

# BMJ Open Interventions facilitating the involvement of relatives of patients with acquired brain injury or malignant brain tumour through the course of disease: a scoping review protocol

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## ABSTRACT

**Introduction** Research identifying the needs of relatives of patients with an acquired brain injury or malignant brain tumours is emerging, and the importance of relative involvement is widely acknowledged. However, the intention of involvement does not seem to be present in current practice and healthcare professionals' routines. The complexity of involvement of relatives is comprehensive, and there is a lack of overview of interventions facilitating and enhancing involvement of relatives. This scoping review aims to identify and map the available evidence on interventions facilitating involvement of relatives of patients with acquired brain injury or malignant brain tumour throughout the disease trajectory.

**Methods and analysis** The proposed scoping review will be performed following the Joanna Briggs Institute's methodology for scoping reviews. Published and unpublished literature in English, Scandinavian and German from January 2010 to August 2022 will be considered. The searches will be conducted using electronic bibliographic databases. This scoping review will consider studies describing interventions provided by multidisciplinary healthcare professionals. The key aspects of the interventions could, for example, be educational, informational, emotional, social or physical support aiming towards involvement of the relatives. This scoping review will consider all study designs, except for literature reviews of all types and designs. The data will be extracted using a data extraction tool developed to record specific data, including details of authors, year of publication, country, setting, study population, study design and key aspects of the intervention (mode, duration, intensity, provider) and type of primary and secondary outcomes applied to measure the interventions. The results will be presented in tabular form, accompanied by a descriptive summary related to the objective of the present scoping review.

**Ethics and dissemination** This scoping review is conducted as part of a larger postdoc project, which has been approved by the Danish Data Protection Agency (ID P-2020-547). The results will be disseminated through a peer-reviewed journal and presented at local, national and international conferences on brain injuries and brain cancer.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We will employ a comprehensive search strategy developed with a research librarian. However, the possibility exists that we will miss some relevant studies especially as the term involvement is difficult to clarify as an unambiguous concept.
- ⇒ Limiting our search to studies published from 2010 to 2022 may exclude some earlier studies on the topic. However, this decision was made because scientific interest in this topic has increasingly focused on relative involvement within the last 10 years.
- ⇒ This review will only consider studies written in English, Scandinavian or German, so this may result in interventions not being identified.

## INTRODUCTION

Acquired brain injury (ABI) and malignant brain tumour (MBT) are severe diseases that often share some similar symptoms that may impact the patient's cognitive, physical, social and psychological well-being. Symptoms depend on the injury or tumour location and may be physical (aphasia, hemiparesis, fatigue, apathy and seizures), psychosocial (anxiety, stress and depression) and cognitive (concentration problems, personality changes, reduced attention and short-term memory).<sup>1 2</sup>

Suffering from an ABI or MBT has significant consequences for both the patients and their relatives.<sup>3</sup> The significant consequences constitute new caretaking tasks for the relatives, leading to patients depending more on their relatives' support and advocacy.<sup>3</sup> The impairments may affect the patient's ability to enter a collaboration with healthcare professionals (HCPs) and participate in decision-making about their care and treatment.<sup>2</sup>

The importance of involving relatives in care and treatment is widely acknowledged within the healthcare system.<sup>4</sup> First, relatives may need to become active parts of the patients' care because they are influenced by the patients' clinical outcomes as their everyday lives are bound to be changed after diagnosis. Second, a relative's advocacy for the patient plays a significant role where the patient may be unable to communicate or act. Third, relatives can provide crucial emotional support and insights in terms of relevant information to optimise these outcomes.<sup>5</sup> Fourth, the involvement of relatives can contribute to a better quality of care and treatment, leading to a higher satisfaction with the hospitalisation for patients, relatives and HCPs.<sup>6</sup> Finally, research has shown that involvement of relatives over the course of disease is linked to better outcomes for individuals with brain injury.<sup>5,7</sup> Thus, facilitating relatives as active members of the treatment team may not only enhance unmet information and practical support needs,<sup>3</sup> but it may also benefit patients by optimising clinical outcomes.<sup>5,7</sup>

The relatives to patients with an ABI or an MBT have their own needs induced by the increased caretaking tasks.<sup>6</sup> Research shows that relatives to patients with an ABI or MBT often suffer from anxiety and depression, which may affect their ability to be involved in the patient's course of the disease.<sup>6,8</sup> Research has illuminated that relatives' have needs related to information and education, and support to adjust to the changed emotional, psychological and social aspects.<sup>3</sup> If these needs remain unmet, relatives may experience poor emotional and physical health, such as decreased well-being and a lower quality of life.<sup>9</sup> Little has been explored about relatives' needs for involvement in the disease trajectory of patients with ABI or MBT. However, a scoping review has illuminated the need for relatives of patients with ABI to be primarily related to information, communication and support from HCPs, which is important not only in being able to understand the situation, but also to be involved in care and decision-making.<sup>10</sup> On the contrary, a scoping review reporting on the wants and needs for involvement of relatives to patients with an MBT identified that relatives were already involved in the disease trajectory but expressed a need for a stronger connection with HCPs because their relatives' needs changed rapidly as the disease progressed. If HCPs are able to identify and ultimately meet relatives' wants and needs for involvement, this might improve their coping, patient satisfaction and high-quality nursing care. HCPs may be able to increase the capacity of relatives in their new role as caregivers if they can identify and use relatives' wants and needs for involvement in collaboration with their relatives.<sup>10</sup>

Involving patients and relatives in care and treatment has become a political necessity in many countries and in healthcare systems around the world.<sup>11</sup> However, little attention has been given to the conceptual meaning and intention behind the concept of involvement.<sup>12</sup> Involvement, shared decision-making and collaboration are all concepts closely related and are frequently used

interchangeably.<sup>11</sup> The fact that there is no clear understanding and definition of involvement and the intentions behind may influence the applicability of involvement in clinical practice, maybe because it also remains unclear to HCPs how involvement should be carried out.<sup>4</sup> Nevertheless, there seems to be some agreement that the meaning of involvement implies 'an active doing' and a collaboration or partnership between patient, relative and HCPs. In this scoping review protocol, we use the terminology 'involvement', which refers to relatives taking an active role in the individual care of the patient and in decision-making in all aspects of the care continuum and throughout the disease trajectory. Thus, involvement refers to different aspects of the care continuum, for example, participation in decision-making concerning treatments, sharing information and knowledge, goal setting, discharge planning, active involvement in nursing care and in exercises. The involvement of relatives should be limited to whatever level the patient is the most comfortable with or capable of appraising.

Over the past few decades, there has been an increasing interest in relatives to patients with ABIs' health and well-being, hence acknowledging that an ABI involves the whole family.<sup>13</sup> In relation to MBTs, it has been suggested that MBTs should be considered a 'family disease' and that patients and relatives should be conceptualised as a family unit rather than relatives being considered individuals separate from patients.<sup>14</sup> However, it still remains challenging to implement involvement in current practice, and studies showing how involvement can be achieved are lacking. Identifying the current evidence of interventions to involve relatives is assumed to be the first step in implementing new relative-involved routines. Scoping reviews enable researchers to summarise a range of evidence to convey the breadth and depth of a field.<sup>15</sup> If no appropriate interventions exist, then the results from the scoping review are needed to inform the development of new interventions.<sup>13</sup>

A preliminary search for existing scoping reviews and systematic reviews on the topic was conducted in Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library and PubMed in April 2020 and updated in December 2021. No relevant protocols or completed systematic or scoping reviews were found.

### Study aim and research questions

This scoping review aims to identify and map the available evidence on interventions facilitating the involvement of relatives through the course of disease in patients with an ABI or MBT by answering the following two research questions:

1. What are the key characteristics (type, duration, core elements) of the interventions provided by multidisciplinary healthcare professionals that facilitate the involvement of relatives in patients diagnosed with an ABI or MBT?
2. What outcomes/measures have been reported in the literature when testing or evaluating interventions

facilitating the involvement of relatives in patients with an ABI or MBT?

## METHODS AND ANALYSIS

We will conduct a scoping review following the Joanna Briggs Institute's (JBI) methodology.<sup>15</sup> The JBI reporting checklist was consulted when preparing this protocol.<sup>15-17</sup> In addition, the present protocol and future corresponding scoping review are reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Review guidelines (PRISMA-ScR).<sup>16 18</sup> A scoping review is a type of evidence synthesis that aims to systematically identify and map the breadth of evidence available on a particular topic.<sup>15</sup>

### Inclusion criteria

The research team has established the criteria for the inclusion of studies to be reviewed. Further clarification and refinement of the inclusion criteria are outlined below.

### Population

This scoping review will include studies in which the data are collected from participants who meet the following criteria: studies reporting on the involvement of relatives (18+) of patients (18+) with an ABI (traumatic brain injury and stroke) of any severity or MBT (WHO Grades 3 or 4). Relatives are identified by the patient as the person providing informal care. Informal care is generally defined as the unpaid care provided to older and dependent persons by a person with whom they have a social relationship, such as a spouse, parent, child, other relative, neighbour, friend or other non-kin.<sup>19</sup> We seek interventions provided by multidisciplinary HCPs (nurses, physiotherapists, occupational therapists, social workers, neuropsychologists, speech-language pathologists, oncologists, neurosurgeons and neurologists). Interventions focusing only on involving the patients will be excluded.

### Concept

The overarching concept of interest for this scoping review is all types of interventions facilitating the involvement of relatives through the course of disease in individuals with an ABI or MBT. By involvement we refer to different aspects of the care continuum where relatives can participate, for example, in promoting medication adherence or making decisions about treatment, being physically at the bedside, providing different practical aspects of nursing care provision or attending doctor appointments with the patient. The outcomes of the included interventions may produce/present both quantitative and qualitative data. Results will be reported both narratively, using qualitative data from, for example, semi-structured interviews and/or observations of intervention activities and/or quantitative, using data from, for example, questionnaires. The outcomes of the interventions may include, but are not limited to, improvement of the level of anxiety or depression, experienced satisfaction with the level and content

of information (the delivery of information and how this influenced relatives' involvement), quality of life, caregiver burden or shared decision-making. Key aspects of the intervention may include various intervention modalities, such as educational, emotional, informational, communicational, cognitive-behavioural, social or physical interventions. The mode of delivery of the intervention may include in person (individual, groups), online or telephone.

### Context

This scoping review will consider studies conducted in all settings (eg, inpatient and outpatient, primary care, long-term care institutions, homes, communities, hospice or other care facilities). The review is not limited to a particular country or healthcare system.

### Eligible study designs and studies

This scoping review will consider all types of quantitative, qualitative or mixed methods studies, reports or those describing interventions facilitating the involvement of relatives to patients with an ABI or MBT. Grey literature, such as dissertations, conference proceedings, reports and documents on organisational websites, will be included. Literature reviews of all types and designs will be excluded. Only studies in English, German or Scandinavian languages will be included because of time and budgetary constraints.

### Databases and additional sources

We will search the electronic bibliographic databases; MEDLINE (via PubMed), CINAHL (via EBSCO), Cochrane Library and EMBASE (via OVID). The search for grey literature will be conducted using websites such as Google Scholar, Grey Matters and Bielefeld Academic Search Engine (BASE). The reference lists of pertinent papers will also be searched.<sup>17</sup>

### Search strategy

A three-step search strategy will be used to develop a systematic search strategy. The first step, an initial and limited search on MEDLINE (via PubMed) has already been performed. After this first step, an analysis of the text in the title and abstract of the retrieved relevant studies and index terms used to describe the studies. Key terms will be determined through discussions between two authors (RG and IP) and a research librarian.

The second step will include a final literature search using all identified keywords and index terms across the four databases, Grey Matters and BASE. The search will be iterative as the authors become more familiar with the evidence bases; additional keywords, sources and search terms found to be applicable will be incorporated into the search strategy. Consultation with a research librarian will guide the design and refinement of the literature search. The search will use keywords and Medical Subject Headings (MeSH) terms (see [table 1](#)). The search date range filter of 2010–2022 is selected because of the increased scholarly focus on relative involvement since 2010; the

**Table 1** Search terms

Participants/population	Concept	Context (family)	Context (involvement)
Acquired brain injury	Intervention	Relatives	Involvement
Stroke	Measures	<b>Family</b>	Family needs
<b>Brain injuries</b>	Measurement	Cares	<b>Decision-making, shared</b>
Glioblastoma	Scales	Family relations	Relative involvement
Brain cancer	Instruments	Wife	Shared decision-making
Malignant brain tumour	Assessment scale	Husband	Continuity of patient care
Glioma	<b>Knowledge</b>	Partner	<b>Patient participation</b>
	<b>Education</b>	<b>Child</b>	<b>Family practice</b>
	Information	<b>Spouse</b>	Collaboration
		<b>Siblings</b>	
		Brother	
		Sister	

Highlighted in bold: MeSH (Medical Subject Headings) terms.

context for the involvement of relatives has changed markedly since 2010 because of a growing elderly population, the introduction of fast-track programmes and shortened hospital stays. Because of the extension of the time frame for conducting the scoping review, an update of the search was conducted in August 2022.

A full search strategy for the PubMed database is provided in online supplemental file 1.

In the third step, the reference list of the identified reports and articles will be screened for additional studies. The titles and abstracts of all identified studies potentially eligible for inclusion in the review will be screened, and full-text versions of included articles will be obtained. The authors of primary studies may be contacted for further information, if needed.

### Study selection

All studies will be identified through the databases, and hand searches will be exported into EndNote X8.1 software (Clarivate Analytics, Pennsylvania, USA). Duplicates will be removed before each entry is screened for eligibility. Then, all the titles and abstracts of the retrieved studies will be uploaded to the Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia) for conducting the screening process.<sup>20</sup> The results of the searches will be summarised and presented in a PRISMA-ScR flow chart.

Study selection will be conducted in two stages. First, titles and abstracts will be screened against the inclusion criteria by the entire research team. Then, all potentially relevant full-text studies will be retrieved and screened for inclusion in the final review by the entire research team. Any disagreements will be resolved through discussion and consensus within the entire research team.<sup>16 18</sup>

### Data extraction

According to the JBI methodology, a data extraction tool will be developed to ensure the extraction of relevant information from the selected studies (online supplemental file 2).<sup>15</sup> This will enable a logical and descriptive summary of the findings aligning with the objective and

research questions of the review. Further, it will facilitate the identification of potential gaps in the literature. The data extraction tool will be inspired by the TIDieR (Template for Intervention Description and Replication) checklist items.<sup>21</sup> The data extraction tool will be trialled on three studies to test whether adequately detailed information on the included studies will be obtained. The first two authors will independently extract the data from the included studies using the developed data extraction tool. The key information included in the data extraction tool will be as follows:

- ▶ Author(s).
- ▶ Year of publication.
- ▶ Country.
- ▶ Methods.
- ▶ Study design.
- ▶ Setting.
- ▶ Study population.
- ▶ Key aspects of the interventions facilitating the involvement of relatives:
  - Type of intervention.
  - Modes and provision of the intervention.
  - Duration, intervention intensity or dose.
- ▶ Primary and secondary outcomes of the intervention.

If the data extraction tool requires any revision, it will be discussed and decided on by the research team. Any modifications will be detailed in the final scoping review. The authors of the included studies will be contacted to request missing or additional data, if required.

### Collating, summarising and reporting the results

As recommended in the JBI scoping review guidelines, the results from the data extraction tool will be collated and summarised in a tabular form accompanied by a descriptive summary relating the key findings.<sup>16</sup>

### Patient and public involvement

No patients or the public were involved in the design and conception of this study. However, a panel of relatives will be involved in reviewing the results after publication of the scoping review protocol. We anticipate that, by including

the relatives in this stage of the research process, it will validate and nuance our findings into a national context, making the findings relevant to relatives. The perspectives and knowledge from the panel are important because it is the first step in a complex intervention aiming to develop an intervention facilitating relative's involvement in the patient's care and disease trajectory. In addition, a panel of HCP within the neurosurgery specialty will be consulted prior to submission of the scoping review. We anticipate that the HCP may provide great insight about how to present our results to ensure optimum knowledge uptake by clinicians.

## DISCUSSION

This protocol outlines the methodology as recommended by the JBI methodology, which will be used to guide our scoping review.<sup>15</sup> This is an essential step in the review process because it ensures that the final scoping review has been carefully planned and documented to promote comprehensiveness, rigour, transparency and a focus on applicability to clinical practice.<sup>22</sup>

The primary outcome of the present scoping review will be a summary of interventions facilitating the involvement of relatives through the course of disease in patients with an ABI or MBT. From the included studies and using a data extraction tool inspired by the standardised tool TIDieR checklist, the authors will provide a descriptive summary of interventions facilitating and enhancing the involvement of relatives through the course of disease to patients with an ABI or MBT. Using tools such as the TIDieR checklist allows researchers to use a common language when reporting the design of their interventions and ensures that there is enough information present to allow for replicability of interventions, thus allowing for an increased ability to implement research results into practice.<sup>21 23</sup>

The review resulting from this protocol will summarise how interventions are being reported, who the participants are, the providers of the interventions and the outcomes of these interventions. The findings from this review may guide future research in developing intervention studies to achieve involvement and accommodate relatives' support needs. The review might also contribute to the development of a valid tool for clinical practice to systematically identify the relatives' changing needs for involvement at different stages of the care and disease trajectory, including information delivered at appropriate times to ensure that relatives feel prepared and supported when they assume their caregiver role at home. An initial step in this process is to determine which intervention components are being frequently used.

## Schedule

- ▶ October–December 2021: Initial literature search and protocol writing.
- ▶ January–August 2022: Protocol writing, development of search strategy and literature search.

- ▶ September–October 2022: Screening, charting and collecting data.
- ▶ November–December 2022: Analysis and writing scoping review.
- ▶ February 2023: Submission of the final scoping review, involvement of a panel of relatives and HCP.

## ETHICS AND DISSEMINATION

This paper presents the protocol for a scoping review of interventions targeting the involvement of relatives in patients with an ABT or MBT. The study has been approved by the Danish Data Protection Agency (ID P-2020–547). This review will advance knowledge of the way relatives are involved in care and disease trajectory when a significant other has sustained an ABI or MBT. The results will be disseminated through a peer-reviewed journal and reported at local, national and international conferences on brain injuries and brain cancer.

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**Contributors** RG (corresponding author) has contributed to the planning, conducting, reporting of the work and has submitted the study. SN, LA, MIL, MAV and IP have contributed to the planning, conducting and reporting of the work. MAV has contributed to the planning, conducting and reporting of the work. RG is responsible for the overall content as guarantor and accepts full responsibility for the work and the conduct of the study, had access to the data and controlled the decision to publish. The corresponding author attests to the fact that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

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