QUALITIES IN THE SHORT LIFE
Psychological Studies Relevant to Patient and Spouse in Malignant Glioma

AKADEMISK AVHANDLING
som med vederbörligt tillstånd av Rektorsämbetet vid Umeå Universitet
för avläggande av doktorsexamen i medicinsk vetenskap
kommer att offentligen förvaras i Rosa salen (sal B), Tandläkarhögskolan,
Norrlands Universitetssjukhus, den 15 november 1996 kl.09.00

av
Pär Salander, leg psykolog.

Fakultetsopponent: Docent Ullabeth Sätterlund Larsson,
Tema kommunikation, Linköpings Universitet,
Institutionen för vårdlärarutbildning, Göteborgs universitet.

From the Department of Oncology
Umeå University, Sweden
ABSTRACT

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Pär Salander, Department of Oncology, Umeå University, Sweden

This thesis deals with psychological issues concerning patients with malignant gliomas, and their spouses. There is no known medical cure, and the patients have a limited survival expectancy. Therefore studies evaluating new treatment modes, an overall supportive atmosphere, and attempts to avoid imposing unnecessary strain are necessary.

Thirty consecutive patients with astrocytomas, grade III-IV, were included in a clinical trial with estramustine phosphate in addition to conventional treatment with surgery and radiotherapy. Both the patients and their spouses participated in the present study which aimed at a deeper understanding of the psychological processes relevant to their situation. By means of repeated thematically structured interviews, patients and spouses were followed separately during the entire course of the disease process. In addition to these interviews, all patients were assessed with a mini-mental examination, and five-month survivors were tested with a comprehensive neuropsychological battery. Questionnaires on reaction to the diagnosis and assessing psychosocial well-being were also administered to the patients.

The interviews were analysed with grounded theory methodology and the findings were juxtaposed to concepts in psychoanalysis and coping theory. The main finding was that the patients, despite or owing to their severe medical situations, showed a marked capacity to create protection and hope. By means of biased perception they created an 'illusion' that palliated their strain. This finding is related to object-relational psychoanalysis with obvious implications for the crucial discussion on telling bad news. Another finding was that the spouses displayed different crisis trajectories depending on the overall status of their partners. Different senses of the relationship were related to different modes of coping. Especially spouses to patients with personality changes were put under severe strain and ought to be acknowledged by medical staff. Patients with no obvious deficits five months after termination of primary treatment nevertheless evidenced, at neuropsychological testing, a pronounced deficiency in long-term memory, but no clear impairment in global intellectual capacities. Estramustine phosphate was found to have a negative impact on sexuality and might be one causative agent behind the decline in long-term memory, but these adversive effects did not seem to affect psychosocial well-being. The selective reminding technique proved to be sensitive in detecting deficits and is recommended in future clinical trials affecting the CNS.

Key words: astrocytoma, communication, coping, defence mechanism, denial, glioma, hope, memory, neuropsychology, quality of life, spouse.
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Pär Salander
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To my daughters
Johanna, Stina and Sofia
"The real voyage of discovery consists not in seeking new lands, but in seeing with new eyes"

Marcel Proust
ISBN 91-7191-236-3

Cover illustration: Sofia Salander, 8 years

Printed in Sweden by
Solfjädern Offset AB
Umeå 1996
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Key words: astrocytoma, communication, coping, defence mechanism, denial, glioma, hope, memory, neuropsychology, quality of life, spouse.
This thesis is based on the following papers, referred to in the text by their Roman numerals.

I  The creation of protection and hope in patients with malignant brain tumours.  
Salander P, Bergenheim T, Henriksson R.  

II  Long-term memory deficits in patients with malignant brain tumors.  
Salander P, Karlsson T, Bergenheim T, Henriksson R.  

III  Brain tumor as threat to life and personality: The spouse's perspective.  
Salander P.  
*Journal of Psychosocial Oncology* [in press 1996;14(3)].

IV  How to tell cancer patients - a contribution to a theory of diagnosis-communication.  
Salander P, Bergenheim AT, Bergström P, Henriksson R.  
Submitted, 1996.

V  Sexuality, psychosocial well-being and cognitive function in patients with malignant glioma treated with estramustine in addition to radiotherapy.  
Salander P, Karlsson T, Bergenheim AT, Henriksson R.  
Submitted, 1996.
INTRODUCTION

The human brain consists of more than 180 billion cells. Fifty billion of these cells are directly engaged in information processing and each of them reach up to 15,000 physical connections from other cells (Kolb & Whishaw 1990). The brain is structured in such a complex way that we still know very little about it. It is significant to basic processes constituting life; it is the center of mobility, perception, cognition and emotion. In short: it makes us the people we are, to ourselves and to our loved ones. In a sense, the brain is the creator of civilization, computer technology, social welfare, the Alhambra in Granada, nuclear weapons, poverty and the B-52 bombing of Hanoi.

Acknowledging the importance of the brain, diseases in the brain are phenomenologically perceived as a threat of very great dignity. Due to the possible social and psychological impact, a disease in the brain challenges neuroscience and requires interdisciplinary co-operation with psychology.

This study is about malignant glioma, the most common primary brain neoplasm. It is a combined effort involving medicine and psychology to benefit both the patient and the spouse.

CLINICAL BACKGROUND

Epidemiology and aetiology

The annual incidence of primary intracranial tumours is about 17 per 100,000 inhabitants. Approximately half of these tumours are of neuroglial origin and among the neuroglial tumours the malignant gliomas (astrocytomas grade III and IV according to Kernohan and Sayre [1952]) account for the majority (Kallio 1988).

In northern Sweden the annual incidence of malignant gliomas during 1977 to 1985 was about 4/100,000 (von Schoulz 1990) which is in accordance with what has been reported from other countries (Kallio 1988). Since there are around one million inhabitants in the catchment area of the University Hospital in Umeå the expected annual incidence is 40 patients.

The age distribution shows a peak incidence for malignant gliomas in the age group 50-59 years with a slight preponderance for men (Kallio et al 1991). Concerning the causes of the disease, associations have been found with exposure to chemical substances, to electromagnetic radiation and radiotherapy, to head trauma, and to high socioeconomic status (Demers et al 1991). However, many of these suggested factors have been disconfirmed in other studies, and in a comprehensive review (Thomas and Waxweiler 1986) it has been concluded that the evidence suggesting environmental factors is not conclusive. Although hereditary genetic factors seem to play a minor role in the aetiology, they deserve more attention (Bergenheim 1994).
Diagnosis - treatment - prognosis

Even if computed tomography (CT) is a powerful diagnostic tool, the definite diagnosis is possible only through surgical efforts obtaining specimens for histopathological examination (Bergenheim 1994).

In addition to obtaining tissue for histopathological diagnosis the goal of surgery is to debulk the tumour and relieve symptoms of raised intracranial pressure. However, radical surgery is not possible due to the characteristic way the malignant gliomas grow with arms of proliferating tumour tissue and migration of tumour cells into normal tissue (Salford et al 1988). Extensive surgery prolongs the expected median survival from a couple of months to four to seven months (Salman 1994).

Radiotherapy is a well-established treatment of malignant gliomas. As it is well-known that radiotherapy may cause damage to the CNS (Gamis et al 1991, Wara and Larson 1991, Mulhern et al 1991, Schultheiss et al 1995) there has been a change in the administration from whole brain irradiation to irradiation of limited fields. This does not seem to impair the prolongating effect on survival (Sheline 1990). A common radiotherapy schedule is daily fractions of 2 Gy up to 56-60 during a period of six weeks. Combined with surgery the median survival time is increased to ten to twelve months (Sheline 1990). The potential contributions from chemotherapy, immunotherapy and other treatment modalities are less clear but under discussion and development. Overall, less malignant histology, young age, good performance status measured as Karnofsky index (Karnofsky et al 1948) and possibility of surgical resection, seem to be prognostically favourable factors (Kallio et al 1991).

Despite treatment the malignant glioma is a disease with an extremely poor prognosis. Therefore, any new treatment modality harbouring a beneficial role for the patient should be carefully evaluated.

General neurological and mental manifestations

The variety of the clinical presentation of the supratentorial malignant glioma is nearly unlimited. Even if it is a simplification, it is conventional to consider the signs and symptoms as either general or focal. General manifestations of the tumour reflect increased intracranial preassure. Focal manifestations are due to extensive cerebral involvement by the tumour with destruction of surrounding tissue and possible metabolic abnormalities. The most common general symptom is intensive headache, later in the disease process frequently accompanied by nausea, vomiting, papilloedema and sometimes dizziness and instability (Kraemer and Bullard 1994). Mental changes may range from minor disparities in cognitive function and subtle changes in personality to psychomotor asthenia and depressed consciousness. Impairment in judgement, reasoning and verbal fluency may occur, and the patient may give an impression of apathy and
somnolence (Harsh and Wilson 1990). A seizure is another of the more common presenting symptoms, and it is often experienced as dramatic.

**Frontal neurological and mental manifestations**

Focal manifestations due to lesions in the frontal lobe may produce effects in the realms of movement, behaviour, personality and cognition. Tumours affecting the precentral gyrus may result in different forms of motor deficits, as dynamic apraxias (Luria 1980), loss of strength and speed in contralateral hand and limb movements, or hemiparesis affecting arms or legs or both (Harsh and Wilson 1990, Kolb and Whislaw 1990). Different forms of aphasias may occur due to tumour infiltration around Broca's area, primarily acting on the patient's ability to speak spontaneously and fluently (Brown 1985).

Even if it is a consistent finding that lesions to the frontal lobe may cause personality changes, these changes vary from patient to patient. The change is more prominent in cases of bilateral involvement (Kraemer and Bullard 1994). That dramatic removal of unilateral frontal tumours and frontal brain tissue may cause only limited but subtle changes is demonstrated by a classical case described by the renowned Dr. Wilder Penfield (Penfield and Evans 1935). His colleague extirpated the right frontal lobe of Penfield's sister who had developed an oligodendroglioma. She recovered rapidly after the operation and resumed her duties as wife and mother of six children. The neurosurgeon concluded that she was her normal self. According to Dr. Penfield's evaluation she in fact retained her humor, memory, intelligence, power of insight and social relatedness. However, when once visiting his sister, Penfield noticed her inability to properly prepare a dinner. He concluded that she had lost her capacity for planned administration. Problems with initiative and with sustaining a complex, purposeful and goal-directed behavior, not easily detected in a structured test situation, are often associated with damage to the dorsolateral areas of the frontal cortex (Luria 1980).

Executive dysfunctions can be conceptualized as, in different degrees, relating to volition, planning, purposeful action and effective performance, implying self-correction and self-monitoring (Lezak 1995). The patients may manage well in a highly-structured and well-acquainted situation, but, in spite of preserved intellectual capacity, they dramatically fail when it is up to themselves to bring about goal-directed behaviour. Disorders in personal autonomy in patients with frontal lesions resulting in proneness to imitation and utilization behaviour have been described by Lhermitte under the heading of 'environmental dependency syndrome' (Lhermitte et al 1986, Lhermitte 1986). The patients become easily distracted (Goldberg and Costa 1987). Severe lesions may result in apathy, inertia, indifference and an inability to manage activities of daily living (Stuss and Benson 1984).

Another classical and illustrative case of frontal lobe lesion is that of Phineas Gage (Kolb and Whislaw 1990, Damasio 1994). In 1848, Phineas Gage survived a dynamite
explosion that blasted an iron tamping bar through his left cheek, through his frontal lobe and out of the top of his head. From being appreciated as fair and "the most efficient and capable" foreman he momentarily "was no longer Gage". He became:

"fitful, irrelevant, indulging at times in the grossest profanity, manifesting but little deference for his fellows, impatient of restraint or advice when it conflicts with his desires, ..." (Blumer and Benson 1975, p.153).

Although his perception, memory, language and overall intelligence seemed intact, he could not resume his work, but lead a wandering life. He lost his reason and his ability for social interaction. Typically these more obvious personality changes are associated with bilateral orbitofrontal lesions (Harsh and Wilson 1990). The lack of social skill may be seen as an expression of loss of self-awareness and self-reflectedness (Stuss and Benson 1987).

In a classical comprehensive Swedish study of frontal brain tumours Rylander (1939) found that the patients' premorbid personal characteristics seemed to become more prominent. Thus people who were cheerful and easy-going seemed to become more euphoric while others accentuated their withdrawal and dysphoria.

Temporal neurological and mental manifestations

Tumours in the temporal lobe may cause different alterations in movement, hearing, vision, speech and memory (Harsch and Wilson 1990). A sense of disequilibrium with a tendency to fall to the contralateral side and ataxia may occur (Harsh and Wilson 1990). Among the perceptive disturbances is the problem in the selection of auditory and visual input. This implies a difficulty in processing simultaneous information (Kolb and Whislaw 1990). Tumours around Wernicke's area may result in auditory agnosia for speech, i.e., an inability to comprehend spoken language. The patient speaks fluently but seem to have lost the knowledge of the basic rules of the acoustico-semantic relations. Her/his speech becomes incomprehensible due to paraphrasic errors and neologisms (Baker et al 1981). Other patients develop anomia. They have a preserved language comprehension but difficulties in naming objects in general or in naming specific categories of objects (Ellis and Young 1993).

In 1953 a man who had long suffered from major epileptic seizures underwent surgery with bilateral resection of the medial temporal lobes and hippocampal areas. The operation resulted in a nearly complete anterograde amnesia and he became the classic case 'HM' (Ellis and Young 1993). Ever since, the neocortex of the medial temporal lobes and the hippocampus, more than any other area, have been related to long-term, or secondary, memory (Baddely 1986).
Parietal neurological and mental manifestations

Lesions close to the sensory cortex and its association area may lead to defects in discriminant sensation and to an inability to integrate sensory data concerning the body's spatial relationships (Harsh and Wilson 1990). In the controversial Gerstmann syndrome the patient is unable to indicate his own fingers. Other symptoms associated with this syndrome are: inability to write, perform mathematical operations, and right-left confusion (Botez 1985). These symptoms, especially agraphia and acalculia, together with aphasias, are more typical signs of left parietal lesions. Some of these aphasic patients have a reasonable capacity to understand spoken and written language but are unable to write or speak due to the use of inappropriate and meaningless words. Others show fewer signs of communication deficits but are nearly completely unable to read or write (Botez 1985). Others still have all these abilities with the exception of the capacity to make use of prepositions and expressions with a spatial content (Luria 1980).

Disturbancies due to right parietal lobe lesions may display more obvious effects on spatial processing. Tumours may disrupt the integration of sensory and spatial information with a detrimental effect on evaluation of spatial relations and on movements in space. As a result failures in geographical orientation, dressing apraxias, constructional apraxias and lack of awareness of the contralateral visual field (visuospatial neglect) may occur (Ellis and Young 1993).

Concerning memory it has been shown that the parietal areas are crucial to primary, or short-term, memory (Warrington and Weiskrantz 1973). It has been proposed that lesions may cause impairments due to deficits in the integration of sensory inputs (Kolb and Whislaw 1990).

Occipital neurological and mental manifestations

It is rare to find malignant gliomas affecting the occipital lobe. However, lesions may in different ways alter vision, cause visual field defects or cause illusions and hallucinations (Joynt et al 1985). When encroaching upon the parietal junction, different forms of agnosias may occur, as for instance an inability to recognize colors or familiar faces (Kraemer and Bullard 1994). If, instead, the tumour invades the splenium of the corpus callosum, it may result in a reading disability with a preserved capacity to write (Joynt et al 1985). Overall, the manifestations of lesions in the occipital area are related to the parietal lobes due to the sensory and speech areas in the adjacent parietal lobes (Harsh and Wilson 1990).

Concerning site and manifestations

With this rhapsodic and dense description of possible manifestations of different tumour sites in mind, it may not be out of place to remind the reader that brain tumours manifest themselves differently from patient to patient. The clinical presentation may, or
may not, be dramatic. The fact that tumours manifest themselves differently from, e.g., stroke, has convincingly been shown by Anderson et al (1990). By comparing lesions by tumour and stroke anatomically matched for location and size they revealed marked differences as regards symptoms. The authors concluded that cognitive impairment resulting from a tumour is relatively mild. However, the variability in the tumour group is great and cases of extensive tumours may even be associated with normal cognition. As an example, none of the patients with tumours involving Wernicke's area had paraphrastic speech in contrast to nearly all in the stroke group. This is probably possible because tumours, at least initially, replace more than destruct neural structures. It has also been proposed that patients with malignant intrinsic brain tumours manifest greater cognitive deficits than patients with less progressive tumours and that this difference more amounts to neuropsychological measures than to psychometric intelligence (Hom and Reitan 1984)

There are differential deficits in lateralized tumours: left hemispheric lesions are often associated with verbal deficits and right hemispheric lesions with performance deficits (Hom and Reitan 1984, Gubta and Jain 1990). However, the strength of the association between tumour site and neuropsychological manifestations has been questioned by several investigators (Kanzer 1942, Haas et al 1982, Fisk and Del Dotto 1990). Haas, for instance, found that all left hemispheric tumour patients in their study evidenced anomic aphasia irrespective of more specified tumour location.

In a recent study, Lilja et al (1992) suggested that patients with malignant gliomas, in contrast to other lesions, display more signs of 'panic-related anxiety' and 'pathological regression' on a test monitoring subconscious processes. The outcome was not related to tumour site. There is also a discussion with respect to hemispheric differences concerning emotional states. Left hemispheric lesions have been found to be associated with anxiety and depression, and right hemispheric lesions with euphoria and indifference (Goldstein 1948, Gianotti 1972, Starkstein et al 1987). It has been proposed that this difference is related to hemispheric specific defects regarding affective communication (Heilman et al 1993), but others have shown that a self-administered personality inventory, MMPI, also reveals similar hemispheric differences (Gasparini et al 1978). However, others question whether there really exists any hemispheric assymetry as regards depression (House et al 1990).

The previous description of focal manifestations is mainly based on implications from studies of more or less clear-cut cases and small homogenous groups. Case study is the proper method in neuropsychology because it enables a deeper understanding of the working brain, and thus facilitates the development of theories of the functional organisation of modules responsible for normal and abnormal brain activity (Ellis and Young 1993). When the prominent incentive to knowledge is limited to a clinical description of typical deficits and range of deficits of a patient population, it may be more appropriate to carry out a quantitative assessment based on relevant neuropsychological
tests (Hannay 1986). Within this perspective, there are few studies aimed at an assessment of cognitive abilities in glioma victims.

**Cognitive assessments**

The severity of the symptoms in brain tumour patients increases the urgency or need for appropriate treatment. An assessment of higher cortical functions is therefore a manifestation of the disease, but also of the applied treatments. Concerning children, an increasing number of studies report neurocognitive impairments, including learning disabilities, memory deficits and decline in global IQ (e.g., Lannering et al 1990, MacLean et al 1995, Schultheiss et al 1995). In adults, the outcome of the limited number of studies is less conspicuous.

Neuropsychologic impairments in long-term adult astrocytoma survivors, treated with radiotherapy and chemotherapy in addition to surgery, were first reported by Hochberg and Slotnick (1980). They selected patients who had not been able to return to work or to reestablish social relationships at least one year after termination of radiotherapy, despite being able to care for themselves and without signs of tumour recurrence. The patients (9/13 high grade gliomas) demonstrated a performance consistent with estimated premorbid ability (verbal IQ on WAIS). In contrast, tests that required attention and immediate problem-solving ability were performed more poorly. The diffuse impairments were not related to tumour site, and focal deficits appeared insufficient to account for the impairment. They concluded that diffuse impairment of cerebral functioning may prevent long-term survivors from returning to previous occupational and social relationships.

Another similar but prospective study evaluated a heterogenous group of 49 brain tumour patients who had received different schedules of radiotherapy and/or chemotherapy (Maire et al 1987). They found an impairment with respect to operational tests but with preserved full scale IQ (WAIS) from five months after termination of primary treatment. In studies of long-term survivors analogous difficulties with performance are found, but severe cognitive impairment as well as dementia may also be present (Awwad et al 1990, Imperato et al 1990).

**Everyday life assessment**

Studies addressing the everyday life of brain tumour patients are mainly restricted to the patient's functional status by Karnofsky performance status (Karnofsky et al 1948) or similar assessments determined by the physicians. This is primarily due to the fact that these studies are clinical trials comparing the outcome of different treatment regimens. Several studies, for instance, have shown that the functional status improves as an outcome of chemotherapy in addition to surgery and radiotherapy (e.g., Müller et al 1985, Stewart 1989, Knerich et al 1990). However, placing performance status on a par with assessment of everyday life has been shown to be insufficient, especially when evaluating...
patients that are functionally better off (Mackworth et al 1992). By and large, there are only a few studies directed to a broader psychosocial evaluation of brain tumour patients' everyday lives.

In a study of six long-term (> 5 years) survivors of malignant glioma the patients did not manifest anxiety (HAD-scale) but complained of impaired quality of life mainly due to loss of independence and self-confidence related to altered appearance following treatment and the incidence of seizures. Two of these patients were able to resume work and a close to normal family life (Awwad et al 1990). Similarly, Lieberman et al (1982) evaluated patients treated for high-grade glioma and found that only one out of eight long-term survivors (> 2 years) maintained an independent lifestyle. In contrast, Kleinberg et al (1992) selected 30 patients, mainly with high-grade gliomas, recurrence-free one year (median 3.5 years) after completion of radiotherapy and detected that more than 60% had resumed work. Interestingly they noted that no patient who did not return to work within four months after completion of radiotherapy was able to return to work at a later date.

Structured interviews and self-assessments to evaluate the well-being of patients with low-grade gliomas were utilized by Taphoorn et al (1992). The patients experienced personality changes, and the most common complaints were fatigue and sleepiness. The patients also showed an increased mean score on depression and anger. Notably, the partner's view on the patient's everyday life-functioning was generally more critical.

**Impact on spouse and family**

There are studies focused on families of children with brain tumours, but to the best of our knowledge there are no studies addressing the family issue of adult brain tumour patients. However, from the precedings and from acknowledging the impact on family life due to personality change/psychological problems in the field of closed head injuries (e.g. McKinley et al 1981, Brooks 1985, Liss and Willer 1990), it is obvious that this is a crucial area (Goldberg and Tull 1983, Amato 1991, Guingouain 1991). This is also underlined by studies on spouses of patients with other neoplastic diseases (e.g., Northouse and Northouse 1988, Keitel et al 1990, Howell 1986). These studies emphasize the stress put on spouses of cancer patients, that feelings of helplessness are common, and that the spouses' overall well-being may be affected.

The spouses of patients with brain tumours are important as informants of the patient's condition (Penfield and Evans 1935, Rylander 1939, Christensen 1989, Taaphorn et al 1992), but even if the presumable influence on their own life circumstances has been acknowledged (Fallowfield 1995) it has obviously been overlooked as an area of research.

In summary: Although substantial research has been devoted to neurological and behavioural effects of brain lesions and brain tumours, there is significantly less knowledge regarding neuropsychological effects of the malignant glioma disease.
Furthermore, there are hardly any systematic studies about the everyday life of these patients, and there is no systematic knowledge about how these patients and their spouses deal with their new life situation. The gloomy prognosis might explain this current lack of knowledge, but it also motivates studies that, not the least, may make it easier for the medical staff to avoid putting unnecessary strain on the patients and their families.
AIMS OF THE STUDY

The overall purpose of this study was initially expressed in broad terms. It was very much embodied in the typical starting-point for grounded theory research, and could be phrased as, "What is going on here psychologically?". We wanted to know more about psychological factors of clinical relevance around the short lives of the glioma victims by consecutively following a number of patients and their spouses during the entire course of the disease process. Gradually, during the continuing research process, some areas crystallized as being of special interest.

Because the patients were included in a clinical trial, it was also of great interest to study side-effects and to evaluate neuropsychological performance. The analysis of available data was primarily focused around six subsequent goals.

* To describe a consecutive group of patients with regard to clinical presentation and mental manifestations in an everyday life context.

* To investigate conscious, but mainly subconscious, psychological ways the patients and spouses dealt with the threat from the severe malignant glioma disease.

* To relate the findings regarding the patients dealing with their strain to contemporary psychoanalysis as a starting point to a model for telling bad news.

* To describe the brain tumour disease out of the spouse's experience and to discuss available coping strategies.

* To implement a comprehensive neuropsychological investigation in a homogenous group of patients with respect to diagnosis, treatment and time of assessment.

* To evaluate possible side-effects of treatment with estramustine phosphate in addition to surgery and chemotherapy, especially effects concerning sexuality, psychosocial well-being and neuropsychological performance.

The all-embracing ambition was to discuss the findings in relation to everyday clinical practice: how to fish out means and actions that may support the subjects, and how to avoid blunders that may affect patients and spouses negatively. In brain tumour disease much of the anguish of cancer diseases is condensed. Thus, findings from this thesis may also be of value in discussing patients' conditions outside the studied group of patients.
PSYCHOLOGICAL CONCEPTUAL FRAMEWORK

The theory of psychoanalysis or, in broader terms, dynamic psychology, holds a special place when discussing how to take care of patients who are traumatized or put under severe strain. Clinically it is the frame of reference for the development of the theory and methodology of crisis-intervention (Bellak and Small 1965). Psychoanalysis also constitutes the basis of the widespread research on coping behaviour. Prominent pioneers within coping research are trained within the psychoanalytic community and/or make use of psychoanalytic concepts in a qualified manner as a starting point for research and theoretical development. A threat causes anxiety which activates some sort of manoeuvre to eliminate anxiety and thus restore equilibrium.

PSYCHOANALYSIS - DEFENSIVE PROCESSES

In an essay entitled "The neuropsychoses of defense" from 1894 Freud made use of the term 'defence' for the first time. In this essay he also touches upon basic themes that will constitute the skeleton of the psychoanalytic theory of defensive processes (Sjöbäck 1973). He stated that a disturbance in normal mental functioning may be caused by an 'idea', i.e., a perception, a thought, or a memory. A distressing affect arises and the person tries to ward off the idea by a more or less conscious act of forgetting. Freud furthermore introduced the concepts of 'mental energy' and that warding off might imply that the non-acceptable idea becomes separated from its 'excitation'.

Even if continously transformed this early paper very much comprises the skeleton of psychoanalytic theory. After further clinical practice and self-analysis Freud stipulates that the mental energy is instinctual and primarily of a sexual nature, the 'mental apparatus' is invented and the topographical hypothesis defined by its conscious, preconscious and unconscious systems. These systems correspond to different functional (primary process/secondary process) and motivational (pleasure principle/reality principle) characteristics. The hypothesis deals with the accessibility of mental content and a censorship, which by means of 'repressions' carry out the duty of a "watchman of our mental health" (Freud 1900, p. 567). Successively other mechanisms were added to the repressions.

However, in clinical practice the topographical hypothesis displayed contradictions and was abandoned. Freud replaced it with the tripartite model which is more complex and constituted by the three systems, id, ego and superego. These systems are related to the former topographical systems as well and to their functional and motivational characteristics. The tripartite model was more flexible and ready to deal with conflicts and thus evidenced a greater capacity to encompass clinical findings. When confronted with external or internal events that cause unmanagable excitation it is the task of the ego to
effect its function, i.e., "the task of self-preservation" (Freud 1933, p.145). Anxiety is set as the immediate operative cause of these tasks, i.e., the defensive processes. Anxiety is the affect proper that causes repression.

The theory was launched in 1923 in "The Ego and the Id" and has ever since then remained basic in psychoanalytic theory. It is based on the thought that instinctual energies and internal sources are the primary targets of the defensive processes. External reality may also be the target, but this refers to that external reality gives rise to temptations of instinctual drives. According to Fenichel (1946), the defensive attitudes that are directed to the external world and the instincts can by no means be separated; where there is 'denial' there is also 'repression'.

Defense processes against external reality

After Freud's early notion that defensive processes were directed against external threats and after the invention of the hypothesis of mind, he was mainly concerned with the antagonism within the systems. Freud also acknowledged that the question of defences against external threats was an unresolved issue (Freud 1895). However, in the 1920s he touched on the matter in a couple of essays, including "The Loss of Reality in Neuroses and Psychoses", "The Infantile Genital Organization" and "Fetischism" (Sjöbäck 1973). The thesis in these papers seems a bit contradictory, due to successive reconceptualizations but, according to Basch (1983), also due to German-English translating difficulties (the different meanings of 'Verleugnung').

Following Basch, Freud actually discussed (more clearly from 1927) two different defensive processes in relation to external reality, 'denial' and 'disavowal'. By the former he meant the psychotic's repudiation of reality. By the latter the more common situation where the percept had not been repudiated, but its significance to the observer had evaded by means of for example distortion, rationalization or misinterpretation. According to Freud, the little boy does not deny that the little girl lacks a penis but he avoids anxiety by disavowing the personal significance of this sight (Freud 1925). In another paper he discusses two sons dealing with the trauma of the death of their father. The sons oscillate between refusal and acceptance, the important point being that both attitudes are at the same time present but alter as to domination (Freud 1927).

Painful reality is avoided by a split that permits simultaneous acknowledgement of reality and the wished-for situation to take place. When unable to simply turn away the disavowal is a compromise that, in traditional terms may be said to sense both the reality and the pleasure principle. Disavowal is an ubiquitous defence against external reality in the same sense as repression is directed against demands emanating from the internal world (Freud 1940). Freud's subsequent advocates, including Anna Freud, have not embodied the above presented distinction between denial and disavowal. A common position is to regard denial as the proper defence against external reality, non-pathological
in childhood but pathological in adults. Denial comprises the repudiation of aspects of reality by fantasies and day-dreams (A Freud 1946).

Examples of typical defensive processes

Over the years, Freud's theory of defensive mechanisms has been elaborated and commented upon by other theorists. New hypotheses have evolved reflecting the development of psychoanalysis from a theory purely focused on instinctual drives to a theory that embodies the importance of social relationships. Interpersonal and social behaviour is no longer confined to being a secondary by-product to biological drive (Eagle 1984). This challenge to traditional Freudianism was opened up from within by psychoanalytic ego-psychology in the fifties. Hartmann (1964) typically emphasized that there was behaviour and mental functioning independent of instinctual drives. The acknowledgement of the social world as a primary cause of psychic conflict and adaptation, to a different extent, has exerted influence on main streams in contemporary psychoanalysis, e.g., the object-relational school (Kernberg 1983) and the Chicago school of psychoanalysis (Kohut 1977). Kohut is a prominent advocate of those repudiating instinct theory. His self-psychology is centered around a separate line of narcissistic development. The instinctual drive is replaced by the striving for a cohesive self and for self-esteem, and the interpersonal world are made objects of this self. Development is equal to the ability to gradually relinquish the use of self-objects to an increasing ability to rely on oneself. Due to a child's own lack of power the parents that were made self-objects by idealization can successively be regarded as separate persons. The threat that may need defensive manoeuvres in ongoing life is not a libidinal danger but a danger to the self and self-esteem. Even if Kohut does not discuss defensive processes in line with Freud, it is reasonable to look at his strategies for developing and maintaining a cohesive self as phenomena parallel to defences.

The presentation below of some defences relevant to the present research consists of more traditional concepts and concepts from modern analytic theory. Denial and disavowal are omitted as they have been presented above.

Introjection

Introjection is primarily the prototype of instinctual satisfaction. It is a matter of 'taking in', thus very much the opposite of the more well-known 'projection'. However it may also be seen as the prototype of "regaining the omnipotence previously projected onto adults" (Fenichel 1946, p.148) and thus given a more social content.

Identification

In contrast to introjection, identification implies a change in the self-image of the identifying person in line with the identified. It is therefore more thorough than taking in
clearly-defined ideas. The rationale behind identification may be both love and affection as in anaclitic identification and fear or hatred as in identification with the aggressor (Sjöbäck 1973). Identification is basic in personality development.

Isolation
The essence of isolation is keeping apart that which actually belongs together. Spatial or temporal intervals may be interpolated to separate the two realms that are to be kept apart. Separating spheres of life, contradictory feelings, ideas from their emotional cathexis are different expressions of isolation. Different kinds of phobias, as well as fairy tales dealing with the good mother and the wicked, are examples displaying isolation (Fenichel 1946).

Reaction formation
The impulse is expressed by an opposite or contradicting attitude. It may be detected by its reinforced nature. The typical example of reaction formation is when exaggerated cleanliness or sense of order disguises instinctual demands for dirt or disorder (Fenichel 1946).

Undoing
Undoing resembles reaction formation, but goes a bit further. Something is done which actually or in imagination is the opposite of something done before. Typically this is seen in behaviours representing expiations, it magically annuls antecedent acts (Fenichel 1946). Spitting three times when you see a black cat annuls its association to something dangerous.

Rationalization
Behaviours linked to instinctual demands that are not compatible with the superego are reformulated in a more opportune language (A Freud 1946).

Projective identification
The concept of projective identification emanates from Melanie Klein and from the more traditional 'projection', but it adds the importance of the interactive interchange (Kemberg 1975). It is a complex and elusive term, difficult to define but of unmistakable importance in contemporary psychoanalytic theory. The person projects unbearable feelings or thoughts onto someone else, but identifies with the projected content and by exercising control over that person also tries to control the expelled part of oneself. This may also be considered as a way of communicating non-verbally: to get the other to understand one's position and hopefully be able to facilitate one's dealing with the unbearable (Rosenfeld 1987).
Idealization/merging

In Kohut's psychology the child idealizes the parental image as a means to overcome unavoidable shortcomings and frustrations of reality. A narcissistic equilibrium is maintained by adding the idealization to the grandiose self. Gradually this process is tamed and more mature ways of relating evolve. However, in pathological development there is an arrest, and a feeling of union with the idealized self-object is a prerequisite to avoiding emptiness and "desintegration anxiety". The person merges with the fantasy of the object (Kohut 1971).

COPING THEORY - STRATEGIES

The concept of coping has, in different appearances, been with us for a long time. It emanates from adaptational research, and the psychoanalytic theory of defences is a clear forerunner, especially when seen within an ego-psychological frame of reference (Lazarus 1993). Coping is a complex concept and is utilized in a multitude of research fields, not the least in the fields of disablement, chronic diseases and cancer. Researchers find different coping strategies, and there is a multitude of different coping-repertoires. To some, the strategies are restricted to the mental sphere (Lipowski 1970), to others they comprise activities and mental elaborations (Weisman 1979, Lazarus and Folkman 1984). There is no Swedish term distinctly corresponding to the concept, although I think that 'hanteringssätt' approximately covers its meaning.

The relationship between coping theory and the psychoanalytic theory of defensive processes has not been satisfactorily clarified (Weisman 1979). Haan (1969) proposed a tripartite hierarchy where coping was the most healthy and mature adaption mode in relation to the neurotic defensive process and the least adaptive ego-failure where the person fragmented. Others do not agree with this division. Weisman (1979) seems to relate them more pragmatically by regarding the crucial difference in terms of the recognizability (coping behaviour is more easily recognized compared to defences) and the understandability (coping behaviour is more easily understandable) of the problem to be faced. To him coping and defending often come into action simultaneously. It is not clear whether the concepts reflect different processes or whether they relate vertically and the difference is primarily a question of visability. Weisman, as many other researchers in this field, borrows labels for some of his coping strategies from psychoanalysis and defence theory. However, he recognizes it as more sympathetic to call a behaviour 'coping' instead of 'defending'. He also evaluates the coping strategies as better or worse when giving the following advice on how to become a good coper:
"1. Avoid avoidance; do not deny.
2. Confront realities, and take appropriate action.
3. Focus on solutions, or define a problem into solvable form.
4. Always consider alternatives.
5. Maintain open, mutual communication with significant others.
6. Seek and use constructive help, including decent medical care.
7. Accept support when offered; be assertive, when necessary.
8. Keep up morale through self-reliance or resources that are available.
9. Self-concept is as important as symptom relief.

Historically, evaluating coping strategies is not uncommon (Heim 1987). Researchers have dichotomized dimensions that have more or less inherently been alluded to positive and negative values. Haan (1977) frankly asserts that:

"A man who does not include intersubjective reality within his intrasubjective reality does not know and cannot understand himself and in time becomes an odd creature who cannot cope with the stress he generates for himself with his own thoughts." (p. 163)

The common dichotomization has different conceptual appearances: Lipowski (1970) discusses 'minimization' versus 'vigilant focusing', while for instance Horowitz et al. (1980) use the bordering concepts 'denial' versus 'intrusion'. Richard Lazarus and Susan Folkman (1984) have criticized the utilization of 'coping' as a valued style or trait, where some strategies a priori are regarded as better than others. Their well-known and widely-accepted definition states that coping is:

"the person's constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." (p. 141)

According to them, coping is, due to the demands at hand, mainly 'problem-focused' or 'emotion-focused'. The function of the former is to act on reality itself, while the function of the latter is to change the attention paid to the stressor or to change the relational meaning of what is happening. Even if they do not disregard the possibility of more or less stable coping dispositions, their emphasis is on a dynamic description of a process out of contextual and temporal influences. Their "Ways of Coping" questionnaire is based on eight strategies: Confrontational coping, Distancing, Self-controlling, Seeking social support, Accepting responsibility, Escape-avoidance, Planful problem solving and Positive reappraisal (Lazarus 1993). These strategies are not inherently valued, but the
outcome must be assessed out of the specific situation where they are at work. Whether they are *adaptive* refers to their effectiveness in improving the adaptational outcome, their *success* refers more to subjective well-being and whether they are *consolidated* refers to their stability. Lazarus and Folkman thus emphasize the importance of separating the process of coping from its outcome.

**THE TANGENTIAL POINT OF 'DENIAL'*

It is obvious that the relationship between the concepts of coping and defence mechanisms is indistinct. While, for instance, 'planful problem solving' is easily categorized as a coping-strategy, 'denial' refers to both conceptual frameworks. In a sense 'denial' may be seen as the tangential point between these frameworks. It has long been pointed out that this mechanism has been misused as an overinclusive concept covering a wide variety of both psychotic and normal processes (Janis 1958).

Acknowledging this fault, Lipowski (1970) instead utilizes 'minimization' to encompass all these divergent processes. Lazarus (1993) also avoids 'denial' in his questionnaire and he questions the relationships between denial, avoidance and illusion and wonders whether it is possible to look at the changed relational meaning in emotion-focused coping as a healthy form of repression or denial. Although not included among his coping strategies, Weisman (1979) clearly states that denial is an act within the coping process. According to him it is a process that repudiates what cannot be avoided and substitutes it with something more agreeable. Denial has thus assumed many guises and has been conceptualized in various ways. It is presented as a meta-defence, exploited by other defences, and there are three orders of denial. According to Weisman first-order denial is a repudiation of diagnosis or fact of illness. Second-order denial implies a disassociation between diagnosis and its secondary implications (e.g., symptoms), while third-order denial signifies renunciation of decline or impeding demise. The concept of 'middle-knowledge' is closely related to these outlines, stating that the patients are knowing as well as not knowing at the same time.

To others, the concept of denial is just regarded as one coping strategy among many. By means of questionnaires answered by breast cancer patients it has been suggested that 'positive reframing' ("I've been looking for something good in what is happening") is a very common strategy, while 'denial' ("I've been refusing to believe that it has happened") is a rare strategy (Carver et al 1993). Denial was furthermore related to increased distress. Aside from the fact that the self-report questionnaire probably detects an attitude more than reality, it is dubious to implicitly define 'denial' as a conscious point of view. A more substantial approach to the issue was made by Watson et al (1984). Following interviewing, the patients' responses were judged as expressing different levels of denial in accordance with a broader definition (Complete denial, Denial of
diagnostic implications, Denial of affect and Acceptance; Hacket and Cassem 1974).
Although nearly identical as to subjects and time of assessment, their results contrasted to
those of Carver et al. Denial was now found to be related to reduced distress.

**To conclude:** The concept of denial is operationalized from different stipulating
conceptual frameworks, and this fact is a plausible explanation for contrasting research
results. To some, 'denial' comprises its essence in psychoanalytic theory as an
unconscious repudiation of reality and less obvious distortions. To others, 'denial' seems
synonymous with conscious avoidance. Still others tend more naively to disregard its
existence (Wennberg et al 1992). Nevertheless, it is a distinguished concept, widely used
in research, discussed in clinical practice and in need of more clearly-defined demarcation.
QUALITATIVE INQUIRY

A scientific movement started up at the beginning of this century, eventually becoming institutionalized as the Vienna Circle of Logical Positivism under the head of Rudolf Schlick (Lincoln and Guba 1985). Based on the philosophies of David Hume (1711-1776) and August Comte (1798-1857) and in the spirit of Ernest Mach, an extreme advocate of operationalism and 'reality as sensations', the Circle wanted to create demarcation-criteria against metaphysics. Science, they postulated, is equivalent to establishing correlations to observables, and all scientific explanations consist of hypothetic deductions from these established regularities (Keat and Urry 1982). According to the idea of a unified science the criteria also applied to social science. The positivists did not succeed in promulgating their ideas to the fields of ethics, religion, politics or philosophy, but their impact has undoubtedly been profound in academic sociology and especially in psychology (Lincoln and Guba 1985). Leading psychologists proclaimed that "Whatever exists exists in some amount" (Thorndike 1918) and measurements became the language of psychology. In psychology, the phenomenological tradition evolving from Wilhelm Dilthey (1833-1911) and Husserl (1859-1938) emphasizing the lived experience as the subject matter of psychology, became a more marginalized academic discourse (Karlsson 1993). Sayer (1992) evaluates this period as one of 'methodological imperialism'.

More than psychology, academic sociology has been able to resist the positivistic dominance. This may be due to the tradition of field- and case-studies with its dependence on subjectivity and acknowledgement of the significance of the context (Starrin 1994). In Europe the 'Institut für Sozialforschung' in Frankfurt headed by Max Horkheimer and later Jürgen Habermas also played a prominent role in their critical evaluations of different scientific disciplines, including psychoanalysis (Keat and Urry 1982). In the Unites States the pragmatism of John Dewey and the symbolic interactionism of George H. Mead played a similar role in developing a sociology where the understanding of social processes and interaction stands at the center of attention (Strauss 1987). The qualitative or naturalistic tradition is by the hermeneutic approach more self-evidently deeply rooted in disciplines like archaeology, anthropology and ethnology.

There has been an extended philosophical criticism concerning the applicability of logical empiricism to the social sciences and accordingly a growing interest in research within the naturalistic paradigm (Lincoln and Guba 1985).
Grounded theory

Between 1920 and 1950, the Chicago school of sociology, was centered around the pragmatic naturalistic approach to the study of human behaviour advocated by Dewey and Mead. Preferably, research was based on field studies. Due to a lack of explicit methological procedures, not the least concerning analysis, the school was criticized by the established scientific community (Robrecht 1995). Its approach was said to be more impressionistic and artistic rather than rigorous and scientific (Bernstein 1985). The challenge it faced was to provide a more precise explanation of its methods.

In the early 1960s Anselm Strauss, with experience from the Chicago school, joined Barney Glaser, who at that time was more familiar with quantitative surveys in sociological research. Out of their experiences from a field observational study of hospital staff’s dealing with dying patients (Glaser and Strauss 1965), they wrote their path-breaking book, The Discovery of Grounded Theory (1967). From the ground up, the investigator by purposeful and systematic analysis of data builds conceptual categories. The method was attempted to offer a rigorous, orderly guide in which data collection and analysis were seen as parts of the same process. It stressed that theory must evolve from data, not prior knowledge, and they urged scholars to "theorize from the data rather than from the armchair" (1967, p. 14).

According to Strauss grounded theory is not a specific method or technique. Rather:

"it is a style of doing qualitative analysis that includes a number of distinct features, such as theoretical sampling, and certain methodological guidelines, such as the making of constant comparisons and the use of a coding paradigm, to ensure conceptual development and density." (1987, p. 5)

Often the goal of the discovery is to detect the essence of the basic social processes that people use to deal with the problematic situations in which they find themselves (Benoliel 1996). Gradually however, and not the least due to different research experiences, new questions concerning methodology emerged and the theory was amended and extended in different directions. Strauss and Juliet Corbin have developed a complex set of analysis procedures, a manual, to guide the researcher (Strauss and Corbin 1990). This step has been criticized because it diverts attention from data, the heart of grounded theory, towards operational procedures (Robrecht 1994) and has even been termed a positivistic explication of grounded theory (Riessman 1994). Glaser himself argues that his former partner Strauss has left grounded theory and proposes 'conceptual description' as the proper name for Strauss' new school (Glaser 1992). While the methodological differences seem to be obvious, the philosophical differences seem to be more disputable. To some, Strauss reflects a realist ontology (Riessman 1994), to others, that is the position of Glaser (Annells 1996). Anyhow, the possibility of a 'discovery' epistemology
has been challenged by Kathy Charmaz (1990, 1991). She states that external reality cannot be discovered out of nothing and offers an social constructivist reframing of the method.

Grounded theory in the present study
The characteristic features of the implementation of the grounded procedure in the present study (Papers I and III) may be described as follows:

1) Data was collected by repeated thematically structured interviews. There were no ready-made questions, but the interview was anchored around certain themes that were discussed (Kvale 1983). The aim was to let the participants express themselves in their own words and with their own narratives. During the interview it is up to the interviewer, with an open mind, to bring forth dimensions he finds important to further consideration. During the interviews, notes were taken down and the interviews were recollected and immediately transcribed. The rationale behind this procedure instead of tape recording was to produce a practicable amount of pages to analyze.

2) The text was then subject to open coding. This is a process of naive reading. Expressions and narratives of interest were marked and ideas of meaning in the text were written down, collected and sorted into categories. Successively the material takes on a structure which elucidates the social processes under study.

3) Based on the evolving preliminary structure the interviews are subjected to selective coding. The core categories were systematically related to other categories in a process of refinement and development. New categories may be found and integrated.

4) A theoretical draft was laid out and then evaluated by a reviewing of the interviews. Fitness is checked and modifications made until a general match is reached.

These stages were not clearly separated, but in an ongoing process simultaneously interrelated. This concerns both data-collection and analysis. The overall research process is well-described by the expression 'constant comparisons to find similarities and differences' (Strauss 1987).
Appraisal of social and behavioural characteristics

In addition to the interview themes, structured questions concerning vital social, behavioural and cognitive characteristics were asked. The questions emanated from a scale invented by L'hermitte (1986) when studying the impact of frontal lobe damage on social behaviour. Items from his self-administrative scale formed the basis for the
interview questioning. Patients and spouses were asked whether different features (apathy, stereotyping, indifference, disinterestedness, dependency on the social environment, lack of attention, programming disorders, reduced cognitive control, restlessness, impulsivity, euphoria, cheerfulness, disorderly conduct, indifference to moral or social rules, disorders of mental and emotional control) remained as before, or if a slight or obvious difference had occurred. In addition to the behaviour change, traditionally related to frontal lobe dysfunction, some cognitive deficiencies (disturbances as to memory, comprehension, spatial orientation and speech) were also asked about. The data from this questioning was used as a back-up to the data from the thematically structured interviews.

**QUANTITATIVE ASSESSMENTS**

*Reaction to Diagnosis of Cancer Questionnaire (RDCQ) - Paper I*

This questionnaire was developed by Frank Stromberg (1989) and aimed at assessing the initial reactions of individuals to the diagnosis of cancer. Ambulatory cancer patients were asked "What do you remember of your feelings after you received your diagnosis of cancer?". After content analysis of the answers and further procedures a 36-item questionnaire was administered to a series of ambulatory patients undergoing treatment, preferably patients with lymphoma, breast, colorectal, or lung cancer. The mean age was a bit more than 50 years of age with a slight preponderance of men. The majority of the patients had received their diagnosis within the last year. Factor analysis displayed six factors reflecting different reactions to diagnosis: on the one hand Hopelessness, Denial, Fatalism and Future uncertainty as distressing factors, on the other hand Fighting spirit and Stoic acceptance as confronting factors.

Denial (e.g.: "I refused to accept the diagnosis") in RDCQ is judged negatively as a distressing factor. This is contrary to Greer et al (1978, 1990) who found denial (typically: "It wasn’t serious, they just took off my breast as a precaution") prospectively to be related to a favourable prognosis. Out of their study they developed the Mental Adjustment to Cancer (MAC)-scale, which is a scale similar to RDCQ, but with a contrasting evaluation of 'denial' (Greer and Watson 1987).

The RDCQ is utilized in Paper I as a validity check when identifying patients with a reduced critical discrimination and when differentiating successfulness of coping.

*Standardized Mini-Mental State Examination (SMMSE) - Papers I, II, V*

The SMMSE is a screening instrument of cognitive function. It is a more standardized version of the commonly used Mini-Mental State (Folstein and Folstein 1975). The SMMSE consists of eleven questions and is easily administered. It has shown to differ between different clinical conditions (e.g., dementia, affective disorders and neurosis)
and displays a test-retest reliability of approximately 0.9. There were no improvements in the scores after three weeks, indicating absence of a learning effect (Molloy et al 1991). Out of a maximum score of 30, a group of 63 normal subjects with a mean age of 73.6 years displayed a mean score of 27.6 (Folstein and Folstein 1975).

The SMMSE is made use of in Papers I, II and V to identify patients with cognitive impairments.

**Psychosocial well-being scale - Paper V**

This scale is part of a quality of life questionnaire carefully validated in a study of 31 patients with inoperable lung-cancer (mainly non-small-cell lung cancer) in different treatment modalities (Kaasa et al 1988). It consists of ten items covering different dimensions of psychosocial well-being (e.g., "Have (you) lacked confidence in yourself?") and two questions aimed at finding out a more global assessment (e.g., "Thinking about how life has been the last fortnight. Are you generally satisfied or dissatisfied?").

The scale is utilized in Paper V to assess the life satisfaction of the patients in the different treatment modalities.

**Neuropsychological tests - Papers II, V**

A comprehensive neuropsychological test battery was created out of established neuropsychological tests and is more extensively presented in Paper II. It was centred around assessment of memory, as memory is a vital cognitive domain, of obvious importance to everyday life and conspicuously sensitive to brain damage (Lezak 1995). The battery was designed to assess three aspects of memory: prospective memory, the ability to use visual imagery and the difference between short-term and long-term memory. Prospective memory was assessed since it mimics everyday uses of memory and it was evaluated by means of the Rivermead test (Baddely 1987). Visual imagery is important since a preserved visual capacity indicates an ability to compensate for possible memory impairment. It was evaluated by means of 20 nouns-to-be-remembered with high (e.g., 'mountain') and low (e.g., 'explanation') levels of imagery (Molander 1984, Paivio 1986). It has recently been shown that temporary storage of information (short-term memory) and permanent storage of information (long-term memory) may be impaired independently of each other in brain damage (Baddely 1986). These storages were separated by means of the selective reminding technique (Levin 1986).

The selective reminding technique employs multiple presentation of items-to-be-remembered. In the present studies the 20 nouns with different levels of imagery were presented five times. Tasks, primarily taken from the Swedish version of the revised Weschler scale (Bartfai et al 1986) were interspersed with the different trials: Digit Span, Digit Symbol, Arithmetics and Vocabulary. In addition to Vocabulary, verbal ability was
assessed by means of reading/recalling the fable about "The Lion and the Fox" (Christensen 1974) and speech production by word fluency, FAS (Lezak 1995). Conceptual ability and abstract problem solving was evaluated by Picture Arrangement from WAIS-R, Wisconsin Card Sorting Test (Heaton 1981) and Ravens Progressive Matrices (Raven 1977). Another established test, Kohs Blocks (Lezak 1995), measured the patient's ability in spatial construction.

Although focused on aspects of memory function, the battery was thus also designed to assess verbal ability, logical conceptual ability, spatial construction and perceptual scanning. Vocabulary, as an expression of verbal comprehension, is ordinarily resistant to diffuse brain damage and is therefore an indicator of premorbid cognitive capacity (Lezak 1995). On the contrary, speeded tests, as for instance Digit Symbol reflecting the ability to perceptual scanning is known to be sensitive to diffuse brain trauma (Lezak 1995).

DESIGN OF THE STUDY

Patients and next of kin, mainly spouses, were by repeated interviews followed during the course of the disease process. In addition to these qualitative inquires, the quantitative assessments were made at certain time-points. The time-schedule of the data-collection is presented below.

![Figure 2. Data-collection in a time-perspective.](image)

**Interview 1**

After disclosure of diagnosis at discharge from the neurosurgical department, the patient and spouse met an oncologist to discuss the impeding treatment at the Department of Oncology. Those who at this time were included in the clinical trial with estramustine were asked whether they wanted to participate in a further investigation aimed at a deeper understanding of the experience of being struck by a brain tumour disease and of being the spouse of the diseased. After complied the researcher was introduced to the
participants by the oncologist for a more comprehensive discussion about the project and to make appointments for the first interviews. The patient and spouse were interviewed independently usually within one or two days after the inclusion. Otherwise, the interviews were held about a week later upon return to the hospital for radiotherapy. The patient was always interviewed first.

All interviews were thematically structured interviews intended to cover themes relevant to the factual situation. The first interview was focused on symptom presentation, the first visit to a doctor and the further experiences of medical care until the actual moment of diagnosis-communication, knowledge and ideas about the disease, subjective well-being and perspective on the future. Concerning positive and negative experiences of care and support from family and friends, the participants were asked to narrate the experiences as 'critical incidents' (Flanagan 1953). By way of this technique it may be possible to pass the well-known difficulty in interpreting patients' expressed satisfaction with care (Larsson et al 1989, Tishelman and Sachs 1992). The spouse was also asked to appraise the patient especially concerning mental capacity and personality change. All participants were also asked some structured questions concerning sociodemographics.

The first interview corresponds to clinic and to the intake-interviews within the field of psychotherapy/social work, but contrasts in the sense that it covers different themes without the intention of bringing about a focused problematization. It does not converge, but follows interesting tracks within the different themes. The openness meant that the interviews lasted from half an hour to a bit more than three hours.

The RDCQ and the SMMSE were administered to patients prior to interviewing.

**Interview 2**

The second interview took place when the patient was to be discharged from the hospital after a six-week period of radiotherapy. The themes on this occasion were accordingly focused on: the experience of caring during the six-week period of radiotherapy, doctors' consultations, physical and psychological well-being, knowledge and ideas about the disease, relationship to family and friends, daily activity and future plans. Again, the critical incidents were queried and the spouses were also asked to appraise the patient's overall status.

The SMMSE was administered prior to interviewing.

**Interview 3**

From research concerning closed head injuries it has proven that after a period of five months the benefits from the adaptive process seem to be settled. At this point the contours of the new reality are established (Brooks 1985). Accordingly, the third interview was conducted five months after primary treatment and in order to capture the
everyday life of the participants the interviews on this occasion preferably took place in their homes. The themes accordingly covered daily activities: relationships to the partner, children, friends, neighbours and questions concerning to spare time, work and future. What was changed, in what sense, and what was still the same? The questions regarding subjective well-being and critical incidences were put as before. The spouses were also queried about changes in their own health that may have arisen and if any visits to physicians regarding their own health had occurred.

In cases where the patient did not survive five months after radiotherapy, the fourth, concluding interview incorporated relevant aspects of this interview and was thus slightly extended.

The interviews were concluded by the structured phase aimed at appraising the patient's social and behavioural characteristics from features described by Lhermitte (1986) (see Method p. 24-25).

The neuropsychological tests were administered to patient and spouse prior to interview. A prerequisite to administration of these tests was absence of focal neurological deficiencies and absence of signs of tumour recurrence on computerized tomography scan. The respective spouses constituted a control group. The rational behind this was that, in addition to expected similarities regarding age, education and allied parameters, they share similar experiences as members of the same family.

Interview 4

The last and concluding interview was held about a month after the partner had died. The focus of this interview was the experiences during the period from the preceding interview throughout decline and death, as well as to reflect upon the entire course of the disease process. How was s/he? How did s/he react? What could have been facilitating? Positive/negative incidents? How do you feel now? What about family and friends?

Due to long distances in northern Sweden, the main parts of these interviews were held by telephone. An important point in preparing for the interview was the call for the appointment a couple of days in advance. Some topics were presented and it is my conviction that this short conversation served as a vital 'warm up'.

PARTICIPANTS

In a clinical study of patients with Astrocytoma III-IV, treatment with estramustine phosphate added to conventional treatment with surgery and radiotherapy was evaluated. The first thirty patients that passed the inclusion criteria and agreed to participate in this psychological study were included. The inclusion criteria were: age 18-70 and performance status 0-2 according to the WHO-scale.
Table 1: Performance status according to the WHO-scale.

<table>
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<tr>
<th>Score</th>
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<tr>
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<td>Able to carry out all normal activity without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out light work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all self care but unable to carry out any work; up and about more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self care, confined to bed or chair more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled; cannot carry on any self care; totally confined to chair or bed</td>
</tr>
</tbody>
</table>

Out of 32 consecutive patients, 30 were included in the trial and agreed to participate in this study. All except one next of kin complied. Due to the significant dominance of spouses (24/29) the next of kin group will be labelled 'spouses'. Informed consent was obtained individually from patients as well as from spouses. Relevant characteristics of the participants are shown in Table 2.

All patients underwent surgery (biopsy, subtotal- or macroscopical total resection) and post-operative radiotherapy. The irradiation was given as parallel opposed fields with a margin of 2 cm and scheduled as 2-Gy fractions, 5 days a week to a total dose of 56 Gy (6 MV photons). Patients who were randomized to additional treatment received estramustine phosphate orally at a dosage of 280 mg twice daily from time of diagnosis (before starting radiotherapy) and for a period of three months ahead or until disease progression. All patients received corticosteroids before surgery and during radiotherapy. Generally they received betamethason during radiotherapy at a daily dosage of 2-4 mg.

**The data base**

Due to the disease process the number of interview-participants decreased with time. Table 3 displays the number of patients and spouses participating in the different modes of data collection.
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Table 2. Characteristics of all included participants.
Table 3. Number of patients and spouses participating in different interviews and assessments.

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<td>9 death</td>
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**Representativity**

There were twice as many male patients as female patients. The age of the patients was evenly distributed around the mean of 54.3 years (median 54 years). Concerning age this is in line with the findings of Kallio et al in their Finnish population based study. However, it differs as to sex; they found just a slight preponderance of men (Kallio et al 1991).

The distribution of tumour sites of the participating patients is well in accordance with what has been presented by others with a dominance of frontal and temporal tumours and with no hemispheric differences (Kraemer and Bullard 1994).

**Clinical presentation and delay**

Due to the vivid variety of clinical manifestations it is not meaningful to pinpoint all the clinical expressions. The presentation of the symptoms below is based on the patients' and spouses' subjective experience of the paramount symptoms, when questioned about how it started. It is not a systematic presentation, but it is intended to display a variety of impressions from clinical reality. When discussing delay, it must be kept in mind that it is problematic to assess delay with precision. At what point in the development of symptoms does the delay start? When there is an acute onset of headache it is obvious, but what about fatigue? This problem especially concerns 'patient delay', defined as time elapsing from more obvious onset to consulting a physician. 'Physician delay' is
defined as time passing from first physician consultation to arrival at the neurosurgical department.

**Headache**

For twelve of the patients, clinical presentation is centered around headache. The headache was experienced as more intense than ordinary headache and in about half of the cases it was closely accompanied by vertigo and/or vomiting. To others it was associated with double vision or a tendency to fall on the contralateral side. Some patients developed seizures in the form of absences. It is interesting to note that while the patient indicates the acute onset of pain as the starting point of the disease, the spouse quite often adds, or begins with a narration of a preceding story of fatigue, slowness, irritation or executive dysfunction:

"He talked about making a lot of things. However, when I called his attention to the fact that he didn't execute his plans, he was annoyed and denied that he had spilled out any intention whatsoever."

Due to the intensity of the headache the majority of these patients contacted a physician within a week's time. The patient with the longest delay waited about four months before seeing a doctor. He had a bilateral frontal tumour, and after a divorce he lived alone. His relatives had noticed that he often was asleep when they contacted him and that he had stopped keeping his house in good order. They knew he was working a lot, but got annoyed and told him to clean up. He worked as a crane operator and his foreman later revealed that he often vomited when he came down, that he often forgot his meal or key or was late. He was not his normal self. When he became glassy-eyed and stopped talking to his next of kin they interpreted it as an expression of aggression. However, as his overall decline progressed and they noted that he wet himself they told him to consult his physician. He refused and not until they pushed him into the car did he come to the hospital. There, the relatives had to argue with the physician to convince him that the patient had gone downhill on his own and was not affected by alcoholism.

In another case of long delay, the patient had experienced headache for a couple of months before he consulted his general practitioner. He complained about stomach pain and headache. He did not experience any further cerebral symptoms and due to self-medication with analgetics he could endure the headache, but developed a stomach complaint as an adverse effect. The general practitioner diagnosed gastric ulcer, but challenged his intensive analgetic medication, and sent a referral for CT-scan. The brain tumour was detected and after a short visit at the local hospital he was sent home to wait for the referral to the Department of Neurosurgery in Umeå. However, he had to wait five
weeks for this call. According to the wife these were the most horrible weeks of her life. She phoned the physician at the local hospital repeatedly, but:

"He behaved so strangely. He really emphasized that it was a troublesome operation, that it might give him six months and the irradiation another three months and added that 'for what life shall we save him?'. It was as he didn't want anything to be done, that it was no point in doing anything, and that we should be satisfied with taking the world as we found it. He sort of wanted to make a break. It ended with my saying that he is going to be operated on and he replied 'I see, that's what you want'. He did not care."

The relatives contacted the neurosurgical department themselves.

A typical example of long physician-delay concerned a man that worked all day in front of a computer. He experienced headache in connection with pain in the neck. The general practitioner interpreted it as work-related. He was repeatedly on short sick-leave and in periods he worked half-time. He developed vertigo and occasionally he vomited. Other days he felt better. He started acupuncture. However, the headache intensified and after four months he saw his doctor again. A CT-scan was carried out, the tumour was detected and he was operated on the next day. In other cases the period of physician delay is interrupted when the more or less continous headache is followed by the acute onset of another relevant symptom, e.g., a seizure.

The mean physician delay in the 'headache-group' was about seven weeks with a range between five days and six months.

Seizures

In different ways nine of the patients described the onset in terms of seizures, be they focal motor seizures, grand mal seizures or absence seizures. Some just described that they suddenly fell. The seizure was often associated with other symptoms such as slurring one's words or numbness. However, there were also more global symptoms preceding the more acute onset. The spouses added descriptions of fatigue, falling asleep in the middle of the day, irritability, sensibility to noises or other socially detectable manifestations of dysfunction. After experiencing the seizure, only one patient waited more than two days before consulting a physician, although there were a couple of patients with a preceding delay.

The most exceptional case in this respect was a man in his sixties with a right parietal tumour, living by himself. According to his next of kin, a nephew, his personality had markedly changed six months previously. He was bad tempered and easily irritated, and he seemed to lose his sense of time. He did not let the home nurse in, and when questioned, he answered laconically. He suddenly fell in the tub and was taken to the emergency unit. A couple of days later his relatives succeeded in accompanying him to the
psychiatric department. They thought he was depressed. After two weeks he was at the
neurosurgical department.

If we exclude one doubtful case, the mean physician delay in the 'seizure-group' was
about one month with a range between one day and four months.

Motor and sensorial dysfunction

Four of the patients primarily evidenced motor or sensorial dysfunctions. A woman in
her fifties with a left parietoccipital tumour experienced vertigo together with memory
disorder and coordination difficulties. She noticed with astonishment how she put the
dishes in the wrong cupboards and a cup of tea beside and not on the table. After an
epileptic seizure a couple of days later, she saw the general practitioner. A few days later
the tumour was diagnosed by CT-investigation.

With the exception of the following case, both patient and physician delay was short in
this group of patients.

A recently retired carpenter and his wife noticed how he suddenly could sleep late in
the mornings, and again and again until 11 p.m. After a couple of months he saw his
G.P. As nothing seemed to be wrong with him, a return visit was booked three months
later. During that time his wife visited him at their summer cottage where he was to build
a playhouse. She observed that nothing had happened with the playhouse and that he,
quite unlike his usual self, was drowsing on the sofa. He was now unable to unbutton his
shirt, he fumbled occasionally, he had fallen once, and walked with a shuffling gait. She
forced him to go to a new consultation, but did not join him. When discussing his general
condition of health with the physician he commented on his problem with buttons by
requesting the manufacturers of buttons to pull themselves together. A lot of medical
examinations were done (including x-ray of thorax), but nothing was found. His
deterioriation progressed and after another month and a half, the family brought him to the
emergency unit. A CT-scan detected a tumour in the thalamic region. The total delay was
about seven months, and it seems within reason to believe that his vigorous and
frolicsome avoidance-manner contributed to the physician’s inability to follow proper
diagnostic tracks.

Mental dysfunction

In five patients the crucial symptomology was centered around the mental sphere.
While out in the forest and picking berries, the husband suddenly found his wife sitting
on a stump with a blank expression on her face and disregarding questions put to her. She
was mentally absent. They brought her to the primary care unit and they were referred to
the hospital. Suddenly she was herself again, but in forthcoming days she was anxious
and obviously prone to visual illusions and paranoid reactions. Within a week a CT-scan
detected a right frontal tumour.
A man in his fifties suddenly realized that he was unable to do his crossword puzzle. He did not remember things as before and the family noticed that he expressed himself oddly and rambled. He ignored the gravity of the manifestations, but his wife insisted on his seeing a physician. At the medical ward she challenged the policy of expectancy and the CT-scan confirmed her suspicion; he had a left temporal tumour.

Another man with a left temporal tumour was driving the car when his wife, sitting beside him, noticed that he no longer could talk. He moved his lips but no words came out. They stopped to buy cigarettes and he uttered "45 amperes" instead of "45 crowns". He did not seem to bother that she called an ambulance. A short while later he had a seizure. According to his wife, the immediate CT-scan detected nothing. He was sent home. In spite of intensive headache with pressure towards the eyes, the repeated visits to physicians ended up with a reference to earlier examinations and that 'everything is okay'. The close relatives did not recognize his condition and described him metaphorically as not being sober. Things got worse; due to his headache none of them could sleep at night, he fell, and started vomiting. Back to the emergency unit a new CT-scan detected the tumour. Since the first visit to the emergency room and first CT-scan, 93 days had passed.

Others have suggested that many patients with malignant gliomas have an earlier experience of attacks with panic-anxiety (Lilja 1992b). The participants in this study were systematically questioned concerning earlier history of anxiety, but only a couple of patients confirmed an earlier experience of anxiety.

There was practically no patient delay in this group, and with exception of the extreme case presented above the physician delay was restricted to two to four weeks.

Spouse and delay

It is obvious that patient delay is not just a matter of symptomatology, although the more dramatic or alien, the shorter the delay. However, close relatives are also important. The spouse is important because s/he has a contextual reference of observation of antecedent symptoms and is thus able to more objectively value the change that has taken place. In many cases it is thus the spouse who pushes and initiates the physician consultation and the longest patient delay concerns patients who were living alone.

Regarding physician delay the spouses had a similar function. As has been presented above, they were, in a couple of cases, their partners' delegates, challenging the physicians and arguing that an X-ray of the brain was an urgent necessity. Due to their contextual knowledge, they intuitively felt that the disease was in the brain. We have also displayed a couple of cases where it seems obvious that physicians have been trapped within their own preconceptions and thus unable to listen to clinical reality.
Everyday life after treatment

It is not easy to give a valid account on how the patients' everyday life manifested itself during the course of time after primary treatment. I have tried to make a qualitative division of the patients' surviving time into 'time of everyday life' and 'time of disease'. 'Time of everyday life' is defined as time that in relevant areas resembles life as it was lived before becoming diseased. Family life, work, spare time interests, friends and acquaintances are such relevant areas. Life goes on to a certain extent in some of these areas, even if the intensity does not have to be the same. The crucial point is that there is no dramatic break in life-continuity. The disease is acknowledged, but it does not wipe out everyday life. In contrast, 'time of disease' is defined by the loss of everyday life. The patient and family life is then occupied by the disease, it is the center of life. 'Time of disease' corresponds to the medical term 'disease progression', but is not identical. Some patients, despite diagnosed disease progression, were in fact even able to stick to their educational activities. Basically, 'time of disease' is not a medical, but a psychosocial concept. The assessments of time below are based on qualitative judgements from joint patient and spouse interviews. They are solely my own.

Nineteen out of 29 patients (66%) were judged to reexperience time defined as everyday life when coming home after primary treatment. The median time of this ordinary life was a bit more than five months. The variation was striking: three patients experienced 'everyday life' more than one year, one of them almost four years (range 1-46 months). Out of the fourteen that were not retired, eight (57%) resumed work or former studies. With a few exceptions, those who resumed work only worked part-time at their own pace. The median time at work was three months (range 2-38). It was obvious that the capacity at work differed considerably: to some, time at work was more of a social and rehabilitative activity, while two of them in fact seemed to be engaged as earlier. The young patients that resumed their studies were quite engaged even after the obvious onset of the disease progression. It is interesting to note that one of them, despite obvious adverse effects of the palliative treatment with steroids and cytostatics in addition to overall fatigue, still was able to complete his compulsory practise, connected to his studies, at a health care center. The other one tried to get into a new study course after receiving his first cytostatic treatment. Nonetheless, he had to give it up after two months. Ten out of 29 patients (34%) did not come to terms with ordinary life after the brain tumour diagnosis and primary treatment. Most of these patients were mentally or physically disabled.

During the 'time of the disease', working activities ceased, physician consultations became more frequent, it was more difficult to keep up with spare time activities and the spouses were sick-listed in order to take care of their next of kin to a greater extent. The time of decline had started and they had to look after their partner. The median (and mean)
disease time of the 24 patients eligible (2 alive, 3 unavailable) to judge was five months (range 0.5-11 months).
MAIN FEATURES OF PAPERS

**Paper I: The creation of protection and hope in patients with malignant brain tumours**

When interviewing 30 consecutive patients with malignant glioma (astrocytoma III-IV) at the time of diagnosis and primary treatment it was evident that the majority of them seemed to feel rather well. There was an obvious discrepancy between their objective medical situation and their state of mind. As the disease is a threat from outside that by no own action is changable, the patient has to rely on mental means to deal with the strain.

The purpose of this paper was to find out how the patients mentally coped with the threat by analyzing their expressions and narratives made during the interviews. In contrast to main studies on coping in this area we were not primarily interested in how they consciously expressed themselves on this topic, i.e., what they said they were doing, but instead on what they preconsciously and unconsciously actually were doing.

The interviews were thematically structured, intended to cover various relevant themes that would shed light on how the patients experienced their life situation: experiences of medical care from first symptom to present time, information and knowledge about the disease, relation to significant others and prospects for the future. Spouses' interviews, a mini-mental examination (SMMSE) and a questionnaire (RDCQ) were also used to assess the patients' mental status. Eleven patients were excluded due to mental impairment, and thus 19 were left to final analysis. Their interviews were analyzed by means of grounded theory methodology, by open coding and categorizing.

The main finding was that most patients, despite awareness of the fact that the brain tumour exposed them to grave danger, were able to use a broad repertoire of cognitive manoeuvres to create protection and hope. This process originated from different sources: the body; helpful relations; cognitive schemata; and handling of information. The finding is considered as an expression of how the patient brings together reality and hope, thus creating her/his own illusion. The manoeuvres were furthermore related to corresponding concepts within the psychoanalytic theory of defences and contemporary concepts within coping theory. The overall impression was that the traditional defence concepts did not quite encompass the findings as the manoeuvres more allude to a constructive activity than to warding off.

**Paper II: Long-term memory deficits in patients with malignant brain tumors**

There are few prospective controlled studies dealing with the neuropsychological function of adult malignant glioma patients. Knowledge on cognitive performance may be important in the perspective of adverse effects of treatment but also in the perspective of affirmative and supportive interventions.

At five months after completion of radiotherapy, those patients out of the initial 30 that did not evidence focal neurological deficits or tumour recurrence were tested with a
comprehensive neuropsychological test battery. Eleven patients (37%) were eligible and their spouses constituted the control group. The battery was designed to measure different neuropsychological abilities with emphasis on memory functions. Memory function is known to be sensitive to brain damage. In addition to prospective memory, the memory function was evaluated regarding possible differences as to visual imagery but also as to differences between long-term and short-term memory. The latter differentiation was implemented by the selective reminding technique.

As to verbal episodic memory the outcome was clear-cut. The patients showed a dramatic impairment as regards long-term memory compared to short-term memory. No differences were detected on prospective memory or the ability to use visual imagery. Furthermore, no differences were found on global intellectual abilities or verbal comprehensive abilities. However, there were nominal differences on some speeded tests. The implication of the fairly selective deficiency on long-term memory is discussed in relation to possible causative agents, to the information process and rehabilitative efforts.

**Paper III: Brain tumors as a threat to life and personality - the spouse's perspective**

It is a well-known experience had by many clinicians that spouses to brain tumour patients are put under great strain. Despite this fact, there are no previous studies focusing on this issue.

The purpose of this paper was to contribute to the alleviation of this lacuna by means of interviewing spouses to brain tumor patients during the course of the disease process. Twenty-four spouses, related to 24 of the 30 patients, were interviewed separately at time of diagnosis, completion of radiotherapy, and five months later in their homes. At this point a new sense of reality might be expected to have been present. All participating spouses were also interviewed a short while after the patient's death. The interviews were thematically structured and covered certain themes such as: medical care experiences, knowledge and ideas about the disease, the relation to the patient, family, work, spare time and future. Taken together the themes were expected to elucidate crucial aspects of their life circumstances.

Grounded theory analysis by means of continuous repeated comparisons to find similarities and differences detected a pattern of different crisis trajectories related to modes of spouses' sense of relationship and major coping. The first crisis trajectory is crisis delayed to disease progression. This comprises spouses who described their partners as being their normal selves. The spouses typically adjusted to their partners way of palliating their distress by means of creating illusions. This way of coping implied an experience of closeness. However, at time of disease progression the spouses reoriented themselves towards previously-withheld thoughts, and the crisis flared up. The second crises trajectory comprises spouses to patients who were neurologically disabled. In these cases the crisis typically was immediate at time of diagnosis. The spouses did not ally
with the patients' illusions. The relationships were primarily characterized by a changed mutuality with dependency. The major coping process was the process of mourning, i.e., to redefine the relationship from loving to caring. The third type of crisis was crisis delayed to coming home. These spouses experienced their diseased husbands as physically in good shape, but with altered personalities, featuring loss of critical discrimination. The relationship was marked by a loss of mutuality. Initially these spouses allied with their partners' confidence and illusions. However, when coming home they found that the wished for and expected change back to the partner's former self did not take place. They were still demanding and the crisis became manifest. The only coping strategy available was that of distancing geographically.

The paper also discusses other factors contributing to the spouses' situation and coping possibilities, and concludes by emphasizing the importance of acknowledging the spouses as separate individuals with their own needs.

**Paper IV: How to tell cancer patients - a contribution to a theory of diagnosis communication**

This paper may be seen as an extended discussion of the implications from the findings in Paper I.

In medical literature there seems to be a consensus concerning the importance of disclosure of bad news. This fact reflects a dramatic change in attitude, and from being an exception it has nearly turned out as taken for granted to disclose all that can be said. However, when dealing with the empirical side of this issue, clinical reality seems to be a bit more ambiguous. As regards patients, it is not evident that they prefer total disclosure and as regards physicians, their implementation of disclosure is far from unconditioned. Briefly, they argue against rigidity in the information procedure and they are not convinced that it is in the patient's interest to deliberately be given all information. This topic is of obvious importance since a failure in relating diagnosis may cause an arrest in the patient's coping with anxiety and reduction in well-being as a result.

These contradicting findings highlight the importance of a theoretical perspective when dealing with "How to tell cancer patients". Descriptive statistics do not guide in individual consultations. The purpose of this paper was to contribute to filling the vacuum between quantitative research and practical advice by advocating a theoretical model to doctor-patient communication.

In Paper I we displayed the creative ability of patients struck by a malignant glioma. In the present paper those findings are considered from a psychoanalytic conceptual framework emphasizing the significance of the child-parent relationship as a precursor and guiding model to the patient-doctor relationship. The physician may unconsciously be seen as a protector against death and as a provider of an environment facilitating the creative process. Clinical implications from this model are discussed and the overlooked
Freudian concept 'disavowal' is advocated as a valid concept encompassing the patient’s creative process.

**Paper V: Sexuality, psychosocial well-being and cognitive function in patients with malignant gliomas treated with estramustine in addition to radiotherapy**

Thirty consecutive patients were included in a randomized clinical trial with estramustine phosphate in addition to conventional treatment with surgery and radiotherapy. The drug is a derivative of estrodiol and nitrogen mustard and is a well-known cytostatic in the treatment of advanced prostatic carcinoma. Evaluation of the adverse effects of the drug has been poor. However, not the least due to the short life-expectancy of patients with malignant glioma, this is an issue of special importance.

The purpose of this paper was to evaluate the adverse effects on sexuality, psychosocial well-being and cognitive function in a limited number of patients. Due to the small and different number of eligible patients, quantitative analysis was combined with qualitative evaluation. Sexuality was evaluated by means of repeated interviews with patients and spouses (n=19, of 30 patients), subjective well-being by a self-administered questionnaire (n=14), while cognitive function was assessed by means of a comprehensive neuropsychological battery focusing on memory capacity (n=8).

The results evidenced that estramustine phosphate had the expected detrimental effect on sexuality in male patients. Furthermore, it is not out of the question that the drug caused impaired cerebral functioning by affecting long-term memory. However, these effects did not seem to cause a reduction in psychosocial well-being. On the contrary, patients who had received the additional cytostatic treatment in fact scored nominally a bit higher on well-being. The results are discussed within the context of the patients' overall changed life situation.
GENERAL DISCUSSION

TRUSTWORTHINESS OF THE QUALITATIVE STUDY

As outlined previously, this study relies both on qualitative and quantitative methodlogy. In the scientific establishment the criteria of scientific rigour is rooted in positivistic philosophy and the core concepts of validity, reliability, objectivity and generalizability have a certain meaning. If the meaning of the concepts is applied to a study within a naturalistic paradigm, the study in question by definition must be regarded as unscientific (Sayer 1992). Different paradigms require different criteria of scientific rigour in the same sense as different languages are built upon different grammatical rules. It is not more advisable to evaluate a naturalistic study with positivist scientific criterias than it is to speak Turkish with Swedish grammar. Before discussing the different criteria of scientific rigor in more detail it may be appropriate to illustrate the main dimensions separating the paradigms. The table below is from Lincoln and Guba (1985, p. 37).

<table>
<thead>
<tr>
<th>Axioms about</th>
<th>Positivist Paradigm</th>
<th>Naturalistic Paradigm</th>
</tr>
</thead>
<tbody>
<tr>
<td>The nature of reality</td>
<td>Reality is single, tangible and fragmentable</td>
<td>Realities are multiple, constructed and holistic</td>
</tr>
<tr>
<td>The relationship of the knower to the unknown</td>
<td>Knower and known are independent, a dualism</td>
<td>Knower and known are interactive, inseparable</td>
</tr>
<tr>
<td>The possibility of generalization</td>
<td>Time- and context-free generalizations (nomothetic statements) are possible</td>
<td>Only time- and contextbound working hypotheses (ideographic statements) are possible</td>
</tr>
<tr>
<td>The possibility of casual linkages</td>
<td>There are real causes, temporally precedent to or simultaneous with their effect</td>
<td>All entities are in a state of mutual simultaneous shapening, so that it is impossible to distinguish causes from effects</td>
</tr>
<tr>
<td>The role of values</td>
<td>Inquiry is value-free</td>
<td>Inquiry is value-bound</td>
</tr>
</tbody>
</table>

Conventionally, the criteria for trustworthiness has been encapsulated within the concepts of 'truth value', 'applicability', 'consistency', and 'neutrality' (Lincoln and Guba 1985). With different views of reality (subjective versus objective) and ultimate scientific purposes (discovery versus verification) the answers to the questions posed by these concepts must be different. A structured overview of the relations between the different criterias from Hamberg et al (1994) is presented below:
<table>
<thead>
<tr>
<th>PRECONCEPTIONS</th>
<th>QUANTITATIVE</th>
<th>QUALITATIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal validity</td>
<td>TRUTH VALUE</td>
<td>Credibility</td>
</tr>
<tr>
<td>Reliability</td>
<td>CONSISTENCY</td>
<td>Dependability</td>
</tr>
<tr>
<td>Objectivity</td>
<td>NEUTRALITY</td>
<td>Confirmability</td>
</tr>
<tr>
<td>Generalization</td>
<td>APPLICABILITY</td>
<td>Transferability</td>
</tr>
</tbody>
</table>

Figure 3. Indicators to describe scientific rigour in research.

**Truth value**

The truth value is typically evaluated by the confidence that the results of a study (dependent variable) are attributable to the controlled variation of the independent variable and not to artefacts. Traditionally high 'internal validity' is thus related to designs where it can be demonstrated that history, maturation, subject selection, etc. do not account for the results.

As qualitative research deals with the discovery of human phenomena, as they are lived and perceived by subjects rather than verification of *a priori* hypothetical conceptions of external reality, its truth value resides in the faithfulness of subjective experience and in interpretations. Within a postmodern perspective, Kvale (1996) argues that knowledge in social sciences is a linguistic and social construction of reality and that validity accordingly must be related to quality of craftsmanship, to communication on the findings and to its pragmatic utility. Findings may be related to at least three communities of validation: the subjects, the general public or the theoretical communities. Furthermore, that the complexity of validating qualitative research need not be a sign of its weakness as a scientific method, but may, on the contrary, be due to its power to detect complexities of reality.

The *credibility* of a study commonly refers to the studied subjects' ability to recognize themselves in these descriptions and interpretations or others' ability to acknowledge the experiences after just reading about it (Sandelowski 1986). A prerequisite to credibility is therefore a certain degree of closeness and ability to create a working alliance with the subjects under study. The closeness of the investigator-subject relationship is at the same time a threat to credibility in the sense that the investigator may have difficulties in
separating own experiences from the subject's experiences. This may lead to 'premature closure' or 'going native' (Lincoln and Guba 1985, Sandelowski 1986). Continuous reflections by the researcher as an own subject is thus important and I think that my own extensive experience in psychoanalytic psychotherapy under supervision is of credit to this study. As is well-known, the essence of psychotherapy is to focus the patient closely without losing one's own platform (Wolberg 1967).

With the words of Lincoln and Guba it is more probable to gain credible findings if:

"the inquirer is able to demonstrate a prolonged period of engagement (to learn the context, to minimize distortions, and to build trust) to provide evidence of persistent observation (for the sake of identifying and assessing salient factors and crucial atypical happenings), and to triangulate, by using different sources, different methods, and sometimes multiple investigators, ..." (1985, p. 307)

The present study is based on repeated interviews with patients and spouses. The initial interviews were carried out at the hospital, but the follow-up interviews were to a large extent in the patients' home. This has provided a basis for being well acquainted with their life-circumstances. Actually, I have felt being close to many (not all!) of the patients and spouses, and in a few cases the function as a significant supportive person or psychologist has been obvious. Therefore, contacts with some of the participants have not been restricted to the interview occasions: we have talked by telephone and met at the hospital at time of regular follow-up or when sent into the ward. In this perspective as well, my professional experience has been of considerable value.

The most important mode of triangulation in this study is triangulation as to source. The patient and spouse interviews cover different pieces of interrelated reality but they also cover the same points and the spouse interviews may therefore be a source with which to evaluate the validity of patients' statements and vice versa. The methodological triangulation, by the utilization of quantitative assessments, to some extent also serves a similar purpose and underlines to potential of 'contextual validation' (Diesing 1972).

Other techniques to establish credibility are 'negative case analysis' and 'member checks' (Lincoln and Guba 1985). The ideal object of the former is to refine the analysis until it, without exceptions, accounts for all cases. Practically, of course, this is impossible. However, as we chose grounded theory as method of analysis, the technique of negative case analysis is inherently basic to the analytic process (see Figure 1). The other technique, 'member checks', implies that members of the studied group are given the opportunity to react to collected data and interpretations. I have not made use of this technique formally, but rather informally. Actually, with a perspective from grounded theory, I find it self-evident that this is part of the process of data collection. The dynamics of the inductive approach is to 'play back' summaries, condensed statements
and interpretations to the person who provided it for reactions, as well as to ask for comments on appropriate ideas emanating from the interview of another respondent (Glaser and Strauss 1967). The thesis of Paper III, on spouses' reactions and coping possibilities, has furthermore been presented to some spouses of brain tumour patients outside the present study. The thesis has been discussed in the termination phase of therapeutic relationships as a means to concluding a lived experience and to externalization. At the same time, we must be aware that, of course, 'member checks' cannot be used as an ultimative criteria for the interpretation's truthfulness. It is not a 'pass or fail' test. Nevertheless, with different purposes, the way of relating has basic similarities with the process of gaining rapport in psychotherapy (Wolberg 1967, Kvale 1996).

Due to the closeness between knower and known it is hard to believe that qualitative inquiry would not convey a great potential of truth value. Perhaps then:

"there is some truth in the quip that quantitative methods are reliable but not valid and that qualitative methods are valid but not reliable." (Britten and Fisher 1993)

Consistency

Traditionally the demand for consistency is termed reliability. It is a question of stability in the assessments, of replicability. A procedure (test administrator or the scorer together with the instrument) is reliable, a prerequisite for validity, if it displays the same results on different occasions.

However, just as an open interview cannot be repeated any more than the same river can be crossed twice, reliability to the naturalistic inquirer is a contradiction in terms. Due to the first interview, reality as a construction in the mind of the respondent has changed. In that sense I agree with Britten and Fisher, reliability is a problem. In fact, the conventional reliability criteria is an anomaly when applied to naturalistic research, because of the contrasting views of reality: reality as objective, out-there and reality as subjective, constructed. By the same reason there can be no replication in the traditional sense (Marshall and Rossman 1989, Strauss and Corbin 1990).

Furthermore, as the qualitative inquirer preferably is interested in exploring complex connections in an everchanging surrounding, variations rather than snap-shots are the focus of interest (Hamberg et al 1994, Sandelowski 1986). The alternative term encompassing the requests for solid adaptation for change is dependability. In the same sense as a valid study is a reliable study, a study meeting the demands of credibility also meets the demands of dependability.

Repeated interviews is one potential in safeguarding dependability. Even if this applies to the present study, the strength of the dependability would have increased with an even more flexible design. In addition to the settled interview-schedule, the participants more
systematically should have been interviewed at identified turning points (e.g., coming home, progressed disease). Overall, a flexible design, that as grounded theory permits a simultaneous collection and analysis of data, is favourable to establishing dependability. For the same reason reliability in the quantitative sense would undermine validity in the qualitative sense (credibility) (Sandelowski 1986).

**Neutrality**

Neutrality refers to freedom from bias in the research process. Traditionally this is equal to safeguarding objectivity, i.e., what concerns a number of subjects contrasting to individual experiences, by the use of value-free instruments that distances the knower from the known. Through this procedure, knowledge of reality is gained.

To the qualitative inquirer this is self-deception. No protocol can change the fact that all inquirers change the subject under study. All questionnaires have their embedded preconceptions. Acknowledging the illusion of objectivity is a prerequisite to control the potential bias from the researcher's preconceived assumptions. To secure neutrality of the findings in a study is a question of checking that these findings really are founded in data and not primarily the product of idiosyncratic convolutions of the researcher's brain. This is an issue of utmost importance to trustworthiness of qualitative research and its omission has surely contributed to criticism of subjective bias (Mays and Pope 1995). As mentioned previously, this criticism is the context to the development of grounded theory. By a frame of methodological structure, grounded theory would supply qualitative research with a safeguard against undue subjective bias. Rigour regarding neutrality is achieved by securing confirmability by focusing on data and the interpretation of data: it should be possible for another trained researcher to look at the data and come to essentially the same conclusions (Hamberg et al 1994). This stresses the importance of a rigorous description of assumptions and methods, particularly with regard to data analysis (Mays and Pope 1995).

There are several different and more or less structured ways of implementing these audit-procedures (Lincoln and Guba 1985). In Paper I we made use of independent psychologists who read a sample of the interviews with the task of detecting phrases that might announce mental strategies from a presented list of cognitive manoeuvres. Overall they could confirm our analysis. However, this procedure could be challenged as being half-hearted. An unprejudiced check would seem to be more radical. The problem is that it is quite plausible that the result would be another way of conceptualizing the data. This would be unlikely to disprove the former conceptualization, it would merely justify the existence of multiple realities. Reality is a construction. Paradoxically, in this case an unprejudiced check would therefore in fact have been a less radical ensurance of confirmability. Besides, we were not interested in all potentially available alternative conceptualizations. We were interested in confirming/disproving our own findings.
The conceptualizations and interpretations made can also be presented to other researchers or clinicans well-acquainted with the subject under study. The question is whether the interpretations encompass their experiences or not. It is quite a difference if they react to it with curiosity, regarding the presented ideas as verbalizations of their 'tacit knowledge', or if they feel indifferent and have obvious problems in recognizing and understanding what is presented. In different stages of the research process, when the analysis became more substantial, drafts were presented to and discussed with the qualitative research group at the Department of Family Medicine and with staff at the Department of Oncology familiar with the participants under study, but also with brain tumour patients in general. Especially in Paper III this form of ensuring confirmability was salient. Due to the complexity of the analysis (the interrelatedness of all parts to the whole) it was unattainable with an affirmation procedure similar to that of Paper I.

A shortcoming in the present study as regards the attainment of confirmability is that the main part of the interviews were not audio-taped. This fact restricts the possibility of an unimpaired audit trial. The rational behind taking notes, rather than tape-recording and transcribing is twofold.

First, and primarily, it is a question of dealing with the most well-known problem of qualitative research, namely that of drowning in data. A sixty-minute interview corresponds to about 20-25 pages of transcribed text. As this project with its design was supposed to comprise approximately 120 interviews, it would have ended with 3,000 pages of text ready for analysis. This is by no means extreme in qualitative research, but it implies that time-consuming steps must be taken to condense data. It also challenges the capacity of the human brain. According to Kvale (1996) even 1,000 pages is too much to handle. In the present design this process may be said to correspond to the taking of notes: the crucial issue of separating what is and is not of interest. Of course, this procedure challenges the inductive 'tabula rasa' ambition, it may be difficult to detect phenomena far away from the preconceptional perspective. These phenomena may not have been noted. On the other hand, the procedure gives credit to the processing of data. The researcher's immediate transcription of the interviews was experienced as a valuable moment which facilitated reflection and early comprehension of the data. In a way the interview was processed once again.

Second, a tape-recorder alters the interview situation. Even if there is a process of successive habituation, the problems of tape-recording are probably underestimated. From my own experience of transcribing texts, I have seen the dramatic shift in psychotherapeutic sessions when a tape-recorder or video-camera has been introduced. This is detected by interpreting the unconscious communication (Langs 1978, 1979, 1982). The patients, for instance, may unconsciously communicate by means of metaphors that they feel like they are in a situation of cross-examination or that they are on stage. This may violate openness and increase proneness to socially acceptable answers.
As a compromise it was decided in the beginning that a couple of interviews were to be audio-taped to allow a confirmability-check. The decision to drop the recording was hastened when a couple of spouses expressed doubtfulness when exposed to the procedure. Overall, there are pros and cons as concerns audio-taping. When making decision, the capability of the craftsmanship and the delicacy of the subject under study must be taken into consideration. A limited number of interviews, unexperienced researcher, and less-ticklish subjects, are factors which speak in favour of tape-recording.

Applicability

The importance of research results is to a great extent dependent on their applicability to realities beyond the one subjected to inquiry. Generally this is termed external validity or generalizability and relates to the representativeness of subjects, tests and the testing situation (Cook and Campbell 1979). Randomized sampling and the presence of statistical significance are the core factors of external validity.

Qualitative research challenges the rational behind these theses and questions the validity of context-free generalizations. In line with the axioms constituting the qualitative approach, applicability is not just a question of the sending context but to the same extent of the receiving context. It is a matter of transferability, or fittingness (Lincoln and Guba 1985). The implication of this shift in meaning is that when making inferences, the final burden of proof is primarily a matter for the person who seeks application outside the investigated context. Still, it is the responsibility of the original researcher to provide sufficient data to make the transferability judgments possible.

Of course, small sample sizes and the method of 'theoretical sampling' emphasize the importance of paying attention to similarities when transferring results. But it also signifies that, due to the character of qualitative findings as theoretical modelling, transferability, or theoretical generalizability, is dependent on clinical recognition of described phenomena (Morse and Johnson 1991). Paradoxically, this implies that concepts may be found to have a high applicability although contextual variables are highly diverting. As an example, the concept of 'protection and hope from the body' obviously has a usefulness far beyond from the phenomenology of brain tumour patients. Furthermore, the more comprehensive the theoretical sampling, and the more conditions and variations may be discovered and built into the theory, the greater the transferability (Strauss and Corbin 1990).

In summary: Quantitative research as an activity of deduction and qualitative research as an activity of induction are based on more or less articulated epistemological axioms. Canons of sound science are inevitable but they must be redefined to fit the complexities of social phenomena and the realities of qualitative research. Out of mutual respect, different approaches have to be evaluated from their own inner logic. During the past decades there has been an increasing debate concerning criteria of scientific soundness in
qualitative research (see, e.g., *Qualitative Health Research*). Different scientists advocate different criteria and evaluative procedures (seemingly to a great extent depending on that new questions are posed in different realities) but the concepts of *credibility, dependability, confirmability and transferability* and their operationalizations reflect issues that are central to this discussion. It must also be acknowledged that in the same sense that the question posed by the curious researcher should guide the selection of method and not vice-versa, the judging of a qualitative study must be attained by criteria appropriate to its idiosyncracy. The criteria are by no means absolute, but merely guidelines to answering the basic questions that every scientist should pose when designing a research project:

"How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of? What arguments can be mounted, what criteria envoled, what questions asked, what should be persuasive on this issue?" (Lincoln and Guba 1985, p.290)

**VALIDITY OF THE QUANTITATIVE ASSESSMENTS**

In Paper I we made use of the RDCQ as a measurement of the reaction to the communication of the malignant brain tumour diagnosis. The assessment was primarily intended to be used as a check when dividing the patients within the group and as an additional source when identifying patients with a reduced critical discrimination. We chose the RDCQ because we simply did not know of any other instrument. Today we would probably have chosen the MAC-scale instead (Greer and Watson 1987). It is similar, but far more well-known and based on quite another experience.

The relevance of the comparison with another group of cancer patients, an ambulatory and heterogenous group of American cancer patients undergoing treatment made in Paper I, may be questioned. Comparisons between groups in different sociocultural contexts must always be made with due caution (Breetvelt and van Damme 1991). However, the purpose of the actual comparison was restricted to giving an indication of whether the studied group of patients deviated in a more obvious sense. They did not. Yet, this may not be taken to mean that these different groups reacted in a similar manner. It only means that we do not have indications of contrasting coping strategies. Furthermore, in a quite recent questionnaire study of a large group of brain tumour patients in different stages of the disease process, the reported anxiety and depression did not differ from that reported by patients in general medicine (Giovagnoli et al 1996).

In Paper II a clear-cut memory deficiency as regards long-term memory was detected. Recently, similar findings have been presented by others. In studies of long-term survivors of malignant gliomas Archibald et al (1994) evidenced impairments above all in verbal memory and sustained attention, and Giovagnoli and Boiardi (1994) found tests of
memory, attention and word fluency to be most sensitive in detecting subtle dysfunctions. In a pilot study of five low-grade glioma patients, a long-term memory deficit was detected without evidence of impairments in any other neuropsychological test with the exception of information-processing speed (Armstrong et al 1993). The memory impairment was detected a couple of months after radiotherapy with a rebound about half a year later. These studies suggest that radiation therapy may cause the impairments, although there are studies challenging this assumption (Taaphorn et al 1994).

In Paper II we also discussed the possibility of relating the impairment to tumour biology, surgery, and/or chemotherapy. However, the discussion did not consider the fact that all patients in Paper II (and probably most patients in studies mentioned above) received corticosteroids. Steroids, like dexamethasone may impair declarative memory performance in adult subjects, probably due to a selective effect on the hippocampal formation (Newcomer et al 1994). This is an oversight that must be taken into account when designing studies for further research in this area.

DENIAL, DISAVOWAL AND ILLUSION

The majority of patients in this study evidenced an impressive repertoire of cognitive ways of coping with their strain. Lacking behavioural ways to manage the threat, they reconstructed reality by a positively reframed perception. As illustrated in Figure 4 (from Paper I) they combined 'reality' with 'hope' and thus created an illusion.

Figure 4. The illusion as a combination of protection/hope and reality (From Soc Sci & Med 1996;42:993).

This finding was striking, and as shown in the juxtaposition of concepts in psychoanalytic psychology in Paper I, the defensive concepts did not quite encompass
these findings. Even if many manoeuvres alluded to defined defence mechanisms, most of them nevertheless seemed to be a bit distant. As an example, 'perceiving the contrast' as a manoeuvre gives the impression of being a creative way of exploiting the experience of threatening symptoms, to make something good out of them. 'Undoing', on the other hand, as the related defence mechanism, is more thorough and tied to magically wiping out what has happened. This can be understood as an expression of the important difference between defence mechanisms as conceptual abstractions and defensive behaviours as observable phenomena (Wallerstein 1983). Complex behaviour-configurations may be seen as constellations of classic defence mechanisms (P Kemberg 1994), and an infinite number of defensive manoeuvres may thus be related to a limited number of defence mechanisms. Still, it seems difficult to connect the cognitive (or defensive) manoeuvres 'finding meaning' and 'changing perspective' to any corresponding defence mechanisms. These manoeuvres seem more linked to basics in existential psychology (Frankl 1965).

It is not indisputable whether it is appropriate to look at patients victimized by a severe disease with the same eyes with which we regard people with neurotic disturbances. In the first case the patient is struggling with a threat from external reality, in the latter case the threat is primarily from within. It may, for instance, be argued that a process aimed at adapting to an external threat, nearly by definition must be more unconcealed. However, the importance of paying attention to the differences is not restricted to whether the processes are alike and thus may be well-described with the same conceptual framework. The topic is also of obvious clinical relevance because the psychoanalytic defence theory is connected to psychopathology (Vaillant 1994), but also to treating neurosis through the revealing of unconscious motifs or by correction of distorted beliefs (Eagle 1984). In short: by means of awareness the patient is cured by orienting towards internal reality. Is this approach applicable when the subconscious motif is to adapt to a real threat to life?

In Papers I and IV and in a previous chapter we discuss the relationship between defence mechanisms and coping strategies and we particular challenge the utilization of the concept of 'denial'. It is used as an umbrella concept covering unconscious repudiation as well as conscious attitudes, implying contradictive research results (Watson et al 1984, Scheier et al 1986, Frank Stromberg 1989, Carver et al 1993). Furthermore, it is a clinical experience that it is used overinclusively, embodying a wide range of situations where the patient behaves unexpectedly. The present research does not solve these problems but nevertheless, from a clinical point of view, is a contribution to this important discussion.

According to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association 1987), 'denial' is "a [defence] mechanism in which the patient refuses to acknowledge some aspects of external reality that would be apparent to others". This is probably a definition with a wide acceptance among clinical psychoanalysts. In
"...considerable research evidence suggests that overly positive self-evaluations, exaggerated perceptions of control or mastery, and unrealistic optimism are characteristic of normal human thought. Moreover, these illusions appear to promote other criteria of mental health... These strategies may succeed, in large part, because both the social worlds and cognitive processing mechanisms impose filters on incoming information that distort it in a positive direction; negative information may be isolated and represented in as unthreatening a manner as possible." (Taylor and Brown 1988, p. 193)

Clinically it seems appropriate to regard the detected cognitive manoeuvres and the process of disavowal from this perspective of illusions of everyday life (of course this is not contradictory to relating manoeuvres to defence mechanisms). It may be suggested that the cognitive manoeuvres, as operationalizations of the mechanism of disavowal, are expressing the normal process of illusion-formation when put under severe strain. The process becomes more visible.
It may be objected that this discussion is just playing with words and that changing concepts does not alter reality. However, mental models as social constructions have a profound impact on our way of dealing with reality. The cognitive manoeuvres may be seen as reflecting defensive processes, illusion-formation or whatever may be suggested. The crucial point is to be aware of the fact that different frameworks are, in addition to fittingness, also related to differences as to communication and to the establishment of the patient-staff relationship.

RESULTS AND PROSPECTS

First, in this inquiry it was detected that most of the studied 30 patients made use of subconscious mental elaborations to palliate their psychological strain. The successfulness in their coping seemed to depend on this creative process but their physical well-being, personality, life-experiences and life-context may also have contributed. In spite of an awareness of the severity in their life-situation most of them were not filled with despair and hopelessness but able to regain some hope. This may be described as a clinical surprise and actualizes the significance of the distinction between the 'life-world' and the 'medical world'. The patient reconstructs reality while medical staff primarily acknowledge patient reality in terms of diagnosis, treatment and prognosis.

The patients' elaborations are easily encompassed by the normal social-psychological phenomena of illusion-formation or by the overlooked Freudian defence against external reality, 'disavowal'. It is proposed that these manoeuvres should be kept apart from 'denial', which implies perceptual omissions.

The design from this study should be transferred to a similar setting with another cancer disease, e.g., lung cancer. Do lung cancer patients deal with their strain in a similar manner? Their prognosis is also poor, but the CNS is not primarily involved and the patients' brains are not operated on.

Second, the acknowledgement of the patient's life-world as an intermediate area (Winnicott 1971) is rewarding when discussing the essentials of the doctor-patient dialogue. The establishment of the intermediate area in this dialogue is very much equal to establishing a proper relationship when telling bad news. The model is attractive because it is based on an asymmetry as to need, desire and communication (Model 1990), and the area is reminiscent of a reflection of the parent-child relationship. This is an issue of great importance since telling bad news in cancer care is encountered thousands of times every day. It is associated with fear and anxiety (Buckman 1984, Andrae 1994) and blunders may cause an arrest in the patient's coping ability with subsequent anxiety and depression (Cooper and Watson 1991). Nevertheless, this humble model acknowledging the doctor-patient asymmetry may in a sense challenge the contemporary approach emphasizing informed consent, individual responsibility and full disclosure.
There is an obvious lack of theoretical contributions in this area. There are statistics and good advice, but there is a lack of psychology concerning the doctor-patient relationship. The 'intermediate area' has earlier been made use of in a psychoanalytic study of psychotherapeutic relationships with dying cancer patients (Hägglund 1978). The present study proposes that concepts from the psychoanalytic discourse are also applicable to everyday patient-physician relationships. The propositions have to be evaluated and developed by qualitative prospective studies of patients' and spouses' narratives and by observation of doctor-patient dialogues. There are a lot of substantial questions to be reflected upon. What parameters constitutes the physician as a holding environment that subconsciously protects the patient from the dangers of reality, from death? Is it possible that the attachment to the protective object on an unconscious level may be equal to attachment to life and that separation is thus equated with death? Medicine and patients would benefit from evolving knowledge on this type of issue.

Third, it is important to pay attention to spouses of brain tumour patients. Their everyday life contextual knowledge of the patient's behaviour may be critical when finding the proper diagnosis. This study also detected spouses' different crisis trajectories and available coping strategies. It highlights the importance of paying attention to spouses from the moment of diagnosis and throughout the course of the disease. Basically, it is a matter of supplying a personal platform, of being available in the sense that prevents spouses from experiencing a claustruum. A crucial issue is communication of information.

Fourth, the brain tumour disease is associated with cognitive dysfunction as evidenced by episodic long-term memory impairment. The impairment is a clinical reality, but it is still unclear whether it is caused by the infiltrating tumour itself and/or by different treatment modalities. Surgery, radiotherapy, chemotherapy and corticosteroid medication may cause memory impairment. The possible contribution of these treatments in the present context is still open to question. Further investigations should preferably be based on repeated neuropsychological assessments. The selective reminding technique was found to be a sensitive instrument in detecting deficiencies. The technique is also a suitable tool, when evaluating the possibility of alternative radiotherapy schedules in order to shorten the time of treatment.
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Avhandlingen berör psykologiska aspekter kring patienter med den allvarliga hjärtumörssjukdomen malignt gliom och deras närmast anhöriga. Den dåliga prognosen vid denna sjukdom motiverar studier som kan ge upphov till nya behandlingar och som söker vägar att förstå de psykiska påfrestningarna i denna utsatta situation.

Trettio patienter med astrocytom grad III-IV deltog i en klinisk undersökning med estramustinfosfat som tilläggsbehandling till kirurgi och strålbehandling. Dessa patienter involverades konsekutivt tillsammans med sin närmast anhörige (oftast make/maka) i denna studie som syftade till att fördjupa kunskapen om de psykologiska skeenden som aktualiseras vid svår hjärtumörssjukdom.


Ett centralt fynd i denna studie var att patienterna uppvisade en påtaglig förmåga att skapa skydd och hopp, trots eller tack vare sin utsatthet. De var medvetna om allvaret i sjukdomen men genom att betrakta verkligheten i en speciell belysning så minskade de sin utsatthet. Via 'mentala manövrer' skapade de en 'illusion' som en förening av skydd/hopp och bister verklighet. Patienterna rekonstruerade på så sätt sin världsbild på
ett sätt som för tankarna till Winnicotts 'övergångsområde'. I studien relateras vidare dessa 'mentala manövrer' till psykoanalysens försvarsmekanismer. Det hävdas att försvarsbegreppen täcker vissa manövrer men inte andra och att 'disavowal' (desavouera) mer än 'denial' (förneka) återspeglar innebörden i den rekonstruktiva verksamheten. Att patienten befinner sig i 'övergångsområdet' ger oss vidare möjlighet att bättre förstå den uppgift som vi står inför när vi skall lämna svåra sjukdomsbesked. Det saknas teori på detta område och genom fallbeskrivningar söker vi vidare belysa de möjligheter som finns i dessa betraktelsesätt.

For de anhöriga är sjukdomen inte bara ett hot om partnerns död utan också om dennes personlighetsförändring och det egna livets fortsättning. De anhörigas krisprocess uppvisade olika förlopp och till stor del var detta avhängigt hur deras partner fungerade. Speciellt svårt hade de anhöriga till de personlighetsförändrade patienterna och det är angeläget att sjukvården uppmärksammar dem. Det handlar helt enkelt om att betrakta dessa anhöriga som enskilda individer med egna behov samt att förstå vikten av att de har en egen livsplattform.


Möjliga bieffekter av estramustinfosfat studerades med avseende på sexualitet, psykosocialt välbefinnande och neuropsykologiskt funktionsnivå. Estramustinfosfat hade i de flesta fall en negativ inverkan på männens sexualitet och visade sig också kunna vara en av andra orsaker bakom den funna minnesstörningen. Biverkningarna tycktes dock inte påverka hur patienten upplevde sitt allmänna välbefinnande. Denna biverkansstudie är mer av pilot-karaktär men den aktualiserar viken av att vidare undersöka möjliga neuropsykologiska effekter av cytostatika och annan cancerbehandling. 'Selective-reminding' tekniken visade sig vara ett känsligt instrument för att upptäcka cerebrala störningar och tekniken rekommenderas i framtida utvärderingar av behandlingsförsök som inbegriper centrala nerver.
ACKNOWLEDGEMENTS

Special thank to:

All the patients and spouses who participated in this study.

My supervisor, Professor Roger Henriksson, head of the Research Department of Oncology. First of all I am greatful for your frank and outspoken way of introducing me to and supporting me in various fields of the medical community. Although I dare say that your experience of qualitative inquiry at the beginning of this project was meagre, without your personal way of showing confidence, your breadth of vision, your never-ending scientific curiosity, I doubt this project would have been completed.

My co-supervisor, Assistant Professor Tommy Bergenheim, Department of Neurosurgery. One of the strengths of this project has been interdisciplinary cooperation: the analysis of a shared topic from different perspectives. This thesis has very much benefited from your skills in interdisciplinary cooperation. No one has shown the same kind of fervour to critically, but respectfully, comment on the drafts of this thesis like you have, and actually this chiefly concerns the more soft psychological parts.

My old friend, collegue and mentor in neuropsychology, Thomas Karlsson, PhD. Your knowledge of the state of the art of neuropsychology is impressive. I am greatful for your generosity in sharing ingenious ideas and of giving clear answers to hazy questions.

My mentor in psychoanalytic theory and practice, Gunnar Windahl, PhD. I admire your ability to combine devotion to the field of contemporary psychoanalysis with critical scientific evaluation. I am greatful for your kind way of sharing brilliant thoughts and for always being available to provide advice and hidden references.

Dr Per Bergström for co-authorship and my colleagues Rein Havama and Mona Wilhelmsson for helping me test the confirmability of this thesis.

Professor Bo Littbrand, head of the Department of Oncology. I have always been aware of your concern for my work in psychosocial oncology and your backing when it comes to the essentials of doing research; time and finances.

The members of the qualitative research group at the Department of Family Medicine: Gunilla Bring, Lars Dahlgren, Katarina Hamberg, Ann Hammarström, EvPa Johansson, Berit Nilsson, Gunilla Risberg, Helena Stenberg, Kerstin Ternulf Nylin and Göran Westman. In the last three years we have met regularly to discuss books, papers and our own drafts. I am grateful to the group as a scientific forum for critical evaluation of qualitative research and for its friendly and encouraging atmosphere.

Department secretaries Karin Gladh and Pia Granlund, research nurses Elisabeth Karlsson and Gunilla Israelsson, and the staff at the Research Department of Oncology. I appreciate the helpful and inviting atmosphere you created even though I am something of an ugly duckling. A special thank to Mikael Johansson for computer assistance.
Finally, thanks to my dear wife Katarina. I dare to say that we have gone through one or two controversies throughout the years. Mainly it has been about time. I am grateful for your concern about this thesis and especially for your sharp critical comments on methodological issues. Your contribution as life companion and scientific advocate has been extensive.

I am also grateful for financial contributions from The Research Foundation of the Department of Oncology, Umeå University and The Swedish Association for Cancer and Traffic Victims (Cancer och Trafikskadades Riksförbund, CTRF).