How can healthcare professionals work with families to address misaligned expectations of recovery in brain injury rehabilitation? A scoping review

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BIOGRAPHIES

1. Jessica Blake is a Specialist Neurological Occupational Therapist and aspiring clinical academic working in specialist inpatient neurorehabilitation in Norwich, United Kingdom (UK). Jessica also has a background in healthcare research, working as a Senior Research Associate on a range of projects utilizing qualitative and mixed methods methodologies including; community involvement in end-of-life care, research implementation in care homes, occupational therapy student placement models, and sleep interventions for people living with dementia.

   Jessica has recently been awarded an National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (ARC EoE) Research Fellowship. As part of this fellowship, she is exploring how the expectations of families of brain injured patients are addressed when these are misaligned with clinical opinion (MERIT study). Jessica has since been awarded a Higher Education England (HEE) fellowship with University of East Anglia (UEA) to support her development as a clinical academic, where she will use the findings of the MERIT study to develop a doctorate application.
2. Guy Peryer is a chartered psychologist and chartered scientist. He has a PhD in applied psychology and complex systems. He has worked as a lecturer in Health Sciences and as a senior research fellow within NIHR Applied Research Collaboration East of England (ARC EoE). He is now Director of Education and Research at St Christopher's Hospice in London, UK.
3. Rachel Dance is a Senior Stroke Physiotherapist at the James Paget University Hospital (JPUH) NHS Foundation Trust in Norfolk, UK. A graduate from UEA MSc.

Physiotherapy (pre-registration) in 2014, she has more recently completed a pre-Masters research internship in 2023. This has since led to a balanced role of acute stroke clinician and embedded researcher.

A grateful recipient of UEA HSCP Catalyst Scholarship funding, she is currently co-leading a program to improve semi-supervised practice in the acute setting. Other ongoing projects include 'Right to Rehab'– a co-designed training program to upskill health care assistants working on the stroke ward. She is also currently working on a systematic review exploring factors influencing stroke survivor physical activity in acute and subacute stroke units.

4. Dr Sheryl Parke is a Highly Specialist Clinical Psychologist working part-time in the National Health Service (UK) in specialist neurorehabilitation services and part-time as a Clinical Lecturer on the UEA MSc Clinical Associate in Psychology degree apprenticeship course.

   Sheryl is interested in research in clinical neuropsychology, the use of creative approaches to support fatigue following brain injury, and how to support families and carers following a family member having a brain injury. She also has a keen interest in workforce sustainability of the psychological professions.

   Sheryl trained as a Clinical Psychologist at UEA with her doctoral thesis researching how mindful music listening can impact on workplace stress and cognition. She is currently undertaking further specialist training in Clinical Neuropsychology at the University of Bristol. She is the coordinator of the National Network of Clinical Psychologists working in Specialist Neurorehabilitation.

5. Dr Aidin Aryankhesal, currently a Senior Research Associate at UEA, brings approximately 15 years of experience in healthcare management, health systems, and health policy. His research and teaching expertise spans a broad methodological spectrum, encompassing qualitative methods, such as grounded theory and ethnographic studies, as well as quantitative approaches, particularly systematic reviews and meta-analyses. Over the past two years, he has contributed to the TIMES project, which investigates sleep management strategies for individuals living with dementia.
6. Morag Farquhar is Professor of Palliative Care Research at UEA. She has conducted health services research for over 30 years, predominantly in supportive and palliative care (London/Manchester/Cambridge universities and UEA). An early graduate nurse (King's College London), with an MSc in Medical Sociology, her PhD (University of London) addressed the definition and measurement of quality of life in older people. Research interests include person-centered care, unpaid/family carers, breathlessness in advanced disease, and developing/testing of interventions using mixed methods. Programs of work include the development and dissemination of the Support Needs Approach for Patients (SNAP: https://thesnap.org.uk/), a web-based resource for unpaid/family carers of breathless patients (https://supporting-breathlessness.org.uk/), and a novel Carer Support Nurse role (https://arc-eoe.nihr.ac.uk/research-implementation/research-themes/palliative-and-end-life-care/carer-support-nurse-pilot). She co-developed version 3 of the Carer Support Needs Assessment Tool (CSNAT) and has subsequently been part of the CSNAT Intervention team (CSNAT-I: https://csnat.org/). She is also Theme Lead for the NIHR Applied Research

Collaboration East of England's Palliative & End of Life Care Theme (https://arc-eoe.nihr.ac.uk/research-implementation/research-themes/palliative-and-end-life-care) and co-leads NIHR Applied Research Collaboration's Palliative & End of Life Care National Forum (https://arc-eoe.nihr.ac.uk/leading-nihr-forum-improving-palliative-and-end-life-care-across-england).

How can healthcare professionals work with families to address misaligned expectations of recovery in brain injury rehabilitation? A scoping review

INTRODUCTION Most survivors of severe acquired brain injuries will have significant long-term disability. During inpatient rehabilitation, families often have expectations of recovery that do not match healthcare professional opinion. This impacts on patient care, service processes, professional-family relations, and wellbeing. This review aimed to understand how family expectations are managed in this setting, and to explore potential areas of improvement.

METHOD A scoping review was conducted by searching CINAHL, Medline, EMBASE and Web of Science. Krieger et al's 'Conceptual Building Blocks' provided a framework to analyze the data using a 'best fit' framework synthesis approach.

RESULTS Twenty-one papers were included in the review. Six sub-themes within three overarching themes were generated, which explored recommendations for effective expectation management. The sub-themes within the 'staff behaviors' theme were 'appropriate information provision', 'open communication' and 'prioritize family'. Sub-themes within 'system behaviors' were 'cultural change' and 'increased resource'. 'Rehabilitation as a shared process' was the third theme.

DISCUSSION Misaligned expectations of recovery appear to reflect a range of unmet family needs related to their position within the healthcare hierarchy, professional-family communication, and their involvement in rehabilitation processes. Early identification of family and healthcare professional expectations alongside regular review may prevent misunderstanding and conflict.

Keywords: brain injury, rehabilitation, family, expectations, hope, uncertainty, bad news

INTRODUCTION

Most people who sustain severe or moderate acquired brain injuries face significant long-term consequences. 60-67% of survivors have moderate to severe disability upon discharge from hospital, often comprising a range of physical, cognitive, emotional, and behavioral changes (1-3). Prognostication following brain injury can be uncertain. For example, 50% of traumatic brain injury patients requiring inpatient rehabilitation deteriorate or die within 5 years of their injury, whilst 20% make improvements sufficient to live at home independently (4, 5). Specialist inpatient neurorehabilitation therefore comprises three pathways: restoration of function, disability management and neuro-palliative rehabilitation, all of which may change, oscillate, or overlap during an admission (6). Regardless of the pathway, rehabilitation of people with severe acquired brain injury requires more investment in terms of human, structural, and technological resource than any other disability (7-9). The severity of the injury, intensity of treatment, and recovery uncertainties place significant emotional burden on family members (3).

In this context, families can have hopes and expectations of their relative's recovery that are not met during inpatient rehabilitation. Healthcare professionals (HCPs) often perceive families as having over-optimistic expectations that need to be managed, although pessimistic or conflicting views between relatives also occur (10-12). These misaligned expectations can cause HCP-family conflict that is difficult to resolve, reduce service satisfaction and hinder service processes, including discharge planning (10, 13). HCPs spend significant physical and emotional resource addressing these expectations, which can be a distressing process for them as well as for families and patients. (14).

To date, there are no evidence-based interventions or guidelines for effective

expectation management in brain injury rehabilitation that could be tested, nor is there a literature review exploring the topic area in detail. For example, guidelines from British Society of Physical and Rehabilitation Medicine and National Institute for Clinical Excellence (NICE) for stroke and neurorehabilitation acknowledges the need to 'support' and 'train' families alongside patients, but does not mention their expectations or how these may be managed. (6, 15). In recognition of this paucity, a scoping review was conducted. The purpose of the scoping review was to generate hypotheses about effective practice for future testing, as there is currently not enough data to test a hypothesis as part of a systematic review (16). Evidence from a range of academic disciplines was therefore sought to deepen understanding and identify evidence gaps as a precursor to further research.

Review Questions

RQ1: How do healthcare staff work with families (of brain injured patients in inpatient rehabilitation) to address misaligned expectations of recovery?

RQ2: What factors help or hinder effective expectation management?

RQ3: What are the areas of improvement when managing the expectations of family members in this setting?

METHODS

The scoping review protocol was registered on Open Science Framework on 6th June 2024 (17). A preliminary search of MEDLINE and the Cochrane Database of Systematic Reviews identified no current or underway scoping or systematic reviews on the topic.

Eligibility Criteria

A date limit of 20 years was set to balance recent medical advances with adequate data quantity. These advances are relevant to this research, as improved medical care has meant more people with severe brain injuries are surviving with significant long-term disability (18). Pediatrics and end of life care were excluded, anticipating that families of these patients were likely to have specific support needs that may not be generalizable. Exclusion of non-OECD countries was also added to improve generalizability, as the mechanism of injury, treatment and outcomes in brain injury differ significantly between high and lower-middle income countries (19-21). Studies in critical care setting were excluded, as this is before the inpatient rehabilitation phase. Similarly, studies that focused on the patient on or after discharge and that did not also involve experiences of the inpatient rehabilitation phase were also excluded (table 1). Literature reviews were excluded, but references within relevant reviews were hand searched.

Table 1

Table 2

JB and GP devised and refined the search terms (table 2). JB conducted database searches on Medline (PubMed), CINAHL (EBSCO), EMBASE (Ovid) and Web of Science between 26th September and 10th October 2023 (figure 1). JB hand searched the references of included papers and completed forward citation tracking where possible.

Figure 1

Data Extraction

JB compiled a study characteristics table comprising date of publication, study design, methodology, country of origin, participants, setting, and findings (appendix 2). This was to determine how recent the literature was, what types of data were included, the generalizability of the findings to inpatient rehabilitation in the United Kingdom, and who was and was not represented within the study. As this review aimed to explore family expectations of recovery, it was particularly important to understand whether family voices were well represented in the literature, and by what method this data was obtained.

As this review aimed to give a general overview of the current evidence base as a precursor to more extensive study and did not aim to test a hypothesis, critical appraisal of the literature was not conducted. This is in line with current PRISMA guidelines for scoping reviews (22).

Data synthesis

The study adopted a framework synthesis approach to enable what was anticipated to be an unwieldly data set to be organized coherently and efficiently, and to enable a more consistent interpretation of the data between researchers. The five steps of framework analysis (familiarization, identifying a framework, indexing, charting, mapping and interpretation) were followed (23). Therefore, after familiarization with the literature included within the review, a framework was sought to extract and process the data using the ‘best fit’ framework synthesis approach (24). The ‘best fit’ approach recommends completing a second literature search to identify relevant frameworks as a ‘best fit’ for data analysis. JB therefore completed

an additional search for relevant frameworks using the BeHeMoth search strategy (table 3) (25).

Table 3

JB conducted the 'best fit' searches on Medline, PsychInfo, and CINAHL (figure 2) on 23rd May 2024. In line with the 'best fit' approach, relevant frameworks or models included within the literature were evaluated for relevance to the topic area and potential applicability to the review question. Of 4,243 results, seven papers contained relevant frameworks. Of these, three were excluded due to the parameters of the framework not being clearly defined (26-28), and two frameworks focused exclusively on goal setting and therefore would not capture the breadth of data within the literature (29, 30). The Family Resilience Framework (31) was trialed by SP and JB but then discounted, as the focus on family resilience was too narrow in the context of expectation management. The framework described in Krieger et al. (32) was therefore used as a 'best fit' to support data analysis. This study describes the 'Conceptual Building Blocks' needed to develop a complex intervention for stroke caregivers. Whilst the study is not specifically about expectation management, it is centered around the development of interventions to support family members of people with brain injuries and includes experiences within the inpatient rehabilitation phase. The framework comprises a clear yet comprehensive range of relevant themes and appeared to be a helpful way to organize this complex data set (appendix 1).

Figure 2

JB indexed data against the 'Conceptual Building Blocks' framework, after piloting it with SP and AA to confirm suitability. 10% of papers were independently indexed by AA and then

compared, with discrepancies discussed and reflected upon. Data that did not fit within the framework was categorized as 'other' and was subject to secondary thematic analysis. JB then charted the data. The results informed the generation of six exploratory themes by JB, RD, MF and GP as part of the mapping and interpretation phase. The study results were then sense-checked by Patient and Public Involvement and Engagement (PPIE) representatives from a local group for carers of people with brain injuries.

RESULTS

Screening

8,902 studies were screened for eligibility for the scoping review. Twenty-one studies were included, including three studies identified through hand-searching. Appendix 2 provides a summary table of included studies.

Of the 21 papers, six originated from Canada (33-38), five from the UK (10, 14, 39-41), four from Australia (27, 42-44), two from New Zealand (45, 46) and USA (47, 48), and one each from Denmark (49) and Italy (7). Three papers were published in the last five years (7, 14, 42). Most were published in healthcare and rehabilitation journals. One study was a sociology paper (40), and one was a PhD thesis (10).

Seventeen studies were qualitative, two were quantitative (7, 10), one was purely theoretical (27), and one was Participatory Action Research (46). Eight of the papers were stroke specific (36, 37, 40, 42, 44, 47-49) , five explored traumatic brain injury (33-35, 38, 46), five explored acquired brain injury in general (7, 10, 27, 43, 45), and three explored neuro-rehabilitation, including brain injury (14, 39, 41) . Fourteen papers included

unpaid/family caregivers or family members as participants, whilst six included HCP perspectives exclusively.

Key Themes

Six sub-themes were generated which fell into three themes: ‘staff behaviors’, ‘system behaviors’ and ‘rehabilitation as a shared process’ (figure 3). In line with aims of the scoping review, themes and sub-themes were generated as exploratory hypotheses for the improvement of expectation management in this setting.

Figure 3

System Behaviors

Cultural Change

Healthcare culture, which continues to be influenced by the biomedical model, privileges the opinion of professionals and the needs of brain injured patients over family members (7, 34, 35). This power imbalance was identified as a barrier to effective HCP-family communication and collaboration (7, 11, 27, 33, 37, 41, 48, 49). Family members reported feeling overlooked and not listened to during the rehabilitation process. When their views conflicted with professional opinion, relatives could be branded as ‘difficult’ and their involvement in rehabilitation and decision-making could be limited (11, 33, 49).

> In rehabilitation we were told, ‘‘We need the relatives…to find out what happened with this trauma injury, to know how the accident victim is doing’’. But when you tell them about how things have gone, they do whatever they want. I often had the feeling that they weren’t listening to me, that it was always the practitioners who had the final say. They were always right’. (33)

Although family views were underprivileged in healthcare settings, HCPs expected that families would provide information about the relative, observe and report any changes in their condition, and attend meetings and therapy sessions, which may be some distance away from their home and during working hours (36, 38, 48, 49). They were also expected to engage in training to perform care and rehabilitation tasks. Failure to meet these expectations resulted in HCPs assuming that family members were less competent or committed to care for their relative. Family members could therefore feel under pressure to comply with HCP expectations in terms of their availability, conduct, skill acquisition, and adoption of caregiving duties upon discharge (27, 34, 40, 48).

> Professionals assumed there would be one family member willing to take on the role of main carer, with the assumption that whoever was NOK (commonly spouse or adult child) would be the designated main carer, followed by a process of assessing that person's suitability. (40)

Increase Resource

Lacking the resource to manage the needs of families, in addition to the complex needs of patients, was reported as a key barrier to developing healthy HCP-family relationships. HCPs reported a lack of time and availability to provide patients with the expected level of rehabilitation and to support family members (34, 35, 39, 42, 44, 49). Pressures on length of hospital stay also reduced the time available for families to come to terms with what is often a sudden and catastrophic event, and to be adequately prepared to support their relative on discharge (40, 42, 47-49).

> I would like to give more time to families but feel constrained by my workload for the shift and sometimes you see husbands or wives or carers and you know in your heart they are finding things difficult and that is very hard and I feel it's part of my work… (SA1) (44)

Working with families in this setting was perceived by HCPs as demanding and required

significant emotional resource (7, 14, 33-35, 39, 49). The reviewed papers reported HCPs' feelings of fear, powerlessness, or failure when delivering bad news to family members (14, 33, 39). When faced with the uncertainty of brain injury prognostication, some HCPs feared giving families the wrong information, causing upset or false hope (33, 35, 44, 49). Discomfort with these conversations sometimes resulted in HCPs' avoidance of these discussions altogether and emotional withdrawal (33, 34, 39). HCPs reported feeling ill-equipped to deal with these conversations and highlighted communication in these scenarios as a training need (14, 33, 35, 39, 49). These difficulties spanned healthcare professions but were more pronounced among less experienced staff.

> One particular case in the last few months that has kept me up at night, has had me worried sick about coming into work. Worried about how I was going to approach that family, how I was going to deal with it. (Participant H, more than 5 years' experience) We are dealing with long term disability and we're almost dealing with the acute stages of anger and coming to terms, [it] can be really emotionally hard for the therapist as well. (Participant I, less than 2 years' experience) We feel responsible, particularly as a caring profession. Sometimes it's hard on us because we can't make them better. (Participant J, between 2 and 5 years' experience) (14)

Staff Behaviours

Appropriate Information Provision

Updating families with regular clear and accurate information about the patient and their progress was important and influenced relatives' satisfaction with services (7, 27, 33-36, 38, 46, 49). Family uncertainty, feeling unprepared for discharge, and less collaboration were reported by both families and HCPs as consequences of inadequate information provision. Both families and HCPs highlighted the importance of accessibility (14, 27, 33, 34, 37, 43, 44). This included avoiding medical jargon and being mindful of overloading families with

too much information. It was acknowledged by HCPs that the stress of the situation may affect comprehension and absorption of information (34, 37, 44, 47). Repeating information and providing it in a range of formats, such as in writing, verbally and in formal meetings, was recommended by both families and HCPs to support understanding. Having a consistent single point of contact to co-ordinate and facilitate communication between families and the supporting team was also seen by both parties as helpful and increased trust (11, 14, 34, 36, 46).

Families reported that information was rarely volunteered and that they would have to spend time seeking it out (33, 35, 43). However, some HCPs found it difficult to ascertain how much information to give family members and when (34, 36, 44). HCPs also acknowledged that families would be accessing information about brain injury from a range of sources outside of the healthcare setting, including friends and family, the internet, and books, and that care providers must be prepared to engage with this learning (14, 37).

> There was consensus that carers who are experiencing heightened levels of stress have difficulty retaining verbal information. It is hard for them to take it all in, in the beginning they are so stressed and so anxious they can't retain the information and that is why I think it is important that it [information] is reinforced for them. (A)(44)

> The more staff provided ICs with prompt and accurate information about the patient's care and treatment and keeping them updated regarding key decisions, the more the caregivers actively participated in the care treatment process, in both its delivery and design. (7)

Families and HCPs highlighted the importance of practical information to facilitate collaboration in rehabilitation and support their transition to a caregiving role upon discharge

(7, 27, 34, 36, 39, 40, 42, 44, 46, 47). This included training in activities of daily living and rehabilitation strategies. This practical support allowed families to make informed decisions based on a better understanding of the patient's condition.

> Participants also made use of the client's family members to reinforce the information given in the bad news conversation. Therefore, ensuring that family members had seen the person carrying out a task or 'doing something' was seen as important: The family, sometimes I invite them to a therapy session … and that's really helpful if they can see what's going on … seeing something makes you understand so much better (participant 002).(39)

Open Communication

Twelve studies emphasized the importance of maintaining hope during the rehabilitation process (10, 11, 14, 27, 33, 35, 37, 39, 42-44, 46). Hope was considered by HCPs and families as a 'therapeutic and powerful' tool that supported the family's involvement in rehabilitation, their wellbeing, and resilience (10, 14, 27, 43). Some papers reported that HCPs were not hopeful enough, and that there was too much emphasis on avoiding 'false hope' (27, 43). HCPs were encouraged to communicate with positivity and optimism about the possibility of improvement. However, several studies advised that this optimism should also be realistic (11, 14, 27, 39) and acknowledged the difficulty of balancing these two principles. It was reported that the definition of 'improvement' may be different for HCPs and families, which might lead to misaligned expectations of recovery (38, 47, 48). Recommendations to support realistic optimism included adopting a strengths-based approach that focussed on a person's abilities rather than disabilities, being positive about the likely benefits of rehabilitation interventions, and family involvement in goal planning.

> On one hand we want to give people hope but on the other we need people to be at least in the right frame of thinking. (Participant C, more than 5 years' experience)(14)

> Many family members expressed concern that the rehabilitation process did not adequately foster hope. They reported receiving information from clinical staff was “the worst case scenario” (SO 6 and 13) or “doom and gloom” (SO 1 and 6). They said that such information, delivered in meetings left them feeling fearful and “never coming out of it feeling better” (SO 6). (43)

It was important to both families and HCPs that communication about a patient’s progress was clear and honest (7, 14, 33-35, 38, 39, 42). However, this was not always achieved. Answers to difficult questions, or where there was uncertainty, were often vague or avoided altogether by HCPs. This appeared to be linked to HCPs’ anxiety about making errors that may cause further distress, avoiding false hope, or their discomfort with communicating uncertainty (14, 33, 35, 39, 44, 47, 49). However, some families interpreted this lack of information as purposeful hiding of the truth or incompetence, which adversely affected HCP-family relationships and the family’s adjustment process (14, 33-35). HCPs reported frustration at not being able to alleviate family uncertainties, as they faced the same uncertainty themselves (14, 33-35, 39, 44, 47). An uncertain prognosis combined with the complexity of brain injury made managing family expectations very difficult. It was recommended in two research articles that HCPs disclose these uncertainties to families to maintain trust and align expectations (33, 34).

> Patients and above all the family tended to feel frustrated at not getting answers. They often felt ignored and wondered whether clinicians were being honest with them. Most participants said that this lack of communication undermined the confidence of the patients and their families, because they had the feeling that the physicians and professionals were ‘hiding the truth’.(33)

> I think it’s about being clear in the things that you’re saying ’cos sometimes you can put so much fluff around it that actually the actual message doesn’t get through. (Participant F, between 2 and 5 years’ experience) (14)

In additional to retaining hope, managing uncertainty, and communicating clearly, communicating with empathy was key. Families wanted to feel cared for and listened to, with acknowledgement of the emotional and practical hardship they were going through as they navigated the significant life changes that accompany a severe brain injury (27, 34, 39, 41-44, 46, 49).

Prioritize Family

Healthcare services' focus on caring for a brain injured patient as an individual often came at the expense of family needs (11, 35, 36, 48, 49). Family members were supported to learn skills in preparation for future caregiving. However, this would usually be later in the rehabilitation process without sufficient time to embed the learning, and without thorough assessment of their capacity and understanding of the caregiving role. The emotional and psychological wellbeing of families was also frequently overlooked by HCPs, as was the understanding that each family is unique and needs tailored support (37, 46, 48). Two papers highlighted the challenge of balancing the needs of both patients and their families, particularly when family expectations conflicted with the patient's best interests (11, 49). Assessment and intervention to support family wellbeing and readiness for caregiving were proposed by HCPs as possible solutions to ensure they were adequately supported and prepared to meet the long term needs of the patient (11, 14, 34-36, 46, 48). Peer support from families in similar situations was recommended by HCPs and families to provide emotional support, enhance coping, and aid preparation for the future (34, 36, 43, 44, 46).

It was acknowledged by both families and HCPs that the expectations of family members changed as their relative moved through the care continuum and families went

through their own complex process of adjustment [34-38, 45, 47-49]. There is limited time available during acute rehabilitation for families to grieve following a severe brain injury, and this could hamper relatives' acceptance of discharge processes (42, 44, 47, 48). Both parties saw early intervention as an important strategy to help families anticipate the likely outcomes of the injury to prepare for the future, and to make more informed decisions about care (10, 11, 34, 36, 42, 46-48). These interventions might include education about the injury and its consequences, practical training, orientation to the rehabilitation setting, involvement in goal setting, and building rapport. A keyworker fulfilled this role in two studies (14, 46). One paper described the benefit of having rehabilitation co-ordinators based in local hospitals to manage the transition between settings (46). However, most studies did not identify a specific profession to support this early intervention.

> Personally speaking, I think it saves a lot of firefighting down the track ... just that whole communication thing. If you're being open and talking to the patient right from—and the family—right from the beginning, there won't be any surprises down the track, like 'What do you mean the patient's coming home like this?' (11)

Rehabilitation as a Shared Process

Encouraging family members to be involved in patient care and therapy helped foster their sense of inclusion in rehabilitation processes and facilitated understanding of the patient's current level of ability [16, 27, 35, 37, 40, 41, 47, 50]. However, some family members reported that they were not considered as assets to the patient and rehabilitation team and felt excluded [35, 36, 39]. In some instances, family involvement was a controlled event, where families were invited to sessions with permission from HCPs but were not actively involved (35, 40). Involvement could also be restricted by HCPs when family members were seen to be working against the interests of the patient or when HCPs wished to retain control of care

decisions (7, 11). However, HCPs reported that some families were reluctant to be involved in rehabilitation or needed prompting to do so, particularly when their expectations were pessimistic (10, 49).

> It's a good opportunity when they [family carers] come in, I think you can sit and talk to them about what the patient's able to do, but until they see it they haven't really got a grasp perhaps or a concept of what they're doing or how they're doing. (physiotherapist, control site) (40)

> According to the majority of families, physicians and professionals should recognize their skills and knowledge. The family is the expert on its situation of everyday life with the person with TBI. (35)

Goal setting with family members was considered helpful to elicit buy in to rehabilitation processes. Family involvement was essential for person-centered goal setting, as relatives were able to share knowledge of the patient's premorbid values and interests if the patient was unable to disclose this themselves (46). Working towards shared goals facilitated a sense of focused collaboration between families, patients, and staff. Setting short term goals enabled family members to appreciate the steppingstones and time required when working towards a more ambitious long-term goal (11, 39, 41, 46). However, family involvement in goal planning was sometimes avoided by HCPs due to the high expectations of family members and the stress this might place on the patient (11).

> I think that in many respects actually, the goals are possibly more of a reality check for the family … it's a tricky balance between hope and um, and acceptance of what is going happen (Elaine)(11)

Collaboration with families, as opposed to just involvement according to HCPs, families, and patients, develops mutual trust and recognizes the strengths and experience of all

stakeholders (7, 27, 33-35, 38, 39, 46, 49). Using this approach, families are active participants and equal contributors to a patient's rehabilitation, contributing to goal setting, therapy programs, and problem-solving. This partnership reduces the risk of conflict as the family is included within the rehabilitation team on equal terms and is present as a decision maker. One paper suggested that collaboration in this manner may support family adjustment to the significant lifestyle changes that are necessary following a severe brain injury (42). However, some HCPs were concerned that some families lacked the necessary skills to collaborate in care processes (7, 35)

> Throughout rehabilitation, education is seen as a two-way process because the rehabilitation professionals are experts in brain injury recovery, and the family members are the experts in the history and life roles of the client. (46)

The reviewed evidence suggests there is relationship between the three overarching themes (figure 3). For example, healthcare professionals' increased awareness of the impact of power dynamics (system behavior) on family-professional relationships may support more effective collaboration (rehabilitation as a shared process) [9, 35, 36]. Conversely, treating rehabilitation as a shared process may, over time, encourage positive staff and system behaviors, as the advantages of collaboration are appreciated and embedded within healthcare culture. Due to the exploratory nature of this review, the exact nature of these processes would need further study.

DISCUSSION

This review indicates that families that a range of factors contribute to misalignment between HCP and family expectations, and as a result there are multiple ways to address it. One key contributing factor is that family members' needs and opinions are not always prioritized. This means that family expectations of recovery may not be identified or addressed during a

patient's rehabilitation until discharge planning commences and conflicts arise. Ensuring that the needs and expectations of family members are identified early and are regularly reviewed may prevent this conflict. The Carer Support Needs Tool (CSNAT) is an evidence-based tool that has been used in palliative care to identify the individual needs of family carers and prompt tailored support (50). Adaption of the CSNAT for families of people with brain injuries may enable HCPs to better understand and address individual family needs, avoiding misaligned expectations and any resulting conflict.

Improving communication between HCPs and families is needed to ensure both parties know what to expect. The importance of staff training in 'bad news conversations', is described in The National Service Framework for Long Term Conditions (51), a 10-year United Kingdom government policy for people living with long-term neurological conditions. It is recognized that the delivery of these conversations impacts the quality of HCP-family relationships and facilitates adjustment to a life-changing diagnosis (52). However, where there is prognostic uncertainty, information sharing between HCPs and families is inhibited and these conversations are less likely to take place.

The concept of communicating uncertainty has been explored extensively in palliative care research (53, 54). Uncertainty is also acknowledged within recent clinical guidelines for the treatment of those in Prolonged Disorders of Consciousness (55), but this predominantly relates to survival and the withdrawal of life sustaining treatments in its early management. Therefore, in the context of brain injury rehabilitation, HCPs may benefit from more support to communicate uncertainty and to deliver 'bad news' conversations. The emotional impact of these discussions on HCPs was a key finding within this review. Alongside formal training, increased opportunities for supervision and emotional support may therefore be of benefit.

Collaboration between HCPs and families was identified within this review as an important way to develop shared expectations. Collaboration, as opposed to merely 'involvement', emphasized the need for families to be considered as equal partners within the rehabilitation process. Goal setting is a well-documented approach to joint working that appears to be well implemented (11). However, greater consideration is needed to support collaboration in other areas of the rehabilitation process, such as equipping willing family members to deliver rehabilitation interventions outside of therapy sessions and improving HCP confidence in family members' competency. This may improve patient outcomes and improve family understanding of the patient's needs well before discharge.

Some of the themes within this study may appear common sense and may therefore be perceived by HCPs to be something they are already doing. However, PPIE conversations about the findings of this study indicate that this is not the case. The reviewed literature, combined with these discussions, revealed several areas of 'unconscious incompetence' (56), where HCPs seem unaware of the impact of an action on HCP-family relationships and expectations. For example, postponing a conversation until an outcome is more certain was perceived by some families as HCPs hiding the truth. Further understanding of these 'unconscious' areas may benefit clinical practice and merits further study.

Hope was a key theme within the review, with several papers identifying the need for HCPs to maintain a realistic optimism about recovery to support family coping and adjustment. 'Unrealistic optimism', when personal future outcomes are predicted with excessive positivity, is a widely reported phenomenon within psychological research (57). Whilst these beliefs can result in negative consequences, such as undesirable health behaviors, the literature also acknowledges potential psychological, emotional and physical

benefits (58). The costs and benefits of 'unrealistic' expectations for families and patients therefore warrants further exploration before an intervention is developed to manage it.

Limitations

The review had several limitations. First, it was time and resource limited. As a result, elements of the literature screening and data analysis were completed by a single researcher, risking researcher bias. Second, due to time constraints, grey literature was not explored comprehensively, which may have limited the breadth of the review.

CONCLUSION

Misaligned expectations of recovery from brain injury appear to reflect a range of unmet family needs. These needs relate to the family's position within the healthcare hierarchy, HCP-family communication, and their level of involvement in patient rehabilitation. The needs of families may develop and change as their relative progresses through the care continuum and as they navigate their own grief.

Whilst these findings are exploratory, HCPs may wish to consider what and how information is communicated to families and whether this could be adjusted to support better HCP-family relationships. Consideration of how they might elevate family members' position within the healthcare hierarchy is also recommended, which might include increasing opportunities for them to be collaborators in their relative's care.

These exploratory findings would benefit from further research before developing an intervention to improve family support. This would include deepening our understanding of the impact of misaligned expectations on HCPs, patients, families, and services, and

exploring the practicalities of extending opportunities for collaboration in a climate of low resource.

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CONFLICT OF INTEREST

The authors report no conflicts of interest.

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APPENDICES

Appendix 1: *'Best fit' framework used for data synthesis (32)*

Subtheme/source of information	*Main theme*	*'Conceptual Building Block'*
Empowerment (caregiver, professional, observation)	'Psychosocial advices'	Content
Emotional support (caregiver, professional, observation)	Coping strategies	
Capability to act (caregiver, professional)	Resource activation	
Self-protection (caregiver, professional)	Problem-solving strategies	
Anxiety reduction (caregiver, professional)		
Future orientation (caregiver, professional)		
Hope (caregiver)		
Mourning process support (professional)		
Caregiver needs assessment (professional)		
Conflict management (professional)		
Social involvement (professional)		
Active caregiver communication (caregiver, professional, observation)	'Personalised information'	
Structural guidance (caregiver, professional)	Information transmission	
Process orientation (caregiver, professional)	Information brokerage	
Medical translation (caregiver, professional)		
Education (medical, rehabilitation, care process) (caregiver, professional)		
Administrative support (caregiver)		
Optimisation of the care and support system at home (caregiver)		
Psychosocial skills (professional, observation)	Professional support	Human Resources
Family support skills (professional)		
Expertise concerning social law and welfare system (caregiver)		
Risk assessment (professional)		
Working experiences (caregiver, professional)	Social skills	
Network building skills (caregiver, professional, obs.)		
Perspective adaption skills (caregiver; professional)		
Active listening skills (professional)		
Communication skills (professional, observation)		
Reflection skills (caregiver)		
Relationship building skills (professional)		
Conflict solving skills (professional)		
Empathy (caregiver, professional)	Personality traits	
Open mindedness (caregiver, professional, observation)		
Appreciation (caregiver, observation)		
Tolerance (professional)		
Active case finding (professional, observation)	Outreach counselling	Personalised Approach
Accessibility (caregiver, professional, observation)	Focal person support	
Structured personalised information provision (caregiver, professional)		
Guidance trough the stroke survivor trajectory system (caregiver, professional, observation)		
Context tailored support (professional, observation)		
Direct communication mode (caregiver, professional)	Face-to-face communication	
Relation building (caregiver, observation)		
Family support (professional, observation)	Participation	
Active involvement (professional, observation)		
Through all phases of the stroke survivor rehabilitation trajectory (caregiver, professional, observation)	Long-term support	Timing
Since the beginning (professional, observation)	Through all phases	
Flexible end (professional, observation)	As early as possible	
	As long as needed	
Convenience (professional, observation)	Flexibility	Setting
Privacy (professional)		
Trustful atmosphere (professional, observation)		

Appendix 2: ***Table of study characteristics***

Authors (Date) Origin	**Purpose**	**Source type Design** ***Method***	**Participants**	**Patient Group** ***Context***	**Findings**
Aadal et al. (2018) *Denmark*	To explore nurses' role in addressing relatives of stroke patients during rehabilitation.	Research *Qual.* Focus groups, interviews	Nurses	Stroke *Inpatient (3 different settings)*	Considering family needs and preparing them as future caregivers conflicts with treatment timescales and a healthcare system that focuses on patients as individuals.
Bulsara et al. (2021) *Australia*	To understand the experiences of care from stroke survivors, carers, and staff perspectives.	Research *Qual.* Interviews	Staff, Stroke Survivors, relatives	Stroke *Inpatient & community*	There was a mismatch between staff experiences of the reality of provision and the expectations of stroke survivors and families. Lack of time, urgency to regain mobility, post shock recovery, uncertainty about the future and the importance of accepting help once home were key themes affecting expectations.
Cameron et al. (2013) *Canada*	To explore stroke caregivers' needs across the continuum, comparing caregiver and healthcare professional perspectives	Research *Qual.* Interviews	Caregivers, HCPs	Stroke *0-1yr post stroke in range of settings*	Caregiver informational needs change across the continuum. A family-centered model of care and weekend/evening working to support working caregivers would be beneficial. Caregivers benefit from active participation and training to prepare them for discharge.
Farnese et al. (2020) *Italy*	Evaluation of co-production to engage family from a staff perspective	Research *Quant.* Questionn aire	Staff from 5 neuro-rehab units	Severe ABI *Inpatient*	Family's low motivation to engage or collaborate with HCPs was associated with limited collaboration, low influence on healthcare decisions and lack of information provision.

					Staff does not perceive value in caregiver participation.
Fisher et al. (2018) *Australia*	A theoretical framework to help professionals include family as active members in rehabilitation	Research *Theoretical* NA	NA	ABI *Rehabilitation*	Described the family-directed approach to brain injury model, which provides a theoretical framework for educating and training family members as facilitators of healthcare, promoting competence rather than dependency on service systems.
Foster et al. (2012) *New Zealand*	Development of family-support strategies	QI *Participatory Action Research*	data from over 1000 service users	TBI *Inpatient*	Key family support strategies identified were: (i) early engagement, (ii) meeting cultural needs, (iii) keeping families together, (iv) active listening, (v) active involvement, (vi) education, (vii) skills training, and (viii) support for community re-integration.
Kupiers et al. (2014) *Australia*	Patient and family experiences of involvement in rehabilitation	Research *Qual.* Interviews	Patients, families	ABI *Inpatient*	Fostering hope is important for positive clinical outcomes. Families also need informational, practical, emotional, and peer support.
Lefebvre & Levert (2012) *Canada*	To understand the needs of people close to individuals with a TBI and the services offered to answer these needs.	Research *Qual.* Focus groups	Families, HCPs	TBI *2-year post injury*	Families need information on the health problem. They need to know diagnosis, prognosis, and influencing factors as well as the processes involved in rehabilitation, care, and other services.
Lefebvre & Levert (2006) *Canada*	Experiences of disclosure of diagnosis and its resulting deficits	Research *Qual.* Interviews	families, patients, HCPs, physicians	TBI *Inpatient & community*	The quality of the disclosure of bad news is strongly influenced by the medical uncertainty

					surrounding the TBI and difficulties managing family emotions
Lefebvre et al. (2005) *Canada*	Experiences of people with TBI, family and HCPs in critical care through to rehabilitation	Research *Qual.* Interviews	TBI, family, service providers/ HCPs, physicians	TBI *Inpatient & community*	Mutual trust and communication will help HCPs, families, and patients navigate uncertainty following brain injury
Levack et al. (2009) *New Zealand*	Clinician perspectives of engaging families in goal setting	Research *Qual.* Interview	Clinicians	ABI *Inpatient*	Goal-planning appeared patient-centered rather than family-centered. Clinicians identified concerns about extending family involvement in goal-planning
Lutz et al. (2015) *USA*	Understanding the needs of stroke patients and their family caregivers as they transition through the stroke care continuum	Research *Qual.* Interviews	Caregivers	Stroke *Inpatient*	Steps to improve family preparation include (a) risk assessment (b) identifying and prioritizing gaps between patient need and caregiver commitment or capacity (c) developing a plan to improving caregiver readiness.
Lutz et al. (2017) *USA*	A theoretical model for improving stroke caregiver readiness and identifying gaps in caregiver preparation.	Research *Qual.* Interviews	Patients, Caregivers, case managers	Stroke *Inpatient & 6mo post discharge*	As caregivers move through different phases, they do not have a good understanding of the role to which they are committing and are often underprepared to take on even basic tasks to meet the patients' needs on discharge.
Meader (2012) *UK*	Exploration of carers' wellbeing, expectations, and involvement in their relative's rehabilitation	Research *Quant.* Questionn aires	Caregivers, staff	ABI *Inpatient and community*	Carers' expectations over-optimistic initially. Greater over-optimism was linked to more significant declines in wellbeing
O'Brien et al. (2014) *Australia*	1. To explore health care provider perceptions of	Research *Qual.*	HCPs	Stroke *Stroke services*	Healthcare providers highlight 3 key support needs (1) navigating transitions through care to

	stroke carer roles and support needs 2. To examine carer needs across the stroke care trajectory to develop an Optimal Health Program to support carers	Focus groups			home, (2) delivery and receipt of information, and (3) understanding the impact of stroke
Peel et al. (2020) *UK*	Health professionals' perspectives on breaking bad news	Research *Qual.* Interviews, focus groups	HCPs	Neurology *Inpatient*	There was a need for better management of patients' and families' expectations. Breaking bad news was seen as emotionally demanding yet often unrecognized work.
Sadler et al. (2018) *UK*	Examines the process of training informal carers on stroke units using the lens of power.	Research *Qual.* Interviews, Observational Notes	Staff, carers, patients in 10 study sites	Stroke *Inpatient, community follow-up*	The process of training informal carers on stroke units was not simply a matter of transferring skills from professional to lay person but entailed disciplinary forms of power intended to shape the conduct of the carer.
Sexton (2013) *UK*	Experiences of occupational therapists when having bad news conversations about long term disability	Research *Qual.* Interviews	Occupational therapists	Neurology *Hospital, inpatient, and community rehab*	Bad news conversations were important yet under-recognized clinical tasks. Therapists had different approaches, including collaboration and avoidance. These conversations have an emotional cost to staff.
Shook & Stanton (2016) *Canada*	Perspectives on stroke education	Research *Qual.* Interviews	Patients, caregivers	Stroke *Inpatient*	Caregiver education needs to be personalized and delivered at the right time. Trial discharges and home passes help integrate education with personal experience.
Talbot et al. (2014) *Canada*	Perceptions of the implementation	Research *Qual.*	Patients, carers, staff	TBI	The collaborative care approach has several benefits, including

	of a collaborative care approach	Interviews		*Hospital & inpatient rehab*	improved communication, coordination of services, and better preparation, awareness, and involvement of patients and families.
Young et al. (2008) *UK*	To explore perceptions of goal setting from the perspective of patients, lay carers and rehabilitation staff.	Research *Qual.* Interviews	Patients, former patients, informal caregivers, staff	Neurology *Inpatient*	All 4 groups considered goal setting to be beneficial, increasing motivation and providing reassurance for patients and carers.

TABLES

Table 1*: Inclusion and exclusion criteria*

Inclusion Criteria	**Exclusion Criteria**
- Acute/Sub Acute rehabilitation - Moderate – Severe Brain Injury - About HCPs' management of family expectations - English Language - Published within last 20 years - >50% participants have / are involved in acquired brain injury	- Children (under 21) - End of Life / Withdrawal of life sustaining treatment - Critical Care - Outpatient/Community - Transitional care only - Non-OECD country - Editorial / Commentary - Literature Review

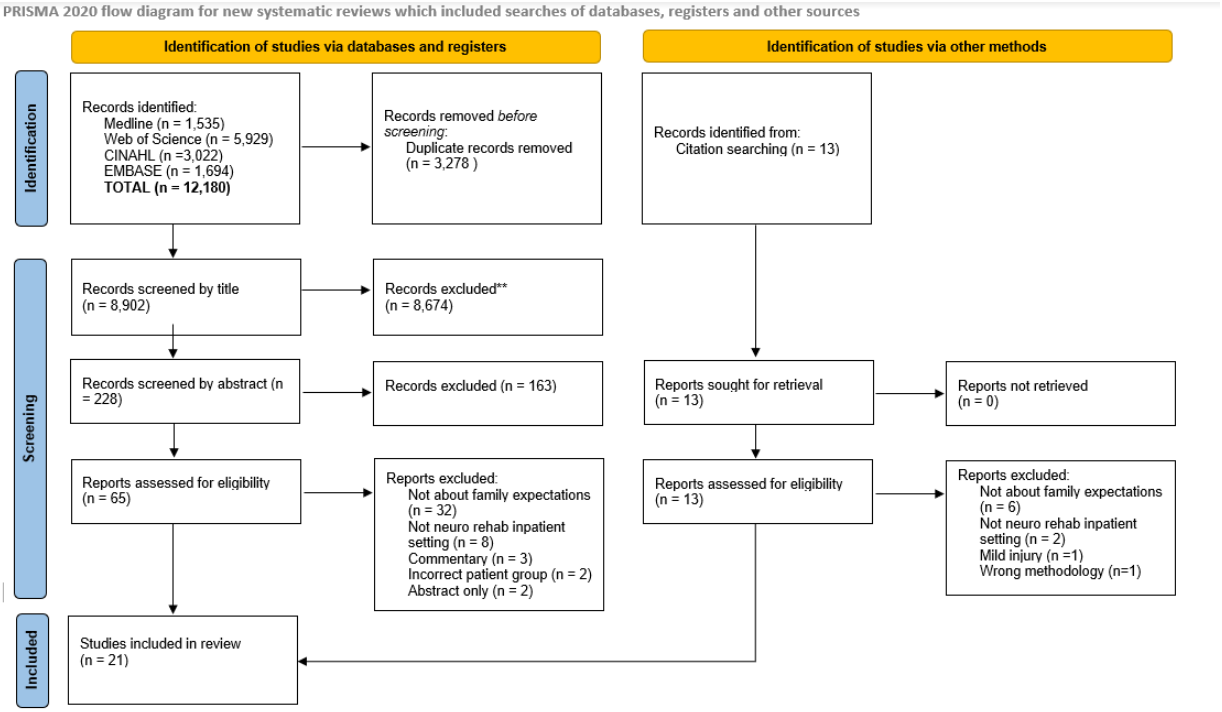
Table 2*: Example search strategy: (Medline)*

Mesh Terms	• Brain Injury OR STROKE • Professional-Family Relations OR Hope OR Motivation • Family AND
Population	Brain Injur* OR Stroke OR Haemorrhage* OR coma OR vegetative OR "disorder of consciousness" OR "minimally conscious" OR "unresponsive wakefulness" OR UWS OR TBI OR ABI OR "Cerebral Vascular Accident" OR CVA AND
Population	Famil* OR caregiver* OR spous* OR partner* OR relation* OR "next of kin" OR surrogate AND
Intervention	Expect* OR goal* OR hope or achiev* OR aspir* OR motiv* OR drive OR denial OR "bad news" OR unrealistic OR optimis* OR pessimis* AND
Context	Hospital or inpatient or acute or sub-acute or "secondary care" or "intensive care" or "critical care" or "tertiary care" or in-patient
Filters	All fields English Language Date parameters 2003 - 2023

Table 3*: BeHeMoTh search strategy for identifying appropriate analysis frameworks*

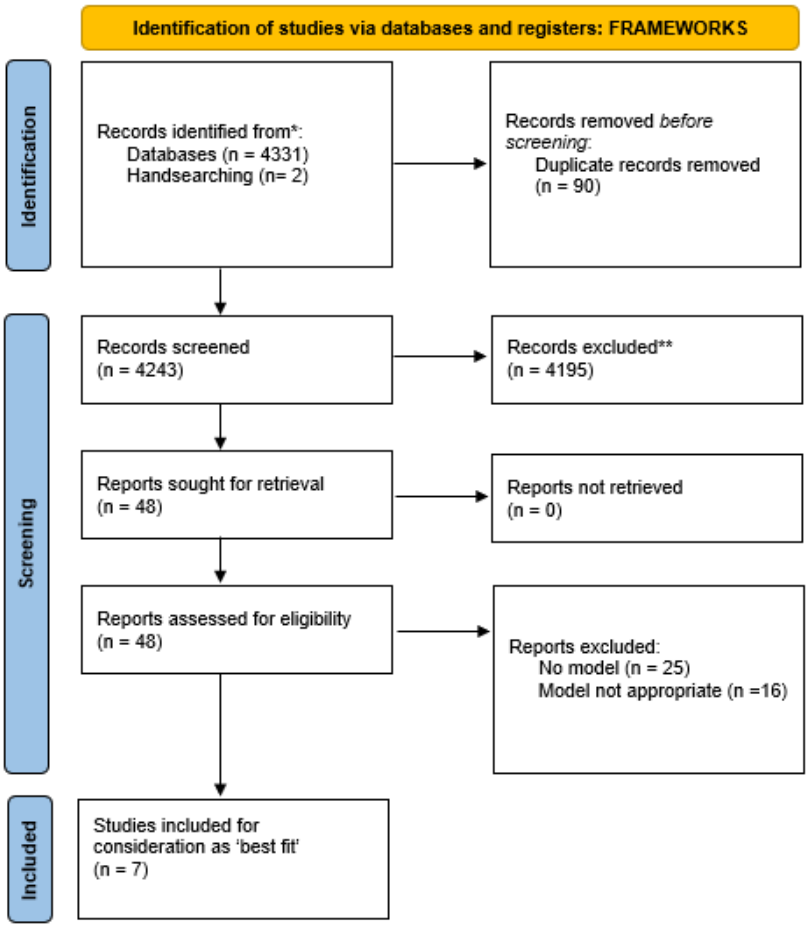
Be: Behavior of Interest:	"family or families or relative* or caregiver* AND hope* or expect* AND clinician* or health* professional* or nurse* or physician* or doctor* or therapist*
He: Health Context	"Brain Injur*"
E: Exclusions	paediatric* or pediatric*
MoTh: Models or Theories	model* or theory or theories or framework* or concept* or conceptual
Strategy:	(Be AND HE AND MoTH) NOT E

FIGURES



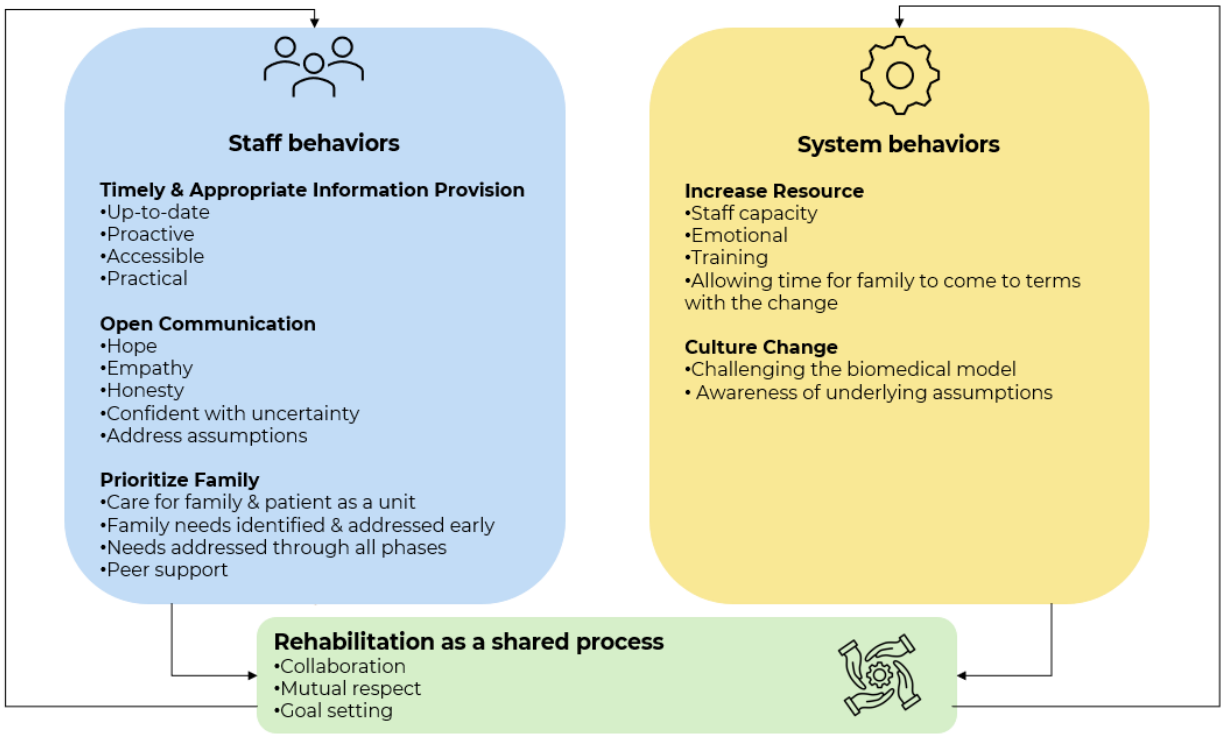
*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71



Captions

Figure 1: *PRISMA statement for scoping review*

Figure 2: *PRISMA statement for 'best fit' framework*

Figure 3: *Compiled themes and sub-themes*