

Pathways from symptoms to medical care: a descriptive study of symptom development and obstacles to early diagnosis in brain tumour patients

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Background. The time between experiencing symptoms and treatment in cancer diseases is a time of insecurity and despair. Brain tumour disease is a severe disease with dramatic manifestations and it is important that this time be kept as short as possible.

Methods. A consecutive sample of 28 patients with malignant gliomas and their spouses were interviewed about symptom development, help-seeking and experiences of medical care. The cumulative development of their symptoms was described and factors acting as obstacles to medical care were identified.

Results. Most spouses witnessed months of global dysfunction preceding the symptom leading to physician consultation. The patient factors 'less alien symptoms', 'personality change' and 'avoidance'; the spouse factors 'spouse's passivity' and 'spouse's successive adaptation'; and the physician factors 'reasonable alternative diagnosis', 'physician's inflexibility' and 'physician's personal values' were identified as obstacles on the pathway to appropriate medical care. The importance of acknowledging the power of the spouse as a provider of substantial information from everyday life facilitating differential diagnosis is stressed.

Keywords. Brain tumour, cancer, delay, primary care, spouse.

Introduction

The time from symptom appearance to diagnosis and treatment in cancer is known to be a time of anxiety and despair.¹ In cases of brain tumours, the disease influences brain function, and anxiety may be accentuated by the initial dramatic manifestations of the disease. Through physical and/or mental handicaps, the disease affects the patient but, more than other cancer diseases, her/his family as well.²

Irrespective of possible impact of early diagnosis on prognosis, it is thus important that the pathway to medical care be as short as possible. Diagnosis is a

prerequisite for treatment and in the mind of the victim, treatment is hope and a promise of a future.³

The mental manifestations of brain tumour disease may impair the patient's ability to proper judgement as well as his/her ability to act appropriately. This may affect the help-seeking process, but it may also make it more difficult for the physician in primary care and the hospital to find the correct diagnosis.

This study describes the symptom development of a consecutive sample of patients with malignant gliomas and displays factors affecting the patient's pathway to medical care. Its purpose is to detect and highlight factors worth paying attention to in order to facilitate diagnosis. This subject has not been studied previously in brain tumour patients.

Method

At the University Hospital of Umeå in northern Sweden, 30 consecutive patients with the diagnosis of malignant

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glioma (astrocytoma grade III–IV) were prospectively included in the years 1991–1993 in a project studying psychological aspects of brain tumour disease.⁴ The inclusion criteria were: age 18–70 years and performance status 0–2 on the WHO scale ('ambulatory and capable of all selfcare but unable to carry out any work; up and about >50% of waking hours').

All the patients and, with one exception, all the spouses agreed to participate in the present study. The patients and spouses were interviewed separately after the patients had undergone surgery and received diagnoses from the histopathological examination. Two patients were excluded from the study after this interview due to difficulties in evaluating their experiences. The final sample thus consisted of 28 patients: 18 men and 10 women, with an even age-distribution around the mean of 55 years.

The interviews were thematically structured and focused on symptom presentation, the first visit to a physician and further experiences of medical care until the actual moment of diagnosis communication at the neurosurgical department. Key questions were:

- When did you first suspect that you were sick?
- What were the symptoms?
- To whom did you turn?
- What happened?
- What information did you receive?

The spouses were asked the same questions from their point of view. Performing parallel interviews of patients and spouses made it possible to triangulate the data.⁵

Symptoms and help-seeking

The findings in Table 1 are centred around the 'trigger' symptoms in boldface type i.e. the symptoms which patients and spouses alleged as a reason for consulting a physician. The table enables us to capture the symptom development leading to physician consultation (preceding symptoms to the left of the trigger symptom), as well as the further course of symptom development before diagnosis (symptoms to the right of the trigger symptom). In the description below, the trigger symptoms are grouped into four categories: headache, seizure, motor or sensorial dysfunction and mental dysfunction.

Headache

Headache was more persistent and intense than ordinary headache, and in about half of the ten cases it was closely accompanied by vertigo and/or vomiting. Some patients experienced symptoms described as 'This is more than a headache, it is something else. Analgesics don't work'. In Table 1 this is labelled 'extreme headache'. Seven patients first turned to primary care for help, and three patients to the emergency unit. Two were

immediately referred for a CT-scan (C1, see below, and C8). The others were diagnosed as 'sinusitis' (C2 and C7), 'work-related' (C3), 'inflammation of the balance nerve' (C5), 'pregnancy?' (C6), 'headache due to tension' (C8) or just sent home for expectant management (C4). In three of these cases, the later CT-examination was pushed by the respective spouses' challenging these managements (C4, C5 and C9).

It is interesting to note that while the patients in this group indicated the acute onset of headache as the starting point of the disease, the majority of spouses in fact added, or began 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 spelled out any intention whatsoever." (C2)

The mean duration of these more global symptoms was 7 months (range 0–2 years).

Seizure/falling

After experiencing a seizure or falling, these nine patients practically immediately turned to consultation. Five first turned to primary care and four turned to the hospital. All but two patients were referred for CT-examination. These two patients received the diagnosis 'inflammation of the balance nerve' (C14) and 'sinusitis' (C15). In the case of 'sinusitis', further examination was insisted upon by the spouse.

In line with the headache group, the spouses in this group added descriptions of preceding symptoms: memory disorder, fatigue, falling asleep in the middle of the day, irritability or other socially detectable manifestations of dysfunction. Headache was also a common preceding symptom. The mean duration of these symptoms was 5 months (range 0.5–2 years).

Motor or sensorial dysfunction

Five patients first consulted their GP and one patient consulted the hospital. Three were immediately referred for CT-scan (C20–22), and in one case the spouse pushed for the referral (C20). The others were diagnosed as 'adverse effects of hypertensives' (C23), 'minimal stroke' (C24) and one was sent home for expectant management (C25).

Compared to the headache and seizure group, preceding diffuse symptoms were less prominent in this group of patients. The mean duration of these symptoms was less than 1 month (range 0–5 months).

Mental dysfunction

In three patients, the crucial symptomatology motivating physician consultation was centred around the mental sphere.

TABLE 1 *The cumulative development of symptoms from how it started to time of diagnosis according to the joint version of patients and spouses*

Case	Age	Sex	Group		Preceding time	Diagnosis time
1	65	M	H	Fits of shivering, feebleness, loss of initiative . . . headache , gastritis	24	2.5
2	45	M	H	Listlessness, loss of initiative . . . headache . . . extreme headache . . . vomiting	12	0.5
3	40	M	H	Headache, pain in the neck . . . vertigo, vomiting . . . extreme headache	0	4.5
4	70	M	H	Headache, vomiting . . . pain in neck and arm . . . hemiparesis	24	0.5
5	50	F	H	Tiredness . . . dizziness, headache . . . hemiparesis	1	0.5
6	32	F	H	Fatigue, irritation . . . headache, queasiness, vomiting . . . double-vision, anhedonia	2	1
7	36	M	H	Loss of initiative, sensitivity to noise . . . tired, slow, headache . . . seizure	2	6.5
8	70	M	H	Meekness, slowness . . . headache , concentration difficulties	3.5	0.5
9	49	M	H	Somnolence, personal decay . . . incontinence, headache , vomiting, memory disorder	4.5	1
10	66	M	H	Headache . . . extreme headache . . . disequilibrium, veering left, vomiting	0.5	2
11	47	M	S	Somnolence, fits of headache . . . seizure	24	4.5
12	62	M	S	Irritation, memory disorder . . . falling . . . confusion	5.5	0.5
13	44	F	S	Squinting, headache . . . seizure . . . vomiting	0.5	1.5
14	43	F	S	Sensitivity to noises . . . disequilibrium, falling . . . fever, urinary retention . . . extreme headache	1	0.5
15	49	M	S	Headache, vomiting . . . falling . . . veering left, dyspraxia . . . loss of appetite	0.5	1.5
16	54	M	S	Tiredness, irritation . . . dysphasia, seizure . . . headache . . . extreme headache, vomiting, fainting	6	3.5
17	51	M	S	Slight hemiparesis . . . seizure	0.5	0.5
18	64	F	S	Headache, vertigo . . . seizure	4.5	1
19	54	F	S	Irritation, tiredness . . . vertigo, headache, memory disorder, co-ordination difficulties . . . seizure	0.5	0.5
20	60	M	MS	Memory disorder . . . rambling, perceptual distortions	0.5	0.5
21	67	F	MS	Slight dysphasia . . . falling . . . slurring her words	1	0.5
22	48	M	MS	Hemiparesis	0	0.5
23	58	F	MS	Numbness in legs and arms	0	0.5
24	59	M	MS	Somnolence . . . numbness, slurring his words . . . seizure	5	2
25	65	M	MS	Different sense of taste, concentration difficulties , fits of shivering	0	1
26	68	F	Me	Mentally absent . . . vomiting . . . paranoia, anxiety, confusion	0	1
27	57	F	Me	Fatigue . . . memory disorder, vertigo . . . headaches . . . seizure	5	0.5
28	65	M	Me	Fatigue . . . fatigue . . . dyspraxia, slight hemiparesis, falling . . . hemiparesis	9	5.5

'Trigger-symptom' for the first physician consultation is indicated with bold-face type. Time of preceding symptoms to trigger symptoms (preceding time) and time from first physician consultation to arrival at the neurosurgical department (diagnosis time) are given in months (0.5 = 1–14 days, 1 = 15–30 days, etc).

H = Headache; S = Seizure; MS = Motor or sensorial dysfunction; Me = Mental dysfunction.

They were all escorted by their respective spouses to the family physician. One patient, who later turned out to be psychotic, was immediately referred to hospital (C26), the others were sent home for expectant management. However, in both these cases the spouses pushed for a referral. Case 28 was the only case in this study in which the physician consultation was triggered merely by the diffuse preceding symptom. In all other cases the trigger symptom was more symptom-specific.

Factors becoming obstacles on the pathway to medical care

Patient factors

Three different factors were identified that made patients less inclined to identify themselves as sick and in need of help: 'Less alien symptom', 'personality change' and 'avoidance'.

Less alien symptoms. As headache is so common in everyday life, it is easily attributed to trivial causes. It

was often seen from an everyday life context which postponed help-seeking: 'problems with the new glasses', 'sitting in front of the computer, now all day long' or 'stressed by my mother's death'. In contrast, a seizure is an alien symptom. It is dramatic, distant from our earlier body experiences and hard to connect to a satisfying explanation. In the absence of such an explanation, it exposes us to more stress, and a seizure nearly always implied immediate consultation.

Personality change. In a couple of cases this was easily identified as an obstacle. Mr Nine (C9) waited for about 4 months before seeing a doctor. He did not enter the pathway to medical care due to a personality change in connection with living alone.

Mr Nine had a bilateral frontal tumour. His relatives had noticed that he was often asleep when they contacted him and that he had stopped keeping his house in good order. It was later revealed that he had headaches and vomited, that he often forgot his meal or key or was late for work. 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. His overall decline progressed and when 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.

Mr Nine's absence of help-seeking behaviour was obviously related to the development of a frontal lobe syndrome. He had lost the ability to judge his situation and to initiate action according to his needs.

Avoidance. Avoidance and avoidance-like strategies are often discussed when dealing with cancer patients and their way of coping with the perceived threat of the disease.⁶

Mr Twenty-eight was known as a 'positive person'. His wife noticed that he seemed to have lost all his energy and, quite unlike his usual self, he slept late in the mornings. He saw his GP, but in absence of findings, he was sent home with a return visit booked. He drowsed on the sofa, was unable to unbutton his shirt, walked with a shuffling gait and had fallen once. According to his wife, 'If they had seen him at home, everyone would have realized that it had something to do with his brain'. His wife pushed him to revisit his GP before the scheduled visit. When discussing his general health condition with the physician, he commented on his problem with buttons by demanding that the button-making industry get its act together. Still, the examinations detected nothing. His deterioration progressed and the family brought him to the emergency unit. A CT-scan detected a tumour in the thalamic region.

It seems within reason to believe that his vigorous and frolicsome avoidance-manner also contributed to the physician's inability to follow what was going on.

Spouse factors

As has been discussed earlier, spouses took an active role in the help-seeking process. Quite a few spouses pushed the patient to consultation, and they also questioned its outcome. They acted as substitute for the patient's lack of judgement and activity, and as laypersons they relied on their knowledge of the patient from an everyday life context. 'Spouse's passivity' and 'successive adaptation' were thus obstacles on the pathway to medical care.

Spouse's passivity. The spouses seemed to be affected by the preceding symptoms more than the patients, and in nearly half of the cases, close relatives initiated the consultation with the physician. If Mr Nine had cohabited, it is hard to believe that he would not have been pushed to primary care earlier, and the pathway to appropriate medical care would certainly have been shorter if the wife of Mr Twenty-eight had accompanied him to the consultations. On the other hand, it is probable that Mrs Twenty-six would have suffered greatly if her husband had not been by her side and immediately realized that she needed help. They were out in the forest picking berries when she suddenly stopped talking and just sat on a stump with a blank gaze. She did not take notice when he insisted that she must see a doctor. He called their daughter. By means of her importance to her mother she managed to persuade her and they could escort her to primary care.

Spouse's successive adaptation. This might also contribute to lengthening the pathway. Initially, the spouse of Mrs Twenty-one noticed that she sometimes dropped her suffixes when talking, and a couple of weeks later she fell when they were walking on the beach. Since she seemed otherwise normal, these incidents were dismissed with a wave. When some friends commented that she was slurring her words, Mrs Twenty-one tried to assure them that it was no big deal. However, by way of their comments, her spouse was exposed to a new perspective on the preceding symptoms and it became obvious to him that she was not well. He escorted her to the primary care unit and she was immediately referred to hospital.

Physician factors

Provider factors which may hinder early diagnosis include organizational causes such as administrative blunders and overwork. However, the analysis below focuses on the physician in the diagnostic process and will not consider organizational factors.

Reasonable alternative diagnosis. This was an obstacle of signal importance for early diagnosis. Headache, for instance, has a myriad of reasonable causes that seem more likely than a brain tumour. This factor was even more obvious when the 'reasonable diagnostic context'

harmonized with the patient's everyday life explanation. The context might be a chronic disease.

Mr Twenty-four was a diabetic who began to 'fall asleep whenever he sat down'. Later, his left arm became numb and his slurring more pronounced. The GP confirmed his own suggestion that he had probably suffered a minimal stroke, and he received preventive medical treatment. However, he later had a seizure and his wife took him to the emergency unit at the local hospital.

In other cases, the initially 'reasonable diagnostic context' was more work-related. Mr Three had a new job and sat all day at his computer. Soon he experienced headaches in connection with pain in the neck. In line with Mr Three's opinion, the GP interpreted it as work-related. However, he proceeded to experience spells of vertigo and occasionally vomited. He was repeatedly on short-term sick-leave from his job and started acupuncture treatment. Still, he only got worse and was sent to a CT-examination by the GP.

Physician's inflexibility. Sometimes physicians seemed to have difficulties in abandoning an initial diagnosis. Mr Fifteen was treated for 'sinusitis', but his general state of health worsened, with intensification of the headaches and vomiting. He also veered to the left when riding his bicycle and noticed that he suddenly was not able to make use of his hedge-clippers or knot his tie. He returned twice to the physician and asked for a referral to the hospital. However, before he received an appointment at the hospital, he became unable to walk and his wife escorted him to the emergency unit.

After a seizure, the emergent CT-examination of Mr Sixteen was negative. Despite the severe progression of the disease, repeated visits to the hospital ended up with a reference to earlier examinations and assurances that 'everything was okay'. After weeks of despair, extreme headache and another seizure, his wife insisted on a new CT-scan, which detected the tumour.

In addition to physician inflexibility, these cases reveal the importance of communication concerning peculiar symptoms from everyday life as well as the significance of the spouse as informant.

The physician's personal values. Once Mr One's brain tumour had been detected at the local hospital, he was sent home to wait for the call from the neurosurgical department. After 5 weeks his wife phoned the physician at the local hospital; however, according to his wife

"He behaved so strangely. He strongly emphasized that it was a troublesome operation, that it might give him six months and the radiation another three months and added, 'for what life shall we save him?'. It was like he didn't want anything to be done, that there 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 was 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. According to Mrs One, the 5 weeks of waiting were the most horrible weeks of her life. During that time they had been provided with a malignant diagnosis but no treatment had been initiated.

Discussion

The consecutively and prospectively followed malignant glioma patients in this study display a variation in symptomatology in line with previous reports: headache and seizure are the most common symptoms experienced at the time of diagnosis.^{7,8} However, the present study differs as to the identified prevalence of mental symptoms early in the disease process. More than 50% of the patients recalled preceding mental symptoms, e.g. fatigue and irritation, which is nearly three times as common as has been presented in a previous major study by McKeran and Thomas.⁷ This discrepancy may be due to methodological variation—compared with their study, our sample is limited, their definition of 'initial' as well as 'mental' is unclear, but it may also be due to additional information gathered from the spouse interviews in the present study. That we detected a higher prevalence of mental symptoms may also be taken to mean that we saw earlier phases in the disease process, before these symptoms were overshadowed by the more acute onset of the disease. According to McKeran and Thomas, the time from first symptom to final diagnosis was nine and a half months (in fact longer if adjusted to the same diagnostic group as in the present study). Not surprisingly we, about 30 years later, found this time to be shorter—at least 3 months shorter. The main cause for earlier diagnosis is probably to be found in technical advances, such as the CT-scan. However, it cannot be ruled out that a changed patient–physician relationship may also have contributed. To what degree did patients and spouses challenge the physicians' judgement and to what degree were the physicians receptive to the patients' and spouses' opinions at that time?

The majority (20/28) of patients first turned to primary care. Eight (40%) were immediately referred to the emergency unit at the local hospital. Since headache is an extremely common symptom in primary care and a GP theoretically (given that all patients in Sweden with intracranial neoplasm first consult a GP) is confronted with a brain tumour patient only once every third year, the difficulty in differential diagnosis can hardly come as a surprise.⁹ The most common alternative diagnoses were 'sinusitis' and 'inflammation of the balance nerve'.

The wide variation in time from physician consultation to diagnosis reveals that a multitude of factors exert an

influence on the diagnostic process. The time to diagnosis is thus not just a matter of symptomatology, although the more dramatic or alien, the shorter the time. In cases of personality and mental changes, it is obvious that spouses' motivation and actions for seeking help are of crucial importance, substituting for the patient's lack of insight and motivation. The social surroundings are thus important. The spouse is important because he/she has a contextual reference of observation of antecedent symptoms of a more general kind, and is thus able to value more clearly the change that has taken place.

The spouses contributed to shortening the time to diagnosis. They were, in quite a few cases, their partners' delegates, challenging the physicians and arguing that an X-ray of the brain was an urgent necessity. From their lay-knowledge, they just knew that the patient was severely victimized. Their responsibility for the help-seeking process, but also for the new life-situation after primary treatment, put a certain burden on their shoulders.

By and large, studies on spouses of cancer patients underline their distress. It has been found that spouses' distress was greater than patients' in cases of surgically treated cancers, and it has also been found that spouses' physical health might be affected.^{10,11} The fact that personality change more than somatic deficiency is the crucial issue to cope with underlines the psychosocial strain put on spouses of brain tumour patients.¹² In recent analysis of the changed life-situation of the spouses in the present study, different crisis-trajectories were identified.¹³ These trajectories were highly dependent on the patients' overall status, and the concepts of 'mutuality' and the spouse's 'personal platform' turned out to be of explanatory value. Spouses who, due to changes in the patient's personality, experienced loss of mutuality in the relationship, and who had few connections outside the relationship, were worse off. The author stresses that spouses should be viewed as separate people with their own needs and prospects, and not just as supportive instruments for their ill partners. In line with this, it is proposed that from the time of diagnosis throughout the entire course of the disease process, the spouses of brain tumour patients should be assigned a physician of their own (in Sweden preferably a GP). Although the spouses' health may be affected, the primary value of having one's own physician would be to implement an opportunity for reflection on one's own life-situation. In due course, a variety of crucial questions has to be reflected on.

Conclusions

- (i) The majority of patients with malignant glioma first consult their GP.
- (ii) The pathway to medical care is longer when the patient has less-alien symptoms, displays personality change or is prone to avoidance, when the spouse is

passive or subjected to successive adaptation and, when there are easily accessible alternative diagnoses, the physician is inflexible or acts on personal evaluations.

- (iii) Patients describe their symptoms in terms of bodily experiences and acute onset, while a majority of the spouses also narrate stories of months to years of diffuse preceding symptoms and global changes.
- (iv) In order to shorten the time to proper diagnosis it is important to acknowledge the spouses as informants. When in doubt, it is advisable to contact the spouse and ask both the patient and the spouse for preceding symptoms and peculiarities in everyday life. Fatigue for 4 months, intensifying headache for 4 weeks and suddenly being unable to explain how to use the lawnmower are indications of a disease beyond 'sinusitis'. That the patient in fact is escorted by an active spouse may be a crucial indication worth reflecting upon.

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References

- ¹ Risberg T, Særbye SW, Norum J, Wist EA. Diagnostic delay causes more psychological distress in female than in male cancer patients. *Anticancer Res* 1996; **16**: 995–1000.
- ² Fallowfield L. Helping the relatives of patients with cancer (Editorial). *Eur J Cancer* 1995; **31A**: 1731–1732.
- ³ Salander P, Bergenheim AT, Bergström P, Henriksson R. How to tell cancer patients: A contribution to a theory of communicating the diagnosis. *J Psychosoc Oncol* 1998; **16(2)**: 79–93.
- ⁴ Salander P, Bergenheim T, Henriksson R. The creation of protection and hope in patients with malignant brain tumours. *Soc Sci Med* 1996; **42**: 985–996.
- ⁵ Lincoln YS, Guba EG. *Naturalistic Inquiry*. London: Sage, 1985.
- ⁶ Watson M, Greer S, Blake S, Sharapnell K. Reaction to diagnosis of breast cancer. Relationship between denial, delay and rates of psychological morbidity. *Cancer* 1984; **53**: 2008–2012.
- ⁷ McKernan RO, Thomas DGT. The clinical study of gliomas. In Thomas DGT, Graham DI (eds). *Brain Tumours: Scientific Basis, Clinical Investigation and Current Therapy*. London: Butterworths, 1980: 194–230.
- ⁸ Kraemer DL, Bullard DE. Clinical presentation of the brain tumour patient. In Morantz RA, Walsh JA (eds). *Brain Tumors: A Comprehensive Text*. New York: Marcel Dekker, 1994: 183–213.
- ⁹ Roland M, Jamouille M. La cephalée en médecine générale: situation et démarche clinique (In French.) 'Headache in general medicine: status and clinical evaluation'. *Rev Med Brux* 1996; **17(4)**: 288–292.
- ¹⁰ Keitel MA, Cramer SH, Zevon MA. Spouses of cancer patients: A review of the literature. *J Counseling Develop* 1990; **69**: 163–165.
- ¹¹ Howell D. The impact of terminal illness on the spouse. *J Palliative Care* 1986; **2**: 22–30.
- ¹² Liss M, Willer B. Traumatic brain injury and marital relationship: A literature review. *Int J Rehab Res* 1990; **13**: 309–320.
- ¹³ Salander P. Brain tumors as a threat to life and personality: The spouse's perspective. *J Psychosoc Oncol* 1996; **14(3)**: 1–18.