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The feasibility of a brain tumour website

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A B S T R A C T

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Purpose: Patients with a high-grade glioma (HGG) and their caregivers have imminent and changing informational and supportive care needs. The purpose of this study was to investigate the feasibility and safety of a Danish brain tumour website (BTW) in patients with HGG and their caregivers. We hypothesized that the BTW would be feasible, safe, helpful and convenient for individuals to obtain support and information.

Methods: This is an exploratory, prospective six-month feasibility study. Two separate samples were collected: 1) a nationwide sample consisting of BTW visitors over a six-month period and 2) a sample of patients with HGG (n = 9) and their caregivers (n = 8) interviewed three months after being introduced to the BTW.

Results: The BTW was accessed from 131 different Danish towns and cities, and from ten different countries. The website had 637 unique users. The interviews identified one overarching theme 'challenges and barriers'. Being newly diagnosed, patients described a chaotic and overwhelming life situation and had difficulties in identifying with their new and changed role. When using the BTW, some patients and caregivers experienced technological challenges, while the former also experienced cognitive difficulties. Caregivers greatly appreciated that the BTW was available and that easily accessible specialists could answer their questions.

Conclusion: The BTW attracted nationwide interest and activity, but the burden of being newly diagnosed with HGG combined with a low level of internet skills and cognitive deficits were barriers to participation.

Trial registration number: ISRCTN22038059.

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Introduction

High-grade glioma¹ (HGG) is the most devastating and life-threatening disease among primary brain cancers (Omuro and DeAngelis 2013), and even though multimodality treatments such as neurosurgical resection or biopsy, radiotherapy and chemotherapy (Hottinger et al., 2012) have improved HGG prognosis

(Preusser et al., 2011), long-term survival is poor (Mrugala et al., 2012; Hottinger et al., 2009; Lovely et al., 2013). This underscores the need for supporting health-related quality of life (HRQOL) in patients with HGG and their caregivers (Boele et al., 2012). Despite the increasing evidence that patients with HGG have imminent and changing rehabilitative and supportive care needs (D'Angelo et al., 2008; Molassiotis et al., 2010; Sizoo et al., 2013; Walbert and Khan, 2014; Rooney et al., 2013; Halkett et al., 2010), only few rehabilitative and supportive care intervention studies have targeted this specific population and its caregivers (Piil et al., 2014b).

When given optimally information about the prognosis (prognostic information) can be a catalyst in promoting the individual's adjustment to the diagnosis (Innes and Payne 2009). A gradual increase in severity of the disease and treatment-related symptoms

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¹ Abbreviations: HGG: High-grade gliomas; HRQOL: Health-related quality of life; IBI: Internet-based intervention; BTW: Brain tumour website; KPS: Karnofsky Performance Status.

can reduce activity levels (Walbert and Khan 2014, Koekkoek et al., 2014; Moore et al., 2012), forcing the patient to make necessary adjustments in everyday life (Piil et al., 2014a). Symptoms of e.g. dementia have a negative impact on everyday life, as patients lose the capacity to function independently (Rooney et al., 2011). For example, patients become dependent on caregivers for transportation when they lose their driver's license due to seizures. Limitations like this affect the patients' likelihood of and ability to participate in general rehabilitation programmes (McCartney et al., 2011), which may result in health disadvantages for the HGG population. An Internet-based intervention (IBI) may be an alternative for patients too challenged to participate in traditional face-to-face programmes (Forducey et al., 2012). Family members also have a need for support to alleviate the stress related to the caregiver role (Boele et al., 2012; Petruzzini et al., 2013; Cavers et al., 2012; Cornwell et al., 2012; Hricik et al., 2011; Madsen and Poulsen, 2011). Caregivers experience limitations in daily life, as they often need to be readily available to assist the patient (Madsen and Poulsen, 2011). One of the advantages of IBI is that visitors can choose the information, time and place suitable for them. In addition to providing easy access to disease-specific information (Osei et al., 2013; Stanton et al., 2013; Sublett, 2013; Cugelman et al., 2011), IBI is a convenient way to interact with specialists and/or peers (Frensham et al., 2014; Griffiths et al., 2006) for both patients and caregivers (Nicholas et al., 2012; Boots et al., 2014). When IBI enables cancer survivors to share experiences, it can bolster a sense of self-efficacy and control (Stanton et al., 2013; Hoybye et al., 2005). Moreover, IBI allows participation from home (Kukafka et al., 2002), which may be especially beneficial for those at risk of becoming socially isolated (Cavers et al., 2012). There is, however, inconclusive evidence regarding the effects of IBI (Gorlick et al., 2014; Schrader et al., 2014), as this type of intervention is prone to high attrition or non-use (Gorlick et al., 2014; Chiu and Eysenbach 2010). Approximately 90% of all households in Denmark had Internet access in 2013 (Statistics, 2014) and data shows that patients with HGG and their caregivers search for information about their disease on the Internet (Piil et al., 2014a). The Danish population has a high level of familiarity with accessing online services as all official communication with the authorities is digital. An IBI has the potential to be implemented as an individual, convenient way of accessing information and receiving support (Griffiths et al., 2006). The aim of this study is to investigate the feasibility and safety of a Danish brain tumour website (BTW) (hjernekraeftnetvaerk.dk) in patients with HGG and their caregivers. Safety will be studied based on whether BTW users experience unnecessary emotional distress.

Materials and methods

Study design, participants and recruitment

This mixed methods study investigates the feasibility of a newly developed nationwide BTW (Polit et al., 2012). This paper is inspired by the CONSORT EHEALTH checklist, V1.6.1 (Eysenbach and CONSORT-EHEALTH Group 2011, Eysenbach, 2013; Consort, 2011). Two separate samples were collected: 1) a nationwide sample of BTW visitors over a six-month period and 2) a sample of patients with HGG and their caregivers interviewed three months after being introduced to the BTW as its first users. Data were collected in parallel and analysed separately (Creswell et al., 2011).

1) Nationwide study sample

The nationwide BTW was available to all patients with HGG and their caregivers in Denmark. To recruit participants nationwide in Denmark, an information packet containing a letter for the heads of

hospital departments, pamphlets for patients/caregivers and posters of the BTW were distributed to 24 hospital departments in Denmark, including four neurosurgical, four oncological and 16 neurological departments, as well as the national brain tumour organisation. They were encouraged to place the pamphlets in relevant hospital waiting areas. No follow-up procedure was carried out to determine whether or not the material had been distributed to patients and caregivers. Because this was a feasibility trial, public advertising was not used.

2) Interview study sample

Patients and their caregivers were recruited using a consecutive sampling strategy from March to May 2014 at the Department of Neurosurgery, Rigshospitalet, University of Copenhagen, and informed about the study on their first postoperative day. The interview study sample comprised all eligible patients and caregivers during a three-month period who agreed to learning about the BTW and participating in interview after three months. Written informed consent was obtained before discharge from the hospital. Participants included were ≥ 18 years of age, newly diagnosed with HGG (WHO classification grade III/IV) and their caregivers, able to speak and understand Danish and had access to the Internet. There were no restrictions regarding computer skills and/or experience. Since this study required active, independent activity, a Karnofsky Performance Scale (KPS) ≥ 60 at baseline was considered a necessary prerequisite for adequate participation purposes. Participants were given face-to-face verbal and written instructions on the content and interactive function of the BTW, including the opportunity to ask specialists questions, to interact with peers and to access relevant HGG-specific information. The guidelines for acceptable conduct on the BTW were outlined and anonymity assured. Study participants were given a pamphlet providing a link to the BTW. They were taught how to access the BTW and offered assistance with the first login. Once logged in new users received an automatic BTW welcome e-mail. Registered with the Danish Data Protection Agency (02865-30-1219) and the Research Ethics Committee in the Capital Region of Denmark (H-2-2013-135) this study was carried out in accordance with the Declaration of Helsinki (WHO, 2000).

Intervention: the BTW

The purpose of the BTW (hjernekraeftnetvaerk.dk) was to meet the need for acquiring prognostic information to be given at a pace and amount that respects the individual strategy of patients with HGG and their caregivers. Improved access to brain cancer specialists throughout the HGG trajectory has the potential to fulfil their information needs.

Design

Embedded in an existing health care software platform (sundhed.dk) with a fixed design, the BTW was designed and developed based on the professional clinical and scientific knowledge of a multidisciplinary team, as well as the experiences of patients with HGG and their caregivers (Piil et al., 2014a; Diaz et al., 2009).

Specialists

The BTW was facilitated by a moderator (KP), specialists from departments of neurosurgery (nurse, physician and neuropsychologist) and oncology (nurse and two physicians), a specialist in neurology (physician), a specialist in rehabilitation (physiotherapist) and a health care social worker from a palliative department. The diverse expertise of this nine-member multidisciplinary team

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