VOCALLY DISRUPTIVE BEHAVIOUR IN SEVERELY DEMENTED PATIENTS IN RELATION TO INSTITUTIONAL CARE PROVIDED

by

Ingalill Rahm Hallberg
VOCALLY DISRUPTIVE BEHAVIOUR IN SEVERELY DEMENTED
PATIENTS IN RELATION TO INSTITUTIONAL CARE PROVIDED.

AKADEMISK AVHANDLING
som med vederbörligt tillstånd av Rektorsämbetet vid
Umeå Universitet för avläggande av doktorsexamen i medicinsk
vetenskap kommer att offentligen försvaras i
Landstingssalen, Landstingets centralförvaltning,
Blekingevägen 23, Kristianstad, fredagen 9/2 1990 kl 09.15

av

Ingalill Rahm Hallberg

Umeå 1990
Vocally disruptive behaviour in severely demented patients in relation to institutional care provided.

Ingalill Rahm Hallberg, Department of Advanced Nursing, University of Umeå, S- 901 24 Umeå, Sweden, Department of Psychiatry I, University of Lund and Care Research and Development Unit, Kristianstad College for the Health Professions and University of Lund, Lasarettsboulevarden 18, S- 291 33 Kristianstad, Sweden.

ABSTRACT

Thirty-seven patients identified as vocally disruptive and a control group, selected from 264 patients at psychogeriatric wards were studied. Tape-recordings of their vocal behaviour, ratings of their functional performance and symptoms related to dementia, observations of their behaviour, activities and interaction with caregivers were performed. Seventeen plus sixteen caregivers were interviewed to give their interpretation of the experience behind the behaviour and describe their own experience of it. The severely demented vocally disruptive patients were found to be significantly more physically dependant, disorientated at the ward and prone to confusional reactions but they had a more preserved speech performance than the controls. The vocal activity expressed such as helplessness, pain, fear and protest. Some were emotionally indifferent and a few expressed positive emotions. Caregivers interpreted the behaviour as an expression of anxiety related to such as abandonment, dissolution and loss of autonomy. They also expressed a strong wish to comfort the patients but felt unable to do so. The patients' daily life was characterized by idleness and solitude. Caring activities and interactions were dominated by physical procedures performed in a fragmentary and rapid way. Two hypotheses are generated. 1. Vocally disruptive behaviour develops influenced by sensory deprivation and the brain damage. 2. The care provided is influenced by caregivers experiencing anxiety in the patients as well as experiencing a conflict between the care they would like to provide and the care they actually provide. This evokes anxiety in them which elicits defence mechanisms leading to emotional withdrawal from the patients and task oriented care. The results are discussed in a nursing perspective based on existential thoughts, psychoanalytic and psychosocial theory.

Key words: Dementia, vocally disruptive behaviour, shouting, nursing care, sensory deprivation, understimulation, anxiety, object relation theory, caregivers' reactions, E.H. Erikson's theory.
From the Department of Advanced Nursing, University of Umeå in collaboration with the Department of Psychiatry I, University of Lund and the Care Research and Development Unit, Kristianstad College for the Health Professions, University of Lund, Sweden.

VOCALLY DISRUPTIVE BEHAVIOUR IN SEVERELY DEMENTED PATIENTS IN RELATION TO INSTITUTIONAL CARE PROVIDED.

by

Ingalill Rahm Hallberg

Umeå 1990
To my children, Lina and Johannes, 
my mother, Elvy and the memory of my father, 
Algot, to whom I am closely related 
representing, just like life itself at this 
very moment, both future and history.
Vocally disruptive behaviour in severely demented patients in relation to institutional care provided.

Ingalill Rahm Hallberg, Department of Advanced Nursing, University of Umeå, S- 901 24 Umeå, Sweden, Department of Psychiatry I, University of Lund and Care Research and Development Unit, Kristianstad College for the Health Professions and University of Lund, Lasarettsboulevarden 18, S- 291 33 Kristianstad, Sweden.

ABSTRACT

Thirty-seven patients identified as vocally disruptive and a control group, selected from 264 patients at psychogeriatric wards were studied. Tape-recordings of their vocal behaviour, ratings of their functional performance and symptoms related to dementia, observations of their behaviour, activities and interaction with caregivers were performed. Seventeen plus sixteen caregivers were interviewed to give their interpretation of the experience behind the behaviour and describe their own experience of it. The severely demented vocally disruptive patients were found to be significantly more physically dependant, disorientated at the ward and prone to confusional reactions but they had a more preserved speech performance than the controls. The vocal activity expressed such as helplessness, pain, fear and protest. Some were emotionally indifferent and a few expressed positive emotions. Caregivers interpreted the behaviour as an expression of anxiety related to such as abandonment, dissolution and loss of autonomy. They also expressed a strong wish to comfort the patients but felt unable to do so. The patients' daily life was characterized by idleness and solitude. Caring activities and interactions were dominated by physical procedures performed in a fragmentary and rapid way. Two hypotheses are generated. 1. Vocally disruptive behaviour develops affected by sensory deprivation and the brain damage. 2. The care provided is influenced by caregivers experiencing anxiety in the patients as well as experiencing a conflict between the care they would like to provide and the care they actually provide. This evokes anxiety in them which elicits defence mechanisms leading to emotional withdrawal from the patients and task oriented care. The results are discussed in a nursing perspective based on existential thoughts, psychoanalytic and psychosocial theory.

Key words: Dementia, vocally disruptive behaviour, shouting, nursing care, sensory deprivation, understimulation, anxiety, object relation theory, caregivers' reactions, E.H. Erikson's theory.
This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.


II  Hallberg IR, Nordmark Å, Edberg A-K, Johnsson K, Norberg A. The phenomenon of vocal activity in institutionalized severely demented patients identified as vocally disruptive by caregivers. Submitted for publication.

III  Hallberg IR, Norberg A. Staff's interpretation of the experience behind vocally disruptive behaviour in severely demented patients and their feelings about it. An exploratory study. Aging & Human Development, accepted for publication.

IV  Hallberg IR, Norberg A, Eriksson S. A comparison between the care of vocally disruptive patients and that of other residents at psychogeriatric wards. Journal of Advanced Nursing, accepted for publication.

V  Hallberg IR, Luker KA, Norberg A, Johnsson K, Eriksson S. Staff interaction with vocally disruptive demented patients compared with demented controls. Aging, Clinical and Experimental Research, accepted for publication.

VI  Hallberg IR, Norberg A, Johnsson K. Verbal interaction during the lunch-meal between caregivers and vocally disruptive demented patients. Submitted for publication.

The papers are reprinted with kind permission of the respective journal.
INTRODUCTION AND REVIEW OF THE LITERATURE

This study is concerned with institutionalized severely demented patients exhibiting vocally disruptive behaviour seen from a nursing perspective.

Nursing

Nursing is mostly concerned with the patient and his functional ability in relation to his daily life in order to maintain health (Carnevali 1986). The concepts inherited in nursing are said to be person, health, environment and nursing (Fawcett 1984). The philosophy behind the concepts and the way they are linked together give a nursing theory that is clearly different from other nursing theories (Fawcett 1984). The idea that nursing is one concept of nursing is somehow illogical (Meleis oral communication 1987). It seems more appropriate to define the fourth concept as nursing intervention (cf Travelbee 1977), consisting of interaction and nursing activities based on a thorough analysis of the patient's needs and problems.

Interaction is considered to be the core of nursing by several nursing theorists (cf Meleis 1984, cf Chinn & Jacobs 1986). In a theoretical model, retroductively developed, it was proposed that from a specific philosophic stand-point the nurse therapeutically uses herself to compensate for the patient's inability to manage his self-care (person) (Athlin 1988). This requires the use of the nursing process. All of it take place in a supportive environment and organization further endorsed by education (environment). The model could be further developed by emphasizing that the therapeutic relationship entails nursing activities and is integrated in interaction (nursing intervention) and that it aims at promoting health for the patient (health). Hence, the four central concepts of nursing are included in the model which might serve as a useful guide to the study of the vocally disruptive behaviour of the severely demented.
Theoretical perspective

Existential* man is seen as experiencing - interpreting and taking actions at the present moment in order to create wholeness and meaning in relation to himself, other human beings and his world. Hence, man can be seen as living in and realizing himself in different kinds of relationships; to himself (Being one's self), as part of and in interaction with other human beings (Being with) and the world (Being in the world) (cf Heidegger 1962) (Figure 1). The present moment establishes itself in the light of its history and future (Perls 1969). Thus, man at each moment gives form to his history and future. How this is achieved and maintained depends most likely on man's personal physical and psychological conditions in relation to his environment. The achievement of wholeness and meaning presupposes awareness of the opposite dimensions; destruction (death) and meaninglessness (cf Heidegger 1962). Anxiety is evoked when these basic actions of human nature are restrained or distorted. Tillich (1952) suggests that anxiety ontologically is the 'state in which a being is aware of its possible nonbeing' that the awareness of nonbeing as part of one's own being produces anxiety. Existential anxiety is said to be of three different types; anxiety about fate and death, emptiness and meaninglessness, guilt and condemnation.

The development of psychological requirements to handle oneself in relation to others and the world can be regarded both from an individualistic and a psychosocial perspective.

A psychoanalytic perspective is chosen to understand the development of the individual personality (Figure 1). From this perspective the infant develops little by little a personality in relation to an important other (object) and later on others. The I becomes able to interpret, understand and relate to other human beings, at first only to parts of the other but later on to whole others. Anxiety changes from the early types of global and panic-like anxiety, organismic distress, anxiety about annihilation, anxiety about

*The term existential is used to name the person's reaction to the human situation.
Fig 1. Theoretical perspective

separation, to later types like anxiety about loss of love and anxiety about guilt and conscience (cf Mahler 1968, Blanck & Blanck 1974). The types of defence mechanisms used develop from the early ones like denial, projection, to more mature mechanisms like repression, rationalization and sublimation. From being autistically related to the world, identity develops and become differentiated, constantly cathexing the representations of the self and others. The development is seen as influenced by the congenital preconditions and has an impact on the early relationships to the important other(s). It influences the autonomous functions of the I, for example memory and thinking
Thus, the person gradually separates and individualizes himself, develops strength and mechanisms through which he understands, interprets and takes actions in order to create wholeness and meaning in the handling of himself, others and his world. Also, he gradually develops relationships to himself, to others and to his world.

The relationship between existential and psychological anxiety is difficult to grasp. Here the view has been taken that the type and globality of psychological anxiety are dependent on at which stage of development the person functions. It is related to situations he is confronted with and that he cannot handle because of conflicts or deficits in his personality. Existential anxiety on the other hand is related to situations where the person is confronted with questions concerning the being; with nonbeing and meaninglessness. Hence, both can be present at the same time (cf. Davidson 1989).

For the psychosocial perspective Erikson's theory of "eight stages of man" (1982) has been chosen since it is concerned with man's development throughout the life-span (Figure 1). According to Erikson (1982) the I develops throughout life in interaction with other human beings through eight crises; trust - mistrust, autonomy - shame, initiative - guilt, industry - inferiority, identity - identity confusion, intimacy - isolation, generativity - stagnation and integrity - despair. Each crisis consists of two opposite experiences (thesis, antithesis) which the person has to work through and solve. Out of each crisis a virtue develops (synthesis); hope, will, purpose, competence, fidelity, love, care and wisdom depending on how oneself is confirmed or disconfirmed in relation to others and the world (Erikson et al. 1986). Each stage does not only focus on the manifest crisis of the period but also on the past and future crises as they project themselves at the present moment and have to be presolved or resolved at that stage. Old man's experience of the crisis concerning integrity - despair, thus, presupposes that the crises trust - mistrust, autonomy - shame, etc., are resolved at that level of development (Erikson 1982). Hence, events in life are
viewed differently depending on the present crisis and the influence of earlier and future crises and developed virtues. Moreover, the solutions and virtues are attained over and over again towards the stage of integrity versus despair in the achievement of wisdom of life. That process goes on in interaction with the experience of oneself, others and the world. The person receives support to find positive or negative solutions of the eight crises of development. The individual personality could be regarded as the tool with which the person handles this developmental process. Thus, the personality affects the solution to the crises as well as the physical requirements.

**Concepts of nursing applied to patients with severe dementia**

The thesis is concerned with the severely demented patient and the institutional environment since the patients studied were severely demented people and in many ways the ward had taken over and become their world.

**The patient suffering from dementia**

Human beings are seen as perpetually engaged in understanding - interpreting the meaning of the world which faces them (cf Heidegger 1962). Being demented might mean that one finds oneself out of time and space, with a fragmentary or more or less destroyed capacity for understanding - interpreting and taking actions so that wholeness and meaning are achieved in relation to oneself, others and the world. The cognitive disturbances of for instance memory and judgement as well as agnosia, aphasia and apraxia (Sulkava & Amberla 1982, DSM-III-R 1987, McLean 1987 a, McLean 1987 b) most likely make it problematic for the demented patient (he) to understand, foresee and handle the I in relation to himself, others and the world. There is an extensive body of knowledge describing the impact of dementia on the ability to handle the basic needs of daily life (Gilleard 1984, Reisberg 1986, McLean 1987 b, Beck & Heacock 1988) communicating (Athlin & Norberg 1987, Bayles & Kaszniai 1987, Hart 1988) as well as on the capacity for selective atten-
All of it is part of what it takes to realize oneself in the world and to experience the virtues of life (cf Erikson 1982). When the patient is confronted with situations he cannot handle, he is reduced to a catastrophic condition. This is a basic threat to his realizing himself (Goldstein 1952). It implies that dementia is a real threat to the experience of the being. Anxiety about fate and death as well as anxiety about emptiness and meaninglessness might be part of the severely demented patient's experience and can be explained by his lost ability to interpret and foresee as well as to take actions and organize himself and his situation in an understandable way. The question whether existential anxiety could be evoked and experienced by the severely demented patient is related to the question whether one must be able to perceive and interpret one's existence on a cognitive level to be able to experience anxiety. According to Goldstein (1952) anxiety originates from the inner experience of being confronted with nothingness. Hence, it might be useful to make a distinction between the ability to experience the existence (oneself, others and the world) and the ability to understand and handle it on a cognitive level.

It is believed that anxiety reactions are common for dementia (McLean 1987 a,b, Beck & Heacock 1988, Salzman 1988). The catastrophic reactions (Goldstein 1952, Sim & Sussman 1962, Maas 1988) imply that the patient experiences anxiety, agony or hostility overtly shown in the behaviour. It is assumed that the stress threshold present in dementia of the Alzheimer type becomes lower and lower. The experience of stress leads to anxious behaviour, which might result in dysfunctional behaviour if there is no intervention (Hall 1988).

Changes of the personality and behavioural disturbances are recognized to be a concomitant of dementia (Rosin 1977, Ballinger et al. 1982, Reisberg 1987, Devanand 1988, Swearer 1988) and a factor contributing to the decision to institutionalize the person (Sanford 1975, Morycz 1985, Silliman 1988). Different terms and approaches have been used to study the type and frequency of behavioural disturbances. Rubin et al. (1987) used the terms passive, agitated and
self-centered behavioural changes. He found that agitated behaviour increased throughout the course of dementia. Passive behaviour was present early in the disease while all types of the above behavioural problems were common when the patients reached a severe stage of dementia. Reisberg et al. (1986) described the behavioural changes as paranoid and delusional ideation, activity disturbances, diurnal rhythm disturbances, affective disturbances, anxieties and phobias. Teri (1988) reported that an increasing number of behavioural problems like wandering and agitation was related to the increasing severity of the disease, while problems like hallucinations and restlessness did not correlate to the degree of the disease. Since there is a lack of standardized definitions of behavioural changes it is difficult to compare and draw any conclusions concerning their occurrence. From a nursing perspective it is a problem that the literature on behavioural changes does not explore the emotional experiences behind them. It could be assumed that the experience precedes the behaviour (cf Laing 1967). Thus, interventions aiming at the experience rather than the behaviour may be preferable.

It has been suggested that developing dementia means that the person proceeds through a series of retrogressive stages all the way back to psychological infantility (Leeds 1960, cf Ajuriaguerra & Tissot 1975). The diminished cortical control puts the demented person into a situation where primitive psychological and physical reactions are available mostly (cf Goldstein 1940). Goldstein (1952) suggests that the disturbed capacity for abstract reasoning in a brain damaged person has a tendency to make attention, emotional reactions and memory operate concretely. The patients disturbed ability to handle and hold situations which presupposes deliberation makes him prone to releasing tension immediately. Anxiety is evoked not by his awareness of reality but simply by experiencing it. It seems reasonable to assume that analoguously with the situation of the infant the anxiety evoked in the demented patient in different situations is dominated by the early types of global and panic-like anxiety, organismic distress, anxiety about annihilation and about separation, while later types like
anxiety about loss of love and anxiety about guilt and conscience are more rare (cf Mahler 1968, cf Blanck & Blanck 1974). Perhaps also the type of defence mechanisms used, the way of relating to and experiencing others as parts or whole persons as well as the cathexing of the self, others and the world are more similar to how the infant handles others and the world than to how a person with a mature personality acts. The adequate way to interact with a person influenced by the early mechanisms of handling the I, others and the world is quite different from the way to approach a mature person influenced by the later types of anxiety.

In conclusion, it can be said that being severely demented means that the person's physical and psychological abilities to relate to himself, others and the world are severely disturbed. There are some similarities with the infant's position in the world but being demented is characterized also by the impact of organic defects combined with normal function and the preserved memories of earlier experiences. The disturbed ability to communicate might reduce the demented patient to loneliness. In every day situations many demented persons may frequently be confronted with meaninglessness which evokes anxiety for existential and psychological reasons and activates the negative poles of the life crises. This is of course not always the case. Seemingly some severely demented patients find ways to give meaning to their own world.

Health from a demented patient's point of view

Being healthy could be regarded as the opposite of suffering from a disease (Boorse 1977). Becoming healthy then requires effective treatment of the disease. Since dementia at present is incurable, health cannot be obtained for the severely demented patients. This view brings about some uncertainty about what to aim at in the care provided (cf Smith 1986). Being healthy might also be understood in the light of Erikson's theory of "eight stages of man" (1982) as the experience of wisdom in the current stage of development and in the light of projections from earlier stages to the
present. Wisdom stems from the conflict between integrity and despair. Care promoting the experience of integrity within the person (Kihlgren et al. 1990) and adjusted to his physical and psychological capabilities could provide the prerequisite for the demented patient's experience of wholeness and meaning. It seems logical then to assume that in order to promote integrity also trust, autonomy, initiative, identity, industry, intimacy, and generativity have to be supported. To look at health in this way might be more useful to the care of the severely demented patient, since it emphasizes the experience of wholeness and meaning in the situation rather than being related to the curing of the disease.

Nursing intervention for the demented

Accordingly by means of an approach influenced by existential, psychoanalytic and psychosocial thoughts the demented patient needs support to engage in relationships and activities and in the interpretation of himself, others and the world. Thus, in the every day situations relationships and caring activities aim at providing an experience of wholeness and meaning for the patient. The relationship between caregiver (she) and patient becomes therapeutic when this kind of experience is provided. Attention is directed towards the understanding of the experiences behind the behaviour and towards the situation in which it occurs in order to understand how it is related to the experience of wholeness and meaning. Behaviour is seen as an expression of something that cannot be fully understood without exploring the experience behind it. Neither can it be studied outside the context where it occurs.

This is in accordance with the fact that interaction between staff and demented patients is often emphasized because it is so vitally important to the demented (cf Haugen 1985, cf Hanley 1984, for review see Beck & Heacock 1988). The demented patient's decreasing ability to communicate verbally and nonverbally (for review see Athlin & Norberg 1987) increases the demands on the caregiver to communicate
in a manner that maintains the relationship as long as possible. The patient is assumed to be sensitive to negative nonverbal communication and it has been stated that the use of touch might be a direct way of communicating with the demented patient supplementing the verbal communication (Beck & Heacock, 1988). Inherent in providing physical care is the communication of the nonverbal type (by the physical closeness) which can purposefully communicate experiences of meaning and wholeness or purposelessly the opposite experience. The difficulties of the communication between patients and caregivers most likely reduce both parties to loneliness.

The nursing activities needed are related to the demented patient's activities of daily living. The activities need to be performed in a manner that is adjusted to the difficulties in perception, memory and orientation as well as to the need for activity and social interaction (for review see Beck & Heacock 1988) and in a way that supports the patient's experiences of wholeness and meaning (cf Kihlgren et al. 1990). Also caring interventions offering a release from anxiety and catastrophic reactions need to be provided (Beck & Heacock 1988). According to Hall (1988) the progressively lowered stress threshold causing anxiety and dysfunctional behaviour makes the demented patient more sensitive to stress factors such as fatigue, change of routine, excess demands and overwhelming stimuli. Care must take that into consideration. The nursing activities provided have to be integrated into the demand for interaction with the patient as a whole person and they must not be concerned only with the task performed in a personal manner. The caregiver also needs to attend to the patient as a person with a basic need to relate to himself, others and his world.

Caregivers' commitment to the patient is believed to be crucial when it comes to regarding the patient either as an object or as a subject (Athlin et al. in press). However, mutuality may be a must to maintain commitment (Ekman et al. subm). Since the severely demented patient has great difficulties in communicating the caregiver does not receive any feedback (Hirschfeld 1981, Åkerlund & Norberg 1989-1990). Thus, the caregiver is reduced to loneliness which
might threaten her commitment. However, thanks to an emotionally close relationship the caregiver may serve as a container for the emotional strain of the patient, i.e. be sensitive, attend, and respond to it in a therapeutic manner (cf Bion 1977, Haugsgjerd 1983 a). It seems logical that the maintaining of emotional closeness to the demented patient to realize the containing function evokes anxiety in the caregivers due to the suffering they experience in the patient (cf Kernberg 1979). Anxiety about separation in particular due to the lost mutuality in the relationship might be evoked in them. The emotional strain on the family caregivers of demented patients has frequently been reported (for review see Gillearrd 1984). It has been suggested that anxiety in relation to death, isolation, freedom and meaning is evoked in them (Levine et al. 1984). It seems reasonable to assume that similar emotions are evoked in professional caregivers as well. Tedium and the risk for developing burn-out have been reported among caregivers caring for demented patients (Åström et al. 1987). The experience of anxiety in these caregivers might precede and/or accompany a state of tedium and/or burn-out or the experience of powerlessness (cf Hughie 1967, Åkerlund & Norberg 1989-1990). The anxiety evoked in caregivers may manifest itself in defence reactions in the individual caregivers (Åkerlund & Norberg subm) and by the social system developed among them (Menzies 1970, Kernberg 1979, Homer 1984).

Environment for the demented

The possibilities of the demented to adapt to or change their environment are limited. It has to be adjusted to them (Miller 1977, Hanley 1984, Jefferey & Saxby 1984). As it has been concluded that the self realizes itself by interpreting, understanding, and acting in relation with oneself, others and the world environmental conditions must be regarded as part of the care provided. By elaborating the conditions in order to make them suit the individual patient, care could enhance the patient's experience of wholeness and meaning.
In order to adapt the environment to the patient it is, as stated by Svensson (1984), important to differentiate between the patient's covert and his overt competence (the inner true competence versus what is shown and can be measured). A grave underestimate of the patient can be made if overt competence is mistaken for covert competence. Reduced covert competence, as in the case of dementia, makes the patient more vulnerable to the too low or too high pressure from a maladjusted environment (Svensson 1984). This may press the patient to develop negatively and cause or increase 'a spiral of senility' leading to vegetation (Barns et al. 1973).

Two environmental components are assumed to be especially important to the demented patient; cues and stability. Cues refer to the amount and form of social and physical information available for the patient. Stability refers to the environment as constant, and physically as well as socially legible for the patient, i.e. directed to the patient's sensory and physical function (Robert & Algase 1988). Other environmental components that have been found effective in the treatment of demented patients are for example measures improving orientation ability and increasing stimulation, activity and social contact with other patients, relatives and staff as well as making environment as normal as possible (Haugen 1982). This is in accordance with Svensson (1984) who claims that environmental conditions like integrity, security, support for activity and compensation for perceptual losses are important in the care of the elderly.

In conclusion it seems that in order to enhance the demented patient's function and experience of integrity, the environment must be adapted to his covert competence both physically and psychosocially. Moreover, it seems that the environment should provide experiences of activities and social belonging which are a prerequisite for the realization of oneself. Hence, the caring activities, the interaction and the physical environment could support the patient's experience of wholeness and meaning if they were designed to promote the patient's integrity, i.e. support the positive poles of the eight crises of life (Erikson
and were adjusted to how dementia physically and psychologically affects the patient (Kihlgren et al. 1990). In the literature the question of how to reduce anxiety by environmental conditions has not been discussed. However, firstly environmental conditions in general must not evoke anxiety. Secondly further research into what evokes anxiety in the individual patient must be done in order to provide the optimal experience for each patient.

Vocally disruptive behaviour in demented patients

Accordingly, with the perspective chosen, all human behaviour could be seen as a communication act (Watzlawick et al. 1967) and as an expression of experiences in the person (Laing 1966). Hence, studies elucidating in what way vocally disruptive behaviour is a communicative act and what kind of experience there is behind it, seem important but have not been found in the literature.

Although no prevalence studies have focused on vocally disruptive behaviour among demented patients per se, investigations of behavioural disturbances have in some cases also reported the frequency of screaming and shouting. Sandman et al. (1988), for example, reported from various types of long-term care wards. They found that 3.9% of the investigated patients (n=3600) screamed or shouted every day and 8.8% sometimes every week. The behaviour was considerably more common in demented than in non-demented patients. Rosin (1977) found shouting in 29 of 81 institutionalized demented patients admitted to a ward for patients with disturbing behaviour. Also in home-care patients have been reported to be noisy and to shout (Gilleard 1984). Comparisons are difficult to perform since there is a lack of descriptions of the behaviour. In case-studies vocally disruptive behaviour has been described as a repetition of sounds (Zachow 1984), echolalic expressions, screams (Greenwald 1986), repetitive monologues (Birchmore & Claque 1983) and calling (Baltes & Lascomb 1975). Thus, from the caregivers' perspective echolalia (Schuler 1979) and perseverations (Sandson & Albert 1984, Bayles et al. 1985) might be regarded as vocally disruptive behaviour. This behaviour could be considered to be
intentional and communicative (Prizant 1983).

No studies have been found attempting to investigate the antecedents of vocally disruptive behaviour although suggestions like sensory deprivation, attention-seeking, anxiety about separation, stress and overstimulation have been made (Stokes 1986).

Only few studies have dealt with the drug treatment of this behaviour. Greenwald et al. (1986) reported successful treatment with L-tryptophan in a case-report. Surgical treatment has also been taken into consideration (Robertson 1987).

The other studies found, have in common that they are case-studies describing interventions mainly using a behavioural approach to treat the behaviour. Treatment-outcome of e.g. aversion therapy by electrical shock in a 24-year-old profoundly retarded woman (Hamilton & Standahl 1969) and visual screening in a severely retarded boy (Dick & Jackson 1983) was examined. Furthermore a behavioural approach has been suggested to reduce screaming behaviour in the elderly (Hoyer 1975) and it has been used (Baltes & Lascomb 1975, Birchmore & Claque 1983). So have stimulation and validation techniques (Zachow 1984). Although some of these studies express the underlying assumption that the behaviour can be caused by understimulation there have been no attempts to identify such antecedents. These studies also seem to be based on the assumption that vocally disruptive behaviour is connected with experiences of unpleasantness, agony or/and discomfort.

It appears somehow illogical to assume that the antecedents to the behaviour are the poor standard of the activities and social experiences in which the demented patient has to realize himself and then apply techniques not directed to the source of the behaviour.

In these studies no attempt was made to investigate the patient exhibiting the behaviour, the environmental conditions under which it occurs, or how people close to the patient experience the behaviour and react to it. Nor were any attempts made to understand what kind of experience lies behind such behaviour. The approach used in the previous
studies has been behaviouristic rather than holistic. From a nursing perspective it seems important to understand how physiologic, psychologic and environmental factors (caring included) interact and influence the occurrence of vocally disruptive behaviour as well as what it communicates, i.e. the experiences behind it.

AIMS OF THE STUDY

Due to the lack of research, which could serve as a basis for the testing of hypotheses this study was designed as a descriptive study aiming primarily at generating hypotheses. Hence, an inductive approach was chosen (Taylor & Bogdan 1984) to outline the study and a retroductive approach (Walker & Avant 1983) to analyse the data. A broad description of the behaviour and the context in which it occurred was used to investigate both what was actually going on and how the behaviour was interpreted (cf Hodge 1984) as the interpretation of the behaviour influences the way one responds to it (cf Kelly & May 1982).

The study aimed at describing:
- the vocal activity with reference to its content, duration and pattern
- caregivers' interpretation of the patients' experiences behind the behaviour and the caregivers' own reactions to it
- the patients' physical, psychosocial functional performance and behaviour in comparison with a control group
- the care provided as for activities and interaction with others in comparison with a control group.

SUBJECTS

The psychogeriatric wards (264 patients/16 wards) within 4 health districts in southern Sweden were investigated as for the number of patients exhibiting vocally disruptive behaviour. The patients were identified by the nurses on the ward as patients who had been regularly noisy, uttering repetitive words, sentences or sounds for long periods during the two previous weeks. There was a discussion in the group of
caregivers in the presence of two researchers whether these patients met the requirements. These subjective judgements made by the staff were used since no operational definition was available. Out of the 264 patients investigated 40 patients were defined as vocally disruptive (15.2%) at 14 of the 16 wards. Most wards housed 2-3 patients identified as vocally disruptive. Informed consent for participating in the study was given for 37 of these patients. Thus, the study group includes all patients, but 3 with vocally disruptive behaviour. Controls were randomly selected, matched for sex, from the remaining group of patients not exhibiting vocally disruptive behaviour at the above wards.

A convenient sample of 17 + 16 caregivers on duty on a particular day was chosen for interviews. The interviewees were all experienced in the care of vocally disruptive demented patients.

The number of beds at most wards varied from 18 to 20 and the staffing from 0.6 to 0.7 caregivers per bed (all professions included, but night personnel excluded). The personnel were mainly licensed enrolled nurses (psychiatric and somatic) and registered nurses (20-30%). Care was performed according to a task assignment system. This system was combined with a 'contact person system', which meant that a caregiver was assigned to each patient and was responsible for his personal belongings and contact with his family.

All patients were included in studies I, IV and V. Due to the poor technical quality of 4 (II) respectively 3 (VI) tape-recordings of the 37 patients identified as vocally disruptive, only 33 were included in study II and 34 in study VI. For study III tape-recordings (2x3 minutes/patient) of the medium intensive vocally disruptive behaviour of two demented female patients were played to 33 caregivers.

METHODS

The patients' functional performance and symptoms were assessed by means of Katz' ADL index (Katz & Akpom 1976) and the Organic Brain Syndromes scale, (OBS scale) (Gustafson et al. 1985) (I). The OBS scale consists of two subscales, the
first scale measures patient orientation. The other subscale measures functional performance and symptoms related to dementia. The response scale on this subscale was extended by three more steps, evenly distributed in order to ensure that it was sensitive enough to identify any kind of differences between severely demented patients.

The assessments concerning orientation were made by the author. Under the supervision of the author the other subscale was completed by 3-4 caregivers who knew the patients well. Inter-rater reliability was secured by another group of personnel completing the scale again in 21% of the cases. It was calculated by means of Spearman's rank correlation coefficient (rs) (Siegel 1956) and varied in each item between rs=0.93 and rs=0.98.

Principal component analysis with orthogonal rotation of the varimax type was applied to the responses of the orientation subscale in order to analyse the responses for any underlying structure (Polit & Hungler 1983). Setting a 10% limit of total variance three components representing orientation to person, to time and to past and present events emerged. Taken together they explained 61.2% of the variance. For each patient a standardized score was calculated for these principal components which in turn were used in a discriminant analysis (Polit & Hungler 1983).

The same statistical methods were used on the other subscale measuring the presence of functional performance and symptoms related to dementia. Seven factors (functional performance and orientation in the ward, fluctuations in mental state and emotional disturbances, speech performance, psychomotor slowing, mobility, hostility, presence of delusions and hallucinations, sensitivity and euphoric state) each explaining more than 4% of the variance, were extracted. Together they explained 63.6% of the variance.

All vocally disruptive patients were recorded as for their vocal activity during 12 hours (7.00 am - 7.00 pm). Tape-recordings were made continuously. The recorded activity was transformed into graphics (II). Notes were made on the graphs in order to separate the patients' activity from background noise and to identify episodes of vocal activity.
A scheme for the analysis of the vocal activity (covering 07.00 am-01.00 pm) was developed by listening to a sample of it from each of the 37 patients (II). The status of word production and the vocal content were analysed. Notes were also taken regarding the number, length and intensity of each period of vocal activity and what sort of activity the patient was involved in. The categorisation of word production and content was performed independently by two persons on 10% of the vocal episodes.

The tape-recordings were also typed out as for the verbal interaction taking place between caregivers and patients during the lunch-meal (VI). A theoretical framework was retroductively developed (Walker & Avant 1983) based on the tape-recordings and some literature. Three dimensions of verbal interaction were analysed; the content from a relationship aspect based on the Erikson theory of "eight stages of man" (1982), the content from a task/person aspect (cf Bales 1958) and the process of verbal interaction with regard to the clarity of cues and synchrony established during the process of interaction (cf Barnard 1981, Athlin & Norberg 1987).

A responsiveness index (cf Crow et al. 1980) between caregiver and patient was calculated by multiplying all the added numbers of interactions from each part by 100 and dividing the number of the interactions of the caregivers by the number of the interactions of the patients.

Interviews were performed with 17 caregivers, clinically experienced in the care of severely demented patients. In the presence of the author they listened to tape-recordings of the vocal activity of 2 demented patients, unfamiliar to them (III). Immediately afterwards they were asked to write down how they thought that the patients experienced their situation, if the behaviour had any communicative meaning, if so, what did it communicate, what kind of emotions the behaviour evoked in them as caregivers and lastly what they would have liked to do for these patients. They were asked not to think of the particular patients they had listened to but to rely on their experience of patients behaving like the recorded patients. Thus, the interest focused on the general type of emotions evoked by earlier patients.
The responses to the four questions were analysed regarding caregivers' interpretations of the experiences behind vocally disruptive behaviour and the emotions evoked in them. Open coding was used independently by two researchers (Glaser 1978). The categories identified were discussed until consensus was reached (Leininger oral communication 1987). In order to make sure that theoretical saturation had been obtained another similar group of 16 caregivers was selected after the first analysis (Glaser 1978).

Semi-structured observations (IV,V) were performed of 15 hours/patient between 07.00 am-10.00 pm by specially trained observers (RNTs, RNs). The observations were collected in 3-hour periods and spread over 2 to 4 weekdays. They focused on behaviour, activities and interactions between caregiver and patient. Notes were taken at 5-minute intervals. This method was decided on since the exploratory work had revealed that very little took place in the patient's life (Hallberg et al. 1986). Thus sampling techniques seemed difficult to apply (cf Armitage 1986). To minimize bias effects extra observations collected during the first 6 hours on each ward were discarded from the data analysis. The data collection took 4 to 5 weeks in each health district. The Kappa coefficient was used to calculate inter-observer reliability with regard to the agreement on the number (K 0.61) and the type of interaction (K 0.77) and activities (K 0.61 for numbers K 0.92 for type of activities). The Spearman rank correlation coefficient was used to calculate inter-observer reliability regarding the length of the interactions (rs 0.80) and activities (rs 0.82) initiated by staff. The data were analysed by the use of 95% confidence intervals (CI) and multiple regression analysis with group as the dependent variable (Polit & Hungler 1983).

The categories in focus for the observations and the structure of the analysis were outlined by the observations of a previous exploratory study (Hallberg et al. 1986). Observations were quantitatively analysed as for the type, amount and frequency of activities, and for the interaction and behaviour initiated by staff differentiated from those initiated by the patients themselves. Interactions were
labelled procedural, social, activating or corrective depending on what elicited them. The activities identified were hygienic care (washing, elimination, dressing) help to move, nutritional care (breakfast, coffee, lunch, dinner, etc.) medical care (e.g. blood tests), activities concerning safety and lastly activating care (personally initiated or supervised person activity, versus supervised group activity).

RESULTS

The distribution of diagnoses, age, duration of the disease and time spent continuously in institutions was similar in vocally disruptive patients and controls (Table 1). The regular and temporary intake of psychotropic drugs was higher (ns) in the vocally disruptive patients.

These patients were severely disorientated as for time and past and present events but their orientation to person was better preserved (I). They were highly dependent on their caregivers for their orientation at the ward, hygienic care, and elimination but less dependent for nutrition. Their speech performance was disturbed although to a smaller extent regarding receptive speech. Their state deteriorated episodically showing a high degree of anxiety, aggressive behaviour, irritation, hallucinations, illusions and perseverations.

There was no significant difference between the two groups regarding orientation to time, person or past and present events. However, the vocally disruptive patients were significantly more disturbed in their functional performance and orientation at the ward. They were also significantly more prone to confusional reactions (including anxiety) hallucinations and illusions but had a significantly better preserved speech performance and were less prone to sensitive reactions than the controls.

The patients identified as vocally disruptive exhibited vocal activity for a mean time of 161.1 minutes between 7.00 am-1.00 pm (II). The mean number of episodes was 19 and the mean length of the longest episodes/patient was 73.6 minutes. For most of the patients the vocal activity con-
## Table 1. Description of vocally disruptive patients (V) and controls (C).

<table>
<thead>
<tr>
<th></th>
<th>V (n=37)</th>
<th>C (n=37)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AGE (md)</strong></td>
<td>85 years</td>
<td>85 years</td>
</tr>
<tr>
<td><strong>SEX Female/Male</strong></td>
<td>24/13</td>
<td>24/13</td>
</tr>
<tr>
<td></td>
<td>(64.9%/35.1%)</td>
<td>(64.9%/35.1%)</td>
</tr>
<tr>
<td><strong>DIAGNOSIS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia of the Alzheimer type*</td>
<td>19 (51.4%)</td>
<td>21 (56.8%)</td>
</tr>
<tr>
<td>Multi infarct dementia**</td>
<td>11 (29.7%)</td>
<td>12 (32.4%)</td>
</tr>
<tr>
<td>Pick's disease</td>
<td>1 (2.7%)</td>
<td>1 (2.7%)</td>
</tr>
<tr>
<td>Dementia NUD</td>
<td>6 (16.2%)</td>
<td>3 (8.1%)</td>
</tr>
<tr>
<td><strong>DURATION OF DISEASE (md)</strong></td>
<td>5 years</td>
<td>6 years</td>
</tr>
<tr>
<td><strong>DURATION OF STAY AT HOSPITAL (md)</strong></td>
<td>2 years</td>
<td>2 years</td>
</tr>
<tr>
<td><strong>CONSTANT USE OF PSYCHOTROPIC DRUGS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuroleptica</td>
<td>25 (67.6%)</td>
<td>19 (51.4%)</td>
</tr>
<tr>
<td>Sedativa</td>
<td>8 (21.6%)</td>
<td>3 (8.2%)</td>
</tr>
<tr>
<td>Hypnotica</td>
<td>17 (45.9%)</td>
<td>10 (27.0%)</td>
</tr>
<tr>
<td>**TEMPORARY USE OF DRUGS *****</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-3 times</td>
<td>15 (40.5%)</td>
<td>9 (24.3%)</td>
</tr>
<tr>
<td>4-6 &quot;</td>
<td>4 (10.8%)</td>
<td>1 (2.7%)</td>
</tr>
<tr>
<td>7 or more</td>
<td>2 (5.4%)</td>
<td>1 (2.7%)</td>
</tr>
</tbody>
</table>

* 1 (2.7%) have both DAT and MID diagnoses
** 3 (8.1%) have both MID and DAT diagnoses
*** during time when observations were collected (2 weeks)

The vocal activity consisted of unarticulated sounds. However, it also developed into articulated words or sentences. The phrases or words were mostly expressions of helplessness, pain, protest, fear, despair or the need for someone else. Hence, they seemed connected to negative emotions. The vocal activity also consisted of long seemingly nonsense monologues which appeared to be emotionally indifferent, serving the purpose of self-stimulation rather than expressing emotions. Lastly, the vocal activity consisted of initiating dialogues or commenting, in an often irritated tone, on what was going on nearby the patient. Vocal activity occurred mainly when the patients were alone and inactive but also during the physical caring procedures. The analytical method used did not generate any patterns of occurrence that could be identified.
The caregivers interpreted the vocally disruptive behaviour as mostly intentional and meaningful although not always conscious (III). Their interpretations were allied to the experience of anxiety in the patients. Seven categories of interpretations emerged. They were, in order of frequency, anxiety about abandonment, anxiety about dissolution, anxiety about loss of autonomy, anxiety because of threats to integrity, expressions for bodily needs and reactions to the environment. Lastly, the behaviour was interpreted as imitative and automatic.

The dominating emotional reactions evoked in the caregivers were experiences of powerlessness and insufficiency as caregivers. The caregivers also felt irritation, fatigue, anger and guilt, sometimes even hate, for not being able to help. They found it very trying to provide care for these patients. On the other hand they described a strong wish to comfort, understand and help the patients; an expression of empathy and maternal affection for the patients was manifest in the responses.

The care provided for the vocally disruptive patients consisted of physical caring activities (hygienic, nutritional, medical care and activities to ensure safety) (IV). All in all, the mean time of such care was less than 1.5 hour. The mean time for activating care was 16.9 minutes for the vocally disruptive patients and 21.8 minutes for the controls. It was mainly individually organized and initiated by the caregivers but not supervised by them. Thus, the patients were pleaded to themselves and to passivity (89%) for most of the 15 hours observed. Left on their own the patients were involved in repetitive behaviour like clapping, rubbing and picking. Exhibiting vocally disruptive behaviour were most common in the study group and wandering in the control group.

The care provided was conducted in a rapid and fragmentary way, i.e. the caregivers came and left several times during the same procedure. Although the vocally disruptive patients were physically more dependent on their caregivers than the controls there were no significant differences in the care provided for the two groups. The only type of caring activities showing any significant relationship to vocally dis-
ruptive behaviour was a smaller amount of activating care. In conclusion the patients' daily life was characterized by idleness. They were left to solitude and inactivity except for the physical fragmentary and rapid care provided.

The verbal interaction between caregivers and vocally disruptive patients was elicited for procedural, social, activating and corrective reasons (V). The total time spent in interactions during the 15 hours of observation was in mean less than 1 hour and 15 minutes/patient elicited for procedural reasons, while social interactions lasted for less than 4 minutes. Activating interaction occurred during less than 1 minute, while interactions because of corrections of undesired behaviour occurred during 1.5 minutes.

Most of the verbal interaction episodes were shorter than 1 minute. Such short interactions occurred in about 44% of the procedural, 70% of the social, 72% of the corrective and 40% of the activating interactions. Hence, verbal interactions like caring activities were fragmentary and rapid.

Although more dependent, the vocally disruptive patients did not have more procedural interactions. Corrective interactions were the only type significantly related to being vocally disruptive even though social and activating interactions occurred more often in the controls. Both groups were reduced to isolation especially since the interactions taking place between them and other patients were sparse and visitors were rare. Thus, the dominant contact with another human being occurred when procedural matters were carried out.

The verbal interaction taking place during the lunch-meal focused on the task performed (VI). Few verbal messages had a personal character immediately before, during or after the procedure. The verbal content analysed for its relational aspect suggested that autonomy, identity and initiative (in order of how common) were given the strongest support. Verbal interactions supporting trust, industry, intimacy, generativity and integrity were seldom or not at all observed. Synchrony in interactions was found in 38-44% of the episodes during the initiating and working phases and less often during the terminating phase of the interaction. It
was established either because the caregiver gave clear cues, was sensitive, responsive and/or did not lose the communicative thread or because the patient was sensitive and/or clearly expressed what he wanted. When synchrony was not established it was either because the caregiver did not give clear cues and/or was not sensitive and responsive to the patient or because the patient did not respond.

### Hypotheses generated

**Environmental conditions and brain damage in interaction**

Spatial disorientation (Figure 2), physical dependence and the tendency to confusional reactions (I) in interaction with environmental factors like human isolation, long periods of inactivity and sedentary life (IV, V, VI) give rise to sensory deprivation due to the sparse human stimulation, the scarce auditory and visual stimulation and the poor stimulation of proprioceptive receptors (IV, V, VI).

The environmental conditions also give rise to periodic overstimulation due to the rapid and fragmentary way interaction and caring activities are performed in, as well as to the sound level, movements and persons at the ward which the

<table>
<thead>
<tr>
<th>INDIVIDUAL PREREQUISITES BESIDE THE GENERAL PROBLEMS OF DEMENTIA</th>
<th>INTERACTIONS WITH CONDITIONS OF DAILY LIFE</th>
<th>EFFECTS ON ONESELF</th>
<th>EXPERIENCES OF ONE'S EXISTENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>High degree of physical dependence.</td>
<td>Social isolation.</td>
<td>Lack of opportunities to have the I positively reflected in relation to the self, others and the world.</td>
<td>Experiences of fragmentation and meaninglessness.</td>
</tr>
<tr>
<td>Inactivity.</td>
<td>Lack of opportunities for self-fulfilment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disorientation at the ward.</td>
<td>Sedentary life.</td>
<td>Fewer stimuli for hearing, sight and proprioceptive receptors; sensory deprivation.</td>
<td></td>
</tr>
<tr>
<td>Tendency to confusional reactions.</td>
<td>Fragmentary caring interactions and activities.</td>
<td>Increased disorientation and confusional reactions.</td>
<td></td>
</tr>
</tbody>
</table>

**Fig 2.** **Environmental conditions and brain damage in interaction.**
vocally disruptive patient has difficulties to perceive and interpret adequately (IV, V). The sensory deprivation gives few and inadequate situations where the patient can realize himself which confronts him with nothingness. Hence, the vocally disruptive behaviour (II) is seen as an expression of anxiety or agony due to sensory deprivation.

**Emotional strain on caregivers**

The caregiver senses agony and distress (III) in the patient (Figure 3). She wishes to understand, comfort and help him but feels unable to offer any release from the agony (III). Thus, an emotional conflict arises in her. The care she provides (IV, V, VI) is performed in a highly task oriented and impersonal manner leaving the patient very much to himself. This means that the wish to comfort and release from agony or distress (III) does not manifest itself in action. The caregiver's experience of the vocally disruptive behaviour and the emotional conflict between what she would like to do (III), what she is able to do (III), and what she actually does (IV, V, VI), evoke defence mechanisms distancing her emotionally from her patient. Hence, an emotional withdrawal takes place in the relationship between the patient and caregiver, which in turn makes care more task oriented (IV, V, VI).

<table>
<thead>
<tr>
<th>CAREGIVERS' INNER SITUATION</th>
<th>INTERACTION WITH ENVIRONMENTAL CONDITIONS</th>
<th>EFFECTS ON CAREGIVERS</th>
<th>EFFECTS ON CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpretation of anxiety as the experience behind the vocally disruptive behaviour.</td>
<td>Task assignment system.</td>
<td>Emotional conflict between what is experienced as the right thing to do and what is possible to do in relation to what is actually done.</td>
<td>Defence reactions resulting in emotional withdrawal from the patient, focusing on the task at the expense of the person.</td>
</tr>
<tr>
<td>Desire to help and comfort.</td>
<td>Few caregivers.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No means to ease the patient of his anxiety.</td>
<td>No organized way of giving cognitive and emotional support to caregivers.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience of meaninglessness and helplessness.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Fig 3 Emotional strain on the caregiver evokes defence reactions.
DISCUSSION

The study aimed at describing patients exhibiting vocally disruptive behaviour from a broad perspective in order to obtain hypotheses that could be tested in further studies. Hence, the results represent a broad survey of severely demented patients at psychogeriatric wards, their behaviour, the care they receive, how caregivers experience this behaviour and react when caring for the patients. The hypotheses generated thus can only be applied to these settings and to demented patients in the final stages of the disease. On the other hand all patients identified as vocally disruptive at the psychogeriatric wards within a county council were included which makes it reasonable to believe that the data were broad enough to generate some valid hypotheses. Psychogeriatric wards were chosen since it was likely that they housed vocally disruptive patients.

No analysis has been done as for subgroups within the group studied. Therefore it cannot be excluded that the hypotheses generated might be more applicable to some subgroups within the group studied; for example, the patients exhibiting a high amount of repetitive behaviour or a high level of anxiety. Neither were any investigations made of side effects caused by drug treatment, which can in fact lead to problematic behaviour (cf Fatis et al. 1989). However, drug treatment can also be assumed to decrease problematic behaviour which might in turn have decreased the differences between the two groups.

The patients were identified by the caregivers using a broad definition of vocally disruptive behaviour which included rather than excluded patients. This method of identification was preferred to develop clinical definitions to be used in future research instead of applying a theoretically made up definition not based on clinical data.

By having the caregivers identify the patients there was the risk of bias. Their private likes or dislikes might have influenced which patients were identified (cf Kelly & May 1982). The alternative way of letting the researcher identify the patients would have been time consuming. A control group was used since the fact that patients were identified
as exhibiting vocally disruptive behaviour could be assumed to affect the care provided (Kelly & May 1982, Ingham & Fielding 1985). The control group was selected by lotting patients of the same sex and from the same wards as the patients exhibiting vocally disruptive behaviour. Other matching variables, such as use of drugs, main diagnosis, severity of the disease, may also be important. However, it would have been difficult to identify controls at the same wards which was considered to be the most important variable to match for.

The ratings were performed by caregivers who knew the patients well. This approach was chosen because patients could not cooperate in a test situation. The ratings reflected the patients' overt competence rather than their covert competence (cf Svensson 1984). There was again the risk that the caregivers' likes or dislikes influenced their ratings. Biased assessments should most likely have been reflected in the inter-rater reliability but this was satisfactory. The responses to the ratings were, however, skewed in the sense that most patients had high scores on most of the items, which influence inter-rater reliability positively. A principal component analysis was applied to bring the items into structures rather than using isolated items. Generalizations concerning the identified factor structure have to be made with caution since the sample was skewed (only severely demented patients).

Continuous tape-recordings (II, VI) of each patient identified as vocally disruptive were performed, which made it possible to base the qualitative analysis (I) on whole episodes of vocal behaviour. It is, however, a disadvantage that no tape-recordings were made of the patients in the control group. Therefore it cannot be excluded that they also exhibited vocal activity. Being identified as vocally disruptive might depend on the type, continuity and amount of such behaviour.

To gain insight into the experience behind vocally disruptive behaviour (III) interviews were based on the idea that transference, countertransference (Heinemann 1960) and projective identification (Ogden 1982) take place between patients and caregivers, using the caregivers as vicarious
informants for the patients. However, the caregivers' interpretation could be either projections of their own internal reactions to the patients or actual transference of emotions from the patient and sensed by the caregiver. The interpretations might also reflect the emotional reactions in both parties. Transference, countertransference and projective identification are believed to take place in the relationship between patients and caregivers and to evoke more primitive reactions if patients suffer from intense anxiety during long periods (cf Searles 1979). Haugsgjerd (1983 b) described this process as a transference of 'psychic pain' between patients and caregivers. The findings give insight into how caregivers interpret the experience behind such behaviour. Whether that also reflects some internal reality in the patients could not be confirmed. The caregivers' interpretation of the experience behind the behaviour pointed at anxiety which is in accordance with reports revealing that anxiety is often present in dementia (for ref. see introd. p 12). The results need further testing in experimental studies.

The observations (IV, V) were performed continuously. Thus, both tape-recordings and observations were collected in a time-consuming way. During the exploratory phase attempts were made to develop ways of sampling. However, it turned out to be difficult since the activities going on were few and irregular. By time sampling important information might have been lost due to the fact that an event is rather short and irregular (cf Armitage 1986). Video-recording would have been preferable or possible to use as a complement during interaction episodes for instance. The group of observers were different at each hospital. Thus, observations could have been negatively influenced by the observers performing the observations in different manners. To control such differences the introduction and continuous education were held by the same person throughout the data collection. Also control for inter-observer reliability was performed by the same two persons. Both observations and tape-recordings are believed to affect the behaviour of the persons recorded or observed (Polit & Hungler 1983) which might affect behaviour positively. If that is the case the
number of interactions and nursing activities would be overestimated rather than underestimated.

Firstly, the interpretation of the results was that vocally disruptive behaviour develops as a result of the interaction between the effects of environmental conditions (caring included); sensory deprivation and the brain damage in the severely demented patients. The vocally disruptive patients (II) were physically dependant, disorientated at the ward and prone to confusional reactions, to a higher extent than the group of controls. These conditions might be a consequence of the localisation of the brain damage (cf Hagberg & Ingvar 1976, cf Gustafson et al. 1978, cf Hagberg 1986) affected by the environmental conditions. The care provided for vocally disruptive patients could be expected to be adjusted to human basic needs, to the general meaning of being demented, to the individual person's functional capacity (cf Browne 1985) and in particular to the tendency to be anxious, confused, disorientated and physically very dependant. No such adjustments, were seen, however. Daily life offered few sensory stimuli. Nursing interventions consisted of limited fragmentary interaction episodes elicited for procedural reasons (V). The verbal interaction (VI) taking place was task oriented, supporting mainly the processing of the crises of autonomy versus shame and identity versus identity confusion (cf Erikson 1982), aspects that are more technically oriented than for example, trust and intimacy. Synchrony was vaguely established which can be supposed to increase confusional reactions rather than reduce them. The activities of daily life (IV) were characterized by idleness. Fragmentary and rapid physical care dominated which might be experienced as overstimulation by the patient and be combined with the sensory deprivation mentioned earlier. Thus, the care provided rather increased the experiences of 'not being able to understand' which in turn confronts the patients with nothingness and meaninglessness. This could evoke further anxiety. The patients exhibited a high amount of repetitive behaviour appearing to be either seemingly emotional indifferent or related to strong negative emotions. Hence, the studies gave evidence leading to the hypothesis that sensory deprivation plays a role in the develop-
ment of vocally disruptive behaviour. The fact that the controls lived under the same conditions without developing such behaviour might be explained by the fact that their brain damage affected their functioning differently and that they had a better preserved physical functioning which gave them other options to release themselves from the under-stimulation and social isolation (e.g. by wandering). Also the environmental conditions may have been more maladjusted to vocally disruptive patients because they had other needs.

Social isolation and understimulation are believed to increase problems like behavioural disturbances in demented persons (Ernst 1978, Haugen 1982). Sensory deprivation in normal persons seems to give rise to reactions such as anxiety, restlessness and confusional reactions (Ernst & Badash 1977, Zuckerman 1979). However, no studies have been found making clear what is to be regarded as sensory deprivation or social isolation for a severely demented person, or what can be regarded as a normal amount of stimuli and human contact. What the interventions used in the case-studies of vocally disruptive behaviour have in common is that they increase the amount of activities and human contact (for ref. see introd. p 19). However, that is not regarded as the treatment option. Thus, the effect of the interventions used supports the idea that sensory deprivation is present.

Secondly, the care provided was seen as a result of the caregivers' situation. They wished to help and they were confronted with patients with disturbed behaviour which they saw as an expression of anxiety about abandonment, about dissolution, and about loss of autonomy, due to threats to integrity etc. (III). The patients actually also expressed themselves in terms of helplessness, pain, protest and fear (II). Yet, care characterized by inactivity leaving patients to themselves was provided (IV, V, VI). As the caregivers felt unable to help the patients the described conflict was thought to elicit defence mechanisms in them resulting in emotional withdrawal from the patients and task oriented care.

The hypothesis is built on the assumption that the severely demented patients experience anxiety sensed by their
caregivers. This idea is supported by the results of the ratings (I) and by the fact that the patients themselves expressed words or sentences that in their content can be assumed to relate to anxiety: "Help, I cannot manage this! Can no one come!" (II). Also in the literature anxiety is frequently described as present in demented patients (for ref. see introd. p 12). The hypothesis is also built on the idea that there is some likeness between the anxiety present and existential anxiety on the one hand and/or the more global type of anxiety evoked in infants on the other. The interpretations of the experience behind verbally disruptive behaviour supported this (III). By the disturbed communicative ability loneliness was in fact present in both parties which probably evokes anxiety about separation in them. Caring for severely demented patients in itself is believed to provoke anxiety due to the continuous decline and severe changes of a human that caregivers are confronted with (Menzies 1970, Haugsgjerd 1983 b, cf Smith 1986). The caregivers interpreted anxiety as the experience behind the patients' behaviour. Moreover, the behaviour in itself possibly also puts some pressure on them. These factors taken together may increase the amount of anxiety in caregivers (cf Ogden 1982), who indicated that they experienced a conflict evoking strong negative feelings in them (III). In order to handle this anxiety defence reactions are believed to arise in them (Menzies 1970, Smith 1986, cf Åkerlund & Norberg subm). Hence, an emotional distance between patients and caregivers arises and makes the care provided focus on the task rather than on the patients' individual needs. However, this hypothesis is based only on a small group of caregivers and of assumptions needing further investigation. Thus, the data must be interpreted with some caution.

The hypothesis mentioned first (p 30) can be tested by implementing a kind of care that increases human contact and activities adjusted to the patients' capabilities and needs. Thus, the care must be outlined on the basis of a thorough assessment and analysis of the individual patient's needs and the environmental conditions. By a systematic approach to the patient (cf Laurence 1986) the emotions behind
vocally disruptive behaviour may be identified so that they can form a basis for the care provided.

The second hypothesis (p 31) can be tested by means of clinical supervision focusing on the caregiver's interpretations of the individual patient's emotional experiences and the caregiver's own emotional reactions to the patient and the caring situation. Hence, support should be given to the caregiver to enable her to deal with the anxiety evoked in her in relation to the patient. This relationship makes it necessary for her to be emotionally close to the patient and to take on a containing function (recognize anxiety and permit it to exist, respond to it in a manner that decreases it in the other person) (cf Bion 1977, cf Haugsgjerd 1983 a) and to separate what is evoked in herself by the patient's situation and what is sensed for herself. This close relationship is assumed to be complicated in the interaction with severely demented patients as the interpretations cannot be verbally confirmed.

There is little knowledge about how daily life is best adapted to severely demented patients' covert competence (cf Svensson 1984), basic needs for relationships and activities and about how an experience of wholeness and meaning is ensured for the patients. Continuity and contact with others might be connected to the experience of wholeness while cues and involvement in activities might be connected to the experience of meaning. If the hypotheses suggested are valid the care provided for vocally disruptive patients was untherapeutic rather than therapeutic for them. The informative conditions of the environment (of which care is part) are assumed to help establishing the concept of the self (cf Haugen 1982). The conditions described might have led to the patients' experiencing themselves in a fragmentary manner. The conditions of vocally disruptive patients, their relationships to others and the world seen from an existential perspective might evoke further experiences of desorientation and anxiety confronting them with nothingness and meaninglessness. From a psychological perspective anxiety of the earlier and global types like anxiety about annihilation or loss of others might be evoked. It seems reasonable to assume that the emotions cannot be held back or be deliber-
ately processed and are thus given full momentary expression or are regulated by repetitive activities (cf Goldstein 1952). Therefore, the severely demented patients' capacity to handle oneself, others and the world is reduced both by their own internal physiological and psychological capacity and by the environment's not being adapted to them.

A vicious circle seemed to start by the caregivers' sensing anxiety in the patients and experiencing anxiety in themselves. When trying to avoid this anxiety they involuntarily provided a situation that increased anxiety in the patients and so on. If this is the case it seems important to support caregivers in what they experience as difficult when caring for the severely demented patients exhibiting vocally disruptive behaviour (cf Svalander & Widén 1983). It is difficult to establish and maintain a therapeutic relationship that supports the experience of wholeness and meaning for the patients. The organisational structure (Miller 1985), leadership (Isohanni 1983) and clinical supervision must support and make the basic ideas of the person, health, environment and nursing intervention in general and of vocally disruptive demented patients in particular explicit and put into action in the care provided.

GENERAL CONCLUSIONS

The results of the studies reported gave support to the development of 2 hypotheses;
- Vocally disruptive behaviour in institutionalized severely demented patients develops as a result of the interaction between the environmental conditions (care included) and the effects of the brain damage on the person.
- The caregivers are influenced by an emotional conflict between what they wish to do and them experiencing an inability to do so, which elicits defence mechanisms resulting in emotional withdrawal from the patients and task oriented rather than person oriented care for the patients.

One can also conclude, that in spite of the fact that dementia is an organic brain disease it may from a nursing point of view be useful to understand the patient's situation from an integrated existential, psychoanalytic and
psychosocial perspective. Hence, the caregivers' interest should focus on the understanding of the experiences behind the vocally disruptive behaviour and on what the basic human needs influenced by the brain damage are. Anxiety seems to be an important emotion present in both patients and caregivers. To provide care that supports wholeness and meaning is seen as representing optimal health for the severely demented patient. In order to promote such experiences in the patient the caregivers can elaborate the environmental conditions, the interactions and the caring activities. These conditions taken together represent the therapeutic relationship between caregivers and patients, inheriting a possible release from anxiety and securing experiences of wholeness and meaning in both parties. Since it is extremely difficult and anxiety provoking to establish and maintain a therapeutic relationship with severely demented patients it must be strongly supported by supervision of the caregivers.
ACKNOWLEDGEMENTS

This study was carried out at the Department of Advanced Nursing, University of Umeå, in collaboration with the Department of Psychiatry I, University of Lund and the Care Research and Development Unit, Kristianstad College for the Health Professions, University of Lund. I would very much like to express my gratitude to everyone; relatives, friends and colleagues who have contributed, helped me and been supportive and understanding throughout this work.

I wish to express my sincere gratitude to:
- Professor Astrid Norberg, Umeå, for being so positive and encouraging, for criticizing me and all the time for trying to push me beyond the stage at where I was.
- Associate Professor Sture Rayner, Lund, for his continuous great interest in my work, for his support and for his interest in nursing research.
- Associate Professor Sture Eriksson, Umeå, for his patience when initiating me into the mysteries of statistical analysis.
- Dean and Director of Kristianstad College for the Health Professions Bernt Lindén who realized the importance of care research and provided the possibilities to carry it out.

I also would like to express special thanks to:
- patients, their relatives and staff for their support and cooperation
- my colleague, Ms Kristina Johnsson, as well as all the observers for their help in the data collection
- the former visiting Professors at the Care Research and Development Unit, Kristianstad College for the Health Professions; Professor Karen A Luker, Liverpool, for supervising the outline of the study, Dr Sally J Redfern, London, for her supervision during the data collection and Dr Barbara Wade, London, for statistical advice
- the administrative department at Kristianstad College for the Health Professions for all their help and willingness always to solve the critical problems occurring along the process, especially Ms Kristina Andreasson, Ms Margit Nilsson, Mr Herbert Ottebrink, Tommy Friberg and Bert Andersson and Ms Lisbeth Ochsner, librarian,
- my colleagues at the Department of Advanced Nursing, University of Umeå, for 'opening their door' when I came from the south and for their friendly never ending and skilful criticism, and Ms Inga Greta Nilsson in particular
- Mr Christer Forsberg, psychotherapist, Kristianstad, for fruitful criticism of the use of psychoanalytic theory,
- the staff at Kristianstad College for the Health Professions and the Care Research and Development Unit for their interest and support, and Ms Agneta Sternerup, Lunds' Computer Center.
- Ms Åsa Sundh, Department of English, University of Umeå, for revising the English.

Last and most I would like to thank my beloved children, Lina and Johannes, who have closely accompanied me along the road and always been so patient and shown me love and affection.

The study was supported by grants from the County Council of Kristianstad, the Medical Faculties, Universities of Lund and Umeå, Greta and Johan Kock's Memory, the Claes Grochinsky Foundation, The Freemason od Skåne, Skånska Provinsiallogen, Kristianstad and the Swedish Nurses' Association.
REFERENCES


Athlin, E., Norberg, A., Asplund, K. Caregivers' perceptions and interpretations of severely demented patients during feeding. A task assignment system. Scand J Caring Sci. Accepted for publication.


Åkerlund, B.M., Norberg, A. Isolation A psychological defense reaction to ethical conflicts in dementia care. Subm.
