

Dying of awareness: the theory of awareness contexts revisited

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Abstract In this paper, I employ a grounded theory approach to extend an existing theory. My starting point is the theory of awareness contexts, first formulated in 1965 by Strauss and Glaser. Using introspective ethnography, I illustrate that the way patients and relatives emotionally cope with terminal information defines the kind of awareness context. I therefore suggest that the open awareness context should be split into three different contexts. In the suspended open awareness context, the patient or kin ignores or disbelieves the message communicated by the physician. In the uncertain open awareness context, the patient or family member dismisses the bad parts of the message and hopes for the best outcome. In the active open awareness context, the patient or relative accepts the impending death and prepares for it. This revision reclaims the emotional power of terminal illness from the viewpoint of patients and relatives and adapts the theory to changed structural conditions.

Introduction

Even when patients are dying, they remain unpredictable and whimsical. I had that old lady whom I told everything and at first she understood but then the next day she cried and claimed she was getting better and didn't need chemo anymore. I talked her out of that and (. . .) she was back on chemo but then I heard that she would go on a cruise with her friend. Who understands?

(Physician in interview, translated from Dutch).

She didn't cry, but pushed it to the back of her mind and said 'what's for tea?'

(A husband describing the reaction of his wife to the announcement of her terminal condition.) (Seale 1991b: 949)

In the quarter of a century since the discovery of the theory of awareness contexts (Glaser and Strauss 1965), it remains one of the bedrock examples of the grounded theory approach (see Glaser and Strauss 1967; Strauss 1986). Employing theoretical sampling and elaborate coding processes, Glaser and Strauss constructed four dominant awareness contexts which capture the interaction around terminal illness in the structural setting of a hospital.

Attracted by the dense ethnographic material of *Awareness of Dying* (Glaser and Strauss 1965) and *Passing On* (Sudnow 1967), I intended to research how nurses cope in their daily interaction with terminal patients in a Belgian general hospital. In order to do this, I participated for three months as a sociologist on a gynaecological-cancer ward and a pulmonary ward in a general hospital, taking the position of student nurse. At the beginning of the fieldwork period, I was drawn into the role of family member of a hospital patient when my mother became terminally ill. This intense, personal experience with terminal disease transformed my study and formed an incentive to explore Glaser and Strauss' theory of awareness contexts.

The grounded theorist starting with an existing theory needs to do more than merely surmount the limitations of the starting theory. The researcher needs to follow through the process of developing dense, emergent concepts and an integrated theory which fits the empirical material. According to Strauss, the one provision for the starting theory is that it too needs to be carefully grounded in research (Strauss 1986: 306). As Strauss' own example of discovering a new theory by using Davis' *Deviance Disavowal* (1961) theory illustrates, the researcher focuses on what is rendered invisible (Star 1991) in the theory.

The substantive and methodological purpose of this paper is to insert my own experience as a relative of a terminally ill patient in the process of theory construction and extend the theory of awareness contexts using grounded theory methodology.

Awareness of dying

The limitations of the context of awareness theory can be pointed out by using Strauss' strategy of looking for what the theory is about and what is omitted. Glaser and Strauss' substantive theory of awareness contexts is about the management of information needed by a terminal patient or family member and controlled by the hospital staff. The patients evolve from closed awareness, where they do not know their medical condition, to open awareness, where the life-threatening condition is known to the patient and medical staff. Inbetween are the contexts of suspicion awareness and mutual pretence. The transition from one context to the other depends on the replacement of a lack of information with medical knowledge of the

impending death. Each discussion provides a description of the social structural conditions that enter into the context and the consequent interaction, the change of interaction when the patient shifts from one type of awareness context to another, and the consequences of this interaction for the interactants and the structural setting, that is the hospital and the ward.

What is missing in the theory? The emphasis on management of information presents the analysis as an interactional drama played out in the confines of structural conditions. But this extension downplays the emotional dimension of being a terminal patient and dying in a hospital. Glaser and Strauss suggest that most of the patients are looking for information and want to be aware of their dying condition. However, it is not clear how the emotional response of the patient to the information relates to the existence of the different awareness contexts. Glaser and Strauss discuss some of the implications of full disclosure in a separate chapter, but the links with the theory of awareness contexts are not specified.

Also, the theory is concerned with the transfer of information from medical and nursing staff to patients. By doing this, Glaser and Strauss analyse the situation from the viewpoint of the medical representatives and the hospital institution. The definition of the situation of the patient or family member is mentioned when it fits in with the values and routines of the medical world. The physician or nurse decides when a patient or family member is ready for disclosure and how much everyone needs to know.

This filling in of what has been left out of the extant theory is a useful first step towards extending its scope. A different strategy for altering a grounded theory is to look at the structural conditions which have been changed since the theory was formulated.

In 1965, Glaser and Strauss wrote that '69 to 90 per cent of the doctors (depending on the study) favor not telling their patients about terminal illness' (p. 119; see also Glaser and Strauss 1968). According to a study by Novack and collaborators (1979), by 1977 the ratio in the U.S.A. had been reversed: more than nine out of ten physicians said that they usually disclosed all information. A comparative study of random samples of adult deaths in 1969 and 1987 in Great Britain showed that significantly more dying people knew of their impending death. The difference was attributed to an increase of informed terminal cancer patients (Cartwright *et al* 1973; Cartwright 1991; Seale 1991b). In the decade between, the threat of malpractice suits (Elkeles 1982), powerful anti-authoritarian forces (Illich 1975), continual media exposure resulting in better informed patients (Dunn 1978), and the rise of the hospice movement (Fulton and Owen 1982; Saunders 1978; Parkes 1985) pushed doctors towards informing their patients (Faden and Beauchamp 1986; Rothman 1991). Recent comparative studies in the U.S. and Western Europe (see Cassileth *et al*

1980; Seale 1991b), have confirmed that in general physicians tend to inform their patients of their terminal condition.

Based on Glaser and Strauss' theory, one should expect that now more people care for relatives, or die as patients, in a context of open awareness. Interestingly enough, more information does not necessarily result in open awareness. In different discussions Williams (1989) and McIntosh (1977) report that, although patients are told the medical truth about their condition, they do not always listen or make sense of what they are told. This poses a profound challenge to the theory of awareness contexts; there seems to be something else necessary, apart from an increase in information, to create open awareness.

I have noted three weak points in the theory of awareness contexts: the emphasis on rational negotiation at the expense of an emotional response to the terminal condition; the dominant medical perspective; and the conceptual problems of open awareness contexts in the age of informed consent. The next step is to return to the empirical material and modify the theory using a grounded theory approach. The main empirical material of this paper is my own experience as a relative of a person who is diagnosed as terminally ill. None of the existing sociological studies provide thick accounts from the point of view of a family member. For ethical and practical reasons, family members have not been interviewed during the critical process of revealing a terminal diagnosis and prognosis. In some studies, primary carers have been interviewed a considerable time after the bad news was communicated (Higginson *et al* 1990; Hinton 1980) or after the death of their patient, family member, or friend (see Cartwright 1991; Seale 1990; Townsend *et al* 1990). Other information is gathered by observation on hospital wards (Field 1989; Glaser and Strauss 1965; McIntosh 1977). However, unlike patients, family members are not limited to the physician-patient dyad for information. Most family members are able to consult a wide number of sources which are almost impossible to observe. Also, some of the turmoil of emotion work regarding death and terminal illness is not open for observation and requires active introspection to reveal. Introspective ethnography (Ellis 1991) is therefore a unique way to open private, personal experiences for sociological inquiry (see Ellis 1993; Rosaldo 1987). Instead of Ricoeur's 'comprehension of the self by the detour of the other' (quoted in Rabinow 1977: 5), I argue for the comprehension of the other by the detour of the self. Based on my narrative, I will suggest modifications in the theory of awareness contexts.

My-story

When I was organising my research plans, I had no deep personal experience of the end of life. This distant position changes dramatically during

the Friday of the second week of my participation/observation in the research hospital when my mother has 'some kind of an accident'. That is what my father tells me when he informs me that he brought my mother to the emergency unit of the university hospital in our city. He urges me to come home. I rush to the hospital thinking about the last time I saw my mother and about the patients on my research ward, hoping that my mother is better off than they are. I have no idea what is wrong with her.

In the university hospital, I find my brothers and father standing around my mother. She lies in a little room curtained off from the hallway. She wears a white cotton hospital gown and her hair is a mess. Her right arm lies limply at her side. My father pinches her right foot and asks her if she feels this. She doesn't answer or react but looks at me instead. Her glassy stare goes straight through me. My father snaps his fingers to get her attention and asks my mother our phone number. His voice sounds angry and desperate. My mother does not remember our number. She tries and tries again, but instead of the numbers, she utters only unintelligible sounds. She gives up. She closes her eyes. The corners of her mouth start trembling. She cries. Tears drip from her glasses on the gown. My father leaves the room. He also cries. It is the first time I have seen my father cry. I take my mother's hand while my brother dries her glasses. We wait until the last moment to leave the emergency department. When we leave, my mother cries again. It hurts to leave my mother there alone. She sobs. We promise to be back the next morning. Driving home, I ask my father if they know anything, 'they' referring to the physicians, the nurses, the entire medical world. He answers that they have scheduled some tests and that we all have to wait for the results, but they thought she has had a severe stroke or something similar. The doctor also mentioned that there is a possibility of more strokes in the future with a very uncertain outcome. I don't know exactly what a stroke means in my mother's case, but I don't ask any further questions. My mother's physical appearance tells me that whatever she has had is a reason to worry. I feel confused and have knots in my stomach.

That is when uncertainty takes over. Nobody knows what to do or what to say. Nobody feels like eating. My youngest brother, Dominiek, turns on the television, tries to read a comic book at the same time, puts it down, and goes outside for a walk. My father calls four times to the hospital to check if there is any improvement. The third time he calls, the nurse tells him that my mother is sleeping. Later, he goes to the bank and withdraws a considerable amount of money with his banking card. I feel lost in a thick fog, a chill. I cannot hold on to thoughts. Maybe a stroke is not as bad as we guess. But 'stroke' sounds very threatening - danger coming from everywhere - ready to destroy us. Maybe it is hereditary. Didn't my mother's father die when she was eighteen? At once, I remember a talk between my mother and one of my aunts. My mother said that she would never like to be ill and dependent. To the astonishment of my

aunt, my mother said that she would prefer to commit suicide. Although we used to share reading preferences, she refused to read Bernlef's novel (1984) about amnesia. I also remember that my mother once ran away from a hospital because she felt claustrophobic in the CT-scan. A thousand memories flash up, fade away and flash up again, an endless movie. Curled in a ball, I fall asleep.

The next day my mother has been transferred to the neurology ward. While she is gone for some tests, I enter the nurses' office. I introduce myself to the nurse who is filling out forms and tell her that I am a student nurse and the son of the patient in room 228. I ask her what my mother's condition is. I know that the nurse is not allowed to give me a diagnosis until explicitly requested to do so by the physician, but I hope that my status of 'student nurse' will create a common frame of reference. It does. She tells me that without any doubt my mother has had a CVA. She adds that they have to wait to see if the situation would grow worse or if my mother's condition would stabilise. She checks my mother's chart and says that it doesn't look very good. I nod as if I understand everything and walk back to the room. I have the impression from our short dialogue that if I really was a student nurse, I should know what a CVA is.

Later that day, the diagnosis of 'CVA' is also made by the physician. He explains to my father that my mother has small blood clots in her veins which go to her brain and block the blood and oxygen circulation. This is called a cerebral vascular accident. My father asks how bad my mother's condition is, what should he expect, could it be cured, will it improve, could she go home? The physician keeps his reply vague; everything depends on the amount of the thickness of the remaining embolisms, but my mother had a rather critical CVA. He will prescribe medication to dilute my mother's blood, but of course he can not go beyond a certain dilution threshold. We will have to wait. I am not really satisfied with the answers from the physician. The feelings of uncertainty remain. Now we know that my mother has something with a Latin name and that her blood isn't what it is supposed to be, but how will this situation evolve? The physician doesn't want to answer any further questions; his beeper goes off and he leaves. My father is angry and mumbles a curse. His shoulders hang down. He looks at me. He says: 'Your mother has been working all her life and was planning early retirement next year'. I know - he already told me this yesterday. It is very sad. We both hate waiting; we hate not knowing what to expect.

On Monday, I go back to my observation hospital, approximately fifty miles away, and decide not to mention my mother's 'accident'. I continue my talks with the nurses as before and help them out as usual, but my mind is not totally with my work. I still try to figure out what a CVA means, and what I should expect. Should I go home and spend time with my mother, or should I work on my dissertation? I don't know what to do,

but for the moment, I feel better being away from home where I can sort out my thoughts. Still many questions remain, and I call home regularly to see if they know something more. But no one does anything but wait and hope. My father tries to convince the physician that my mother might as well be at home. He says that they don't do anything for her and that the room is too dark. She can lie in a bed at home and take medication.

The next Friday I am making the bed of a patient who was discharged from the ward with Linda, a nurse. Linda asks me the tricky question about how this ward differs from the one on which I observed before. I tell her that I have the impression that on this ward the nurses are more involved with the well-being of their patients. She is surprised to hear this and tells me that she has worked on a neurological ward where she felt much closer to her patients. I ask her to describe the neurological patients. She mentions that they had been mainly 'CVA' patients. I become very attentive, but try not to sound too interested. I ask her what CVA means. Linda gives me the same definition as the physician: an interruption of blood flow to the brain which results in the loss of brain functioning. She says that it was a very sombre ward to work on. Many of her patients were old, and their condition improved very slowly or not at all. 'What about the younger patients?' I ask, thinking about my mother. While straightening the sheets, she answers: 'Oh, there weren't too many of them. It is a bad sign if someone has a CVA at a young age. These people usually have bad blood circulation. They have a couple of months or sometimes a couple of years ahead, but there is a high probability that they will die in the near future from a new CVA. If they have a severe CVA, they won't recover. You only get them back to a certain level with intensive therapy'.

I freeze and look at the ground. This confirms my fears. My mother has had high blood pressure problems all her life, and last year she had slight paralysis problems with her left arm. This is not her first cerebral vascular accident and will probably not be her last. Linda's casually spoken words convey more truth to me than all other sources could have. She speaks from accumulated first-hand experience and has no reason to hide or embellish anything because she doesn't know about my mother. The pieces of the puzzle fall together. I interpret Linda's message as an announcement of terminality. My mother has a condition that will be fatal in the near future.

Here I stop my story. The uncertainty wasn't over yet. But the talk with Linda was a turning point. I finally understood what was happening to my mother. I *knew* what to expect and I could prepare myself for what I considered to be the inevitable. I was aware that every single day that my mother lived counted. I was still worried and upset, but at least I knew what I could expect from the future. Tomorrow was still uncertain, but the challenge was to make today as unforgettable and good as possible. I therefore urged my father to take my mother home as soon as he

felt comfortable doing so. In the months to come, my mother made small progress through intensive physio and speech therapy. My father took early retirement. Rivalries between the brothers disappeared, and with the help of many friends, the remaining 14 months of my mother's life were very intense.

Dying of awareness

From a medical point of view, my family and I had been in a context of open awareness from the early onset of the crisis. When my mother was first admitted to the emergency department, the physician explained my mother's diagnosis in lay terms: she had suffered from a severe stroke. He pointed out the signs, and we could observe the effects of the stroke for ourselves. He also mentioned that more strokes could follow with a very 'uncertain' outcome. In the medical context, this announcement implies a terminal condition with a limited prognosis. When my mother was transferred to a ward, the previous diagnosis and prognosis was confirmed both by a nurse and by the neurologist. My mother had suffered a critical CVA. The physician's reluctance to answer our questions and his strategy of emphasising uncertainty left space for hope but did not dismiss the seriousness of the situation. And when I asked Linda about neurology patients in general, she provided (possibly over-generalised) information about patients with conditions comparable to my mother's and again confirmed what was communicated earlier.

However, in the way I experienced the crisis, I was only in an open awareness when Linda told me what I could expect. In the emergency department, the word 'stroke' was meaningless to me. The abbreviation 'CVA' and its definition made clear what had happened to my mother, but I did not grasp the tacit knowledge that this was a life-threatening condition until Linda explained the hopelessness of younger patients with CVAs.

The term 'context of open awareness' lacks the conceptual refinement to capture these different experiences and nuances. Although patients or family members possess medical knowledge, they may not really grasp the situation based on information alone. The disclosure of a life-threatening condition causes an emotional crisis which undermines all taken for granted definitions of self and identity. The patient or relative deals with this information in different ways. I therefore propose to extend the theory of awareness contexts by developing new categories to include the diversity of viewpoints of family members and patients.

The context of open awareness should be split up into three different contexts, which have in common the fact that the medical staff informed the patient or family member about the terminal condition. This is why they are *open* awareness contexts. The difference between the three lies in *how* the patient comprehends this information and reacts emotionally.

It is important to note that these three contexts of awareness are not part of a staged model. They are interpretations of the situation and the patient or family member can, and usually will, shift back and forth between them, based on the ad hoc interpretation of the information.

In the first case, the patient bluntly ignores the information. This is the *context of suspended open awareness*. Although patients and relatives in this context receive on several occasions an explicit diagnosis and sometimes even a prognosis, they disregard this information. From the viewpoint of the patient or family member this information is distorted, overly pessimistic, or simply false. Viewed from the point of view of the medical and psychological world, these people are in a state of total denial (Weisman 1972).

Secondly, when confronted with bad news, the patient or family member disregards the negative aspects and holds on to the chance of a good outcome. This context of awareness is called the *context of uncertain open awareness*. People in this context do not dismiss the possibility of a fatal outcome, but they prefer the uncertainty of not understanding exactly what is going on. They pick and choose in each message; hope is more important than a certainty of death.

Finally, we come to the context which Glaser and Strauss call open awareness, and I rename the *active open awareness context*. When confronted with the information, the patient or family member accepts the full implications of the message and acts accordingly.

For the empirical support of these categories, I will use four studies which were strongly influenced by the grounded theory approach and by the theory of awareness contexts. I will refer to Glaser and Strauss' own discussion of the disclosure of information in a American Veterans' Administration hospital (1965: 119–135), Taylor's study of the disclosure of breast cancer by physicians in a Canadian hospital (1989), McIntosh's research on the management of uncertainty in a cancer ward in Scotland (1977), and finally my own experiences and study of terminal care in a Belgian general hospital (Timmermans, 1991a–b, 1994).

1. Suspended open awareness

In the context of suspended open awareness, the patient or family member blocks out the information that has been provided about the terminal condition. It is as if the disclosure never happened. The relative or patient is in a state of disbelief.

Suspended open awareness can occur in three circumstances. It might be a transitory condition after the disclosure of the terminal condition and prognosis. As reported by Glaser (1966), the policy of physicians to make blunt direct statements enhances the chances that the information becomes barred. Disbelief is an initial reaction to cope with the shock of disclosure. The open awareness context is nascent: the news has been given but its radical consequences has not been fully assimilated. The

patient will then evolve to one of the two other kinds of open awareness contexts. I observed how a patient reacted apathetically to the news of terminal cancer and only wondered whether she might go home soon. When the physician rephrased his message, the patient created a scene. She accused the physician of lying to her. However, two days later the patient asked a nurse if she could speak to the hospital chaplain to discuss the inevitable. Also, my father initially could not believe the situation of my mother since she was going to retire and she was too young to have a stroke.

Secondly, for some patients the context of suspended open awareness is the preferred level. Disbelief becomes permanent. Often not only the terminal condition but even the sick condition will be questioned. Small improvements in the disease will be faced with the same indifference as deterioration. These people might continue to make unrealistic long-term plans, leave the hospital and rely on alternative medical treatments, or totally isolate themselves and become ignored by the staff.

Thirdly, suspended open awareness might happen in situations where illnesses either deteriorate or improve more than expected. Where these patients had been in an active open awareness or in uncertain open awareness, the progressive deterioration or improvement of their condition caused them to doubt the outcome of the disease. A physician told me of a patient who, when she relapsed, unexpectedly started to make travel plans for when she would be out of the hospital (see also Charmaz, 1991).

In all these instances, the impending death is a taboo subject. It has been broached once, but according to the reaction of the patient, there is an implicit understanding that the subject is not open to discussion.

The consequences of this form of awareness depend on how long the suspended open awareness is sustained by the patient or family members. A family member or patient who at first absolutely denies the message, but after the initial shock wants more information, will need to bring up the subject. In Taylor's study, it seems that the 'therapist' surgeons staged the disclosure over two days to give the patient a chance to come to grips with the diagnosis. The first meeting was centred round the disclosure, the second meeting considered possible treatments. Glaser and Strauss (1965) describe how patients or family members who continue to deny the diagnosis end up withdrawing from contact with everyone and remain in a state of hopelessness. In this limited sense, they become non-interacting, non-cooperative patients; the nurses can not 'reach' them. In one case, a nurse observed that a patient obviously shortened his life because of his period of anxiety and withdrawal. Charmaz (1987) gives examples of patients who are written off by the medical professionals because of their denial.

As pointed out by Glaser and Strauss, the benefit of the open awareness context is that patients, relatives, and the medical staff can prepare

for the impending death. In the suspended open awareness context this preparation is obstructed. The medical staff might hint at opening up the context of awareness, but the patient or relative who disregards every clue undermines the staff's efforts. This awareness context forces secrecy on the interaction between the patient and the medical team and restricts palliative care-giving.

2. *Uncertain open awareness*

Physicians remain the gatekeepers of information. Although there is a trend towards informing patients, at the same time physicians may not always consider it in the best interest of patients and relatives to know the plain, full clinical truth. Physicians withhold information, soften information, give miracle anecdotes, or counterbalance the disclosure with treatment possibilities. Taylor's study (1989) shows how three strategies of the physician's disclosure can enhance the context of uncertain open awareness. While disclosing the terminal condition, the physician may admit uncertainty about the diagnosis and prognosis; the physician can dissimulate, rendering a diagnosis and prognosis which he or she knows to be unsubstantiated clinically; or the physician can evade the clinical substantiated diagnosis by repressing information (see also Bond 1983).

In an interview, a physician defended the use of evasion and dissimulation:

What do you think I'm going to say to her . . . 'Look lady, you're going to be dead in a few months. Your kids are going to be orphans. Forget it, I'm not going to operate it at all. The stuff has spread and it's no use?' At least, with my approach, the poor women will have a few months of peace. I know I'll probably have trouble convincing her to have the 'cyst' radiated. She doesn't really have to know . . . That way she'll have some peace, even if it's only a short time . . . (Taylor 1989: 127).

In disclosing the information and opening up the awareness of the patient or relative, the physician might leave enough uncertainty so that hope is possible.

McIntosh (1977) linked the management of uncertainty with hope in a very powerful way:

The proposition that patients would attempt to cope with uncertainty by seeking to find out about their condition presupposed that they would want to know what they had and what the outlook was likely to be. Many did not. They would rather suffer from uncertainty than know the truth. They did so because for them, to suffer the uncertainty was preferable to the risk of losing their hope. Suspecting and knowing are entirely different things. So long as a patient did not know, he

could always retain the hope that he might not know, he could always retain the hope that he might not have cancer. In other words with uncertainty there was hope. (McIntosh 1977: 94, italics in original).

This linkage of uncertainty with hope is the core of the uncertain open context of awareness. It is agreed upon by physicians, nurses, patients, and family members alike; people literally live by hope (Field *et al* 1992; Miyaji 1993; Saunders 1978). When there is no longer any hope, people fear that the patient may become isolated and abandoned or become socially dead (Sudnow 1967).

Taylor and McIntosh's research dealt with cancer patients, but the uncertain open awareness context is found over a whole range of conditions and diseases. AIDS patients hope that they have fifteen more years to live and that a cure can be found in the intervening time. They might thus accept the diagnosis but create a perhaps unrealistic prognosis. CVA or myocardial infarction patients hope that their stroke or heart attack was a one-time event, and that they beat the odds.

Different strategies are used to search for hope-giving clues, and interpret bad news as hope-giving. In all studies, the tendency of patients and family members to look for alternative explanations, selectively interpret clues and rationalise is mentioned. When my mother made some small progress in her speaking through intensive speech therapy, even I, the most sceptical member of my family, started to doubt the dark future perspective. In my research, I witnessed a patient who received radiology on his shoulder asking the doctor whether his *arthritis* was improving. Although the man had undergone surgery to remove a malignant tumour on his elbow and was explicitly told so, the doctor nodded. Afterwards the doctor told me that the patient needed some hope. In the same way, family members might not only overestimate but also underestimate medical uncertainty.

Another tactic is the polarity game (Glaser and Strauss 1965: 133). The patient asks questions about the most extreme life-and-death implications of the illness. These almost crude questions usually result in an answer which takes the hopelessness of the situation away. For example, one evening in the hallway of the research hospital a daughter of a dying, unresponsive patient stopped a nurse and asked: 'How long does he have (to live)?' Embarrassed, the nurse answered: 'I don't know. Nobody knows!' When the daughter returned to the patient's room, we heard her saying: 'See, they don't know anything. It's probably not as bad as we think'.

Finally, patients in uncertain awareness contexts tend to compare themselves with fellow patients who are in a worse condition. The severe physical deterioration of the fellow patient makes the comparison favorable for the patient in the uncertain context of awareness. Roth described this phenomenon at length in his discussion of polio recovery (Roth

1963). For terminal patients the comparison serves as a reassurance. They are not in the worst position; other patients are worse off. When the terminal diagnosis of my mother was disclosed, I also compared her appearance to the middle-aged female cancer patients on my research wards. My mother seemed much better than they were.

Because of the almost endless possibilities for alternative explanations and rationalisation of little setbacks, the interaction between medical professionals and patients and family members in an uncertain open awareness is very flexible. The nurses and physicians do not feel the need to discuss the coming death with the patient, but they can discuss death-related matters if they leave a margin for hope (Field 1989). The patient might be urged to settle business affairs because 'you never know, and it is a good thing to do anyway'. Davis (1960) described this phenomenon as the use of uncertainty for functional and institutional purposes.

3. Active open awareness

In active open awareness the patient and family members understand the full implications of the impending death and try in one way or another to come to terms with it. The patient no longer hopes for a recovery.

However, this does not mean that all hope is abandoned and that the patient simply waits to die. The patient or relative can find peace of mind in thoughts of a religious afterlife. In the Catholic hospital where I did my observations this occasionally became the main feature of the context of awareness. It was also the case that the nurses opened up the awareness of patients by referring them to a chaplain and forcing physicians to disclose the condition to the patient before the conversation with the chaplain (see also Glaser and Strauss 1968). Even without religious help, patients and family members can find rest in reflecting on their own lives, in optimising the last days, weeks or months together – as was the case in my family and on staging a farewell with friends and family. The patient may want to settle financial affairs.

The recent development of hospice care makes it easier for patients and family members to prepare actively for death. Hospice care patients are reported to be more likely than conventional care patients to know that they are dying (Seale 1991a). Patients and family members tend to be in a context of active open awareness. Once in hospice care, nurses and physicians will administer a palliative treatment aimed at comfort and an alleviation of pain and assist the relatives and friends with psychological and social needs.

The most radical form of preparation for death in a context of open awareness is to pursue death. Patients who are in pain or prolonged extreme discomfort, or who are very old may simply want to die (see Strauss and Glaser 1970). They accept the end of their life and hope it will soon be over with. They might merely wait to die or might actively help the process by withdrawing or committing suicide.

A context of active open awareness became the idealised context of awareness for representatives in the medical world and thanatologists such as Kubler Ross (1969), whose definitions of terminal care have been adopted in numerous textbooks. These authorities presented a psychodynamic model of dying where acceptance of the impending death is the 'better' way to die. When dying patients die in unawareness or without reaching the stage where the death becomes fully open for discussion, the consequences may be persistent for the medical staff. Studies mention dissatisfaction, guilt, perceived negligence, and even burn-out (Benoliel 1987–1988; Field 1989; Gray-Toft and Anderson 1981; Keirse *et al* 1981). I have previously argued that unrealistic expectation patterns dismiss the actual work of taking care of terminal patients (Timmermans 1993). Support for this claim can be found in Glaser and Strauss' discussion of the ambiguities of active open awareness for patients, relatives and medical staff (1965 Chapter 6).

Conclusion

In this paper, I have extended the theory of awareness contexts based upon my own experience as a relative of a terminally ill patient and studies influenced by a grounded theory approach. Awareness contexts are defined as 'what each interacting person *knows* of the patient's defined status, along with his recognition of the others' awarenesses of his own definition' (Glaser and Strauss 1965: 10, my emphasis). The substantive purpose of this paper has been to modify the meaning of 'knowing'. The disclosure of a terminal condition is considered an emotional crisis for the messenger and the recipient of the message. A physician reflects in an interview: 'I hate this part of the work. I feel terrible always, it never seems to get easier. Knots in my stomach a mile wide in that walk from the lab to the patients . . .' (Taylor 1989: 113–114). However, after the disclosure, the patients and relatives are the ones who have to cope with the new situation.

My own struggle to come to grips with the end of life of a loved one increased my awareness for the position of relatives and patients in a hospital setting. Using introspective ethnography, I came to understand that family members and patients are powerful actors in the construction of an awareness context, and that information does not necessarily lead to open awareness but that the way patients and relatives emotionally cope with the terminal information determines the kind of open awareness context.

The most important implication of this modified theory of awareness contexts is that there is not one optimal or appropriate emotional response to a terminal diagnosis. Acceptance of the impending death may be more appropriate for some patients and family members in certain

conditions and it may be more functional for the organisational working of the hospital staff, but one open awareness context cannot be imposed upon all patients or family members. As Lofland (1985) showed in the case of grief, a reaction to terminal disease varies over space and time and depends upon the interactional context and the character of the selves experiencing a loss through death. Beilin (1981) showed that 'denial', which most thanatologists consider a dysfunctional defence mechanism against terminal awareness, preserves relationships threatened by knowledge of terminal illness. Each emotional response to the disclosure of the terminal condition shifts the open awareness context with effects for the self-image of the patient, the work of the medical staff, the interaction between all actors, and the structural organisation of the ward and hospital.

Holland and collaborators (1987) surveyed oncologists in 22 countries, concluding that oncologists in the U.S. and some countries in Europe are more likely to disclose fully the terminal clinical condition of the patient than their colleagues in the rest of Europe, Asia, and South America. The structural conditions in the latter countries probably resembles the situation of Glaser and Strauss' San Francisco Bay area study where physicians, nurses, patients, and relatives live and die in the traditional contexts of awareness, and where most of the interactional tactics are focussed on retrieving and distributing information. In the countries where the rule is that patients should be fully informed, the modified contexts of awareness will better fit the empirical material. In the structure where patients are informed, the focus of the interaction is on interpreting the information and coping with it.

The modification of the context of awareness theory also illustrates the open-endedness of theory construction. Further cross-cultural research on terminal care might show the necessity of suggesting new amendments. I invite readers to apply their own experiences to the modified theory.

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