

Assessment of a brain-tumour-specific Patient Concerns Inventory in the neuro-oncology clinic

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Abstract

Purpose Brain tumour patients may struggle to express their concerns in the outpatient clinic, creating a physician-focused rather than a shared agenda. We created a simple, practical brain-tumour-specific holistic needs assessment (HNA) tool for use in the neuro-oncology outpatient clinic.

Methods We posted the brain tumour Patient Concerns Inventory (PCI) to a consecutive sample of adult brain tumour attendees to a neuro-oncology outpatient clinic. Participants brought the completed PCI to their clinic consultation. Patients and staff provided feedback.

Results Seventy seven patients were eligible and 53 participated (response rate=68 %). The PCI captured many problems absent from general cancer checklists. The five most frequent concerns were fatigue, fear of tumour coming back, memory, concentration, and low mood. Respondents used the PCI to formulate 105 specific questions, usually about the meaning of physical or psychological symptoms. Patients and staff found the PCI to be useful, and satisfaction with the instrument was high.

Conclusions This study demonstrates the clinical utility of the brain tumour PCI in a neuro-oncology clinic. The combination of a brain-tumour-specific concerns checklist and an intervention to focus patient agenda creates a simple and efficient HNA tool.

Keywords Brain tumour · Holistic needs assessment · Patient Concerns Inventory

Introduction

Attending a brain tumour clinic can be a stressful time for patients. Imaging investigation and neurological assessment need to be completed and discussed, so it is not unusual for the consultation to focus on a physician-driven agenda centred mostly on radiological and physical findings. However, having a brain tumour is well recognised to affect a person in many other ways. Frequently reported symptoms include headache, epilepsy and personality change [1, 2]. Practical problems may relate to finances, driving, working, walking or speaking [3], or to communication, cognition and memory [4]. As a result, many brain tumour patients come to clinic with complex and diverse questions and needs. They may struggle to fully express them during relatively brief and otherwise busy appointments.

Holistic needs assessment

One way of identifying the complex needs of cancer patients is through holistic needs assessment (HNA). The delivery of HNA in routine cancer care is recommended by the government and national-level non-profit organisations [5–8].

HNA is a structured approach to gathering information, covering all domains of care, including the physical, mental, social and spiritual. The process aims to ensure that the person's concerns are identified and that attempts are made to address them. HNA tools are practical clinical documents and are distinct from

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BRAIN TUMOUR PATIENT CONCERNS INVENTORY	
1 Please tick any issues that have been a concern for you recently:	
<div style="text-align: center; background-color: #FFD700; border: 1px solid black; padding: 2px; margin-bottom: 5px;">PRACTICAL</div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Child care <input type="checkbox"/> Financial benefits <input type="checkbox"/> Holidays <input type="checkbox"/> Housing <input type="checkbox"/> Insurance <input type="checkbox"/> Recreation <input type="checkbox"/> Transport or driving </div>	<div style="text-align: center; background-color: #FFD700; border: 1px solid black; padding: 2px; margin-bottom: 5px;">PHYSICAL</div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Appearance <input type="checkbox"/> Appetite or eating <input type="checkbox"/> Bathing or dressing <input type="checkbox"/> Breathing <input type="checkbox"/> Changes in urination <input type="checkbox"/> Concentration <input type="checkbox"/> Constipation <input type="checkbox"/> Co-ordination <input type="checkbox"/> Diarrhoea <input type="checkbox"/> Epilepsy, or seizures <input type="checkbox"/> Fatigue, tiredness or low energy <input type="checkbox"/> Feeling swollen <input type="checkbox"/> Fever <input type="checkbox"/> Headache <input type="checkbox"/> Indigestion <input type="checkbox"/> Memory <input type="checkbox"/> Metallic taste in mouth <input type="checkbox"/> Mobility/getting around <input type="checkbox"/> Mouth sores <input type="checkbox"/> Nausea or vomiting <input type="checkbox"/> Nose dry/congested <input type="checkbox"/> Pain (apart from headache) <input type="checkbox"/> Sex or intimacy <input type="checkbox"/> Skin dry, or itchy <input type="checkbox"/> Sleep <input type="checkbox"/> Speech <input type="checkbox"/> Tingling in hands or feet <input type="checkbox"/> Vision <input type="checkbox"/> Weakness in arms or legs <input type="checkbox"/> Weight change </div>
<div style="text-align: center; background-color: #FFD700; border: 1px solid black; padding: 2px; margin-bottom: 5px;">FAMILY</div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Dealing with children <input type="checkbox"/> Dealing with partner <input type="checkbox"/> Ensuring support for family </div>	
<div style="text-align: center; background-color: #FFD700; border: 1px solid black; padding: 2px; margin-bottom: 5px;">EMOTIONAL</div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Anger or irritability <input type="checkbox"/> Fear of tumour coming back <input type="checkbox"/> Other fear, anxiety or worry <input type="checkbox"/> Personality changes <input type="checkbox"/> Sadness, low mood or depression </div>	
<div style="text-align: center; background-color: #FFD700; border: 1px solid black; padding: 2px; margin-bottom: 5px;">SPIRITUAL</div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Difficulty relating to God <input type="checkbox"/> Loss of faith <input type="checkbox"/> Loss of meaning to life </div>	
2 Now please tick any specialty you feel you need further referral to:	
<div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Chaplain <input type="checkbox"/> Dietician <input type="checkbox"/> Palliative care services <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Psychiatrist </div>	<div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Psychologist <input type="checkbox"/> Occupational therapist <input type="checkbox"/> Social worker <input type="checkbox"/> Speech and language therapist <input type="checkbox"/> Someone else (<i>specify below</i>) </div>
	<div style="background-color: #00FFFF; border: 1px solid black; padding: 2px; display: inline-block;">Please turn over>></div>

Fig. 1 The PCI

psychometrically validated quality of life (QOL) instruments.

Simple measures, such as the use of existing cancer checklists like the Distress Thermometer (DT) [9], may increase the acceptability of HNA. However, general checklists may not include important symptoms specific to brain cancer, such as headaches, cognitive impairment

and epilepsy. The development of disease-specific HNA tools is actively encouraged [7].

The Patient Concerns Inventory

The concept of the Patient Concerns Inventory (PCI) has been proposed for use in HNA. It was first developed for use in

3 Using your answers on the other side to help guide you, please write down up to four questions you would like to ask the doctor in clinic (you don't have to use all four if you don't want to).

Thank you. Your answers will help focus the consultation on things that are important to you.

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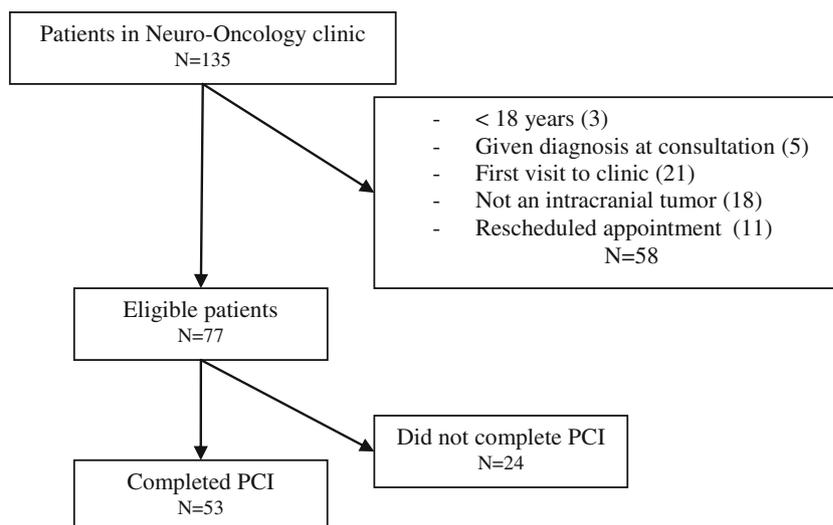
Fig. 1 (continued)

patients with head and neck cancer. In the original study, patients completed the PCI before their outpatient clinic appointment. Their responses were used to guide the consultation immediately afterwards [10].

The core feature of the PCI is a checklist of disease-specific potential concerns which the patient may recently have experienced. A range of clinically relevant HNA-related features can be added, such as a list of associated professional specialties to which the patient may request referral. Since it is intended for use in practical clinical situations, a further strength of the

PCI concept is that it can be readily adapted to different diseases on the basis of experienced opinion rather than in the time-consuming process of formal psychometric validation.

The flexibility of the PCI allows it to be adapted further to encourage patients to formulate specific questions about their care. Traditional question-coaching interventions may be seen as either highly generic (e.g. question prompt lists designed for distribution to all patients, [11]) or resource-intensive (e.g. personalised one-to-one interviews, [12]). The PCI is aimed at the

Fig. 2 Flowchart of study recruitment

gap between generic and face-to-face structured question prompting.

Aims

In keeping with previously published literature on the PCI, we aimed (1) to develop and publicise a brain tumour PCI, (2) to report common concerns reported among patients participating in its initial study, (3) to report specific questions asked by patients regarding their care and (4) to summarise feedback on the PCI received from patients and clinical staff. In designing a practical clinical document rather than a formal QOL instrument, we did not aim to psychometrically validate the PCI.

Methods

Development of the brain tumour PCI

The PCI was developed by discussion among senior experienced clinical staff including a consultant neuro-oncologist and a senior Clinical Nurse Specialist. The draft tool was presented at the academic neuro-oncology board meeting where suggestions for refinement of the item list were invited from other senior clinicians.

Four steps were involved in its development. (1) The concept was based on the original head and neck cancer PCI, which was found to have good patient acceptability and utility. We reviewed the head and neck PCI and retained only items likely to be relevant to neuro-oncology patients. (2) We then added relevant items from the European Organization for Research and Treatment of Cancer (EORTC)-BN20 [13], a psychometrically validated brain-tumour-specific QOL instrument, and (3) from the problem checklist of the National

Comprehensive Cancer Network (NCCN) DT, which is designed to cover general cancer-related concerns. Permission was obtained from the relevant authors to use their instruments in this way. Finally, (4) we reviewed the item list and added any remaining clinically appropriate problems or specialties to which patients may wish referral.

The brain tumour PCI (Fig. 1) is divided into three sections. In section 1, patients can identify recent concerns from a checklist of 48 items. In section 2, patients can specify neuro-oncology-related professional specialties to which they would like referral. In section 3, patients are invited to use their previous answers to formulate up to four specific questions that they would like answered during their consultation.

Subjects

Patients eligible to participate in its initial study were adults (age ≥ 18 years) with an intracranial tumour, attending the neuro-oncology outpatient clinic of the Western General Hospital in Edinburgh during the study period (June 17th until August 19th 2009). Patients were excluded if they were attending clinic for the first time or were being given their histological diagnosis during consultation. We also excluded patients whose appointment had been made at short (<1 week) notice because they would be unlikely to receive the study pack before attending clinic.

Process and feedback

An information leaflet, the PCI, and an 'initial feedback' form were posted to patients before their clinic appointment. The initial feedback form was designed to be completed before clinic. It asked how long patients took to complete the PCI,

Table 1 Characteristics of responding and non-responding patients

	Eligible patients (<i>n</i> =77) <i>n</i> (% of eligible)	Completed PCI (<i>n</i> =53) <i>n</i> (% of completers)	Did not complete PCI (<i>n</i> =24) <i>n</i> (% of non-completers)	<i>p</i> value
Sex				0.65
Male	42 (55)	28 (53)	14 (58)	
Age				0.11
18–34	13 (17)	6 (11)	7 (29)	
35–59	48 (62)	34 (64)	14 (58)	
>60	16 (21)	13 (25)	3 (13)	
Steroid use				0.24
Yes	19 (25)	11 (21)	8 (33)	
Anti-convulsant use				0.77
Yes	43 (56)	29 (55)	14 (58)	
Time since therapy				0.23
0–12 months	36 (47)	23 (43)	13 (54)	
13–24 months	8 (10)	8 (15)	0 (0)	
25–36 months	7 (9)	3 (6)	4 (17)	
37–48 months	6 (8)	4 (8)	2 (8)	
≥49 months	18 (23)	13 (25)	5 (21)	
Unknown	2 (3)	2 (4)	0 (0)	
Diagnosis				0.27
Glioma	55 (71)	35 (66)	19 (79)	
High grade	35 (46)	25 (47)	10 (42)	
Grade IV	22 (29)	15 (28)	7 (29)	
Grade III	13 (17)	10 (19)	3 (13)	
Low grade	20 (26)	11 (21)	9 (38)	
Other	22 (29)	18 (34)	5 (21)	
Meningioma	14 (18)	11 (21)	3 (13)	
Craniopharyngioma	1 (1)	1 (2)	0 (0)	
Pituitary adenoma	1 (1)	0 (0)	1 (4)	
Gliosarcoma	1 (1)	1 (2)	0 (0)	
High-grade B-cell lymphoma	1 (1)	1 (2)	0 (0)	
Medulloblastoma	1 (1)	0 (0)	1 (4)	
Pineoblastoma	1 (1)	1 (2)	0 (0)	
Ganglioglioma	1 (1)	1 (2)	0 (0)	
Glioneuronal tumour	1 (1)	1 (2)	0 (0)	

whether they completed it themselves, how hard it was to complete and whether any concerns should be added to the checklist.

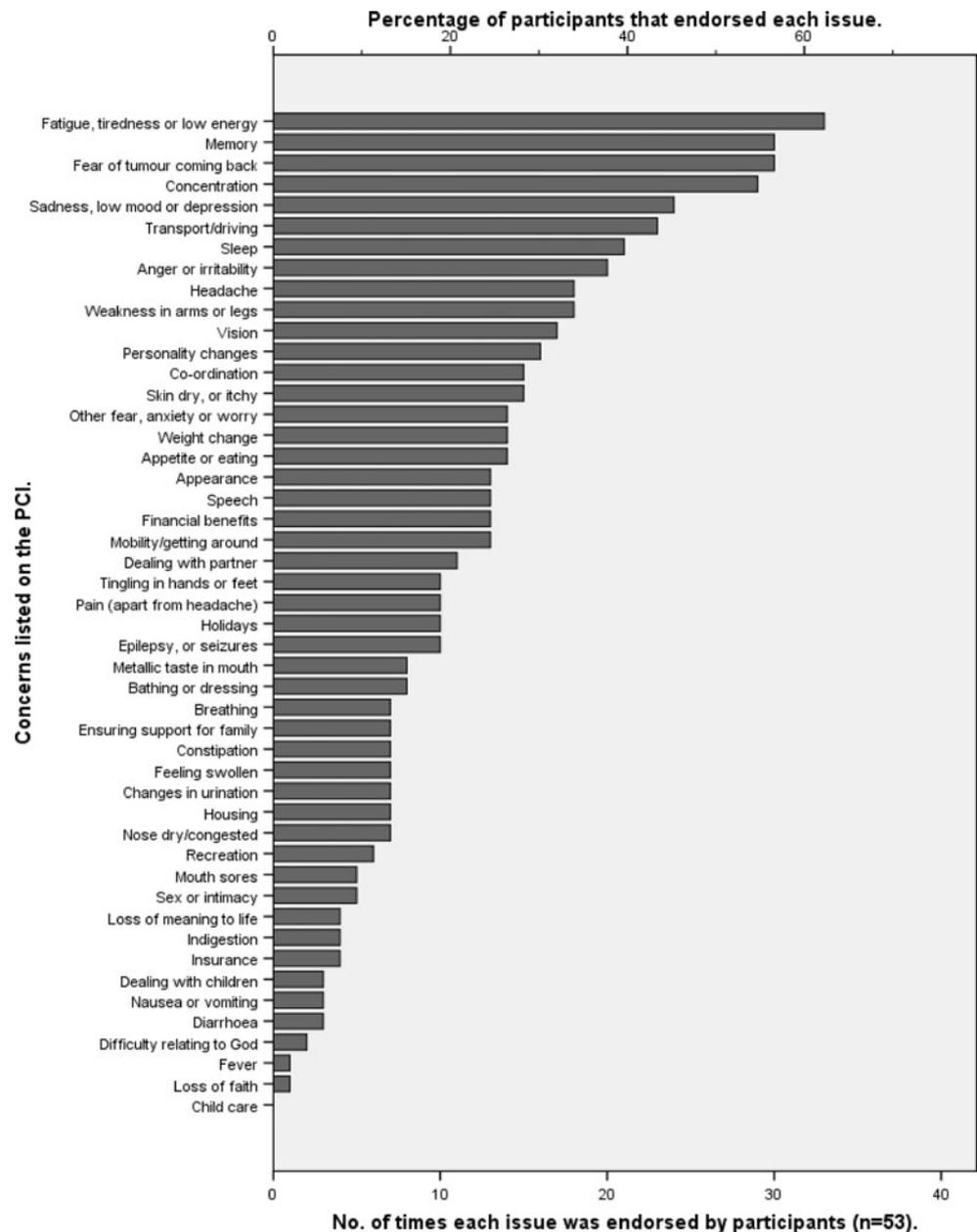
In clinic, completed PCIs were placed with clinical notes for use by medical staff during the consultation. Use of the PCI was left to the discretion of individual clinicians. Patients who had chosen not to complete the PCI had their consultation as usual. After the clinic, PCI completers were invited to fill out a ‘final feedback’ form. This form asked whether the PCI was useful for the consultation, and whether in the patient’s opinion it had improved the understanding between them and their doctor.

Clinicians completed a ‘staff feedback’ form at the end of every clinic, asking whether the PCI had improved understanding with their patient, whether the PCI had influenced consultation length, whether any concerns should be added to the checklist, and their overall impression of the PCI.

Statistical analysis

Demographic details were obtained from clinical notes. Tumour grade was based on current WHO guidelines. Duration of follow-up was calculated from the end of

Fig. 3 Frequencies of individual concerns



primary therapy (the latest of surgery, radiotherapy or chemotherapy). Demographic variables were examined using chi square or Fisher's exact test as appropriate. The specific questions asked by patients were reviewed and grouped into heuristic categories.

Ethical standards

The project was submitted to the local Research Ethics Committee who confirmed that formal ethical permission was not required for this attempt at service development. All patients gave informed consent to take part prior to inclusion in the study.

Results

Eligibility and response rate

Seventy seven patients were eligible to participate during the study period, and 53 of them completed the questionnaire (response rate 68 %, Fig. 2). No significant demographic differences were found between eligible patients choosing to complete and not to complete the PCI (Table 1).

Common concerns

Almost all participants (50/53, 94 %) reported at least one concern. The median number of concerns identified was eight

Table 2 Frequency of referral requests by speciality

Speciality	Referral requests, <i>n</i> ^a
Chaplain	0
Dietician	2
Palliative care services	2
Physiotherapist	5
Psychiatrist	1
Psychologist	2
Occupational therapist	3
Social worker	0
Speech and language therapist	2
Someone else (specify)	2 ^b

^a Four patients requested referrals to two specialities; one patient requested three

^b ‘Surgeon’ (*n* = 1); ‘Someone to listen’ (*n* = 1)

(range 0–36). The most frequently reported concerns were ‘Fatigue, tiredness or low energy’ (33/53, 62 %), ‘Fear of the tumour coming back’ (30/53, 57 %) and ‘Memory’ (30/53, 57 %).

Seventeen concerns were endorsed by >25 % neuro-oncology patients: of these high-frequency concerns, nine are either not listed or only partially addressed on the NCCN DT (concerns regarding memory, fear of tumour coming back, concentration, headache, weakness in arms or legs, vision, personality changes, co-ordination and speech). The frequency of all concerns is shown in Fig. 3.

Referral requests

One quarter (13/53, 25 %) of all participants expressed a wish to be referred to another specialty, most frequently physiotherapy (five patients, 9 %). The frequency of all referral requests is shown in Table 2.

Question asking

Seventy percent (37/53) of participants used the PCI to ask a total of 105 questions. The largest category of question (52/105, 49.5 %) was about symptoms, whether physical, e.g. ‘Is my increase in seizures due to my tumour growing?’, or psychological, e.g. ‘I have become very angry and easily upset, is this normal?’ Other questions revealed concern about social problems, MRI interval scanning, tumour recurrence, general procedures of care, prognosis, the consequences of surgery and the role of ancillary treatments. Many were idiosyncratic to the patient’s individual symptoms or circumstances and may not have been anticipated by clinicians. All questions asked by patients are listed, verbatim, in Table 3.

Table 3 Questions asked by patients using the PCI, which could then be addressed in the consultation

Category of question	Exact question asked
Symptoms	Why do I get so angry now when I used to be very passive? I can’t control myself and blow up at nothing.
	Why are my energy levels so low?
	What is the reason for my awful mood swings? Will it get better?
	If I am going to have problems with pituitary gland when would this happen and what would be the symptoms?
	Intimacy.
	Concentration.
	Is it possible to get clear clarification of what caused my double vision—this is slightly better since the operation—and would referral for prism be the correct way forward?
	Food related tiredness?
	I feel breathless. It sometimes feels like my breathing is very slow at times.
	I’d like clarification re general ‘mapping’ of my skull at present and likely future realignments. Is apparent tinnitus in my right ear linked?
	Dryness of right outer ear—does it apply to inner ear too? As seems like dead skin cells.
	I have pain and cramps in the side of my face and jaw. Is this normal after radiotherapy and will it go away?
	Personality changed over time, now noticeable.
	Memory—very poor.
	How long before my hair grows back?
	When should bloating/swelling leave my stomach?
	How do I overcome poor concentration and low energy levels?
	Out of sight very often turns out to be out of mind, then panic sets in when I cannot recall if an action has been completed. Is this part of the picture I have to live with?
	Tingling sensation in lower leg. I thought this might be due to medication, which has since been stopped but symptom persists—why?
	Movement in hand—is that going to be the same from now on?
	Symptoms—what to look for if it is to return.
	If my tumour was to return to the affected area, how would I cope with this both mentally and physically? Would I need a lot of care and would it have an effect on my body?
	Always have a fear of still having pressure on my brain at the left side or it being swollen. When I get headaches they seem to start on the affected area and move round to the left side of my temple.
I have fear and anxiety that my left side will go wrong somewhere as I have had a lot of pain over the last few weeks like stiffness and flappy foot.	
My memory I feel is weak at times but it is more short term than long term.	

Table 3 (continued)

Category of question	Exact question asked
	I have fatigue tiredness mostly in my arms but also my legs.
	Are my personality changes permanent? These changes have led to marital problems.
	My scalp is itchy and flaky, will this subside?
	I have become very angry and easily upset, is this normal?
	Regarding what's happening with the seizures.
	Right side—is it going to get worse?
	Will it end me up in a wheelchair?
	Ear—have been suffering from vertigo during the past 3 days.
	My reading ability has deteriorated even further. What are the prospects, if any, of an improvement in this area?
	My memory and concentration have deteriorated even further. What are the prospects of improvement?
	As a whole, I don't feel that anything is obviously worse, although I am noticing general body aches and pains far more, together with twitches and itches. Is this normal?
	My teeth hurt.
	When speaking to someone I start to speak very quickly and my words all get muddled together.
	If I have something to say to someone I have to say it there and then or I completely forget what it was I had to say.
	When I walk I find I always bend forward to check where I put my feet. I have had a few falls which I put down to uneven impairment.
	I feel very inferior and stupid.
	Lost hearing in left ear, hearing aid I find difficult in right ear.
	Is there anything I could do to help get rid of the tiredness and weakness?
	Apart from antidepressants is there any advice on helping to get rid of the depression?
	Is there anything I can take to help with the headaches?
	Breathing—problem since fall left hand side at breast bone.
	Memory—unable to tell day-to-day which day is which.
	Sleep—I could sleep all day and night.
	I suffer regularly from headaches above my left eye. Would this be related to the tumour?
	My big toe on my left foot is numb—could this be related to the tumour?
	After my operation I lost partial vision in my right eye. Will this get worse as I get older?
	Can my memory start to go soon, or later in my life?
	I have lost a lot of weight—will my metabolism get checked?
	When I am on my own how do I know if I have had a seizure or just fallen and knocked myself out? I found

Table 3 (continued)

Category of question	Exact question asked
	myself bottom of stairs with broken wrist. I don't know how.
	Are the symptoms I am getting normal?
	Do you think my heavy eyelids will go back to normal?
	Will my vision get better or worse?
	Will my memory get better? I forget things and say and do things I don't remember.
Social	I get anxious about my employment—expectations and ability to return to full-time work. Can I expect further improvement?
	Housing.
	Travel/insurance—currently been denied medical cover. Is this likely to be reconsidered after a period of time after removal of tumour or last seizure?
	I am by myself for most of the day. Do you have any suggestions as to what I can do to rectify this?
	Transport or driving.
	When can I drive again?
	Will I be able to play rugby again, or other sport?
	When is it safe to fly?
	The matter that causes me the most frustration and depression is not being allowed to drive when I know I am more than capable. I would like the doctor's help in this.
	No wife—divorced because of personality change.
	I feel fortunate that I am able to work full time but regards daily grooming, socialising—would it be possible to have access to more than one hair-piece every 6 months?
	Holidays—can I fly? When would that be OK to do? Any medicine to take on hold in case of symptoms recurring?
	Fear of returning to work in what kind of role they will put me in that I can handle with pressure coping and stress.
	I am beginning to think about reapplying for my driving license. Is this sensible? Also implications with seizure medication.
	Concerned that driver's licence only renewed for 1 year, when previously given for 3 years. Aware DLA decision is based on hospital report.
MRI	Why no MRI scan this time?
	Will I have any further MRI scans?
	Will I need another scan?
	Will I have a further scan?
	Why scanned only once a year?
	Will it be possible to have my next MRI scan in the morning and wait for the results? I am very apprehensive about the tumour's progress.
	When is the scan?
	Can I get scans to give me peace of mind?
Recurrence	Tumour reoccurrence.
	If my tumour recurs, what treatment is available?

Table 3 (continued)

Category of question	Exact question asked
Procedures of care	I have begun to think about the possible return of the tumour. Are there any statistics relating to this and if so is it likely to be more aggressive?
	Is headache a symptom of return of tumour?
	Is my increase in seizures due to my tumour growing?
	No one seems to be looking at the whole picture. I find it upsetting that I can't talk to one person who can put me in the picture about my illness, as one department does not know what another one is doing.
	After the MRI I would love to speak with the neurosurgeon about my scan, not with the oncologist who is reading my notes and can't understand my questions.
	Explain in full what palliative care offers?
	Should I be seen by a local doctor about my epilepsy and medication?
Prognosis	Why was I not advised at last year's appointment about changes noticed on the rim of the brain?
	What is the long-term prognosis?
	Time-line until the inevitable?
	What happens next?
Consequences of surgery	Do brain tumours generally spread to other parts of the body?
	When will I know if the tumour has reduced?
	It's my understanding that during the operation the neurosurgeon had to cut through some nerves to remove bits of tumour—can I expect any problems from this in future?
Ancillary treatment	As this is my first appointment since the operation we would like to talk through what was done. Although we spoke with the neurosurgeon in the hospital it's not always possible to take everything on board.
	Can I stop the dexamethasone without any suffering or can I continue?
	Is it OK to use eyedrops?
Other comments	Herbal medication.
	I have been coming to these appointments/asking questions for 9 years, my questions this time will depend on the results of the MRI scan taken on the morning of the appointment.
	Have not reached the level of helplessness yet to be worried about anything more than the usual.
	Questions will be generated dependant on results at consultation.
	I don't know much about my illness and what to expect in the future. All the information I have found out on my own seems to point to surgery as the main treatment, but I believe that is not an option in my case.

Patient feedback

The initial feedback form was completed by 45/53 (85 %) patients. Most (36/45, 80 %) had completed the PCI by

themselves. In the rest, it was completed by the patient's main carer. Time reportedly taken to complete the PCI varied from <5 min (11/45, 24 %) to >20 min (12/45, 27 %). Most patients (27/45, 60 %) completed it in <15 min. Participants generally found the PCI 'quite easy' or 'very easy' to complete (41/45, 91 %). Most (40/45, 90 %) viewed the checklist as comprehensive, although three participants suggested adding an item about difficulties in hearing.

The final feedback form was completed by 32/53 (60 %) patients. Almost all respondents thought that the PCI was 'useful' or 'very useful' (30/32, 94 %). A large majority also perceived a better understanding with their doctor during the consultation, as a result of using the PCI (28/32, 88 %).

Staff feedback

Twenty one feedback forms were returned during the study period. Overwhelmingly (20/21, 95 %), the PCI was seen as aiding communication with the patient. Other benefits reported were 'Provision of focus during consultation' and 'The ability to address more subjective and psychosocial issues'. Compared to patients seen in the same clinic without a PCI, clinicians usually considered that the PCI had benefited consultations (13/21; 62 %). However, PCI consultations were perceived to last longer (14/21, 67 %). Other drawbacks included difficulties such as 'Too many concerns were ticked'. Overall, however, the PCI was seen as useful (19/21; 91 %).

Discussion

Main findings

The brain tumour PCI is a cancer-site-specific HNA tool. It is low cost, simple to implement and easy to complete. It is designed to be more sensitive to the needs and concerns of brain tumour patients than general cancer checklists. Many of the most frequently endorsed concerns in the current study are absent from, or less clearly defined in, more generic cancer checklists. The PCI assisted patients practically in formulating and asking questions, which often related to the physical or psychological symptoms of brain tumour. Many questions were of the sort which it might be difficult for clinicians to anticipate and which may not otherwise have been raised. Patients' understanding with their doctor appeared to be improved and both patient and staff satisfaction with the instrument was high.

Limitations

Limitations of the study should be considered. The sample size was small in this single-centre study, but covered patients with a range of brain tumour types. We did not compare

satisfaction with the PCI against satisfaction with more general cancer checklists. Satisfaction may have been high simply because patients appreciate the process of HNA. We did not investigate differences between patients with different histological types of brain tumour or between patients at different points in the disease trajectory. Although staff feedback identified slightly longer consultations as a consequence of using the PCI, we did not make an objective measure of differences in consultation length.

Implications

Nevertheless, the brain tumour PCI is a potentially useful tool for patients and clinicians. Neuro-oncology patients differ in important ways from other oncology patients. In the first PCI study in head and neck cancer, patients were most concerned about ‘Fear of recurrence of the tumour’, ‘Dental health’ and ‘Chewing’ [10]. Neuro-oncology patients shared the fear of recurrence, but were otherwise most highly concerned about ‘Fatigue’ and ‘Memory’. Disease-specific HNA tools are explicitly endorsed by UK cancer authorities. General cancer screening checklists may not adequately capture the range of pragmatic and clinically relevant concerns of brain tumour patients.

The PCI concept can also improve doctor–patient communication by helping patients to formulate questions for clinic. Interventions designed to improve patient question-asking significantly increase patient satisfaction [14]. Question-asking by patients can be influenced by at least three broad factors: perceived acceptability, the ability to remember and articulate questions, and success in receiving answers [15]. The PCI supports patients at all three levels. First, patients may be reassured that it is appropriate to ask questions about issues presented on a checklist. Second, they are encouraged to write questions down, helping them to remember and articulate their worries. Finally, the PCI reminds doctors in clinic to address patient needs, providing answers, managing their concerns appropriately, potentially reinforcing question-asking for future consultations. Its simple yet individualised nature may lend it an advantage over either more generic or more costly question-prompting measures.

The PCI shares some characteristics with existing brain-tumour-specific QOL instruments [13, 16]. Both approaches (PCI and QOL checklists) invite patients with a brain tumour to report recent difficulties. There are, however, important differences between the two concepts. QOL measures are psychometrically validated, with rigid item lists, often utilise graded responses (e.g. Likert scales) and are designed primarily for use in research. The PCI is explicitly designed as a pragmatic, flexible checklist for practical use in clinical situations, where it can help the process of HNA.

Future studies could investigate potential differences between patients with distinct brain tumour diagnoses,

differences between countries with different healthcare models, and how patient needs and concerns may change over time.

Conclusions

This single-centre study is the first to demonstrate the clinical utility of the PCI concept in neuro-oncology patients. The combination of a brain-tumour-specific concerns checklist and an intervention to increase patient question-asking creates a powerful, but simple and low-cost HNA tool for use in neuro-oncology. Further research will develop and trial the brain tumour PCI for use in clinical practice.

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References

1. Chang SM, Parney IF, Huang W (2005) Patterns of care for adults with newly diagnosed malignant glioma. *JAMA* 293:557–564
2. Kaye AH, Laws ER Jr (eds) (2001) Brain tumours: an encyclopedic approach, 2nd edn. Harcourt, London
3. Khalili Y (2007) Ongoing transitions: the impact of a malignant brain tumour on patient and family. *Axone* 28:5–13
4. Chandana SR, Movva S, Arora M, Singh T (2008) Primary brain tumours in adults. *Am Fam Physician* 77:1423–1430
5. National Institute for Clinical Excellence (2004) Guidance on cancer services: improving supportive and palliative care for adults with cancer. The manual. National Institute for Clinical Excellence, London
6. National Cancer Action Team (2011) Holistic Needs Assessment for people with cancer—a practical guide for healthcare clinicians. National Cancer Action Team, London
7. National Cancer Survivorship Initiative (2010) Assessment and care planning workstream, April 2010. Department of Health, London
8. Scottish Cancer Coalition (2011) Priorities for action. www.scottishcancercoalition.org.uk/action.html. Accessed 10 March 2013
9. The National Comprehensive Cancer Network (2012) Clinical Practice Guidelines in Oncology: Distress Management. V2, 2013. http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#distress. Accessed 10 March 2013
10. Rogers SN, El-Sheikha J, Lowe D (2010) The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic. *Oral Oncol* 45:555–561
11. Langbecker D, Janda M, Yates P (2012) Development and piloting of a brain-tumour specific question prompt list. *Eur J Cancer Care* 21: 517–526

12. Hacking B, Wallace L, Scott S, Kosmala-Anderson J, Belkora J, McNeill A (2012) Testing the feasibility, acceptability, and effectiveness of a ‘decision navigation’ intervention for early stage prostate cancer patients in Scotland—a randomized controlled trial. *Psychooncology*. doi:10.1002/pon.3093
13. Taphoorn MJB, Claassens L, Aaronson NK, Coens C, Mauer M, Osoba D, Stupp R, Mirimanoff RO, van den Bent MJ, Bottomley A, EORTC Quality of Life Group, and Brain Cancer, NCIC and Radiotherapy groups (2010) An international validation study of the EORTC brain cancer module (EORTC QLQ-BN20) for assessing health-related quality of life and symptoms in brain cancer patients. *Eur J Cancer* 46:1033–1040
14. Kinnersley P, Edwards AGK, Hood K, Cadbury N, Ryan R, Prout H, Owen D, Macbeth F, Butow P, Butler C (2007) Interventions before consultations for helping patients address their information needs. *Cochrane Database Syst Rev*. Issue 3. Art. No.:CD004565
15. Roter D (1977) Patient participation in patient-provider interactions: the effects of patient question-asking on the quality of interactions, satisfaction and compliance. *Health Educ Monogr* 5:281–312
16. Armstrong TS, Mendoza T, Gning I, Coco C, Cohen MZ, Eriksen L, Hsu MA, Gilbert MR, Cleeland C (2006) Validation of the M.D. Anderson Symptom Inventory Brain Tumour Module (MDASI-BT). *J Neurooncol* 80:27–35