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## Patients' experiences and care needs during the diagnostic phase of an Integrated Brain Cancer Pathway

### *A Case Study*

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### **Title**

Patients' experiences and care needs during the diagnostic phase of an Integrated Brain Cancer Pathway: A Case Study

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### **Conflict of Interest**

None

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### **Abstract**

**Aim and objective.** To identify and describe patients' experiences and care needs throughout the diagnostic phase of an Integrated Brain Cancer Pathway.

**Background.** A malignant brain tumour is a devastating diagnosis, which may cause psychological symptoms and cognitive deficits. Studies have shown that the shock of the diagnosis, combined with the multiple symptoms, affect patients' ability to understand information and express needs of care and support. Unmet needs have been reported within this group of patients, however, the experiences and care needs of patients going through the diagnostic phase of a standardised Integrated Brain Cancer Pathway have not previously been explored.

**Design.** A Case Study design was used to provide detailed information of the complex needs of patients being diagnosed with a malignant brain tumour.

**Methods.** Research interviews and direct participant observation of four patients during hospital admission, brain surgery and discharge were conducted in a Danish university hospital. Systematic text condensation was used to analyse the data material.

**Results.** Four major themes were identified: information needs, balancing hope and reality while trying to perceive the unknown reality of brain cancer, not knowing what to expect and participants' perceptions of the relationship with the health care providers. The analysis revealed that participants were in risk of having unmet information needs and that contextual factors seemed to cause fragmented care that led to feelings of uncertainty and loss of control.

**Conclusions.** Brain tumour patients have complex care needs and experience a particular state of vulnerability during the diagnostic phase. Through personal relationships based on trust with skilled health care providers, participants experienced an existential recognition and alleviation of emotional distress.

**Relevance to clinical practice.** Patients receiving a brain tumour diagnosis experience unmet care needs in several areas during their hospital stay. There is a need for interventions from health care providers.

**Key words**

Brain cancer, brain neoplasm, malignant glioma, patient perspective, care needs in hospital, supportive care needs, hermeneutic-phenomenological approach.

## **Introduction**

Becoming a patient, managing symptoms and having to navigate in the health care system while going through several rapid examinations, including brain surgery, can be an overwhelming experience with constantly evolving care needs (Cavers et al., 2012; Cavers et al., 2013). The qualitative and quantitative literature on supportive care needs in patients with primary malignant brain tumour is continuously increasing, particularly with a focus on documenting the time immediately after diagnosis (Catt, Chalmers, & Fallowfield, 2008; Davies & Higginson, 2003; Ford, Catt, Chalmers, & Fallowfield, 2012; Moore et al., 2013; Sterckx et al., 2013). However, patients are likely to experience symptoms and feelings of anxiety already when being referred to hospital due to the suspicion of a primary malignant brain tumour (Goebel, Strenge, & Mehdorn, 2012; Palese, Cecconi, Moreale, & Skrap, 2012). Therefore, the purpose of this paper is to provide an in-depth description of the patient experience and care needs during the hospital stay in the diagnostic phase of a brain cancer pathway. We define the diagnostic phase as starting at the patient's referral to fast-track neurological diagnostic work-up, lasting throughout the neurosurgical evaluation and treatment and ending after the patient receives a final diagnosis of a malignant brain tumour.

## **Background**

Receiving the diagnosis of a primary malignant brain tumour is a shocking and life-changing event for patients who are confronted with a drastically shortened life expectancy (Sterckx et al., 2015). Even before the final diagnosis is confirmed, patients often experience a decline in their physical and cognitive functions that limit their activities and affect daily life (Cheng et al., 2010). The symptoms evolving depend on both the location and size of the brain tumour. Patients may experience headache, seizures, short-term memory loss, motor impairment, decreased energy and concentration levels, and visual or speech disorders (Chang et al.,

2005). Furthermore, patients with malignant brain tumours range among the group of cancer patients who experience the highest emotional burden due to the combination of the life-threatening diagnosis and the rapidly changing cognitive deficits and neurological symptoms (Armstrong, Cohen, Eriksen, & Hickey, 2004).

The current treatment regime includes a combination of surgery, radiation therapy and chemotherapy (Preusser et al., 2011) each adding potential side effects to the patients' condition (Holdhoff & Grossman, 2011; Taphoorn & Klein, 2004). First, the patients go through brain surgery, as maximal tumour resection before adjuvant therapy has been shown to prolong patients' lives (Stupp et al., 2009). If resection is impossible, a biopsy is performed. This enables a neuropathological examination of the tumour tissue which is the only way to establish the final diagnosis and plan the specific adjuvant therapy (Hottinger, Homicsko, Negretti, Lhermitte, & Stupp, 2012). After the surgical intervention, patients typically wait five to fourteen days for the final diagnosis. Consequently, a working diagnosis of "suspected primary malignant glioma" is commonly used from the time of the patient referral to hospital and until the final establishment of the histology diagnosis. This means that patients are far in the phase of diagnostic work-up and initial treatment, before receiving the final life-threatening diagnosis (Danish National Board of Health, 2016).

In Denmark, patients suspected of having a primary malignant brain tumour are referred to the Danish "Integrated Brain Cancer Pathway" (IBCP). The IBCP is an effective standardized fast-track pathway, aimed solely at patients with high-grade tumours, as soon the diagnosis is confirmed by histology (Danish National Board of Health, 2016). This selection seems reasonably, as nearly 80% of primary malignant brain tumours are gliomas and 50% of these cases turn out to be glioblastomas with poor survival (Preusser et al., 2011). The main reason

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for implementing the IBCP in 2009 was poor survival of Danish brain tumour patients, why the pathway involves several highly specialized departments, all collaborating to secure the patients' rapid diagnostics and treatment (Laursen & Rasmussen, 2012a). Even though the IBCP has proven to be effective and to create faster courses for the patients (Laursen & Rasmussen, 2012b), the collaboration and interaction with several specialized health care providers may present a challenge to the involved patients. Firstly, several studies have shown that the shock of having a potential fatal disease combined with the multiple symptoms, often affect the patients' abilities to understand and retain information, communicate with health care providers and express their individual care needs (Halkett, Lobb, Oldham, & Nowak, 2010; Langbecker, Janda, & Yates, 2012; Sterckx et al., 2015). Secondly, after implementing the Danish pre booked fast-track program, treatment and care is now organized within a minimum of inpatient hospitalization (Danish National Board of Health, 2012) leaving limited time for information, asking questions and engaging in dialogue with health care providers. Because this severe disease directly affects the brain, a malignant brain tumour is different from most other forms of cancer and causes patients to have unique care needs (Philip et al., 2015). This may explain the high rates of unmet supportive care needs within this patient group that have been reported in several international studies (Catt et al., 2008; Diaz et al., 2009; Halkett et al., 2010; Leavitt, Lamb, & Voss, 1996; Lepola, Toljamo, Aho, & Louet, 2001; Lobb, Halkett, & Nowak, 2011). While the literature on understanding life with a primary malignant glioma has been growing, only a few studies, published within the last decade, provide information on the patient experience and care needs in the early phase of the disease trajectory. The major themes of studies focusing on the early phase include the shock of being diagnosed and the disruption of the patients' lives, the need for clear and consistent information, emotional and existential needs, dependency on one's carer and challenges when navigating and interacting with those in the

healthcare system (Catt et al., 2008; Cavers et al., 2012; Halkett et al., 2010; Lobb et al., 2011; Ownsworth, Chambers, Hawkes, Walker, & Shum, 2011; Sterckx et al., 2015).

In these studies, information on the patients' experiences of going through the diagnostic work-up, the brain surgery and the post-operative period are specifically sparse. In order for health care providers to better understand the needs of these patients before and after surgery and to develop the appropriate support in accelerated cancer care, more research is required.

### **Aim**

The aim of this paper is to identify and describe the experiences and care needs of patients going through the diagnostic phase of the Danish Integrated Brain Cancer Pathway.

### **Research design**

The human experience is always connected to a context, why a case study design was chosen (Flyvbjerg, 2001). A case study is capable of capturing the real-life situations with its multiple wealth of details, variations and complexity (Yin, 2014). The design enables the researcher to explore social events and relations in “real time” as experienced by patients in a hospital context and allows for a systematic collection and analysis of textual data material obtained from structured interviews, informal conversational interviews as well as direct observations.

More knowledge of the reality which patients with malignant brain tumour face is necessary due to 1) the many departments and health care providers involved in the IBCP and 2) the multiple symptoms that patients experience. By choosing a descriptive longitudinal single case design, it is possible, at several different time points and in different contextual settings, to explore how patients experience their fundamental care needs in the first phases of the



IBCP. The design thereby enables us to capture real life situations of the patient experience of the “transitions” between different departments and to gain specific knowledge of who is interacting with the patient, about what and when. The longitudinal design also allows for direct feedback from the patients under study, giving the researcher the opportunity to test if interpretations and statements are understood correctly, and not merely a product of the researcher’s own assumptions and presuppositions.

### **Participants and setting**

Four participants were included in the study (Table 1). The overall inclusion criteria were: (1) referral to the IBCP because of a MRI verified tumour in the brain, suspected by an experienced neurosurgeon to be a primary malignant cancer, (2) 18 years of age or older, (3) ability to speak and understand Danish, (4) ability to express a verbal response and giving confirmed consent, (5) not having a history of mental diseases, (6) not having severe physical diseases to avoid participants being accustomed to the patient role and (7) not being employed at a hospital as this would entail knowledge of the hospital organisation and could affect the experiences of patients.

Furthermore, to bring forth nuances of the experiences and needs of participants in the IBCP a strategic selection (Yin, 2014) was used to ensure patient variation regarding gender, marital status, work status, symptoms at referral and age. This was achieved; however, as shown in table 1 only a minor variation was achieved concerning the age difference. Still, this was anticipated as gliomas occur most frequently between 58 and 78 years of age (Rasmussen et al., 2017).

A highly specialized Danish University Hospital with full neuro-oncology service was chosen as the site for the case study of the IBCP. Three of the four selected participants were referred to the IBCP during their stay at the Department of Neurology at the University Hospital. The remaining participant was referred to the IBCP while being admitted to a regional department of neurology, due to acute admission on the suspicion of stroke. All participants received treatment and care at the Department of Neurosurgery in the University Hospital.

### **Method**

All data were collected between 9 April 2015 and 5 May 2016 by the first author. Participants were identified as eligible for the study by the nurse coordinators of the IBCP. If the participants gave their permission, the researcher contacted them and oral and written consent was obtained.

To ensure in-depth knowledge of the participants' experiences interviews were conducted repeatedly over several days/weeks and combined with field observation. The longitudinal design allowed the relationship with participants to develop slowly as trust built up and allowed the researcher to gain an insight into the experiences of the participants. Field observation began with the participants' referral to the IBCP at the University Hospital and ended within a week after the participants had been informed of the final histological diagnosis. Participants were followed physically by the first author in "real time" through the Departments of Neurology, Neuroradiology, Neurosurgery and Oncology at the University Hospital. Observations were carried out between seven o'clock in the morning and seven o'clock in the evening as most care activities regarding information, communication and

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support took place in this time interval. Observations followed participants' trajectories and took place in the setting of the outpatient clinics; the wards during hospitalization, during computerized tomography scans (CT) and magnetic resonance imaging (MRI), at the operation theatre during brain surgery and the post-surgery observation at the intensive care unit. The data collection was terminated when participants were transferred to either rehabilitation, another cancer pathway as result of the final diagnosis or admitted to a hospice for palliative care. For this reason, the number of days of direct observation of the participants differ. Moreover, the busy hospital setting limited the number of interviews, which it was possible to perform while maintaining the privacy of the participants. For example, participant number 2 was placed in a bed room with three fellow participants for several days which allowed little privacy for interviews.

Table 2 shows the sources of data collected.

An interview guide reflecting the three main themes of the case study protocol, information, communication and support, was used for the research interviews. The guide was modified for each interview, depending on the situation and point of interest at the time of the interview (Yin, 2014).

Planned interviews were recorded electronically and transcribed verbatim. Recordings of spontaneous interviews were conducted when the researcher found it appropriate to ask participants for oral consent. When recording was inappropriate, the first author either wrote field notes documenting the participants' exact wording during the conversation or afterwards dictated the remembered conversation to capture the important statements, while still fresh in memory. Even though direct observation is very time consuming (Yin, 2014), it was essential

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in this study, as we wanted to take into consideration the contextual influence of the IBCP on participants' experiences. When appropriate, the views of participants therefore were explored directly in the actual situations unfolding in practice (Yin, 2014). This meant the discovery of several important aspects. Firstly, we saw that experiences expressed by participants, as being highly frustrating in the actual situation, were several times reported as "a minor issue" by the participant when later addressed in an interview. It seemed as if participants had already "moved on", maybe because of the stressful situation of being in the IBCP. Secondly, when doing the interviews, participants several times referred to very complex situations, which the first author was only able to understand fully because she had been present in the actual situation. Thirdly, the participants interviewed all had an impaired memory and often needed assistance from the first author, regarding the names of people, times and locations of the events which they were trying to explain. This is a well-documented challenge for brain tumour patients, as studies have shown that memory loss and cognitive problems are amongst the most common symptoms, depending on tumour size and location (Chang et al., 2005). In addition, the surgical procedures can cause symptoms (Talacchi, Santini, Savazzi, & Gerosa, 2011), just as dealing with the shock of the expected diagnosis can affect patients' ability to recall situations and experiences (Lobb et al., 2011). This highlights the advantages of combining methods in data collection when striving for a nuanced and detailed knowledge of patients' experiences of supportive care needs.

### **Data analysis**

All transcripts were uploaded to QSR NVivo 11©software (QSR International (UK) Limited) to keep data organized, structured, and assessable for in-depth investigation. The analysis was a hermeneutical phenomenological process and data were analysed inductively using systematic text condensation (STC) as described by Malterud (Malterud, 2012; Malterud,

2017). The method of STC was conducted on the transcribed research interviews and on the transcribed notes from field observation. The analysis followed the four steps of STC (Table 3) and was made by the first and last author who reviewed the transcripts independently and discussed the data to enhance rigor. During the analytic process, memos with analytic ideas were reread to look for any alternative interpretations of the data.

All findings were validated (Yin, 2014) by securing that every result was supported and confirmed by at least two different data sources. An example of the analytic process is displayed in table 4.

### **Ethical considerations**

Permission for data collection was obtained from the Danish Data Protection Agency, as required by Danish law and all requirements for safe data storage were adhered to. The study protocol was submitted to the Central Denmark Region Committee on Health Research Ethics who decided approval was not required due to the non-biomedical character of the study. The ethical guidelines of the Northern Nurses' Federation were respected (NNF, 2003) and participants were informed about the purpose of the study and of their right to withdraw from it, at any time, without it having consequences for their further treatment. Given the stressful situation and vulnerability of the participants, the author team continuously discussed ethical considerations throughout the process of collecting data in clinical practice. A constant awareness of ethical issues and making fast “ethical” decisions was necessary, e.g. deciding to leave the hospital ward to give the family some privacy.

In addition, a psychologist trained in performing crisis counselling was available and a “do no harm” code of practice was established. This demanded the first author to interfere if situations occurred that could harm the participant in any way and was used for example, when a health care provider offered a fasting participant water. Along the study and prior to any recording, participants were asked for informed consent. As their situation changed during the study, it was appropriate to give the participants a renewed chance to withdraw from the study. Furthermore, due to the risk of neurological and cognitive deficits evolving, the involved health care providers were also consulted several times, regarding how they assessed the participant’s condition. Often the health care providers also asked the participants, on their own initiative, whether the first author was allowed to observe and became natural gatekeepers protecting the participants.

### **Findings**

Variation in the participants’ experiences and needs in the IBCP was most visible in relation to work status and family status. The one participant still working expressed worries about the financial impact of the disease, being the sole provider in the family. Furthermore, it seemed to add to the stressful situation that his employer needed regular updates of his expected return to work. We also found that the family status of the participants had an impact during the hospital stay. While the visits by spouses often would last for several hours, which meant that they would attend the consultations at the hospital, other relatives mostly paid shorter visits and only attended consultations if asked to. In this way, the participants with a spouse were observed to receive more practical and emotional support. The analysis of the main code groups and sub-groups led to 4 major themes: 1) information

needs, 2) balancing hope and reality while trying to perceive the unknown reality of brain cancer, 3) not knowing what to expect and 4) participants' perceptions of the relationship with the health care providers.

### **Information needs**

Participants reacted in different ways after receiving the first message of the brain tumour diagnosis. Participant 2 and 4 accepted the neurologist's offer to see the scan showing the tumour and asked questions regarding the possible causes of the tumour. These participants appreciated the information, "It was nice to get the facts on the table... concrete and direct information...after all, I did ask for it myself" (Participant 4). Participant 1 and 3 did not ask any questions at all and even declined seeing the scan, stating they did not have the courage. They tried to avoid negative information which they were not ready to master. At this stage, health care providers recommended participants to seek professional help, e.g. a psychologist or priest, but none of the participants followed this advice. Participants replied they would prefer talking to a psychologist, however, this was not a service offered by the hospital. In order to receive psychological aid, patients were expected to first obtain a referral from their general practitioner. After doing this, participants had to locate a suitable psychologist, make an appointment and arrange for transport, all while having symptoms and while following the busy schedule of the fast-track IBCP. Taking on this task simply may have required too much of the patients already lacking energy and feeling overwhelmed.

The lack of energy also affected some participants' ability to understand written information. In both the Department of Neurology and Department of Neurosurgery, participants were provided with several information pamphlets. However, only participant 4 in fact read the pamphlets, which she regarded as very helpful, as it repeated and elaborated on the

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information given by the health care providers. The rest of the participants were aware of having received the pamphlets, but either said they did not have the energy or lacked the courage to read the material, even though some expressed feeling an obligation to do so. Participants argued, they would read the material later on, if they felt they needed more information, "I have got the pamphlets" (I: Have you read them?) "Well no, I have not.... Nevertheless, I do have them"; "I thought I would just wait until I need it" (Participant 3). Especially participant 1 and 3 seemed to maintain control of their situation by choosing the level and content of information e.g. by filtering out the written material provided or not asking questions. However, when participants did not read any of the provided material, it had a profound implication on their level of knowledge. Not only did they lack more thorough information on what to prepare for when going through the IBCP; they also lacked practical information regarding the time following surgery and the support offered by the departments. In addition, some of the participants experienced that it was a challenge to obtain the information they needed due to their short-term memory being impaired by the tumour. Participants were fully aware of this impairment. During a consultation, the neurologist urged the participant to ask questions and asked if there were any he wanted to ask right now, and the participant replied: "Yes, I do have some questions, but I have forgotten it all in a minute anyway....." (Participant 1).

When participants were asked what they experienced as being most helpful in the consultations, they answered how they valued getting some facts, but in a way which did not take their hope away:



“He explained it well and he said what he could do and didn’t promise to do more than he could. And I think that is really fine, that they don’t promise more than they can keep. And they don’t look at the dark side either” (Participant 3).

Participants also experienced it as helpful when doctors made time for pauses during the consultations, allowing them some time to think and ask questions. Supplementary explanations from health care providers to the participants’ questions and being given choices, e.g. whether they wanted to see the MRI scan or not, were also highlighted as important in the stressful situations.

### **Balancing hope and reality while trying to perceive the unknown reality of brain cancer**

In this early phase of the IBCP, participants constantly shifted between the hope of returning to life as it was before and the new reality of having a brain tumour. Participants continually had to adjust what they were hoping for, as they gradually received more information of the results of the diagnostic workup. Even when participants did understand that the tumour could be cancerous, they still kept hoping for the health care providers to be wrong. They tried to rely on the other possibilities mentioned, for as long as possible, despite being told that this was very unlikely. Participants were constantly searching for the positive messages in the health care providers’ information and they interpreted the information given, in the light of their understanding of cancer, ”Almost everybody knows someone who have had this (cancer) and who made it to the other side, so I trust I will do the same” (Participant 3).

The impact of the participants’ preunderstanding of cancer was evident after the initial neurology consultation at the hospital, where participants had to wait for further examinations. When the results came back, three participants received the message that no

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sign of tumours were seen in the scan of thorax, abdomen and pelvis. All three participants and their carers reacted by expressing feelings of great relief and thankfulness and they interpreted it as a positive sign that the tumour cells were limited to the brain. Some even cried with relief and celebrated the result with wine and dinner.

In the same way, if the neurologists said the tumour was small and operable, participants interpreted it, as if only they got past the operation, life could continue as usual: "Well he (private neurologist) said it was smooth which is a good sign, and that it was the size of a pea. Then I thought... well, then this little pea just has to be removed" (Participant 3).

All participants made positive interpretations of their results at this stage. Even though they were told early on that they were referred to the brain cancer pathway, and phrases such as "suspicion of malignancy" were often used by the different doctors and nurses at the hospital, it did not seem to bring about any real significance to the participants. One participant expressed her understanding of the situation as: "If only they can remove what is up here [pointing at her head] then I will not die from it. That was my initial thought" (Participant 3).

It appeared as if their lack of knowledge of the IBCP and of the incurable nature of malignant brain tumours, allowed them to struggle to understand what the consequences could be, if the suspected diagnosis was to be confirmed.

After going through the consultations in the Department of Neurology, all participants understood they had a tumour in the brain but seemed to have no idea of what it would mean to their lives. On the other hand, the health care providers used terms as "suspected

glioblastoma” in the medical journal right from the very start. Health care professionals would also say, “He is really sick... it is a question of months” or “they do not know what they are facing...” when talking to each other without the participants and carers hearing it. In an attempt to establish the participants’ understanding of the suspected brain cancer at this point before the surgery, participants were interviewed about what the neurologist had said. One stated:

“Well, she did say they had found a lump and that they cooperate with [name of hospital] why I have to go there” (I: Did she tell you, what they suspected it to be?) ”No, she did not” (I: Did this conversation make you any wiser?) “No” (Participant 4).

This answer appeared to be in contrast to what this participant was actually told by the neurologist who explained the result of the MRI. The neurologist clearly stated that the participant was now in the IBCP due to the suspicion of a cancer in the brain. Furthermore, she prepared the participant for the possibility of subsequent treatment of radiotherapy and chemotherapy, due to the tumour looking cancerous. However, at the time of the interview the participant did not seem to recall or fully understand the information received, or perhaps simply suppressed it due to its negative nature.

Regardless of the fact that the participant had received an honest opinion about the expected diagnosis from the neurologist, it did not seem to make much of a difference on the participant’s experience and understanding of the disease, she could be facing.

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As the four participants received their final diagnosis of malignant cancer in the brain, they reacted surprised and shocked, even though the health care providers had tried to prepare them for the diagnosis. The most likely reason for this was that participants and health care providers in general seemed to have very different preunderstandings of the suspected diagnosis of cancer in the brain which influenced their ability to understand each other. The participants' perspective was to hope for evidence to dismiss the suspected diagnosis, due to the rarity of the disease and not feeling sick. The perspective of the health care providers on the other hand seemed to be the exact opposite, as they searched for evidence confirming the suspected diagnosis. Their knowledge regarding the statistics of brain cancer, the familiarity of patients having subtle symptoms and their experience of brain cancer as an incurable disease influenced their understanding of the situation.

### **Not knowing what to expect**

Participants experienced the surgical evaluation at the Department of Neurosurgery very differently. Participant 1 and 2 left the consultation with the same information that they had received at the Department of Neurology, as the neurosurgeon stated that nothing could be said of the tumour's origin before it was removed. Not until a pathologist had examined the tumour tissue, would it be possible to make a diagnosis and discuss treatment options. However, participant 3 and 4, who went through the same type of consultation, felt in a state of shock afterwards, because of the information provided. Sitting in front of the neurosurgeon, they were told what the suspected diagnosis of incurable brain cancer meant and were advised to plan their future. These participants were provided with thorough information on the likely side effects of brain surgery. In addition, they were prepared for the anticipated after treatment, being a combination of radiotherapy and chemotherapy that

would be ongoing for nine months. However, they had not anticipated any prognostic information, and when they reflected on the situation afterwards, they expressed that they would have liked to know more of the content of the consultation before coming. They had had the impression that the consultation would only concern the “practicalities” of the operation itself, why they had not wanted to bother asking their grown-up children to attend which they now regretted. At the same time, they appreciated getting the facts, enabling them to start dealing with the situation.

Accordingly, participants were in general not able to prepare for what the consultation at the Department of Neurosurgery would in fact entail, as this seemed to be decided by the individual neurosurgeon, who seemed to have different preferences for sharing information on the possible future.

Furthermore, participants experienced that communication was often hampered due to the many different health care providers involved in the IBCP. Because health care providers had different opinions regarding how much information to share with the participants, health care providers sometimes expected participants to have received more information during prior consultations, than they actually had. This is illustrated by the case of Participant 1:

The first neurologist who this participant met, chose to describe the result of the MRI saying: “You had a scan yesterday...[pause] and we have found a tumour in your brain. It looks malignant”. After this consultation, the result of the CT TAP scan being normal was provided to the participant by a second neurologist who articulated the brain tumour as: “You have something in your head”. When the participant was evaluated by a neurosurgeon, he was shown the MRI and the neurosurgeon said: “You have something there, there and there and we really do not know what it is or if it requires after treatment. We can take a sample of it, and we can do that already tomorrow”. As the spouse asked, “do we know if this is cancer?”, the neurosurgeon replied: “We cannot leave out that option”.

When this participant was interviewed about his understanding of the neurosurgery consultation just afterwards, he answered, "I only understood that; it is the operation you know. They do not know what it is..." (Participant 1). On the actual day of the operation, the neurosurgeon who was to perform the surgery, met the participant for the first time and they talked for five minutes. During the brain surgery, the neurosurgeon stated to the first author: "Isn't he funny? When I talked to him, I had no impression of him having received any information prior, even though the medical journal from yesterday clearly states, highly malignant, and one can see, it has been said during every consultation that this is what we expect".

The participant's way of interpreting the information given, was evidently a cause for wonder for the neurosurgeon. However, the field observations showed that participants were not always provided with the information, in such a clear and direct manner, as one could think when reading their medical record. These findings seemed to relate to the documentation reflecting the knowledge and experience of the health care providers, rather than what the participant was actually told.

### **Participants' perceptions of the relationship with the health care providers**

This theme was most prevalent in the interviews with participant 3 and 4. When the participants were asked to tell about their experiences of the first consultations at the Departments of Neurology and Neurosurgery, they emphasised nurses, nurse coordinators and doctors who they felt had established a personal relationship to them. Participants described situations with these specific health care providers who they felt had recognized them as equal human beings and had acknowledged their extreme and life-changing situation.

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“We were having an equal dialogue. It was not like “I know-it-all”, ”..also, he sits down himself, hmm, and he is present, right? And he, he does not have to think about, “what am I to say now”, he already thought that through! That is how I experienced it. He had prepared what he wanted to say” (Participant 3).

This made the participants feel reassured, ”... it was a good conversation. He is a pleasant doctor; he was nice and made me calm” (Participant 4). Even though participants met several health care providers in each department, they all were able to remember the names of the ones who they felt, had “seen and understood” them. This was opposed to the general observation made throughout the IBCP of participants struggling to remember names of staff and departments. Having met with and gotten to “know” the neurosurgeon seemed to be of great importance. Participants had a profound wish to have the brain surgery performed by the neurosurgeon who had seen them in the outpatient clinic. Participants would argue either in terms of established trust saying, ”It is important for me that the surgery is performed by the same doctor I spoke to... he’s the one that makes me feel safe” (Participant 4), or they would stress the importance of being able to communicate well, “We know each other now and I know I can talk to him” (Participant 3).

If another surgeon was scheduled to perform the operation, participants expressed feeling disappointed, “Well, I do know him a little now. The other one is probably also skilled, it is just that I spoke with him and he was so pleasant and so skilled” (Participant 3).

When seeing the neurosurgeon participants had hoped for, working at the department on the day of surgery, it could result in participants feeling rejected, “When he is here anyway, he could really just as well have fixed me” (Participant 3).

The health care providers acknowledged the participants’ wishes for seeing the same neurosurgeon, but argued it was not always possible due to the organisational planning and urgency of the fast-track surgery. Participants also felt disappointed when health care providers gave vague answers or were unable to answer their questions.

“No, but the first [consultation] was just a chit-chat. It made no difference. I could damn just as well have talked to my general practitioner. He knew just as much, I think. No, then you are too young and inexperienced to do.... No, I don’t know. I was not impressed by that” (Participant 3).

Participants perceived health care providers as being experts and therefore expected them to be able to answer all medical and practical questions. In general, the importance of establishing trustful relationships with skilled health care providers seemed to be essential, when having to put one’s life in the hands of strangers.

## **Discussion**

This study provides an understanding of the experiences and care needs evolving during hospitalization in the early diagnostic phase in the Danish IBCP as described by patients. The findings show that cancer in the brain causes patients to have unique care needs which they



often do not advocate throughout the fast-track programme. The findings also suggest that although the standardized IBCP has proven to be highly effective (Laursen & Rasmussen, 2012a; Laursen & Rasmussen, 2012b), this model of medical care presents several challenges to vulnerable patients. When diagnostic and treatment planning becomes the main focus of patient consultations and the dominant quality measurement is on the time frame of pathway elements, the patients' need for care as a relational activity with an emotional engagement may not be realized.

In the period before the final diagnosis, we found that patients experienced distress due to the uncertainty about the diagnosis and treatment, simply due to not knowing what the IBCP and the future would entail. High levels of emotional distress have been documented in the early treatment phase and is suggested to be even higher at this time, than in the later stages of the disease (Goebel, Stark, Kaup, von Harscher, & Mehdorn, 2011). This highlights the importance of health care providers to be sensitive and attentive to the patients' care needs. At this point, health care providers have to act accordingly to the demands of the IBCP, providing an urgent and effective plan of action but just as important, they have to respect the patients' vulnerability and needs in a time of crisis.

Throughout this phase, patients struggled to maintain a positive attitude. They put emphasis on the positive messages but experienced being in an "existential limbo" constantly shifting between the hope of returning to a normal life and the frightening possible reality of an unexpected early death. This fluctuation between hope and despair, existing already in the time before the final diagnosis of cancer in the brain, has rarely been described but was also

found by Cavers et al. (Cavers et al., 2012). The state of flux is a known pattern of adjustment to the diagnosis for cancer patients (Brennan, 2001) and supports the suggestion that brain tumour patients are on an existential journey already before getting the final diagnosis which make them particularly vulnerable.

All four patients expressed feelings of vulnerability due to the hospital setting and a need to feel recognised as equal human beings by the health care providers attending to them. In general, patients evaluated the social interactions with health care providers based on whether they felt they were being seen, heard, understood and respected as individuals. This need has been described as “longing for existential recognition” and has been found to affect not only the self-confidence and symptom experience of patients but also the strategies and abilities to master stressful situations (Lind et al., 2014). We found that the feeling of being recognised seemed to have a huge influence on the patients’ experience of the consultations and the information provided in the IBCP. This is in line with the findings of previously studies (Philip et al., 2014; Spetz, Henriksson, Bergenheim, & Salander, 2005; Sterckx et al., 2015) where patients required health care providers to engage in a personal relational function and not merely take care of the practical tasks during examinations and consultations. In patients with benign tumours, the establishment of a personal relationship with the neurosurgeon was found to help patients feeling less distressed and helpless. These patients further expressed that they did not just want their surgeon to be capable and confident but also to show compassion, as signs of compassion was interpreted as the neurosurgeon could be trusted and would act humanely (Rozmovits et al., 2010). In addition, several studies have argued of the importance of a providing a stable relationship with members of the medical staff and especially the neurosurgeon (Fletcher, das Nair, Macniven, Basu, & Byrne, 2012; Philip et al., 2015; Rosenblum et al., 2009). Fletcher et al. found that the stable trustful relations

enable patients to use self-preservation strategies, for example choosing to avoid information they do not feel ready to master and instead trusting the neurosurgeon completely to take over (Fletcher et al., 2012). In this way, a relationship based on trust may compensate for the lack of specific information often experienced by patients either due to the use of patients' self-preservation strategies, the cognitive deficits caused by the brain tumour or an impaired ability to attain information due to the overwhelming situation. In our study, all patients mentioned the significance of the relationship to the health care providers and especially their experience of the relationship to the neurosurgeon performing the brain surgery. They described how the neurosurgeon made them feel calm, secure and understood. This is in accordance with research stating that feelings of fear and anxiety, evoked by the diagnosis of a brain tumour, can be eased by the patient experiencing the physician as being personally engaged in the clinical interaction (Rosenblum et al., 2009). When patients experienced health care providers who took a professional distance and did not engage in a personal relationship, they expressed feeling disappointed, frustrated and alone. A consistent relationship with a doctor over time has also been found to be critically important in order for patients to be able to maintain and negotiate hope. Previously studies have shown that patients' hopes change over time, why prognostic information must be provided according to the individual patient's preferences and how much the patient is ready to know, in order to be meaningful (Fletcher et al., 2012; Halkett et al., 2010; Philip et al., 2015; Piil, Juhler, Jakobsen, & Jarden, 2015; Rosenblum et al., 2009). It seems reasonable to assume that having a personal relationship would allow for the doctor to easier identify the individual information needs and preferences of the patient.

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In the study by Rosenblum et al. (Rosenblum et al., 2009) it is argued that a turnover in the health care providers taking care of the patients may result in fragmented care and lead to frustration and feelings of abandonment in patients already feeling vulnerable. We found that the organization of the IBCP contributed to patients experiencing fragmented care, as all patients met several health care providers, due to the involvement of several different specialized departments. Consequently only one of the patients experienced having the brain surgery performed by the neurosurgeon she met in the outpatient clinic. In addition, none of the patients received the final histology diagnosis from the neurosurgeon having performed the operation.

In our study, fragmented care was also identified as the result of what seemed to be individual personal preferences and beliefs of neurosurgeons. When consultations entailed prognostic information which patients had not been prepared for they reported feelings of uncertainty and a sense of losing control. The unpreparedness resulted in diminished ability to act, like having invited close relatives to participate in the consultation.

Previous research has highlighted the importance of ensuring consistent information to patients throughout their disease trajectory (Fletcher et al., 2012; Philip et al., 2015; Rosenblum et al., 2009). However, we identified maintaining continuity could be challenging due to the many different health care providers involved in the IBCP. Again, personal preferences of health care providers seemed to play a role, as some believed in telling as much as possible to prepare patients for the future, while others did not find it appropriate to

disclose information ahead of the final diagnostic result. Regardless of the different preferences of health care providers, the documentation provided in the patients' medical journals consistently seemed to reflect an expectation of malignancy to be found, perhaps due to the experience of health care providers.

It was not investigated in this study whether the different communication strategies of the health care providers reflected their professional experience. However, it has been suggested by Lobb et al. (Lobb et al., 2011) that the communication skills of younger, and less experienced health care providers are more likely to vary. This may be taken into consideration when organizing the care of the most vulnerable patients who are in need of an expert team who is capable of informing them of the typical treatment of malignant brain cancer and of the trajectory of the IBCP.

### **Limitations**

This single site case study was carried out in a Danish University Hospital and the results reflect patient experiences within this specific context. The participants in the study were all above the age of 60 years why younger participants might have experienced going through the IBCP differently. For example, younger people may have less faith in authorities than older people, why it may be easier for them to ask for the care they need. In addition, the participants in this study experienced a severe symptom burden that may very well have increased their feelings of dependency and vulnerability. Considering these limitations, the study results may be used for analytic generalization (Yin, 2014) in order to explain the common experiences of patients being diagnosed with cancer in the brain.

## **Conclusion**

This study is, to our knowledge, the first to describe the patient perspective of going through the diagnostic phase in the Danish IBCP and illuminates the complexities of the needs of patients suffering from brain cancer.

The analysis revealed that the participants in our study had very different needs regarding information and communication and were in risk of having unmet information needs throughout the pathway. Even though participants received much information, their understanding was hampered by cognitive impairment, use of self-preservation strategies like maintaining hope and avoiding information and by the stressful situation of a possibly devastating illness. Furthermore, contextual factors like information being provided by several different health care providers seemed to lead to fragmented information and care, causing feelings of uncertainty, loss of control and frustration.

Overall, we found that the situation of participants was best characterised by a particularly state of vulnerability. A vulnerability that seemed to create an immense need for establishing trustful personal relationships with skilled health care providers allowing for existential recognition and alleviation of emotional distress.

This study demonstrates that although patients share the wish for an effective fast-track programme, the contextual factors of the IBCP are likely to have resulted in undermining the participants' need for a stable relational dimension throughout the pathway. We suggest to focus more on the significance of the relational encounter between patients and health care providers, in order for the IBCP to sufficiently meet this dimension in patient care.

### **Implications for nursing practice**

The findings reveal several areas calling for attention and intervention from health care providers working with patients in IBCP. We recommend directing more attention towards identifying and evaluating the cognitive ability and debilitating symptoms of patients. In this way, patients may avoid having to confront demands from health care providers which these patients, unlike other patient groups, are unable to handle. The symptoms of a patient with brain tumour may be subtle and not directly visible and therefore risk being overlooked, especially as patients spend a short amount of time in the hospital due to fast-track programmes. If patients are met with expectations they are unable to fulfil, it is likely to add to their feelings of loss of independence and vulnerability. In addition, as this cohort is known to have difficulties in expressing own needs, it is of vital importance that health care providers acknowledge that these patients often do not ask for the care they need and cannot be expected to do so. We believe these conditions and needs are unique to patients suffering from brain tumour, and therefore calls for development of a specialized medical care model, providing a more proactive and individual patient tailored care.

A proactive approach could involve health care providers to pose questions that identify the patient's individual wishes and needs, in order to ensure that information is provided according to the patient's different self-preserving strategies. Furthermore, making time for pauses and allowing patients to think and ask questions, was considered a help to the patients in our study who had difficulties expressing their needs due to cognitive impairment and the shock of hearing the diagnosis. We also suggest providing incremental doses of information as preferred by patients in the study of Rosenblum et al. (Rosenblum et al., 2009) combined with the offer of a written resume of key statements from the consultations. This is anticipated to provide support to patients who may not remember the information given due

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to experiencing a shock or due to having impaired memory or ability to concentrate for a longer period. By proactively choosing a strategy, aiming to identify the patients' individual preferences and information needs, health care providers may be able to both respect patients' vulnerability and fulfil the patients' need for immediate information.

We also recommend the development of a guideline for information, based on discussions and joint decision what patients should be told to expect and prepare for regardless of the physician seeing the patient. This, we believe could enhance the patients' ability to act and feel in control and does seem necessary due to the many different health care providers involved, all of whom have different preferences and beliefs. Furthermore, ensuring a precise documentation in the patients' medical journal of the information the patient is given throughout each consultation, may allow for providing more continuity and for a better understanding of the patients level of knowledge. This would furthermore diminish the possibility of ethical dilemmas occurring, considering that patients in Denmark are able to access their medical journal online. Finally, we advocate for a greater consciousness with regard to the patients' need to establish stable professional relationships with health care providers which are based on trust. By recognising care as a relational activity demanding emotional interaction, health care providers may be able to provide patients with a universal sense of togetherness.



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**Table 1. The four strategically selected patients**

<b>Patients</b>	<b>Gender</b>	<b>Age</b>	<b>Final diagnosis</b>	<b>Social and family status</b>
1	Male	64	Primary brain tumour, multi focal, Glioblastoma multiforme grade 4, located in brain stem and cerebrum	Lives with his wife in a house, one adult son. Works full time, receives no help prior to admission
2	Male	78	Solitary Brain Metastasis (3 cm) located in fossa posterior, cerebellum, small cell lung cancer	Lives alone in a house, no children, sister lives close by. Retired, receives no help prior to admission
3	Female	63	Primary CNS Lymphoma (cancer), located in cerebrum	Lives with her husband in a house, two adult sons. Early retirement, receives no help prior to admission
4	Female	69	Primary brain tumour, Glioblastoma multiforme grade 4, located in cerebrum	Lives with her husband in a house, adult son and daughter. Retired, receives no help prior to admission



**Table 2. Sources of data collection**

Informants	Number of days of direct observation at hospital	Number of research interviews with patients
1	12	2
2	4	2
3	12	7
4	10	5
	Total 38	Total 16

**Table 3. The four steps in systematic text condensation (Malterud, 2017)**

Step of analysis	Objective	Systematic text condensation
1	First impression of the data material and overall themes	The first and last author meticulously read the 16 interviews several times to create an overview of the data material. This process enabled preliminary themes about patient experiences in the diagnostic phase of the IBCP to be identified and ensured that the initial themes were based on what the participants had mentioned in the interviews
2	Identifying and sorting meaning-units	In the second step, parts of the text in each interview were selected and coded by the first author as “meaning units” having the potential to provide information of the preliminary established themes
3	Grouping of codes	The third stage of the analysis involved dividing the codes into code groups, containing the specific experiences of participants regarding each theme. The last author reviewed and commented on the code groups and any discrepancies were discussed with the first author until agreement. Each thematic code group encompassed several meaning units with diverse descriptions of participants’ experiences. By sorting these, more content specific subgroups were developed and a condensate based on all the meaning units was created
4	Synthesising the content of the condensates	The last step of analysis was rewriting the content of the most important subgroups into an analytic text adequate to describe the phenomenon of being diagnosed with a brain tumour. Finally, the whole analysis was reviewed to make sure it still represented the empirical data in a fair and valid way and quotations to illustrate the participant experience were added

**Table 4. Example of analytic process**

Preliminary established theme	Code group	Subgroup	Condensate from subgroup
Patients' experiences of support during the IBCP	Patients' perceptions of the relationship with the health care providers	Experiences regarding nurse coordinators	Patients found the nurse coordinators to be a support when they proactively offered their attention and help and allowed for a personal relationship to be established