

**Toward a Sociology of (Gendered) Disgust:  
Perceptions of the Organic Body and  
the Organization of Care Work**

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### **Abstract**

Based on a reinterpretation of a study of 105 relationships between homebound dependent fathers and mothers and their adult sons and daughters, this article discusses incontinence as a social and cultural phenomenon. Care work has other people's bodies as its working field. The social norms and cultural symbols that surround the intimate parts of the body affect the way care work is organized, gendered, culturally understood, and socially stratified. To lose bodily control and the capacity to keep the disgust related to bodily fluids hidden from the eyes of others, seems to put the individual's identity and human dignity at risk. The disturbing presence of odors, sights, and textures seem to have a disruptive effect on close relationships. The article further discusses how bodily dimensions of care add new burdens to modern family life in different social contexts, and contribute to expand the gap between men and women in different cultures of care. This seems to be related to how ideas of individualism structure are structured by the economic and social conditions in which people live their everyday lives.

## **Introduction**

Norway, like other modern Western societies, is experiencing a change in the demographic structure of the population. Health care advances and associated declining mortality rates foster a vertical expansion of more and more families into three, four, or five generations. The number of people over 80 years old has grown, and the fastest growing cohort of older citizens is comprised of those 85 years and older. Among the oldest old, chronic illness, disability, and lingering dependency on others for their care is a virtual certainty. This is not unexpected, and the natural decline and decay of their bodies are expressed by an increased demand for health services.

The Norwegian welfare state's response to this situation is to stress family members' moral obligations for their aged parents and relatives. Given the gender-based division of labor, women's role as caretakers in the family is more stressed than men's. This is not an adjustment to be found only in Scandinavian welfare states. Cutbacks in formal services to the elderly seem to reinforce the traditional societal injunction that families should take care of their own in other post-industrial societies as well (Sussman 1985).

However, "taking care of their own" might imply different patterns of institutional and individual adjustments, given the variations in cultures of care that exist among Western societies. In Scandinavian welfare states, taking care of their own does not necessarily mean that families do not receive any kind of help from the public welfare services. The primary care responsibilities may be defined as being the family's. But public organized home assistance services are available to help them in their caretaking of elderly frail relatives. Such services are culturally and politically considered a supplement rather than a substitute for family care and are widely accepted as a qualitative good and reliable solution of modern work-family balance problems.

In the U.S., however, the lack of an institutionalized and culturally accepted welfare state and good public care services for the homebound elderly complicates the relationship between employment and informal care – more for women than for men. Data from several national U.S. studies indicate that approximately three-quarters of all informal caregivers are women (Stone et al. 1987). The possible implications of this for the relationship between gender, employment, and informal care are complex. Many female carers experience delayed re-entry into the paid labor force because of their caring responsibilities. Others withdraw from the labor market for similar

reasons. Between 9 and 11% of carers are estimated to have relinquished employment because of their caring responsibilities (MacBride-King 1990). And daughters are much more likely than sons to withdraw from paid employment for these reasons (Stone et al. 1987).

Even if most dependant elderly still live in their own homes and receive necessary help from their close kin, a picture of a "cold" society where families abandon their helpless elderly mothers and fathers has been created. However, empirical evidence supports the opposite (Gautun 2000; Isaksen 1996; Nordhus, Isaksen, and Waerness 1986). Women, or more correctly, middle-aged women, might be overburdened with care responsibilities in a situation where they also work full-time in the labor market. (In Norway in 1980, 45% of employed women between 40 and 54 years of age worked full-time. In 1997, 56% of employed women in the same age group worked full-time, 28% worked long part-time, i.e. [20 - 36 hours a week], and 16% worked short part-time, [1 - 19 hours a week]. (Labor Market Survey 1997)

Efforts to combine the demands for elder care with full-time employment place women at especially high risk for anxiety, depression, fatigue, reduced well-being, health problems, and other symptoms of overload (Applegate and Kaye 1993). Today, the average Western woman can plan to spend 17 years of her life taking care of children and 18 years assisting aged relatives ("Mother's Bearing" 1989). In the U.S., as in Norway, there is a care deficit in the population (Hochschild 1998; Nordhus, Isaksen, and Wærness 1986). While needs for care have grown, the supply of it has declined in the public; as the proportion of frail older people increases, the ranks of their potential family caregivers dwindle. Social institutions adjust to this situation in many different ways, depending on the type of care.

In public debates and in the making of social policy, there is a tendency to talk about informal family care for dependant elderly in terms of moral reciprocity – "What they did for you as a child, you have to do for them." Adult grown-up workers, family providers, and even grandparents, are defined as "children" of frail elderly parents. Talking about "parent - children" relations in this kind of care easily gives rise to associations that hide and disguise complex and difficult realities for the carers as well as for the dependants.

This paper is based on a reinterpretation of a study of 105 relations between homebound dependant mothers and fathers and their primary caregivers (Isaksen 1996). By interpreting a

narrative of a woman I call Brenda, I highlight some bodily dimensions of caring that are often neglected and overlooked in studies of care.

### **Brenda's Work and Family**

Brenda is a widow in her mid-40s. She works full-time as a preschool teacher and lives with her 17-year-old daughter, a 20-minute walk from her elderly parent's home. Her father suffers from severe physical balance problems and incontinence. For many years, Brenda and her mother have taken care of him at home. Over the years, her mother has developed severe health problems herself, and she is now emotionally and physically burned out and depressed because of the burdens and worries her husband's dependency has caused her. She needs daily help and support to manage the stress in her situation. Her husband has now and then spent some weeks at various nursing homes, and when I interviewed Brenda, she and her mother had agreed to apply for a part-time bed for him on a more permanent basis. (This would allow him to be at home for some weekends, Christmas, and some weeks in the summer, etc.)

The father supported this solution mainly because he found it emotionally difficult to be dependant upon his wife's and daughter's help with personal hygiene. He found it easier and more convenient to receive this kind of intimate help from professional nurses.

Brenda's husband died in an accident when their daughter was still a baby. He was his parents' only child, and over the years, his mother has developed needs for practical help and emotional support and turned to Brenda for these. Brenda has a married brother who lives in another town. She had tried to press him to share the care for their parents with her, but she hadn't succeeded.

I feel my brother has betrayed me...leaving all the responsibilities to me. When thinking of it, I feel really angry.... Why should he just take it for granted that I'm the one to take care of it all? He could have called more often and at least be interested in what is going on here.... But he calls only every third week or so.... Even if he can't give any practical help, he could at least give me his emotional support.... But you know, the men...they just don't care.

Brenda was upset and frustrated because of what she experienced as a lack of understanding of her situation from the local welfare authorities to whom their application for public

care for her father was sent. She felt that they didn't respect her status as a professional full-time worker and single provider:

I understand that they have to give highest priorities to the most dependant elderly and that the staff in the nursing home have too many patients to take care of. Their possibilities are limited, and I know they work hard, but administration ..... they *could listen* to the problems families have, too.... I have had a lot of stress in my job. Since I am responsible for the budget in the child care institution where I work, and the local authorities have reduced the budget this year... I have had a hard time to make ends meet. And then I have my daughter to take care of and all the troubles with my father and all on the top of it.... Some weeks ago I nearly crashed with my car two times within a few days.... Then I understood that I was too stressed and tired of it all... It has been too much for me.

The welfare authorities stressed her moral obligations as a daughter and woman to push her to take on more care responsibilities than she felt she could deal with. Neither did they understand the particular kind of stress that is related to care for incontinent persons or listen to what her obligations meant for her everyday life.

Brenda loved her parents and described the relation between herself and them as emotionally close. Her relation to her father had become more difficult, and she thought it was a consequence of his loss of bodily control and the decline in masculine authority and status he felt came with it:

He has always been an emotionally difficult person. But he loved walking and could walk for hours.... It was his way of getting rid of emotional tensions.... But now...you know, it's difficult for him to deal with the fact that he cannot go for a walk without help neither inside nor outside the house.... He cannot even take care of minor maintenance tasks in the house anymore because his eyes are not what they used to be...and then his "stomach problems" [i.e., his incontinence].... He just can't accept it...and he takes it out on us.... My mother has to take most of it.... But still....it is....you know...it does not make it easier for none of us.

Her mother's health problems worried Brenda. Because her father had experienced earlier stays at the local nursing home in a positive way, she felt that a part-time bed for him would improve the situation for all of them. Her mother could get more time for herself. Her father would get the kind of help he preferred, wanted, and needed and know that his wife could have some more of the

personal time she so desperately needed to recover. And Brenda could spend some more afternoons and weekends with other members of her family, her daughter, and her friends.

Brenda's family life reflects a social pattern in many modern people's lives. One aspect of this pattern is the lack of male participation in informal caregiving.

### **Absent Sons**

When we talk about child care, "absent fathers" are often discussed as a problem. But in informal care of frail elderly, in particular of those in need of hands-on care, "absent sons" are a problem rarely focused on. Sons tend to contribute with practical matters like taking care of parent's economic matters, maintenance of their house, mowing their lawns, and doing their shopping (Gautun 2000; Hicks 1988; Isaksen 1996; Wright 1986). These tasks are relatively easy to schedule and combine with jobs and other interests. They are also less stressful and less emotionally burdensome than hands-on care. Even if recent studies indicate that men are taking on more of the kind of informal elder care that usually has been understood as typically female (Lingsom 1997), the kind of care that implies emotional involvement and intimacy is still left to women. An interesting trend in Norway is for professional sons and daughters who work full-time to help their parents more than adult children who work fewer hours (Gautun 2000).

The kind of care work female kin is responsible for is more unpredictable and difficult to schedule and manage without feelings of not giving good enough or sufficient care. The more daily help elderly dependant parents need with their bodily matters (bathing and showering, personal hygiene, eating and dressing), the more often they are taken care of by daughters and/or daughters-in-law (Hicks 1988, Isaksen 1996). And women generally provide these high levels of care with little outside assistance.

In the field of caring that is related to the intimacy of the body, sons and other male kin are socially and literally absent for different reasons. As in Brenda's family, sons more often than daughters tend to move away when they marry. Daughters' families tend to buy homes near their parents (Gautun 2000; Ungerson 1987). This makes it easier for them to drop by every day when daily care is needed.

Dependants, both men and women, seem to prefer female help when they need assistance with intimate and personal care (Gough 1994). Because most of the oldest elderly with extended

loss of control over bodily functions are female, male kin might be culturally excluded from intimate hands-on care by social rules and norms that regulate the personal space of the body in cross-sex relations.

This also might help explain why sons of dependant, bedridden mothers more easily get support from the public health services and community services than daughters and wives (Isaksen 1996; Stoller 1990). Men seem to benefit from the traditional gender role expectations that perceive caregiving, like child rearing, as a role in which men require more assistance than women (Enright 1991).

Another explanation might be related to men's taken-for-granted role as family providers. But even if they do not have families of their own to take care of, their participation in the labor market is rarely questioned by the local welfare offices. Two examples from my study of patients' records in five local welfare offices illustrate this point:

NN is 86 years old. She lives in her son's house. Her son travels a lot in his job, so she spends too much time on her own.

BB is 89 years old. She lives with her daughter. Her daughter sleeps in the living room so she can help her mother if needed during the nights. The daughter has no financial possibilities to leave her job or reduce her working hours. She is a widow like her mother.

The daughter's labor market participation needed an explanation, but the son's job was not questioned. There was no suggestion that he find another job that demanded less travelling and made it easier for him to spend more time with his mother.

In the latter case, the daughter's role as a widow was used to support her. In Brenda's case, even if she was a single provider for a 17-year-old girl, she felt that her role as a widow didn't legitimate her status as a full-time worker. But she was a healthy woman in her 40s, and BB's daughter was in her mid-60s. The age of the primary caregiver seems to have some moral meaning linked to it. It may be "easier" to stress a relatively young, single woman's moral obligations for dependent parents than those of a woman in her 60s. Given the tendency to talk about care for homebound elderly in terms of "parents-children" relations, a woman in her 40s might still pass as a "child." But to talk about a woman close to the age of being retired herself as a "child" is more difficult. If this is so, the stressing of moral aspects of caring is stronger in the phase of life when

labor market participation often is combined with raising children and having a family life of their own. Changing diapers on small children is, however, not always comparable to changing diapers on an elderly mother and father.

### **Fear of Becoming “Dirty” and “Untouchable”**

The most common fear among terminally ill people is that of losing control over their physical functions. Part of this fear is based on an idea of becoming “dirty” (Cline 1996). Becoming dirty means in this context to have a feeling of being “untouchable” because of the fears bodily fluids evoke in others.

Brenda’s father was worried about his wife’s health and felt he burdened her with his dependency. Even if it was humiliating for him as her husband to experience a loss of control over basic bodily functions, it was worse for him to have his diapers changed by his daughter than by his wife. As a man, born and raised in a culture where social independency and bodily self-control are vital in the social construction of masculinity and of fatherhood, he may easily feel that his self-respect and dignity are at risk when his intimate body parts have to be cleaned by his daughter.

Recent studies have shown that intimate, hands-on care among both heterosexual and homosexual partners is emotionally difficult to live with over long periods of time (Isaksen 1987; Wrubel and Folkman 1997). Partners taking care of boyfriends with AIDS have some dimensions in common with elderly couples in which one is incontinent and dependant upon the other’s care: The shadow of death is present, feelings of loss are hard to take, and the care-giver has to manage his or her own emotional reactions because to effectively help the partners deal with his or her feelings. But since the givers and the receivers have a history of shared sexuality, the meanings attached to the caregiving are different among partners and lovers than among parents and adult children. One difference is related to the existence of the incest taboo. Another is related to the emotional costs and kind of emotion work that has to be done when a “child” is responsible for the daily caretaking of an old mother and/or father.

### **Feelings of Shame, Humiliation, and Taboos**

Hochschild (1983) distinguishes between “emotional labor” that employers require in paid jobs and the unpaid efforts of family and personal life, which she refers to as “emotion labor”. In both cases, she wants to identify an intentional management and display of one’s own feelings, usually undertaken in order to influence the feelings of others. Taking care of people who have lost control of basic functions requires a kind of emotion work that includes a constant awareness of the feelings of “having lost one’s identity as a human being” that often come with loss of control over basic functions.

Incontinence in particular is reported to be one of the most emotionally stressful burdens of care (Blannin 1987). The particular closeness to taboos related to bodily fluids, smells, and sights and the sometimes conflictual and ambiguous feelings such experiences might give rise to need to be very skillfully managed. The emotion work is aimed to protect the recipient from feelings of humiliation and loss of human dignity.

Incontinence is burdensome for the dependants because of the feelings of shame, humiliation, and taboos that are associated with loss of bodily control. A male doctor, when for the first time, he experienced a need for help with his basic functions, said:

To lay in bed, and against all physical rules, and I may say psychological rules as well, and do what you normally do at the toilet was a humiliating experience of the helplessness patients feel when help with basic functions is needed. Why did I never question this part of caring when I worked as a doctor? For us, defecation was only an abstract category in the patient’s medical record (Dahle, 1999).

When Brenda talked about how emotionally difficult it was for her to deal with the anger her father expressed as a response to the humiliation he felt, she said she understood her father’s feelings of helplessness and powerlessness. It was terrible for her to experience her father in such a situation. He had always been a sporty man, a “strong and healthy mountain climber,” she said. In a Norwegian context, being a married man, father, provider, and a mountain climber is an expression of a successful masculinity. She indirectly reveals that her father valued the well-being of a healthy physical body and the ideas of masculinity linked to it.

### **Masculine Identity and the Loss of Bodily Control**

Research on how men think of the bodily dimensions of masculinity shows that many men, when getting married and becoming fathers, experience their “settling down” as “letting their bodies go” (Watson 2000). Thus their period of masculinity-affirming behavior – real or imagined – comes to an end. Men often admire other men who continue to keep their bodies in shape and think they are dealing with their masculinity in a successful way. Because sport is a core issue in masculine cultures and is directly linked with the body and control over it (and over other men’s bodies), physical control over the body is central in masculine identities. Even if physical control over one’s basic body functions is an important part of feminine gender identities, too, the reasons for the importance of control are somewhat different (Peake, Manderson, and Potts 1999).

Given these cultural norms in masculine cultures, Brenda understands her father’s loss of body control from his point of view – as a “fall” from being on the top in a masculine culture to being “down under,” – an identity travel from “paradise to hell,” so to speak. The feelings of having lost one’s human identity can sometimes be so present in caring for incontinent people that photos of the dependent “as he or she used to be” are pinned to the wall over their beds (Cline 1996).

In her emotion work for her father, Brenda has to ignore her own feelings to protect him from being even more hurt than he already is and assure him that she still thinks of him as the person he used to be. Knowing how much her father appreciated being a tough sportsman who is used to the mountains, she sometimes drives him to the nearest mountain scenery and helps him take a short walk. She wanted to help her father deal with his feelings of loss, and in so doing, she had to pretend that his anger and embarrassment didn’t hurt her and try to help her father accept his dependency. In addition, she has to cover her own feelings of grief and sorrow because she knows she is going to lose him.

Even if Brenda understood her father’s reactions, it was emotionally hard for her to be confronted by his anger and despair on a daily basis. She felt she had to violate his self-respect to help him. As a result, the relation between Brenda and her father had changed from being close and warm to being difficult and more detached because she felt she needed distance from him to protect herself emotionally. Brenda’s emotional withdrawal is also a strategy to protect herself from her own feelings of loss.

Brenda's experiences confirm the findings of a British study of intimate care (Parker 1993). When providing intimate care for older family members no longer has a periodic character, but becomes the normal situation, carers tend to develop special techniques to distance themselves from those they care for. If carers are left alone without any kind of assistance, as most caregiving women actually are, loving relations can easily turn into colder and emotionally detached ones. An acceptable solution seems to be securing a full- or part-time bed in a nursing home or letting the most intimate care be taken over by in-home health services.

### **Intimacy, Sexuality, and Nakedness**

When dependants need help with basic bodily functions, they have to undress and expose their intimate body parts. In most Western cultures, nakedness is associated with sexual intimacy. The link between nakedness and closeness is both literal, in that nakedness permits physical touch and closeness, and metaphorical, in that to be naked is to divest oneself of protection and disguise (Twigg 1997). But being naked when others are dressed is also an expression of powerlessness and helplessness. How carers and dependants deal with such feelings may vary according to the contexts in which they are embedded. Sometimes those being cared for take on the responsibility to loosen up tensions that may occur in cross-sex relations. Diamond (1992:86) writes in his work on narratives from nursing home care:

It is not as though it was planned that a man should give women showers. What was shocking during the first weeks, however, was that it was not planned that a man should not give them. It was as though, given the age differences, the available labour, and the dictates of the shower schedule, gender did not matter. It did matter, as several residents observed. Sometimes they would make sexual remarks, tell a joke, even venture an overture, if not a serious one. 'How ya doin' in there?' I asked Mrs. Ryan as she showered. 'There's only one thing I want from you, baby', this eighty-eight-year-old fired back, with a twist of voice that left no doubt about the innuendo.

What Mrs. Ryan could do (i.e., sexualize the situation and make a joke of it) is a strategy Brenda's father, given the existence of incest taboos and social norms that regulate father-daughter relations, hardly could choose. That may be the reason he chose anger as an emotional strategy to

protect himself and his daughter from feelings of embarrassment and shame when diapers had to be changed. His anger was probably related to a fear of evoking feelings of disgust in his daughter, and her emotional response was to ease the emotional pain when she cleaned him. But to calm down anger and embarrassment implies self-control and conscious work on your own feelings of powerlessness and grief.

Brenda's father's fear of evoking feelings of disgust in his caregivers, especially because he is taken care of within the frame of a loving relationship, might be expressed in feelings of anger. But studies show that when hands-on care is given with genuine concern, respect, and affection for the receiver, the caregiver's own sense of disgust need not be salient (Wrubel and Folkman, 1997). The absence of disgust on the part of the caregiver helps to reduce the dependant's feelings of embarrassment and shame, but the emotion work needed to reduce tensions and stress may require a mutual understanding of what both parties need to deal effectively with their feelings.

Feelings of disgust are especially complicated to deal with when concretely related to the most taboo body products: feces, urine, phlegm, and vomit (Dahle and Isaksen forthcoming). Disgust reactions related to sexual dimensions of intimate hands-on care tend to be regulated more by moral norms and mental pictures of what is and is not "accepted intimacy." In regulations of sexual intimacy, feelings of disgust seem to be recruited to defend the self against psychic incorporation or any increase in intimacy with a repellant object (Tomkins 1963).

The sexual dimensions of intimate care might also be related to age. A recent study among elderly hospitalized patients in need of intimate care reported that patients mainly did not feel the sexual dimensions as an embarrassing part of their helplessness. But they thought it could have been an issue if they had needed intimate care when they were younger (Boge 1999). One male patient said, however, that he did not like the idea of having his sexual organs washed by a male nurse (although he had not experienced it). Another patient (a woman) said that she had disliked the idea of being helped by a male nurse, but when a young male nurse had come to her bed to help her, she hadn't felt embarrassed or ashamed. Cultural images of cross-sex intimacy in care relations may sometimes be more complex to deal with on the mental level than in the lived life.

In Brenda's case, the cross-sex intergenerational nature of her relationship with her father may, consciously or not, be a positive support for her family in their demand for public assistance.

More interesting is the undercommunication of cultural meanings and social experiences directly related to her father's medical diagnosis, incontinence. Throughout the interview, Brenda talked about the incontinence as "his stomach problems", and stressed how these problems exacerbated their situation.

Studies done on bodily dimensions of caring among gay and heterosexual partners and spouses, care given by sons and daughters to dependant mothers and fathers in same-sex and cross-sex relations, and care among friends and neighbors all indicate that intimate hands-on care that includes touching, seeing, and smelling disgust-related body products is extremely difficult to deal with (Applegate and Kaye 1993; Blannin 1987; Isaksen 1996; Wrubel and Folkman 1997). The next logical questions are, however, rarely raised: What kind of social and cultural phenomenon is this? How can it be explained? How is it related to the general structures in society?

A Foucaultian approach to incontinence would be to understand the phenomenon as an abnormality of vital importance to our comprehension of normality. By understanding the disgust-related dimensions of hands-on care, we can apprehend the basic bodily principles in our culture's construction of human dignity and what it means to "be a human being". This approach takes us directly into the philosophical and cultural questions of the embodiment of human identity. Conceiving human identity as a question of how our individual minds and souls are culturally and socially constructed is *one* approach to the question of human identity. But if we want to develop a broader understanding of how human identities are bodily present in social practices and in "lived life experiences," we have to include the relational aspects of human bodies.

The intimate and bodily care during which our vulnerability as bodies is present and implicitly understood is mainly experienced in close relationships. The emotion work done in families has in general been taken for granted and is still a silenced and invisible work (DeVault 2000; Hochschild 1983, 1998). But the *combination* of emotion work and intimate hands-on care that is so important for the maintenance of human dignity, identity, and respect of dependant elderly people has been even more socially and culturally silenced.

### **Silent Silences and Noisy Silences: The Ambiguous Body**

Informal care work for frail elderly is in general invisible because it is private and unpaid, not defined as work, but as an “activity” that comes “natural” because it is done by women. But the lack of cultural visibility is also a consequence of our culture’s perceptions of old people and their bodies. Also woven into our complicated social mechanisms is modern people’s fear of bodily decay and loss of control over basic functions

Brenda was in a difficult situation. Her experience of her father’s incontinence is hard to talk about because of the mental pictures and ambiguous feelings it stirs up. Instead of talking about her experiences and feelings for her father at meetings with the local welfare authorities, she stressed her role as a full-time working mother as a strategy to strengthen her application for institutional public care. Adjusting herself to this situation, Brenda had to participate in the social mechanisms that maintain the invisibility of her social experiences of intimate care work. When she talked about how she helped her father take showers, she referred to it as “washing”. The drying of her father's body was not mentioned, even though drying is reported to have a more intimate character than showering (Twigg 1999). When her father suffered from diarrhea, the changing of his diapers became "hard turns" because of his "stomach problem." The smells, texture, and sights that are so difficult to confront were consciously or unconsciously left out by Brenda.

Caregivers who provide assistance by coping with body products such as vomit, feces, and urine and who provide baths and other personal care are mostly female. But when this kind of care is given by men, its invisibility is also striking. A recent study of caregiving in gay partnerships in which one had AIDS concludes that hands-on, intimate care that involves seeing, smelling, and touching disgust-related body products was so “ordinary” that the caregivers rarely focused on it and mentioned it only when the interviewer asked them to describe exactly what they did in a given situation. In other words, this work is so invisible that even those who do it can't see it.

If I had met Brenda ten years ago, she would have been able to refer to the changed quality in her relationship with her father in meetings with the welfare authorities. But because the gap between supply and demand for care services has widened in the last ten years, human and relational reasons are no longer given the same weight as, for instance, the status of the applicant’s health. Brenda’s father could eat without help, could wash his face and hands, and was mentally

present most of the time. He did not have bedsores, and he was still able to participate in meaningful social conversations.

Because Brenda's father's health status was better than that of the average nursing home patient, the welfare authorities wouldn't put him on the high-priority list. This focus on *individual* health status covers the *relational* nature of human dependency and all the work that is done in the caretaking of frail family members. Brenda's worries about her mother's failing health, the tensions between her mother and father, and the problems Brenda experienced in her relations with her father that had been exacerbated by the incontinence were not an accepted issue in her negotiations with the local bureaucracy.

The local welfare authorities' attitude and focus on the moral correctness of family care may make it difficult for caregiving women to express their complex feelings of embarrassment and shame that result from dealing with unpleasant smells and touching of taboo bodily products. Cultural rules for appropriate behaviour do not allow talking aloud about such experiences. Besides, one who expresses feelings of distaste and shame connected to the caretaking of one's own parents risks exposing the close family members' helplessness in an unethical way.

*Care* is a word with a warm and loving quality, and it is difficult to detach it from this positive normative affect. Complex and conflictual feelings and emotions in family care therefore have a tendency to be socially silenced. The cultural invisibility of the kind of care Brenda is giving her father is also expressed by the lack of an adequate language to articulate her social experiences. There is little or no public discourse of the body and its functioning. As Twigg (1999) points out, the body occupies a territory in which language itself is problematic, awkwardly polarized between the medical-clinical and the vulgar-demonic. It's hard to find words that are true to the experience. The absence of ordinary language reflects the privatization of these aspects of life. It is, however, a paradox that when people are asked to describe an old person's body, the social silence is transformed into a cultural "noisy" silence.

### **Modern Images of Aged Bodies**

In popular literature, the aged body is often described as unattractive because it is associated with images of bodily decline, organic decomposition, and death (Cavallius 1998).

Ethnographic studies carried out in Sweden report that people tend to perceive older human bodies as open and unlimited. Symbolically, these bodies were linked to ideas of death, danger, and disease. Many descriptions of aged bodies focused on open mouths, throats, phallises, vaginas, and buttocks, and the main impression was the picture of the aged body as grotesque (Cavallius 1998).

These images of old people's bodies are one expression of a contemporary youth-centered culture. The focus on young, sexually appealing, and beautiful bodies contributes to an increased level of ageism in Western cultures. One complicated aspect of ageism is the tendency to dwell on bodily failure, deploying crude stereotypes and humor to objectify and depersonalize older people (Twigg 1999). Ageist attitudes emphasize the body as opposed to the person and tend to reduce the status as an individual and social being with a personal history rooted in lived experiences.

However, images often have a life of their own. In Brenda's eyes, her father was still the sporty mountain climber. In a culture that tends to reduce an older person's personality and lacks a proper language to articulate social experiences linked to unwanted (and uninvited) closeness to natural organic functions of the body, the emotional and social complexities in Brenda's life might remain silent and invisible. This is not only because she is dealing with bodily products. It is also because what she removes from her father's body (urine and feces) is among the group of products that modern people deem the most dirty of the dirtiest, literally and symbolically (Dahle and Isaksen forthcoming). These are the products everyone avoids seeing, touching, and smelling, but they still are an important part of our health and everyday life.

### **The Hierarchy of Dirt**

We usually consider dirt disgusting and disagreeable. In psychoanalysis (Freud 1908), as well as in social anthropology (Douglas 1966), dirt is defined as "a matter in the wrong place".

Dirt is culturally defined and exists only in the eyes of the beholder. People's reaction to dirt is reaction to ambiguity – because dirt involves reflection on the relation of order to disorder, life to death, and being to nonbeing (Douglas 1966). Every human life is embodied, so there is hardly any idea of dirt and pollution that does not have a primary physiological reference. The relational aspect of human embodiment is related to the fact that human beings hardly can pollute themselves. Defining or experiencing individuals as dirty is a dimension of social interaction. That's why other people's

bodies are important for the individual's understanding of what can be experienced as dirty and clean.

As Lawrence Kubie (1937) points out, dirt cannot be merely a question of matter's translocation in space. We need to understand how different kinds of dirt are related to each other and how they are socially ranked and ordered. There exists a difference between honey and slime, between food and feces, or a thousand other similar and perplexing contrasts.

Dirt is related to objects, smells, and textures of which human beings tend to deny the existence. And there are certain kinds of dirt that individuals don't even want to *think* of. These are the qualities of what is looked upon as dirt, defined in terms of conventionally accepted norms of adult behavior.

Through socialization, we have internalized emotional and sensual patterns of reactions based on a ranking of different kinds of bodily products. Each elicits images of smell. Dirt is something that smells bad and has some disgusting elements in it. Anything that smells bad, strange, or unlike what one expects is often viewed with mistrust and aversion. "Smells are taken to mean dirt only when they signal either consciously or unconsciously the threat of contamination from a body's interiors" (Kubie 1937: 393).

Dirt and bad smells are related to ideas of danger and disease. The tendency to use the bacteriological etiology of infectious disease may be a rationalization of the fear of dirt and an imagined contamination. Western human beings have an unconscious hierarchy of dirt that is expressed in the degree of emotional intensity with which we approach or avoid different bodily products. In other words, bodily products can be listed in order from the cleanest to the dirtiest. We may understand the idea of a dirt hierarchy this way: "Clean" body products give rise to positive and emphatic feelings, for instance, tears on a child's cheek or a mother breastfeeding her newborn. Human milk and tears were ranked among the cleanest in the empirical testing of Kubie's idea that was done in the United States in 1968 and 1972 and in Norway in 1997 (Dahle and Isaksen forthcoming; Ross, Hirt, and Kurtz 1968). And the farther down the ranking list, the more negative the feelings and the stronger the intensity of contempt and disgust, given the intimate relationship between images of unesthetic sights, bad smells, disease, and danger.

Urine and feces were not considered among the dirtiest and most disgusting products in 1968 (vomit and blackheads were the dirtiest ones). But in a 1997 study of 411 Norwegian health care students, feces were rated the dirtiest product of the body (Dahle and Isaksen forthcoming). This product is usually socially visible only in care for very small children and dependant elderly people. According to Kubie, the ranking of bodily dirt products also reflects the social hierarchies in society. The male body is considered symbolically cleaner than the female body, young people's bodies are cleaner than older people's bodies, and rich people's bodies are cleaner than poor people's bodies. This is expressed through our images of dirty and clean parts of the body:

1. Softness, wetness, sliminess, and hairiness, are always looked upon as dirtier than hardness, dryness, and the absence of hair.
2. Old age represents a piling up of undischarged remnants of a lifetime of eating and drinking and is dirtier than youth. For example, chemicals in food are stored in our bodies and might cause cancer in old age. So growing old means growing dirty. Infants are cleaner than the elderly.
3. A prominent and outjutting part of the body carries a presumption of cleanliness. A cavity, cleft, hole, or pit in the body carries the presumption of dirt. The smooth parts of the body are cleaner than the wrinkled parts. Thinness is cleaner than fatness.

Fantasies of bodily dirt might have a greater impact on people's social life than the concrete experiences of bodily dirt and waste products. Kubie suggest that studying how people's images affect social life is as important as observing their actual management of body products. Incontinent people's view of what other people might think of them as social and moral human beings if they sense some weak (or stale) smells of urine or learn that they no longer are able to control their bladders affects their social life and is experienced as a fear of losing their moral and social dignity.

This fear has its roots in the social and cultural meanings of contempt and disgust. Dirt is closely connected with intense feeling of disgust and ideas of disease and danger. Smells that evoke images of danger easily give rise to feelings of mistrust and aversion, and the social consequences might be that one is avoided, consciously or not, by persons one wants to share one's social life with. Incontinence is about being wet when one is expected to be dry. Because it is, at least in Australia (Peake, Manderson, and Potts 1999), associated with overweight, it is also about being fat. Incontinence is linked to images of the wrinkled and hairy parts of the body – to cavities and clefts – and to old age. Females suffering from urinary incontinence tend to explain their sufferings as

symbols of lack of self-control. They understand their bladder troubles as their own lack of control over diet, weight, and exercise after childbirth. It is their own indulgence and inability to effect domination of mind over body.

Kubie (1937) understands the entire process of growing old as one of growing dirty. But on the social level, babies also can be experienced as dirty, depending on what kinds of bodily fluids are culturally accepted as "normal" for babies. Parents of babies with diseases like projectile vomiting might think that friends avoid them because of the risk of being exposed to a disgust-related body fluid like vomit (Peake, Manderson, and Potts 1999). Because middle-aged women may have frailties parents to take care of at one end and grandchildren at the other, they might, in this perspective, be clean ones (at least in the moral sense, because roles like daughter and grandmother are usually defined as clean) caring for the clean/dirty children and dirty/dirty elderly. But care work for both babies and the old is contextualized and embedded in social and cultural structures. And the dirt dimensions of it has material, cultural, social, and emotional consequences.

### **Incontinence as a Social and Cultural Phenomenon: Three Dimensions**

Care work can be understood as dirty work for a number of reasons, and dirt can be discussed on different levels. Mary Douglas (1966:159) defines dirt as "essentially disorder." There is no such thing as absolute dirt; it exists in the eyes of the beholder. Our reaction to dirt is our reaction to ambiguity because dirt involves reflection on the relation of life to death, order to disorder, and being to nonbeing. Each culture must have its own notions of dirt and defilement, which are contrasted to its notions of the positive structure that must not be negated. I use these three dimensions in my discussion of incontinence as a social and cultural phenomenon:

1. Life/death dimensions
2. Being/nonbeing dimensions
3. Order/disorder dimensions

### **Life/Death Dimensions: Danger, Death, and Disease**

Intimate care is something that younger people usually need only periodically but older people may depend on for years (Boge 1999). In some nursing homes, the majority of residents

may be dependant upon help for personal hygiene. The mix of odors from the particular kinds of soap used in nursing homes, the smells from bodily products, and the food served may not always be pleasant Diamond (1992:196) writes:

After receiving meds, most residents drifted back into the day room to join the others in the place where the day had begun at 7:30 a.m. As a consequence of forty or more people sitting in the room all day, the air became dense and foul-smelling from the breathing, coughing, the food that had passed, the bodily smells that had collected, and the cleaning chemicals used to combat them. Visitors frequently got pale and weak when first confronted by the odors.

The negative social reputation nursing homes seem to have as caregiving institutions may be an expression of the cultural interaction between ideas of dirt, bad smells, danger, disease, and death. This interaction gives care work for the frail elderly a touch of emotional and cultural disgust often ignored in studies of care work. One reason for this silence is related to our culture's denial of death in general. The denial of death exists on different levels. On the individual and psychological levels, it might be understood as an expression of increased life expectations regarding the quality of life and expected predictability of the way of dying, depending on the individual's personal biography.

Elias (1985) argues that the ways Western societies organize their care for old and dying people might be understood as reflections of the modern processes of individualization. The problems (post)industrial societies have in their attempts to organize good care for dying persons reflect the anxieties associated with bodily decay and death. When interacting with persons one knows or thinks have reached the final stage of their lives, people are reminded of their own time-limited existence. Such moments of social interaction where death is present invite reflections of one's own mortality and point to the fact that all individuals are organic beings and share this dimension of life. Reflections like these may undermine the core idea of individual differences in individualistic cultures. One type of emotional response to such insights may be to protect oneself by putting up affective walls between oneself and the dying person(s). In doing this, one takes part in the social mechanisms that have the denial of death as a cultural end product. The intensity of disgust reactions stirred up when one is confronted with bodily decay and age-related diseases illustrates the strength of the individual's psychic needs to avoid reminders of our animal origins. Being a *social* person in Western cultures is linked to the idea of *not* being an animal.

Modern human beings live longer than ever in Western history, and death has become marginalized, organized, and taken care of in socially and culturally invisible spheres of society. The fact that caring for dying people traditionally has been and still is a part of the taboo dimensions of women's work is another important part of an explanation of why intimate care work for frail elderly is socially invisible and considered culturally "dirty." Women live longer than men and develop age-related diseases more often, which means that most frail dependant and hospitalized patients are female. The generally low social status of elder care is a result of the fact that it is given to dependant and dying women by working-class women, at least when dependants are taken care of in nursing homes or by a public in-home welfare service.

Death has always been a significant part of the historical experience of women because much of the actual care of the sick and dying falls on their shoulders. Most people today end their lives in medical institutions, where most employees are females, so this is still an important part of modern women's lives (Cline 1996). Birth and death still belong to the "mysteries of life" and have an ambiguous character. In medical cultures in hospitals and other health care institutions, diseases and suffering that have an ambiguous status have low prestige in the medical hierarchy (Album 1991). The social and cultural ranking of care work is linked to the bodily organs in question. The heart, the brain, and the blood represent life and death, but they represent more than that; they symbolize the human self and identity in Western cultures.

Chronic suffering related to ageing processes is ranked among the lowest in the medical stratification of prestige. Incontinence related to old age is among the lowest of the lowest. However, caring for patients with this affliction includes really hard physical and emotional work. Bathing, feeding, changing diapers, cleaning bedsores, lifting, and transferring people in and out of bed are heavy, sometimes unpleasant tasks. This is low-paid women's work. (Jobs at MacDonaldds, Burger King, and similar businesses might be more attractive than caretaking work. The pay is about the same, the work is more predictable because clients don't die, or get sent to the hospital during the night, and the work is not so closely associated with human waste products and unpleasant duties.)

Providing intimate, hands-on care is culturally defined as feminine. Intimate care seem to be difficult to combine with ideas of masculinity. The masculine perception of care work (for elderly in

particular) is connected to an attitude that care work is all about “bumwashing and bedpans” and is therefore of little worth and dignity (Eitunggjerde 1988). Studies of career patterns among male nurses show that, when they are faced with carrying out intimate care for other males, the associations to homosexual intimacy were for some very embarrassing. Other men reported that “all the bumwashing” made them feel like low-caste individuals and threatened their masculine identity (Vigdal 1995).

A survey of young unemployed men in European countries concluded that a majority of young men preferred to stay jobless if the alternative was working in the care segment in the labor market (*The Economist*, Sept. 28th - Oct. 4th, 1996). Care work, and care work for frail elderly in particular, seems to be both experienced and imagined as dirty work. The kind of dirt in care work is not only concrete; it is also, on the cultural level, an expression of the vulnerability, relationality, and ambiguity of the human body. The reaction to this kind of bodily dirt is the reaction to the ambiguity associated with the life/death-dimension.

### **Being/Nonbeing Dimensions: The Individual and the Relational Body**

In care work for incontinent elderly people, one experiences that loss of control over basic functions feels like loss of one’s identity and dignity as a *human being*. This uncertainty of what “I am” when physical functions can’t be managed by will is, in this context, an expression of the relation between being and nonbeing. Urinary and fecal control are part of the process of enculturation, of being human. An experienced or imagined inability to master these basic functions is a symbolic and literal negation of social personhood.

Loss of bodily control means that one wets oneself. Urine smells, and if one smells of urine in a culture where one is expected to smell nice, such breaches may be understood as symptoms of asociality and lack of good morals (Peake, Manderson, and Potts 1999). When basic bodily fluids that are so overloaded with ideas of dirt, disgust and contempt become (too) present, it becomes difficult to distinguish between sociability and animality. The ambiguity of the human body and human life exists as a secret part of modern cultures, and it is *meant* to be kept as a secret.

Defining bodily fluids as dirty is one aspect of this ambiguity. Another is the incontinent person’s experience of the relation between the social visibility and the presence of this kind of dirt

and how it affects the person's feeling of having his or her human identity put at risk. The fear of being seen and defined as dirty tells us about the positive structure that cannot be negated – the basic idea that humans *different* from other living creatures, something *more* than living organisms. The embodied dimension of this “more” is the ability to control basic body functions like urination and defecation. When this limit between nature and culture no longer is clear and unquestionable, the ambiguity of the body becomes visible and can easily evoke a feeling of disgust.

In some contexts, disgust may be a feeling somewhat different from fear in that fear is primarily a response to actual or threatened harm to the *body*, whereas disgust might be a response to actual or threatened harm to the *soul* (Rozin, Haidt, and Mc Cauley 1993). But in other contexts, fear *and* disgust are co-experienced. As Miller (1997) points out, fear without disgust sends us fleeing to safety and to a sense of relief, but disgust gives us the burden of cleansing and purifying, a much more intensive and problematic labor than mere flight, one that takes more time and one at which we fear we may not have succeeded. Pure fear decays much more rapidly than the slowly decaying, always lingering disgust.

The cleansing and purifying of the incontinent body, practically, emotionally, and symbolically, is about restoring and re-creating the social individuality and identity of the incontinent person. But the feeling of disgust has a time aspect. It is, as mentioned earlier, when people have to deal with taboo bodily fluids on a daily basis, *over time*, that feelings of disgust become difficult to avoid.

Given the centrality of the soul in our Western understanding of what a human being is, feelings of disgust might be evoked when we are confronted with people who appear to be more bodies than individual persons. As bodies, all humans are alike; it is our souls and minds, our interactive making of ourselves as social and cultural persons, that make us different and separate from one another. As such, the embodied dimensions of Western individualism are related to having control over one's body – and over one's emptying functions in particular.

On the biological level, urination and defecation are among the body functions we all share with all kinds of living organisms, but on the cultural level, they are rendered private and kept hidden from the eyes of others. Losing control is associated with losing one's dignity and human identity because it makes visible what, according to cultural standards, should be kept private in order to

maintain the construction of humans as different and separate from each other. All aspects of our life that remind us of our organic nature seem to be associated with feelings of disgust (Rozen and Fallon 1987).

On the theoretical and philosophical levels, it is possible to understand the definition of individuality in Western societies as based on a denial of the fact that, as bodies, we are all alike and that we, as bodies, have common needs that must be met. There are many cultural and social differences in the contexts where human basic needs are met, and some contexts are defined as more feminine, more prestigious, and as having a higher emotional, economic, and ethical status than others.

### **Order/Disorder Dimensions: Ambiguity and Anomie**

The order/disorder dimension of incontinence as a social and cultural phenomenon is linked to questions of social integration and feelings of connectedness in society. As mentioned earlier, when intimate care for family members becomes the “normal” situation, carers tend to develop special techniques to distance themselves from the dependants. The intimacy in the relation and the quality of care changes, and the care becomes more difficult to provide.

Caregiving daughters often suffer from social isolation as friends and other family members avoid visiting because of the ambiguous feelings evoked by images of old, incontinent people (Hicks 1988). Earlier studies of family care indicate that senility and incontinence seem to cause breakdowns in family relations over time when carers are left alone with the burdens of such care. The emotional costs of being experienced as a violator of the dependant’s personal modesty and human dignity several times a day affect the caregiver's mental and physical health.

The dependant’s feelings of anger, humiliation, and helplessness and the caregiver's feelings of grief and loss have disruptive consequences for family bonds, probably because of the dimensions of incontinence that I have discussed previously. The kind of disgust related to the presence of the ambiguity of the body is rooted in deeply felt taboos and normative regulations of family bonds. The ambiguity of the body has in this context an anomic status because of the loss of a feeling of belonging that tends to develop among carers and among the dependants when loss of control over basic body functions has to be dealt with in the family for longer periods of time.

### **Toward a Sociology of (Gendered) Disgust**

Brenda's struggle to balance family and working life is embedded in a Norwegian context in which her care for her family is organized. The possibility of her modeling the kind of care she thinks meet the various needs of members of her family is framed by the care deficit in society in general, the reorganization of a welfare state confronted by the globalization of the economy, and Brenda's position in the labor market. As a daughter, mother, and woman in a sex-segregated society, Brenda is automatically defined as a primary caregiver by the welfare authorities. She is, for reasons explained earlier, in a position where the most burdensome and stressful dimensions of her care for her father are undercommunicated and kept socially silent in her negotiations with the local welfare bureaucracy. Brenda is trying to deal with the maintenance of her own identity as a working professional woman and tries to find a balance between "care as work" (paid and unpaid) and "work as care" (her own self-realization). In her negotiations with the bureaucrats, she tries to protect both her own and her father's identity. She is fighting to maintain his status as a protecting and loving father and husband and his dignity and identity as a respected human being. Through this work, Brenda insists that she, as well as her father, has a right to define the premises on which they want to be present in their own lives and social practices.

When providing intimate, hands-on care for her father, Brenda is aware of his vulnerability – how easily his human identity and self-respect can be violated. Dealing with his fear of being seen as disgusting because of his incontinence is an important and identity-confirming part of her care and emotion work for him. Brenda works with time against her. Being responsible for daily caring for incontinent people over time tends to change former emotionally close relations into more detached and difficult ones because of the disgust-related aspects of such care. Her relation to her father is changing, and the feeling of connectedness and level of social integration in her family are at risk. This is the genuine social aspect of the dirt she is dealing with – given an understanding of dirt as "essentially disorder" (Douglas 1966).

The theoretical aspect of Mary Douglas's work points to an understanding of the individual as a relational and embodied human being. All human individuals are embodied and, as bodies, we are dependant and vulnerable. An analysis of incontinence as a social and cultural phenomenon

clarifies how the idea of individuality in Western cultures is based upon bodily control and a denial of our body's vulnerability, organic nature, and time-limited existence.

However, how individualism affects different cultures of care and its social consequences in different societies are still underresearched. The Norwegian labor market is structured in relation to the existence of an extended welfare state whose services are culturally accepted and defined as qualitatively good. In the United States, the lack of public organized care services for the frail elderly complicates the relationship between work and family in a different way than in Norway. Although American ideas of individualism might be a reason for the lack of willingness to organize care for dependant members of society on a collective public level, the Nordic citizenships are based on an understanding of individual self-realization as a collective responsibility. But self-realization has different meanings for men and women, and the right to realize one's personal potentialities in the labor market is unequally distributed on the social ladder. Having legitimate access to public services that are understood as a supplement to and not a substitute for family care eases the balance between family and work and contributes to the kind of stability and feelings of connectedness and integration that is necessary in societies where rapid changes have come to be seen as "normal" economic conditions. How the bodily dimensions of care add new burdens to modern family life in different social classes and contribute to expand or narrow the gap between men and women and between different cultures of care has to be discussed within the frame of how ideas of individualism structure the economic and social condition and vice versa in which people live their everyday lives.

Care work has other people's bodies as its working field. What kind of work needs to be done, the amount of it, and in which context it is organized constitute the material dimensions of care work. The social status, pay, and prestige linked to it are outputs of both structural conditions and the social status of the receivers. Caring for an incontinent ex-president is more prestigious than caring for an incontinent working-class mother – even if the pay is the same.

Care work is, in most societies and cultures, associated with femininity and is female-dominated work. The intimate knowledge of the human body in its different stages of life, from the embryo to the dying body, constitutes an awareness of its vulnerable and relational nature. Life as well as death, small children as well as the oldest ones, are taken care of mainly by women, and the ambiguous dimensions and the organic nature of the body are biologically, socially, and culturally

present in the caretaking among the newcomers and the dying, so such work has a certain kind of disgust related to it. Because care work is socially stratified, whether performed in families or in the labor market, the disgust aspect varies with the material and cultural contexts in which the care is organized.

Care work is mainly women's work, and the feelings of disgust it tends to evoke are linked to our society's understanding of femininity and masculinity – as defined in different social groups and classes. That's why a sociology of embodied disgust is a gender issue.

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