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Development and piloting of a brain tumour specific question prompt list

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Abstract

The objective of this research was to develop a question prompt list aimed at increasing question asking and reducing the unmet information needs of adults with primary brain tumours, and to pilot the question prompt list to determine its suitability for the intended population. Thematic analysis of existing resources was used to create a draft which was refined via interviews with 12 brain tumour patients and 6 relatives, readability testing, and review by health professionals. A non-randomised before-after pilot study with 20 brain tumour patients was used to assess the acceptability and usefulness of the question prompt list, compared with a 'standard brochure', and the feasibility of evaluation strategies. The question prompt list developed covered seven main topics (diagnosis, prognosis, symptoms and changes, treatment, support, after treatment finishes, and the health professional team). Pilot study participants provided with the question prompt list agreed that it was helpful (7/7), contained questions that were useful to them (7/7), and prompted them to ask their medical oncologist questions (5/7). The question prompt list is acceptable to patients, and contains questions relevant to them. Research is now needed to assess its effectiveness in increasing question asking and reducing unmet information needs.

Keywords

brain tumours; information; patient information; adults; communication

INTRODUCTION

Brain tumour patients and carers self-report high levels of unmet supportive care needs, particularly with regard to information, communication and accessing ancillary services (Janda *et al.*, 2006, Janda *et al.*, 2008). Both patients and carers have been shown to want detailed, practical, individualised information about what to expect in the future and potential eventualities, such as cognitive impairment or seizures, before such events occur (Halkett *et al.*, 2010, Sherwood *et al.*, 2004, Rozmovits *et al.*, 2010). Patients have called for this information to be provided early in the disease journey, such as pre-operatively or before discharge from hospital (Janda *et al.*, 2006, Wyness *et al.*, 2002, Rozmovits *et al.*, 2010).

However, a number of factors may impede information delivery and processing. Treatment is often initiated quickly after diagnosis (Janda *et al.*, 2006), and detailed prognostic information cannot be provided until a histopathological diagnosis is made (Halkett *et al.*, 2010, Widenheim *et al.*, 2002). Improved neurosurgical techniques have led to earlier discharge, such that only minimal support and information can be provided during hospitalisation (Barr, 2003, Schubart *et al.*, 2008). Patients' information seeking and comprehension may be hindered by cognitive, physical and/or emotional impairments caused by the brain tumour or treatment, or due to difficulties coping with their diagnoses (Leavitt *et al.*, 1996).

An additional difficulty with information about emergent issues is that they mostly will not be known at the time of consultations (Schubart *et al.*, 2008). Patients and carers may not know 'what to ask' (Schubart *et al.*, 2008), and expect health professionals to proactively provide relevant information (Janda *et al.*, 2006). However, patients and carers have also reported difficulties in coping when 'too much' information was provided 'too soon' (Halkett

et al., 2010). Some report that 'unwanted' or 'unnecessary' information about 'preparing for the worst' or 'things that might happen' was forced upon them, causing distress and 'taking away' hope (Widenheim *et al.*, 2002, Orabi *et al.*, 2005, Lobb *et al.*, 2011, Rosenblum *et al.*, 2009).

Few interventions to assist patients, carers or health professionals to exchange information have been developed for or evaluated in the brain tumour setting (Davies and Higginson, 2003, National Institute for Health and Clinical Excellence, 2006). However, research with cancer and other chronic disease populations suggests that encouraging patients to ask questions fosters the provision of tailored, personally relevant information (van der Meulen *et al.*, 2008, Dimoska *et al.*, 2008). This has been commonly achieved through a question prompt list (QPL), which consists of a structured list of questions about illness and treatment (Butow *et al.*, 1994), usually developed from focus groups and interviews with patients and health professionals (Dimoska *et al.*, 2011).

Patients are typically given a QPL prior to a medical consultation, to read through and determine the questions for which they would like answers (Dimoska *et al.*, 2008). A recent review of randomised controlled trials found a small but significant increase in the number of questions asked among patients given QPLs than controls (Kinnersley *et al.*, 2008). Significantly, cancer patients given QPLs have been shown to ask more questions about topics traditionally viewed as difficult, such as prognosis (Brown *et al.*, 2001) and end-of-life issues (Clayton *et al.*, 2007), without increasing patient anxiety or consultation duration (Kinnersley *et al.*, 2008).

The aims of this research were to: 1) develop a brain tumour specific question prompt list (QPL) with the intention of reducing unmet information needs; and 2) examine the

acceptability of the QPL and feasibility of outcome assessment among adults recently diagnosed and/or undergoing treatment for a primary brain tumour.

METHODS

This project took part in two phases: the development of the QPL, and the subsequent pilot testing of the intervention. Protocols for each phase of this research were approved by ethics committees from relevant institutions.

Question prompt list development

Development followed the principles outlined by O'Donnell and Entwistle (2003) to ensure the QPL was appropriate to its audience, understandable, usable, and accessible. The iterative process of development had five phases, involving existing resources and feedback from patients, carers, and health professionals.

Draft content of QPL formed from thematic analysis of existing resources

To minimise participant burden, we compiled an initial draft QPL based on the themes and sub-themes identified by a thematic analysis of four types of existing resources: 1) 14 QPLs sourced from peer-reviewed journals and patient materials; 2) five randomly selected, currently available, patient information brochures; 3) recommendations for patient information from the (then draft) guidelines for the management of glioma produced by the Australian Cancer Network (2009); and 4) information that should be provided to patients with brain tumours, suggested by health professionals in a previous study (Langbecker *et al.*, 2007).

The thematic analysis involved several readings of the source materials to enable familiarisation with the data and subsequent identification of the core themes, utilising open coding, axial coding and selective coding. In open coding, questions from QPLs and items from other resources were compared for similarities and differences, and conceptual labels

applied to allow grouping into categories (Glaser and Strauss, 1967). Initial codes were scrutinised during axial coding to ensure they were fully elaborated and developed. Finally, in selective coding, relationships between codes were mapped to allow integration around central themes, which were grouped together, re-examined and refined. Throughout the process, reference was made to initial sources, to ensure their meanings were not lost in the analysis.

The themes identified formed topics for the QPL, and at least one question was written for each theme. Several questions were written for themes with more codes, to allow more detail to be provided (see for example, Table 1). Questions relating to unmet supportive care needs and/or topics reportedly difficult to talk about were included, such as costs of medical treatment (McFarlane *et al.*, 2008). Questions were written in plain language, avoiding jargon, and using short sentences to avoid undue reliance on memory (Weih *et al.*, 2008).

Prior to the next step, the draft QPL was reviewed by a medical oncologist specialising in neuro-oncology, and consumer advocates, to identify any possible omissions or problematic questions.

QPL refined using feedback from patients and carers

A convenience sample of patients and carers was recruited via newsletters and presentations to members of The Cancer Council Queensland Brain Tumour Support Service, and letters sent to select past patients of a private neurosurgical clinic. Eligibility required that a person was either diagnosed themselves or cared for a person diagnosed with a brain tumour in the previous three years.

After obtaining informed consent, the draft QPL was mailed to participants. After one week, telephone interviews were conducted with participants to identify additional topics,

questions they found difficult to ask, information they wished they had received, or received later than desired, and any were irrelevant or inappropriate questions.

An iterative process of review was used, whereby the first draft was provided to four consecutive participants. Changes suggested by these participants were integrated, and the next version provided to a new sample of four participants. This cycle continued until saturation was achieved, defined as occurring when no new topics or deletions were suggested in four consecutive interviews.

Readability assessment and redrafting

Assessment of the readability of the draft QPL was conducted following modification based on patient and carer feedback, and review by health professionals. The average reading ability of adults in countries such as the UK, US and Australia, is the sixth grade level (Freda *et al.*, 1999), and it is recommended that patient information materials should not exceed this level (Davis *et al.*, 1990, Sullivan and O'Connor, 2001, Weih *et al.*, 2008). Readability analyses used three formulas: the Flesch-Kinkaid grade level; the Statistical Measure of Gobbledygook (SMOG); and the Fry readability graph. When readability analyses suggested the QPL required literacy beyond the sixth grade level, guidelines for improving readability and understanding were applied, including: reducing sentence length (Weih *et al.*, 2008); replacing complex words with simpler alternatives (Rose *et al.*, 2003); and removing words which may not be meaningful to readers (Sullivan and O'Connor, 2001).

QPL reviewed by health professionals

After readability was optimised, the modified QPL underwent a verification process to ensure that health professionals expected the questions to elicit useful and highly important information during consultations. A purposive sample of eight health professionals with

backgrounds in nursing, medical oncology, social work and care coordination who were involved in brain tumour patient care reviewed the QPL.

Format of QPL designed and tested with patients and carers

After all previous steps were completed; the text of the draft QPL was incorporated into a booklet format with appropriate font, graphics and illustrations. Four common design principles were followed:

- large, simple font (Rose *et al.*, 2003, Weih *et al.*, 2008);
- white space around the text (Rose *et al.*, 2003);
- figures, pictograms or other appropriate illustrations (Estrada *et al.*, 2000); and
- subtitles and/or lists to break up the text (Sullivan and O'Conor, 2001).

Other measures incorporated to improve readability and suitability were:

- colour coding of different sections;
- clear page numbering and a table of contents;
- inclusion of illustrations of persons from a variety of ethnic and demographic backgrounds; and
- notes pages so that patients or carers could write down answers received from health professionals, or additional questions.

Using the iterative method previously described, a further group of past patients and carers gave feedback regarding the layout, design and face validity of the QPL as a whole.

Question prompt list

The seven main themes identified by thematic analysis, which formed the structure of the QPL, are shown in Table 2. Characteristics of the 12 patients and six carers who reviewed the draft QPL are shown in Table 3. All participants reported that they would have liked to have received the QPL when they, or the person they cared for, was diagnosed.

Review of the QPL by health professionals led to a reduction in the QPL's length and the rewording of selected questions. After initial readability analyses reflected a higher than desired sixth grade reading level, the QPL was re-worded in accordance with published guidelines for improving the readability and understanding of health information (Weih *et al.*, 2008, Rose *et al.*, 2003, Sullivan and O'Connor, 2001). Final readability scores were: Flesch-Kincaid: grade level 4.8; SMOG: grade level 8; Fry: grade level 3-4. Although the SMOG score was still higher than desired, it was due to the inclusion of words with more than three syllables, such as 'medicines' and 'therapies'. Familiarity with these medical words that are commonly used and understood may increase reading ease, even when the words are long (Meade and Smith, 1991). Furthermore, research has highlighted the need to avoid simplifying patient materials to an exaggerated degree as they may appear childish (Rose *et al.*, 2003). As such, it was decided not to further modify the QPL.

Following the integration of feedback from participants and results obtained from the readability analyses, the draft QPL was professionally designed and printed. Copies were sent to past participants for further review, however, as all comments were positive, no additional changes were made. The final QPL consisted of a 33 page A5 booklet, entitled 'It's okay to ask' (Appendix 1).

Pilot testing

The acceptability of the QPL and feasibility of outcome measures was examined within a non-randomised before-after study with control group. To ensure study methods were feasible and to allow the commencement of the study whilst the QPL was under development, the first ten participants were assigned to the control group, and the subsequent ten participants were assigned to the QPL group.

Population and recruitment

Patients were recruited from four hospitals in Brisbane, Australia. To be enrolled, patients had to have: 1) been diagnosed with a primary brain tumour and received their diagnosis from a doctor; 2) been diagnosed in the previous six months and/or be undergoing treatment for their tumour; 3) be able to speak and read English sufficiently to read the intervention or control materials; 4) be aged 18 years or older; 5) be able and well enough to complete interviewer-administered questionnaires; and 6) be recommended for participation by their doctor or other health professional. The baseline interview was conducted within one week of informed consent.

Intervention and control conditions

Following the baseline interview, all participants were provided (personally or by mail) with a booklet entitled 'About brain tumours', produced by the Cancer Council Queensland ('standard brochure'). Participants in the QPL group also received the QPL.

Outcome measures and analysis

Patients' data were obtained using interviewer-administered questionnaires. This data collection method allowed the participation of persons with disabilities that could hinder completion of written questionnaires, and the identification of problematic instructions or questions. Follow-up interviews were conducted at least four to six weeks after the baseline interview, to allow the participant time to read and if desired, use the QPL in medical visits.

Acceptability of the QPL (or standard brochure) was assessed at follow-up based on 17 questions (several sourced from a previous QPL study (Clayton *et al.*, 2003)) regarding the usefulness of the QPL, timing of its delivery, and its use in medical consultations. Participants were also given the opportunity to comment on the QPL or standard brochure in open-ended discussion.

We hypothesised that the European Organisation for the Research and Treatment of Cancer (EORTC) Information module (QLQ-INFO25), which is designed to assess the quality and quantity of information received (Arraras *et al.*, 2007), may be a suitable outcome measure for assessing the QPL in future studies. Although this module has been validated with cancer patients at different stages of their disease (Arraras *et al.*, 2010), to the best of our knowledge, it has not been previously used with patients with brain tumours. According to QLQ-INFO25 instructions, responses to the 25 items were collated into four subscales: information about the disease, information about medical tests, information about treatments, and information on other services. Single items assessed whether or not participants had received written information, or information on CDs/tape/video, satisfaction with the amount of information, desire for more information, desire for less information, and helpfulness of information received (Arraras *et al.*, 2007).

Patients also reported their quality of life (EORTC quality of life questionnaire QLQ-C30 and brain cancer module QLQ-BN20), information and participation preferences (two questions from the Cassileth Information Styles Questionnaire (Cassileth *et al.*, 1980) and the Krantz Health Opinion Survey Information subscale (Krantz *et al.*, 1980)), self-efficacy in coping with cancer (Cancer Behavior Inventory (Merluzzi *et al.*, 2001)), social support (ENRICH Social Support Instrument (Vaglio *et al.*, 2004)), history of depression and anxiety (using two questions developed for the study), psychological adjustment and distress (Impact of Event Scale, Distress Thermometer, and single item questions), and demographic information. The duration of each interview was recorded as a measure of feasibility. Disease and treatment information was abstracted from medical records with permission.

Descriptive statistical analyses were conducted using SPSS version 17.0 (SPSS Inc., Chicago IL), reporting on mean or median scores, and standard deviations or ranges.

RESULTS

The characteristics of the 20 participants are shown in Table 3. The most prevalent tumour types were glioblastoma (40%), oligodendroglioma (20%) and meningioma (15%). By the end of the study, all patients had had surgery, 65% had received radiotherapy, and 50% chemotherapy. At baseline, the median time since diagnosis with a brain tumour was 1 month (range 0-46 months).

All participants completed baseline questionnaires, and 17 completed follow-up questionnaires. One patient was too unwell and withdrew, and two were lost to follow-up.

Acceptability of the QPL or standard brochure

All patients received the standard brochure and/or QPL as planned. Two patients in the QPL group reported that they did not read the QPL. Patients' responses regarding the acceptability of the standard brochure or QPL are shown in Table 4. All QPL participants agreed (either 'somewhat' or 'completely') that the brochure was 'helpful', and six out of seven agreed that it 'made it easier to ask questions'. All agreed that there were questions in the brochure that were 'useful' to them, and six that the brochure helped them to 'put some of their questions or concerns into words'. Only one participant found it overwhelming to read the QPL. Responses from control group participants about the standard brochure were also predominantly positive. However, control group participants were less likely than QPL group participants to 'agree completely' with positive statements about the brochure. In addition, three of the eight control group participants reported that it was overwhelming to read the standard brochure.

One patient from each group reported that the brochure they received was not the 'right length', reporting that it was 'too short'. Patients who received the QPL reported that it

prompted them to ask questions of their medical oncologist (5 participants), radio-oncologist (4), neurosurgeon (2) or another member of their health care team (2).

About three-quarters of participants reported that they had enough time to read the QPL (57.1%) or standard brochure (87.5%) before their medical appointments, but 40% of participants reported that they would have preferred to receive the brochure (QPL or standard brochure) at a different time. On average, time since diagnosis was greater in participants who would have preferred to receive it at a different time (median 6.5 months, range 1-46) than others (median 0 months, range 0-12). In qualitative discussion, all patients who mentioned timing reported they would have liked to receive the brochure when they were first diagnosed, for example, “before initial contact with doctors, or at least before the first outpatient department visit – before you get stuck in the system” (participant 5).

Qualitative data from the semi-structured interviews with participants confirmed their overall positive perception of the QPL (Table 5).

Feasibility of outcome assessment

The median time to complete the baseline interview was 34 minutes (range 21-60), and the follow-up interview was 33 minutes (range 19-51). Of the baseline interviews, face-to-face interviews were slightly shorter in duration than telephone interviews (median 31 minutes versus 34 minutes).

Descriptive statistics for the proposed measure of outcome, QLQ-INFO25, are shown in Table 6. As participants were not randomly allocated to QPL or control groups, statistical comparison between groups was not made. Overall, participants reported that they received more information about medical tests than any other topic at both baseline and follow-up, followed by information about treatments. Almost all patients (85%) reported the receipt of written information at baseline, but 60% wished to receive more information at this time.

The percentage of patients who wished to receive more information increased to 77% at follow-up. The mean change score was above zero only for one subscale, information about the disease.

DISCUSSION

This research aimed to develop a brain tumour specific QPL to assist patients to obtain the information they want and need. Our preliminary evaluation suggests the QPL contains questions that are relevant to this group of patients, are seen as useful, and that prompt patients to ask questions of their health professionals.

At 33 pages, our QPL is considerably longer than previous QPLs developed for other cancer patient groups (Brown *et al.*, 2011, McJannett *et al.*, 2003, Dimoska *et al.*, 2008). Our QPL includes a number of topics specific to brain tumour patients, such as seizures, cognitive impairment, and behavioural changes, which are less relevant to patients with other cancer diagnosis. In addition, a number of questions were included for each topic. This approach was chosen as patients differ in the importance they place on different details within a category, and have limited ability to process information at any one time (Feldman-Stewart and Brundage, 2004). A focus on details rather than global categories of information may allow patients to select the items most relevant to them (Feldman-Stewart and Brundage, 2004). The suitability of this approach was supported by pilot study participants, all but one of whom reported that the QPL was the 'right length'; while the dissenter suggested it was 'too short'.

Study participants given the QPL later in the disease period were most likely to report that they wished to receive the QPL at another time, most commonly, early in the disease trajectory. The appropriateness of supplying the QPL soon after diagnosis is supported by research which has shown that information seeking is highest in the period surrounding

diagnosis, when attempts are made to understand recommended treatment and prognosis (Schubart *et al.*, 2008). Although patients and carers are likely to have further, differing information needs later in the disease trajectory (Rutten *et al.*, 2005, Squiers *et al.*, 2005, Luker *et al.*, 1996), use of the QPL over time may increase patients' comfort with actively participating in consultations, facilitating change in behavioural norms which discourage questioning health professionals (Street, 1991). The provision of the QPL soon after diagnosis may enable patients to discuss which likely side-effects or cognitive and behavioural changes they may experience, before these changes occur, consistent with the desire for information about emergent issues reported in the literature (Wyness *et al.*, 2002, Janda *et al.*, 2006, Rozmovits *et al.*, 2010).

The low amounts of information reported to have been received by participants in this pilot study, and high proportion of participants who reported a desire for more information (60% at baseline), confirm the need for interventions such as a QPL. At baseline, 85% of participants reported that they had received written information, and 25% information on CD, tape or video. However, clinical practice guidelines recommend that all patients be provided with written information, and recommend the use of other media (Australian Cancer Network Adult Brain Tumour Guidelines Working Party, 2009).

Our QPL was developed with the input of patients, carers and health professionals; however acceptability has only been tested with patients at this stage. Previous studies have found high rates of unmet information needs among carers of brain tumour patients (Janda *et al.*, 2008, Parvataneni *et al.*, 2011), who may take supportive or independent roles in information seeking, dependent on the patient's cognitive status (Sherwood *et al.*, 2004, Arber *et al.*, 2010). We thus expect the QPL to be valued by carers, although this must be assessed in future studies.

Further research is also needed to determine the sensitivity to change of the proposed outcome measure, the QLQ-INFO25. A recent international validation study demonstrated its reliability and validity, however responsiveness to change was observed only for one scale (information about other services) (Arraras *et al.*, 2010). If responsiveness of the QLQ-INFO25 can be shown, it may be a useful adjunct or alternative to traditional measures of QPL effectiveness such as counts of questions asked (obtained by audio-taping consultations) (Kinnersley *et al.*, 2008).

Although our sample size was small, the characteristics of our pilot study participants suggest that the perceived helpfulness of the QPL was not affected by participants' cognitive or motor impairments. We were also concerned that our sample may be biased in some important way, such as towards people who utilise information seeking as a coping strategy (Timmermans *et al.*, 2007). However, 85% of participants reported wanting to know as much information as possible, consistent with the 87% reported in two large cancer cohorts (Cox *et al.*, 2006, Jenkins *et al.*, 2001).

As participants in the pilot study were not randomly allocated to control or QPL groups, a direct comparison of the intervention on the proposed outcome measure was not appropriate. However, the inclusion of a control condition suggests participants' positive response to the QPL was not (solely) due to socially acceptable answer patterns. Positive perceptions of the usefulness of the QPL were also supported by the qualitative data obtained.

CONCLUSION

We have developed a brain tumour specific QPL that has the potential to assist patients and carers to ask questions of their health professionals. This print-based QPL appears to be

acceptable to, valued, and used by patients. Feedback about the timing of QPL delivery suggests it should be given to patients in the early stage of diagnosis and treatment.

Further research is needed to assess the views of carers and health professionals, and optimise evaluation strategies. Formal testing of the QPL's effectiveness in increasing question asking and receipt of information should be conducted, preferably in a randomised controlled trial.

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Tables

Table 1: Questions about oral medications from the QPL

What can I do if I have problems taking my pills?

How long do I have to keep taking these medications?

Should I keep taking my existing medicines whilst I am on these?

Will these medications have any effect on my existing medical conditions?

Can I get these tablets from my usual chemist?

Should I buy all the repeats up front, or could my prescription or dose change?

If I have a seizure, should I keep taking my seizure medication? Should I change the dose?

QPL, question prompt list

Table 2: Topics for brain tumour specific question prompt list

Topic	Questions regarded
Diagnosis	Tumour type, location, extent, cause, tests, telling people about the diagnosis, coping with the diagnosis
Prognosis	Cure or control, quality of life, malignancy and spread, natural history, predicting prognosis
Symptoms and changes	Identifying and understanding problems, cognitive, behavioural and personality changes, emotional and mood changes, seizures, changes to appearance, lifestyle changes
Treatment	Overall treatment plan, understanding and choosing treatments, practical and procedural issues, clinical trials, complementary and alternative medicines, self management, palliative care, oral medications, chemotherapy, radiotherapy, surgery
Support	Services and organisations, information, emotional support, practical issues, financial issues, spiritual and cultural, peer support, family and friends
After treatment finishes	Plan for the future, recovery and rehabilitation, work, driving, end of life issues
The health professional team	People providing care, multidisciplinary team approach, visits and appointments, contacting your team, help communicating

Table 3: Demographic and illness characteristics of participants

Characteristic	QPL development		QPL pilot	
	Carers (n=6)	Patients (n=12)	Patients (n=20)	
	Number	%	Number	%
Age, years: <i>median (range)</i>	56.5 (54-62)		53.5 (28-63)	
Sex				
Male	3	50.0	5	41.7
Female	3	50.0	7	58.3
Marital status				
Married or living together	5	83.3	10	83.3
Other	1	16.7	2	16.7
Education (<i>highest level completed</i>)				
Junior or senior high	2	33.3	4	33.3
Trade or certificate	0	0	4	33.3
University	4	66.7	4	33.3
Tumour type ^a				
Meningioma	2	33.3	6	50.0
Glioblastoma	2	33.3	1	8.3
Oligodendroglioma	1	16.7	2	16.7
Other ^b	1	16.7	3	25.0
Therapies used to treat the tumour ^a (<i>multiple responses allowed</i>)				
Surgery	6	100.0	12	100.0
Radiotherapy	3	50.0	7	58.3
Chemotherapy	2	33.3	4	33.3
Location				
Major city			14	70.0
Regional			6	30.0
Attitude towards information about illness				
Want only information needed to care for self			1	5.0
Want additional information only if good news			2	10.0
Want as much information as possible			17	85.0
Impairment reported in medical record (<i>multiple responses</i>)				
Memory			7	35.0
Attention			6	30.0
Visual			3	15.0
Motor			7	35.0
Distress thermometer score ≥ 4			12	60.0
Treated in a private hospital			12	60.0
Spoke a language other than English at home			2	10.0

^a For carers, refers to the tumour and treatment characteristics of the person supported by the carer

^b Other includes astrocytoma, ependymoma, mixed glioma, pituitary adenoma

QPL, question prompt list

Table 4: QPL and control group participants' views of the QPL or standard brochure at follow-up

	QPL group: opinions about the QPL (n=7)				Control group: opinions about standard brochure (n=8)					
	agree completely	agree somewhat	neither agree or disagree	disagree somewhat	disagree completely	agree completely	agree somewhat	neither agree or disagree	disagree somewhat	disagree completely
I found the brochure to be helpful	4	3				2	5		1	
The brochure made it easier to ask questions	4	2	1				6	1	1	
There were questions in the brochure that were useful to me	3	4				1	6			1
The brochure helped me to put some of my questions or concerns into words	3	3	1			1	6		1	
I found it overwhelming to read the brochure	1			2	4		3		3	2
I think the brochure will be useful to me in future	4	1		2		1	6		1	
The brochure was easy to understand	7					1	6		1	

QPL, question prompt list

Table 5: Participants' feedback about the QPL

"[The] brochure was great to help get an overview and prepare for what was ahead. [I] had difficulty with talking with doctors beforehand." (participant 15)

"Loved the brochure, showed it to my GP, and he was very impressed. [He] said they should make one for all cancer types." (participant 14)

"[The] brochure didn't answer enough of what [I] needed to know, but I liked to be able to take it and ask doctors" (participant 12)

"I gave the brochure to my sons to read, even my 15 year old had no problems, it was easy to understand" (participant 19)

QPL, question prompt list

Table 6: Descriptive statistics for Information Received (EORTC QLQ-INFO25)

	Baseline		Follow-up		Change	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
Scales:						
Whole questionnaire	47.0	12.5	45.3	13.4	-3.1	14.2
Information about the disease	45.4	19.4	49.5	21.7	3.2	21.7
Information about medical tests	62.2	20.5	59.8	24.8	-5.6	26.9
Information about treatments	48.1	15.4	39.2	18.2	-11.8	20.8
	%	(n)	%	(n)	%	(n)
Single items: ^a						
Received written information	85.0	(17)	55.0	(11)	35.3	(6)
Received information on CD, tape or video	25.0	(5)	23.5	(4)	23.6	(4)
Wish to receive more information	60.0	(12)	76.5	(13)	41.2	(7)
Wish had received less information	0	(0)	5.9	(1)	5.9	(1)

^a proportion and number of participants whose response changed presented for dichotomous items