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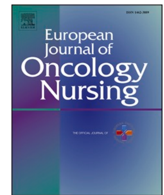

“Try to keep things going” – Use of various resources to balance between caregiving and other aspects of life: An interview study with informal caregivers of persons living with brain tumors in Sweden

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ABSTRACT

Purpose: Persons living with brain tumors may experience severe impairment, requiring social support (i.e., informal care). Although informal caregiving can be rewarding, it can also lead to physical or psychological burdens. The aim of this study was to explore how informal caregivers of persons living with brain tumors use resources available to them, including social support, to balance caregiving with other aspects of life.
Methods: Sixteen informal caregivers (14 partners, two adult children) of persons living with brain tumors, varied in gender (10 female, six male), age (26–79 years), and caregiving experience (1–20 years) were interviewed. Data were analyzed using conventional content analysis.
Findings: We generated nine categories representing informal caregivers' strategies grouped by resources used. Intrapersonal resources were used for: *Flexibly adjusting to changing life situations*; *Separating the care recipient from the illness*; and *Reflectively renegotiating self-expectations*. Interpersonal resources were used for: *Coping together with the care recipient*; *Sharing responsibilities within the family*; *Seeking guidance from persons in similar situations*; and *Grouping social relations by function*. Healthcare and community resources were used for: *Active collaborations with healthcare staff* and *Accessing professional and community resources for mental well-being.*
Conclusions: Informal caregivers used their intrapersonal, interpersonal, and healthcare and community resources in various ways for mainly emotional and instrumental support. More informational support from healthcare was desired, indicating that healthcare services, along with patient and caregiver organizations, may be able to enhance such support for informal caregivers. This could, in turn, allow more flexibility to manage caregiving alongside other life commitments.

1. Introduction

In Europe, cancer is one of the leading causes of morbidity and mortality (European Commission, 2022). Persons living with cancer are often dependent on support from informal caregivers due to complex care needs and the fact that much of the cancer treatment takes place in outpatient and home settings (Sklenarova et al., 2015). In this study, we focus specifically on informal caregivers of persons living with a primary brain tumor in Sweden. An informal caregiver is “a person who provides—usually—unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework” (Eurocarers, 2020). Commonly, an informal caregiver is a family member or relative, but can also be, for example, a friend or a neighbor (The Swedish and care competence centre, 2022).

In 2021, approximately 1400 people in Sweden were diagnosed with brain tumors, accounting for 2 % of all cancer diagnoses (National Board of health And Welfare, 2023). Brain tumors may cause significant impairment, including neurological (e.g., headache, visual perception deficits, impaired speech, seizures, loss of mobility, fatigue), cognitive (e.g., memory loss, difficulty concentrating), and executive functioning impairment (Sage et al., 2019). Providing informal care to persons living with brain tumors may include varying degrees of support: personal care (e.g., help with dressing); medical care (e.g., managing medications, monitoring symptoms); physical care (e.g., assisting with training

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exercises); household tasks (e.g., cooking and cleaning); and administering insurance and financial issues (Goodman et al., 2020). As the condition deteriorates, informal caregivers may also experience increasing responsibilities regarding decision-making, problem-solving, and communication with members of the family and healthcare providers (Piil et al., 2015).

It is acknowledged that informal caregivers can gain satisfaction from providing care, which can sustain them in their role, lead to increased self-esteem and improved relationships (Brown and Brown, 2014; Nolan M. et al., 1996; Quinn et al., 2019). Satisfaction can arise from the relationship with the person living with illness, from feeling appreciated and supported in their role as informal caregivers, and from a sense of achievement (McKee et al., 2003; Balducci et al., 2008). Such positive impact of caregiving can protect against negative experiences, i.e. caregiver burden (Balducci et al., 2008). Caregiver burden can include experiences of physical and psychological burden, including stress, anxiety, and depression (Applebaum et al., 2016; Paek et al., 2018). Apart from burden caused by providing care, work or family-related obligations may lead to additional strain on the informal caregiver (Benson et al., 2023; Boumans and Dorant, 2021). Research has reported that informal caregivers of persons living with brain tumors experience unmet needs in emotional, informational, and continuous social support, including support to cope with personality changes in the care recipient and feelings of social isolation, adding to caregiver burden (Paterson et al., 2024; Pointon et al., 2023). Because informal caregivers may often take on a large amount of caregiving responsibility at short notice, they have also expressed a desire for a stronger connection with healthcare professionals to get support with rapidly changing needs (Guldager et al., 2023). However, informal caregivers do not have a clearly defined role in the healthcare system and may therefore receive limited support in coping with challenges or even go unnoticed (Tranberg et al., 2021; Cahill et al., 2023).

A person's ability to cope with challenges related to caregiving is dependent on the resources (e.g., financial resources, skills, tools, helpful people) that are available to them (Lazarus and Folkman, 1984). In this study, we are particularly interested in how informal caregivers use their own resources as well as social support resources that they identify within their families, social networks, communities, and healthcare. Social relations may be valued for differing and sometimes contrasting qualities, on the one hand supporting the daily management of living with brain tumors, and on the other hand supporting individuals to disconnect from their caregiver role (Dahlberg et al., 2022). Social support can be classified into different categories (Langford et al., 1997; House, 1981) including *emotional* support (showing affection, empathy, commitment, and trust), *instrumental* support (providing practical or financial support), *informational* support (providing communication assistance, advice, or counseling), and *appraisal* support (providing confirmation and feedback for self-evaluation).

The national care program for tumors in the central nervous system and the Swedish national informal caregiver strategy emphasize the importance of adequate caregiver support to help balance caregiving with other aspects of life (National Board of Health and Welfare, 2021, Regionala Cancercentrum, 2023). In Sweden, support services for informal caregivers are more developed than in many other EU countries (including, e.g., cash benefits for informal caregivers, innovative technological solutions, and support groups) (Wieczorek et al., 2022). Despite a large range of services in Sweden, they are offered unevenly across regions and municipalities and there are unspoken normative and cultural expectations on family members taking on caregiving duties (Cahill et al., 2023). To improve support services, we need to better understand the resources that informal caregivers need and use to cope with challenges related to caregiving. The specific aim of this study was to explore how informal caregivers of persons living with brain tumors use resources available to them, including social support, to balance caregiving with other aspects of life.

2. Method

2.1. Study design

We used a descriptive qualitative research design based on semi-structured interviews analyzed using conventional content analysis (Hsieh and Shannon, 2005). Consolidated criteria for reporting qualitative research (COREQ) guided the reporting of this study (Tong et al., 2007).

2.2. Participants

This study was conducted within the research program "Patients in the driver's seat! A multimethod partnership program on patient-driven innovations", in which persons with lived experiences as patients or informal caregivers and researchers collaborate in research. An informal caregiver to a person living with a brain tumor provided input to the study design and the interview guide. A previous study focusing on relations that matter to informal caregivers and persons living with brain tumors (hereafter referred to as care recipients) prompted us to further explore how informal caregivers reason about balancing caregiving with other aspect of life (Dahlberg et al., 2022). Therefore, informal caregivers who participated in that study were recruited to be re-interviewed. To achieve variation in gender and caregiving experience, additional participants were purposefully recruited in collaboration with clinicians at Karolinska University Hospital in Stockholm, Sweden, from June to October 2020. Informal caregivers to adult persons living with brain tumors were eligible to participate if they were at least 18 years old, spoke Swedish, and had at least one year of caregiving experience. The reason for requiring at least one year of caregiving experience was that we wanted informal caregivers to have transitioned out of the initial phase after the diagnosis. This phase has been described as the most chaotic (Chen et al., 2021), and may therefore be too early for informal caregivers to be able to focus on balancing caregiving with other aspects of life. Clinicians identified participants among informal caregivers who accompanied their care recipients to hospital visits and informed them about the study. Those who were interested received written information and were, upon their approval, contacted by MD to schedule an interview. Sixteen participants were recruited and provided their informed consent to participate; all were family members (partners or children) of the care recipient (Table 1). The study was approved by the regional Ethics Committee (registration numbers 2015/2216-31/5 and 2018/1718-32) and followed the Helsinki Declaration 1964 and its later amendments (World Medical Association. World Medical Association Declaration of Helsinki, 2025).

2.3. Data collection

In connection with scheduling interviews, participants were provided with a worksheet to identify resources that they experienced as important to their caregiving or for their well-being. The worksheet prompted them to identify and list resources within five domains: (1) next of kin and close social relations; (2) other important social relations (e.g., workplace, patient organizations, sport clubs); (3) healthcare

Table 1
Participant characteristics.

Caregiver characteristics	N = 16
Gender	
Female, n (%)	10 (62)
Male, n (%)	6 (38)
Age range, years (median)	26-79 (51.5)
Range of caregiving experience, years (median)	1-20 (3)
Relation to care recipient	
Partner, n (%)	14 (88)
Adult child, n (%)	2 (12)

services; (4) municipal care services; and (5) other resources (e.g., social insurance agency). The rationale for asking participants to reflect on their resources prior to the interview was our assumption that this could make them better prepared to discuss which resources they may use or lack to balance caregiving with other aspects of life. In a previous study, we found this approach useful to stimulate conversations about the quality of social relations (Dahlberg et al., 2022). We developed a semi-structured interview guide (Appendix 1) addressing informal caregivers' challenges related to caregiving and maintaining their own well-being, how they manage these challenges, and the resources they utilize or lack. MD conducted the interviews between August and December 2020. informal caregivers chose the interview setting (telephone, in-person, or Zoom). All interviews were audio-recorded, transcribed verbatim, and ranged from 43 to 114 (median 56) minutes.

2.4. Data analysis

NVivo version 12 (QSR, 2018) was used to code and categorize the data. The analysis was performed using content analysis with a conventional approach (Hsieh and Shannon, 2005). First, MD read the transcripts to become immersed with the data and labeled text responding to the research question with descriptive codes (i.e., nodes in NVivo). AB and CW read a selection and coded some of the initial interviews in parallel with MD in order to calibrate and discuss the coding strategy. Thereafter, MD re-coded all the interviews and made revisions based on input from AB and SA, who read four coded interviews. In the next step, MD made refinements and grouped related codes into categories. In discussions between MD, AB, SA and CW, categories were refined and grouped according to the types of resources used. Memos were used to track the analysis process, contributing to rigor and trustworthiness. The analysis was performed in an iterative process with repeated discussions until all authors agreed with the final grouping and labeling of categories. Examples illustrating the coding and categorization are provided in Appendix 2.

3. Findings

We classified the resources that informal caregivers used into intrapersonal (i.e., informal caregivers' internally available resources), interpersonal (i.e., resources found within social networks), and healthcare and community resources (i.e., publicly and privately funded services for health and wellbeing). Furter, we generated nine categories representing strategies that informal caregivers use to maintain a healthy balance between caregiving and other aspects of life. The strategies are organized by types of resources used, as shown in Table 2. Illustrative quotes from the informal caregivers (identified by relation to care recipient and years of caregiving experience e.g., Female partner; 8 yrs) have been translated from Swedish to English.

Table 2
Types of resources and strategies used for balancing caregiving with other aspects of life.

Resources	Strategies
Intrapersonal resources	Flexibly adjusting to changing life situations Separating the care recipient from the illness Reflectively renegotiating self-expectations
Interpersonal resources	Coping together with the care recipient Sharing responsibilities within the family Seeking guidance from persons in similar situations Grouping social relations by function
Healthcare and community resources	Active collaboration with healthcare staff Accessing professional and community resources for mental well-being

3.1. Intrapersonal resources

3.1.1. Flexibly adjusting to changing life situations

Informal caregivers described how their situation was constantly threatened by change related to the illness. The care recipients' deteriorating physical and cognitive functioning implied that informal caregivers reduced their time away from home and took on more responsibilities for family functioning (e.g., household duties, planning, decision-making, social activities). Managing illness progression involved continuous problem-solving and adaptations. Informal caregivers explained how their gained experiences, combined with a mindset of flexibility, solution-orientation, and pragmatism, enabled them to circumvent problems and challenges that arose.

> I imagine that I'm a pragmatic person. See things for what they are. If there's dirt on the floor, well, then it's dirt on the floor. It is what it is. And there's no point in getting upset because it already happened. So, how do we get to the solution orientation mode? (Male partner; 2,5 yrs)

To avoid being overwhelmed with the practical duties and emotional burdens and expectations, informal caregivers used what they described as "survival strategies" (Female partner; 5 yrs): a built-up preparedness to cope, which included being selective and to prioritize and adapt their activities to make room for both caregiving and activities for their own well-being (e.g., physical exercise, coffee with friends, or alone time to sort thoughts and relax from caregiving).

3.1.2. Separating the care recipient from the illness

Cognitive and behavioral deterioration in the care recipient affected informal caregivers' relationship with the care recipient and their ability to have stimulating conversations. With time, informal caregivers experienced that it could become easier to identify symptoms related to the illness and separate these from the person: "I mean … it's an expression of her stress or brain fatigue, which easily turns into irritation, towards me or the children, you know" (Male partner; 7,5 yrs). Informal caregivers shared experiences illustrating how they tried to focus on positive aspects, such as the care recipient's qualities, capabilities, and interests. One informal caregiver highlighted that picking up on other informal caregivers' positive experiences (e.g., through social media) helped the positive reinterpretation of own experiences. Informal caregivers described that, with time, they found comfort in looking back with pride of what they had achieved, including upholding normality and for not giving up.

3.1.3. Reflectively renegotiating self-expectations

Putting the care recipient first was experienced as an emotional and practical strain, which could be very difficult to deal with in the long term. At the same time, informal caregivers reasoned that their ill partner likely did not demand their constant presence or to be on call. As one participant put it, they "might exaggerate (their) own significance" (Male partner; 2 yrs). Nevertheless, from the informal caregivers' narratives, it became clear how acknowledging their own needs could be a struggle:

> I've become more egoistical. I don't have it in me, so I've had to work hard to put myself first … I've started to focus more on the little things like maybe to not rush home. Simple things like if I feel like having a coffee at a café in the sun. I wouldn't have done that before, because I got stuck in a notion that they need me more than they do. (Female partner; 4 yrs)

By learning to prioritize their own needs, informal caregivers felt that they could preserve their own well-being, while also strengthening their ability to be a supportive partner or family member. This reflects how informal caregivers renegotiated their self-expectations, which could also include accepting help from others, although asking for and getting support was difficult: "We are in a situation that is

incomprehensible, that scares a lot of people. And many really want to be there, but they don't know how – I hardly do" (Female partner; 4 yrs). Some described that this change caused a feeling of loneliness as informal caregivers, which exhorted them to reflect on how to convey their support needs if and when they appeared. Some had made efforts to become better at asking for and accepting help from others. Others had started using external support (including paid support services) for duties such as house cleaning and grocery shopping to free up time.

3.2. *Interpersonal resources*

3.2.1. *Coping together with the care recipient*

Although care recipients personalized the illness that was the source of burdens and challenges, informal caregivers described that the care recipient could be the informal caregiver's closest companion and an important support resource in their coping. The value of open and honest conversations with the care recipient was emphasized. Such conversations could help them in airing everyday problems and challenges, but also in dealing with more existential concerns, such as grieving the illness situation, talking about death, and planning a future without the care recipient "to leave no stones unturned" (Female partner; 2 yrs).

> It has really helped me that my mom and I could talk about her death. I will carry those conversations with me for the rest of my life. It's like … and I'm sorry that my brothers and my dad didn't dare … Mom and I cried a lot … but it was like … something really beautiful to grieve together. (Daughter; 2 yrs)

To prevent relationships from being "defined by the illness" (Male partner; 15 yrs), informal caregivers described how they made joint efforts with the care recipient to take 1 day at a time. Some also described how they planned for both time on their own and meaningful activities together with the care recipient, such as a trip or joint everyday activities (e.g., cooking, exercising, or socializing with family and friends). Such activities served to create positive events and momentary respite from caregiving and the illness situation.

> It's a pick-me-up, you know. You can … there are no limits to how much you can degenerate. So yes, for example this trip … I mean, life was darn dull before that and so we went for two days, and it was great. And that is exactly the effect that we want, you know. (Male partner; 6 yrs)

3.2.2. *Sharing responsibilities within the family*

Family members could have both positive and negative effects on caregiver burden. For example, informal caregivers with younger children expressed how they felt an obligation to safeguard their children's childhood and protect them from being negatively affected by the illness situation by creating positive and joyful experiences together. On the other hand, family members could also be important emotional support resources to informal caregivers. Over time, informal caregivers experienced that family members developed a higher degree of sensitivity and receptiveness to each other's needs and feelings (e.g., by giving space for time alone or actively stepping in when needed). One of the participants described how they experienced that their family had transitioned from "chaos mode" to "normal mode" (Daughter; 1 yr). Additionally, caregiver duties could be shared collectively within the family to alleviate individual caregiver burden.

> If you disregard the fact that we live under this wet blanket all the time, we are a well-functioning family and we like to be together. Not all families do that (laughter). So, it's really double-edged … I believe that our children have become much more mature than they would have been, and we have … probably a different relationship than we otherwise would have had. (Female partner; 4 yrs)

3.2.3. *Seeking guidance from persons in similar situations*

Informal caregivers described how they sought emotional as well as practical support from persons with similar experiences who could relate to the illness situation and its impact on caregiving and other aspects of life. Specifically, people with similar experiences could help in interpreting information, giving advice on how to navigate the healthcare system, and on how to tackle short and long-term burdens of caregiving. For some informal caregivers, peer organizations or forums provided a platform where they could exchange experiences and receive as well as provide support, which could lead to a sense of kinship. Others described how they had been able to identify persons with similar experiences – as an informal caregiver or as a person living with illness – in their existing social networks (e.g., among friends, relatives, or colleagues).

> I have a friend who also … he doesn't have cancer, but a permanent illness. And so, I talk a lot with him … and he gives me perspective on what it's like being in my wife's situation. I mean, he's the equivalent … towards his wife … he's the sick one, so what's it like for him? And he has been ill for about as long [as my wife], and he also has children, and it affects his relationships a lot. (Male partner; 15 yrs)

3.2.4. *Grouping social relations by function*

The informal caregivers described how the illness situation influenced their social relationships. While some relationships were challenged or faded away, others became stronger and more important. Informal caregivers described how they prioritized and nourished relationships with close and carefully selected individuals who actively showed interest, concern and understanding – relationships that were "always there" (Female partner, 5 yrs). Such individuals were described as go-to persons, whom informal caregivers could trust and with whom they could share their innermost thoughts and could speak out, unfiltered, "without having to think about anything other than me being me" (Female partner; 4 yrs). By being able to identify unexpressed needs, these individuals enhanced the informal caregivers' ability to cope with, for example, a changing relationship and conflict with the care recipient.

> [To] have someone to talk to, where you can let it out … Even where you think that you're exposing your partner, but that you have to be able to express … and that you can't discuss with your partner. That – I think that's important. But it has to be with someone who you trust one hundred and ten percent, someone who doesn't tell. (Female partner; 12 yrs)

Some described a sense of lost identity in social networks where the focus was primarily on the illness, the ill person, and caregiving. Informal caregivers stressed the importance of nourishing their social networks separate from caregiving. Such social networks helped with focusing on other things and taking one's mind off the illness situation, which could be interpreted as a way of using *self-distraction* to balance caregiving with other aspects of life.

> I have these people … we talk more about general things … To me it doesn't have to be me talking about myself, but to have real conversations … I have created some contexts like that … Like this weekend, I'm taking three friends to our summer house … They have been through divorces and that's a life crisis too, so … we talk about other things. So, I give more time to that type of company. (Female partner; 4 yrs)

Another valuable group for informal caregivers were supportive employers and colleagues who facilitated combining work and caregiving, and provided an environment separate from the illness situation. The informal caregivers described that adjusted employment with reduced work hours, changed work assignments, and the ability to work from home and to take time off for clinical visits had facilitated the practical aspects of caregiving without having to resign from work. Some had changed jobs to accommodate their situation, rather than

quitting working, in order to sustain a sense of belonging and social space in the workplace. Others had chosen to continue to work past their retirement. The focus on work performance gave a sense of meaningfulness, control, and normality, and offered important distractions and recovery from caregiving.

> According to me, [it's] what you have to do … so that you have the time and energy to [support your wife]. You have to go to work so that your brain can be occupied by tiresome PowerPoints instead … and focus on, and do, something else. So that life does not stop. So, to try to keep those things going. Because that gives you normality. (Male partner; 2,5 yrs)

3.3. Healthcare and community resources

3.3.1. Seeking active collaboration with healthcare staff

Several informal caregivers expressed surprise or frustration regarding the limited healthcare guidance and support targeting informal caregivers specifically, while others felt that healthcare's focus was rightfully on the care recipient. Some expressed uncertainty about what support they could expect and where to turn for guidance. When informal caregivers accompanied the care recipient to clinical visits, they received information mainly regarding healthcare plans and the care recipient's clinical status. Some informal caregivers also shared experiences of more active involvement and collaboration with healthcare professionals, in particular with contact nurses and so-called "neuro teams" (i.e., care teams consisting of occupational therapists, speech therapists, physiotherapists, counsellors, and dieticians who provide rehabilitation at home for people with neurological illness or injuries). As the following quote illustrates, shared decision-making was experienced to enhance informal caregivers' sense of inclusion.

> When I told the contact nurse that [the care recipient's veins] had become difficult to puncture … they suggested to coordinate [treatment injections] and sampling … And the doctor's like "that's super smart" … And so, we decided that during the meeting. They have different roles and different perspectives on things, so that is perfect … Both to see that they respect each other's roles, but also that they have an open dialogue towards us and each other, is super important to our sense of security. Absolutely. (Female partner; 20 yrs)

3.3.2. Accessing professional and community resources for mental well-being

Some informal caregivers sought professional support services (e.g., counseling, psychoanalysis, body therapy, or mindfulness) for emotional support and mental well-being, for themselves and their family members. Informal caregivers paid for these services on their own, which could be a challenge. Although these services did not provide illness-specific support, they were perceived as important complements to healthcare and informal support resources. For informal caregivers with children, schools could be an additional source of emotional support, providing comfort and understanding for the illness situation.

> We've had a really good school! … When [the care recipient] got sick … at the teachers' conferences, they always checked, well, how are the children? … Are there any tendencies? Do they seem OK? And so they called and kept me informed and told me everything was cool … They were fantastic. (Female partner; 4 yrs)

4. Discussion

This study explored how informal caregivers of persons living with brain tumors use their available resources, including social support, to balance caregiving with other aspects of life. Our findings show that informal caregivers combined intrapersonal, interpersonal, and healthcare and community resources to both cope with challenges related to caregiving and to make space for valued activities and relationships disconnected from caregiving. The sections below discuss how these resources were used for various purposes.

4.1. Using intrapersonal resources for problem-solving and emotional regulation

The participants in our study were able to effectively use intrapersonal resources to solve practical problems and regulate emotions. The participants' narratives suggest that some of their intrapersonal resources may (at least for some) have developed or strengthened as a result of their caregiving experience. Examples are the reported experiences of improved problem-solving skills and an increased ability to prioritize time for making room for valued activities besides caregiving. Effective problem-solving abilities have been associated with a decrease in negative outcomes among caregivers, such as anxiety and depression (Tao and Zhang, 2019). This makes problem-solving approaches a common element of educational interventions for informal caregivers (Farquhar et al., 2016; Fu et al., 2017). Whether any of the informal caregivers in this study had taken part in educational interventions focusing on strengthening specific skills was not assessed. Nevertheless, their ability to apply problem-solving to flexibly adjust to changing life situations suggests that they used problem-focused coping strategies (Lazarus and Folkman, 1984) to change the terms of the situation causing stress.

Our findings also contain examples of how informal caregivers renegotiated self-expectations and tried to focus on positive aspects in their relationships to the care recipients to reduce experienced caregiver burden. For example, participants described how they separated the care recipient from the illness, which may be interpreted as a cognitive reappraisal tactic to decrease negative emotion by invoking a sense of distance from aspects related to illness (McRae et al., 2012). Although this is not necessarily a positive reappraisal tactic, participants experienced that it helped them to focus on positive aspects. Thus, these strategies indicate that our study participants had an ability to apply positive thinking, which has been shown to have a favorable effect on the quality of life among informal caregivers to persons living with brain tumors (Baumstarck et al., 2018). While positive thinking may not change the situation causing stress, it may have supported informal caregivers in emotion-focused coping (i.e., managing emotional distress associated with the stressful situation) (Lazarus and Folkman, 1984). Given the wide age range of our study participants, it is relevant to consider that older adults may have enhanced emotion regulation capabilities compared to younger adults, which may in turn be linked to higher levels of well-being (Urry and Gross, 2010). While the ability to use detached reappraisal decreases with age, the ability to use positive reappraisal increases (Shiota et al., 2009).

4.2. Using close interpersonal resources for mutual instrumental and emotional support

Important interpersonal support resources consisted of meaningful and reliable social relationships. Family members, including the care recipient, were often the nearest and most accessible social resources, with whom the informal caregivers had developed an understanding for each other's needs and strategies for mutual support. Despite being the source of caregiver burden, care recipients were simultaneously described as an important source of support when dealing with emotional challenges related to illness and illness progression. This supports previous research suggesting that a positive relationship between the informal caregiver and their care recipient can contribute to reducing the strain of caregiving (Archbold et al., 1990). This has also been described as common dyadic coping, which refers to how the care recipient and their significant other engage together in shared problem-solving or joint emotion-regulation (Bodenmann et al., 2019).

Common dyadic coping may have involved additional family members, as suggested by participants' descriptions of how caregiver duties could be collectively shared within the family. In future research, it would be of interest to explore the joint perspectives of the care recipients' closest caregiver (i.e., the primary informal caregiver) and those of other family members who may provide informal care themselves. This could contribute to a more nuanced understanding of the support needs of various caregivers, who may have different roles and experiences (Bodenmann et al., 2019; Zemp et al., 2016; Ferraris et al., 2022; Badr and Acitelli, 2017). Related to informal caregivers' use of resources, one question in particular to explore is how caregivers can be supported in becoming aware of and mobilizing their unique resources within the family as a means to cope.

4.3. *Using interpersonal resources for disconnecting from caregiving duties*

Interpersonal resources beyond the family provided other types of instrumental support. For example, flexible work arrangement sustained informal caregivers to balance work with care. Sustaining work and a professional network is important for financial security and can help to maintain a sense of normality (Nicklin et al., 2023). Our findings also suggest that social relations, such as co-workers or friends, were a source of emotional support. They were also used for venting emotions and frustrations about illness and caregiving, and for self-distraction, which helped informal caregivers to temporarily disconnect from caregiving and the care recipient. In terms of coping, such strategies are sometimes viewed as dysfunctional strategies (Lazarus and Folkman, 1984). However, our findings suggest that these were experienced as important resources to balance caregiving with other aspects of life.

4.4. *Using persons with similar experiences and healthcare staff for informational support*

Persons with similar experiences, and to some extent healthcare staff, were perceived as sources of support in building caregiving knowledge and capacity. Previous studies have reported on informal caregivers' desire for information about their care recipient's illness, illness status, and support for preparation for illness progression and care coordination (Ownsworth et al., 2015; Coolbrandt et al., 2015). The experiences and expectations of healthcare support services targeting informal caregivers' personal needs were mixed. However, some described experiences of individualized information regarding the care recipients' clinical status and treatment, in combination with collaborative relations with healthcare professionals, which had supported them in their caregiving. A designated point of contact among healthcare staff may facilitate access to such information and narrow the gap between informal caregivers and healthcare (Ford et al., 2012; Vargo et al., 2016). Further, including informal caregivers in care teams has been recommended to help informal caregivers improve their preparedness for daily caregiving (Stephenson et al., 2022). Apart from healthcare staff, persons with similar experiences were particularly valued for their ability to relate, which makes them important resources in being able to provide tailored informational, emotional, as well as appraisal support based on lived experiences (Gage-Bouchard et al., 2015).

4.5. *Implications for practice*

Compared to countries like the United States and Netherlands where informal caregivers are generally perceived as resources, they are more likely to be regarded as co-workers or co-producers of care in Sweden (Cahill et al., 2023). Some of the participants in our study had experiences of being actively involved in discussions regarding the care recipient's treatment. However, our results also indicate that some experienced a lack of informational support and guidance combined with uncertainty about the support that they could expect. Thus, there is an opportunity for healthcare providers to engage more with informal caregivers to both assess their needs, help them to navigate the healthcare system, and contribute to their knowledge and capacity building. Furthermore, our findings suggest that informal caregivers relied primarily on their social networks for both instrumental and emotional support. Given the variation in access to intra- and interpersonal resources for support, there may thus be an opportunity to improve support services offered not only by healthcare, but also by other organizations. For example, community organizations for patients and/or informal caregivers have been suggested as suitable hosts for support services (Coumoundouros et al., 2024). Peer support programs can help to connect informal caregivers with peers, reduce social isolation, and offer support and guidance to self-care (Joo et al., 2022). However, previous research has shown that informal caregivers may be hesitant to actively seek external support because of various perceptions or misperceptions of caregiver obligations and rights to support (Delepau et al., 2018; Coumoundouros et al., 2024), as well as experiences of stigma (Ownsworth et al., 2015). This highlights the importance of proactively reaching out to informal caregivers with support offers. Although the findings of our study are based on a Swedish setting, we believe that the suggested implications for practice may also apply to other countries.

4.6. *Limitations*

This study contributes to existing literature on challenges that informal caregivers of persons with brain tumors experience (Chen et al., 2021; Ownsworth et al., 2015), and how they cope (Saria et al., 2017; Guariglia et al., 2021). However, there are limitations that need to be considered. Participants were recruited from among informal caregivers accompanying care recipients to hospital visits, which may have introduced a selection bias (Simundic, 2013). The sample diversity was limited, being predominantly female and under-representing individuals from various cultural backgrounds. Additionally, based on information from the interviews, most care recipients were in a stable stage of illness, limiting the perspectives of informal caregivers caring for individuals in more advanced stages, in which support needs of both the care recipient and their informal caregivers may be more pronounced. Consequently, the transferability of the results to a broader population of informal caregivers may be limited. Furthermore, factors such as tumor stage, severity, and sociodemographic characteristics were not assessed, which could influence caregivers' stress perceptions, resource assessments, and coping responses (Teixeira et al., 2018; Wang et al., 2020). These factors would have provided a more comprehensive understanding of the study population (Korstjens and Moser, 2018), enhanced the transferability of findings and informing future caregiver support interventions (Kirvalidze et al., 2023).

5. Conclusions

Our findings show that informal caregivers of persons living with brain tumors used intrapersonal, interpersonal as well as healthcare and community resources in various ways to cope with challenges related to caregiving and to balance informal caregiving with other aspects of life. Emotional and instrumental support was mainly provided within the family as well as more distant social relations and networks. People with similar experiences were sources of informational and appraisal support related to caregiving. However, informal caregivers expressed a need for more informational support from healthcare. The various uses of resources for support described in this study may help healthcare, along with patient and caregiver organizations, to enhance support services for informal caregivers. This could, in turn, allow informal caregivers more flexibility to manage caregiving alongside other life commitments.

CRediT authorship contribution statement

Marie Dahlberg: Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Carolina Wannheden:** Writing – review & editing, Project administration, Methodology, Conceptualization. **Stefan Andersson:** Writing – review & editing, Methodology, Conceptualization. **Ami Bylund:** Writing – review & editing, Supervision, Methodology, Conceptualization.

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Declaration of competing interest

The authors declare that they have no competing interests.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2025.102779.

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