting through implied a return to better times. Usually, the future was foreseen as a continuation of pre-disease past, a time full of potential, to be guaranteed through recovered bodily capabilities.

Frequently, the present of "getting through" was perceived as a "disruption" in the flow of time: "The last six months [of CTX] were merely a stopping point". Disruption and continuity, however, needed not be mutually exclusive. They had joined paradoxically in one woman's experience: Shortly before she assessed a standstill of time, she had looked back into this period saying: "I got kind of old...complained more, bitched more". While her outer time had stopped, her inner age, perceived bodily time, had rushed on. In the flow of possible activities time gushed or trickled, often both simultaneously, but in different dimensions.

In younger women, the body's inner age leaped by years into CTX induced menopause. Continuous use of one drug and bothersome hot flashes reverberated into the circadian rhythm: "Tamoxifen makes me wakeful during the late morning hours, about three o'clock. I'm usually awake for an hour or two and then go back to sleep". Bound to the body's (neuro-hormonal) rhythmicity, day and night time appeared in new dimensions as the body suddenly aged.

In embodied senses of time, such as patience or impatience, boredom or excitement, varying aspects of temporal dimensions are joined. These senses evolved from the intensity with which activities could be (or were) engaged in. Energy, skills, concentration, as well as some dedication are mandatory for any involvement, active or receptive. As CTX or progressing disease eroded some of these bodily anchors of involvement, qualities of being-in-time seemed to change. Impatience or boredom tended to creep up in instances where patients had hitherto understood self as able to determine how their time should be spent, or with what it might be filled. Impatience or monotony seemed to reflect a paradox: Loss of assumed mastery over the quality of one's time, and simultaneously, distancing self from what happened. In instances when the women were able to get involved receptively through their readiness "to accept what comes" their embodied sense of time vacillated between patience and endurance.

Past activities and present experiences secured a certainty which contrasted powerfully with pervasive future apprehension or concern whenever "cannots" thrust aside competencies. Both ability and inability to project tomorrow's possibilities originate in the body's capacities to allow for, or thwart the "I can".

Sense of Certainty and Uncertainty. As certainty, taken-for-grantedness' anchor dwindled and uncertainty unfolded, distinct dimensions of uncertainty confronted patients. Bodily reactions to CTX and illness progression weakened patients' ability to trust in themselves. Confidence in their abilities to engage in life's challenges vanished as energy for the "I can" was lacking. As the body's clues in taste and smell changed, eating became an erratic, uncertain endeavor. From the inability to engage in mental or physical work emerged the loss of that security which emanates from belonging to familiar social settings. Time perspectives became inconsistent as past and present lost their touch of safety and future lurked in its unpredictability. The stronger these certainty pillars became challenged, the less coherent seemed the woman's world: "Everything seemed to be going to pieces". Growing uncertainty fostered patients' resorting to cognition in search of new information and/or an altered self-understanding.

Certainty was experienced as embodied actuality. For newly diagnosed women, at uncertainty's core were questions such as "how will the body respond"? What treatments are mandatory to cure the cancer? "Gray areas" of anticipated physical responses to CTX referred to loss of hair and impact of nausea and vomiting. Uncertainty around alopecia varied: What were the odds of losing all hair as compared to "probably have hair thinning"? What would she look and feel like without or with short hair?

> I have suffered because of the fear of having my hair gone...I like my hair fine. I like it. It's fine, but I didn't know that I would like it until I cut it.

There is no certainty, but fear and alarm in anticipating a not yet embodied loss. Inherent in her liking how she looked with short hair lay new found self-security.

After disease recurrence, the worrying question was if the body would respond at all and for how long treatments could halt or reverse progression. As this question haunted her, pervasive loss of self-confidence was expressed by one young woman with recurrent disease: "I wanted to try to find some work and now I feel too insecure and I don't know what tomorrow will be so I cannot engage myself".

Uncertainty pervaded in the breakdown of activities. Uncertainties around eating contained aspects of food qualities and quantities, as well as where and when it would be timely to eat at all. Discourses around eating mirrored the shakiness of strategic eating regimens when confronted with the body's arbitrary, yet arbitrating power of liking or refusing foods. Floundering hunger became quite predictable as a consequence of CTX. As disease advanced, cravings showed up in anticipation;

but when the look, smell, texture and taste of food actualized these cravings, patients often experienced bodily repulsion. They stopped knowing what they wanted: "What do I know...what was good yesterday is bad today". As hunger and eating were no longer synchronized, previously self-evident routines and embodied patterns associated with (shared) meals became eroded.

Energy fluctuations could be predicted, to a certain extent, by women who had CTX experience. For certain patients, an inability to predict what activities they would be able to perform was the only predictable aspect of their outlook. For others, predictions faltered when nausea and vomiting patterns changed, when their ability to sleep or eat altered, or when new drugs were used.

As long as pain occurred in patterns and from known sites, patients retained some power of prediction. Uncertainty was compounded by

> not being sure really what it is - there is no pattern...it comes and goes. Sometimes I think that I'm imagining it...- and then it begins again. So I know it's not in my head.

Certainty and uncertainty vacillated around pain. Is there actually pain or is it imagined? Certainty appeared in grades and in different dimensions: Once pain was sure, its actuality still left open possibilities for involvement, the body's reactions to analgesics, as well as the intertwined relationships between these aspects. And, what is this pain's meaning in regards to diagnosis and prognosis? In Rosenblum's (1988) words: "You are bombarded with sensations, which come from within, but which are not anchored in meaning". The familiar "language" of bodily actualized meanings had grown dumb, leaving a vacuum of pervasive uncertainty of ambiguous or unfamiliar meanings.

Not only is the body a foundation for confidence as action, but it is the condition for the security of belonging to a world through embodied involvement. As bodily incapacities impeded patients' work or living in familiar settings, their self-understandings became shaken. Lost security of belonging was yearned for: "Getting through" implied that there was, in the past, and will be in the future, a safe world for being again the persons they knew they had been.

As if lost embodied actuality and security could be replaced, patients tended to resort to factual knowledge about their condition. This attempt to gain certainty through learning to know the body and one's future chances was so pervasive, that I shall deal with it separately in chapter six: "Knowledge about the body".

"I can's" dissolution into its integral, bodily founded dimensions was accompanied by intense feelings of emotional and mood changes. It is to the description of these feelings that I shall now turn.

Emotions and Moods

Emotions and moods permeated whatever patients did or what happened to them. Mostly they were not spoken of as an individual issue. Rather, they were perceived as climates that pervaded couples' and families' activities and relationships. As one son said:

> I think it's an emotional roller coaster. I think when time gets tough like this, I guess you'll have high points and low points. Before my mother was sick, we were just on a steady plane. But now...we're certainly happy and then next thing we know we're feeling pretty sad about it...up and down.

Moods and emotions varied qualitatively, over time, and in association with events. Comparable to varying light colors and intensities in which things show up differently, there were basic moods which tuned people (like violins) towards the world. Things happened in the light of these background moods.

Illness awareness resembled a dark ambiance, always in the background. It was not fully clear if this murky ambiance was part of themselves, or if it came from outside. The mind seemed to be a favorite locus for that ambiance's internal residence. Alluding to the uncertainty of illness' outcome: "It's always there - it never leaves you...it's in your mind"; or, reflecting back on six months of CTX:

> ...why talk about something in the past that you really want to forget about, knowing that you'll never forget about it, but talking just keeps it going, and there's no real value in doing that.

In these instances, "it" (the awareness) had become embodied, imprinted in the (brain's?) cells to such an extent, that forgetting had become impossible. "Its" light quality had changed, the world showed up in darker shades than before.

Reflecting the being mode of "it", people talked about "being worried" or "concerned", a stance profoundly different than "having problems". One family explicitly pointed to this distinction by saying that they had no problems, but that they were worried.

A more external stance was reflected by one couple who perceived their situation as "gray area" of "high ambiguity" that "caused perpetual anxiety". Looking forward to times beyond CTX's termination, she said:

> We've had some rough years and so I'd like to have a boring year...a normal, but uneventful year. I'm hoping that I don't have any emotional traumas. Just being able to start doing what comes easy and natural...

Here, emotional traumas appear as owned transiently, inflicted by gray ambiguities during abnormal times. In such instances, people took great pains to deal with what they understood to be problems needing to be solved. Successful dealing with problematic situations was acknowledged by pointing to a switching of feelings from burdening to alleviating.

However, "overwhelming" situations could not always be mitigated through problem solving. For example, patients and family members talked about "freaking out", experiencing "panic" or "high anxiety", "fearing" recurrence or dying, or being "demoralized" when results did not match expectations.

More specifically, in relation to cancer as "a stigma" or with a suddenly bleeding breast (after lumpectomy), two women felt "embarrassed and humiliated". All of these feelings were associated with notions of "cannot": The incapacity to escape an overwhelming situation and the inability to predict or to control bodily reactions with certainty.

Only partially within the reach of influence, moods and emotions, like strength or tiredness, were always there in some quality. Strong emotions emphasized that what happened did matter. Further, changes in emotions or moods never appeared as occurring in a vacuum, nor as quantifiable units. People felt strongly or not, vaguely or clearly, consistently or inconsistently, fleetingly or persistently. Feelings were usually discernable as contrasting with the inner atmosphere that had last entered awareness, or were implied in what people talked about. As abilities, confidence, anticipation and perception of independence or dependence changed, the moods and emotions shifted or "swung" between "good" and "bad", "high" or "low", "better" or "worse" etc. mirroring people's relationships to their world. Referring to her Parkinson's disease which she perceived as much more debilitating than cancer:

> There's always anxiety. I feel like I'm trapped...I used to be a person who could adjust to anything like that. But now anything counts as stress, any change. And I'm not well, I'm still healing [from cancer] I'm not really happy with that situation.

Feelings, on an existential level, let patients "know" who and where in life they were. A close, existential connection between feelings and energy was often implied. Two women, out of very different situations, explicitly mentioned this relationship. In the words of one who had come back after severe illness aggravation:

> One of the things is reassessing where I am - after being so sick then to suddenly feel good again, and feel strong and energetic again.

In regard to having regained some control over her life, namely by deciding against a mastectomy, another said:

> It's just a whole different perspective for me because the decision has just brought me to a real place of being, I mean, I've been happy, I've been happy for the last week and a half. It's the first time I've been happy since I've been diagnosed. It's really so. I feel energized.

Against "I cannot's" dark background of feeling "awful" and emotional hardship, reality in its actuality appears in the lightness of good feeling and happiness.

While climates such as worrying or being concerned cast their light into life at all times, feelings linked to the energy-tiredness yin-yang, or to vacillations between illness exacerbations and remissions, were described as "unbalanced emotions" and primarily perceived in their burdensome qualities as cyclical "irritabilities", "feeling depleted" or "consumed". These feelings have either promoting or disabling qualities. Similar in a certain degree to reservoir-energy, people felt filled or depleted with specific emotions. Different, however, from the banking concept of such energy, these feelings fluctuated in a yin and yang mode: To be full of anxiety implied depletion from joy or hope. Analogous to embodied energy, "feeling good" helped to "bear" and "handle" future exigencies. And, as energy seems to radiate from a body, one husband observed his wife's "bright eyed happiness" as associated with her experience that listing things to be done made her feel more competent again, after CTX had induced loss of memory and concentration.

Because of their yin-yang balancing quality, moods and emotions could not be replenished like reservoir energy. Yet, activities as diverse as sharing with others, keeping busy, reading, or seeking information, meditating, and crying, were consciously chosen in order "to make me feel better". Patients and often families even more, tried to tip over the emotional balance from feeling anxious or fear<u>ful</u>, to again becoming joy<u>ful</u> or hope<u>ful</u>.

In summary, awareness of emotions and moods indicated what mattered to patients in four related areas. 1) Although distinguished in words, the feelings and moods appeared in close relation to and conjunction with enabling or disabling levels of strength, with the intensity or absence of tiredness, nausea, and pain. 2) Emotions accompanied increasing or decreasing confidence in self's abilities to manage or control things; and 3) to have faith into the future. 4) Emotions were closely linked to perceptions of freedom or constraint as these grew out of what seemed still, again, or no longer, possible. In other words, what mattered was also a condition for emotional and/or mood switches.

As the embodied "I am able to" wavered, so did the senses of independence, power, control and future's predictability. Frequently, expressions of "cannot's" powerlessness were accompanied by notions of being forced or coerced. It is to these "musts and "have tos" that I shall now turn.

"I Must" or "I Have To"

"I can" made things show up as "coming easy and natural". Reality then appeared, to some extent, as within range of one's "choice" or determination. Implied herein was an understanding of freedom that allowed one to engage in most activities with as much vigor, interest and time commitment as one decided to invest. Reality easily appeared as a world in which freedom from constraints depended basically on one's capacity to master or control all the odds.

As "I can" temporarily or increasingly evaded and "I cannot" surged, impelling "musts" and "have tos" sneaked into patients' experiences. Notions reflected in these words indicated a loss of perceived freedom from impediments. "Musts" and "have tos" occurred on different levels and encompassed diverse dimensions. Ultimately, these changes had their foundation in the body: A body now perceived as an urging force. The body powerfully entered awareness through new features and their consequences to which the women had to accommodate themselves. Additions to and losses from previously known bodily manifestations blended to new conditions.

World Constituting Bodily Urges. Characteristically, bodily urges appear as a switch from states of bodily non-attention to more conscious awareness levels indicating that the urges need to be taken care of, so that no harm should arise to bodily integrity. Ordinarily, in healthy lives, physical needs or "musts" appear within a gamut of urgency degrees. Hunger differs from thirst, urgencies to excrete vary considerably from the coercion to breathe.

On the time axis, there is ample variance in how immediately urges demand to be attended to, how frequently they happen in a 24 hour cycle, and how much attention they demand. Breathing goes largely unnoticed, while suffocation appears as alarming and becomes almost instantly life threatening. Hunger, on the other hand, can be endured for weeks. Yet, hunger (or appetite's) satisfaction may take on elaborate attention, much planning and may easily grow into a full time preoccupation, while healthy breathing demands almost no consideration. The urge to excrete can be suppressed for some limited time. Beyond that, urination and bowel movements take on an explosive, coercive character. The divergent qualities and intensities of these ever recurrent time periods spent in alleviating daily urges and needs constitute and reaffirm over time the foundation for life's pleasurable and smooth taken-for-grantedness.

Certainty in and predictability of living grow largely from the trust of the unobtrusiveness of these urges. Attention mandated by breathing or sweating for example, are minimal. They occur almost independently of one's heed as long as they do not interfere with the social code of decency. On another awareness level, coughing, sneezing, urinating and bowel movements can be partially postponed. Yet, they defy ultimate voluntary control by erupting with relieving effect. Typically, the awareness of urgency disappears as soon the need has been taken care of, often leaving behind pleasant sensations of alleviation and satisfaction. Once more, awareness and cognition become free to focus on any other content.

In the dimension of space and social appropriateness, conventions tightly prescribe and monitor public and individual practices that deal with bodily "musts" of any kind. Deeply embodied, these practices are integral parts of every day individual and social life. For example, bodily distances between people are to some extent dictated by sounds and smells that emanate from bodily urges. All cultures prescribe places in which it is decent or taboo to eat, sleep, or excrete.

A sense of mastery grows from the habitual patterns in which bodily urges occur. This sense is contained between choice and coercion. The more urgent bodily needs appear, the less choice remains, whether they ought to be responded to, or not. There is no deliberate decision making in these instances. However, choice and decision making play a role as long as needs can still be distinguished from urges and further, on the level of how, when, and with what means bodily urges can be satisfied. Nevertheless, even in their compulsory appearance, bodily urges are so self-evident and pervasive, that taking care of them usually happens as a habit, this is, neither with full intention nor randomly by chance.

Recurrent bodily urges and needs structure time, predetermine spaces and places in which they are taken care of. Urges and rhythms ground confidence and certainty in the body and thus in life's predictability. Paradoxically, its inherent component of compulsion does not impede fundamental senses of self-reliance, freedom, and predictability to flourish.

World Disrupting Bodily Urges. Bodily manifestations with strongly urging components reflected treatment effects and also, in some cases, disease progression. (Although scientific-professional language trivializes CTX's toxic effects on the metabolism of healthy cells as "side effects", it was the impact of these effects which caused major "musts" for the patients). Bodily urges signaled problems or breakdown by entering conscious awareness persistently and by narrowing or even eliminating habitual patterns of taking care of them. At the same time, formerly unexperienced urges forced decisions which left the women with little or no choice. "Musts" emerged as consequences from changes in the realms of energy and tiredness or pain, as well as nausea, eating and vomiting. Alterations in bodily appearance like alopecia, weight changes, mastectomy, or premature menopause, all repercussions from body-invasive procedures, provoked "musts".

These "musts" pervaded lives and worlds, appearing with diverse flavors of urgencies and thus, emotions. Decisions had to be made in all affected realms and dimensions of the "I cannots". Others had to be involved where the women previously had felt independent. As their abilities and appearance changed, they had to depend more on others' acceptance and tolerance. Patients had to come to terms with the illness' future unpredictability. They felt thrown into a pervasive awareness of uncertainty and had to confront life's finiteness. Emotional tribulations tended to tint "must's" hardships even more.

In times of energy depletion, lack of concentration, as well as pervasive fatigue the women were forced to reduce their activities. Besides feeling ailing, they had to deal with the consequences of work left undone or poorly accomplished. Home cleanliness, food preparation, and in young families child care, became compromised as "a lot of things [were] just sliding". Things slid not only in the homes, but at work places as well. Sliding implies "have tos" on two levels: Having had to let go of one's grasp on events, and having to live with the unpredictability caused by sliding things. Sliding things demanded of family members' and co-workers "more patience and tolerance" and many times, their willingness to jump into the gap. Furthermore, in times of incapacity, bodily care had to be relinquished to others.

Nausea, vomiting and pain inflicted "musts" which could not be ignored. In this way they resembled, to some extent, everyday bodily urges like excretion or exhaustion. Yet, the "musts" necessitated by these urges differed in quality from the familiar transient ones associated with excretion or tiredness.

Nausea for example, had a clinging, irritating presence to it, which simultaneously inundated the women's world and disgusted them. The urge to withdraw into sensual and spatial isolation was mandatory for most patients. Often, irritation was such that conflicts arose with family members who wanted to be supportive. Frictions needed to be eased. Further, nausea's repulse demanded narrow adherence to certain kinds of food. On the fourth day after CTX:

> ...I love having warm soup. It's so nice to have change from eating chicken products which are one of the few things I can consume that I don't hate.

Days of nausea were marked by loss of choices, forced decisions, an almost compulsive flight from any source of additional sensory and emotional stimulations. Stimulations lost their engaging and challenging richness. Perceptively reduced to irritations, they added emotional affliction to a profound loss of being a self in charge of the situation. In an existential sense, patients became "wiped out" through nausea and vomiting, regardless of how autonomous and controlling, or receptive they usually were.

The eruptive power of vomiting forced the women to take precautions and to surrender themselves to their unpredictable bodies. Few options of movement were left. A narrow selection of places to be and equipment to use were mandated by privacy, the needs to dispose of the vomitus and to refresh oneself. The "musts" of vomiting included enduring painful, repulsive bodily sensations.

Pain's driving force was to understand what was wrong and to return, as soon as possible, to the familiar, self-evident non-pain state of bodily well-being. Like low energy, pain called to awareness the woman's limited abilities by confronting her with "cannots" and the sequelae of un-done activities. Pain, nausea and vomiting powerfully promoted the search for means to eliminate them and often, concentrated all remaining vitality to fight them. Inherent in the plight of enduring energy depletion, fatigue, anorexia, nausea, vomiting and pain was the yearning for relief and resurgence of vitality.

Finally, suffering such a multitude of bodily inflicted "musts" tended to undermine the understanding that body, life and world could be taken for granted. Patients and family members took all precautions within their range of abilities to prevent or mitigate the aftermath of multiple "musts". Many felt compelled to become vigilant:

> I think I just still am very conscious that I want [the] quality of my life to stay good and not to get too casual

> about it again. That's probably not a problem but it's something that I need to be really aware of.

Once the body's frailty or vulnerability had entered awareness for good, most patients found themselves obliged, but not always convinced, to make profound changes in their lives. Changes included switching to "healthy foods", seeking psychotherapy, and challenging long term (marital) relationships. Some consciously re-devoted themselves to their families.

In summary, world disrupting bodily urges differed from those which constitute the human world on all four dimensions. 1) On the temporal dimension, they had changed from intermittently entering conscious awareness to preoccupying the mind, often to the exclusion of other things. Physical urges embodied time in a range of modes, from stoic endurance to fervent attempts at evading their grip. These urges with their inherent defiance of being pacified could not easily be prevented from encroaching on one's life-world. They constituted a mind engulfing power, difficult to escape.

2) Bodily "musts" promoted patients on one hand to shun places, and on the other, to transgress spatial taboos. They also forced some women to permit persons to intrude on intimate (bodily) spaces.

3) By eluding elaborate and concerted efforts to make the urges and/or at least, their accompanying suffering disappear, bodily "musts" eroded patients' and families sense of mastery and confidence in their abilities to control what happened.

> There's nothing you can do to stop her from throwing up. Nothing, no medicine that I've seen, nothing that we could make her eat that makes her stop [throwing up].

Thus, the foundations of patients' (and families') sense of mastery shattered and pervasive feelings of powerlessness arose. Some felt thrown into a mode of being what they had neither chosen nor were willing to embrace; while others tried to "accept and comply" with what they could not change and confided in powers beyond self.

4) As bodily "musts" and their emotional and social aftermath encroached on all fundamental aspects of these women's being, their certainty about and trust in life's predictability wavered. They had to live the uncertainty which emanated from their "unstable body" (Rosenblum, 1988).

Not only the body's existential dimensions generated "musts": For most women, "have tos" surfaced in relation to concerns about who they would be and what they looked like when bald, or with changed hair styles, weight gains or losses, after the amputation of a breast, and premature menopause,.

"Musts" Concerning the Visible Body. The scary and uncanny thing about ghosts and spirits is, that they are disembodied, invisible and untouchable. In contrast is the body's visibility and palpability reassuring and reality constituting. By giving out pervasive clues about who one is, it displays to others and partially to self the individual's unique human presence.

Physical shape and hairdo are among important features to distinguish one person from another and to tell women apart from men. Cancer of the breast attacks an organ and body part which is widely associated with female nurture, beauty and sex, even with femininity per se. Various CTX agents affect fast growing cells thus causing hair thinning and/or alopecia. Moreover, certain drugs induce menopause, and/or cause weight gains through water retention, accumulation of adipose tissue and/or periodical increase of appetite. In contrast, progressive disease stands out by its rampant wasting of bodily mass and substance.

Thus the menace of illness and/or treatment to bodily features especially associated with womanliness is fourfold: 1) Changes ranging from alterations in hair quality and density to the loss of virtually all body hair; 2) weight gains and losses in a culture of almost obsessive weight consciousness regarding the female body; 3) mutilation of breast symmetry and bodily integrity, and 4) cessation of menstruation with its accompanying features like hot flashes, vaginal dryness and often, decreased sexual impetus.

All changes in appearance, with the exception of bodily emaciation in late stage disease, are induced by interventions done with curative intent. "Musts" associated with the body's visibility therefore began with having to make decisions about what kind of treatment(s) ought to be implemented. Over time, certain decisions had to be postponed or made over again, depending on how the cancer responded to treatments.

The permanent character of "musts" connected with mastectomy and premature menopause is different from the "have tos" that accompany alopecia or weight gains which are closely associated with CTX. Yet, in their unique power or in concert, these "musts" potentiated women's experiences of powerlessness and profound grief.

<u>"Musts" Connected to Hair Loss</u>. Three sensory sources contributed to "must's" affliction on women who suffered from partial to total alopecia. Hair loss was experienced simultaneously by touching, seeing, and sensing it. Further, "a vital aspect of [their] social identity has

been taken away" (Rosenblum, 1988).

With varying time lag after initiation of certain CTX agents hair started to fall out and baldness grew. In the period of hair shedding, hair cluttered shared space, baring an ambiguous testimony: Uncontrollable and somewhat untidy. It had to be picked from clothes, pillows, furniture, the floor and cleaned from combs, the sink, etc.

> My hair started to fall. As I was brushing I had to clean it [brush] three times. It's everywhere. She [daughter] said, look and see what's on the back of your robe. And I thought there was a spot or something and...it was hair all over the place. ...I'm finding hair everywhere. If I'm talking to somebody, it's falling down my face and all over my clothes and all over my brush.

Neither could "hair all over the place" be ignored, nor could its previous, now balding place on the skull, this characteristic feature of the head, be overlooked.

> For me it was just the hair - I cried over this more than anything else. To see it, just brushing it, touching it and it just falls off. I'm not used to short hair...Nausea does not last too long - the hair, I gotta see myself everyday when I get up - every day. That's hard.

Women who wore their hair long felt forced to cut it shorter. After their initial grief over this loss, many came to like their new appearance: "It's fine, but I didn't know that I would like it, until I cut it". Yet, cutting it was often just the first step towards full baldness.

Considerable turmoil arose from finding the right wig or head cover, and then, to get used to wearing it. Wigs needed to fit the face and be affordable. Often however, they were awkward or too hot to wear, which compelled women to buy and wear hats, turbans, scarfs or to go bald as long this could be socially done. Skull sensations in the realm of temperature and touch reminded them of their loss. Such sensations demanded flexibility in wearing one cover over another at certain times, or required a woman to endure her skull irritation until she could safely relieve herself from it.

The head's prominence in appearance makes it unlikely that changes in coiffure and cover go unnoticed by others. To the knowledgeable beholder, a balding or bald woman is suspected of having cancer. To those women who felt "stigmatized" by the disease and wished to keep it a secret from others, alopecia caused problems of passing "for normal" (Goffman, 1963).

Some patients put all their creativity and previous experiences into making themselves look attractive. One woman had a funny name for each of her four wigs, capturing how she looked in it. Yet, prosthetic or covering up devices did not replace their own hair. Going to the hair dresser or shopping for fashionable hats, both activities widely cherished, took on an impelling character: "...it was a real drag to be forced to do things that aren't of my choosing".

Unless they had experienced considerable wasting of bodily substance during disease exacerbation, none of these women "chose" to gain weight. "Musts" in the realm of body weight changes were comparatively benign.

Weight Changes and "Have Tos". Albeit weight changes were mentioned sometimes in the interviews, they never elicited patients' major concerns. This fact may be an important indication pointing out the differentiation between phenomena that are lived through the body, and others to which one is clued through cultural awareness.

"Have tos" were concerned with restraining food intake with the goal to keeping weight constant and to prevent gains. In this regard, patients did not differ from their weight vigilant, healthy counterparts. However, "musts" grew stronger, when the drugs they were on thwarted patients' endeavors and they gained weight despite their efforts. Further, in instances where the aim was to lose weight, patients were strongly discouraged from doing so by health care providers. They had then to postpone plans to a time after CTX.

On the other side, loss of body weight was not deplored as such. It was the loss of appetite and energy as well as the rise of fatigue which promoted "musts" for the women, not the de facto loss of pounds or changes in Gestalt. Neither weight gainers nor losers mentioned spontaneously problems with clothing which arose from alterations in body weight.

If at all, weight associated "musts" appeared as sequelae of deviation from a cultural ideal rather, than as promoted by the transfigured awareness of a changing body. Patients were concerned about how they looked. They cared about what impression others might have, if they had not seen them for some time: They wanted to appear good looking. In all of these concerns, however, body weight seemed to be submerged. A marginal component, it's ups and downs were rationally monitored on scales, but their pound-quality escaped lived awareness. By occurring slowly, weight gains or losses elude sensory qualifications until their magnitude makes them visible and sensible.

Both, alopecia and weight changes occurred in tandem with CTX or illness: Once CTX or illness progression were stopped, hair grew anew and the body tended to revert to its pre-insult Gestalt. "Musts" inflicted by these changes faded, as their promoters disappeared. In contrast, scars, breast changes due to lumpectomy, the emptiness of one side after mastectomy, (future breast reconstruction), changes in one arm and its axilla remained irreversibly visible and/or sensible in a different way as compared to before.

"Musts" Elicited by One Breast. There was a chain of "have tos" associated with the fact that one breast was jeopardized by cancer. "Musts" started with either feeling a lump or with a suspect/positive mammogram. Both called for attention. In a culture of high cancer vigilance and early detection programs (e.g. breast self-exam, mammography) such findings were difficult to ignore over time. Once discovered, the lump's constant bodily presence thwarted the ability to forget it, even during months or sometimes years of medical observation. Rolin (1976; p.15) described the quality of this awareness switch as: "Not worrying about the lump but not forgetting it either".

Once suspected as malignant, the lesion mandated further medical interventions: Biopsies, lumpectomies, and to many women mastectomy seemed to be their "safest" option. Some considered breast reconstruction as the only option for their rehabilitation as a woman.

Ultimately, all "musts" came from two sources: First, from uncertainty around the core question of what surgical intervention might be life saving. Second, "musts" had their roots in the potential visibility of disfiguring effects from surgical interventions. However, while existential uncertainty "colored" all patients' future outlook, women did not feel equally vulnerable to the aftermath of losing one breast.

Deciding for or against mastectomy was a "real emotional issue" to one woman:

> I hate it and it's a real drag for me...it's going to be extremely hard on me....People at work have kind of cliches of, well: 'you know it's just a useless gland', 'it's not who you are'. And...I know it's not who I am but still I just feel like I'm going to be mutilated, so I don't like it.

To others, the loss of one breast could be accepted if it saved their life; or: "Losing my hair has been much harder than losing my breast" (Rosenblum, 1988).

Visible effects from breast surgery included bleeds, scars, the disappearance of one breast and lymphedema in the affected arm. In these interviews, breast reconstruction appeared as a future, not yet realizable hope for many of the younger women. (Reconstruction plans needed be postponed to a time after CTX's termination and the body's full recovery from "side effects").

Bleeding from an infected wound after two lumpectomies was a "humiliating" experience for one patient. Twice within a few days, her bloody shirt revealed the reality of her injured breast to herself and strangers: Once at church and once to her male boss and co-workers. Humiliation mirrored her inability to control what happened in her breast and who witnessed her disease through concrete sensual confrontation, rather than just (abstractly) knowing about it.

Patients had to decide whom they allowed to see or touch their scars, or the flat place where the breast used to be. Should the partner be exposed to it? and what about the children? What impact could such sensual knowing have on relationships? And last, but not least, how did this mutilated body feel to the woman, how did it reveal who she was herself?

> [I] can't think of a lot of negative things except for me, personally,, sometimes, speak for myself, personally, there is some loss of sense of sexuality, being without breast and without hair.

Through their loss of breast(s) and hair, women felt "thrown out of routine" into "vulnerability". They felt forced into a state of being they had not chosen. Existentially, "being without breast and without hair" threw women out of their previous self-understanding as a proud owner of an attractive, beautiful, regular body into being revealed as wanting through their body. Indeed, this revelation needed to be monitored in situations ranging from intimate, full revelation to total concealment in public.

Quite contrary to telling about others' support and involvement in dealing with falling hair, assisting patients with purchasing and getting used to their head covers, their engagement in "maintaining" the patient's strength and weight, these interviews were silent in accounting for breast-loss-concealing strategies.[11] Perhaps - in this culture - unfamiliar looks of a bald woman's head and the social lack of ease with a person's anorexia readily elicited others' involvement, while the breast's intimate associations reinforce women's dealing with prosthesis issues alone. Hardly visible, yet pervasive if experienced, was premature menopause.

Premature Menopause. Only a few commented on CTX induced menopause and its hot flashes. Although less visible to others than hair loss, the women felt irritated by bodily temperature imbalances. These

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[11] For detailed description of such strategies see Rolin, (1976).

disrupted their feeling able to respond with ease and consistency to the outer world's temperature. In Rosenblum's (1988) words:

> I no longer had any sense of what "room temperature", that euphemism for a sharable external reality, was. I had not reliable information from my body about the temperature of the outside world.

Both blushing and room temperature inadequate clothing are visible clues to others. Menopausal bodily changes were sensed and impacted on a woman's intimate relationship. To a young mother of one child these bodily sensations were persistent reminders that her child bearing years were past.

In summary, the body's visibility to others (and self) makes the person a part of a shared world, and an apparent carrier of cultural understandings: What it means to be a Western woman. Treatments effected visible, culturally sensitive features. Visibility varied from high, continuous prominence in alopecia to sudden but evanescent changes in facial tint caused by flushing, from noticeable changes in body weight over time to lasting mutilation of the bosom.

The degree of a woman's yearning for looking like her previous, familiar self determined what social situations showed up as embarrassing or humiliating and what activities were associated with "musts" or "have tos". Whatever the "must" activities were for different women, they always served in one way or another to disguise or minimize deviance from previous normal appearance.

Theoretical Summary

Embodiment, or the experienced body appeared in two modes, as "I can" and "I cannot". Yin-yang like, "I can" always includes, to some extent, "I cannot" and vice versa. All performance is dependent on and influenced by these modes of capability. Intricately linked through bodily capabilities and colored by moods and emotions, the reality of self-in-the-world emerges. Major features of the two modes are depicted below:

	I can	I cannot
Appearance of the world:	taken for granted possibilities open/ unlimited freedom from constraints	falling apart, limited possibilities "I must/I have to"
Appearance of embodied self:	grounded certain, confident in the future self-confident independent mastering active - receptive easy going strong, vigorous known to self comfortable involved in daily activities	ungrounded uncertain, future unpredictable vulnerable dependent unable receptive, less active un-easy, laborious weak, frail unknown to self suffering disrupted habits and routines
Bodily appearance:	whole healthy	mutilated unwell
Emotions and moods:	joyful confident hopeful	sad anxious/scared despair

"I can" and "I cannot" are both dependent on and consequences of levels of energy, fatigue, the ability to eat, drink and digest, as well as pain. Perceptions of reality, composed of temporal and spatial senses, notions of trust and confidence or uncertainty reflect fluctuations between "I can" and "I cannot". The modes are both colored and impacted by moods and emotions.

"Musts" and "have tos" are sequelae of "I cannot" as well as of (altered) bodily appearance due to therapeutic procedures. Changing bodily urges cause "musts" and "have tos" to appear; they too impact upon perceptions of reality. "Musts" and "have tos" force self into actions and activities which, in turn, appear in modes of "I can" or "I cannot". As the body vacillates, yin-yang-like, between high and low capabilities, so do performance, skills, perception of reality, and to the extent these changes are visible, bodily appearance.

As the body allows for "I can" to pervade, self shows up as capable and confident, the world as predictable and largely as taken for granted. The reverse is true in bodily weakness which, in the experience of these patients, was mostly caused by medical treatments, above all CTX, or by disease progression.

Self-understanding is grounded in embodied capabilities and arises from self-in-the-world relationships. "Cannots" and "have tos" of disease and body-subjection to treatment influence bodily capabilities and thus a person's identity and embodied relationships with the world. Changing embodied situations solicit people into learning and applying (new) knowledge.

In chapter five I shall examine changes in "I"-body-world relationships which appeared as sequelae of bodily subjugation to medical treatments. Chapter six explores ways of knowing about the body and its disease.

CHAPTER 5

MEDICAL BODILY SUBJECTION: RELATIONSHIPS

Background

As an individual's sense of invincibility, mastery and independence is embodied through "I can's" enabling capabilities for involvement with the world, so too are meanings of vulnerability, powerlessness and dependence. The latter feelings rise in the mode of "I cannot" and are inherent in many activities done to one's body by other people.

This chapter focuses on practices of bodily subjection. Such practices vary widely from nurturing coddling to harsh disciplining; from directing the other into an assumed right way to be or to become, to domineering objectification denying the person's authority (Foucault, 1979). Things are done to the body of others for many reasons: e.g. designating it as belonging to a larger group, to beautify, rejuvenate, or to improve its assumed short-comings and, to mend or heal it. Punishments frequently include bodily subjugation.

Certain bodily interventions are intended to be permanent. Circumcision or face lifting are of this kind; whereas the transiency of others - e.g. hairdo and coloring, or body painting - allow for new decor, as time goes on and fashionable meanings change. Medical interventions too, cause temporally limited or permanent changes in the body and/or its looks.

Pain may or may not be part of things done to the body. In torture, pain is intentionally inflicted, while it is an unwanted, but often inevitable, sequel in many medical interventions. Pain tends to be more accepted if bodily beautification or improvement are aspired, while it intensifies experiences of bodily affliction and mutilation.

Bodily interventions on others are practiced within a wide array of consent degrees, from full, informed approval to coercion against the victim's will. Decorations like tatoos or ear piercing might be asked for, time and pattern of the procedure can be chosen. Initiation rites or assumed life saving actions on the other hand, can be performed with little or no individual consent. Punishments are forced upon people.

Usually, _medical_ interventions are sought for. However, their physical impact, although consented to before procedures begin, is generally perceived as invasion with ambivalent meaning. In the case of cancer, such infliction is consented to not by choice, but by desperate, intentional determination. Later, sequelae of such consent are often experienced as detriment and forced constraint (Schilder, 1986).

Interpretations color the meanings of things done to the body. They encompass a gamut of potentially conflicting meanings. In addition to the meanings inherent in what is done to or for the person, embodied memories of past inflictions, as well as the relationship between the subjected individual and the people doing things, is pivotal in how procedures done to the body are experienced.

Treating the Body With Cancer

It is clear that, what is done with medical rationales to the body, is also done to the person. Nonetheless, medical parlance and practices are often set up as if the body were unincumbered by sensations of a living person. Colored by such Cartesian assumptions, the organism appears as a material system to be manipulated by the powers of care givers' minds and science.

Professional work on the body started after the women had decided to seek medical assistance for their dealing with breast cancer. This mutual endeavor was called "fight for survival". By and through this alliance a woman was implicitly or explicitly faced with the medical premise that her body must be harmed for the sake of rescuing her life. Thus, the women accepted technological rescue devices and manoeuvres which each had the potential to destroy embodied life.

In the view of both women and professionals, the fight was set up as confrontation between technological forces (usually operations, CTX[12] and RTX) and cancer. In this setup body and cancer were understood as foes. The body's position thus was paradoxical: As an obstacle to easy access it had to be overcome and, through such surmounting, technological assaults (which targeted cancer) the body was at risk to be harmed and/or even destroyed by both the cancer and the medical onslaught.

Professional subjugation of bodies must be looked at as arising from this background. Women's experiences however, were more complicated: Having agreed to fight for their lives, they found themselves thrown into the plight of having to endure procedures in places away from home, to bear "side effects" and to live with disabling and mutilating consequences from treatments. All of these further encumbered lives already burdened with illness per se.

By definition, medical subjection entails at least two parties:

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[12] Similar effects were expected and experienced when patients underwent RTX. Throughout this chapter, (with exception of quotes), when CTX is mentioned, RTX might be considered as well.

The professional who acts upon the sick who endures with more or less agreement. Medical acts are interactional and accompanied by strong intentionality. The organism is expected to respond predictably and yield results of scientific satisfaction.

In the women's experience, matters were complicated by unclear boundaries between those who acted and who or what was subjected to such acts. Interactions with curative or palliative intent took place between "I" and "my body", "I" and "it" (body or cancer); between "them", "us" or "I" and "me", "my body" or "it" and, conversely, "my body" or "it" would "respond" to me, "us/them doing chemo" or any other of "our /their" interventions. The body showed up as incalculable. In contrast to "I can's" clear indication of agency, when "I can" diminished or faltered, the attribution of who did what to the woman, her body, or the cancer got muddled.

The Body's Appearance Under Different Agents

"They" as Agents

In this analysis descriptions of professionals and their acts appear as they were perceived and understood by the women. Medical practice and its accompanying language deeply influenced patients' perceptions of their body, its processes and parts.

"They" (= professionals[13]) appeared in two main modes: 1) actively inflicting procedures, and 2) as proposers, prescribers of treatments, estimators of outcome effects, removed from direct interventions. In close association with patients' mandate, their focus was cancer

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[13] Quotation marks are only used to differentiate references to professionals from those of other 'they'.

eradication. Metaphorically, in these stories, the organism appeared in varying, yet not mutually exclusive analogies: As territory, obstacle, in pieces, and more faintly as ally in or traitor of therapeutic endeavors.

"Their" task was not an easy one. "They" engaged in a war-like endeavor (Sontag, 1978), because the body, its cell processes, tissues, and organ systems did not function in that intricate, seemingly straight forward and predictable manner as is suggested by (patho)physiology books. Cancer is conceived as cellular aberration, suggesting that strategies are used to weaken the abnormal and annihilate the insidious. (Of course, many healthy cells are destroyed in this process). Cure, the battle's goal, implies eradication of cancer from the body. Unfortunately, malignancies, more than other diseases, challenge medical technological supremacy over the body in this battle towards cure. As in other circumstances, when results fall short of expectations, there is a tendency to do more in the same vein in order to do it all, or better and thus, at the end, to beat the odds (even if the goal might be elusive). Metaphorically, this was the situation out of which professionals acted and therefore, only very few women remained untouched by the impact of martial battlefield images in their experiences (see analysis 1, chapter seven).

The Body as Territory, "They" as Scouts. War allusions permeated three kinds of professional interactions with that cumbersome impediment called organism which lay between medicine's technical potential and the elusive cancerous growth: 1) By diagnostic testing, the body, like war territory, was mapped out and topographically explored, in order to locate the enemy. 2) Through invasive procedures the territory was accessed; things were either removed from, or added to it. Territorial inferences and information about the enemy were extracted from physical samples. 3) Territory had to be entered for the destruction and removal of parts that had surrendered to the enemy.

Various methods were used to make bodily territories visible and landmarks known (e.g. mammographies, other x-rays, computerized tomographies (CT), physical assessments). Penetrated by invisible waves, touched by machines, instruments, and hands, professionals scrutinized the body for its hidden secrets. On occasions, the body was perforated for the influx of dye on a reconnoitering mission.

Diagnostic testing served to detect what was not obvious in the body. Mapping the territory-body aimed at making visible what usually is hidden from sight (Foucault, 1973). One moment of bodily flow would get frozen into an image to show in contours, density and shading a picture for an on-looker's interpretation. For purposes of objectification, the organism was begged to hold still, since movement and the fluidity of living processes would usurp their static depiction.

Of course, women's experiences with, and understandings provoked by professional actions differed often substantially from those implied by "them". Physical confrontation with detecting hands, scrutinizing instruments and machines brought to women's awareness the vulnerability of their embodied life. Thrown into a temporal trap with minimal rational incentive to escape, (they too wanted to know), patients were subjected to motionlessness, to unfamiliar spatial configurations, perceptions of lingering or fleeing time, strange sensations of sounds, temperature, and an un-easiness out of which rose experiences of fear and profound uncertainty. What for "them" were activities of physio-topographical documentation, easily grew into a woman's encounter with her living, life-bearing body. One (extraordinary) description follows:

> They put me into this thing (CT). They also gave me a dye which I was not expecting. The guy said you will experience a very warm feeling....The dye does weird things...I was sweating, broke out in total claustrophobia which I've never experienced. I thought...I'm going to die and...I have not said goodbye to the important people in my life....It was one of the most frightening, eerie feelings, the only reason I didn't move was because there was a fucking needle in my arm.

While they "put", "gave" and "told" her, (and attended to the machine) she was encased, immobilized, injected and informed about matters of fact. Pulled out of her lived world in which bodily awareness is suspended within movement and activities, she found herself in imposed world-impoverished isolation, overwhelmed by her body's stillness, sweat, lost spatial range of motion, and faced with her body's apocalyptic potential.

While not all of "their" documenting activities threw women into such dramatic bodily encounters, subjection tended to confront them with their bodies in twofold, paradoxical manner. First, procedures confronted patients with their own bodies as enigmatic objects, while simultaneously, they lived the very inflictions in the heightened bodily actuality of pain and discomfort. Secondly, some of the body's enigmatic qualities became de-mystified by the body's sudden deconstruction into visible, countable units, while its ultimate reactions remained intangible and uncertain.

Beyond documenting bodily topography, professionals accessed the body as if it were a territory from which information could be gained about the terrain's freedom of cancer and the body's own forces which were harnessed as allies in the fight. Further, remedial forces needed to be brought into the organism.

The Body as Obstacle, "They" as Inflictors. The body appeared as obstacle in all cancer access and eradication endeavors. It challenged "their" skills and limited "their" dreams of ever renewable physical resources, such as veins or "blood counts".

Access was not randomly gained, but care- and purposefully targeted. Usually, skin and veins were pierced with needles, tissues cut with a knife in order to shape an entrance or exit which would allow the intended manipulations to be done. Through such holes, bodily pieces were either evacuated or foreign stuff infiltrated.

Professionals used biopsies and operations to target tissues and body parts. Somewhat randomly, evidence of things happening within the body had to be pulled out of tissue contexts, through the skin hole and brought to the microscope, hoping that "they would be able to get it all in a very minor remove". Pathology reports disclosed what the body kept in concealment: "It wasn't quite so good" and further bodily assaults followed.

Interviews were almost mute about operative interventions per se. Operations belonged to the countless "have tos" which women underwent with more or less conviction, fear and anxiety. Their aftermaths concerned them (see latter part of this chapter). But by and large, operative interventions were done in a state of partial or total disembodiment. Local and general anesthesia cut the very connectedness of embodied awareness. Obviously, because of amnestic disembodiment things could not be reported.

All the more were veno-punctures within the realm of embodied experience. Through punctures, skin resistance had to be overcome, as access was searched into the territory's transport system for retrieval of blood samples and injection of material in need of distribution. In many instances, skin perforation was a must for the "big guns" of CTX to be brought onto the battle field. Again, dispersion had to be left up to the system: Drugs were expected to reach the cancer by traveling through the organism's vessels; but no one could be quite sure if they really attained their goal and had the impact they were designed to have.

One woman touched on the salient issues of venous access, important to the majority of women. She reflected on both, "drawing" and "injecting" purposes:

> I said [to physician]: 'No, the veins I have I save for chemo - when it's time for my chemo then I'll go and get my blood test, make sure my counts [are] o.k.' and she said: 'No'... She just wants to see my counts. I can't see coming and going in the morning before work because when I give blood, it makes me very tired and it takes forever to get it out of me....I can't see giving blood when I have no veins and it's hard for me.

Veins and blood (counts) took on lives of their own. By implication, they overshadowed other body parts or processes in the cancer fight.

<u>The Body in Pieces: Divergent Interests</u>. Patient-professional discussions around "using up" veins through "poking" them and the ominous ups and downs of "blood counts" abounded in the interviews. Blood and veins stood out as major concerns for both sides, although for different reasons.

Physicians tended to think in terms of laboratory results, while the women were concerned about and felt protective of their veins. Of course, "blood counts" had oracle-like quality for the patients as well. In regular intervals, the armies of "blood counts", in one woman's words, "the good guys", had to be counted. For that purpose, a fraction of blood was tapped from within a vein and pulled out for analysis. These counts allowed for the estimation of (enhanced or reduced) bodily vitality on one hand, and on CTX's destructive impact on healthy blood cells on the other. With the decimation of "blood counts" speculation rose about its meanings: Were the "bad guys" (cancer cells) diminished to the same extent as the "good guys"? Are there still plentiful fighters against cancer left? What, if the "good guys" get reduced while the "bad guys" remain untouched?

To professionals, veins were a target, a means for the purpose of drawing blood and injecting CTX (or other drugs). On one level veins were purely functional, serving as entrance to and exit from the body. Yet, veins displayed nasty qualities as well, more so, the longer CTX treatments went on. Veins got "bad", disappeared at times, or vanished all together. It took especially skillful nurses to "find" and capture them and to inject safely CTX's aggressive substances.

Veins had the function of transporting these substances into circulation from which they were distributed throughout the territory. In this very function, veins at once were exposed to the toxicity of these substances and simultaneously they were expected to protect the surrounding tissues from these poisons. Leaking veins or para-venous injection of CTX drugs could cause severe inflammation and necrosis in surrounding tissues. Such "complications" were dreaded by the women. Because of the precarious task, veins had to be carefully perforated, entered, monitored and, finally, exited.

For the women it was clear that they had a role in these delicate endeavors, but the professionals were not always open to their expertise and cooperation. Since veins and blood were perceived to belong to the latter constitutively, they felt responsible and protective of them. To professionals, however, veins may have appeared as a challenge to their skills and a means to two ends: Extraction of blood samples and safe injection of CTX.

Not surprisingly, beyond belonging constitutively, many women started to bestow on their veins utilitarian meanings: These appeared as a limited resource. Women either "had" veins (of different qualities), or they "had no" (more) veins. In this mode, veins appeared only through their attribute of guaranteeing bodily access, namely in their technical function to be stuck (an utterly estranged function!). From this use-full perspective, veins could last if utilized carefully; they could be saved by combining their dual purpose (drawing blood and CTX injection), and "messing around" with them was judged as unaffordable waste (besides being painful).

There also seemed to have been a discrepant understanding about blood between women and professionals. While the latter had a strong interest in detailed numbers of differentiated blood particles, the former felt responsible to ration extensive blood-letting for laboratory purposes. Blood too was valuable. Women could not afford to diminish this precious force just for the sake of professional curiosity. Was blood not their ally in the fight against cancer? Did it not sustain their vigor and provided energy for daily living?

The Body as Object to Be Manipulated. Once the body's accessible resources were used up, when "no more veins" were available and continuous treatment was still mandated, the now missing access resource had to be replaced by an artificial piece. Porto-catheters were likely to be "implanted" for that purpose. The planting analogy covered up the device's resemblance with machine spare parts: In contrast to living implants (e.g. plants planted in a terrain), such prosthetic access gadgets were not supposed to grow anything (bacterial colonies), nor were they to behave on their own. Rather, they were supposed to stay fixed in place. "When I got that implant...they got it in upside down. Now they've got to take it all out and do it again". "They" told the patient, that the device had turned by itself. In saying so, they attributed the device with mobility it could never have of its own. (If at all, such a 180 degree turn must be propelled by bodily movement of a loosely installed device).

Manipulation of cellular metabolic processes through CTX provoked pervasive "side effects" (described in chapter four) and was reflected in the blood counts. It was the steering of these manipulative efforts which afforded close professional supervision and vigilance.

While technicians mapped the territory, and nurses as well as laboratory technicians accessed it by overcoming the obstacles, many physicians held a more removed, but highly strategic position in this war. They contrived the whole manipulative effort.

Once Removed: "They" as Strategists. Strategic undertakings for cancer eradication were masterminded by different specialists (e.g. oncologists, radiologists, surgeons). Frequently at the same time - but with minimal orchestration - they pursued specialized strategies to depict, access and penetrate the body; but they all consented in one conviction: The organism had to be overcome in order to abolish cancer. Not infrequently patients resorted to self-protective behaviors; they coordinated visits, tests and carried information from one clinic to the other.

Physicians fought with diverse weapons: With drugs, knives and radiation-beams (and hyperthermia in one instance). Strategic actions were based on expertise and experience, statistical probabilities, and accompanied by optimism, sometimes pessimism. As long as the organism was bombarded with "big guns" it could only be seen as an object. However, as with all strategic assaulting moves, their effect on the target could only be assessed by the victim's feedback. The body too, "responded".

The Organism's Feedback. Treatment effects and new strategies were inferred from "responses" expected from the cancer. But it was the body, in its in-between position, that vicariously yielded indicators for medical measurement and professional definitions of success or failure. Depending on the results, the organism appeared to the women as ally in the fight, or as threatening to succumb to the cancer.

Since "they" could never concretely and with full certainty attack the cancer (and at the same time spare the organism), the body appeared in ambivalence between being an ally in the fight and a thwarter to medical solutions. "They" danced on a narrow rope between losing the body's alliance and curtailing its betrayal. As long as professionals reassured patients that the body showed no signs of betrayal then things seemed hopeful, since full certainty of the cancer's whereabouts could never be achieved. Because of professional inability to know for sure and worse, if their actions failed to eliminate cancer, profound worry and distress pervaded the patients.

A 32 year old woman with progressing disease counted the "little tumors" which developed, where her breast used to be: "I've got 35 of them that I can see, and God only knows what I can't see". Obviously, on one level, she perceived these growths as "signal[ing] the end for me", and she wished that later "we" still had "big gun chemo" in reserve. Yet, on the other hand:

> My body is so wiped out that to put me on any kind of a really heavy chemotherapy, is only in suppressing my immune system more and is only gonna hurt me a lot more than it's gonna help me.

She perceived her physicians' helplessness:

> They throw their hands up, they say...there's just not enough information about this, we don't know what to do. And they keep choosing the most aggressive therapies....They've given me all the big guns and it hasn't done it, and I'm just not willing to keep on...

A devitalized (wiped out) body allowed one little tumor after another to emerge. In the view of her physicians, this same body was un-responsive. It failed to provide the (encouraging) information they would have needed to infer further strategies. Thus, they resorted to the last and heaviest ammunition in their arsenal and proceeded to total attack or, to "salvage therapy", in a professional attempt to extenuate a desperate strategic situation. (The woman died nine months after this interview).

In such instances, when "therapy" surpassed what could be tolerated by the women, professionals tended to search for patients' cooperation in deciding between two equally agonizing options. These were to give the body respite but probably to surrender it fully to cancer, or to continue treatment, thus keeping the cancer somewhat in check but sacrificing all of the body's vigor and many of its world constituting capabilities.

Albeit ideologically stripped from its capabilities, the modern medico-Cartesian organism provoked professional attention by appearing in numerous metaphorical variations. Yet, it was the "responding" body that finally testified to professional glory (no evidence of remaining cancer) or defeat (recurrent cancer). Professionals (and the women) reckoned with bodily reactions. Sometimes, responses appeared in appreciated patterns, but too frequently they signified failures of the most varied and elaborate scientific approaches. In its perceived pivotal position between the cancer (which was part of it) and technology, the organism could both hamper and enhance professional therapeutic efforts. Its intangible, concealing capacity ultimately thwarted scientific medicine's striving for certainty and predictability in disease control.

In summary, from a professional perspective, patients' bodies appeared as the means toward one overriding end: Saving or extending a life through cancer decimation if not eradication. To the scientific mind, the body was a territory, obstacle, or object organism inviting to be topographically explored, accessed for removal or addition of substances and manipulated in its functions. Bodily pieces and parts appeared within three distinctive, but not mutually exclusive possibilities: 1) as removable and/or replaceable; 2) as usable for medical/therapeutic purposes; and 3) as scientific specimens with feedback value.

Although medical-Cartesian metaphors made rational sense to some of the patients, in their illness experience there was no disembodied territory to be cleared of the enemy, no obstacle to be overcome, nor an object to be manipulated. There was an embodied "I", which sometimes joined "them" in the mutual war against a shared, elusive enemy. Often however, "I" had to protect self[14] against their overpowering attacks. But professional subjugation of the body (and the disease) provoked in the women feelings of vacillating relationships within self and towards others.

"I's" Agency

In these interviews, the relationships between the woman, her body, and others showed up as intricate, sometimes a-logical or ambivalent, and constantly switching from one relationship to another.

> They showed me the picture on the x-ray. It was sunburst and it was a very large area. It wasn't a lump. Nobody could feel it. There never was a lump. [A few sentences later:] Now let's get on with it. Let's do the biopsy. Let's try lumpectomy versus mastectomy and if I don't make it, I don't make it. And I didn't. When they got in there, there was a lot more than he had anticipated.

In visual abstraction, the radiography represented to the woman the inside of one body part. As an image it showed, paradoxically, what from the outside could neither be seen nor clearly sensed. Dark and light shadows in uni-dimensional projection warranted interpretation. Absence of normal, healthy configurations indicated pathology, and the

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[14] "I" and self are used synonymously throughout this text.

missing contours of an expected "lump" underscored this tumor's substance-less, evasive, yet invasive character. The picture revealed what was hidden and had defeated tactile detection by anybody, including the woman. She aligned herself with "them" (professionals) to become "we" for cutting options, however, she was the one and only "to make or not make it". As the self didn't make it, the woman's agency seemed to disappear. She emerged neither as in charge nor as victim, as "they got in there", that obscure, dangerous place, her breast, only to find much more cancer than anticipated.

Notions of "I" and "body" could be identical, ambiguous, or split. Affiliation with the body appeared in the vagueness of ambiguous relationships with meanings that changed. Hence, alluding to "my" body or parts of it could abruptly switch into talk about "it", as if "it" were separate from "me". "It" appeared with equivocal meanings as well, indicating the body in one sentence and relating to cancer, or illness-treatment interactions in the next. Furthermore, things were done "to me"; in other instances "my body", or one of its parts were targeted. Some interventions were done by "them", others by "we", or "I". Relational ambiguity inherent in the I-body relationship was revealed through inconsistent use of pronouns, leaping from 1st to 3rd person or referring to the body in possessive terms. Language also disclosed shifting attributions of responsibility for things done to, for, or with the woman.

Experiences were tinted by these ambiguities. Yet, since embodied presence is not necessarily confined to one person, but pivotal for human relationships, the women's experiences easily became families' experiences as well.

> We went from the bad x-ray to the biopsy which was bad news, to the lumpectomy which turned out to be mastectomy and then found out that it was in the lymph nodes and then we go to chemotherapy. So it's been a long trajectory of negatives for the family. Just one thing after another. So now everything that you fear most for a woman, that can happen, has happened. I've lost my breast, and lost my hair...

Step wise progression into diagnostic and therapeutic bodily subjection was a frequently reported experience. Captured in these long trajectories of medical imperatives, experiences showed up as embodied and disembodied, owned and disowned, subjugated and suffered. Inconsistently and often simultaneously, "I" appeared as doer and/or endurer. In situations of "we" agency, women and professionals (families were often included) acted in unison.

"I's" agency over or relationship with the body, as it was treated, varied with the meanings in which the body showed up. The body's fundamental ubiquity throughout the procedures appeared multi-dimensional. Like a prism with countless facets, the body implied its presence in different analogies: As "I's" possession, in the capacity of an ally, betrayer, or impediment, as vanishing into its parts, or in its oneness with "I", and/or in its strength for enduring or suffering. One to several of those facets could flash up at one time, only to disappear and to re-surge in another combination. They seemed to flow from one into another. Experienced bodily ambiguity powerfully contributed to women's ambivalence throughout invasive treatment procedures.

Procedures provoked "I"-body relationships to vacillate between "I"-body congruence and "I"-body alienation. When congruent, things happened to the woman: "I've got all these hairs from the male hormones"; in alienation, the body appeared object-like and distant:

> They restaged me with the MRIs (Magnetic Resonance Imaging)....It showed that the lesions in the liver and the two lesions in my spine were shrunk...[Later in the interview:] I always get my written reports from all these restaging that they do. I copy them and send them to everybody so everybody knows what the medical prognosis is....It's not hearsay or our interpretation of what it is.

Implied in these quotes are notions of possession, but also allusions to a factual reality which was beyond the woman's possibility to undo or to misinterpret: The hair "I" got is difficult to reverse, and pictures of "my" spine (and liver) tell a "medical" (objectified) story about something which "I" is only able of interpreting as a fully embodied experience.

"I"-body affiliations appeared as webs woven of threads coming from women's (changing) self-understanding, flashes in which the body revealed itself as things were done to it, and others' interpretations of what happened. Diverse "I"-body associations emerged at different times. Phenomenologically, these relationships seemed to be rooted in how the experienced body appeared. Hence, it is "I's" perception which will guide the following analysis.

"I" could appear as in charge of and responsible for the body; "I" could be interdependent with, or dependent on the body. "I"-body oneness showed up and so did an object-body which seemed distant from "I".

<u>"I" in Charge of and Responsible for the Body</u> or parts of it, appeared predominantly with protective intentions. Being in charge assumed awareness of the body as valuable possession, one perceived to be in need. Protection of the body included guidance towards its cure, aid in its fight, or shielding it from further harm.

"I's" responsible obligations toward the body were complicated by the body's paradoxical, intricate position in the cancer fight. The body was the place within which that fight took place. Simultaneously it was also both one of the fighters ("aided" by operations, drugs, or radiation beams) and, as the carrier of cancer, indirect target of these very actions.

Treatment regimens were widely perceived as imperatives, therefore as bodily assaults, so that the body needed to be safeguarded as best as possible. Protection aimed at keeping the body in a paradoxical suspension between tolerance and aggression. Further, the body's self-healing powers needed nurturing and the woman's embodied existence demanded to be secured.

As part of these protective activities "I" would consent, bargain, or dissent to suggested treatment protocols, routines, or procedures. One patient bargained with her physicians for

> low dose high frequency chemotherapy:...[to] give my body a chance to heal. I don't believe that the chemotherapy by itself is the thing that's gonna make me well if my body's a total basket case.

Complex and ambiguous, the "I's" protective responsibility was continuously challenged by concerns about the unpredictability of body-therapy-cancer interactions. "I" (and others) expected treatments and the body to "work", as well as the body and cancer to "respond". "Work" for body and treatments were to be successful fighters; the body's "response" implied evidence of cancer's withdrawal. Cancer's "response" meant its loss of bodily stronghold; a cancer which "already developed resistance to drugs" did not respond.

Strangely lopsided were their expectations regarding the "work"-

"response" cooperation between CTX and the body. While the "work" of treatments was envisioned to be martial, the body's "response" was hoped to be simultaneously supportive and forgiving. It would be supportive by allowing CTX to "work" and "work" with CTX, and forgiving by tolerating CTX's assault on its integrity. Hence, a "basket case" body neither served as a supporter, nor ally of CTX in the desperate fight, nor would it be strong enough to withstand CTX's toxic aggression. Therefore, protecting from high toxicity was warranted, in order to regain the body's own healing capabilities.

"I's" protective endeavors were far from being unequivocal or simple. They covered a narrow range lying between two abysses. The body/self was in desperate need of warding off too much "therapeutic" aggression, while concurrently, it had to be protected from cancer's deadly grasp through those same aggressive therapies.

"I's" balancing act on the ridge between too much therapeutic aggression and too little aggressive therapy forced "I" also into decisions to subject the body/self. Never, however, did "I" appear as an un-ambivalent self-subjugator. When heavy treatments were applied, "I" tended to align self with others to become "we", or yielded, with more or less conviction, to "them" who inflicted what, in turn, "I" was expected to endure.

In the following example no explicit split between "I" and body showed. But the fighting parties were complex and showed switching delineations: "I", husband and CTX on one side, were involved in the battle against cancer on the other side. In an other stance, "I" opposed CTX and thus disagreed with physicians and husband:

> I'm not sure that I agree with the doctors that you just go on having the chemotherapy until it no longer works. I'd like to reserve it like silver bullets so that I don't become immune to the drug....Not only that, I think it's important that I have a respite from it [CTX].

Her husband wished to continue CTX as long as possible:

> ...because the next level of defense is more toxic. According to [doctor] there is a something, incredibly toxic. It'll definitely kill the cancer or it could kill the patient too. We are contemplating: Do you go to that extent?

"I" (and husband) appeared in the ambiguity of subjugating strategists as they wished to use "silver bullets" selectively, (or continuously). Simultaneously, "I" felt compelled towards triple, paradoxical self-protection: 1) Preventing the loss of the body's immune-protection through intermittent exposure to CTX; 2) protecting the body from cancer spread through toxic ammunition; and 3) protecting self from being killed by the very forces, she at once wanted to use and to contain.

In its responsibility for the body, "I" tended to vacillate between guiding and aiding the body through imposition of procedures with curative intentions, (thus subjugating it to physical and chemical insults) and protecting it from these debilitating invasions. Besides deciding about complying with, or challenging prescribed CTX and other therapies, protective behaviors included eating special foods, taking alterative medications, and restricting energy expenditure. These endeavors were also geared towards recovering or enhancing the body's endowed strength and its immune system's own aggressive forces, but also, to feel better. (In chapter four I described such behaviors).

"I's" responsible stance towards the body was frequently associated with possessive allusions, such as "my body", "my blood counts", "my veins" etc. "I" dominance over a valued, yet belonging possession grew out of "I's" assumed responsibility after the body's taken-for-grantedness had been jeopardized. As long as the body seemingly complied by "responding" to the satisfaction of everyone, its implied status as one more of "I's" material possessions (commonly perceived to entitle the owner with decisive rights and obligations over them) did not get challenged.

However, halting or unclear bodily responses tended to relinquish unquestioned materialistic "I" dominance. The body would then reveal its belonging to, or appear as being an integral part of self and interdependent with "I".

<u>"I"-Body Interdependence</u> tended to show up in tandem with "I's" high hopes towards a body-as-ally cooperation in the fight against cancer. In instances of perceived "I"-body alliance, their relationship resembled one of bargaining interdependence, with self still in the position to propose the bargain. Yet, "I" seemed to be more empathically in tune with the body. Mutually responsive and responsible, "I's" alliance with her body looked something like this:

> I was afraid my white blood count was real low and I might get pneumonia so I was very careful for a few days. Tried to drink vitamin C and especially careful not to get chilled. I rested and got better. My white count went up.

In this deal, guidance and aid (use of anti-cancer therapies, supportive, relieving actions) were "I's" contribution, fighting the cancer through its own means (e.g. immune system) was expected of the body, while cancer elimination would reward the whole person.

Frequently, special foods were eaten in order to augment "blood counts", thus to improve the body's own fighting capabilities and to reduce its vulnerability. Women learned "to listen" to their bodies, to take bodily signs into consideration in daily activities. In attempts to strengthen the body through purification, they tried to entice its cooperation by giving up "bad habits" (e.g. smoking, drinking, junk food) and adopting new, "healthy" daily routines. Interdependent "I"-body relationships were also fostered by imaging and relaxation methods as well as through attempts at keeping a "confident attitude and thinking positively". Women who had learned imaging techniques tended to hold on to them after they terminated CTX because "it makes me feel good". Through attentive tuning into bodily sensations and feelings, meditative practices were intended to entrust the body's self-healing powers.

Compared to "I's" being in charge of the body, interdependence attributed to the body qualities of its own and quite some power. "I's" stance however, seemed still full of ideas and resources in how to bargain with the body. Many of these "I"-body deals were mercantile and to some extent reciprocal in nature, as well as strategically conceived: If "I" am kind and gentle towards the body, it will honor my deeds by responding with a successful fight and thus save me. This relationship was sustained by much hope and faith that this was both a chance and the road towards improved health as compared to pre-disease times.

Disappointing or lacking bodily responses, however, were inclined to deeply disturb the "I's" ruling over, or interdependence with the body. Usually, it was the body's unpredictable ambiguity between treatment and cancer that bestowed upon "I" a continuous, deep concern. In such times "I" became driven to take a less imposing, but more dependent, or humble stances towards her body.

"I's" Dependency on the Body seemed associated with the body's wavering "responsiveness" to treatment. The concept of a "responsive" body often appeared as strangely skewed, restricted to positively interpreted physical reactions only. No effects, or signs of disease exacerbation, were likely to be down played euphemistically as "poor" or "no response".

A responding body was assumed to indicate, through "side effects", that CTX "worked". (There was, however, no guarantee that a correlation - magnitude of "side effects" equals CTX's impact on cancer growth - really existed). Further, the body was expected to deliver evidence of diminished cancer activity and finally and hopefully, to bring forth long term proof of having conquered the cancer.

No clear predictions existed about how long or to what extent the body would respond. Irregular patterns or lack of response were characteristic of illness progression; while, after phases of disease exacerbation, relief from disease manifestations stood for renewed responsiveness. Minimal, or no CTX "side effects" stirred the suspicion that the body (thus the cancer) had not responded:

> I don't have very many side effects...nonetheless I can't help but think that if the rest of my body is not responding to CTX, what makes me think the cancer will?

One frightening aspect was that cancer lurked within that body on which the "I" was so dependent. "I's" existence relied on that "rest of my body" that constituted the "not cancerous". Although most women did not as explicitly distinguish between a plagued part and the body's (healthy) whole, they clearly separated cancer from body. Thus, the body assumed a pivotal place between cancer and the "I".

Cancer definitely was not the "I". It appeared as something alien, bad, invading. Usually invisible, not (any more) palpable (after excision), not sensible until its metastatic stages, cancer had uncanny, almost disembodied qualities. If "I" was to survive, cancer's invasion into the body had to be stopped and the body rid of it. Without the body's collaboration, "I" could not become cancer free. Against this background, the body seemed able to switch in its alliance between "I" and the cancer.

A responsive body appeared as more cooperative to "I", while an unresponsive body was likely to be perceived as surrendering to cancer. When cancer seemed to take over, the body was perceived as having given in, as betraying "I". Strong feelings of being forsaken could overwhelm the woman: "I just hate when my body gives up".

In such situations, the impetus to augment treatment, or change to different protocols arose. On occasions, this was also a time for stopping further bombardment of an unresponsive cancer, thus relieving the embodied self from unsuccessful subjugation to invasive procedures.

Cancer "response" differentiated effective, "working" treatments from futile ones, while bodily "responses" (euphemistically called "side effects") served no curative purpose, yet profoundly affected the women's lives. Often, these appeared as impediments to self and hauntingly reminded "I" of its bodily dependence. "Side effects" had the power to appear like a wedge between "I" and the body's usually unobtrusive, skillful functioning. The body or parts of it would then catch "I's" awareness through their resistance to habitual use. As (potential) obstacles in daily life, bodily impediments influenced women in their treatment decisions:

> ...I was concerned about the physical side effects of the surgery - preventing me - especially my right arm - [I] worried about what I can't do, preventing me from doing things - working and driving...because I am very self reliant and self sufficient. Being dependent on other people really bothers me...

Through its hindrances, the body brought to awareness its constitutive, life and world shaping force (see chapter four).

In "I's" dependence the body showed up in its self-limiting power. An impediment to "I's" endeavors, the body dictated "I's" (remaining) possibilities. Feelings of being forsaken or despair frequently accompanied this relationship.

Procedures could also enforce perceived "I"-body oneness, as well as "I"-body alienation. Mostly, oneness appeared in self-characterizations, or as suffering, while the abstract, disembodied, object body was projected against an emotional void.

"I"-Body Oneness or congruence tended to be implied when bodily features were described as being self, or when, in the wholeness of experience, the subjugated body became one with the suffering "I". In the following quote, both aspects are alluded to:

> I'm thinking about reconstructive surgery. I don't like being asymmetrical. I worried about having unsuccessful surgery...to be mutilated. [There] was some discussion about just having a double mastectomy and forgetting about it (reconstruction). That's been tormenting me - which way to go.

The aftermath of "treatment" left this woman asymmetrical and mutilated. Embodied in her asymmetry were worries about further subjugations and torments concerning a decision between two equally unwanted options. In the reality of torment the embodied self appeared in its undifferentiated wholeness.

Body and self, it seemed, became unified and held together in painful, emotional experiences, elicited by invasive procedures. In the body-"I" union of affliction, life-worlds tended to become narrow and "gray".

Suffering and the body are deeply intertwined. Disembodied suffering is unimaginable. Of all human experiences, suffering might be the one in which the body enters awareness with such life transforming power, that ignoring the body is not possible any more. Suffering showed up ambiguously and paradoxically: Not chosen, it appeared as experience inflicted from outside one self, yet also happening within and overwhelming the self. Beyond the woman's power to withdraw from suffering, or to undo it, it brought to awareness the body's presence as being: Self, the pivot between self and others, and the constitutor of her world. Suffering thus brought about "I"-body-world congruence and dissolved that very oneness into fragments.

Suffering was frequently shaped by pain. Two women eloquently described their "I"-body-outside experiences as they talked about the rampant impact of pleural effusion pain. For one patient, this pain prompted multiple drainage attempts (from the outside, with intention to appease the inside):

> [I] couldn't even sleep - my right side was experiencing a piercing-like pain as if an Indian had shot an arrow into my side. [It's] only present when I bend over - there is a dull ache. I'm not satisfied at all with the back pain.
>
> I woke up...in the middle of the night and I had pain in the flank right here, left side and it didn't go from the back to the front. It was just like somebody had driven a stake in it for no reason...it's sort of there all the time in the background.

Pain appeared simultaneously as localized, flashing up in movements, and yet always present. Despite pain's origin from within, it seemed to be inflicted from outside, a reflection of the body's perceived pivotal position between "I" and the world. Disrupted bodily integrity thwarted capabilities such as sleep and finding satisfaction.

Suffering encompassed pain's distinct, yet dominant presence, as previous self-understanding became eroded and the women lost their taken-for-granted relationships to the world. (Testimonies of such suffering are described in chapter four). In the next section I shall deal with the pain and suffering inflicted upon the women by medical procedures.

Suffering: The Subjected Embodied "I" and Others. Threefold meanings inhered in procedures done to the women: First, they had purpose in an uncertain fight against a life threatening cancer; second, they elicited bodily sensations of their own (often by far outweighing (early) cancer's bodily silence); and third, they stood for a relationship between two embodied people, one on each side of a needle, knife, stethoscope, etc. Depending the situation, suffering encompassed variations of all three meanings. Additionally, it included temporal and spatial dimensions.

Women experienced apprehension, often days before procedures were done. Time and place fused in anticipatory nausea experienced by one, while others' nausea became elicited by clinic smells. In its own way of knowing, their bodies transformed specific environmental clues with alarming connotations into embodied sensations of nausea: A physical refusal to eat and resistance to being open for intake. These powerful sensations were ignored and overridden, as "they" (or "we") coerced CTX treatments into the body, by mouth and/or through veins.

Adriamycin's (drug) bright red color triggered profound sentiments of rejection in several. One husband called it "red death". His wife planned on having a party to celebrate the end of her CTX: "There's going to be no red anything served...no red wine, no cranberry juice, nothing". Pushed by world-constituting embodied memories, this woman emptied her world of (deadly) red triggers and abstained from ingesting anything that would make her body repulse again.

CTX had the power to inflict such bodily repugnance in women that they "hated" anything in association with it. In this sense, CTX contributed to un-ambiguous, embodied experiences which left no doubt in their intensity, nor in the un-wavering bearing of their directedness. Yet, professional scientific dogma ignored such reactions as inevitable for the sake of probable cancer eradication.

More fragmenting in its impact and distinctively coloring relationships between patients and disease care providers was the "sticking" of veins. Considerable anxiety inhered anticipation of these procedures, which, if not skillfully done, easily eroded trust and raised substantial fears of permanent harm to the arm:

> They had higher dose and they blew three veins - the physical trauma - arms black and green...The psychological part about the pills is one thing, but the i.v. is a hard thing. I thought I'd get used to it but I haven't. [After this experience] I lost a little confidence in them and myself.

Confidence or mistrust, feelings of security or fear seemed to have roots in that relational, inter-body space between the other, actively engaged, more or less competent person and the self, aroused and vulnerable in receptive sensitivity. Not surprisingly, perceived careless or clumsy application of procedures were at the core of many strained relationships with professionals.

Anticipation and enduring procedures were not necessarily the end of distress. There was the disquieting step by step quality to many procedures, with each of them harboring new potentials for uncertain outcomes and further complications. Once the women had consented to a first intervention they found themselves over and over "having to do another step".

Each new outcome unraveled its immanent meanings, but left future consequences in the dark. Suffering thus occurred in a dual sense: Immediate ramifications of things done to the body tended to elicit pervasive sensations and feelings:

> One thing that was real traumatic was that I have a cavity because of these different lumpectomies.. It just like exploded on me...my front and back of my blouse was bloody...It was just humiliating...

while future uncertainty remained, for a long time, a haunting force to endure further procedures. In the words of the same woman:

> They want me to have a mastectomy. That whole thing has just been hard to deal with and emotional for me...I had hoped for a different outcome. I've had two lumpectomies and besides the biopsy, I've already had three surgeries. I would be going into my fourth and then my reconstruction is fifth...

As long as procedures loomed in the future as options to be "chosen" or rejected, additional uncertainty and ambivalence shaded suffering. Phases of decision making were especially painful for those women who deliberately participated in the process (as compared to those who complied with their physician's orders).

Buried in the question "do I need this (mastectomy, CTX, etc)?" was an uncanny realization that "informed decisions" really were agreements founded on more or less faith, since no one fully understood the body's precarious ecology. Thus, there was little comfort embedded in curative hopes, as long as procedures played havoc in that already upset ecology. Women felt easily compelled to consent to what was explained as science's latest beneficiary recommendations. Patients' attempts to safeguard themselves from devastating "side effects" must have appeared as non-compliance to many professionals: Several eroding patient-physician relationships revealed clashes of convictions coming from unequal sources: Embodied experience versus theoretical scientific prescription.

Professional and social pressure on those who did not concur added considerably to their turmoil. Somehow, they found themselves exposed to arguments similar to the deceitful rationales used in the defense of wars, namely, that something good can be expected to surge from much destruction and suffering. Of those who did consent, many remained ambiguous or even doubtful:

> I hate chemotherapy - I can't wait till it's over. I had major questions of its value to begin with. I did it because I got scared. Also, because that is all my insurance company would pay for.

Undergoing painful treatments without conviction added to debilitation, weakness, and pain the torment of profound doubt that these bodily assaults would ultimately yield life saving effects. Without question, it was the existential concern to survive, in which agreements to subject self to procedures were rooted.

What was done to the body with life saving intentions, easily transcended it in embodied, multidimensional suffering (see chapter seven). Medical treatments elicited disturbing experiences and were surrounded with ambiguous connotations. Painfully invasive to some, insidiously pervasive to others, they diminished physical substance and the integrity of bodily appearance. Further, they eroded the body's energy and the immune system's power to ward off inside and outside threats. Yet, they were used in faith and credited with (sometimes experienced as) gains in terms of future symptom relief and/or tumor decimation and eradication.

Some of suffering's dimensions enhanced "I"-body-world uniting experiences, while others tended to split that very oneness, and so brought to awareness the body's paradoxical, ambiguous nature. Suffering grew out of an enigmatic body which both hosted and fought the menace of death. However, at times that body disappeared into something distant with little connection to self.

Disembodied, Body-Distancing Perceptions were expressed in notions such as: "I had mastectomy", or "I had the pleural effusion liquid...drained". "Having" in these statements did not allude to a possession. It referred to something distant, to a part, but still something relative to self. Often, such reports were uttered in a matter of fact tone. "Having", as opposed to being, seemed to diminish the impact of what happened. One woman pointed to this important difference:

> It's not like you have nausea; it's like you're poisoned. Every cell in your body is not liking this. I'm conscious of that now...

In bursts of "I"-body alienation, the body, or parts of it were featured like assets of self, or objects at "I's" disposition. They seemed matter of fact, loosely associated with "I", but without emotional power over the self. In such instances, it seemed as if the living body had vanished into its anatomical parts and physiological functions, leaving "I" as a disengaged, objective bystander watching things happen and reporting them in scientific concepts to an interested audience. As one woman observed about her situation of failing CTX treatments and severe interpersonal strain:

> I would love to know what the connection is between adrenalin and how fast cancer grows. My guess is that the two are very much related....I have had more adrenalin pumping through my system in the last three weeks than anybody could possibly need for any situation.

Perhaps most poignant in disembodied talk about an object, or alienated body was the emotional neutrality which accompanied it. In the above situation, "I's" short term alienation from her body might have served a self-protective purpose, namely momentary relief from the existential anguish associated with a failing body. Mostly, women would resort to body-objectifying descriptions when they took part in the medical discourse and reflected on their experiences with professional activities. As if trying to slip into a scientific body would protect both, women and professionals, from distressing, embodied vulnerability (see chapter six).

Disembodied, scientific talk about the body served both participants in the drama, because it allowed cover up of the body's existential qualities. For the women, their vulnerability, powerlessness and dependence from bodily functions and others inherent in many "I cannots" and "I have tos" appeared as covered up in body-distancing speech. On the other side, conceptions of a scientific object for manipulation, inspire the professional pursuit of developing still better skills and more potent technological means to fight cancer. Conceptualizing the disembodied organism as scientific challenge, further guards professionals from being too touched and stirred up by patients' vulnerability and suffering. It also helps to blind "them" towards their own human and professional ultimate vulnerability, powerlessness, and dependency.

The Medically Subjugated Body: A Clash Between Different Body Conceptions

Dualistic (Cartesian) views on mind-body relationships tend to assign dominance to the mind and conceive of the body as mind-less matter. From such hierarchical perspective, a cancer ridden organism invites masterminded interventions, because its own resistance seemingly has failed to detect and fight cellular aberration. Rational deliberations facilitate a martial confrontation between technological weapons and cancer, despite or in opposition to the body which makes access to the cancer difficult. This conceptual stance encourages perceptions of the organism as a territorial barrier to otherwise promising strategies in the war against cancer.

Bodily subjection to medical treatment elicited equivocal allusions about who was the responsible agent for what was, or needed to be done to the body. Agent-body relationships reflected, analogy-like, diverse implicit understandings of the body and the agent's role, depending the beholder's side of experience.

Professional agency seemed rather unambiguous. The professionally conceptualized organism appeared territory-, object-, or obstacle-like, as a scientific challenge to be overcome and manipulated. Direct actions either depicted or intruded the organism in attempts to remove, or add substances from or to it. Professionals were also indirectly active through remote strategic planning. From their view point, (not unlike the situation of pregnancy), the organism harbored a growth which could only be accessed through bodily territory. But, (unlike the pregnant body which, in time, gives birth to new life), the cancer invaded body was comprehended as weak and thus in urgent need of potent physical and chemical intervention to assist it in its immediate and long term fight against inherent, elusive death.

In contrast, the lived body emerged as a meaning constituting power by provoking, to a large degree, "I's" embodied relationships with self and others. Visible to others and ever present as self to self, the subjected body brought to awareness its pivotal existence as a meeting point between the woman and those others who inflicted science's latest curative promises upon her.

Patients' relationships to and with the body were very complex, intricate, often paradoxical, and easily flashed up in ambiguous multidimensionality. "I" and body appeared as flowing between "I"-body congruence and "I"-body alienation, including "I"-body affiliations that paralleled responsibility towards a valued possession, bargaining interdependency with an ally, and impotent dependency from a force united with cancer against "I". While self was perceived as distinctly different from cancer, the body seemed able to switch in its loyalty between "I" and cancer, depending on its "response" to treatments.

Procedures elicited embodied suffering. Suffering promoted the body to appear as either in congruence with and/or fragmented from "I" and the world. In pain and suffering the body lost its unaware, non-reflective self-evident character by showing up as a compulsory force that forbade its ignorance in daily activities and decision making.

Although the rationally founded medical subjugation was geared towards an object-organism, by contrast the lived body surfaced as ambiguous and paradoxical. Albeit in theory mutually exclusive, the body was capable of appearing, at the same time, as a whole and in pieces, as owned and compelling, as forgettable and stridently world defining. The more implicit the body, the more in charge the self seemed to be; while bodily pain and unresponsiveness intruded on "I" with suffering's existential power. It was the living, "responding" body which made self, others, and procedures appear as either successful or helpless and powerless towards cancer.

Contrary to the uni-directional model of a mind over body, (to which some women adhered theoretically), it was this fluid multi-dimensionality of their sentient, in many regards previously not experienced subjugated body, which threw the women into a disquieting awareness of existential ambiguity and uncertainty. Lived, embodied certainty, however, was reflected in the body's ubiquity throughout the procedures and manifested itself in switching "I"-body-other/world relationships.

Albeit logical and theoretically convincing, the medical treatment options and applied therapies contained only statistically defined certainties and offered no immediate evaluation of their curative efficacy and efficiency; rather, they inflicted considerable, (but certain) suffering. In a culture with pervasive traditions of normalizing bodily subjection in every day life (Foucault, 1979), the body's rise as powerful but ambiguous and yet convincing determiner of self's relationships to self, others and the world around, tended to kindle unpredictabilities in daily life. Furthermore, existentially convincing, embodied ambiguity of the present thrust scientific, technological deliberations into the realm of future, uncertain probabilities. Bodily subjugation to potent medical techniques thus had little uncertainty mitigating influence, but tended to burden patients with much unknown beyond their illness fate.

Having been thrown into new, fluctuating levels of embodied awareness about existential relationships to self and others/world, it was nevertheless difficult for many to abandon the culture's (false) theory of mind-over-body dominance. They continued to trust, or at least to tolerate the power of scientific explanation to which they were so pervasively subjugated. While, on the existential level, medical subjugation seemed to give back to them an (anxious) awareness of their relation to the body's life constituting power, many searched for reassurance in cognitive approaches towards illness. Cognitively, they retained conceptions of the body as a mechanistic puzzle, which, if only studied and understood well enough, could be forced (or enticed) into eradicating its cancer. Approaches to knowing about the body, disease and treatment are the subject of the next chapter.

Theoretical Summary

Implied in medical practices and scientific rationale, the subjugated body appears as means towards the end of cancer eradication. It has to be overcome with diverse strategies leading to different goals (mapping it to know the whereabouts of cancer; entering it to extract and/or destroy bodily tissue samples; entering it to infuse agents of manipulative power to change cellular metabolic processes). The body is also understood as a feedback mechanism which helps to gauge cancer therapies. Out of their conceptually rational provenance, medical interventions logically assess and target distinct physiological processes.

In the *experience* of bodily subjection and illness the body appears in its identity-constitutive power. It shows up in variations of not mutually exclusive characteristics which suggest *"I"-body-world relationships* of yin-yang quality. I"-body relationships are enacted and, with the exception of perceived body-distance appear with strong emotional coloring. These relationships are influenced by illness characteristics, treatment, professional attitudes and interventions, as well as the patient's self-understanding. Any of these forces alone or in combinations may impact on a person's "I"-body and world relationships. These influences vary through time, are mutually dependent and interactive.

"I"-body and world relationships reflect the clash between theoretical and experienced body understandings. On one side, professional acts are inferred from interpretations of visible, countable, calculable or assumable physio-anatomical details. On the other side, patients' actions are founded in the hope that the body heals and once again becomes subliminal, that its impelling and hampering force disappears from daily life. Therapy "choices" are influenced by "I"-body relationships. Salient features of "I"-body relationships are summarized on the next page.

Summary of "I"-body relationships:

The Experienced Body	"I"-Body Relationship	Reactions
In need of protection	"I" in charge and responsible	Concern, interest negotiations with professionals
As an ally; to be enticed or bargained with	"I"-body interdependence	hope, faith learning from, listening to the body, body friendlier daily routines
As failing, forsaking	"I" dependent from the body	pain, despair, feeling forsaken suffering seeking more, different or terminating therapy
Congruent with "I"	"I"-body oneness	any emotions, in suffering tendency to withdraw from world
Having a diagnosis, condition	Body as distinct and distant from "I"	matter of fact statements, clinical reports to others

CHAPTER 6

KNOWLEDGE ABOUT THE BODY

Forms of Knowing the Body

Two major modes of knowing can be distinguished, one *embodied-sensual*, emotional and perceptual in its quality, the other *mental-rational*, or cognitive. The former is foundation to pre-cognitive, intuitive awareness, grasp and understanding of self and the world. The latter is paramount for analytic problem solving. Mental-rational abilities are anchored in and evolve from embodied-sensual knowing. Perhaps more than in any other field of intellectual pursuit, in the realm of knowing about the body both these modes are intricately and inseparably intertwined. Again, in a yin-yang like relationship, they comprise and influence each other.

1) The *embodied-sensual* mode is an intuitive grasping of a meaningful situation as a whole without explicit discrimination of its components (Merleau-Ponty, 1962/1979; Polanyi, 1962; Dreyfus, 1979; Dreyfus & Dreyfus, 1986; Benner, 1984; Benner & Wrubel, 1989). Embodied knowledge or awareness (e.g. experienced by these women as "I can's" self-evidence), includes skills, recognition of patterns, intuition and a sense of meaningful involvement with one's world. Dimensions of this kind of knowing are characterized by fluidity, marginal consciousness and non-rational awareness. This way of intuitively and pervasively knowing "makes sense" through its being rooted in whole body sensory perceptions. Emotionally and meaning-fully colored on the existential level, this mode of knowing constitutes the background for mental-rational knowledge to emerge and lets analytic knowledge show up as if indi-

rectly lit. In other words, embodied knowing is always already there and influences how situations are cognitively appraised. Much of healthy life's daily activities rely essentially on this mode of knowing.

One of the salient illness experiences, reported by the women, was the partial disintegration of this implicit, embodied-sensual background knowing. In the switch from their able "I can"-body to a world of "I cannots" their fluid background knowing staggered or came to a halt: Their self-understanding and grasp of the world broke down. Such breakdown elicits intense emotional turmoil. None of these patients was untouched by the unfamiliarity of their new, more or less ambiguous, multi-faceted situation. They experienced it in its totality as a human predicament. Chapter four reports how aspects of patients' embodied-sensual knowing broke down.

2) Mental-rational knowing pertains to attempts at cognitively penetrating and elucidating whatever shows up as a problem. Knowledge gained through mental, conscious scrutiny tends to contain abstractions of typical, but generalizable structures, components and relationships of the phenomena under contemplation. The search for such knowledge in every day life, (as well as in science), is problem, concern and interest-driven. Both the need to solve problems and curiosity motivate acquisition of analytic knowledge. Situations judged as problematic warrant disentanglement of their complexity to make them more amenable to interventions and solutions. Conclusions gained from mental problem solving processes generally warrant being tried out or implemented with an intention to explicate, alter, improve, or remedy a situation.

By necessity, this approach demands specification of a focus. In turn, intentional highlighting of certain components and neglecting of others, does require (at least temporarily) reduction and fragmentation of complex, amorphous, problematic situations. Successful mediation of one defined aspect might free mental and instrumental resources for learning about and tackling another problematic part.

In their utterly trying situations of being consciously confronted with existential life-death uncertainties, many women resorted to their intellectual and cognitive capabilities in order to learn and to problem solve. They aspired to discern components in their situation that seemed within their realm of influence and control. Knowledge about specific bodily reactions and processes as well as possibilities to influence them, allowed many women, at least partially or temporarily, to feel "in charge" again. (Examples will follow).

While embodied awareness of their world and sentient understanding of self in subjugation to aggressive medical treatments was shared by all, there were considerable variations in the level of body-objectifying abstractions to which women resorted. This difference was quite striking. It pointed to different modes of being in, and dealing with a similar situation. While some understood bodily happenings on low levels of abstraction and thus remained more in the first, intuitive, mode of knowledgeable awareness of embodied-sensual quality, others excelled in the quest to construct a basis of rational knowledge that served them in making informed treatment decisions.

The subsequent analysis focuses on cognitive and mental-rational knowledge. It will highlight three levels of abstracted knowledge about the body. These levels were neither mutually exclusive nor clearly distinct from each other; rather, they seemed to grow out of each other, but were applied to somewhat different situations. 1) Relatively concrete knowledge tended to be associated with activities patients did to relieve their situations. 2) Medical concepts served to talk about the body. 3) Complex medical knowledge served women in their decision making about the future.

Cognitive and Mental-Rational Knowledge

Relatively Concrete Knowledge

Conceptual knowledge about the human body is readily available through ordinary language and common sense understanding. This knowledge basically represents visible and sensible bodily parts and processes. Visible features of the body (eyes, mouth) and some of their obvious functions (looking, talking, eating) are already easily discerned and named by young children. Notions of internal organs, or clusters of active bodily components (stomach, bladder) and their associated purposes belong to widely shared cultural understandings (yet often without anatomical images). Other internal organs (liver, nervous system) may have names but, unless damaged, they usually are experientially, thus cognitively as well, mute. Individual conceptual notions about the body are corroborated through bodily experiences which make sense within a larger cultural understanding of what the body is all about. In turn, these very experiences tend to give further credence to cultural explanations of the body and its functions.

The women in this study were diagnosed as having a cancerous growth in their breast and, as a result of aggressive therapies, their body manifested itself in unaccustomed ways. Patients' quest for understanding grew from the urgency of grasping what happened and what they could do to mitigate the sequelae of their body's hampering presence in a transformed, hitherto unknown reality. There was knowledge to be gained and applied on levels that varied from vaguely concrete to tentative specifics.

<u>Vaguely Concrete Knowledge</u> guided most activities which were done to ameliorate the aftermath of CTX "side effects". Knowing of this kind was provoked by bodily sensations. For example, there was a pervasive need of knowing what to do to pacify an upset stomach or to diminish nausea. Typically, this kind of knowledge was composed of generic, or only marginally elaborated anatomical and (patho)physiological concepts of affected body parts and processes.

Bodily provoked mental attention was the core of this knowledge. The more powerful pain or un-easiness appeared in awareness, the deeper these states absorbed the women's attention. Attention and knowledge guided the flow of particular activities that were enacted to take care of these afflictions.

Vaguely concrete notions about un-easy bodily features stemmed from disparate sources of knowledge: Vernacular speech and popular medical concepts. These sources exemplified different levels of abstraction.

<u>Vernacular Concepts</u> arose from hurting, feeling, smelling, or seeing, such as "stomach ache", "nausea", or "diarrhea". They were part of bodily pre-illness comprehension. Such concepts made sense because they were rooted in widely shared understandings of what these bodily

states might be and which places in the body were connected with them. Yet, these concepts did not suffice to make fully explicit how for example nausea really felt, when experienced. From this point of view, concrete verbal expressions remained non-specific and insufficient; bodily sensations evaded the defining character of words.

Knowledge of this sort seemed ephemeral. It depended on the presence of sensed divergence from bodily obliviousness. Thus, with fading sensations this grasping knowledge dimmed also and was only recalled mutely by memory if called forth.

Many activities, like lying down or keeping quiet were done intuitively and relied on bodily know-how. Such activities were not implemented in a pre-meditated, strategic attempt to solve a problem. Rather, they seemed to flow, in a taken for granted way, from how women felt in the situation. Ideas or suggestions about what to do (e.g. dietary adaptations) were either transferred from previous experiences, or/and gathered through inquiry from family, friends, fellow sufferers, or professionals. Such attempts to remedy (e.g. intestinal upset) seemed quite common-sensical and were often applied on a trial and error basis.

Besides relating ailments and care taking, causal links between bodily parts and illness effects were used to explicate larger consequences. For example, a "reacting" stomach would appear as a justifying arbiter between "I can" and "I cannot". Connections between body, "I cannot", and its consequences were obvious to patients.

Activities were aimed at making the presence of the stomach and/or nausea disappear from awareness, at restoring them to their mode of being "unknown", meaning un-sensed. The impetus for activities arose from this very embodied knowing; it easily subsided when ailments were taken care of.

Since knowing in this bodily driven way focused on mitigating activities, evaluative awareness too was grounded in improvements or exacerbations rather, than being mental and rational in the assessing of changes. Thus, when ailments disappeared, awareness of their presence blurred or disappeared at the same time. As the stomach reentered that undefined bland internal whole and nausea withdrew its mandating grasp from the wholeness of the patient's being, the women described profound relief and gratitude. Feelings of freedom from the constraints of "I cannot" rose, when awareness penetrating bodily uneasiness disappeared. Not only did freedom from bodily coercive, dis-abling powers grow, but also the freedom of returning abilities came back within a body that, once again, allowed its own forgetting.

In the talk of less verbal women, bodily awareness and experiences tended to appear in the vagueness of these never fully explicit, yet concrete terms. Medical and pharmacological words were rarely part of their vocabulary. These women did what they felt ought to be done, applied what they already knew and tried out, what had been recommended. They seemed less apt at explaining in anatomical-physiological terms what went on in their body and appeared only marginally interested in learning about underlying disease processes. In their adherence to embodied, sensual knowledge they differed from their more verbal, intellectual counterparts who tended to perceive their bodies from a more objective, medico-scientific perspective. (See analysis 1 in chapter seven).

Medical Concepts

Popular Medical Notions were promoted from two sources: 1) through bodily sensations, and 2) through medical treatments. Medical terms were a rich source of seemingly clear cut conceptions and labels for experienced bodily phenomena like: "those kinds of infections...conjunctivitis in my eyes... [and] vaginitis bother me a lot". Such words served as descriptors of bodily happenings, assisting the women to talk in objective, disembodied ways about real bodily irritations such as itching, watering eyes, and vaginal dryness or discharge. They served to pinpoint intelligibly to self and others specific organic states.

Popular medical parlance falls short of evoking repugnance through visual or sensual allusions of what happens in such bodily states. Reflective of a strong cultural drive to sublimate the body, such terminology seems adequate, precise and non-embarrassing to the user (Elias, 1939/1978).

It is interesting to note that popular medical notions seem to have forced aside more embodied, vernacular English terms like e.g. "pink eye". The use of abstracting Latin nouns like conjunctiva, vagina, and the Greek suffix "itis" for inflammation (inflamed = in flames), veil both the bodily places and the in-flamed, burning happenings there. In contrast, vernacular German and Swedish use Germanic words for these body parts and add the respective equivalent for "inflammation" in every day speech; while the Latin/Greek idioms are germane to scientific-professional language.

Although some medical concepts may have been readily available through every day language and previous experiences, others had to be learned when unfamiliar bodily states (syndromes) developed. Many women tended to adopt medical concepts to name the syndromes, but talked about their experiences using vernacular, embodied language:

> I guess what happened physically was that I had the pleural effusion liquid - really cutting down on my being able to function in normal manner - I didn't have any breath, any energy.

The abstract vagueness of having a medical syndrome called "pleural effusion" allowed for some distance from drowning in one's own liquid. Yet, it gained dramatic, concrete, embodied actuality through the liquid's clearly "breath and energy cutting" impact. Hidden in the scientifically neutral statement "I had the pleural effusion liquid" lay the primordial notion that something life threatening had happened, something beyond one's control. Existential anxiety (one form of knowing) associated with feeling her lungs as inundated with "three liters of fluid (which) they managed to get", was covered over in disembodied abstraction. In the same vein, how abstract (and perhaps mentally protective) are "three liters" to a person whose images of volume are cups, pints or gallons?

Many however, did not learn abstract medical (or pharmaceutical) terminology. Pharmaceutical names were especially difficult to remember. Often they escaped memory and got lost in anonymity. Nevertheless, their bodily effects stood out; patients recognized them as unforgettable:

> I had enough [of] the medication they had me on before - that make me gain some pounds. [The] doctor told me it had to do with whatever - it makes everybody gain weight. Some kind of hormones. They make me gain about 13 pounds a month when I was taking them. I gained between 30 and 40 pounds.

Medical concepts could also be tools used for translating culturally repulsive bodily happenings into socially acceptable forms of dialogue. Scientific terminology helped to sublimate culturally un-easy physical states and features such as smelling vomitus, looking into watering eyes, on vaginal redness and discharge, or pleural exudation and watching 40 added pounds changing physical appearance. As confrontative and provoking were the sensual bodily messages in eliciting reactions from self and others, so by contrast, the body in scientific terminology became clean, neutral, and muted into matter of fact disembodiment.

While the body's physicality is both source of and tool for concrete embodied knowledge, language allows such awareness only to be shared in part through its transmutation into mental concepts. Knowing through the body thus always contained a quality of awareness, which words could not make fully explicit.

Medical concepts also included highly abstract notions, not provoked through bodily sensations. Such concepts were introduced through medical treatments. Professionals, by and large, reasoned in a disembodied, logico-rational language; they knew about fragmented organisms (and cancer) through bio-technological parameters. Thus, many women attempted to learn scientific concepts from professionals. They then tried to endow such fully abstract (physiological) notions with embodied experiences.

For example, they were deeply preoccupied about their "blood counts", a concept which, without bodily sensations per se, promoted them to link it to daily actions, the quality of their feeling and intensity of their vulnerability:

> I've had to eat three good meals a day. I'm supposed to get my blood count up and everything.
>
> I am feeling better. The reaction this time is much, much less - I only got 2/3 of it (CTX dose). My white count was better.
>
> My blood count might be a little lower - that's why I get this cold.

Thus "blood counts" - perhaps in place of an older, vernacular notion of "good blood" - seemed to have become symbolical carriers of vitality, hope, and health. They therefore were justified in keeping high numbers. But, without actual lived associations, neither the entities of the counted blood (e.g. white or red cells) nor their numbers per se seemed to make much sense. Rather, such digits seemed to be used as awkwardly as would be calculated miles per hour in the description of a zephyr or storm's blowing sensation on one's skin and hair.

Of course, medical concepts were strongly linked to treatment consequences. These connections were of more interest to women whose approach to the illness included strong intellectual reasoning.

> My white blood count had gone down so far in the hospital that they wouldn't let me have flowers or fresh fruit.

The logic of such relationships implied insights into immunological mechanisms which relied exclusively on learned images. To scientifically ignorant listeners, such statements must sound unintelligible and non-sensical. Scientific logical reasoning, therefore, had little or no convincing power upon patients who did not share these mental concepts and their implied logic.

If not convinced, women would refrain from following scientifically logical recommendations. One patient, for example, remained unconvinced that cancer was not contagious. Over the six months of the study she kept her dishes and eating utensils separate from those of her family, hoping thus, to prevent their contamination.

The less bodily founded or the more abstract the concepts became, the fewer patients occupied themselves with such knowledge. Of course, medical concepts were even less suitable for adequate expression of the experienced body's ambiguities than were either concrete or vernacular speech.

Incommensurable in their very different qualities of knowing, these modes of understanding nevertheless complemented each other to some extent. Since it was the experienced body which appeared as both question and partial immediate answer, a patient's endeavor to know seemed to be continuous and present oriented, as long as her body demanded consideration. For example, bodily responses to new cycles of CTX appeared as unknown until experienced:

> Not knowing how I was going to react - while this is my third time (on CTX) - I still didn't know that this would be a disruption.

Medical concepts helped to grasp and explain what was happening and to put unfamiliar bodily experiences into new conceptual frameworks.

But there was yet more knowledge out there to be pursued. Active participation in treatment decision making requested a grasp of complex medical knowledge. Knowledge of this kind was body-devoid, compared a person's pathophysiology to normative data and was geared towards elucidation of possible future reactions. Compared to the ambiguity and vagueness of bodily reenforced concrete knowledge, complex medical knowledge was paradoxically fraught with disquieting tentative specifics (of one own's case), normative universalities (as they pertain to an abstract, normative organism), and future unpredictabilities of one's bodily response.

Complex Medical Knowledge

Scientific knowledge and thinking impressed as abstract, specific and general: Abstract, as experientially disembodied, specific in terms of naming differential diagnoses and decontextualized patho-physiological processes, and general in the way as a woman's organism compared to norms. Such knowledge was of interest only to a few patients. For them, it was pertinent during decisions about interventions involving high bodily stakes, such as whether to have or not to have a breast removed.

While specificity inhered in diagnostic concepts, uncertainty loomed in the unpredictability of its consequences:

> I happen to know that inflammatory breast cancer is one of the most grave diagnoses....After I had the mastectomy I talked to my doctor and I said: does this improve my chances at all? He said: no...it doesn't improve your chances at all. We don't know if it's going to help at all.

Chance, in this context, equalled probabilities. Abstracted in probabilities, the odds of one specific diagnosis, procedure, or organism were compared to a collection of others of a same or similar kind. Statistical probabilities instilled both hope and despair; they encouraged or discouraged risk taking, depending on which possibilities seemed more probable.

In its trend typical for many who applied complex medical concepts in their decision making, but more cognitive was one patient's approach: She wanted both her own and her husband's decision about mastectomy to be "some kind of objective decision based on some kind of rational thinking". They consulted with professionals, appreciating especially those who "knew [their] statistics". She read scientific literature. It was important that her partner listened to the same information "because I knew I wasn't totally objective". They found out that:

> We do a blind biopsy after I'm all done with the [CTX] treatments. Go back in, take a look at a tissue sampling just to find out if there's any pre-cancer cells left.

If this abstract and fragmented narrative did not stand, like shorthand, for scientific knowledge of incredible complexity, if it were to be understood literally, then it would have to be judged both illogical as a process and absurd as an image. "Going" in there (the breast) "blindly" to "look" and "find out" about remaining potentially deviant cells, evokes the vision of a mysterious ritual on one hand, and reveals inadvertently (science's) blind impotence vis-à-vis the invisible, intangible cancer on the other. Nonetheless, faithful optimism about technological methods of elucidating and trust in the possibility to know scientifically lead them to renounce their previous decision against mastectomy.

> It wasn't a life-threatening decision, it was more [a] decision on whether I wanted to take a risk of a local re-occurrence....I'm optimistic that I'm in the 70% that aren't going to have a recurrence.

Several months later she read in the New England Journal of Medicine that "Tamoxifen...might give another five or 10% or whatever margin" and contemplated use of this drug. (See analysis 3 chapter seven).

Scientific knowledge and perspective helped the women make decisions for temporary treatment alternatives. Yet, they yearned to regain life's lost certainty and self-evidence by making the "right decision". The more they knew, the more in need of knowing certain women seemed to be. Their quest for the ultimate right information, on which the appropriate decision would be founded, appeared to be supported by the belief that there is, or will be knowledge which guarantees certainty. Hence, more and more information had to be "factored in", as if thereby their existential, embodied anxiety could be mitigated.

Fata Morgana like, rational knowledge reinforced patients' delusion that knowing could save them; relentlessly, but in vain, they searched for a paramount, rational saving force that would redeem them from the uncertainty of their embodied plight. As an object of knowledge, their lived body had disappeared; yet, subliminally but unreachable through abstract knowledge, it was pervasively present as the only real, true guarantor of their future.

Body-devoid knowledge about the body, its parts and processes, led to mental images and calculations with countless more or less apparent logical links. This type of knowledge transcended deliberate decisions and intentional actions which were implemented with scientific rationales. These actions were problem oriented, deficit focused and geared towards abolition or reduction of defined deficiencies or malignancies. Deficit orientation implies notions of the whole, the abundant, the normal, against which it only makes sense to evaluate the effects of applied knowledge.

Evaluating their scientific, applied knowledge was extremely difficult. Measurements of treatment success were paradoxical. While technically more or less reliable measures were unreliable if understood in relation to the body's multidimensionality; since they were scanty, fragmented, and applied discontinuously. Bio-medical parameters measured physiological features out of context, in material and temporal cross sections. Furthermore, science offered solely normative knowledge of universal organisms and decontextualized processes. Any one specific specimen could be measured in relation to similar specific specimens from other organisms, but not in relation to the body's own milieu. Thus, one could never know for sure.

Time only would tell. In fact, chronological time became a gauge for the interpretation of processes which took place on biochemical and cellular time. Months and years would tell, with increasing certainty as time went by, if a woman was free from recurrence at the moment of measurement, or not: "Frustrating - the not knowing at this point.- ...It's sort of cruel that one knows not immediately".

Because uncertainty appeared so often in the form of a knowledge-vacuum, to learn more and becoming vigilant about the body seemed like good ideas to some patients, (as if this vacuum could ever be filled). Yet, the anguish of uncertainty would remain untouched at its core; at best it would be mitigated through rational covering up.

Nevertheless, medical knowledge helped in making decisions, all of which included non-rational dimensions such as trust, hope and the optimism that what was done would be right. One woman who decided on "objective" reasons against a mastectomy three months after diagnosis said:

> It's just a whole different perspective for me because the decision has just brought me to a real place of being...I've been happy, I've been happy for the last week and a half. It's the first time I've been happy since I've been diagnosed. It's really so. I feel energized.

Without the gained knowledge she would have felt "a passive participant...passively waiting for the day (operation) to come". Even if it could not provide existential reassurance, medical knowledge tended to enforce confidence of not being fully at the mercy of fate and professional judgements.

In general, to most women, scientific reason was less persuasive than bodily founded knowledge. If not convinced, they would refrain from following scientifically logical recommendations e.g. refusing Adriamycin because its havoc to the body seemed unbearable.

Conflicts occurred when patients' knowledge, usually more grounded in bodily experience, contradicted professional scientific reason. If discrepant, then bodily grounded knowledge tended to override rational logic and thus presented a strong impetus to question, abandon, change, or supplement medical approaches to treatment.

The more explicit and versed in the use of medical terminology were the women, the easier it seemed to make themselves taken seriously and attended to by professionals. Perhaps, such talk eliminated the space for talking about feelings and anxieties, thus protecting both parties from facing their emotions. If eloquently used, scientifically knowledgeable language facilitated and smoothened encounters with professionals: Information was more easily obtained, professional interest and engagement gained, and, in turn, the women acquired more medical insights through such interactions.

Theoretical Summary

Knowledge about the body influences both actions to be taken and perceptions of the body. A changing body triggers the impetus to know. Types of knowledge vary in abstraction.

Concrete knowledge about the body served to describe bodily phenomena and was used to link mitigating activities to bodily states. Talking in abstract concepts helped to camouflage potentially obnoxious or scary bodily features. Specific medical knowledge served those who sought it to make as informed future decisions as possible.

Patients' understandings were somewhere between the ambiguity of experienced illness effects on the body and an abstract, yet pictorial concreteness of anatomical body parts, organs, tissues or cells. Qualitatively incommensurable with each other, knowledge from both sources nevertheless flowed together to become some kind of knowing that fluctuated between awareness through bodily experience and rationality.

Basically, the body forced itself into awareness by appearing as unforgettable through its disturbing presence. In other words, in every day activities the body subliminally reminded the woman of her illness and jeopardized existence. Vaguely concrete knowledge, which usually presented itself within a convincing, fluid, bodily awareness of uneasiness, tended to impel immediate activities geared towards appeasing disquieting sensations. Bodily uneasiness <u>was</u> knowledgeable awareness, an ultimate presence which was difficult to forget. Bodily ubiquity did not always necessitate distinct, mental representations and logical linkages to be constructed, but influenced pervasively if not compellingly protective, soothing, or enduring activities.

Language allowed the naming of some of this awareness and granted communication and expression of embodied states. Naming and defining what took place in the body however, was a difficult, never fully satisfying task, since it implied transmuting bodily non-verbal, rampant knowing into that less paradoxical vehicle, called language. Yet, words, concepts and specific knowledge assisted some patients to make sense out of ambiguous bodily signs and to share them with others.

Patients varied in skill at adopting medical concepts and using them in their encounters with professionals. Less verbally gifted women either reported problematic relationships with disease care providers, or trusted them rather uncritically. Those who learned scientific knowledge seemed to feel more at ease in their discussions with professionals.

"Know more to feel better" (TV slogan for vitamins, 1990) seemed to be a cultural, but deceptive promise that led some into a relentless pursuit to know formal scientific and vernacular explanations of their disease. Knowledge about disease processes and tentative treatment impacts was geared towards anticipating and influencing future bodily reactions in the direction of cure.

Verbally used, scientific knowledge appeared as "objective". Undistorted through experience it covered up many of the body's socially shunned, disquieting phenomena. Many women readily participated in medicine's language game by following its rule, that forbids the use of an embodied teleological vocabulary (adapted from Bauman, 1989, p.170), as long as they search for information and learn to think about their organism in terms of probabilities.

However, at its core, this seeking and applying of complex, medical knowledge was driven by deep uncertainty about a future that had lost its taken-for-grantedness. Existential anxiety could not be appeased by knowing rationally, but possibly by pursuing what seemed meaningful.

In the following chapter I shall explore, paradigmatically, how different women dealt with their situation. The subsequent analysis will re-combine aspects that I analyzed separately in these three chapters.

CHAPTER 7

PARADIGMATIC APPROACHES TO A CHANGING BODY

Possibilities and Certainty

Immanent in the body and the world around it are the possibilities which, once enacted, become the unique web of lived certainties. Although countless in abstraction, possibilities are restricted socioculturally by the practices of specific historic times and places and, on the individual level, by a person's embodied, acquired routines, habits, and convictions.

Possibilities constitute the future. Uncertainty inheres them until out of all of them, one specific constellation becomes embodied reality. Certainty is the embodied present. It builds on, and flows from bodily memories of past experiences. The body's physiological conditions give rise to the multi-dimensional fluidity of past and present experienced reality.

While awareness of past and present are embodied, it is through the mind's capability that anticipation and contemplation of future possibilities are possible. On the other hand, it is the body which guarantees future's unreflected, taken for granted resemblance to what is known as present through past experience.

In cancer illness possibilities which, under taken for granted conditions, flow inadvertently from future into past, suddenly show up as jeopardized or thwarted. What until now had appeared as an abstract possibility - life's finiteness - emerges within the concrete realm of a reality to be lived.

The women in this study saw themselves confronted with this existential challenge. Each woman experienced the challenge in her own way and in congruence with her unique life's history. Yet, were one to compare each woman's particular dealing with her situation as a sewing of her life's quilt, then colors, materials, and patterns appeared in these fabrics which made them witnesses of shared, cultural self-understandings.

All lived in the certainty of chemotherapeutic treatment for breast cancer. At one point in their disease trajectory they had decided to follow this promise-full path towards cancer cure (or prolongation of life). This very decision excluded, at least for the time being, any experiences which were not influenced, in one way or another, by CTX.

Paradigmatic patterns of dealing with a difficult situation did not necessarily appear as mutually exclusive. Rather, patterns often contained elements of each other or surfaced more in certain episodes of life than in others. Patterns depict how the similar situations appeared with diverse imperatives to different persons. Depending on how their situations showed up, relationships to bodies too, appeared in different lights.

In this chapter, I shall analyze three different patterns of experiencing illness and treatments. In a fourth example, two existential self-body relationships will be the focus. At the beginning of each analysis the women shall be introduced and their experiences described, as much as possible, in their own or family members' words. Besides impressions from their interviews (some of which were brief and taciturn) I will describe the women as they impressed me during the research visits, and in the cases of Jane[15] and Anne, beyond the original time of the study.

I chose salient sentences from their interviews as headings for three different patterns of experiencing the illness and treatment impact and two existential self-body relationships:

1) Shin: "Complying and accepting what comes" and

   Jane: "To live till you die, I guess";

2) Sue: "The last six months were merely a stopping point" or "getting through...to get on with things and back to where things were before";

3) Pat: "It [is] a real drag to be forced to do things that aren't of my choosing" or "it [is] important for me to feel like that was some kind of objective decision on some kind of rational thinking";

4) Anne: "Having the strength to deal with whatever comes" or

   Mary: "I hate it when my body gives up".

Patterns of Experiencing Illness and Treatment Impact

1) Living Until You Die I Guess

The Women: One of the two participants who most poignantly lived in this mode was a single, 52 years old Chinese woman. Shin lived with her parents and a younger, unmarried brother in a comfortably large, meticulous, middle class suburban house. The family had come to the United States years ago; among each other, Chinese remained their language. Although fluent in everyday English, Shin's participation in the interviews was hesitant, somewhat inarticulate and she easily let her father tell his impressions of her illness. A friendly woman, she appeared rather shy. Within her family, (and a larger social context?)

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[15] All names are pseudonyms

she seemed to assert herself in what was important to her, e.g. being actively involved in a Christian church (which her family was not). Shin was a bank employee. Three months before the first interview, she had been diagnosed with breast cancer and had undergone a mastectomy. She was treated with Tamoxifen and Cytoxan (Cyclophosphamide), Methotrexate, 5FU (Floxuridine) (CMF). Radiation therapy was planned at the end of six months of CTX. Shin suffered from gastro-intestinal side effects and alopecia. During interviews she either wore a scarf or a wig.

The other woman, Jane, was 70 years old. A white woman, she had been raised in an orphanage in the Midwest. At age 16 she became a widow when her first husband, a policeman, was shot. She shared a cluttered, dog and cat smelling apartment with four other adults, a toddler, two dogs and two cats. (The other people were: Jane's ex-husband, her god-daughter whom Jane had brought up, the god-daughter's black boy friend and their one and a half year old son, as well as a friend of the boy's father). They lived in a predominantly black city neighborhood. Jane never read any of the forms we presented to her, but had us read them to her. She did, however, sign consent forms. (I am not sure if she knew how to read). She seemed to be the one to do the household chores and together with her ex-husband, she took care of the charming, little boy during the absence of his working parents. Jane was friendly and accommodating. She seemed to be the caring center of the household. Not talkative herself, she usually let her ex-husband talk. Occasionally, she would interject her disagreement with him, but often she left his views unopposed. Only in the last interview did she (dare to?) ask that the tape-recorder be switched off as she attempted to tell two incidents which had bothered her. (Racial discriminatory comments about her "grandson's" being of mixed color in a hospital elevator and a drunken "friend" from the street who had come to bet, who of the two, Jane or that friend's sister with breast cancer, would outlive the other). Jane had sought professional help for a bleeding breast and was diagnosed as having metastatic breast cancer. A porto-catheter was inserted for easy CTX access (Adriamycin (Doxorubicin), Cytoxan, 5FU). No mastectomy was performed, but future RTX was planned. Jane was almost bald; she used to cover her head with a plastic shower cap. Jane suffered more from asthma than she did from CTX "side effects". Her dental care seemed neglected; she had a few decayed teeth left.

The Appearance of the Body and the Women's Concerns: Taciturn in their interviews, these women talked about "I cans" and the sequelae of "I cannots" through which their body manifested itself. Shin suffered mostly from the gastro-intestinal impact of CTX, while Jane was hampered by pain, fatigue and the "have to" of frequent hospital visits.

Throughout the interviews, Shin (and her family) were concerned about her "reacting stomach" and nausea's impact on her life. Finding out what food she would tolerate and what would taste appetizing to her palate's changed savor concerned them. There was worry about "how the medicine makes me feel". Often, medication made her feel sleepy and unable to go for walks with her father. She reacted favorably to Chinese powders which her mother provided. Shin had asked her "to get powders for the diarrhea".

Shin's poor eating worried her family and herself. Her reports were detailed in what she ate and what she could not eat. Having been "weak" throughout her life in her father's view, Shin's inability to eat further depleted her already feeble strength and incapacitated her for work, walks, and whatever she usually did. "I try to eat and build up my strength with vitamins" she said in the third interview, (six months) while at the same time reporting a "hurting stomach", mouth soreness, and, if unmedicated, nausea and vomiting. "They give me two pills before I get chemo and that seems to take care of it (nausea)". She associated a "fainting" event with (antiemetic) over medication. Her mother "held" her while she fainted, thus she stayed unharmed. Shin did not share her fainting experience with professionals. The family monitored her recovery and encouraged her to stay at home one day longer to "be sure what her reaction would be". After CTX, Shin used to sleep "about five hours - after it'll be okay. I don't have the nausea not so much at home".

Besides "comply[ing] with what the doctor says" Shin sought and accepted her family's and friends wisdom and support, listened to experiential accounts of other women with breast cancer and read a book on CTX. She hoped to live and "get well again". Although she had been told that cancer was not contagious, she kept her plate and eating utensils separate in order not to "contaminate" her family with disease.

Chemotherapy induced changes in taste, stomach and intestine appeared as powerful determiners of what appeared as edible and what got refused. Embodied strength seemed essential and almost symbolic for her adult womanhood, at least in Shin's father's view. Eating, but only the right food, was associated with strength, vigor and health. Long hours of rest seemed to soothe Shin's body.

Shin never mentioned the loss of her breast nor did she allude to worries about alopecia or other disfiguring experiences. Together with her family, she attempted to appease, to the best of her and the family's knowledge, her body's new, restricting, yet imperative urges as they occurred.

Jane; on the other side, "didn't have any reactions or whatever" albeit "he (physician) [had] said I might get sick to my stomach or might get a fever". She did not consider herself sick; but worried about her family members while in the hospital for three weeks when she was worked up after diagnosis and got a porto-catheter implantation. She felt pain and restriction in movement from that wound. When Jane ran out of prescribed analgesics, she took what her ex-husband gave her for pain, tried to get pain relief through sleep and "keeping busy" and proceeded, after several days, to take the stitches out: "I feel better now - because it was pulling". When she went back for CTX,

> they tried to give me that, what do you call it - chemotherapy. They tried to give it to me through that thing and they couldn't do it. Then they punched three holes in there... Then they sent me down there to x-ray. They found that it was upside down.

She was "terribly upset and concerned" about having to "do it all over again". She "hated" to go to the hospital. Although usually accompanied by one of the two young men who shared the apartment, she inevitably got lost in the complex buildings and diverse administrations of the medical departments in which she underwent procedures. She seemed helpless in her contacts with professionals. Nevertheless, she consoled herself: "Oh Lord! It's not...like I'm having a heart transplant".

Jane's concept of time and days was somewhat vague. "Some time next week" she would have a clinic appointment; or she could not quite remember when things were done to her. Two weeks after the new implant she thought that only one week had passed as she observed in two sentences: "It never hurt, but it's turned red. It's a lot better now".

Early on, under therapy, Jane "got dizzy the other day. He (ex-husband) talked me out of it". Sometimes she felt more tired than before. After six months of CTX "I felt so bad yesterday, I couldn't think...I didn't feel myself"; but the next day "I felt much better". Sometimes the illness "depressed" her. Then, she would get busy, "get my mind off of it", or she would "just pray, that's all". Jane mentioned, as a matter of fact, that her hair still fell out, but that "they" had told her it would grow back.

Analysis 1

Although they differed considerably in their cultural, socio-economic background and family status, as well as in how illness and treatment impacted them, these women displayed similarities in the way they described their embodied situation.

In its self- and world constituting capacity the body appeared as having constituted Shin's "weakness" as a woman. Whatever Shin's energy-of-being (e.g. vigor) may have been, painful CTX "side effects" depleted her capacity for eating. Much concern and strength went into finding food which she tolerated, into eating and keeping the food down. Vomiting both consumed and drained strength. Shin's main source for replenishing strength (she never used the word "energy") remained her ability to sleep. By refraining from walks and taking time out from work she attempted to diminish her fatigue.

For Jane pain from the implant had become a driving force for what she did: Keeping busy, taking her mind off, removing stitches... Jane ate as usual. She alluded to some fatigue, but without implicating that there existed something like an energy or strength balance.

In Shin's situation, diverse "cannots" (intolerable foods, lack of strength) colored her and her family's daily life. Her inability to work distanced her from people she liked, while her presence at home brought her to the close attention of her concerned parents. For Jane "have tos" initiated by the diagnosis and partially sustained by pain (hospital visits) disrupted her and the extended family's routines.

The closeness of both families prevented these patients from being harmed when they (nearly) "fainted". Patients' bodily ups and downs did not escape their families' close attention. Illness and treatment related concerns were perceived as worries rather, than problems by both patients and families. As worries and concerns, the illness was present in everyone's awareness. In a common effort, they tried to safeguard the patient against and to mitigate CTX's diverse impacts.

Buytendijk (1967, p.270) underscored the importance of situational effects on the person who faints in addition to physiological conditions. The possibility for fainting might be greater in situations where trusted others are around than in austere self-reliance. There was no doubt in these women that they were part of, and interdependent with a family which helped each other when in need. Fainting (described only by one more woman who also was part of a concerned family) may have been safer in such environments than in situations where the illness or treatments threatened personal independence.

Both Shin and Jane appeared to know who they are, primarily in relation to their families. CTX's impact on some of their habitual activities (walks or work for Shin; some house work for Jane) seemed not to touch the core of who they perceived themselves to be. Yet, for some time after the operations, Jane's arm, so close to the implant, hampered what she did, thus reminding her of what she did not really want to have on her mind.

Clinic appointments disrupted Jane's otherwise continuous sense of time. She hated the places she was expected to show up. Otherwise, neither her nor Shin's present seemed greatly different from the past. Both patients made the impression of being immersed in the present. Neither did the past appear as the ultimate gauge to measure a now wanting present, nor did the future show up as a dimension to be crafted by one's own will and cleverness. The illness was there to be taken care of, but ultimately, it was beyond their capabilities to make themselves healthy. They thought their future to be in God's hands and hoped, while praying, to live on, "to feel well again".

Shin's daily rhythm changed whenever she was treated with CTX. Nausea, vomiting, and exigencies to drink a lot brought to her awareness those night and early morning hours which, in healthy days, she usually had slept through. Simultaneously, hours and days disappeared in the fog of nausea or in sleep when Shin retired to her room. Neither Shin nor Jane appeared impatient or bored with their state of being. They had a capability to endure what they perceived had to be accepted.

A sense of certainty and continuity surrounded both women: A certainty which seemed related to expectations that life asks to be lived as it comes. They did what seemed within their realm of doing and let others take care of what appeared beyond their power of influence. They took upon themselves to do and undergo what professionals proposed to them, but added, on bases of previous experience or trial and error, what promised momentary or short term relief.

Shy about sharing what happened to them, both women were deeply concerned, less about their own illness, than about their families. Jane got "upset" when she could not find her way around or things went wrong in the hospital. It seemed as if hassles were part of life and that things just were the way they looked. Since they had never expected themselves to be the only masters of their lives, they seemed to withstand emotionally with less turmoil than did others.

Throughout the interviews, bodily appearance was not brought up as a (problematic) theme. Once, Jane ripped off and destroyed her picture from a photograph which had been taken of her and me during an interview, saying that she did not look good. The interview format did not probe for concerns about appearance. To some patients, however, appearance was important. The absence of explicit allusions to appearance in Shin and Jane's situations invites speculative questions. For example: Did bodily appearance matter, but was taboo as a subject of conversation? Was it a lesser concern than the threat of life? Were these women too shy to bring up such concerns spontaneously?

Over all, what impacted most on Shin's world and her understanding of self were the dietary adaptions she had to make in order to keep pains, nausea and vomiting down. Jane's odyssey like journeys through clinic labyrinths elicited in her always new feelings of inadequacy and aversion rather, than growing familiar with a threatening environment. Pragmatic and in tune with bodily sensations, these women seemed to live reality as it presented in day to day feelings and reactions.

Both women searched for means to alleviate the affliction and worries of their situation at hand, they knew of the gravity of their diagnosis. Yet, they did not talk in terms of future uncertainties, lost mastery and control over their lives. The reality of their situation confronted them with different things to take care of than in the past, but on an existential level, no break seemed to have happened between today's illness and yesterday's absence of disease.

Their relationship to the body appeared pragmatic and largely unencumbered by a mind over body approach. Sleeping worked to alleviate some bodily un-easiness and taking the mind off the hurt seemed successful at times.

Shin and Jane talked about themselves from a being perspective (tired, weak, in pain, not feeling like eating) rather than as having a series of physical problems. A mind or self over body dichotomy was absent in their talk, they frequently appeared in "I"-body oneness. When they referred to body parts, e.g. "my stomach reacts" the stomach surfaced as belonging in a constitutive capacity rather, than as one cog-wheel in a possessed, (mal)-functioning machine. Not surprisingly, neither of these women resorted to relaxation or imaging methods in order to entice their bodies into complying to a joint survival endeavor.

Although they reported weakness, fatigue and Shin major nausea, neither woman alluded to notions of body failure. In their present-focussed way, they dealt with what came, as things arose. Professionals appeared as distant prescribers and inflictors, but not as people with whom the women discussed. Patients themselves refrained from long term strategic plans (other than had been prescribed to them), with the exception of Shin's protecting her family from contamination.

Overall, they seemed to live in high "I"-body congruence, largely uninterrupted by major switches between "I"-body dominance, interdependence between "I" and body and "I's" dependence on the body. Because Shin believed, against her cognitive knowing, that cancer was contagious, she protected others from the things she (not just her body or cancer) had been in touch with. Body-"I" estranged talk was absent in these women's interviews.

Suffering appeared as embodied within the lived body's reality, barely aggravated by uncertainty concerning prospective probabilities of disease course and outcome. Neither did the past radiate with such power, that present afflictions appeared potentiated as deficiencies when compared to the glamour of what has been lost.

Both women's knowledge about their body was vaguely concrete, pragmatic, and rose from lived experience. No evidence of descriptive medical vocabulary or sophisticated scientific, theoretical linkages appeared in the interviews. Neither woman used names of drugs or scientific, medical concepts which were not part of a broader vernacular bodily understanding. What they did at home and what happened to them in daily life was not necessarily deemed relevant enough to be brought to the attention of disease care providers. What "they" said or did appeared to happen in a world segregated by place, language, and practice from their every day experiences. Thus, clinic visits tended to resemble trips into an alien world.

Shin conscientiously sought to learn from fellow sufferers and her cultural heritage. Jane followed, to the extent it seemed convincing to her, what she was told by professionals and her family. Both women applied what seemed sensible to them in the hope that what they did, furthered the body's disappearance from awareness. The body seemed to guide their activities, rather than theoretical explanations, or ideological convictions about how things might work.

They also appeared to be immune to the dominant cancer fight paradigm. Neither woman used war or fighting metaphors in talking about the illness. None of them mentioned blood counts nor did they connect CTX "side effects" with a responsive or unresponsive cancer.

Overall, these two women embodied a way of being in the world in which the embodied reality of the present appeared to outweigh the influence of future (uncertain) possibilities. Although the past was present through constant comparisons of how today differed from yesterday or another point in time, present experiences were not judged as exclusively wanting when compared with the past. Further, neither women alluded to self-accusatory blame for the disease, a stance which flows easily from the cultural belief that self is able to control its destiny.

Marginal in regard to the leading contemporary intertwined "medical stories" of "fighting the enemy" and "fixing machines" they seemed not to "write [their] own life" (Ross, 1989). Neither woman had adhered to the illusion of self as being the commanding captain of her life and much of what happened. They may have felt vulnerable as well as at the mercy of others and life's hazards before the illness struck. Thus, no illusions broke down, nor did they feel thrown out of a control they never perceived to have, once reality changed through bodily afflictions. Yet, they subjugated themselves to the very treatments which so pervasively stand for mainstream culture's paradigmatic individualistic control and war metaphors.

Both women understood themselves as a part of a larger group of people from whom they depended in many of life's important aspects and with whom they shared life's daily joys and worries. As much as their family members had an eye on them and worried about the patient, the women worried about their families' well being.

As women, Shin and Jane represented the world of non-intellectual, non-verbal participants in a patriarchal tradition. In this world, at first look, women seemed to comply with the dictates of others, but in fact, often did with conviction what _felt_ good and right to them. Since they did not live the quest for individual independence and strategically achieved mastery of life's possibilities, they seemed less affected by the profound ambivalence which haunted so many women who's sense of self-achieved security had been shattered by the illness.

If the modern self is understood in Cartesian terms as rationally constructing a mental representation of its reality (Taylor, 1989, p.144) these women appear as pre-modern persons. Perhaps because their taken for granted understanding of lived reality had previously not depended on the mind's power over the body, nor on self as responsible for the script of one's life, they appeared as minimally alienated from their bodies. In fact, un-split, embodied experiences seemed to propel their actions rather than ideological, or scientific logic on how mind, body, and world might be connected. Theirs was a rather inarticulate approach to life, grounded in the body's <u>sentient</u> and <u>feeling</u> guidance in daily activities, minimally hidden or camouflaged by rational strivings.

Schatzman and Strauss (1955) suggested that influences of social class on people's thinking and perception are conveyed in their ways of communicating. They observed interviews with lower class respondents to be more concrete, yet vaguer and less illustrative than those of middle class subjects. From the perspective of this study I propose that perceptions of lived body-"I"-oneness are more amorphous than concepts in the split thinking about self and body. Articulation, therefore, is quite trying. Difficulties are even more pronounced in a language which offers fewer embodied concepts than primarily vernacular, pre-scientific languages (e.g. Swiss German or Yiddish) do. (Had she had the possibility of speaking Chinese with us, Shin might have been able to convey more about herself).

Shin and Jane's dealing with the illness, it seemed, was largely unequivocal and self-evident. Beyond obeying professional prescriptions, they did what felt right and made sense in the context of their embodied self-understanding. Without continuous vigilant self-monitoring and associating all happenings to their high-tech treatments, they dealt largely on their own with what came up. From a professional stance, their actions may have appeared as marginally compliant and not always without danger of drug incompatibilities and other threats to the woman's future well-being.

Both, Shin and Jane suffered from bodily pains and discomforts, from "cannots" and "have tos". Yet, they did not grieve a loss of control they never perceived to have had in the first place. Jane's life had been full of suffering. To her, cancer was just one more difficult occurrence to be lived through to the best of her ability.

This mode of being was not entirely absent in the experiences of other women. Yet, its appearance in their awareness was less powerful. As reality appeared through different saliences for others, their suffering underscored what was important to them.

2) Life Put on Hold

The Woman: Sue was in her mid-forties. Together with her husband and two mostly college-absent sons she had recently moved to the West Coast. Temporarily, the family rented a beautiful house in a wealthy neighborhood. After having sold his prosperous business at their previous place, the couple had moved away to plan their lives around a new business, which in turn would determine where they would settle in the future. Besides being a housewife, Sue had volunteer experiences with disabled children. The move had awakened her old dreams of going back to school to earn a degree. She was reluctant to discuss this plan with her husband who showed little support for such an idea.

Breast cancer had come as a profound shock to Sue. She underwent a mastectomy and had hoped that she would be spared from CTX. But then CTX (CMF) was considered inevitable. Hesitantly she subjugated herself to treatment, a strain which promoted her to take up smoking again, from which she had abstained after diagnosis and mastectomy. She planned breast reconstruction at the earliest time possible after CTX termination.

<u>The Appearance of the Body and the Woman's Concerns</u>: "Having cancer" brought upon Sue fear of recurrence and death, "the hurt" to tell her children, and forced her into "having to adjust to cancer and chemotherapy". She said that the illness affected her mentally, as it forced her to acknowledge her vulnerability, emotionally, with profound mood swings, and physically, through mutilation, hair thinning, fatigue and nausea. Cyclic occurring fatigue and nausea "wiped her out" and kept her from doing all of her household chores. She mentioned on the list of "problems and issues": "I cause more work for my husband" and in the third interview she said:

> It was just not a good time. It affected mainly my husband, fixing dinners, taking care of me, attending to my wishes [and] always checking on my wants.

Sue perceived of herself as not being "the happiest person to live with" and saw CTX as "something that had to be done that no one looked forward to". In the six months of CTX "I got kind of old, complained more, bitched more", she said and felt, at the same time, that the "last six months were merely a stopping point".

Sue felt embarrassed and humiliated "to be a cancer patient because of the stigma" and did not "want people to feel sorry or talk about me". She was reluctant to share her experiences with her husband and sons. But she confided in a friend who's son had had leukemia and preferred to cry in the clinic with the nurses when she felt "blue and depressed", because "I felt better to cry around people who knew about this (illness experience) than around people who do not know". Moreover, she did not want to "put it on people at home". Her husband encouraged her to read about cancer and treatment options. He thought that "education makes you feel better. It is generally helpful getting another viewpoint".

Recurrent in the interviews was Sue's yearning of "getting through treatment", or being "helped through" the experience. Once through, at the end of six months, she did not want to

> talk about [cancer] because what's the sense...I kinda want to put it in back of my mind. I feel at the time I was going through it, I needed people to talk to and I was trying to seek those people out and that made me feel better. But now today, after the treatments have been over I don't see any sense to talk to anybody....It's like why talk about something in the past that you really want to forget about knowing that you'll never forget about it, but talking just keeps it going, and there's no real value in doing that.

Instead, now she investigated her options for breast reconstruction. Further, she thought that "attitude is 50% of the (cancer) battle", that keeping a "confident attitude, thinking positive, and practicing what you have been doing (imagery)" would help her "feel better". The future seemed open again to pursue "lots of goals: Decide what we want to do, where we want to do it, [and] get a job". Her regained ability to once again make long range plans was a huge relief.

<u>Analysis 2</u>

In its <u>self and world constituting capacity</u> the body revealed itself in Sue's "feeling bad or wiped out" for some days after CTX and "feeling great" upon its termination. Notions of "feeling wiped out" provoke images of bodily subjection, while feeling bad or great entail mental connotations as well. Sue's feeling good again gained importance, because it contrasted so much with having felt badly. In his reflections on phenomenological subtleties of feeling at ease Pluegge (1957) pointed to ease's hardly graspable qualities such as the body's absence from one's awareness, its breeze-like (hauchartig) appearance in one's disposition towards the world, and the almost indispensable necessity of uneasiness as a contrasting background against which ease stands out.

Sue's notions of strength or energy appeared within dimensions of feeling/being rather than as a possession. Both fatigue and sensations of repulsion by the odors of food held her back from cooking, a task which her husband had to take over. Having to rest more and accept her husband's help in household chores curtailed Sue's sense of independence and self-reliance. She never mentioned pain or soreness, nor changes in her diet. Compared with her major concern, namely being stigmatized as a cancer patient, bodily impact on habits and daily activities seemed mild, not salient enough to be reported spontaneously.

The "stigma[tizing]" reality of "being a cancer patient" promoted feelings of shame and humiliation in Sue. Taylor (1985a, p.53) pointed to the "banal truism" that shame cannot be objective, but "'shameful' can only be explicated with reference to a subject for whom these (emotional) meanings have weight". What then might be the decisive meanings in Sue's life which promoted such shame?

In History of Manners Elias (1939/1978) described painstakingly how, over the past 700 years, as human beings were forced to live closer together, people became more "sensitive to the impulses of others".

Thus, "the code of behavior becomes stricter and the degree of consideration expected of others becomes greater" (p.80). In this "civilizing process" the body, its spontaneous impulses and emotions, became more and more bridled. Paramount for the success of "civilization", feelings of shame played an eminent role in promoting adherence to taken for granted codes of behavior and bodily presentation. Stronger bodily restraint was accompanied with a deepening, but barely conscious split between the intimate and the public and in behaviors pertaining to these spheres.

> More and more, people keep (natural human) functions themselves, and all reminders of them, concealed from one another. Where this is not possible...shame, embarrassment, fear, and all the other emotions associated with these driving forces of human life are mastered by a precisely regulated social ritual and by certain concealing formulas that preserve the standard of shame. (p.190)

Cancer cannot be perceived independently from the body. Cancer is a blemish to many facets of contemporary embodied self-understanding. It attacked Sue to the extent as she had embraced the cultural ideal of female beauty. She had been diet consciously engaged in shaping and surveilling her slender, symmetric body; how could cancer grow in a body which she had mastered so successfully? In a world in which notions of self's responsibility for one's (possessed) body and health are inspiring the fight against disease and death, the occurrence of cancer spoils the self-image of a responsible care taker. How could Sue have failed to ward off a disease which, after all, was physical, and not really part of her? How could she have brought into her and her family's lives the prospect of death, that symbol of utter defiance of control? Further, is the body not at self's disposition, day and night, enabling, skilled, and reliable to propel self into independent living? Cancer thwarts dreams of being free from restraints in one's choosing and, in combination with CTX, dis-ables, let's skills deteriorate, and allows the body to show up as un-trustworthy and in need of other's attention. This body threw Sue into dependence on others.

Lastly, over centuries, a variety of hygiene-procedures (Vigarello, 1988) proved their efficiency by getting rid of remnants of, suppressing, or camouflaging bodily excretions, noises and odors, which at best are considered unsavory and at worst, repulsive. Being "wiped out" from CTX made it more difficult to take care of self and to control bodily mishaps such as vomiting with its smell, stickiness, coarse looks, and to conceal its annoying noise. Indeed, it was impossible for Sue to hide from her husband the whole gamut of bodily grossness and imperfections for which she assumed some responsibility and which reminded her constantly, in relation to him (and others), of being a "stigmatized cancer patient".

How would she look in the eyes of those "who did not know about" the cancer experience, if they knew that she had lost her beauty, failed to stay bodily healthy, that she was, at times, physically dependent on, and a burden to her husband? And that she needed help from experienced others for emotional relief? What, if concealment of her bodily asymmetry, weakness, and sequelae of vomiting could not be maintained in all circumstances? Wouldn't others' feeling sorry for her just let her sag into deeper dependency from their sympathetic moods? Would their pity consolidate perceptions of her as someone who failed to fully master her body and thus to prevent self from unpleasantly infringing upon others?

Once the body's beauty, meticulous appearance and discreet manners lost their taken-for-grantedness as self-accomplished, self-blame was likely to rise. Does self-blame not entail feelings of shame and embarrassment? The body seemed to have betrayed self's efforts to keep its intimate, private world contained. Rather, the cancer inflicted body transgressed into a perceived "other" (public) space, as embodied need for other people's attention and care. A mutilated, weak body abolished the delicate frontier between self's (controlling) autonomy (without need for others' compassion) and scary dependence on others. Dependence appeared as exposure to both the pitiful, worried care of others, and their disguise towards disquieting bodily appearance, covered up through polite distancing.

Certainty, previously part of Sue's self-understanding as a healthy-bodied, self-sufficient and in many regards independent, responsible (house)wife and mother had become thwarted and partially shattered. A rampant loss of perceived mastery provoked unpredictable mood swings and let her "wishes" and "wants" appear as insatiable and burdening others. The present had lost the security which predictable, self-sufficient actions entail.

Most profoundly and with astute awareness, Sue experienced the flow of time as altered and, at the same time, her body as aged. Reality showed up as tunnel-like. A dark place of being, it impressed only as a "through" passage between the bright past and a future with hopefully re-opened possibilities. The reality of dependence and bodily upheaval appeared as depleted of possibilities for mastery by choice and planning. Abundant "have tos" seemed to obliterate any appreciation of those "I cans" still (or newly) within Sue's capabilities.

Gloomy, "getting through" time appeared as motionless. Needs of a culturally shunned body invaded time, prescribed places to go and be, appeared as source of low energy and an impediment to the assumed freedom of a disembodied, mental-psychological self's determination over life. Indeed, if life is perceived as freedom from bodily restraints, as self-actualization by one's own efforts, "getting through" time must appear as un-lived, stand-still time.

Yet, Sue existed "through" all of her treatments and knew, on an embodied, existential level, that she had aged by years. She "got kind of old" without being able to halt or retouch such aging. "Complaining and bitching" as well as crying in a safe place relieved some anguish while Sue went through the slough of "depressed and blue" days.

Embodied "getting through" time stuck with Sue, not allowing her to forget. Once CTX receded into the past and future breast reconstruction promised to make the body's asymmetry disappear, her incarnated memory of what had happened would remain with her for life. Against her wish to forget, Sue had to face that "souffrir passe, avoir souffert ne passe jamais"[16] (Bloy, quoted by Buytendijk, 1948).

In contrast to the appearance of many mundane ailments as transient "departure" from the healthy self (Olesen, 1990) and their tendency to fade without impinging upon one's remembrance, memories of experienced cancer touched the core of Sue's identity. She expressed awareness of the paradox that neither her will of "really want[ing] to forget", nor her denying the experience "any sense" or "value" would abol-

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[16] Suffering passes, having suffered never does

ish this incarnated memory. Her body would hold on to it to the end of her days. Even at its best, Sue sensed, life would never again be what it had been before its taken-for-grantedness got shattered. It was cancer's embodied re-calling which made it impossible to return to that past, seemingly so free of restrictions, to "get back to where things were before".

Through her fine sense of time's anchors in bodily capabilities, as well as her strong feelings of shame once the body slipped from her control, Sue's suffering appeared as "mental" to her. She asked for a psychologist's assistance during her "getting through" passage.

Sue's relationship with the body mirrored the dominant cultural split between mind and body. Strongly focussed on the experience's mental aftermath, Sue reported predominantly what she did to "feel better" emotionally. Guided by shame, she censored to whom she mentioned her illness and how she talked about it. In so doing she might have tried to pacify the body's uncanny dominance in her awareness: By not speaking about it, its disquieting presence might have disappeared temporarily.

Only once did Sue mention physicians. Since they were "concerned with physical things" they appeared as uninvolved with what happened to Sue on a "mental" level. Their quasi-absence left her with important work to do. Her's was to keep a positive attitude which she thought was "50% of the battle". Where others fought their battles mainly within the bodily realm and with chemo-physical technologies, Sue tried to confront her illness with attitude.

To Sue who, in the past, had mastered her body so well, the afflicted body had nevertheless risen to force "I" into new behaviors. With positive thinking she aimed to protect self from further bodily deterioration. Hidden in her yearning for "getting through chemotherapy" appeared the familiar self's dependence on bodily obliviousness. Still, Sue had a notion of "I"-body interdependence: She enticed the body, through imaging, to "achieve a cancer free period".

By focusing almost entirely on the illness' emotional and time disruptive impact, Sue's knowledge about and understanding of body and disease reminded essentially unspoken. By assigning physicians physical concerns only and praising nurses who "listen to me, give suggestions, give me time, love [and are] there for me...[to] hold your hands", Sue projected the perceived mind-body split on these professionals. Physicians worried about the organism, while nurses seemed concerned with her as an embodied person.

Overall, concurrently with a move to an unfamiliar city, cancer had thwarted Sue's assumed mastery over body, emotions, and time. Her planned and chosen life stood still while she underwent CTX. In fact, bodily unavailability to her expectations constituted present misery which showed up in an almost totalizing impetus of "getting through". "Through" time, on one hand, appeared as a bodily encumbered world alien to living out one's choices, and on the other hand, as a driving force to be overcome by a future, resembling the past with an unlimited potential of open possibilities. A profound rupture of time's continuity had occurred. Reality had lost its resemblance to the past and the immediate future of days, weeks or months loomed as un-shapable in terms of deliberative choice, as long the present imposed its "have tos" which "no one looked forward to".

Sue's feelings of shame alluded to a self-understanding of deeply ingrained self-reliance and -sufficiency. From these had grown an assumed responsibility for health, bodily reliability, and an inconspicuous, pleasing social presence. Seemingly limitless possibilities suddenly closed down upon her, excluding her from choices which she had taken for granted before.

Existentially shaken, she perceived herself as aged, unpleasant, moody and wanting. Her despair might have resembled the one described by Kierkegaard in The Sickness unto Death (1849/1974):

> In order to will in despair to be oneself there must be consciousness of the infinite self. This infinite self, however, is really only the abstractest possibility of the self, and it is this self the man[17] despairingly wills to be, detaching the self from every relation to the Power which posited it, or detaching it from the conception that there is such a Power in existence. (p.201)

The body, one positing power to which the choosing self in charge of her life's script had lost its relation, demanded awareness and limited self's abstraction and estrangement from embodied existence. Interpreted from this Kierkegaardian angle, the body's cancerous affliction had not only the power to throw modern, mentally almost disembodied, autonomous people into existential anguish; but a weakened body contained simultaneously possibilities to liberate self from the existential uncertainty and despair of desperately willing to be the master of one's own whole destiny. Some women alluded to leaps in self-understanding which can be interpreted from this philosophical perspective.

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[17] in this context: woman

(See analysis four "having the strength to deal with whatever comes").

"Being forced to do things that aren't of my choosing" deeply concerned other women, for example Pat, as well. Similar to Sue, cancer had bereft her temporarily of many options to select what she considered to be important in life. However, she differed from Sue in that she relied strongly on her rational talents to deal with that "gray, ambiguous" situation which provoked so high anxiety in her.

3) Finding Reasonable Options

The Woman: Pat, a professional woman of 34 years, held a managerial position in a large insurance company. Recently, she and her husband, a craftsman, had moved to the West coast. They lived in a carefully furnished and decorated apartment, which they maintained meticulously. The couple had moved to the area mainly because Pat had found this challenging job, a promotion in her career. Although they had family nearby, they missed friends from the South very much.

Pat's diagnosis of breast cancer profoundly hit the couple. She had undergone a biopsy and two lumpectomies with lymph node excision, before she was treated with CMF. A mastectomy was planned after two to three cycles of CTX. In the case that a mastectomy would not be performed, RTX was considered an alternative.

On top of two "humiliating" episodes of breast-bleeding from slowly healing wounds, Pat worried about what impact CTX might have on her lovely hair. During the six months of therapies, she felt more tired, but never reduced her work load. In the first two interviews the couple talked about the pain of coming to a decision about mastectomy. The last interview served to reflect on future treatment possibilities to reduce her probabilities of cancer recurrence.

The Appearance of the Body and the Woman's Concerns: Pat had experienced the different surgical procedures as "traumatic" and the many physician appointments had a "huge impact on my work". "Having to deal with whether or not to have a mastectomy" was a "real emotional issue". She found herself in "this gray matter" where "they're kind of slightly recommending a mastectomy over radiation". Pat expressed some of her torment and confusion about making this decision:

> I guess in terms of the mastectomy, I guess, I think, I know, I guess, I don't know, I mean, I know what I should do. I guess, should in quotations but it's just that I hate it. I just hate it...I think it's going to be extremely hard on me. I don't know.

Pat sought as much information about her situation as she could find. She had learned that her cancer belonged to a rare classification of "only like three to five percent of all breast cancers". Being categorized into a grouping "no bigger than 10% of all breast cancers" she was told that "mastectomy would probably be necessary".

Heavy hearted, Pat had cut her hair short. She had learned that her "odds" were good, that she would experience "hair thinning" rather, than alopecia. The couple inquired about wigs and looked at hats in anticipation of possible future need.

Pat discussed her situation extensively with friends and many people at work. The couple read popular books on how the mind can help the body heal (Siegel, 1986; Simonton 1978): "We've been getting that message and that's been good and real important".

After the excision of lymph nodes, Pat's arm was swollen and restricted her movement. Three "real demoralizing" weeks went by without

Pat knowing, what she could do with her handicapped arm. The doctors had only told her about "itsy-bitsy"[18] exercises for her fingers and so she did "do itsy-bitsy twice a day...for five seconds". Disappointed and frustrated about the poor results of her exercising she finally found a physiotherapist in her church who taught her to

> use gravity to help with the stretch and then holding that for 60 seconds and then working kind of around the clock and stretch it 20 degrees, stretch it 40, stretch it 60, stretch it 75 or whatever...

Consistent exercise helped Pat "gain an inch every day" in arm mobility. Such progress and learning from the therapist why her arm was more swollen in the evenings, made her feel "psychologically so positive".

Pat mentioned at the end of the first interview that she felt "like I'm being able to be the one to make the decisions about things". Without her husband, she might not have been able to challenge her physicians' advice, since her family and most colleagues cautioned her from risking cancer recurrence by conserving her breast. Her husband's contributions in the decision making process were crucial:

> I think the thing was that we both had to kind of come to the same decision....I just kept asking [husband] "well, what do you think"?....[I]t was important for me to have [husband] be on board with me and to be there too, and because I knew I wasn't totally objective. I knew I had my own anxiety that was real and so part of it was being able to both go and talk to the doctors at the same time and both asked questions because we had different questions and both hear what they had to say...

Seven weeks later, after "both of us (made) the search", extensively consulted with several physicians, and read professional literature, the

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[18] "Itsy-bitsy" comes from the childhood song with hand motions: "Itsy bitsy spider climbed up the water spout". The hand motions mimic the spider's climb.

couple made the decision not to have a mastectomy done, but rather, that Pat would undergo RTX. It had been difficult to reach a decision, because they felt in "a gray area which caused anxiety" and "you can't predict the future and don't know".

> [I]t was important for me, for [spouse] to feel like that was some kind of objective decision based on some kind of rational thinking. So I really did feel like I was objective and that I could hear what they were saying and I wasn't exaggerating them talking about the risk...

Pat acknowledged that "it takes a little bit of courage" to return to the physicians and challenge a decision they thought, the couple had already made following professional recommendations.

> But for us, my orientation is optimistic. I'm optimistic that I'm going to be in the 70% that aren't going to have a recurrence. It's just a whole different perspective for me because the decision has just brought me to a real place of being, I mean, I've been happy, I've been happy for the first time I've been happy since I've been diagnosed. Its really so. I feel energized.. I feel like I can handle the next three months. I bear it. For me, it's been a real energizing process.

After CTX and RTX were terminated, Pat inquired about the benefits Tamoxifen might have for her. She found out that it may improve her "margins" by five to ten percent. Moreover, she now checked her breasts almost every day and felt "some needs to build in some safety factors".

Treatment completion brought also an end to relationships with trusted physicians. Feeling left "out there" and "vulnerable",

> I think there's some anxiousness in me....It's something that just preoccupies me. I didn't use to ever worry about health and living and things like that. It's subtle. Its's just a preoccupation. Fear that I didn't use to have...I don't know. I don't feel panicked. I don't feel depressed. I feel insecurity probably the most.

Pat was uncertain if she should not "suppress" this awareness, "to hold it at bay, to keep it under control". By and large, after treatments ended, Pat's life seemed "a little bit more normal", but she did not know "whether that's good or bad". She yearned for "a boring...uneventful year", a time "where I'm not learning anything".

Analysis 3

Concerns about day to day CTX impact like nausea, loss of energy, or fatigue were virtually absent in the interviews. On a superficial look, daily routines remained largely untouched. The couple continued eating "healthy food", but with more awareness than before. Pat never reduced her working hours, yet, she worked hours in advance in order to take time out for medical care. Although she seldom referred to the body explicitly, it was rampantly present in its self and world constituting capacity: 1) As "forcing" Pat "to do things that aren't of my choosing"; 2) as invoking profound uncertainty upon her, and 3) as jeopardizing the integrity of the visible body. Intricately connected, all three bearings constituted and influenced each other; in the analysis they thus flow easily together.

Some of Pat's unchosen choices concerned the visible body: Cutting her hair shorter and deciding whether or not she needed to sacrifice one breast for better survival chances. Deep anxiety was provoked by the fact that Pat felt bereaved of what she so far had understood to be her freedom of choice. Suddenly, she felt forced to choose between options she would never have considered as choices had she not had cancer. Abruptly, Pat's seemingly limitless regress of rational choices encountered resistance in a body which hitherto had neither solicited "preoccupation" nor "worry", but from now on would be present in her changed awareness.

Conceptually, choice is a child of rationality, or at least of consciousness: There needs to be awareness of alternatives from which one can choose and of conditions which promote choices. For example, health may have seemed to be such a choice under conditions that one ate healthy food, exercised and refrained from cancer promoting habits. Choice is associated with both freedom from impinging forces (illness) and freedom to commit self (to a healthy life style).

In addition to cancer's threat to life, Pat's crisis was one of lost freedom. The body had lost its self-evident obliviousness, that breeze-like subliminal presence as vital condition for what appear to be life's choices. In other words, Pat confronted choices' existential restrictions which forced her into choosing options which, by and large, evaded those rational assessment approaches in which she was so well trained. Uncertainty, for her, was tinted by the loss of an assumed freedom for rational choice.

Aggravating the distress of forced choice was the paucity of those rational certainties on which informed decision making normally is based. In a double bind between two almost equally dreadful alternatives - probabilistic guesses about survival chances versus the certainty of losing, for life, the visible body's integrity of appearance - Pat's anxiety kindled a courage which appeared as seemingly disembodied rationality, a search for "truth free of all ambiguity" (Hawkesworth, 1989). Disguised as "objective decision", (as if a subjective decision were tantamount to irrationally coming up with the wrong decision) Pat leaped from uncertainty into hope-full trusting that she would survive within safe probabilistic margins.

If scientific medical prognostics about probabilistic survival are conceived of as basis for faith-full life decisions, Pat's choices were acts of faith rather, than of rationality. Once faith had liberated her from the double bind, anxiety disappeared and she was "brought...to a real place of being" from which (embodied) happiness and new energies arouse.

Dedicated to back up her decision with objective criteria, Pat seemed propelled by embodied anxiety. Against her rational will, she seemed to leap from an uncertain, mental world into one of faithful hope. Uncertainty's nagging unhappiness gave way to a surge of energy-to-life which, for months, had been absent. The paradox of Pat's leap of faith into a "real place of being" is well described in one of Kierkegaard's reflections (1844/1980, p.172/173):

> Anxiety is the most terrible kind of spiritual trial [Anfaegtelse] - before the point is reached where the same man[19] is disciplined in faith, that is, to regard everything inversely, to remain full of hope and confidence when something happens which previously almost made him faint and expire with anxiety, to plunge fearlessly into something against which he previously knew only one means of safety, to flee and so on.

Although Kierkegaard refers only to spiritual components of anxiety, hope and confidence, these emotional dimensions are deeply embodied. They transcended Pat's whole being. In their light Pat's world appeared either as gray or radiating with happiness and energy. Much in contrast to the numerical quantities which drove Pat's rational search into her future's objective uncertainty, the surge of happiness and energy carried with it embodied certainty.

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[19] woman in this context

In a passage about truth as subjectivity Kierkegaard (1846/1974, p.182) wrote:

> An objective uncertainty held fast in an appropriation process of the most passionate inwardness is the truth, the highest truth attainable for an existing individual.... The above definition of truth is an equivalent expression for faith. Without risk there is no faith. Faith is precisely the contradiction between the infinite passion of the individual's inwardness and the objective uncertainty.

Rationally, Pat risked 30% probability of recurrent disease. Faithfully, at the same time, she believed in the 70% chance of surviving without a mutilated body. As Kierkegaard's definition of truth and faith implies, Pat's passionate decision was an act of faith. Within objective uncertainty she knowingly took upon herself the risk of local recurrence. In contrast to Sue's standing still time, Pat's time appeared as so filled with passionate, rational strivings that she wished the future would no longer force her to learn what she had not chosen to know.

Predominantly, Pat's <u>relationship to the body</u> was one of being in charge. Pat juggled conflicting responsibilities like guaranteeing survival, maintaining the body's unmutilated appearance and regaining its functional integrity. "I" was in charge to come up with safe decisions. To do that, it seemed cautious to detach self from an objectified body, to sublimate it into statistical number brackets and in this abstraction, to compare it to X other organisms. "I", however, retained an anxious awareness that her embodied being might defy the calculus of safety probabilities.

Pat's CTX subjugated body had not challenged "I's" being in charge and responsible. It had not failed Pat in her work capacity; she worked despite its needs. Yet, encumbered by lymphedema, one arm hampered Pat to the extent that she felt "demoralized". She searched for knowledge and performed exercises. Gauged in measures of comparative gain, like in sport events, Pat assessed her arm's daily "progress". In congruence with an assumed detached, objective "I"-body relationship, Pat scored her arm's performance in terms of inches of gained distance and degrees of stretch rather, than in daily movements like grooming or skilled work at home or in the office.

Hidden in the suffering of profound emotional turmoil, the body nevertheless appeared as powerful constitutor of Pat's life. Scared by the body's overpowering "subjectivity" Pat tried hard to contain her "feeling vulnerable" by "not making a big issue of it" when she talked to others. "I didn't frame it in any kind of emotional words. I just talked factually about margins and percentages and things like that".

Paradoxically squeezed between her responsibility for an object-body, "I" was at the same time haunted by self's dependence on the body. After six months of therapy, Pat was left with a new awareness of embodied vulnerability. She was uncertain about mastering intrusive, haunting thoughts. Should she allow them in or need she "keep them a bay"?

Up to the end of CTX, "I" seemed mainly in charge. Self had not been forced into negotiating interdependence, nor was there explicit acknowledgement of the body's subjective power to compel Pat into giving up the rational facade of her approach to embodied issues of life and death.

Professionals did not appear as inflicting bodily hardship. "They" were the ones with the advanced knowledge Pat needed so badly in order to decide and thus, to free herself from the verdicts of others. Pat reported no bodily suffering. She was distraught that "they" forced her into step by step procedures with unknown outcomes. "They" also failed to make her bleeding breast heal swiftly and therefore, were associated with the humiliation she endured. Overall, "they" appeared as less and less powerful the more Pat regained knowledgeable control over her destiny.

Pat's knowledge about the body was of the most abstract kind when compared to that of her fellow sufferers. Concrete knowledge to guide present behaviors hardly appeared in the interviews; nor did Pat connect physiological concepts (e.g. blood counts) with daily bodily experiences. Her concentration was geared towards the future. She investigated statistical facts about cancer-treatment-body interactions and applied these to her own case. Pat performed her homework well. Any outsider might have taken her detached display of particular details as report of a case study. Through assiduity and persistence she convinced her physicians to contribute their share of knowledge and earned their cooperation for the treatment options she chose.

Overall, Pat's approach could be called faithfully rational. Her thinking and speech were very distant from the body. Abstract, probabilistic in her notions of cancer-treatment-body interactions, and objectively gauging her case, Pat seemed to fully embrace a Cartesian mind over body relationship.

Kirmayer (1988, p.57) has pointed to the experiential origins of the "residual mind-body problem" in Western thought. Voluntary and intentional the mind, involuntary and accidental the body, mind and body "symbolize contrasting poles of human experience". Pat's embodied anxiety in an "ambiguous, gray situation" contrasted strangely with the emotionally barren, sterile mental assessments of present arm progress and her own case's future probabilistic outcomes. Involuntary anxiety excelled Pat's endeavors of voluntary, rational pursuit. Though she did not admit it, her body was paradoxically central in both experiences: Its emotional power propelled the (embodied) mind's pursuit of sublimating (through abstraction, objectification or suppression) the same powerful body which constituted the situation into which Pat found herself thrown.

Committed effort and dedication in finding the right decision and courageously pursuing what she believed to be best, promoted a peace of (embodied) mind which Pat had not known for a long time. In this experience of religious coloration, Pat confronted her situation. She took a stance by exerting rational control in the face of the unknown, while, at the same time, embracing the objective uncertainty of her saved breast. Pat's forced choice amidst risky uncertainty enabled her to feel happy, rejuvenated and in control of things which, objectively and rationally, cannot be controlled. Objectivity and rationality were her preferred ways of being. She lived in these dimensions even under circumstances that offered little or no support for rational choice.

Pat chose "objective knowledge", but lived the passion of embodied "subjective" knowing. In Kierkegaard's words (1846/1974):

> ...While objective knowledge rambles comfortably on by way of the long road of approximation without being impelled by the urge of passion, subjective knowledge counts every delay a deadly peril, and the decision so infinitely important and so instantly pressing that it is as if the opportunity had already passed (p.179).

Pat's subjective, knowing passion fulfilled her when she decided in favor of her body's integrity, not the rambling approximations of her factual knowledge.

Pat's passionate attempt to rationally control the uncertainty of her future stood out within this group of women. By no means, however, was she the only one to live out, with full conviction, the mind/body dualism offered by contemporary (medical) culture.

For years, other women had tried to control the body and cancer. The final paradigmatic sketches describe how the body appeared in the lives of two women with advanced disease.

4) Either "Having the Strength to Deal With Whatever Comes" or "I Hate it When My Body Gives Up"

The Women: Anne, aged 31, was a single mother of a five year old girl. They shared a small, crowded two room apartment. Anne had been diagnosed with "inflammatory breast cancer" one year before she agreed to be in the study. She had undergone a mastectomy, RTX and had been treated on different CTX protocols (Adriamycin, CMF, Vincristine sulfate, Prednisone, Tamoxifen). At the beginning of the study she was treated with Vinblastine sulfate, Adriamycin, Thiotopa, Halotestin and at the end she additionally underwent RTX re-enforced by hyperthermia. Anne had given up her secretarial work because of the illness. She received some public financial assistance which barely alleviated the stress of her social and financial hardships. Anne died about nine months after termination of the study, almost four years after her diagnosis.

Mary was 51 and had lived with the illness for ten years. She was married, mother of three grown children and lived with her devoted husband in a beautiful apartment. The family had no financial worries. Mary had suffered three episodes of recurrence over the years. She had undergone a mastectomy, oophorectomy, RTX, several cycles of CTX and had been on Tamoxifen for years. During the study period she suffered a severe exacerbation of disease with pleural effusion, pain, nausea and utter weakness that remained unresponsive to CTX (Aminoglutamide, Hydrocortison, Tamoxifen, Estrogen, MF). Knowing that she might face the end of her life, she refused to subject herself to the severe side effects of Adriamycin which she had experienced once before. Both family and professionals urged her to undergo Adriamycin treatment once more. She remained steadfast, but yielded into trying a not yet FDA (Food and Drug Administration) approved drug (Mitrazantrole). After the third treatment cycle, Mary began to feel better and a "dramatic turn around happened". Once more, Mary could sail on their boat and live in her favorite place on an island in the Caribbean sea. Mary died approximately one and a half years after the study's termination.

In contrast to the women portrayed above (1-3), Anne's and Mary's deaths appeared each as a real possibility within a foreseeable future. Both women were very articulate and had lived with the strong conviction that medicine could cure or, at least, ward off the disease and that the body could be willfully and faithfully enticed into feeling better. Both had embraced a strong mind-over-body approach and adhered to the medical cancer-war paradigm. They had also refused treatments which appeared too costly with side effects if they offered doubtful benefits.

Their interviews testified to much bodily suffering and emotional despair. Mary tried over and over again to "help[ing] myself in a psychological way"; she felt strong support from her deeply concerned and loving family and friends. Anne felt supported through psychotherapy, her hypnotherapist friend and felt carried through tough times by an Indian "spiritual teacher that I absolutely love and adore".

The Appearance of the Body and the Women's Concerns: For both women, the body's life and world constituting power was paramount. Mary felt forsaken by her "failing" body when she was unable to "grit" herself into doing better. The disease had affected most basic bodily functions. Abilities such as breathing, moving, eating, focusing attention had become impossible or very laborious. When she felt at worst her world had been engulfed by a bodily power that she had never encountered before: "We all figured this was it". For several weeks, (until the experimental drug "worked"), Mary was confronted with limits that could not be overcome by will, actions, scientific knowledge, or money. After the dramatic turn around, Mary resumed "being in charge" once again: She "banked her energy" for certain purposes, became "conscious", and vigilant "not to get too casual about it (health) again" in order to maintain "my quality of life".

Anne's bodily weakness, on the one hand, promoted her to inquire into medicine's last scientific advances (monoclonal antibody treatment) and, on the other, to reconcile many of her strained relationships with others. She prayed to be endowed with strength that could carry her through dying, should that be inevitable. "The times I feel the best are the times when I'm serene in spite of whatever is going on". On a more existential level than Pat, Anne encountered a happiness she had never known before:

> In my whole life, I never learned how to be happy and then I got cancer, and because of the (spiritual) work we've been doing, I've been happy. It's ironic... I'm looking for a cure, I would want a cure, but this level is ok. It's like psychologically its ok, spiritually it's ok, I go through my periods of being scared; I go through my periods of wondering if I'm dying...my periods of being very sad, depressed, angry, whatever - the whole spectrum of emotions...but generally speaking, I feel really happy....At this point, I've been able to have almost two and a half years of happiness which is a lifetime. It's funny but the unhappiness has faded, like the past has really become the past. The present is very full of love and of good feelings and of happiness. It's been incredible, it's really been good.

Thrust into the present through a "wiped out body", flooded with emotions, without much future left, the recent past appeared as resolution of a life time.

About one month before Anne died she reflected upon the belief she had held throughout life, that her strong mind and will could make things of her choice happen. Her terminal illness, however, had revealed the body's ultimate arbitrating power over her reality and future possibilities. She felt relieved from having to make things happen and lived the weeks of dying in serene "I"-body unity.

Analysis 4

It was the body's self and world constituting power which brought impending death so rampantly to awareness. Inherent in the inability to replenish reservoir-energy lurked the fading of life's strength: "Everything seemed to be going to pieces". Tiredness engulfed all previous abilities. Its yang brother, feeling energetic, appeared perverted to shadow-like, irresistible urges such as "throw[ing] up" what could not be "held down" any more. Eating or drinking were all consuming tasks which went against the grain of bodily cravings. Pain advanced in its work of "uncreating" the world (Scarry, 1985. p.19). As the radius of life-space shrunk to bedroom size and time surfaced as a future deprived present, the certainty of death's imminence "around the corner" grew. The world retreated as the body grew to all encompassing prominence. Things previously important, ceased to matter, while bodily weakness reshaped self's relationships to self and beyond self.

Knowing about the body became less important. Knowledge revolved around what could help towards feeling comfortable, once options for enhancing survival had closed down. Abstract knowledge about the body lost its fascination to the self once "I" had to come to terms with its embodied finiteness.

"I"-body relationships were inundated by existential concerns. Unambiguously, the body's existential relationship to self's being or not being revealed itself to "I" in terminal suffering. There seemed to remain two possible modes for the self to relate to the body: 1) Either passively, and in despair, resigning to a "giving-up" body (yet another "have to") or, 2) actively, and faithfully, resigning to an embodied strength which might carry the woman through her dying (a new "I'm able to").

Mary might have switched back and forth between these mutually exclusive modes had she not "responded" to Mitrazantrole. Undoubtedly, this turn towards living reinforced Mary's tendency to regain control. In the interviews, she reflected upon grappling with "I's" attempts to "grit" the body into feeling or performing better or, she expressed her anguish when the body defeated "I's" supremacy.

Living in one mode conceals the possibilities of the other.

Passive and despairing resignation allows still for "I" to struggle against its dependence on the body through effort-full attempts to regain charge and responsibility. Faithful, active resignation excludes either-or sovereignty of body over self or vice versa, but demands acceptance of life's embodied paradoxes.

Self's struggle against bodily dependence grows from and is kindled by a culturally reinforced disguise of limits and a resulting weakness in dealing with restrictions. Limited future possibilities, mobility, growth, choice, understanding etc. profoundly challenged "I's" self-reliance. Mary said: "I just can't believe this...that I just cannot make myself feel better". Reality showed up as unbelievable. Embodied mastery, previously always reliable, had vanished leaving an "unreal", unbelievable vacuum of familiar capabilities.

As long as reality did not thwart beliefs about self's assumed power "that we can control every aspect of our lives, including how and even whether we die (the ultimate control)" (Ross, 1989), then bodily limits remain concealed. Mary, privileged through abundant human and financial resources, had been able to <u>make</u> possible, over the years, what to others might have been out of reach earlier on. She might therefore have had little experience in learning what Sarton (1978) put into the mouth of her dying heroine: "When there are limits, it's easier to handle some things". By despairingly hating her "giving up" body, the possibilities which were concealed in what seemed "unbelievable" limits could not show up.

Her belief in possibilities of limitless freedom brought about by willful striving made it difficult to embrace the only real freedom, bounded in and situated by her embodiment. On the other side, Mary's history of bouncing back from limiting bodily intrusions into her active life seemingly full of choices had trained her to expand bodily induced limits (by banking her energy), thus reinforcing self's assumed freedom from bodily limits.

Anne was aware of and worked towards being able to leap into the other mode of relating, "when time comes". Until about two months prior to her death she held the conviction:

> I'm going for cure and then if cure doesn't happen, you deal with that when that comes up. [Hypnotherapist's name] and I've worked a long time to get me to that point.

For Anne, a paradoxical move occurred when she willingly accepted bodily finiteness. Then, the perceived seat of power shifted from her mind-self to her being embodied in a finite body. Instead of trying desperately to make the impossible happen, she gracefully surrendered to that previously so frightening finiteness, which she now experienced as an appeasing, ultimately freeing force. "For once we accept the actual existence of our dying, who can ever have power over us again?" (Lorde, 1980, p.53).

In her last interview, Anne talked about how, in hindsight, undergoing her mastectomy appeared as her "surrender to the process of life ...of development, of evolving". Before, she was "mad at my destiny". In this process, Anne learned to "trust my inner instincts" rather, than reacting stubbornly by demanding that people and things yield to her intentions. Surrendering to embodied life's limits opened up a previously concealed source of happiness. She called it "peace of mind".

Paradoxically, happiness came into Anne's life after she had given up trying to make things happen her own way. In the suspension between letting the past be past and dwelling in what remained possible, given her weakness, Anne experienced "time full with love" or, in Kierkegaard's words a "fullness of time" previously unknown to her (1844/1974, p.22). Kierkegaard's fullness of time _is being_ fully self (as compared to the emptiness of non-being), marked by a total recast of one's life's meaning. The past makes sense in the light of present fulfillment and the future appears congruent and inundated with the moment's commitment. Within the embodied possibilities and limits of her present, Anne's life, it seems, became transformed from past angry, empty despair into faithful surrender to what was coming. It was in this surrender to her body's mortality that she was able to experience her "strength to deal with what ever [came]".

"Peace of mind" grew after "I" had surrendered to the ambiguity of her afflicted, dying body. Peace of mind alluded to a certainty which the inquiring, rational mind seemed unable to know. Once again, paradoxical in its quality, the relating, surrendering mind-self found peace (strength) in living the dying (weak) body's limited possibilities. Whereas the unresigning (seemingly strong) self's defeat vis-à-vis a "giving-up" (weak) body may have yielded more stamina for a continuing fight, it also brought forth feelings of forsakenness and hatred (frailty) towards its limit imposing arbiter-body.

Summarizing Discussion

Each culture endows its understanding of embodied human life with the possibilities it simultaneously reveals and conceals in practices and thought. From the ways in which these six women lived and related to their bodies, we can, paradigmatically, infer much of contemporary Western self-understanding. Embodied self-understanding is intricate, multilayered, dynamic in its processes. It encompasses temporal, as well as spatial dimensions, and is never fully explicit.

Paradigms, in Kuhn's (1970, p.175) double definition, are: 1) an "entire constellation of beliefs, values techniques and so on shared by the members of a given community" and, 2) paradigm

> denotes one sort of element in that constellation, the concrete puzzle-solutions which, employed as models or examples, can replace explicit rules as a basis for the solution of the remaining puzzles of normal science.

Although Kuhn referred to scientific communities and the solution of scientific puzzles, bodily and embodied (self)-understandings are paradigmatic in Kuhn's dual sense.

It would be wrong to conceive of paradigmatic ways of dealing with bodily affliction as one-dimensional or mutually exclusive. Rather, all women alluded to notions of being called upon to yield into an embodied, present oriented flow of life. Shin, Jane, and Anne, (in her last weeks), seemed to feel quite secure without having to master their destiny. Sue, Pat, Mary and Anne, (earlier in her illness trajectory), felt thrown into a mode of being which defied their deliberate and controlling guidance. Theirs were reactions of profound anxiety, frustration, and despair.

To Sue, Pat, Mary and Anne (until late) the body appeared in metaphors widely shared by people in touch with contemporary lay and scientific knowledge: e.g. an anatomical-physiological conglomerate of pieces and functions; a well mastered part of self at one's disposition; self's flaw-less, female display towards others; and a source of renewable well being, if mind-fully attended to. On all these understandings they were challenged by cancer's insidious impact and pervasive "therapeutic" "side effects".

Shin and Jane seemed widely untouched by any of these paradigmatic notions. As if they lived in another time or culture, their bodily self-understanding seemed largely un-split. Neither an object to be mastered, used, or enticed into well being, nor one to display self in alliance with fashionable female portrayals, they seemed not to perceive cancer and its aftermath as problems they were summoned to solve. Their mode of engaging in their plight was worrying and enduring rather, than developing more problem solving skills in a new area.

Rational problem solving with help of scientific knowledge is a contemporary preoccupation. Sue, Pat, Mary and, for a long time, Anne had embraced the belief that almost anything can be manipulated in direction of one's choosing, if only one tries hard enough and uses all available resources. To them the cancer inflicted body tended to present itself as riddled with problems awaiting solutions; yet, existentially, it resisted their rational approaches. Hit by cancer and treatments in its reality shaping capacities, the body confronted the women with altered perceptions of time, space, and certainty, as well as with changes in appearance and the flow of their emotions.

<u>Time</u>, for Shin and Jane appeared as unbroken between past, present and future. It seemed to flow in its usual, pre-illness way. Cancer appeared as something to be endured, worried about, and taken care of, similar to other challenges they had previously encountered. It seemed as if time happened to these women through, and within their bodily

capabilities and sensations rather, than something outside themselves to be influenced by their plans or choices.

Time appeared as profoundly disrupted to the other women. For example, to Sue, who seemed to have notions of time as a vessel to be filled with her own deliberations, time stood still as long as she was forced to "go through" treatments. Or, Pat's time, also perceived as being at her disposition, appeared as crowded with decisions and activities she had not chosen. For these women, the future played an eminent role. It held self's hopes for regained bodily independence presently thwarted by the body's disrupting presence in their awareness.

Ingrained in the dominant culture is a belief that will, perseverance, and hard work will make a better future, that individual happiness can be pursued (the US constitution) if one does the right thing. A happy future, it seems, demands an oblivious or pleasure-full body; a body at one's disposition. Unpleasant bodily presence was thus an ongoing impetus for trying to make the body disappear out of awareness and, to many, to clear future prospects by forgetting its immanent existential messages.

The body always dwells in space. More than time (which allowed an escape into a hopefully better future), space appeared as limited, or forced upon the women through the body's condition (e.g. Jane and Mary). Mobility, in dominant culture premises an able, easily adaptable body which vanishes from awareness without reminding self too frequently of how the present place differs from previous ones. Space too, appeared as within self's choice as long as awareness was unencumbered by the body.

Jane and Mary's intense feelings of frustration rose from spatial clues, but differed in their meaning. More than any other component in her otherwise quite unchanged life, the alien hospital world brought her illness into Jane's awareness. Mary's failing body, on the other hand, seemed to glue her into the narrowness of her bedroom without possibility of being able to flee to places of her choice.

The certainties upon which much of their self-understanding was founded, in the course of the illness faltered. Shin's identity as a Chinese woman and part of the family eroded when the foods she knew lost their taste and remnants of her bodily presence might contaminate others. Uncertainty was mostly associated with spatial dislocations for Jane. Sue's certainty about who she was shattered in the humiliation caused by the body's slipping from her control. An astute awareness of temporal discontinuities enhanced uncertainty's grasp on Sue. Certainty broke down for Pat in the contradiction of forced choices and in the anxiety which drove her to excel in rational problem solving. She and Anne alluded to a new quality of certainty which they experienced once they had faithfully leaped or surrendered into the ambiguities of embodied existence. Certainty's multidimensionality showed up as Mary's world fell to pieces. The body's ultimate power over mind-full attempts to make self feel better convinced Mary in her embodied situation of death's imminence. However, on a disembodied level, she still could not believe what her mind and will were unable to grasp, let alone to make happen.

Perhaps most profoundly, uncertainty pushed Sue, Pat, Anne and Mary in their endeavors. Uncertainty arose wherever culturally assumed certainties such as problems are fixable, resources replenishable and deficits, caused by some neglect, can be corrected with necessary attention, proved as fallacies. Yet, until late in their lives, in their endeavors to deal with pervasive uncertainties these women remained within the frame of cultural self-understandings: Information seeking and learning new knowledge seemed to carry the big promise that knowing more (facts) would alleviate the burden of uncertainty: More knowledge, analogous to the cancer-war metaphor, seemed to promise (more) control over one's fate.

In Shin and Jane's interviews the struggle to know in order to control was strangely absent. They must have gained some certainty by knowing in a more embodied way than most of their adult contemporaries. This made them somewhat comparable to children who's understanding is present focused and intuitive. They seemed to feel secure by being in tune with the ambiguity of knowing through the body.

The <u>body's visibility</u> and <u>appearance</u> emerged as a driving force for Sue, Pat and Mary's endeavors and decisions. Although forced into their situation by the disease, these women felt they had still some possibilities to choose from: e.g. breast reconstruction, saving her breast and "banking" energy in order not to "look droopy".

Embodied appearance mattered to these self-conscious and self-assertive women. The visibility of self's perfection projected by a good looking, (healthy) body concerned Sue and Pat to the extent that (embodied) feelings of humiliation deeply influenced their decisions.

Although Jane, Shin and Anne experienced alopecia, (the other three women had some hair thinning), and breast asymmetry, their concerns seemed less influenced by appearance. Jane and Shin worried about their families of which they felt an integral part. Anne's concerns were focused on survival, resolution of strained relationships and later, finding peace of mind.

On the <u>emotional</u> level, despair seemed to be more pronounced in situations of "I"-body estrangement, while happiness and feelings of fulfillment tended to appear in committed "I"-body oneness. Pat's happiness surged with her belief that she made the very best decision she could in the face of objective uncertainty. Anne's existential happiness appeared when she resigned herself to an embodied strength she had not encountered as long as she thought that she controlled her destiny.

For Sue, Pat, Mary and Anne it seemed as if self was confronted with "choosing" between their culturally shunned, ambiguous, yet existentially reassuring, intuitive body, and pervasive, contemporary promises that they could master their destiny through scientific knowledge, applied mind over body techniques, and use of rationality.

Shin and Jane lived, it seemed, less self-consciously. Theirs was a world without such a multitude of choices. Marginal to paradigmatic contemporary self-understanding, their lives appeared embodied and intuitive, (in Kuhn's second definition of paradigm), thus less shaken on the existential level. Without presuming that they knew how to control, their tolerance for ambiguity and accepting things as they happened, seemed stronger. Suffering was not a new experience in Jane's life and Shin's "weakness" had always had the coloring of vulnerability. Existentially, they might have learned through suffering that lastly, embodied life is ambiguous (and thus eludes illusory mental control). Among their fellow-sufferers, Shin and Jane stood out as an embodied antithesis in a world full of mental control over one's disembodied life.

From the disembodied perspectives of medical (and nursing) sciences, Shin and Jane may appear as more passive, less intentional and vigilantly responsible, thus more unreliable for taking care of their own "health", than were others in the study. They seemed to let things happen to themselves, yet felt accountable for the well being of those around them (e.g. Shin's endeavors to protect her family from contamination). These two women did not fit the image of the modern "homo clausus" (Elias, 1968), living segregated from their body, others, and their world. Shin and Jane appeared to live in the certainty that vulnerability is part of human embodied existence and that vulnerability entails suffering. Indeed, they challenged contemporary scientistic, professional models of active, self-assertive, rational, world-detached, thus disembodied individualism.

Rather, they may have lived out of older, historical notions that being embodied means being intricately linked to, dependent upon, and interdependent with one's world. What to the contemporary seems passive letting happen, may in fact be an active-receiving relationship with the world. Perhaps, the analogy of a swimmer's relationship with water while swimming helps to explicate this relation. Swimming means that one dares to be in the water (which enhances one's vulnerability) and that both floating (receptive, passive) and moving (active, doing) are necessary to keep afloat without tiring early.

Contemporary self-understandings tend to imply that one can a) swim on dry land if one wills and does the right things (and thus escapes the vulnerability of being in the water); and b) if one happens to be in the water, that moving with all one's force keeps one from drowning. In both instances the embodied ability to float in, with, and through currents, streams, and waves seems to be forgotten or not reckoned with. Shin and Jane's giving into a more receptive (floating) relationship with their world made show up both their vulnerability and their unpresumptuous strength of facing that very vulnerability.

CHAPTER 8

SO WHAT?

The Findings and Popular Conceptions of the Body

Individual perceptions of bodily happenings and embodied experiences after the diagnosis of breast cancer and during treatments were the focus of this study. Bodily happenings seemed at the core of changes in women's self-understanding and in how their previously taken for granted life and world appeared to them. The body and self's relations to and through it challenged epistemiologically defined boundaries of scientific disciplines. For example, conceiving of people through the divided "bio-psycho-social" trilogy, (so eagerly embraced in much of nursing literature), fell short in this study.

Any disciplinary division is artificial and thus misleading when the ubiquitous, all uniting, enabling, and at the same time, limiting and undoing human body is subject of reflection. Yet, insights from this study need to be discussed within existing disciplinary frameworks.

Three intricately interrelated view points will serve to elucidate a few problems which seem important if the body is looked at from a nursing perspective. These perspectives are: 1) the body as self, 2) the social body: its relations beyond self, and 3) the being dimension of the body. Of course, these perspectives include other aspects such as historical or biological as well. This discussion will lead into a short reflection on how other than psycho-physiological notions of the body might inspire nursing.

The Body as Self

Traditional theories about the body with individual focus include anatomico-physiological and psychological (body-image) models. Neither of these theoretical approaches served women in this study convincingly in their quest towards understanding what was happening to them while their bodies lost previous self-evidence.

Ultimately, all of patients' relationships to self, others and the world were founded in embodiment. Women knew about their bodies in varying forms and on different levels of abstraction. They suffered from both, the illness and what was done to their bodies/them with therapeutic intentions.

Two central concepts of embodied self-understanding, - "I can" and "I cannot", - both with profound sequelae for the individual, emerged from the analysis. Yin-yang like vacillations between these two modes promoted pervasive, implicit changes in how the body, self, world and others were perceived in relation to each other. Because of rampant bodily obtrusiveness in the "I cannot" mode, factual knowledge about the body, (its functions and what might mitigate the body's antagonistic impact on daily life's activities) was actively explored by many.

In its breakdown, the body emerged as decisive power in patients' awareness. Through it, perceptions of time, place, certainty, autonomy or dependence as well as experienced emotions and moods showed up in new, unfamiliar shades of light. Many patients became highly aware of the body as constitutive of their altered reality.

"I's" intricate relationships to and with its enabling or disabling body ranged from body-"I" oneness to "I's" detachment from an objectified body. On neither pole in this "I"-body continuum of relationships was the body conceptualized as either mental representation of a "body-image", or in terms of traditional anatomico-physiological theories. "I"-body relationships appeared as fluid and equivocal. They tended to mirror the body's paradoxical and ambiguous qualities as they appeared in a woman's awareness. Bodily changes deeply affected patients in their self- and womanhood. In many they elicited profound anxiety and worries.

However, worries about, or references to a "body-image" in Schilder's (1935/1950) terms were never mentioned by these women. The body seemed not to appear as a mental picture. It showed up as multidimensional self, inundated with strong emotions and as enabling or disabling. Relations to self and others were influenced by a woman's whole bodily being, not by an "image".

If anatomico-physiological knowledge was used by patients, it served to account for bodily happenings and as reference or explanation for daily life experiences linked or associated to such events. Factual knowledge about the body might be conceptualized as an approximation to what is experienced and as attempts to grasp or understand what bodily changes mean in one's life. Scientific knowledge about the body, when superimposed on experienced bodily realities, appeared like trying to capture water with a sieve. Nonetheless, knowledge in conjunction with bodily experiences served as mutually enhancing forces at self's disposition to make sense of a difficult situation. To some women, acquiring medical knowledge served as a tool for becoming actively involved in what otherwise seemed just happening to them. Furthermore, the use of medical concepts may have assisted them to give neutralized versions of their bodily distress to others, or, in Elias' (1976) terms, to stifle shame by rationalizing the illness' bodily impact.

Medical concepts gained symbolic power for some patients. They were applied with the aim of sustaining and controlling the body in its assumed fight against cancer. Body imagery (not a body-image) of e.g. blood corpuscles and their functions was used to aid this fight. Thus, fragments of anatomico-physiological theories, although superimposed, were more or less assimilated by most women into their self-understanding. In their knowledge and ways of medically dealing with illness sequelae these patients expressed numerous shared socio-cultural understandings of the body and illness.

The Social Body: Its Relations Beyond Self

Many medical and nursing treatments targeted the body as if it were an obstacle, or a territory between outside weapons and an elusive, inside cancer. Foucault (1979; 1980) pointed to the insidious power bodily (institutionalized) practices have on human self-understanding. Literally, cancer treatments were applied bio-power, directly derived from "a technology of power centered on life" (Foucault, 1980, p.144). Professionals and many of the women acted out of the persuasion that, through tight control and manipulation of physiological processes life could be mastered. Continuously perceived as at the edge between being cleared from disease and being destroyed by both therapies and cancer, the body emerged ultimately as an enigma, resisting many of "I's" and professional efforts. Not infrequently, it defied attempts to be predicted and controlled by bio-technologies, thus causing much anxiety in the women and frustration to those who attempted to cure the disease.

Having embodied a social tradition of mastering and controlling the body to the degree of sublimating it from most of daily activities throughout their lives, the body's uneasy appearance in women's awareness tended to throw them into barely controllable or fully overwhelming situations. As bodily-taken-for-grantedness disappeared, so wavered the sense of control over their lives.

Over centuries, a sense of bodily control slowly developed through an array of socially imposed manners. Once bodily forces seemed bridled, control over one's life and outside environment appeared as attainable to determined minds.

> The autonomous individual self-controls produced in this way (by transformation of interpersonal external compulsion into individual internal compulsion) in social life, such as "rational thought" or the "moral conscience", now interpose themselves more sternly than ever before between spontaneous and emotional impulses, on the one hand, and the skeletal muscles, on the other, preventing the former with greater severity from directly determining the latter (i.e. action) without the permission of these control mechanisms (Elias, 1968, p.257).

It was precisely the awareness of the body's spontaneity and its power to switch from modes of "I can" into "I cannot", in conjunction with profound changes in mood and emotions, which became unleashed by the illness and treatment effects. Bodily changes and resistance to treatment promoted experiences of a breakdown in those mental "control mechanisms" upon which many women had so far relied in most aspects of their lives. Somehow, the pervasiveness of bodily existence circumvent women's conscious permission-giving. The body's partial independence from conscious control deeply frightened these patients. What appeared to many as a personal loss of control may be interpreted as the body thwarting domesticating cultural taboos such as mastering one's body in all circumstances.

Besides its relative independence from mental control mechanisms, the body "responded" to "therapeutic" assaults, often unpredictably. Neither "I" nor those others who treated the body had the amount of control over it that participants in the cancer fight wished. Rather, it was the body which, through changing sensory perceptions like taste, smell, appetite, or sense of place and time re-constituted a woman's unfamiliar world.

Frequently, the body appeared as squeezed between "I's" intentions and the technical power of professionals. Interestingly, it seemed unaffected by meteorological or other, non-human, outside influences. In different Western cultures (e.g. in German speaking parts of Europe or in Israel (Krulik, 1990)) weather changes are frequently perceived as strong influences on how people (and patients) feel in mood, how pains and aches impact on daily chores, and how a person is generally disposed.

Traditionally in Western and many non-Western cultures the human body has been conceived of as an integral part of a larger, interconnected animated and unanimated world beyond individual control (Elias, 1939/1978; Bakhtin, 1965/84; Bastien, 1965; Duden, 1987). For example, in medieval times, water was thought to be able to penetrate the body through the skin's pores and thus to invade it with plague. Therefore, in Europe, water was shunned for centuries as a means for body toilet, while clean clothes, powder, and perfumes were used instead (Vigarello, 1988).

In these interviews, notions of such connectedness to a larger, (inanimate) world were virtually absent. A more or less closed, somewhat defiant system, the body was perceived as something to be manipulated and accessed by "I" and/or others, against its own resistance, for the sake of a good called cure or warding off disease manifestations. Such access demanded overcoming bodily boundaries and meant intrusion into an objectified organism. Segregated from the inanimate world, the body frequently appeared also as separated from others and from "I". Its centuries long domestication by sublimating its "shameful" or "embarrassing" manifestations in public space may have enhanced women's vulnerability and unacknowledged suffering. There is little place for suffering in a disembodied world, since moods, emotions and pain can barely be displayed without embarrassment to others.

Often without explicit acknowledgement, women realized their existential bodily connectedness with and dependence from the world as part of their illness experience. Seemingly, the more they had adhered to "separative intentions" (Keller, 1986) and self-understandings, the more they felt forsaken by a connected body who had thrown them into a changing world and dependence upon others.

The Being Dimension of the Body

Notions of immanent bodily strength existed in concepts such as "energy" (energy-of-being, reservoir-energy) and bodily capacities to cooperate in the healing of cancer. Of these, only energy-of-being was perceived as an existential strength in which all other functions of life dwelled. Until late stage disease, reservoir-energy appeared as mainly within "I's" realm of influence: It appeared as refuel-able and bank-able. A potential for self-healing in the body appeared as dormant and in need of awakening by mind-full efforts such as meditation or "I"-

body bargains.

Perhaps, bodily "strength" came closest to the concept of an invigorating, threefold "anima" (vegetative, sensory, and noetic) of historical body conceptions (Mauss, 1938/1985). Strength allowed patients to feel animated, enabled them to look good, perform well and, usually after a period of weakness, to feel again as themselves.

In none of the described "I"-body relationships in this study the body appeared as noetically (mind-fully) ensouled. Rather, in self's supremacy over the body and even in bargaining situations, the mind appeared as part of a rational self much more, than of the body. In times of "I's" dependency from an alien (giving up, betraying, enemy) body, the body appeared definitely as devoid of a well-meaning soul. Of course, how could, in warfare, an enemy be endowed with the wisdom of a mind-full soul?

Yet, if von Kleist's (1810/1989)) vision of the soul's visible and vulnerable role in movement were to be transposed into the experiences of the women in this study, then illness and treatment needed to be conceptualized as dis-abling an ensouled body. Describing dancers, von Kleist wrote:

> For affectation appears, as you know, when the soul is found at any point other than the movement's center of gravity....Just look at P...her soul is in the vertebrae of her lower back as she bends as if she were about to break....Or look at young F. ...his soul is actually (it's frightful to see) in his elbow (p.417).

Patients in this study knew, through embodied experiences, that they were hit at the core of their strength, vivacity, vigor, vitality, stamina, and skillful mental-bodily performances. Their "soul's" dwelling capacity at the center of embodied movement and activity had been deeply affected and curtailed.

Current diagnostic conventions of individual physical deficiencies and psycho-social problems tend to gloss over the body's pervasive perceptibility. Concepts of an ensouled, animated body amidst an interconnected world would be advantageous over models of a materialistic anatomico-physiological organism and theories of self-as-separate from, or against its body, others, and the world. They would promote one to search for the non-intentional, complex, often ambiguous dimensions of reciprocal body-world relations.

Of course, ideas of an animated body are conceptually challenging since anima (life principle, soul, Webster, 1983) appears as paradoxical in its core. For example, it may be simultaneously ambiguous and certain (e.g. experienced certainty about illness/CTX's unpredictable impact on one's ability to skillfully respond to the soliciting challenges of daily life), or transient and nevertheless constantly present as was patients' embodied awareness of their illness.

Contemplating the body as animated provokes one to acknowledge life's complex paradoxes and ambiguities without a compulsion to reduce them into (un)conscious either/ors (as for example "choosing" cancer over another illness), nor to deduce logically one fragment from another. Rather, conceiving of embodied paradoxes and ambiguities as "une entente qui réunit deux [plusieurs] qualitées opposées, participe de deux [plusieurs] natures différentes"[20] (Robert, 1951), allows for conceptualization of the body as that unifying, ultimate certainty it

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[20] An agreement (meaning) which unites two [several] opposing dispositions (characteristics), each of which derives from two [several] different dimensions (transl. and bracketed inclusions: AK).

appeared to be in the accounts of the women in this study.

It is, however, difficult, if not impossible, for today's scientific, professional self-understanding to leap (back?) into historical, ensouled notions of the body. Neither common medical or nursing practices, nor formal knowledge in physiology or psychology provide easy access into such notions, nowadays considered as esoteric. Yet, conceptions of an animated body, interrelated with its surrounding world, provide a necessary, provocative and alternative background against which contemporary understandings of a detached object body may lose their unquestioned self-evidence.

Chances are that a conceptual dismantling of the body's scientific self-evidence (e.g. as a normative mechanism to be manipulated by self and medical professionals), may encourage further pheonmenological studies of the body. On a philosophical-scientific level, a breakdown of "self-evident" disembodied conceptions of the body might yield similar insights as Pluegge (1967) referred to when he observed that often it is only through the breakdown of the body's self-evidence that existentially important aspects of life surface and elicit patients' (and others') concerns.

The Phenomenological Body and Nursing

On one hand, the ubiquity of the human body in nursing care practice is pervasively evident. On the other, its conceptual absence other than in anatomico-physiological and psychological "body-image" terms is quite amazing, yet not surprising, given the difficulties embodied human experience poses to a logico-rational scientific approach.

Caring For and Coaching Patients: One might conceptualize patients' experiences described in this study as journeys through waters which suddenly made deliberative steering of one's life difficult. After its taken for granted quality had (at least temporarily) disappeared, the body and its relations beyond self appeared like a stream or sea with waves, currents and rapids, often challenging self's mastery of being in full control of life and destiny.

There is an understanding in the profession that nursing care and caring include being with and coaching patients in their illness experiences (Watson, 1979; Benner, 1984; 1988; Benner & Wrubel, 1989; Bevis & Watson, 1989). How then, can patients be accompanied and coached by nurses whose formal knowledge of the human body consists of the Scylla of an objective anatomico-physiological organism and the Charybdis of "problems" in mental, disembodied psycho-social realms (see literature review in chapter one)? Without, or with little grasp of the body's immanent social, (ensouled?) power to constitute self and one's world, professional efforts to coach patients might easily get lost or wrecked in the existentially empty rationales of both or either, Scylla and Charybdis.

Existentially empty explanations and prescriptions tend to deny patients' embodied experiences and thus, to promote a decontextualized disease understanding of their own (e.g. divergent patient-professional interpretations about veins and blood, see pp.175). Such efforts often turn out to be counterproductive because of their non-restorative, patient isolating and alienating effects.

On the other hand, an appreciation of the body's multidimensional, self and world constituting power might facilitate compassionate, tactful being with patients (Van Maanen, 1990). Moreover, such recognition might soften rational approaches to illness as well as strengthen and foster more humble stances towards patients' embodied, existential experiences. Experiences of people who live their illness in less vigilance and/or resolute intentional "I" over/against body relationships may gain credibility rather, than being diminished as listless or non-compliant behavior (see Shin and Jane in chapter seven).

Research: Studies like Schilder's (1986) on restraining the body and Doolittle's (1990) on recovering from stroke elucidated the body's paramount role in interpreting a person's situation in meaningful ways. Restraining the body both thwarted the body's skilled movements in responding purposefully to situated solicitation and impeded its habitual, constitutive temporal and spatial dwelling. Stroke was experienced as a bodily rather than a brain event. Patients lost their sense of active bodily wholeness. One passive, object-like side demanded continuous attention and, despite much willful monitoring, hampered habitual, adept performance. Only in cases where highly valued, to the patient salient, complex abilities (e.g. fishing, crocheting) could be regained, did patients consider themselves as "rehabilitated".

The embodied experiences of women in this study both resembled and differed from the embodied experiences of restraint and stroke described in the studies by Schilder and Doolittle. An obvious similarity is that perceptions of time, space, certainty, emotional stability, autonomy and self-understanding changed as the bodies lost their obliviousness in awareness and its ability to reassuringly and skillfully dwell, perform, and be the person they used to be.

There are, however, pertinent differences to be studied. For example, how infliction of restraint differs from administering CTX. While restraint served hospital staff to maintain disease centered treatments against patients' concerns, CTX was used to fight an elusive enemy, hidden in an obstacle-like organism. Or, in contrasting stroke and CTX experiences: The stricken body appeared as divided, while the CTX loaded body felt pervasively poisoned in its cellular foundations. A better understanding of how embodied experiences are similar or different from one illness or treatment mode to another might give suggestions on how to care more specifically for patients with one illness over another.

Many questions arise from a phenomenological approach to the experienced body: e.g. how might satisfaction of bodily urges impact time, place and certainty perceptions of patients in physical restraints, versus patients with stroke or undergoing CTX for cancer? What do we know about the pain and suffering involved in each of these bodily situations? Can we learn how assisting a person who has lost the presence of one bodily half differs from caring for someone whose "I" negotiates with, or entices her body to cooperate in the fight against death? How is the body experienced by men with breast cancer as compared to women? Or, contemplating other bodily conditions: What do we know about the embodied, existential experiences associated with e.g. myocardial infarction, arthritis or multiple sclerosis? How might healthy aging be similar or different from these and other illness situations?

These and similar questions might be investigated through further research. Conceptually, the body needs to be re-embodied in nursing; the person understood as existentially interdependent rather, than seen as a "self-sufficient closed personality...separate from all other people" (Elias, 1968). This means that world (others and environment) and (embodied) self ought not only be conceptualized (nor researched) as separate entities, but need to be contemplated in their interactive, fluid relationships. Furthermore, analogous to the perception that stroke is a bodily event (in the words of one of Doolittle's (1990) patients: "...I could not move. I became totally dependent and very scared") rather, than a cerebral happening (as considered by professionals), patients' self-interpretations need to be understood as embodied through practices much more than as constructed "in the thoughts" of a society's members (see Berger & Luckmann, 1967 for a constructionist view).

Consequently, research questions as well as methodologies need to be carefully contemplated. For example, the pervasive use of questionnaires in nursing research relies on the assumption that much of lived reality is consciously, cognitively constructed and thus, can be called forth and reproduced by astute questioning.

Nursing Education: Intuitively grasped by practicing expert nurses (Benner, 1984), and thematized in recent nursing research and literature (Benner & Wrubel 1989; Schilder, 1986; Doolittle, 1990), as well as in non-nursing literature (Buytendijk, 1948, 1956, 1958, 1967; Straus, 1956, 1960; Pluegge, 1967; von Blankenburg, 1982; Sacks, 1984, 1987) the phenomenology of embodied illness still seems little alluded to in formal nursing knowledge and thus, in nursing education.

In training nurses to analytically appraise complex (patient) situations, contemporary education favors scientific, disembodying approaches over encouraging students to study illness experiences in their whole, encompassing bodily pervasiveness. The text book body is a normative, decontextualized fragmented entity without obvious relevance to time, space, inside or outside embodied experiences. If every patient who is studied as a (patho)physiological or psycho-social case could, at the same time, be learned about as an embodied being within a meaningful world, nursing care might gain creativity. Such creative approaches can be inferred from Doolittle's (1990) work where she described a woman who, after a stroke, regained some of her fine motor skills through the highly valued activity of crocheting, or from Sacks' own experience of recapturing the unrehearsed use of his leg by the spontaneous act of swimming, after he had (purposefully) been thrown into a pool by his therapist (1984).

Studies of embodied patient experiences confront students with those implicit, almost self-evident meanings which make up patients' worlds. As soon as the obvious fades and the unfamiliar appears, learning becomes more enticing. Against the familiar background of scientific bio-psycho-social patient assessments, glimpses of embodied experiences may appear as new and perhaps even as disconcerting. While learning the routines of nursing care planning tends to introduce novices into a schematic, "objective" view of case management, enquiring into the breakdown of previous self-evidence confronts the learner with his/her own vulnerable, embodied existence. From such confrontations more understanding and compassion for patients are likely to grow.

Nursing Ethics: Concepts of a world and reality constituting body or a "moral body to which we owe respect, help, and care..." (O'Neill, 1985) challenge both utilitarian and deontological lines of contemporary bio-ethical reasoning (Beauchamps & Childress 1989; Davis & Aroskar 1983). At once, they de-emphasize rational, but re-emphasize embodied intentionality and meaningfulness in close, interdependent body-world relationships.

Moreover, acknowledging an animated, ensouled body in the ethical discourse might allow us to re-conceive of suffering as a shared experience, rather than as privately experienced pain which the sufferer often must legitimize in front of or hide from others:

> The inflicting of pain for any purpose requires dissociation from one's own body in order not to suffer with the person in pain. The relief that dissociation affords accounts for the experience in which it can be easier to intervene in someone's pain by increasing it (as in child battering) than simply to witness it and suffer in response (Gadow, 1989).

As Gadow pointed out, one's (embodied) suffering (passion) solicits compassion (with-suffering) in the witness, while (decontexualized) pain easily demands physiological legitimation and for the witness, dissociation from one's body.

In a practice like nursing, in which the body is almost constantly subjugated to multiple inflictions of pain, ethical awareness is warranted of the practical consequences which follow embodied or disembodied conceptions of illness and nursing care. Better understandings of world constituting and world shattering experiences in bodily afflictions may enhance nurses' ability to argue with patients against those medical-technological assaults which reduce the organism into functional systems and pieces, endowed with normative, statistical evidence, and, which conceive of the person as an appendix attached to that conglomerate of potentials.

If the phenomenological body could be re-embodied into nursing practice, ethics, education and research, empathy and compassion might enrich those who practice the profession. This, and similar studies may illustrate how such learning may be approached and what could be gained from studying an in many regards concealed living, rather than a supposedly known, disembodied body.

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Appendix A

Code # ____
Date ____
T_1 ____ T_4 ____ T_5 ____

Chemotherapy Knowledge Questionnaire

PATIENT

Part I. (Completed by nurses from medical record.)

1. Site of interview ____________________.

2. Has there been a change in chemotherapeutic agents since first interview? (Specify)

____

____

3. Other treatment patient is receiving concurrent with chemotherapy:

(a) surgery ____, (b) radiation ____, (c) immunotherapy ____.

PART II. (Investigator fills in patient response)

4. Number of days in hospital since first interview ____________.

5. I would like to know the purposes for your chemotherapy.

	YES	NO
To cure the cancer	___	___
To control the cancer (not cure)	___	___
Unsure	___	___

6. Performance status at time of interview ________________.

Grade	Scale
90-100	Fully active, able to carry on all predisease performance without restriction.
70-89	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work.
50-69	Ambulatory and capable of all self-care but unable to carry out any work activities.
30-49	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours.
10-29	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair.

Code # __________
Date __________
T_1 ____ T_4 ____ T_5 ____

7. Here is a list of drugs commonly given to cancer patients. I would like to know which drugs, if any, you are taking. Please follow along as I read the list and tell me whether or not you are receiving that drug.

____ Actinomycin-D (dactinomycin)
____ Adriamycin (Doxorubicin)
____ Aminoglutethimide (Cytadren)
____ Asparaginase
____ 5-Azacytidine
____ BCNU (Carmystine)
____ Bleomycin (Blenoxane)
____ Busulfan (Myleran)
____ Carboplatin (Carboplat)
____ Chlorambucil (Leukeran)
____ Chlorozotocin
____ CIS Platin (Platinin) (Platinol)
____ Cytarabine (Ara-C, Cytosar)
____ Cytoxan (Cyclophosphamide)
____ Dichloromethotrexate (DCM)
____ DTIC (Dacarbazine)
____ Estrogen
____ Etoposide (VP-16)
____ Floxuridine (FUDR)
____ Fluorouracil (5-FU)
____ Hexamethylmelamine
____ Hydroxyurea

Code # ____________
Date ____________
T_1 ____ T_4 ____ T_5 ____

7. (continued)

____ Interferon (Roferon, Welferon)

____ Interleukin

____ Levamisole

____ M-AMSA (Amsacrine)

____ Maytansine

____ Megace

____ Melphalan (Alkeran)

____ Methotrexate (Amethopterin)

____ Methyl - CCNU (Semustine)

____ Mithramycin (Mithracin)

____ Mitomycin-C (Mutamycin)

____ Nitrogen Mustard (Mustargen)

____ Prednisone

____ Procarbazine (Matulane)

____ Tamoxifen (Nolvadex)

____ Vinblastine (Velban)

____ Vincristine (Oncovin)

____ VM-26

____ Other

8. Since the time your physician or nurse explained the chemotherapy program to you, you've probably learned that some people experience side effects when taking this (these) drug(s). On this page you will find a list of side effects that sometimes occur with different chemotherapy drugs. Many of these side effects may NOT be due to your chemotherapy drugs. Which of these effects, if any, have you actually

Code # ____________
Date ____________
T_1 ______ T_4 ______ T_5 ______

8. (continued)

experienced since you began chemotherapy? Please follow along as I read the list and tell me whether or not you have experienced each of these.

	Experienced	Potential
Anemia		
Bleeding		
Infection		
Low blood count (low white cell count, low red blood cell count, low platelet count)		
Fever - caused by chemotherapy		
Chills		
Fatigue		
Flu-like syndrome		
Headache		
Muscle weakness		
Muscle pain		
Nasal congestion		
Pain - at injection site or at the site of your tumor occurring when you are receiving your chemotherapy		
Pain - abdominal		
Increased coloring of skin under the nails (hyperpigmentation)		
Appetite - decreased (anorexia)		
Constipation		
Diarrhea		

Code # ____________

Date ____________

T_1 ______ T_4 ______ T_5 —

8. (continued)	Experienced	Potential
Liver damage - liver toxicity		
Mouth sores (stomatitis)		
Nausea and vomiting		
Stomach irritation & ulcers (gastric ulcers)		
Taste and smell changes		
Blood in urine (hematuria)		
Red colored urine		
Kidney damage - renal toxicity		
Urinary retention - unable to urinate all the urine that is in the bladder		
Elevated blood pressure, (hypertension)		
Lower blood pressure (hypotension)		
Heart damage-cardiac toxicity		
Shortness of breathing-dyspnea		
Weight - gain with fluid retention (edema, swelling)		
Thinning of hair or baldness		
Skin sensitive to sunlight		
Eyes sensitive to light		
Skin - ulcer (sore) formation if drug is accidentally given into tissue instead of vein		
Skin-redness and peeling (sloughing)		
Skin-changes in areas that have been previously treated with radiation therapy		

Code # ____________
Date ____________
T_1 ______ T_4 ______ T_5 ______

8. (continued)	Experienced	Potential
Skin-hot flashes	______	______
Skin-rash, itching, peeling, hives (dermatitis)	______	______
Skin - acne	______	______
Numbness-tingling in hands and feet (peripheral neuropathies)	______	______
Ringing sensation in your ears (tinnitis)	______	______
Mood changes	______	______
Confusion	______	______
Nervousness, irritability, insomnia	______	______
Difficulty sleeping	______	______
Feminization in men	______	______
Menstrual irregularities	______	______
Masculinization in women	______	______
Sterility	______	______
Weight - gain with fat deposits	______	______
Weakening of the bones (osteoporosis)	______	______
Hair-increased (hirsutism)	______	______
Weight - gain with fluid retention (edema, swelling)	______	______
Thinning of hair or baldness	______	______

---

9. Now I would like you to go through the list on this page again. This time, instead of telling me which side effects you've experienced, I'd like you to tell me which ones you've learned <u>might</u> occur with your chemotherapy. It doesn't matter now if you actually experienced it or not. Please follow along as I read the list and tell me whether or not you think that your drug(s) could produce each of these.

Appendix B

Interviewer ____________________
Recorder ____________________

Family Code ____________
Date ____________ T___

FAMILY IMPACT STUDY

PROBLEM-CENTERED FAMILY COPING INTERVIEW

(PCFCI)

(INTERVIEWER: RECORD NAMES OF FAMILY MEMBERS PRESENT WITH P,SO,A,B,C etc) ____________________
" " " " " ABSENT " " ____________________

Where P = Patient, SO = Significant Other
A,B,C etc = Children/Other Family Members

Directions: Read all of the questions exactly as stated for each occasion. If you offer additional probes, record them. When no response, prompt Patient first, then Partner.

We are going to ask you to identify or name some problems, issues or challenges your family has experienced over the past month. Then we will ask you some questions about the ways you've handled or dealt with one of these issues. What each of you thinks is important to us. Therefore, we encourage you to express yourself as freely as is comfortable for you. It is important to remember that there are no right or wrong answers to these questions.

Problem-Centered Family Coping Inventory

Family Code ________

1. (BRAINSTORM) What would you say were some problems, issues, or challenges that you as a family have dealt with this past month? (INTERVIEWER: RECORD WHO BY P,SO,A,B,C AND IN THE ORDER STATED)

WHO	PROBLEM/CHALLENGE
___	________________________
___	________________________
___	________________________
___	________________________
___	________________________
___	________________________
___	________________________
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2. What would you say was the <u>most</u> important of these problems or challenges? A <u>family</u> problem or challenge is something that affected all of you in some way. (INTERVIEWER: RECORD WHO BY P,SO,A,B,C AND IN THE ORDER STATED: ATTEMPT TO VALIDATE ANY CONSENSUS WITH ALL MEMBERS PRESENT)

WHO	PROBLEM/CHALLENGE
___	________________________
___	________________________
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___	________________________

PCFCI

Family Code ______________

(BASED ON INTERVIEWER'S IMPRESSION)

1. How difficult was it for the family to identify a problems in Question 1?

6	5	4	3	2	1
______	______	______	______	______	______
extremely difficult	very difficult	moderately difficult	somewhat difficult	slightly difficult	not at all difficult

2. How difficult was it for the family to reach consensus in identifying the most important problem in Question 2?

6	5	4	3	2	1	7
______	______	______	______	______	______	______
extremely difficult	very difficult	moderately difficult	somewhat difficult	slightly difficult	not at all difficult	none reached

PCFCI

Family Code ______________

3a. What were the effects of this problem on the family?

b. In what ways was this problem or issue effecting your family?

c. How was this a problem or issue for your family?

(INTERVIEWER: IF EFFECTS ARE IDENTIFIED FROM QUESTION (3a), SKIP TO QUESTION 4. USE ALTERNATE QUESTIONS 3b & 3c ONLY AS NEEDED. GOAL: TO IDENTIFY THE IMPACT OF THE PROBLEM/CHALLENGE ON THE FAMILY. RECORD WHO BY P,SO,A,B,C IN THE ORDER STATED)

<u>WHO</u>

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PCFCI

Family Code ____________

4. We're going to ask each of you to tell us how much or to what extent you feel this issue/problem affected or bothered this <u>family</u>. (INTERVIEWER: DISTRIBUTE RESPONSE CARDS TO EACH FAMILY MEMBER. REFERENT IS TO HOUSEHOLD FAMILY BEING AFFECTED).

6	5	4	3	2	1
extreme amount	large amount	moderate amount	fair amount	little amount	not at all

RESPONSES:

	________	________	________	________	________
	Patient	Significant Other	Child A	Child B	Child C
ORDER OF RESPONSES GIVEN: (#1=1st response given; record by P,SO,A,B,C etc)	________	________	________	________	________

Family Code ______________

5. What did you do or try to do to handle or manage this problem/issue? (INTERVIEWER: PROBE FOR CONCRETE BEHAVIOR OR EMOTIONAL RESPONSES: RECORD EACH SEPARATE AND DISTINGUISHABLE RESPONSE: RECORD WHO BY P,SO,A,B,C MADE THE STATEMENT OR CONCURRED WITH THE STATEMENT).

<u>WHO</u>

1. ___ ____

2. ___ ____

3. ___ ____

4. ___ ____

5. ___ ____

6. ___ ____

6. Who in household participated in managing this problem/issue? (INTERVIEWER: RECORD WHO WAS NAMED AS MANAGING BY P,SO,A,B,C. RECORD VERBATIM COMMENTS IF SPONTANEOUSLY OFFERED).

Patient's response ______________ Significant Other's response ______________

Child A's response ______________

Child B's response ______________ Child C's response ______________

PCFCI

Family Code ____________

7. Did your actions as a family actually change (ALTER OR AFFECT) the problem/challenge? (INTERVIEWER: RECORD SPONTANEOUS COMMENTS OFFERED).

Patient's response: ____________________

Significant Other's response: ____________________

Child A's response: ____________________

Child B's response: ____________________

Child C's response: ____________________

8. What were the effects on you as a family having done what you did? (OR) How did you feel as a family after you did? (INTERVIEWER GOAL: IDENTIFY THE IMPACT OF THEIR ATTEMPTS TO MANAGE THE PROBLEM/ISSUE; RECORD BY P,SO,A,B,C).

WHO

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9. We're going to ask each of you how satisfied you were with the way the family managed this problem/issue. (INTERVIEWER: DISTRIBUTE RESPONSE CARDS FOR EACH FAMILY MEMBER).

	6	5	4	3	2	1
	extremely satisfied	very satisfied	moderately satisfied	somewhat satisfied	slightly satisfied	not at all satisfied
RESPONSES:		________ Patient	________ Significant Other	________ Child A	________ Child B	________ Child C
ORDER OF RESPONSES GIVEN: (#1=1st response given; record by P,SO,A,B,C)		________	________	________	________	________

Family Code ______________

10. Who did family members let know about this problem/issue?

11. When did you talk with that person: before, during or after the problem/issue was occurring?

(INTERVIEWER: RECORD WHO TOLD BY P,SO,A,B,C AND IN ORDER STATED).	(INTERVIEWER: RECORD THE RELATIONSHIP TO RESPONDENT: 2. relative 3. friend 4. work/school assoc. 5. neighbor 6. health provider 7. therapist 8. minister 9. other)	12. (INTERVIEWER: RECORD ANY VOLUNTEERED REASONS FOR DISCLOSING TO THE IDENTIFIED PERSON)	(INTERVIEWER: RECORD WHEN DISCLOSURE OCCURRED: 1. before problem 2. during problem 3. after problem)
____________	____________________	____________________________	________________
____________	____________________	____________________________	________________
____________	____________________	____________________________	________________
____________	____________________	____________________________	________________
____________	____________________	____________________________	________________

13. Anything else you'd like to add before we ask one last general question?

<u>WHO</u>

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CFCI

Family Code ______________

4. What goals do you have for yourselves as a family?

[INTERVIEWER: WRITE VERBATIM RESPONSES; CODE EACH RESPONSE SOURCE BY P,SO,A,B,C. WHEN ONE MEMBER EXPRESSES AGREEMENT WITH ANOTHER'S STATEMENT, WRITE THAT.]

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