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ORIGINAL ARTICLE

Attitudes and preferences toward monitoring symptoms, distress, and quality of life in glioma patients and their informal caregivers

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Abstract

Purpose Glioma patients and their informal caregivers face
many challenges in living with the disease and its disease-
specific consequences. To better meet their needs, a system
to monitor symptoms, distress, and quality of life could prove
useful. We explored glioma patients' and caregivers' attitudes
and preferences toward monitoring in general and specifically
toward paper-and-pencil and computerized (eHealth) options.
Methods In total, 15 patients and 15 informal caregivers par-
ticipated in individual, semi-structured interviews. Interviews
were transcribed smooth verbatim and coded by two re-
searchers independently.
Results Advantages of monitoring generated by participants
include increased awareness of problems and their flow over
time, and facilitating supportive care provision. Disadvantages
include investment of time and mastering the discipline to mon-
itor frequently. Patients reported more disadvantages of moni-
toring, including practical and disease-specific impediments,
while caregivers mentioned more advantages. Preferences for

specific methods mentioned to monitor are highly personal but
most prefer to have an option for face-to-face contact to discuss
results of monitoring with health care professionals even in
computerized instruments.
Conclusions Informal caregivers view a monitoring system
more favorably than glioma patients. In developing an effi-
cient monitoring system to help glioma patients and caregivers
find their way to supportive care, a computerized instrument
with the added opportunity to contact a health care profession-
al seems to be the best option to advise.

Keywords Glioma · Brain tumor · Informal caregivers ·
Supportive care needs · Preferences · eHealth

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Background

Gliomas, the most common primary malignant brain tumors,
can have a devastating impact on the lives of both patients and
those close to them. These tumors lead to neurological symp-
toms that can cause a disease burden distinctly different from
other cancer patients [1]. For example, paresis, visual- per-
ceptual deficits, sensory loss, cognitive deficits, and seizures
are common [2], and changes in personality and behavior can
occur [3, 4].

As the disease progresses, symptoms may become more
pronounced and patients have to rely more on their informal
caregivers. Consequently, many informal caregivers experi-
ence considerable caregiver burden [5, 6], and psychological
distress is reported in approximately half of all family care-
givers [7]. Various studies have explored the needs of both
patients and informal caregivers related to information disclo-
sure and communication, service provision, and supportive
care options [8]. Meeting the needs of patients and informal
caregivers may reduce their symptoms and psychological

distress and improve their quality of life (QOL). Patient- reported outcome measures (PROMs) might help identify symptoms and distress, track changes over time, and could serve as an indicator of relevant topics to discuss [9]. Particularly, monitoring over time in combination with feedback is suggested to provide better insight into problems that patients and caregivers encounter, and to facilitate referral to appropriate supportive care options [10].

Few studies have focused on using monitoring instruments in brain tumor patients [11–16]. Monitoring for QOL issues [11], disease-specific issues [16], and distress and depression [14] was found feasible in neuro-oncology patients in clinical practice. However, none of these studies has included informal caregivers reporting on their own problems. Moreover, in only two studies [14, 16], the focus was on instruments reporting results to patients themselves instead of to physicians.
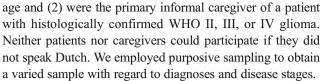
Monitoring can be conducted in several ways: by means of paper-and-pencil instruments and by means of computerized or Web-based (eHealth) applications. It is expected that eHealth applications could prove to be useful tools in implementing monitoring in the health care system, because of 24/7 availability, and report in real-time instead of retro-spectively [17]. In introducing such innovations into clinical practice, it is important to actively engage the end users (i.e., patients and caregivers) in order to improve the effectiveness and uptake [18, 19].

Therefore, the present study aimed at examining the perspective of glioma patients and informal caregivers on monitoring their own symptoms, distress, and QOL. Our research objectives were to discover (1) if glioma patients and informal caregivers are interested in monitoring their own symptoms, psychological distress, and QOL in clinical practice; and (2) what the attitudes and preferences of glioma patients and informal caregivers are toward paper-and-pencil instruments and eHealth applications, and toward face-to-face and automated feedback. Based on study results, suggestions for an efficient way to provide glioma patients and caregivers with the means of reporting their concerns and obtaining appropriate supportive care (e.g., symptom management interventions, physical therapy or psychological support, or more informal supportive care such as peer support groups) are provided.

Methods

Sample and procedure

Adult glioma patients and informal caregivers of glioma patients were recruited at the outpatient department of the VU University Medical Center in Amsterdam. Patients were eligible if they (1) were >18 years of age and (2) were diagnosed with a histologically confirmed WHO grade II, III, or IV glioma. Caregivers were eligible if they (1) were >18 years of

age and (2) were the primary informal caregiver of a patient with histologically confirmed WHO II, III, or IV glioma. Neither patients nor caregivers could participate if they did not speak Dutch. We employed purposive sampling to obtain a varied sample with regard to diagnoses and disease stages.

The nurse practitioner or treating physician introduced potential participants to the study by handing out an information letter. With permission from the potential participants, a member of the research team (FWB or KH) contacted them to ask if they were willing to participate. The semi-structured interviews, taking approximately 60 min, were scheduled either at the hospital or at a location of the participant's preference. All participants were interviewed individually. Interviews were performed until data saturation was obtained in the patient and caregiver interviews separately, meaning that the last interview(s) generated no new information [20]. All interviews were audiotaped. Information on disease and treatment was extracted from the medical records. All participants signed written, informed consent forms and the study was approved after expedited review by the Institutional Review Board of the VU University Medical Center (protocol number 13/309).

Interviews

All interviews ($N = 30$) were performed by one member of the research team (KH). A semi-structured interview schedule was used (see Table 1). Interview topics and questions were based on our clinical experience and literature [21–23]. If open-ended questions elicited little response, prompts were offered.

We proposed three methods of monitoring (see the Online Resource for additional information). Participants were presented with a paper-and-pencil screening instrument (the Patient Concerns Inventory [16] (PCI) for patients; the Distress Thermometer [24] (DT) for informal caregivers). Additionally, it was explained that this can be combined with face-to-face feedback and referral if needed. Furthermore, a computer-based monitoring application was presented: Oncoquest [25], a touch screen application available in the outpatient clinic, which can be paired with face-to-face feedback and referral. Finally, an eHealth application was introduced by means of screenshots: Oncokompas [26], an eHealth instrument available from home, which provides instant tailored feedback and referral to personalized supportive care options. Both Oncoquest and Oncokompas comprise QOL measurements. These different instruments were selected because they vary in the degree to which technology is involved.

Data analysis and reporting

The interviews were transcribed smooth verbatim using F4 software [27]. Data analysis was conducted by two coders

Table 1 Interview topics

Topics	Key questions
1. Unmet supportive care needs	*Current supportive care provision*
	What is your experience with referral to supportive care and use of supportive care options?
2. Willingness to monitor symptoms or problems and referral to supportive care in clinical practice	*Monitoring needs and problems*
	What are your thoughts about monitoring? Could you name advantages and disadvantages?
	How would monitoring be of most use to you; for which symptoms or problems?
	Personalized feedback
	How would you feel about receiving personalized feedback based on the symptoms and problems you have monitored?
	Referral to supportive care
	How would you feel about receiving referral to supportive care options based on the symptoms and problems you have monitored?
	What are your thoughts on a system of monitoring, feedback and referral to improve supportive care provision?
3. Attitudes and preferences towards instruments as a means to monitor symptoms, distress and QOL	*Paper-and-pencil instrument* (*PCI* or *DT*)
	What are your thoughts on this paper-and-pencil instrument?
	Computerized and eHealth application (*Oncoquest* and *Oncokompas*)
	What are your thoughts on these computerized applications?
	Which of these three instruments would you prefer, and why?

PCI Patient Concerns Inventory, *DT* Distress Thermometer, *QOL* quality of life

(WC and FWB) by thematic analysis [28, 29]. Both coders read the transcripts several times to familiarize themselves with the content and highlighted sections of the transcripts that were related to the research objectives and independently selected and coded these into key issues and themes (separately for the patient and caregiver interviews). After every three interviews, the coders discussed their findings, refined the key issues and themes, and resolved possible differences until consensus was reached guided by a third researcher (CvU). Finally, one coder (FWB) examined the raw transcripts again to ensure that the analytical process was robust and to confirm that all data were reflected in the coding. In this paper, the consolidated criteria for reporting qualitative research (COREQ) [30] were followed. All quotes provided were anonymized and translated to English by a professional translator.

Results

Participants

In total, 18 patients received the study information and all were willing to participate (see Fig. 1 for participant flow). Two patients did not show on the scheduled meeting time, and one interview was canceled because data saturation had already occurred. Twenty-four informal caregivers were approached with study information. Six informal caregivers declined to participate: Three caregivers were too busy, two caregivers were too overwhelmed, and one caregiver was gravely ill. In three additional cases, a suitable date for the interview could not be scheduled. Data saturation started after approximately 12 interviews in both patient and caregiver samples, after which an additional three interviews were conducted to ensure that we had indeed reached data saturation. In total, a representative sample of 15 glioma patients and 15 informal caregivers with a wide range of pathologic diagnoses in different disease stages were interviewed (see Table 2 for details). Below, the results that were relevant in terms of the research objectives are described.
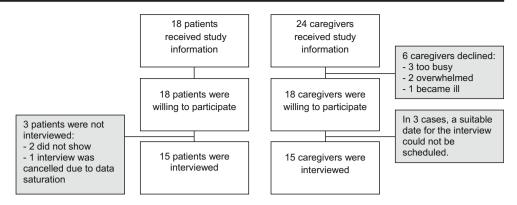
Monitoring symptoms, distress, and QOL in clinical practice

Current supportive care provision

Most patients mentioned to be content with the information provided by the hospital, while many informal caregivers felt this did not suffice or was unclear. Patients indicated that because of time constraints and a varying level of interest from physicians, they did not always feel there was enough attention for the person behind the disease:

Fig. 1 Flowchart of participant inclusion

| 18 patients received study information |
| 24 caregivers received study information |

6 caregivers declined:
- 3 too busy
- 2 overwhelmed
- 1 became ill

| 18 patients were willing to participate |
| 18 caregivers were willing to participate |

In 3 cases, a suitable date for the interview could not be scheduled.

3 patients were not interviewed:
- 2 did not show
- 1 interview was cancelled due to data saturation

| 15 patients were interviewed |
| 15 caregivers were interviewed |

'Yes, it just doesn't feel so… easy and… familiar, so to speak, and you have the feeling that it all has to be done in a hurry, so, I think, yes... never mind.' (Female glioblastoma patient (42 years), currently under treatment)

With regard to referral to supportive care, patients indicated that although their symptoms were heard, supportive care was often only offered if actively requested. At the same time, both patients and caregivers stated that they were uncertain who their treating physician is. Moreover, informal caregivers mentioned to find it difficult to ask for help for themselves, as they feel the patient should be the center of attention. Patients said to receive several forms of supportive care, e.g., a psychologist, rehabilitation, advance care planning, and spiritual care, while caregivers mostly said to rely on support from those close to them.

Advantages and disadvantages of monitoring

Table 3 lists the advantages and disadvantages of monitoring. An important advantage of monitoring indicated by both patients and caregivers is that it can help you learn more about yourself and that it can create more attention for symptoms or issues and their flow over time. Monitoring was mentioned to facilitate the conversation with the treating physician and, therefore, to be useful in preventing the problems from worsening:

'That you… that you had better follow things over time, what is happening to you, how you are doing, yes. Well you know, whether your condition has indeed improved or deteriorated, or your weight... or, those kinds of things. That you are triggered to… to take the necessary action if things are not well.' (Male grade III oligodendroglioma patient (65 years), progressive disease suspected)

Downsides of monitoring were also mentioned. Both patients and caregivers said that it could be difficult to master the discipline to monitor regularly and that it can be time consuming. Furthermore, they feared that it would increase awareness of problems they did not know they had and that it could be difficult to face (worsening) symptoms:

'But I also have to be careful that I do not go and sit there thinking up things, like, what do I find so hard..' (Male caregiver (76) of a grade III astrocytoma patient with stable disease)

Participants who experienced no needs considered monitoring to be pointless. However, patients and caregivers did feel that it might be useful for others who do experience needs and are less able to cope with symptoms or distress.

Preferences regarding monitoring

Patients generated mainly physical symptoms as topics to monitor. Cognitive deficits, changes in personality, mood, and emotional reactions were also mentioned. Caregivers mainly mentioned mental symptoms, such as depressive mood and stress. Moreover, changes in the relationship with the patient and in everyday life, and coping with the patient's symptoms were frequently mentioned. Many topics mentioned by caregivers were associated with grief and acceptance:

'Also the… amount of time I really spend with my husband, quality time. I have been wondering about… those are also things I wonder about. Like, is this normal what is happening here. What… what do people do when you tell them you only have so and so long to live.' (Female caregiver (52 years) of a glioblastoma patient with disease progression)

Both patients and caregivers thought receiving feedback on the results of monitoring was essential. They indicated that with feedback, changes over time become apparent, and it can provide more insight into the problems experienced. Patients would like to know if symptoms are normal,

Table 2 Demographic characteristics of the participants

Participant	Age	Gender	Relationship to the patient	Diagnosis of the patient	Time since diagnosis	Disease status
Patient 1	58	Male	N/a	Glioblastoma	3 months	Under treatment
Patient 2	51	Male	N/a	Glioblastoma	1 year and 3 months	Under treatment
Patient 3	50	Male	N/a	Grade III astrocytoma	3 years	Stable
Patient 4	28	Female	N/a	Grade II astrocytoma	6 years	Stable
Patient 5	50	Male	N/a	Grade II oligodendroglioma	8 years	Stable
Patient 6	65	Male	N/a	Grade III oligodendroglioma	2 years	Progressive disease suspected
Patient 7	73	Female	N/a	Grade II astrocytoma, then glioblastoma	2 years; 7 months	Under treatment
Patient 8	42	Female	N/a	Glioblastoma	6 months	Under treatment
Patient 9	66	Female	N/a	Glioblastoma	1 year and 3 months	Stable disease
Patient 10	50	Male	N/a	Grade III oligodendroglioma	4 years	Stable disease
Patient 11	53	Female	N/a	Grade III oligodendroglioma	1 year and 6 months	Stable disease
Patient 12	51	Male	N/a	Grade II oligodendroglioma	8 years	Stable disease
Patient 13	43	Male	N/a	Grade II astrocytoma	1 year and 7 months	Stable disease
Patient 14	43	Male	N/a	Grade II oligo-astrocytoma	2 years and 5 months	Stable disease
Patient 15	40	Male	N/a	Grade II astrocytoma	2 years and 6 months	Stable disease
Caregiver 1	52	Female	Spouse	Glioblastoma	11 months	Under treatment
Caregiver 2	55	Female	Spouse	Grade II oligodendroglioma, then grade III oligodendroglioma	11 years, 7 years	Stable disease
Caregiver 3	52	Female	Spouse	Glioblastoma	6 months	Disease progression, under treatment
Caregiver 4, partner of patient 11	58	Male	Spouse	Grade III oligodendroglioma	1 year and 6 months	Stable disease
Caregiver 5	53	Female	Spouse	Grade III oligo-astrocytoma	7 months	Stable disease
Caregiver 6	58	Female	Spouse	Glioblastoma	6 months	Disease progression
Caregiver 7, partner of patient 5	52	Female	Spouse	Grade II oligodendroglioma	8 years	Stable
Caregiver 8	45	Female	Spouse	Glioblastoma	4 months	Disease progression, under treatment
Caregiver 9	40	Female	Spouse	Glioblastoma	2 years and 7 months	Under treatment
Caregiver 10, partner of patient 15	38	Female	Spouse	Grade II astrocytoma	2 years and 6 months	Stable disease
Caregiver 11	67	Female	Spouse	Glioblastoma	4 years and 8 months	Stable disease
Caregiver 12	58	Female	Spouse	Grade II oligodendroglioma	6 years	Stable disease
Caregiver 13	76	Male	Spouse	Grade III astrocytoma	6 years	Stable disease
Caregiver 14	53	Female	Spouse	Grade III oligodendroglioma	2 years and 2 months	Stable disease
Caregiver 15	43	Female	Spouse	Grade II oligodendroglioma	6 years	Stable disease

N/a not applicable

considering the circumstances. Several caregivers mentioned that feedback and advice alone could provide solace:

> '*Yes, in itself I do believe that it... may give some relief since you know there is care available. Oh dear, not that you, that I would immediately use it, but I, again believe, the idea that you, the sheer knowing that it is there... that could be very comforting.*' (Female caregiver (52 years) of a glioblastoma patient who is under treatment)

Subsequent referral to supportive care was considered useful by most patients and caregivers. Informal caregivers believed that referral after monitoring can save time and effort to seek out help.

Different monitoring instruments

Tables 4, 5 and 6 provide an overview of participants' thoughts on the different monitoring instruments. Generally, patients felt that any of the presented instruments would be an improvement in existing health care, as it can help guide the discussion with the physician. Some even see its implementation as a form of good "customer service." Patients had various different

Table 3 Advantages and disadvantages of monitoring

	Key issues	Themes	
Perceived use of monitoring symptoms, distress and QOL	Motives pro use	Would be useful to learn more about yourself, to gain insight	Patients and caregivers
		Could create more attention for symptoms and concerns	Patients and caregivers
		Could facilitate initiation of professional supportive care	Patients and caregivers
		A structured approach helps to identify topics to discuss	Patients
		Could help with rehabilitation (e.g. useful for improving physical fitness)	Patients
		Could help you recognize recurring issues	Caregivers
		Would be useful to obtain a clear view of flow of issues	Caregivers
		Would be useful to compare one's own issues with others in a similar situation	Caregivers
		Would be useful when paired with immediate feedback	Caregivers
		Could be useful to prevent worsening of symptoms and concerns	Caregivers
		Could help with process of grief	Caregivers
		Would be useful to learn how to deal with the situation	Caregivers
	Motives con use	Difficult to master the discipline	Patients and caregivers
		Could make you more aware of symptoms and concerns you did not know you had	Patients and caregivers
		It is time-consuming; yet another chore to complete	Patients and caregivers
		Would not be useful when there are no symptoms or concerns	Patients and caregivers
		Reluctance to share details on everyday functioning with treatment team	Patients
		It is unclear who to contact about the different symptoms and problems	Patients
		Would be disappointing to see symptoms worsen	Patients
		Language problems could make monitoring difficult	Patients
		Would not be able to monitor without help from partner	Patients
		Could make you feel like a patient yourself	Caregivers
		Could be difficult to face issues	Caregivers
		Would not be useful when you are already highly aware of your own functioning	Caregivers
	Expected benefits for others	To learn more about yourself	Patients
		Could be useful for others who are less able to cope	Caregivers
		Knowledge that results from monitoring can help others in the future	Caregivers
		Could be useful for research/hospital purposes	Patients and caregivers
		Could put the symptoms into perspective	Patients
		Could be useful when contact with treatment team is not sufficient	Patients
		Could be useful as a legacy for children	Patients

QOL quality of life

opinions on social influence by peers or health care professionals. A few caregivers indicated that recommendation by the treatment team specifically would encourage them to use a monitoring instrument:

> 'I take that seriously, yes. Yes, of course. That… you must take it seriously. I do. Of course, it is not something you can simply wave away. I see it as an exam. No, then, yes then I will.' (Female caregiver (67 years) of a glioblastoma patient with stable disease)

Paper-and-pencil instrument

Patients said the PCI seems to be a simple instrument that would be easy to complete because the different topics are concrete and clear, and believe that it can help recognize problems and initiate discussion (Table 4). As the PCI does not allow for an indication of the severity of symptoms, patients said it only provided a snapshot picture of their concerns, which may hinder its usefulness. Patients indicated that they expected the social cues from face-to-

Table 4 Perceived use of paper-and-pencil instruments

	Key issues	Themes	
Perceived use of a paper-and-pencil instrument: Patient Concerns Inventory (PCI)	PCI is an expected improvement in health care	Topics raised by the PCI can help recognize problems and initiate discussion	Patients
		Topics raised by the PCI are concrete and clear	Patients
		The PCI is simple and easy to complete	Patients
		Indication of the severity of symptoms can follow in conversation	Patients
		Implementing PCI would be good 'customer service'	Patients
		PCI would be preferred in case of visual problems (paper-and-pencil is easier than computer)	Patients
	With the PCI, monitoring symptoms over time seems difficult	PCI provides a "snapshot picture"	Patients
	PCI would be paired with face-to-face feedback	Social cues help in interpretation of feedback/advice	Patients
		Allows you to ask questions	Patients
		Personal contact	Patients
Perceived use of a paper-and-pencil instrument: the Distress Thermometer (DT)	The DT is an expected improvement in health care	The DT can help initiate a conversation about supportive care	Caregivers
		DT is easy to complete	Caregivers
		Topics raised by the DT are relevant to the caregiving situation	Caregivers
		Topics raised by the DT can help reflect on own situation	Caregivers
	The DT seems to have certain restrictions	The DT is too brief	Caregivers
		Answer options do not do justice to subtle fluctuations	Caregivers
		Difficult to monitor symptoms and concerns over time	Caregivers
		Questions are difficult to interpret	Caregivers
		Name of instrument is too negative	Caregivers
	The DT would be paired with face-to-face feedback	Receiving personal attention from health care professional makes you feel acknowledged	Caregivers

PCI Patient Concerns Inventory, *DT* Distress Thermometer

face feedback would help them in the interpretation of the advice provided and would allow them to ask questions.

Informal caregivers felt the DT included relevant topics and could help initiate a conversation about supportive care (Table 4). They expected the DT to be easy to complete. Face-to-face feedback was mentioned to be highly appreciated and could make them feel acknowledged. However, restrictions of the DT mentioned include that some caregivers found it too superficial and that the answer options do not do justice to subtle fluctuations in symptoms or concerns. They indicated that questions were difficult to interpret and that it would be difficult to monitor supportive care needs over time.

Computerized application: Oncoquest

Patients indicated that Oncoquest provides a more detailed description of needs compared to the PCI (Table 5). The option to receive face-to-face feedback was mentioned to be an advantage, although some patients indicated that they would also like to receive feedback in written form:

'*Preferably on paper, but I also say that because of my current… short-term memory.*' (Male grade III oligodendroglioma patient (65 years), progressive disease suspected)

Participants mentioned certain restrictions of Oncoquest, e.g., difficulty of answering multiple-choice questions. Oncoquest's availability at the outpatient clinic only (and not in the home-situation) could limit the frequency of monitoring, and the timing could be poor as, during a hospital visit, they might receive bad news. Other downsides mentioned were investment of time, money (parking costs), increased fatigue as a result of completing a series of questions, and privacy concerns, as it may be unclear to patients what happens with their data.

Caregivers mentioned more advantages of Oncoquest (Table 5). They indicated to expect that completing Oncoquest would not take long, and the answers go straight to the physician. The availability of the instrument at the outpatient clinic was seen as an advantage by some, as at this time, their focus is already on the disease. Others indicated that completing the questions from home would be better:

Table 5 Perceived use of a computerized monitoring instrument

	Key issues	Themes	
Perceived use of a computerized application: Oncoquest	Oncoquest is an expected improvement in health care	Oncoquest can help guide the conversation with the physician	Patients and caregivers
		Improves relationship with the physician	Caregivers
		Provides a more detailed description of symptoms and concerns than PCI	Patients
		Completing Oncoquest does not take long, answers go straight to doctor	Caregivers
	Oncoquest seems to have certain restrictions	Questions are difficult to answer, too many options	Patients
		Answer options (multiple choice) appeal more than with DT, but are still too superficial	Caregivers
		Takes time to answer the questions in a meaningful way	Caregivers
		Investment of time leads to fatigue, and loss of overview	Patients
		With a touch screen application, there are privacy concerns	Patients
		The touch screen application is seen as a 'cool gadget', but not beneficial for self	Caregivers
		Use of a computer could be difficult for certain individuals (elderly; people with low literacy)	Patients
	Perceived (dis)advantages of the availability at outpatient clinic	Availability in clinic is convenient, as you are already focused on the disease	Caregivers
		Elderly people or people who are not used to working with the computer, can ask for help in the outpatient clinic	Caregivers
		Timing of completing Oncoquest is bad in combination with getting test results	Patients and caregivers
		Availability in clinic is not convenient, hospital visit is already stressful	Caregivers
		Availability in clinic is not convenient, would be more practical from home	Caregivers
		Availability in clinic is not convenient, the patient could be looking over your shoulder	Caregivers
		Frequency of monitoring is restricted by availability at outpatient clinic	Patients
		Would cost time in outpatient clinic	Patients
		Would cost money (parking costs)	Patients
	Oncoquest would be paired with face-to-face feedback	Personal contact is an advantage	Patients
		Allows you to ask questions	Patients
		Social cues help in interpretation of feedback/advice	Patients
		Receiving feedback quickly is important	Caregivers
		Prefer to receive advice/feedback in written form as well	Patients
		Receiving personal attention from health care professional makes caregiver feel acknowledged	Caregivers
		Face-to-face feedback would not be a prerequisite (e.g., if filed in medical record, or if there is an option to contact a professional)	Patients
		The combination of eHealth and face-to-face feedback is good	Caregivers

PCI Patient Concerns Inventory, *DT* Distress Thermometer

'*Well, my first thought is not… not like, then and there. Since, as I have already said, the moments that we go to the hospital are always a little tense... and I… I am more focused on my husband.*' (Female caregiver (52 years) of a glioblastoma patient with disease progression)

Face-to-face feedback was again highly appreciated for similar reasons as mentioned by patients.

eHealth application: Oncokompas

Patients expected Oncokompas to empower the user, increasing knowledge of symptoms or concerns while allowing you to take control of your own needs (Table 6). Caregivers expected Oncokompas to reduce the barrier for exploring supportive care options for themselves. Other advantages mentioned included the instant, tailored advice which could facilitate finding supportive care options,

Table 6 Perceived use of an eHealth monitoring instrument

	Key issues	Themes	
Perceived use of an eHealth application: Oncokompas	Oncokompas is an expected improvement in the existing health care	Oncokompas would increase own knowledge of what to do with symptoms	Patients
		Oncokompas allows you to take control of your own symptoms and concerns	Patients
		Oncokompas would facilitate the search for supportive care	Patients and caregivers
		Oncokompas could provide tailored information on the diagnosis and what to expect	Caregivers
		Feedback and advice is instantly provided, much faster than face-to-face feedback/advice	Patients and caregivers
		Information is of good quality, comes from the hospital itself	Patients and caregivers
		Oncokompas has a clear design	Caregivers
		Oncokompas would be appreciated as *addition* to existing health care	Patients
	Using a computer system from home would have advantages	It is convenient, allows you to monitor at a time of your choosing, at home	Patients and caregivers
		Easier to adjust the frequency of monitoring	Patients
		Low threshold for use	Caregivers
		Allows you time to think about the phrasing of problems (in case of language problems)	Patients
		Allows you to read the feedback/advice again later	Patients
		Preferred over face-to-face, because during hospital visits the focus is on the patient	Caregivers
	Oncokompas would have certain restrictions in its usefulness	Lacks personal contact; digital feedback and advice feels impersonal	Patients and caregivers
		Can be difficult to take action following the feedback and advice independently	Patients
		Low expected use of Oncokompas, because it is difficult to monitor your own symptoms independently (discipline; severe fatigue)	Patients
		Answer options in Oncokompas seem difficult to compare with own situation	Patients
		It would take a lot of time to complete the online questionnaires	Patients and caregivers
		Low expected use of Oncokompas, because it takes a lot of time	Caregivers
		Privacy has to be assured	Patients
		There should be room for remarks on the website	Caregivers
		A combination of face-to-face and digital is preferred	Patients and caregivers
	Oncokompas would not be perceived as useful for self	Not useful for self now, but possibly useful at a later stage	Patients

and the trustworthiness of the information provided as it comes from the hospital. Patients and caregivers felt using Oncokompas from their home computer would be convenient, as it would allow them to monitor at a time and frequency of their choosing:

'*I believe yes, that… that would, of course, be very convenient if you could just arrange it through the computer.* […]*. Then you don't have to be there at half past ten.* […] *So yes, that might be even more appealing. Also because you then could do this more often. Without constantly going to and fro.*' (Male grade II oligodendroglioma patient (51 years), stable disease)

Furthermore, patients appreciated being able to take their time to complete questions, as this can take longer in people with language problems. Caregivers especially appreciated the flexible timing, as during hospital visits the focus is usually on the patient and not on them. Patients did stress that Oncokompas should not replace existing health care but rather exist as a supplement.

Patients and caregivers also identified restrictions. With Oncokompas, there is no face-to-face contact with health care professionals, which was experienced as impersonal. Patients furthermore indicated that their privacy should be assured while using the website. They also identified practical difficulties such as undertaking action independently following the

advice. A number of patients indicated they are less able to use computers than before, due to loss of strength in their hands, memory problems causing issues with passwords, and fatigue, language, or visual problems:

'*Yes, I am not someone who… who really likes to, as it were, crawl behind my computer and then... that… that actually takes quite a lot of effort nowadays.*' (Male grade IV glioblastoma patient (51 years), currently under treatment)

Both patients and caregivers expected completing the questionnaires online would take a lot of time. Caregivers explicitly mentioned that this would likely result in a low expected use of Oncokompas.

Discussion

This study is the first to evaluate neuro-oncology patients' and caregivers' preferences and attitudes regarding a system of monitoring symptoms, distress, and QOL, in order to obtain insight into an efficient way to report symptoms and concerns and to provide them with appropriate supportive care options when needed. First, we evaluated patients' and caregivers' issues with the current provision of supportive care. Although in both groups many similar issues were reported, especially caregivers report problems that remain untreated. Caregivers often find it difficult to ask for care for themselves, which is in line with previous studies [4]. This stresses the need to make supportive care options more readily available for caregivers specifically.

To achieve this, a system based on monitoring symptoms, distress, and QOL might be useful. Most glioma patients and caregivers viewed this type of system favorably. Members of our research group have previously investigated the needs of breast cancer and head and neck cancer patients regarding online monitoring [21]. Although many of the more general (dis)advantages generated by those patients are similar, such as enabling one to gain insight into changing symptoms, glioma patients generated additional disease-specific or practical disadvantages. They appear more concerned with the ultimately progressive course of the disease, and cognitive problems that may cause them to need help using this system. Similar difficulties have been found in other eHealth initiatives for glioma patients [31]. Because of these specific difficulties, implementing a monitoring system may be less suitable in this patient population. Indeed, glioma patients' reactions to both computerized monitoring instruments were mixed. A solution could be to have the patient and caregiver complete the instruments' questions together—although this would place additional burden on caregivers and may raise privacy issues.

Caregivers generally viewed a monitoring system more favorably than patients. They indicated that it may facilitate the initiation of supportive care when needed, which could be a consequence of their larger proportion of unrecognized and untreated issues. Many patients and caregivers did stress that feedback of the results and referral to supportive care should be an integral part of using a monitoring system in clinical practice, a notion that is supported by Mitchell [10].

When presented with an eHealth application that provides instant tailored feedback and options for referral (Oncokompas), many patients expected difficulty in taking action independently upon receiving automated feedback. Caregivers expected to benefit more from Oncokompas, as this online system can decrease the barrier to contact health care professionals for their own needs. A requirement mentioned by both patients and caregivers was that completing online questions should not take too long, because of a decreased expectancy of use with an increased investment of time. Moreover, both patients and caregivers appreciated additional options for face-to-face feedback. This could be as subtle as adding the option to contact a health care professional in Oncokompas.

This study has some limitations. The study sample is relatively small and comprises a mixed group of low- and high-grade glioma patients and caregivers, possibly limiting the generalizability of our findings. Because we employed a purposive sampling method to ensure that we included participants with a wide range of neuro-oncological diagnoses in different disease stages, any differences between low- and high-grade populations might not show. In addition, there are relatively few patient participants who had recently been diagnosed, and the distribution in male/female participants is a slight exaggeration of the usual distribution seen in glioma patient and caregiver populations (i.e., more male patients and more female caregivers). Some patients displayed evident issues with memory retrieval, difficulty finding words, and diminished mental flexibility during the interviews. The examples of monitoring instruments were presented on paper (e.g., screenshots), which may have made it difficult for some participants to fully understand the functionalities of the instruments. In further development of eHealth monitoring instruments specifically, a usability test with the intended end users is recommended [32].

To summarize, while the preferred method for monitoring remains highly personal, with some preferring online self-management options and others preferring only face-to-face care, the desired way to proceed is likely to combine online and face-to-face care: "blended care." Developing a computerized form of monitoring with the possibility to contact a health care professional if needed seems to be advised. This, in itself, can raise questions about feasibility and cost-effectiveness which should be addressed in further studies.

Regardless, three general conclusions can be drawn from this study. First, a system of monitoring symptoms, psychological distress, and QOL appears to be viewed more favorably by caregivers than by glioma patients. Second, glioma patients experience disease-specific symptoms that may hinder them in using a monitoring instrument independently. And finally, both patients and caregivers appear to prefer a computerized form of monitoring as long as there is the option to contact a health care professional if needed.

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