

BMJ Open Coping in the role as next of kin of a person with a brain tumour: a qualitative metasynthesis

Anette Windsland Lien,¹ Gudrun Rohde  ^{1,2,3}

To cite: Lien AW, Rohde G. Coping in the role as next of kin of a person with a brain tumour: a qualitative metasynthesis. *BMJ Open* 2022;**12**:e052872. doi:10.1136/bmjopen-2021-052872

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-052872>).

Received 29 April 2021
Accepted 20 July 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Faculty of Health and Sport Sciences, University of Agder, Kristiansand, Norway

²Marie Curie Palliative Research Department, University College London, London, UK

³Department of Clinical Research, Sorlandet Hospital, Kristiansand, Norway

Correspondence to

Professor Gudrun Rohde;
gudrun.e.rohde@uia.no

ABSTRACT

Objective Being the next of kin of a person with a brain tumour is a stressful experience. For many, being a next of kin involves fear, insecurity and overwhelming responsibility. The purpose of this study was to identify and synthesise qualitative original studies that explore coping in the role as next of kin of a person with a brain tumour.

Methods A qualitative metasynthesis guided by Sandelowski and Barroso's guidelines was used. The databases Medline, CHINAL and PsycINFO were searched for studies from January 2000 to 18 January 2022. Inclusion criteria were qualitative original studies that aimed to explore coping experience by the next of kin of a person with brain tumour. The next of kin had to be 18 years of age or older.

Results Of a total of 1476 screened records data from 20 studies, including 342 participants (207 females, 81 males and 54 unclassified) were analysed into metasummaries and a metasynthesis. The metasynthesis revealed that the next of kin coping experiences were characterised by two main themes: (1) coping factors within the next of kin and as a support system, such as their personal characteristics, perceiving the role as meaningful, having a support system, and hope and religion; (2) coping strategies—control and proactivity, including regaining control, being proactive and acceptance.

Conclusion Next of kin of patients with brain tumours used coping factors and coping strategies gathered within themselves and in their surroundings to handle the situation and their role. It is important that healthcare professionals suggest and facilitate these coping factors and strategies because this may reduce stress and make the role of next of kin more manageable.

INTRODUCTION

In 2020, 308 102 people with cancer in the central nervous system were registered worldwide.¹ The diagnosis of brain tumour is very confronting, with 56% of patients experiencing one or more symptoms. Hemiparesis and cognitive challenges are most frequently reported but also headaches, nausea and vomiting, vision challenges, epileptic seizures and personality changes are considered common symptoms.^{2–5} Changes in behaviour and personality are considered particularly challenging, both for the patient and for the next of kin, as these may include apathy,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The qualitative approach makes an important contribution to the research field by providing a deeper understanding of coping factors and strategies used by the next of kin of a person with a brain tumour.
- ⇒ Most of the included studies in this metasynthesis were high-quality studies.
- ⇒ Our sample is highly multicultural with different geographical origins represented and includes different welfare and healthcare systems, and different cultures and religions.
- ⇒ The majority of the sample were women, and a more heterogeneous sample might have revealed more nuanced findings regarding the role of next of kin.

loss of initiative and empathy, indifference, selfishness, physical and mental aggression, impaired emotional control and social skills, and tendencies toward childish behaviour, among others.^{3 5 6} Studies show that the disease can be more challenging and stressful for the next of kin than for the patients. The next of kin have high rates of depression, anxiety, various physical pain, adjustment difficulties, loneliness and high work absence, as well as a reduced quality of life.^{7–11} Studies also show that both patients and next of kin miss additional follow-up, support and information from healthcare providers, family, friends and the community in their struggle to cope with everyday life.^{12 13}

All these strains can lead to next of kin experiencing stress and lack of coping. Lazarus and Folkman define coping as a cognitive and behavioural endeavour under constant change, dealing with external and/or internal demands that a cognitive assessment indicates as stressful or exceeding personal resources. When dealing with these demands, the next of kin has to review available coping strategies to be able to make the situation more manageable, meaning active actions the next of kin use to cope in the situation.^{9 13 14}

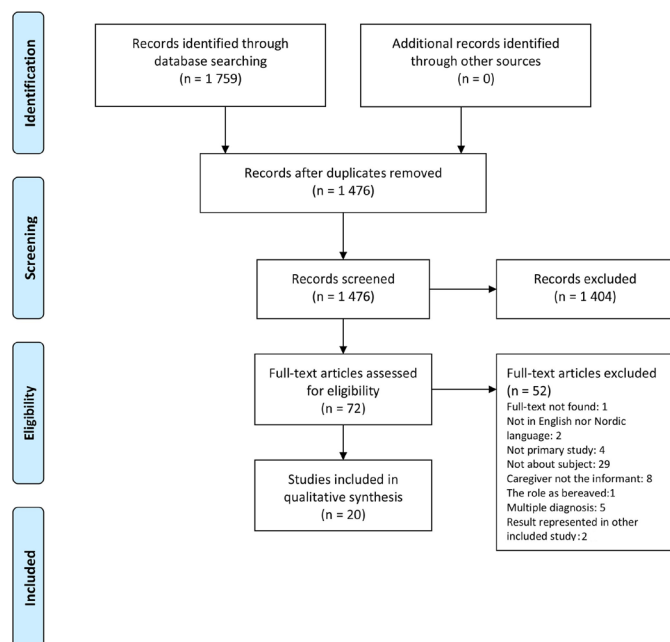


Figure 1 Flow chart of the inclusion process. Source: Moher *et al.*⁵¹

There are some original qualitative studies that have explored coping in the role as next of kin of a person with a brain tumour. To our knowledge, this research has not been synthesised. Such information is of great importance, especially for healthcare providers working with this group of caregivers. With improved understanding, they may be better equipped to facilitate a more manageable everyday life among the next of kin. Previous quantitative research directed at these aspects exists,^{8–11 15} but we were interested in studies that were personal and focused on the lived experience of next of kin, hence the choice of qualitative studies. Therefore, the purpose of this metasynthesis was to identify and synthesise evidence from original qualitative studies regarding the experience of coping in the role as next of kin of a person with a brain tumour. The findings are discussed in the context of Lazarus and Folkman's stress theory¹⁴ and their approach to coping with stress in order to interpret our findings in a theoretical context.

METHODS

Design

The study is a metasynthesis within the interpretative paradigm. It was inspired by a phenomenological–hermeneutic design because the aim was to identify and synthesise qualitative original studies that explored next of kin attitudes and experiences.¹⁶ The metasynthesis process consisted of five steps: (1) formulating the purpose and rationale of the study; (2) searching for and retrieving relevant qualitative research studies; (3) critically appraising the included studies; (4) classifying the findings, and finally; (5) synthesising the findings.

Search strategy

In collaboration with an experienced librarian, we conducted a systematic search in the PsycINFO, OVID, CHINAL and Medline databases via the EBSCO host from January 2000 until 18 January 2022. For search strategy see online supplemental material 1.

The inclusion criteria were qualitative original studies published in English, Norwegian, Swedish or Danish that aimed to explore coping experience by the next of kin of a person with a brain tumour, regardless of tumour type and stage which enhanced their role as next of kin. The next of kin had to be 18 years of age or older. The exclusion criteria were studies that did not clearly identify coping, coping that included the participants' experiences in the role of bereaved and not next of kin, and studies including diagnoses other than a brain tumour.

Search outcome

The search strategy generated 1476 unique citations. Titles and abstracts were screened by the authors using Rayyan, a systematic review management software.¹⁷ A final consensus regarding the eligible articles was obtained through a group discussion between the authors. Seventy-two papers were read in full and evaluated against the inclusion criteria by both authors; twenty of these were included in the metasynthesis. Figure 1 shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart with a full overview of the screening process. The search output is presented in the PRISMA flowchart. The authors read the full text of the eligible articles and independently extracted data from the included studies; this process is also illustrated in figure 1. Consensus for data extraction was obtained as part of a group discussion between the authors. Online supplemental material 2 lists the title, author(s), study country, year of publication, aim, analysis and study participants of all included studies. Most studies were from Europe: Sweden (3), Great Britain (3), Denmark (1), Belgium (1) and Turkey (1); seven were from Canada (3) and the USA (4), two from Australia and two from Taiwan. The tumour type and stage varied. For details, see online supplemental material 2.

Quality appraisal

The quality of the 20 papers was evaluated using the Critical Appraisal Skills Programme (CASP) for qualitative studies. The first evaluation was conducted blinded and independently by AWL and GR whose CASP evaluations were then compared. Using the criteria in CASP for independent assessment, the authors mutually agreed on a final quality evaluation. For details, see table 1.

The included studies that were appraised according to CASP are listed in table 2. All studies had clearly stated the study aim and the qualitative methodologies were considered appropriate. Furthermore, several of the studies had been published in highly ranked journals. The most poorly addressed issue (criteria number 6 in

Table 1 Critical appraisal of the included studies

Author	1. Was there a clear statement of the aims?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate?	4. Was the recruitment strategy appropriate?	5. Were the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	Impact factor
Arber <i>et al</i> ²	Y	Y	C	C	Y	N	Y	C	Y	V	Not found
Arber <i>et al</i> ²⁴	Y	Y	Y	Y	Y	N	Y	Y	Y	V	1.697
Coolbrandt <i>et al</i> ²³	Y	Y	Y	Y	Y	C	Y	Y	Y	V	2.022
Cuttillo <i>et al</i> ³⁰	Y	Y	Y	Y	Y	Y	N	Y	C	V	2.170
Edvardsson and Ahlström ²⁵	Y	Y	Y	Y	Y	N	N	Y	Y	V	3.470
Janda <i>et al</i> ²²	Y	Y	Y	Y	Y	N	Y	Y	Y	V	2.754
Huang <i>et al</i> ²⁷	Y	Y	Y	Y	Y	N	Y	Y	Y	V	2.592
Lipsman <i>et al</i> ³⁷	Y	Y	Y	Y	Y	N	Y	Y	Y	V	2.922
Lou <i>et al</i> ³⁴	C	Y	Y	C	Y	N	N	C	Y	V	2.022
Ownsworth <i>et al</i> ³⁵	Y	Y	Y	Y	Y	C	C	Y	Y	V	4.137
Piil <i>et al</i> ²¹	Y	Y	Y	Y	Y	C	Y	Y	Y	V	1.096
Russell <i>et al</i> ¹⁰	Y	Y	Y	Y	Y	N	Y	Y	Y	V	1.197
Schmer <i>et al</i> ³¹	Y	Y	N	Y	N	N	Y	N	Y	V	1.096
Schubart <i>et al</i> ²⁰	C	Y	Y	Y	Y	N	N	Y	Y	V	3.470
Hrick <i>et al</i> ³⁶	Y	Y	Y	Y	C	Y	N	Y	N	V	1.438
Shortman <i>et al</i> ²⁹	Y	Y	Y	C	C	N	Y	N	Y	V	8161
Strang and Strang ²⁸	C	C	Y	N	Y	N	Y	Y	Y	V	4.956
Tastan <i>et al</i> ³²	Y	Y	N	Y	Y	N	Y	N	Y	V	1.096
Wildeheim <i>et al</i> ²⁶	Y	Y	Y	Y	Y	N	C	Y	Y	V	2.022
Zelcer <i>et al</i> ³³	Y	Y	Y	Y	Y	N	C	Y	Y	V	5.731

Criterion: Y=yes; N=no; C=can't tell; V=valuable; NV=not valuable.

Table 2 Thematic overview showing the studies' contribution to the different themes and subthemes

Author	Coping factors within the next of kin and as a support system			Coping strategies—control and proactivity			
	Personal characteristics	Perceiving the role as meaningful	Having a support system	Hope and religion	Regain control	Proactivity	Acceptance
Arber <i>et al</i> ²			V	V			
Arber <i>et al</i> ²⁴			V				
Coolbrandt <i>et al</i> ²³		V	V	V	V		
Cuttilo <i>et al</i> ³⁰			V	V	V		V
Edvardson and Ahlström ²⁵	V	V	V	V	V	V	
Janda <i>et al</i> ²²			V	V	V		
Huang <i>et al</i> ²⁷			V	V	V		
Lipsman <i>et al</i> ³⁷	V			V	V		
Lou <i>et al</i> ³⁴			V	V	V	V	V
Ownsworth <i>et al</i> ³⁵		V	V	V	V		
Pill <i>et al</i> ²¹		V	V	V	V	V	
Russell <i>et al</i> ¹⁰			V	V	V	V	V
Schmer <i>et al</i> ³¹		V	V				V
Schubart <i>et al</i> ²⁰		V	V	V	V		
Hricik <i>et al</i> ³⁶			V		V		V
Shortman <i>et al</i> ³⁶			V		V		
Strang and Strang ²⁸	V	V	V				V
Tastan <i>et al</i> ³²			V		V		
Wideheim <i>et al</i> ²⁶			V	V		V	V
Zelcer <i>et al</i> ³³			V	V			V
V=valuable.							

the CASP list) was the influence of the researcher on the research and vice versa.

Data abstraction and analyses

As suggested by Sandelowski and Barroso,¹⁶ two approaches to qualitative synthesis were used. The first of these involved qualitative metasummaries of qualitative findings from the original studies. This method is defined as qualitative, but the findings are presented quantitatively. The second involved a metasynthesis that developed new interpretations of the target findings from the original studies.¹⁶ The narrative analysis was inspired by Lindseth and Norberg's phenomenological-hermeneutic methods.¹⁸ Three steps were followed. First, the empirical materials were read several times. Second, after extraction, the target findings were imported into NVivo V.11 data management software for further analysis.¹⁹ The text was read line-by-line to identify meaning units, subthemes and themes. Third, the researchers aimed to achieve a comprehensive understanding of the empirical materials, meaning units and themes, and to relate these to the aim and research question of the metasynthesis.¹⁸ The analytic themes were identified by AWL and discussed with GR. The process of deriving the themes was inductive. The contribution of targeted findings from each of the included papers is outlined, and quotations are used to illustrate and support the findings, something which increases the trustworthiness of the study. To validate the findings, both authors participated in discussions of the empirical analysis and in writing up the findings.

Qualitative metasynthesis enables researchers to identify specific research questions, search for, appraise, summarise and combine qualitative evidence to address the research question. Metasynthesis provides novel interpretations of the target findings from the original studies.¹⁶ In our methasynthesis we identified two main themes: (1) coping factors within the next of kin themselves and as a support system and (2) coping strategies—control and proactivity, each comprising 3–4 subthemes. For a list of the studies that generated findings regarding the main themes and subthemes, see [table 2](#). When analysing and organising the results into themes and subthemes we chose to be in line with the content and meaning of coping in the original included studies, although some of the results could have been considered to also contributed and organised differently. The results will be elaborated below.

Patient and public involvement

No patients or patient organisations were involved in the planning of the study, the analyses or the writing of the metasynthesis. These were based on published original studies some of which included patient involvement.

RESULTS

The results are presented as metasummaries supported by tables and figures, and as a metasynthesis containing

two main themes. The themes are supported by illustrative quotes from the included original studies.

Metasummaries

The 20 studies that were included comprised 342 participants (207 women, 81 men and 54 not classified). The focus was on the following themes: the needs of the next of kin^{2 20–24}; their overall experiences as next of kin^{10 25–27}; coping and coping strategies^{28–30}; postoperative caregiving^{31 32}; being a next of kin in the palliative phase^{33 34}; experienced support factors³⁵; how the caregiving changed over time³⁶ and factors influencing treatment choice in the palliative phase.³⁷ Three of the studies were undertaken 6 months after diagnosis,^{27 30 31 36} and three in the patients' palliative phase or postmortem.^{33 34 37} In six studies the patients were children of the informants.^{10 29 30 33 34}

Metasynthesis

Main theme 1: coping factors within the next of kin and as a support system

Nineteen of the included studies provided data regarding the first main theme; *coping factors within the next of kin and as external support* (see [table 2](#)). This main theme comprised the following four subthemes: *personal characteristics, perceiving the role as meaningful, having a support system, and hope and religion*.

Personal characteristics such as a strong and positive personality were important coping factors for next of kin in new challenging situations.^{25 29 37} Being able to show empathy for the patient and the health professionals was important, if not the situation could easily engender feelings such as discouragement and reproach.²⁵ A positive mood and a sense of humour were also emphasised for the same reasons.²⁹

To perceive the role as next of kin as *meaningful* was important, as it made the next of kin feel needed and productive in the situation.^{23 25 28 31} Engagement and commitment in the care of their relatives were highlighted as important by many next of kin, especially when the patients appreciated the help.²³ The engagement was even stronger when the emotional bond between patient and next of kin was strong.^{20 21 29 35}

But caring for him is something I will do—it is not a burden.³¹ (p81)

However, other studies revealed less engagement and commitment, and underlined anger and reluctance with the new role as the heavy responsibility and sacrifice impacted the next of kin's own needs and wishes.^{21 22 25 31 33}

Having a support system made the role of next of kin easier to cope with. The support was given by family, friends, neighbours, colleagues and workplaces, health personnel, schools, the religious community, people in the local community and even strangers.^{2 10 20–35} The support from healthcare professionals was especially important. This support included emotional support and assistance during patient care and treatment.^{2 10 20–27 29–35}

The importance of assistance such as medical supervision and nursing care was emphasised,^{10 22 29} with next of kin noting that this made it possible to feel like a partner again,²³ while at the same time allowing for anticipated time alone.²⁴ A familiar healthcare professional was crucial in making this possible, because it implied that the patient would receive the best care as they were known to the healthcare professional, and also because the assistance was considered to be less intrusive.^{23 24} To experience the assistance with care as a coping factor, it was crucial that the care was compassionate and of the best quality. These qualities emphasised the healthcare professionals' genuine care and gave the patients and the next of kin hope and a desire to fight the disease.^{10 21 23 26 27 29}

She (neurosurgeon) had to give us some bad news some of the time ... and you couldn't ask for a better manner in her delivery of that bad news, or her support in what we were going through.³⁵ (p8)

When next of kin experienced that their loved ones received a low quality of care or suffered malpractice it caused mistrust of the healthcare system and weakened the experience of healthcare professionals as a support factor.^{10 20 23 24} Emotional support from healthcare professionals implied an acknowledgement that the disease affected not only the patients, but also their next of kin. It also implied that the healthcare professionals recognised and met the wishes of the next of kin for active participation in monitoring the patient's disease course.^{23 25 26 34} Next of kin who did not have such involvement felt ignored, useless and helpless.^{25 29} Supportive conversations with healthcare professionals were highly appreciated by many next of kin. However, this required the healthcare professional's understanding and empathy for the situation of the patient as well as of their next of kin, and preferably that they should be always available.^{21 23 26 30 31 37}

Support from family and friends was invaluable in the care tasks and in coping with the role of next of kin.

Just support from family and friends, that was important to me, and just knowing that I could call on them ...²² (p1098)

Social, practical and emotional support was emphasised and included such things as economic help, childcare, transport and housekeeping.^{10 22 24 25 29–32 34 35} Some next of kin would have appreciated even more support and help from family and friends, preferably given on the family and friends' own initiative.^{20 22 24 25 35 36}

Discussions with family and friends were also important,^{21 24 25 27} and could even create a stronger bond.²⁵ Such a bond required families and friends to understand and recognise the challenges faced by the next of kin.²⁴ Support groups and conversations with other next of kin were also highlighted as important,^{2 22 24 30 34 35 37} as they might broaden the next of kin's understanding of the tumour and what they might expect in the future.²⁷ These conversations could be face-to-face or via the internet.^{2 22 24 30 34 35 37}

From time to time, I need to be able to talk to someone. Because when I lay down in the evening, then it starts to work in the inside.²³ (p411)

On the other hand, support groups were also considered demanding because it was difficult to listen to other families' stories. Furthermore, for some it was considered a waste of time to spend valuable hours with people other than their closest family members.^{10 22 31}

Hope and religion were emphasised as important coping factors. The next of kin hoped that a miraculous treatment would be developed so that their loved ones could survive the disease or just have a better quality of life.^{2 10 20–23 26 33 34}

You see a positive evolution, and everything that goes better is good for her. (...) Nobody can forbid us to have hope. And miracles happen. Whether we believe it or not, that's not the point, it is the only thing to focus on.²³ (p409)

Hope gave a reason to fight, although it weakened in the palliative phase.^{21 26 34} Faith strengthened the hope of healing during the treatment period and gave some form of peace in the final palliative phase. In most cases, hope was related to faith.^{25–27 30 34 37}

Main theme 2: coping strategies—control and proactivity

Eighteen of the included studies provided data regarding the second main theme; *coping strategies—control and proactivity* (see [table 2](#)). This main theme comprised three subthemes: *regaining control*, *being proactive* and *acceptance*.

Regaining control of the situation was a frequent coping strategy, and for most this included gathering enough information to allow an overview of what to expect, something which implied some form of security.^{10 20–23 27 30 35 37}

So it's a, it's a roller coaster of emotion but for the most part I've been, 'What do we need to do? Where do we need to be?' And then just read, read, read whatever I can find out, whatever information because I feel like whatever I know, I can ask for.³⁰ (p34)

The information that was gathered and provided should preferably be adapted to the situation and the disease trajectory, and had been given by healthcare professionals.^{20 22 23 25 27 29 37} The next of kin often hid this information from the patients to protect them and not diminish their hope.^{10 26 30 31 34}

To regain control meant not only control of the diagnosis, but also personal control and control over own reactions. In some cases, the next of kin denied their feelings. Some even denied the entire diagnosis,^{20 25 29 30} and instead focused on being strong for the patient and the entire family.^{23 25 30 32–34 36} One next of kin in Edvardsson and Ahlström's (2008) study²⁵ reported:

I've sort of stowed it all away, I suppose. It is as if I'd experienced it from the outside or seen it on TV. It's often that way with sorrowful things. (p588)

Being proactive, facilitating and encouraging the patient to fight the disease were also important coping strategies, as it felt better than accepting the morbid situation and not do anything.^{10 21 25 26 34}

People ask you how you cope. But what if you were to give up? You've got to cope—and we do have each other! (...).²⁵ (p588)

This implied adopting a healthier lifestyle, including a change in diet and exercise habits, hoping that this would improve the effects of medical treatment^{21 26} or trying alternative treatments.^{10 34} However, an increasing feeling of powerlessness was emphasised if the fight, in the form of these actions and treatments, did not meet the hope of a cure.^{21 23 26 34}

As the disease progressed and life went on there was a strive for normality, particularly in families with children. This lead most next of kin into a strategy of *acceptance*, as everyday life continued. This involved work, school for children and hobbies.^{10 10 26 26 28 28 30 30 31 33 34 34 36} Although this was an important and expected strategy, accepting disease progression or a bad diagnosis was challenging, especially when the patient was a child.³⁴

DISCUSSION

This metasynthesis aimed to explore coping in the role as next of kin of a person with a brain tumour. This generated two main themes: (1) coping factors within the next of kin and as a support system, (2) and coping strategies—control and proactivity. Valuable coping factors included personal characteristics, perceiving the role as next of kin as meaningful, having a support system, and hope and religion. Active strategies to manage the situation involved regaining control, being proactive and acceptance.^{14 38}

Being the next of kin to a person with a brain tumour is considered to be a negative stressor because of the challenging life situation and care tasks. Nevertheless, several next of kin who were included in the metasynthesis expressed a desire to be proactive, fight the disease and to gain control over the situation. This is described by Lazarus and Folkman¹⁴ as a secondary assessment of the situation, in which the next of kin decide which measures to implement. One such measure could be to gain personal control—one of the most important and stress-reducing personal strategies available.¹⁴

A possible explanation for the proactive attitude of next of kin toward the disease may be their obligation and commitment to the patient. Commitment is an expression of something of great importance and can cause some to be willing to meet threats and challenges that he or she would otherwise avoid.¹⁴ However, our findings revealed that the experience of contributing to something meaningful, not the obligation to do so, promoted coping in the situation. We consider that this is caused by the fact that obligation does not automatically make an action meaningful, but rather that it can be experienced

as a compulsion. This assumption is strengthened by the findings that the tasks as next of kin may arouse emotions such as anger and aversion towards the patient and the diagnosis, rather than coping. Several studies refer to the same ambivalent experience regarding commitment and attitudes toward being a next of kin.^{39 40}

Having a support system was the factor that most relatives emphasised as promoting coping. It was described as invaluable something which was also confirmed in other studies,^{41 42} and in Lazarus and Folkman's transactional stress theory.¹⁴ At the same time, in both this metasynthesis and in other studies, next of kin voiced a strong desire and longing for even greater external support.^{41 42} The findings of the metasynthesis also showed that the configuration and arrangement of the support, especially that given by healthcare providers are of great importance. An explanation for the next of kin's experience of unmet needs might be lack of knowledge among healthcare providers about how to assist at the right time. This may indicate that in some cases healthcare providers should pay more attention to offering support in line with the individual needs of the next of kin and the care situations.

The findings of this metasynthesis show that several next of kin considered hope to be an important coping factor, especially during the disease trajectory. Hope has also been shown to be a strengthening coping factor in several studies,^{43 44} and transactional stress theory states that faith and hope are two of the most important personal factors in the cognitive assessment of stressors.^{14 38} Furthermore, according to Lazarus and Folkman,¹⁴ the two factors are strongly related, which is consistent with the findings in our metasynthesis. For several next of kin, hope was strongly grounded in religion. This was especially prominent in the studies conducted in the palliative phase, which indicated that faith is strengthened when there is no hope of curative treatment. The same pattern has also been reported in other studies describing cancer patients' experiences of palliative care.^{45 46}

As the disease progressed, several next of kin chose an acceptance strategy toward the diagnosis and its burden. Their fight against the disease diminished to some extent, and instead the relatives tried to 'normalise' everyday life as much as possible. A similar strategy is also reported by next of kin of other cancer patients, especially in the palliative phase.^{47 48} Lazarus and Folkman describe this as a reassessment, referring to a changed cognitive assessment of the stressor based on new information from the environment and/or the person himself or herself.¹⁴

Strengths and limitations

A strength of this metasynthesis is that the primary search in the databases was conducted with the assistance of an experienced librarian in an attempt to ensure that as many as possible of the relevant studies were included.⁴⁹ Furthermore, most of the included studies were of high methodological quality (see table 2). Our sample was also highly multicultural (see table 1). This attribute strengthens the

validity of the metasynthesis since geographical origin might have affected the study sample because of different participant backgrounds related to different welfare and healthcare systems, cultures and/or religions.

A limitation of our metasynthesis is that one of the 72 articles that was intended to be read in full text could not be obtained.⁵⁰ The formation of the subthemes is also a possible limitation. Some of the subthemes, or parts of their content, could also have been categorised in the other main theme. Both main themes and subthemes overlap in several cases, and we have read similar studies^{26 30} where the findings are categorised differently than in our metasynthesis. We chose to be true to the informants' statements, the organisation and meaning of the original studies that were included, and allocated the findings based on the informants' way of speaking and description of the experience. Another possible limitation is that our sample consisted mainly of women (see online supplemental material 2). A more heterogeneous sample might have revealed more nuanced findings and different experiences of the role of the next of kin.

CONCLUSION

The findings of this metasynthesis show that next of kin experience and use a range of coping factors and strategies in their role. Their experience is marked by individual differences. It is of great importance that healthcare providers offer assistance which is individually adapted to these coping factors and strategies because this may reduce stress among the next of kin. The coping experience seems to go through phases, and further information is needed to fully understand how and when the various factors and strategies are used as the disease progresses. Longitudinal studies would therefore be of particular interest in this field.

Contributors AWL and GR designed the research project and developed the research plan. AWL was responsible for the literature search, while AWL and GR were responsible for the analysis. Both authors were involved in the screening and inclusion of the studies, reviewed the manuscript, and contributed to the revision of the paper. Both authors read and approved the final version of the paper. The guarantor of the work is GR.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Ethical approval was not required for the study.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. The data are secondary analyses from primary qualitative studies.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines,

terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Gudrun Rohde <http://orcid.org/0000-0002-8538-7237>

REFERENCES

- World Cancer Research Fund. Worldwide cancer data, 2018. Available: <https://www.wcrf.org/dietandcancer/cancer-trends/worldwide-cancer-data>
- Arber A, Faithfull S, Plaskota M, et al. A study of patients with a primary malignant brain tumour and their carers: symptoms and access to services. *Int J Palliat Nurs* 2010;16:24–30.
- Voß H, Scholz-Kreisel P, Richter C, et al. Development of screening questions for doctor-patient consultation assessing the quality of life and psychosocial burden of glioma patients: an explorative study. *Qual Life Res* 2021;30:1513–22.
- Armstrong TS, Dirven L, Arons D, et al. Glioma patient-reported outcome assessment in clinical care and research: a response assessment in neuro-oncology collaborative report. *Lancet Oncol* 2020;21:e97–103.
- Noll K, King AL, Dirven L, et al. Neurocognition and health-related quality of life among patients with brain tumors. *Hematol Oncol Clin North Am* 2022;36:269–82.
- Rv H, Holt MH, Bjerva J. Dagpost-basert multidisciplinær tilbud for pasienter Med høygradig gliom: første erfaringer ved Senter for kreftbehandling (SFK), Kristiansand. ONKONYTT, 2016.
- Applebaum AJ, Kryza-Lacombe M, Buthorn J, et al. Existential distress among caregivers of patients with brain tumors: a review of the literature. *Neurooncol Pract* 2016;3:232–44.
- Geng H-M, Chuang D-M, Yang F, et al. Prevalence and determinants of depression in caregivers of cancer patients: a systematic review and meta-analysis. *Medicine* 2018;97:e11863.
- Cavers D, Hacking B, Erridge SE, et al. Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *CMAJ* 2012;184:E373–82.
- Russell B, Collins A, Dowling A, et al. Predicting distress among people who care for patients living longer with high-grade malignant glioma. *Support Care Cancer* 2016;24:43–51.
- Wasner M, Paal P, Borasio GD. Psychosocial care for the caregivers of primary malignant brain tumor patients. *J Soc Work End Life Palliat Care* 2013;9:74–95.
- Applebaum AJ, Buda K, Kryza-Lacombe M, et al. Prognostic awareness and communication preferences among caregivers of patients with malignant glioma. *Psychooncology* 2018;27:817–23.
- Cavers D, Hacking B, Erridge SC, et al. Adjustment and support needs of glioma patients and their relatives: serial interviews. *Psychooncology* 2013;22:1299–305.
- Lazarus RS, Folkman S, Stress FS. *Appraisal, and coping*. New York: Springer, 1984.
- Crooms RC, Goldstein NE, Diamond EL, et al. Palliative care in high-grade glioma: a review. *Brain Sci* 2020;10:10390/brainsci10100723. [Epub ahead of print: 13 10 2020].
- Sandelowski M, Barroso J. *Handbook for synthesizing qualitative research*. New York: Springer, 2007.
- Ouzzani M, Hammady H, Fedorowicz Z. Systematic reviews; 2016. <https://rayyan.qcri.org/welcome>
- Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci* 2004;18:145–53.
- NVIVO, QSR International, 2020. Available: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro Oncol* 2008;10:61–72.
- Piil K, Juhler M, Jakobsen J, et al. Daily life experiences of patients with a high-grade glioma and their caregivers: a longitudinal exploration of rehabilitation and supportive care needs. *J Neurosci Nurs* 2015;47:271–84.
- Janda M, Eakin EG, Bailey L, et al. Supportive care needs of people with brain tumours and their carers. *Support Care Cancer* 2006;14:1094–103.

- 23 Coolbrandt A, Sterckx W, Clement P, *et al.* Family caregivers of patients with a high-grade glioma: a qualitative study of their lived experience and needs related to professional care. *Cancer Nurs* 2015;38:406–13.
- 24 Arber A, Hutson N, de Vries K, *et al.* Finding the right kind of support: a study of carers of those with a primary malignant brain tumour. *Eur J Oncol Nurs* 2013;17:52–8.
- 25 Edvardsson T, Ahlström G. Being the next of kin of a person with a low-grade glioma. *Psychooncology* 2008;17:584–91.
- 26 Wideheim A-K, Edvardsson T, Pålsson A, *et al.* A family's perspective on living with a highly malignant brain tumor. *Cancer Nurs* 2002;25:236–44.
- 27 Huang T-Y, Mu P-F, Chen Y-W. The lived experiences of parents having a child with a brain tumor during the shared decision-making process of treatment. *Cancer Nurs* 2022;45:201–10.
- 28 Strang S, Strang P. Spiritual thoughts, coping and 'sense of coherence' in brain tumour patients and their spouses. *Palliat Med* 2001;15:127–34.
- 29 Shortman RI, Beringer A, Penn A, *et al.* The experience of mothers caring for a child with a brain tumour. *Child Care Health Dev* 2013;39:743–9.
- 30 Cutillo A, Zimmerman K, Davies S, *et al.* Coping strategies used by caregivers of children with newly diagnosed brain tumors. *J Neurosurg Pediatr* 2018;23:30–9.
- 31 Schmer C, Ward-Smith P, Latham S, *et al.* When a family member has a malignant brain tumor: the caregiver perspective. *J Neurosci Nurs* 2008;40:78–84.
- 32 Tastan S, Kose G, Iyigun E, *et al.* Experiences of the relatives of patients undergoing cranial surgery for a brain tumor: a descriptive qualitative study. *J Neurosci Nurs* 2011;43:77–84.
- 33 Zelcer S, Cataudella D, Cairney AEL, *et al.* Palliative care of children with brain tumors: a parental perspective. *Arch Pediatr Adolesc Med* 2010;164:225–30.
- 34 Lou H-L, Mu P-F, Wong T-T, *et al.* A retrospective study of mothers' perspectives of the lived experience of anticipatory loss of a child from a terminal brain tumor. *Cancer Nurs* 2015;38:298–304.
- 35 Ownsworth T, Goadby E, Chambers SK. Support after brain tumor means different things: family caregivers' experiences of support and relationship changes. *Front Oncol* 2015;5:33.
- 36 Hricik A, Donovan H, Bradley SE, *et al.* Changes in caregiver perceptions over time in response to providing care for a loved one with a primary malignant brain tumor. *Oncol Nurs Forum* 2011;38:149–55.
- 37 Lipsman N, Skanda A, Kimmelman J, *et al.* The attitudes of brain cancer patients and their caregivers towards death and dying: a qualitative study. *BMC Palliat Care* 2007;6:7.
- 38 Lazarus RS. *Stress OG følelser: en syntese*. København: Akademisk Forlag, 2006.
- 39 Lin I-F, Fee HR, Wu H-S. Negative and positive caregiving experiences: a closer look at the intersection of gender and relationships. *Fam Relat* 2012;61:343–58.
- 40 Daniela Doulavince A, Altamira PdS R, Regina AGd L. Conceptions of care and feelings of the caregiver of children with cancer/ concepções de cuidado E sentimentos do cuidador de crianças CoM câncer. *Acta paulista de enfermagem* 2013;26:542.
- 41 Nicklin E, Velikova G, Hulme C, *et al.* Long-term issues and supportive care needs of adolescent and young adult childhood brain tumour survivors and their caregivers: a systematic review. *Psychooncology* 2019;28:477–87.
- 42 Sterckx W, Coolbrandt A, Dierckx de Casterlé B, *et al.* The impact of a high-grade glioma on everyday life: a systematic review from the patient's and caregiver's perspective. *Eur J Oncol Nurs* 2013;17:107–17.
- 43 Holtslander LF, Duggleby W, Williams AM, *et al.* The experience of hope for informal caregivers of palliative patients. *J Palliat Care* 2005;21:285–91.
- 44 Leite ACAB, Garcia-Vivar C, Neris RR, *et al.* The experience of hope in families of children and adolescents living with chronic illness: a thematic synthesis of qualitative studies. *J Adv Nurs* 2019;75:3246–62.
- 45 Lina Mahayati S, Allenidekania, Happy H. Spirituality in adolescents with cancer. *Enferm Clin* 2018;28:31–5.
- 46 Alidina K, Tettero I. Exploring the therapeutic value of hope in palliative nursing. *Palliat Support Care* 2010;8:353–8.
- 47 Wang S-C, Wu L-M, Yang Y-M, *et al.* The experience of parents living with a child with cancer at the end of life. *Eur J Cancer Care* 2019;28:e13061.
- 48 Hisamatsu M, Niwa S. Support factors of coping with anxiety in families of patients with terminal cancer. *J Jpn Acad Nurs Sci* 2011;31:58–67.
- 49 Aromataris EM Z, ed. *Joanna Briggs Institute Reviewer's Manual*, 2017. <https://wiki.joannabriggs.org/display/MANUAL/JBI+Reviewer%27s+Manual>
- 50 Salander P. Brain tumor as a threat to life and personality: The spouse's perspective. *J Psychosoc Oncol* 1996;14:1–18.
- 51 Moher D, Liberati A, Tetzlaff J, *et al.* Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009;6:e1000097.

The search strategy for the metasynthesis:

To search the PsycINFO database, we used the following terms: *((qualitative adj2 (research* or design* or stud* or method*)) or hermeneutic* or “grounded theory” or “meta syntheses” or metasynthesis* or metaethnograph* or interview* or phenomenolog* or thematic or themes or experience*).ti,ab,hw,id. or exp qualitative methods or phenomenology AND (caregiver* or famil* or next of kin* or relatives or spous* or wife or husband* or sibling* or sister* or brother* or dependent* or loved one* or parent* or mother* or father* or carer* or care giver*).ti,ab,hw,id. AND glioma*.ti,ab,hw,id. OR (brain adj2 (cancer or neoplasm* or tumor*).ti,ab,hw,id.*

In Medline and CHINAL, we used the following terms: *caregiver* OR famil* OR “next of kin*” OR relatives OR spous* OR wife OR husband* OR sibling* OR brother* OR sister* OR dependent* OR “loved one*” OR parent* OR mother* OR father* OR carer* OR “care giver*” AND (MH “Qualitative Studies+”) OR (MH “Qualitative Research+”) OR (MH “Grounded Theory”) OR Interview* OR experienc* OR phenomenolog* OR (qualitative W1 (research* OR method* OR design* OR stud*)) OR themes OR thematic OR “audio recording” OR audiorecording OR metasynthes* OR “meta syntheses” OR metaetnograph* AND (MH “Glioma+”) OR glioma OR gliomas OR glioblastom* OR brain W1 (cancer OR tumor* or neoplasm*).*

Supplementary materials 2: Characteristics of the included studies.

Author/year/country	Focus	Type of brain tumor and stage of treatment at interview	Recruitment	Participants, sex, and relationship	Method/design	Data collection/analysis
Arber et al. (2010). ² United Kingdom (UK).	Caregivers' need for information.	Malignant * Stage of treatment not described.	Specialist hospital in England.	N = 22 M: 7 and F: 15 17 spouses 3 children 2 parents	Grounded theory.	Semistructured interview/comparative method for generating categories and topics.
Arber et al. (2013). ²⁴ United Kingdom (UK).	Caregivers' need for support.	Malignant * Stage of treatment not described.	Recruited by a nurse at a cancer center in England.	N = 22 M: 7 and F: 15 17 spouses 3 children 2 parents	Grounded theory.	Semistructured interview/comparative method for generating categories and topics.
Coolbrandt et al. (2015). ²³ Belgium.	Caregivers' experience and need for support.	High-grade * Radiation or chemotherapy, or in the follow-up phase after such treatment.	University Hospital in Leuven.	N = 16 M: 6 and F: 10 13 partners 2 parents 1 friend	Grounded theory.	Semistructured interview/thematic analysis inspired by the Qualitative Analysis Guide of Leuven.
Cutillo et al. (2018). ³⁰ USA.	Which strategies caregivers of children with a brain tumor use in the postoperative phase.	15 benign. 25 malignant. Newly diagnosed and newly operated.	Pediatric hospital in the USA.	N = 22 M: 3 and F: 19 All parents	Triangulating mixed-method.	Semistructured interview/thematic analysis.

Edvardson & Ahlström (2008) ²⁵ . Sweden.	Caregivers' experience.	25 low-grade. 2 high-grade. Stage of treatment not described.	The patients had participated in an earlier study.	N = 28 M: 8 and F: 20 15 partners, living together 3 partners, living apart 8 parents 1 sibling 1 child	Not described.	Semistructured interview/qualitative content analysis and quantitative analysis of how the topics were distributed among the participants.
Janda et al. (2006) ²² . Australia.	The need of support for brain tumor patients and their caregivers.	Different types * Treatment phase not described, but time since diagnosis stated: 1–2 years: 22 5 years: 5 More than 5 years: 11	Members of Queensland Cancer Fund's Brain Tumor Support Service.	N = 10 in focus group, n = 8 in semistructured interview M: 4 and F: 18 13 partners 5 children	Qualitative.	Focus group interview and semistructured interview/framework analysis.
Lipsman et al. (2007) ³⁷ . Canada.	The experience of brain tumor patients and their caregivers, and how it affects the choice of treatment.	Malignant * Palliative phase.	Recruited by a neurosurgeon.	N = 22 Further participant information not described	Qualitative.	Semistructured interview/thematic analysis.
Lou et al. (2015) ³⁴ . Taiwan.	The experience and suffering of mothers waiting for their child to die from brain tumor.	Malignant * All patients deceased.	Not described.	N = 10 F: 10 All mothers	Phenomenological.	In-depth interview/Colaizzi's analysis method.

Owensworth et al. (2015). ³⁵ Australia.	Caregivers' experience of support.	6 low-grade. 5 high-grade. All underwent surgery and radiation or chemotherapy. 9 months – 22 years since diagnosis.	Had participated in a different study.	N = 11 M: 6 and F: 5 8 spouses 3 parents	Phenomenological.	Semistructured interview/thematic analysis.
Piil et al. (2015). ²¹ Denmark.	Brain tumor patients' and their caregivers' experience, and their need for rehabilitation and support.	High-grade * The interviews conducted after: 1. Surgical diagnosis 2. Oncological treatment 3,4. Oncological treatment and scan showing treatment effect 5. After treatment	The University Hospital in Copenhagen.	N = 33 M: 10 and F: 23 23 spouses 2 girl/boyfriends 7 children 1 sister	Longitudinal and exploratory.	Semistructured interview/thematic analysis.
Russell et al. (2016) ¹⁰ . Canada.	The experience of children with a brain tumor and their caregivers.	Malignant * Diagnosed at least 3 months previously, stage of treatment not described.	Hospital in Toronto.	N = 12 Based on names: F: 11 stk., 1 stk. unknown All parents	Grounded theory.	Semistructured interview/comparative analysis.
Schmer et al. (2008) ³¹ . USA.	Caregivers' experience concerning care tasks after chemotherapy.	Malignant * During first 6 months of treatment.	The patients' treatment center.	N = 10 Sex unknown 7 spouses 2 daughters 1 son-in-law	Phenomenological.	Semistructured interview/Colaizzi's analysis method.

Schubart et al. (2008). ²⁰ USA.	Caregivers' challenges and unmet needs.	Different types of brain cancer * 6 deceased 2 exacerbations 2 unstable 10 stable 1 terminal 3 recurrent 1 unclear	NeuroOncology Center.	N = 25 M: 7 and F: 18 18 spouses 4 parents 2 children 1 sibling	Grounded theory.	Semistructured interview/open coding and cross-case analysis.
Sherwood et al. (2011). ³⁶ USA.	How caregivers adapt to their new role, and how this role changes during time.	Malignant * Interviewed 1 and 4 months after diagnosis.	A regional hospital.	N = 10 M: 2 and F: 8 5 spouses 2 parents 1 child 1 nephew 1 friend	Longitudinal descriptive design.	Semistructured interview/thematic content analysis.
Shortman et al. (2013). United Kingdom (UK).	Mothers of children with brain tumor—their experience and their coping mechanisms.	Different types and degrees *. All underwent surgery, five radiation, and four chemotherapy. 17–35 months since diagnosis.	Also participated in another study.	N = 6 F: 6 All mothers.	Not described.	Semistructured interview/thematic content analysis.

Strang & Strang (2001). ²⁸ Sweden.	The degree to which patients with a brain tumor and their caregivers cope, understand, and create meaning in the situation.	Malignant tumors, grade 2–4. Treatment stage not described.	Not described.	N = 16 Further participant information not described.	Hermeneutic phenomenological.	Semistructured interview/structural analysis based on hermeneutic circle described by Ricoeur.
Tastan et al. (2011). ³² Turkey.	Caregivers' experience of postoperative phase and homecare.	Different types and degrees * All patients had undergone surgery and postoperative treatment and were being treated at home.	A research and military training hospital in Turkey.	N = 19 M: 4 and F: 6 4 spouses 4 children 1 parent 1 sibling	Descriptive qualitative study.	Semistructured interview/Colaizzi's analysis method.
Huang et al. (2021). ²⁷ Taiwan	The lived experience of parents having a child with a brain tumor during the shared decision-making process of treatment	4 medulloblastoma 3 germ cell tumor 1 glioblastoma 1 astrocytoma 1 ependymoma The interviews were conducted between 1-6 months after the child received the diagnosis	A pediatric oncology ward at a medical center in Taiwan	N=10 M: 3 and F: 7	Descriptive phenomenological study	Semistructured interview/Colaizzi's analysis method.
Wideheim et al. (2002). ²⁶ Sweden.	The experience of a brain tumor from a family perspective.	High-grade glioma. The interviews were conducted 2–3 weeks, 3 months, and 6 months postoperatively.	Not described.	N = 5 Sex unknown 2 spouses 2 parents	Descriptive qualitative study.	Qualitative interviews/inductive content analysis.

				1 adult child		
Zelcer et al. (2010). ³³ Canada.	The experience of brain tumor patients and caregivers in the palliative phase.	Malignant * All patients deceased.	Children’s Hospital, London Health Sciences Centre.	N = 25 M: 9 and F: 16 All parents	Qualitative	Semistructured interview/thematic content analysis.

1 M = Male, F = Female

*=Tumor not further described