


Communication guidelines for healthcare professionals working with adults with changed cognitive capacity and their carers: A scoping review with implications for neuro-oncology

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ABSTRACT

Background: Effective communication in healthcare is pivotal to delivering quality care, with complexity increasing when people have cognitive impairment (PwCI). Cognitive impairments can be subtle to profound changes in executive function. Tailoring communication to these individuals and their families is challenging for healthcare professionals (HCPs). Substantial work has been completed in establishing training programs and guidelines to develop the communication skills of HCPs, including for PwCI. However, cognitive impairment-specific communication training has not translated through to oncology. This review distilled HCP communication guidelines for PwCI to underpin a training resource for HCPs working in neuro-oncology.

Methods: The review followed Joanna Briggs Institute scoping review methods and is reported using the PRISMA-ScR format. Data was sourced from academic, published studies and grey literature using search terms on HCP communication guidelines for working with people with cognitive impairment (e.g. brain injury, dementia). Search criteria were restricted to communication between HCPs and adults in non-residential care settings.

Results: Initial searches yielded 6257 results after duplicate removal. Title and abstract screening identified 603 results for full-text review. 43 studies were identified for data extraction. Key elements for HCP communication were distilled into six categories: 1) concepts in communication - theoretical ideas supporting quality communication; 2) presentation and delivery - how HCPs share content and information; 3) behaviour and actions - undertaken by HCPs to support communication; 4) environment elements - how environments support interactions; 5) engaging with families - strategies for balancing carer communication; and, 6) organisational factors - systems that support quality communication.

Conclusion: Building on expertise from related health areas, these six key elements establish a clear strategy for HCPs to tailor communication to better accommodate PwCI and their families and are central to our development of communication skills training for HCPs in neuro-oncology.

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1. Introduction

Communication in healthcare is pivotal to quality care [1]. Clear communication between HCPs and the people they care for is required for a thorough assessment of health conditions, information exchange and education, and future care discussions [2]. Building rapport with individuals and their families is critical for HCPs to establish sustainable working partnerships, facilitate conversations about a new diagnosis or planning complex treatments, and encourage shared decision-making [3]. Good communication also helps HCPs better understand the individual and their family, who and what is important to them, their health goals, and who is involved with their care [4].

In times of stress, healthcare communication can be extremely challenging [5]. Individuals and their families may be dealing with a sudden and shocking health crisis [6]. They hear unfamiliar terms in unfamiliar places from unfamiliar people; they may feel overwhelmed and exhausted by multiple appointments [7]. How individuals and families react and interact with the healthcare system under these circumstances may be specific to their individual and family experience of health and understanding of the situation. Individuals and family units react differently [6]. Similarly, for HCPs, there can be less-than-ideal working conditions. HCPs may be under pressure, both in the time available and resources at their disposal. They also may feel less confident in interacting with individuals and families in a particular setting [8]. Tailoring communication to individuals in a clinical consultation is well-recognised as essential in quality healthcare [2].

Healthcare communication can be particularly complicated when an individual presents with changing or declining cognition [9]. Cognitive changes can be very subtle, from a small reduction in attention due to a noisy environment to impairments in problem-solving, planning, and memory function [10]. Health conditions such as neurodegenerative conditions (dementia, multiple sclerosis), acquired brain injury (traumatic brain injury, stroke) and some mental illnesses can affect an adult's capacity to think clearly and make decisions [11,12]. People diagnosed with primary malignant brain tumours can also experience changes in cognition [13]. A healthcare consultation relies on information being clearly relayed and understood bidirectionally between the HCP and an individual and their family. Changes to cognition can impact the way a message is understood, responded to, and acted upon [14]. HCPs might struggle to identify these changes in patient cognition and to adjust their communication to accommodate individuals' changed capacity once cognitive changes are identified [15]. Finding the balance between adequate and acceptable information, consent, and collaboration with an individual, while ensuring the inclusion of the family carer(s), is important for all parties involved [16].

Previous approaches to communication skills training in healthcare specifically target a particular diagnosis impacting communication, particularly people with dementia, acquired brain injury, or cancer [16]. Some approaches have targeted support and training for individuals with a diagnosis, or caregiver training with components for communication within healthcare consultations. In oncology, communication skills training for HCPs has focused on specific parts of the disease trajectory, such as diagnosis, decision-making, treatment, survivorship, engaging family carers and transition to end-of-life care [17–19]. However, to date, there has been little guidance for HCPs seeking to understand and accommodate the impacts of cognitive changes and impairment in their communication in the context of a brain cancer diagnosis. Primary malignant brain tumour, or brain cancer, with the potential for cognitive changes due to the impact of the disease and treatment effects [20], is where these areas intersect.

The objective of this scoping review was to identify and synthesise key elements and recommended practices for HCP communication in the context of working with people with reduced or diminished cognitive capacity and their carers. We will leverage these findings to inform further work in the brain cancer domain, given the paucity of research in this context.

1.1. Review questions

We sought to understand 1) What are the recommended communication guidelines for HCPs working with adults who have health conditions involving reduced cognitive capacity and their carers?; and 2) what are the key elements of HCP communication used to support adults with reduced cognitive capacity and their carers?

2. Methods

This narrative scoping review was conducted following the Joanna Briggs Institute (JBI) framework for scoping reviews [21] and the Preferred Reporting Items for Systematic review and Meta-Analysis protocol extension for Scoping Reviews checklist (PRISMA-ScR) [22]. Scoping review methodology was chosen as the most appropriate way to map available evidence and identify the key characteristics in HCP communication with people who have reduced cognitive capacity and their families, as it allows evidence to be drawn from a broad range of literature, including government guidelines, professional grey literature, and academic literature [23]. The protocol for this scoping review was registered on Open Science Framework (doi:10.17605/OSF.IO/6UP3Q) on 18 February 2024 prior to commencing the review.

2.1. Inclusion criteria

Eligibility for this review was based on the Participant Concept Context framework [21].

2.1.1. Participants

Target participants included adolescents and adults, aged 13 years and above, with the defined health conditions (see context), and their carers/caregivers were included. There was no restriction on country of residence, cultural background, or language. Age range of 13 years and older reflects past and current practice of grouping studies with adolescent and young adults together as AYA (13–25 years).

2.1.2. Concept

The concept was to identify elements of HCP communication within clinical practice guidelines, communication models, or frameworks with specific recommendations, research studies or training materials with key concepts articulated. HCP roles included were doctor, nurse, psychologist, neuropsychologist, social worker, occupational therapist, speech pathologist, and care coordinator.

2.1.3. Context

The following health conditions included those with potential for reduced or changing cognitive capacity. These conditions were acquired brain injuries (including stroke, brain injury), neurodegenerative conditions (dementia and multiple sclerosis), serious psychiatric conditions (psychosis, schizophrenia), and glioma/primary malignant brain tumour.

2.2. Exclusion criteria

Studies were excluded if the participants had a congenital and/or a neurodevelopmental condition, such as intellectual disability, developmental disability and autism spectrum disorder, due to the usual onset during childhood and dynamic nature of these conditions and their changing communication needs over time. Studies targeting patient and/or carer interventions, including communication intervention were also excluded, as these studies are primarily focused on a change in the patient/carer participant rather than specific communication strategies for HCPs. Studies were also excluded if they were based in residential care settings due to the different staffing profile. Book reviews, case studies, editorial or opinion pieces and book or book chapters published prior to 2014 were excluded.

2.3. Deviations from the protocol

During the title and abstract review, we identified that the studies pertaining to aphasia were largely focused on communication intervention. Following discussion with the research team (including a clinical neuro-psychologist – KP), the protocol was modified to exclude intervention for aphasia. During full-text review, the selection criteria were modified to exclude communication targeting diagnosis, as we identified another ongoing review specifically investigating diagnosis communication in primary brain tumour.

2.4. Information sources

Published and unpublished materials were sourced. Published studies were identified using Medline (Ovid), CINAHL, PsycINFO, and Scopus databases. Reference lists of the selected studies were hand-searched for relevant material. Unpublished studies and other relevant literature were sourced from ProQuest dissertations and specialised databases ECRI Guidelines Trust and NICE Guidelines UK, with modified search terms. Google search engines and professional association websites were searched to identify relevant grey literature.

2.5. Search strategy

The search strategy, detailed in the [supplementary file - Supplementary Table 1](#) (Medline OVID Search Strategy), was devised based on the population (people aged 13 years and over), concepts (healthcare professional and communication guidelines), and context (health conditions associated with cognitive impairment) and adapted for each database, incorporating MeSH and subject heading variations. Following testing and modifications made in consultation with a university librarian, publication databases were searched on 19 February 2024. Other studies and grey literature materials were sourced via modified search strategies in ProQuest Dissertations, Google Search (conducted 18 March 2024), ECRI Guidelines Trust and NICE Guidelines UK (finalised 23 May 2024). All references were imported into EndNote 20.6 as an initial repository and then uploaded to the Covidence Systematic Review Software [24]. All materials sourced for review from academic and grey literature will now be referred to as studies.

2.6. Study selection

Duplicates were identified and removed using Covidence systematic review software, re-checked with Excel, and manually removed by the first author (DL) in Covidence. Title and abstracts were screened against the inclusion criteria by two raters independently, with DL screening all and other team members (GH, HD, LB, KP) sharing a second screening. Studies meeting the inclusion criteria were reviewed in full by DL for evaluation and final inclusion. 30% of included studies were reviewed by a second team member at the full-text stage to confirm consistency. Disagreements were resolved through discussion between team members.

2.7. Data extraction

A data extraction template was developed by the research team prior to data collection, as shown in [Supplementary Table 2](#) (Data extraction elements). Data from the included studies were extracted by DL and SK. Dual data extraction was conducted for the first 15 studies to ensure consistency. Any discrepancies were discussed and agreed upon by DL and SK. Data was collated and managed in Covidence systematic review software and MS Excel [24,25].

We extracted data for general concepts and approaches in healthcare communication for people with cognitive impairment, where reported; aims/objectives of resource; target health condition and professional group; intended care recipients; key features, characteristics and

resource components; and recommended strategies/guidelines for HCP communication. If available, details about the design process, resource evaluation, strengths and limitations, and proposed further work were collected.

2.8. Data analysis

A narrative synthesis approach to data analysis was taken [21,26]. Identified components were grouped with elements of similar execution and modes, such as concepts and theories, environmental factors, HCP behaviours, communication delivery, working with families and service elements. Data was sorted into Excel, and elements were discussed among the research team to agree on categorising the key elements of HCP communication. As we aimed to scope different levels of communication strategies, we separated data into elements directly undertaken or managed by HCPs, elements managed via systems and organisations, and concepts in communication. As an iterative process, the engagement of carers and families was highlighted as a distinct set of strategies, and following discussion, separated later in the analysis.

We engaged stakeholder feedback to enhance the dependability and confirmability of the findings. The scoping review dataset was presented as a written summary and in online group presentations to stakeholders, including 16 healthcare professionals (6 allied health, 5 nursing, 4 medical, 1 care coordination) and 15 people with lived experience. These sessions were part of a related codesign study approved by Curtin University HREC-80585 and served to generate discussion and feedback, and to provide independent confirmation of the key elements of HCP communication as articulated in the results of this review.

3. Results

Formal database and register searches identified 10540 studies, and a further 198 items were sourced via grey literature and citation searching. Duplicates were identified in Covidence ($n = 4233$) or manually ($n = 248$) and removed. The titles and abstracts of 6257 papers were screened by two members of the research team. Based on the scoping review criteria, 5654 papers were excluded. Of the 603 studies identified for further review, 21 could not be retrieved, leaving 582 studies for full review. There were 539 studies excluded, with 43 studies identified for data extraction in the final review. Refer to [Fig. 1](#) PRISMA chart for exclusion reasons.

3.1. Description of studies

Full details of included studies and resources are presented in the [Supplementary Table 3](#) (Details of all included studies). The majority of included studies were conducted in the United States ($n = 12$) [27–38], nine in the United Kingdom [39–47], eight in Australia [48–54], seven in Canada [55–61], and one each in Austria [62], Belgium [63], Norway [64], Switzerland [65], Netherlands [66] Japan [67] and Brazil [68]. Of the studies included, most addressed people with dementia ($n = 23$), followed by acquired brain injury ($n = 15$), including stroke, glioma/primary brain tumour ($n = 2$) and one each on multiple sclerosis [27] and amyotrophic lateral sclerosis [66]. Four papers targeted communication with people aged over 65 years, and one paper focused on PwCI identifying as Aboriginal or Torres Strait Islander [53].

3.2. Aims of the resource

A range of aims were stated in the targeted resources; some examined the communication experiences of HCPs [38,39,45,50,51,64] and sought to understand the barriers and facilitators in healthcare communication [42,58]. Some resources provided a clear framework for systematic communication in a healthcare setting [44,56,65,66], providing a framework and guidance to support communication for people with cognitive impairment [33,34,36,41,46,51,55,62,68]. Other

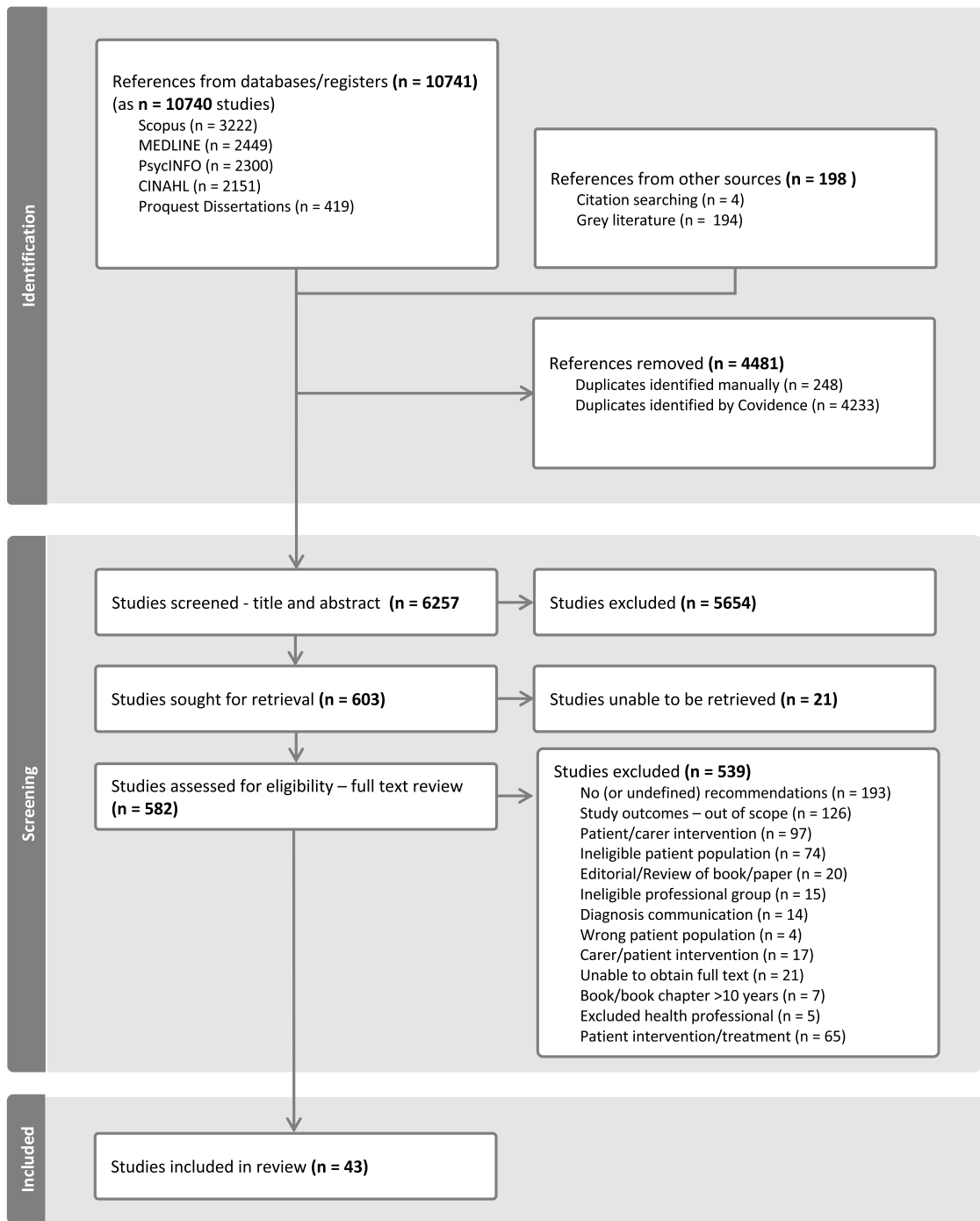


Fig. 1. PRISMA Flowchart.

resources aimed to define specific strategies for enhancing communication for HCPs [28,37,41,48,49,52,59–61], tailoring communication [35,66], respecting patient values [33,47], and instilling a sense of hope [40,57]. Some resources focused on concepts regarding shared decision-making [27,32,67], advanced care planning discussions [31, 37,63] and strategies for collaboration [54] and safety [29] within the consultation. Several papers focused on communication in specific scenarios, such as cessation of driving [30], impact of ageing on communication [32,43], and using communication support tools [50].

3.3. Type of resource

Many resources contained specific communication recommendations (n = 16). Some recommendations included a communication framework [41,46,51,56] or training package [32,35,40,43]. In addition, five resources were derived from primary studies [31,38,50,58,62] and four from reviews [27,29,39,61]. Another group of resources were formulated as communication guidelines [44,53,65,68], with one derived from a primary study [66] and another providing specific guidelines for telehealth [55]. There were four communication fact sheets [48,49,57,69].

3.4. Target beneficiaries

Most resources targeted both people with cognitive difficulties and their carers (n = 22), followed by 19 focusing solely on people with cognitive difficulties, and two addressing carers [61] and older people [43] respectively. One study population comprised only Aboriginal and Torres Strait Islander people [53].

3.5. Target health professional group

More than half the resources targeted general HCP groups and did not specify a discipline target (n = 24). Four studies focused on combined medical and nursing disciplines [27,50,57,64]. Seven studies were specifically targeted to nursing [28,35,36,40,43,45,46], six targeted doctors [30,37,51,59,60,66], and two targeted HCPs with an allied health background [58,62].

4. Key elements of HCP communication

We categorised the key elements of HCP communication with PwCI into six areas: 1) concepts in communication; 2) presentation and delivery; 3) behaviour and actions; 4) environmental elements; 5) engagement with carers and families; and 6) service/organisational elements. Concepts in communication draw together the key ideas supporting communication with PwCI, whereas service/organisation factors identify actions undertaken by health systems to enhance communication for PwCI. The remaining elements identified recommendations specific to those HCPs used to support quality communication when working with PwCI and their families. Key elements of HCP communication with PwCI are summarised in Fig. 2.

4.1. Concepts in communication

We identified nine key concepts in communication that form the basis of quality communication with PwCI (refer to Table 1). These concepts were discussed as part of training programs, theoretical frameworks and practice guidelines. The concepts were presented as overarching themes and ideas supporting communication with PwCI, rather than specific individual strategies for HCPs or health systems.

Table 1
Identified concepts in communication.

Concept of respect, dignity, & hope	[31,40,42,44,65]
Person-centred approach	[37,40,41,43,47,49,51,65]
Family-centred practice	[31,33,43,44,49,51,53,56,63]
Maintenance of personhood	[32,40,41,47,48,53,59,60,65]
Individual preferences of PwCI	[33,37,42,43,45,49,67]
Collaboration	[51,53,56,62,67]
Goal setting	[51,56,62]
Information support	[56,66]
Shared decision-making	[27,31,33,65,67]

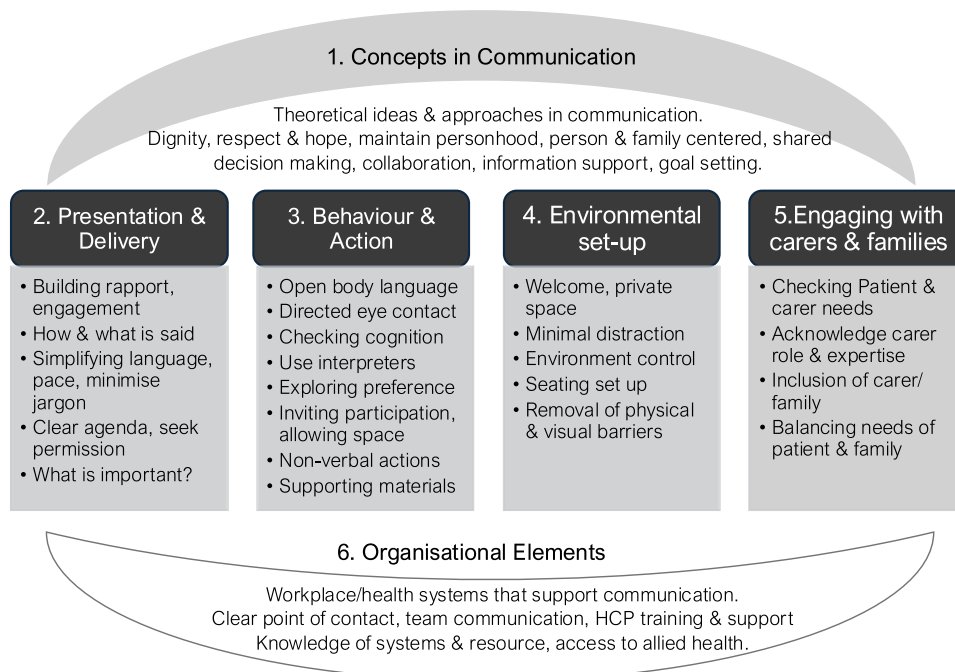


Fig. 2. Key elements of HCP communication for people with cognitive impairment and their families.

Table 2
Presentation and delivery of communication.

Elements	Strategies	Reference number	
Establishing rapport during interactions was considered a vital communication component.	Addressing the individual and carer by name	[28,35,48,49,57,59]	
	Introducing yourself and your role	[32,34,36,45,46,49,68]	
	Be prepared with an agenda for the meeting	[55,67,68]	
	Being friendly and interested in PwCI	[30,46,48,52,54,59,63]	
	Take a positive approach to communication to assist establishing trust	[32,41,49,51,54,57,58,62]	
	Seeking opinion and goals	[37,49,51,54,56,58]	
	Seeking permission	[37,68]	
	Inviting questions	[32,38,46,54,60,68]	
	Modifying your communication delivery	Use simple sentences, keep explanations short	[28,29,36,39,41,46–49,52,61,68,69]
		Avoid jargon, acronyms, and colloquial language	[29,31,49,59,60,68]
Use the full names of people, places and things		[59, 60]	
Speak calmly and clearly, with a normal tone and volume		[28,34,35,48,49,52,54,59,65,69]	
Slow speech down, using regular pauses to improve understanding		[28–30,35–37,39,43,49,55,61–63,69]	
Avoid talking over PwCI and encourage turn-taking		[28,47,54,59]	
Allow time		[29,32,37,41,47–49,51,52,59–61,64,67–69]	
Stop talking from time to time and be comfortable with periods of silence		[29,32,60]	
Speak directly to the PwCI		[30,31,34,36,38,46,68,69]	
Make suggestions rather than give orders		[48,69]	
Minimising the language load for PwCI	Communicate one question, idea, person, or instruction at a time	[28–30,34,39,48,49,58,61,69]	
	Use plain language	[36,57,68]	
	Use yes/no questions rather than open-ended questions	[29,34,36,39,48,52,59,61]	
	Focus on information exchange and direct statements	[59,68]	
	Use language-specific interpreters	[35,37,49,66]	
	Discuss important things first	[36]	
Reinforcing information	Adjust communication for low literacy, culture and gender, as appropriate	[49,60]	
	Summary statements to check understanding	[29,32,34,39,43,52,57,58,61]	
	Verbatim repetition of information	[36,39,43,61,69]	
	Recap complex information	[32,37,52,57]	
	Ask clarifying questions	[32,33,37,43,54–58,62–64,68]	
	Use teach-back strategies	[55]	
Non-verbal expression	Face the PwCI during your communication	[28,35,36,39,43,49,61,65]	
	Maintain eye contact for engagement and drawing attention	[28,32,34,36,48,52].	
	Use body language and gestures to reinforce communication	[29,36,43,48,49,52,59,60,62,69]	

Table 2 (continued)

Elements	Strategies	Reference number
An empathetic communication style is important when communicating with PwCI	Smile at the patient	[48,49,65,69]
	Use of engaging emotional expressions; such as humour or laughter	[30,49,69]
	During telehealth interactions, look at the webcam	[55]
	Communicate with respect and dignity	[41,43,49,54,57–59,69]
Finding the meaning	Acknowledge the individual's emotional experiences	[29,32,37,43,47,54,59,60,68]
	Provide verbal reassurance	[39,43,68]
	Acknowledge the legacy of the person and family	[31,42,58]
Difficult conversations and topics	Identify the personal motivation behind goals and values	[51,62]
	Take time to search for the meaning with the PwCI	[41,47]
	Use a person's history and interests to engage in conversation	[52,59]
	HCPs introduce challenging topics (i.e. Advance Care Planning) over multiple sessions	[33]
	Balance hope with sharing information and difficult news	[63]
	HCPs should lead this conversation	[37,57]
	Start with exploring current experience	[58,63]
		[63]

4.2. Presentation and delivery

This section highlights strategies HCPs use to present and deliver information and care to a PwCI. [Table 2](#) lists distinct elements of presentation and delivery, with the supporting strategies to effect these elements:

4.3. Behaviour and action

Different behavioural strategies and actions for HCPs were recommended to enhance communication with PwCI. [Table 3](#) lists HCP behaviour and action with the supporting strategies identified.

Detailed description of review findings for the four HCP-oriented elements (2–5) and references are presented in [Table 4](#).

4.4. Environmental elements

This section highlights specific environmental elements that can be modified to enhance communication between PwCI, their families and the HCPs. The environmental elements to enhance communication are listed in [Table 5](#).

4.5. Engaging with carers and family members

The involvement of family members and carers of a PwCI is recognised as crucial in discussions regarding treatment [27,32,36,37,42,44,46,49,57,66], to support shared decision-making, and to provide well-sourced information and education [34,44,51,62,63,67,68]. Studies advocated HCPs consider which family and team members are present during the interaction, respect the privacy of those involved [43,49,60,68] and note any gender differences within the family interactions [49]. Involving family members who encourage and support communication [41,59] and promoting consistent communication with family members and carers [48,69] were also recommended.

Recognising the strengths families bring to the situation [42],

Table 3
Behaviour and action in communication.

Elements	Strategies	Reference Number
Action to build rapport	Create a comfortable atmosphere	[30,62]
	Engage in active listening	[36,43,49,51]
	Avoid interruptions and answering phone	[39,43,52,60]
	Tailor communication style to individual	[60,66]
	Ask about the impact on daily functioning	[67]
Establish patient preferences to tailor your communication	Ask how they prefer to be addressed	[49]
	Ascertain how they want family involved	[44]
	Understand and respect cultural norms	[57,60,66]
	Identify PwCI preferences for: information, communication, treatment options and decision-making	[32,37,49,57] [27,37] [37,63]
	Consider using communication support tools	[50]
Non-verbal behaviours supporting communication with PwCI	Use augmented communication devices (board or tablet) to support interactions	[29]
	Adjust approaches for visual, hearing and cognitive difficulties	[49,60]
	Use open body language	[48,69]
	Use light physical contact, including hand touch, for reassurance and maintaining attention	[30,39,48,49,59,65,69]
	Observe the client's body language for use	[29,35,47,52,60,62,64,65].
Support with written material	Use written materials in plain language/alternative languages	[29,45,49,57,59,62,68]
	HCPs writing out information for patient/families	[62,64]
	Draw simple pictures to augment explanations	[36,48,52,62]
	Use materials to encourage conversation (i.e. art, music, talking mats)	[28,50,59]
	Assess cognitive capacity particularly concerning decision-making capacity	[32]
Physical prompts that support communication	Be aware of conversing beyond a PwCI's capacity	[35]
	Encourage communication with physical prompts or visual cues	[41,54,62]
Establish collaborative communication	Use language aids	[49,54,62]
	Seek consensus, collaborative discussion	[32,35,54,56,57,67,68]
	Agree on action plan with all parties	[32,36,46,51,56,57]
	Share information and thoughts when considering options	[27,35,58,67]
	Be flexible in communication style, try another approach if not working	[35,41]
	Arrange follow-up	[34,46]
	Set up for the next appointment	[32,57,67]

respecting the relationship of the carer and acknowledging the burden of caring for someone with a cognitive impairment [31,35] were highlighted as important strategies for engaging families. Other strategies identified include differentiating the experience of the PwCI and the family perspective [38,66], and acknowledging the carer's role and expertise [35,55]. A number of studies identified the importance of assessing the carer's unmet needs [31,63,68], and offering a separate opportunity for the carer to speak with the team [31,38] to secure collateral history [35]. Studies highlighted maintaining flexibility in meeting the needs of PwCI and their family, including communication

preferences [35], whether face-to-face consultations or via telephone, and allowing sufficient time [65] to support communication. One paper recommended that HCPs and systems set expectations with carers about changes to autonomy and capacity with progressive cognitive impairment [31].

4.6. Service and organisational elements

We identified several important organisational elements that promote communication with PwCI and their families. Nominating a key contact pathway for PwCI and their families [11,29] together with a coordinated team approach about who and how PwCI and their families would be engaged [29] was considered a necessary element. Team communication focused on effectively conveying information to the broader team [11,24,37], sharing information about communication disorders [9] and needs [15], and utilising clinicians who know the PwCI well to corroborate history and comorbid conditions [9,15] was highlighted. Training of team members about the impacts of cognitive impairment on communication [11,14,45] is identified as important. Staff knowing about local and available resources, such as support groups [25,30] and supporting PwCI and families to access them [30], in addition to knowledge of advanced care planning [30,43] and decision-making capacity and its application in the clinical setting [30] were important core skills development elements in this area.

Regarding service delivery, recommended strategies were to ensure written information is available to patients and families in a relevant language and format [30] and that interpreters are used where required [9,15]. Healthcare systems can support communication by promoting early referral to allied health services [29], creating advanced care statements [30], and using patient-reported outcomes in routine care [7]. Also, it was identified that routinely checking communication devices for vision and hearing [9,29] promotes effective communication. One paper recommended providing real-life opportunities and support group programs for families to practice skills [37].

5. Discussion

This review has identified key elements and communication strategies used by HCPs when communicating with a PwCI. Recommendations were distilled into six broad groups: four relating to the approach of HCPs in communicating with PwCI, and the remaining two elements relating to theoretical concepts in communication, and strategies that service systems can employ to support quality healthcare communication.

These communication strategies and recommendations intersect with core healthcare communication guidelines. Basic communication skills and supporting frameworks are often taught as part of undergraduate education programs, and professional development activities both within healthcare services, and as extracurricular activities as part of a personal professional development plan [70].

General healthcare communication is underpinned by the concepts of person-centredness, respect, dignity and collaboration [71]. Good communication practice looks to understand a person's experience of illness, their preferences and goals of care, and ultimately, to chart a course of action together [72]. The strategies distilled are consistent with best practice and strongly supported in health communication literature and models [73]. These communication strategies are identified as vital elements of foundational healthcare communication, supporting both individuals and their families to engage more actively in their care.

This scoping review highlights the unique person-centred considerations required to support individuals with cognitive impairment. Presentation of information for a person with a cognitive impairment requires a simplification in delivery; the pace slowed, allowing for processing and response time [28]. The HCP minimises language load by using one idea at a time; information is prioritised and clarified regularly

Table 4
Key strategies in healthcare professionals' communication.

1.	Presentation & delivery
1.1	Establish rapport during any interaction with a PwCI using the following strategies. Address the individual and carer by name [28,35,48,49,57,59] and orientate all parties to the interaction [69]. Introduce yourself, your role, and reason for meeting [32,34,36,45,46,49,68]. Be friendly and interested in them [30,46,48,52,54,59,63] and engage in general conversation [49]. Be positive in your approach to communication [49,54,57,58] and seek to establish trust with client [32,41,51,62] and family carers [31]. Treat the individual like an adult regardless of language or cognitive function [32,48,59,60], by seeking their opinion [58] and permission [37,68], asking questions about their goals [37,49,51,54,56], and inviting questions [32,38,46,54,60,68]. Be prepared [55,67,68] and set an agenda for the meeting [32,57].
1.2	Health professional interaction with PwCI is enhanced by simplified communication delivery . Use simple sentences, keep explanations short [28,29,36,39,41,46–49,52,61,65,68,69], and avoid jargon, acronyms, [29,31,49,59,60,68] and colloquial language [59]. Use the full names of people, places and things [60]. Speak calmly and clearly [35,48,49,52,54,59,65,69] with normal tone [28,49,69] and volume [34]. Slow speech down, using regular pauses to improve understanding [28–30,35–37,39,43,49,55,61–63,69]. Encourage the individual to complete their communication, encourage turn-taking [54] and avoid talking over them [28,47,54,59]. Allow time [29,32,37,41,47–49,51,52,59–61,64,67–69], stop talking from time to time [43], and be comfortable with long periods of silence [29,32,60]. Speak directly to the patient with cognitive impairment [30,31,34,36,38,46,68,69], make suggestions, rather than give orders [48,69]. Follow through on topics of concern with patients [58]. Important to close the communication or interaction by saying goodbye [46].
1.3	Minimise the language load for PwCI by communicating one question, idea, or instruction at a time [28–30,34,39,48,49,58,61,69] and use plain language [36,57,68]. Use yes/no questions rather than open-ended questions [29,34,36,39,48,52,59,61]. Focus on information exchange and direct statements [59,68], and discuss important things first [36]. However, for people with moderate to severe cognitive impairment, avoid direct questions [41,54] in preference, use a more open question style [32,37,58]. Avoid asking for a detailed memory response [35,48,69]. Use language-specific interpreters [35,37,49,66] where needed, be sensitive to low literacy levels and gender, and adjust communication as needed [49,60].
1.4	Reinforce information for PwCI during interactions by using summary statements to check understanding [29,32,34,39,43,52,57,58,61] verbatim repetition of information [36,39,43,61,69] and recap complex information [32,37,52,57]. Ask clarifying questions [32,33,37,43,54–58,62–64,68] and use teach-back strategies [55] to ensure understanding. Summarise the client statements or concerns to show you have been listening [43].
1.5	Reinforce communication intent with non-verbal expression . Recommendations include facing the PwCI during each communication [28,35,61], maintaining eye contact for engagement [28,35,36,39,43,49,61,65] and assisting attention [28,32,34,36,48,52]. During telehealth interactions, look at the webcam and not the screen [55]. Smile at the patient [48,49,65,69], and use laughter and/or humour [30,49,69]. Use your body language and gestures to reinforce your communication [29,36,43,48,49,52,59,60,62,69]. Observe and understand the client's body language for cues [29,35,47,52,60,62,64,65]; low interaction may indicate poor understanding and cognitive impairment [64].
1.6	Use an empathetic communication style when interacting with PwCI. Communicate with a caring attitude through the display of respect and dignity [40,41,43,49,54,57–59,69]. Acknowledge the individual's emotional experiences [29,32,37,43,47,54,59,60,68] and provide verbal reassurance [39,43,68]. Acknowledge and show respect for the legacy of the person and family you are dealing with [31,42,58]. Approach with an open attitude [32,62] and share your worries and concerns [37] with PwCI. Be mindful that hospitalisation can be a big event for older people [49].
1.7	Find the meaning within an interaction with a PwCI is recommended to support communication. Identify the personal motivation behind goals [51,62] and values [51,57,60]. Sometimes, meaning is not immediately clear, take time to search for the meaning with the individual [41,47]. Using a person's history and interests to engage in conversation [52,59], other strategies such as the use of metaphor [47] or autobiographical components [60] support communication.
1.8	The final element in presentation and delivery is dealing with difficult conversations . This review found that patients and carers prefer HCPs to introduce challenging topics (i.e. ACP) [33] and recommended that discussions be held over several consultations [63]. It is important to balance hope with information when sharing difficult news [37,57] and seek permission to discuss difficult topics [37]. Recommended HCPs lead this conversation but avoid a formulated delivery [58,63]. Start with exploring current experience [63] and do not force onward if there is resistance [63].
2.	Behaviour & action
2.1	Actions to build rapport with PwCI and their families include creating a comfortable atmosphere [30,62], actively listening [36,43,49,51], and inviting PwCI and family to contribute and ask questions [32,54]. During the consultation, tailor communication style to individual needs [60,66] and ask about the impact on their daily functioning [67]. Encourage one person to talk at a time [28], avoid interruptions [39,43,52,60] and answering your phone [48].
2.2	Tailor communication by establishing patient preferences . Starting with asking how they would like to be addressed [49] and how they would like family involved [44]. Understand and be respectful of cultural norms [57,60,66]. Identify PwCI preferences for information, communication [32,37,49,57], treatment options [27,37] and decision-making [37,63]. HCPs need to consider communication support tools [50] and understand how people use augmented communication devices to support their interactions [29]. Communication approaches need to be adjusted for visual, hearing and cognitive difficulties [49,60].
2.3	Non-verbal behaviours that support communication for PwCI during interactions entailed approaching the person slowly [39], avoiding gestures without speech [28] and showing a caring positive attitude with open body language [48,69]. The use of light physical contact can be important for reassurance and for maintaining attention [30,39,49,59,65,69] or holding hands to show warmth [48,49,69].
2.4	Communication with PwCI is best when supported by written materials . Provide quality written materials in plain language/alternative languages [29,45,49,57,59,62,68]. HCPs can write out information for patient/families [62,64], and draw simple pictures to augment explanations [36,48,52,62]. Other materials can be used to encourage conversation (i.e. art, music, talking mats) [28,50,59] and always provide credible sources of information [27]. Assessing cognitive capacity using a cognitive assessment tool is recommended, particularly concerning decision-making capacity [32]. HCPs should be aware of conversing beyond a PwCI's capacity [35]. Encourage communication with the use of physical prompts or visual cues to assist [41,54,62] and language aids [49,54,62]. Use statements to maintain and extend conversation [59], and encourage circumlocution to support verbal explanations [39,61]. Shorter interactions may promote the engagement of a PwCI [28].
2.5	Establish collaborative communication by seeking consensus and collaborative discussion [32,35,54,56,57,67,68]. Work towards an actionable agenda and outcome [38,51,64] and gather agreement on the action plan with all parties going forward [32,36,46,51,56,57]. Consider relinquishing control [42] and sharing information [27,35,67] and thoughts when considering an option [58] that supports collaboration and helps to build supportive interactions [54]. Being flexible and adaptable in communication style is important when cognition is fluctuating [41]. Try another approach if your first approach is not working, and do not argue with the patient [35]. Finally, it is important to arrange follow-up [34,46] and set up the next appointment [32,57,67].
3.	Environmental elements: Communication interactions are enhanced by considering environmental elements. Eliminate distraction by reducing background and competing noise [28,34,35,48,49,59,69], selecting a low-stakes [37], calm and quiet environment [35,39,59,61]. Set up the environment for communication by arranging furniture for comfort and to assist PwCI to scan the environment [28,32,49,60]. Ensure adequate lighting [43,49], comfortable room temperature , with no clutter or additional equipment [43]. Culturally informed environments [53,66] and those familiar to people with cognitive impairment facilitate conversation [41,43]. Allow the environment to assist you by being seated at eye level with the person and their family [32,34,37,59], with participants being seated during the interaction [37]. Where possible use any physical prompts in the environment to demonstrate and support your communication [62]. If digital communication is used, use videoconference in preference to phone [55].
4.	Engaging with carers and family members It is widely recognised to involve family members and carers of a PwCI in the discussions regarding treatment [27,32,36,37,42,44,46,49,57,66], providing well-sourced information and education [34,44,51,62,63,67,68]. Consider which family and team members are present during the interaction, respect the privacy of the persons involved [43,49,60,68] and note any gender differences within shared spaces [49]. Involve family members who encourage and support communication [41,59] and promote consistent communication with family members and carers [48,69]. Recognise the strengths that families bring to the situation [42], respect the relationship carer and acknowledge the burden of caring for someone with a cognitive impairment [31,35]. Differentiate the experience of the PwCI and their family perspective [38,66]. Respectfully acknowledge the carer's role and expertise [35,55], and assess their unmet needs [31,63,68]. Offer a separate opportunity for the carer to speak with the team [31,38] and secure collateral history and communication preferences [35]. Flexibility in meeting needs of PwCI and their family, including face-to-face consultations over telephone, and allowing sufficient time [65] support communication. It is important that HCPs and systems set expectations with carers about changes to autonomy and capacity with progressive cognitive impairment [31].

Table 5
Environmental elements to enhance communication.

Calm environment	Eliminate distraction, reduce background/competing noise	[28,34,35,48,49,59,69]
	Separate space, quiet, calm Minimise clutter	[35,37,39,59,61] [43]
Set up the environment for communication	Arrange furniture for comfort and adequate scanning	[28,32,49,60]
Allow the environment to assist you	Adequate lighting and temperature	[43,49]
	Be seated at eye level with the person and their family	[32,34,37,59]
	Use physical prompts	[62]
	Familiar environment	[41,43]
Technology	Culturally informed	[53,66]
	Use videoconference in preference to telephone	[55]

[39]. The HCP needs to consider how an individual's cognitive capacity is established and what additional supports are available to enhance understanding and the communication of the message [35]. How cognitive capacity was screened by HCPs was not explored in this review, but reinforced as an important step in the communication process [32]. Other communication models talked about communication with empathy; however, our recommendations extended this further by highlighting more explicit behavioural engagement, such as smiling, maintaining eye contact, and actions indicating an interest in the person and their family's needs and concerns, all ways to embody a compassionate approach to communication [69]. Thereby, using non-verbal strategies at different levels to engage people with cognitive impairment.

Another area unique to this review was specific strategies regarding the environment that promoted quality communication. These included reducing physical barriers to communication, such as desks and improving environmental comfort (i.e. temperature). Elimination of distraction was highlighted as an important element in promoting quality communication with someone with reduced cognitive capacity [48]. Environmental considerations were not as clearly highlighted in general healthcare communication literature as a pivotal element of communication. However, when interacting with people whose attention and information processing are reduced, the environmental context makes a clear impact on a PwCI's ability to fully engage with the information shared [48,59].

Recently, work has been conducted to determine how to effectively engage carers and families in healthcare encounters. This recognises the pivotal role families and caregivers play in supporting and advocating for a loved one in healthcare. The TRIO communication guidelines developed in Australia emphasised the challenges in providing and maintaining quality communication, not only with people being treated for cancer, but also their loved ones [16]. The TRIO communication guideline intersects with these findings regarding family and carer engagement. While "working with carers and families" was an identified element of our findings, some key differences exist between our findings and the TRIO framework. The intent of the TRIO framework is to improve communication with carers in oncology consultations where the patient has cognitive capacity, an underlying assumption of the TRIO framework. Therefore, a distinguishing factor noted in the results of the current scoping review is the importance of identifying the carer or family member who is best placed to support the active and clear voice of the PwCI [41]. To collaborate effectively, the HCP needs to recognise both the voice and agency of the PwCI, and the important contribution of the family member throughout the consultation [42]. Findings in our review reinforced that while it was important to support caregiver involvement and acknowledge the pivotal role played in the care of someone with cognitive impairment, it was recommended that this be a caregiver who supported and enabled, not detracted from or

spoke for the PwCI. This is a delicate balance for HCPs in the context of changing cognition and diminishing decision-making capacity, particularly when complex treatments need to be understood and consent given. This is the case for individuals diagnosed with brain cancer [15]. Forward planning and consideration of competing needs within the family unit should ideally be at the heart of preparation for clinical communication for PwCI. Further, those concepts of establishing shared decision-making and collaborative goal setting between the treating team, PwCI and caregivers support HCPs to navigate this pathway.

The recent development of the Optimal Care Pathway for Older People with Cancer similarly seeks to navigate the balance of family and carer involvement, while maintaining the agency of the older person diagnosed with cancer [74]. This work, together with studies in this review targeting older people with cognitive impairment [32,43,49,64], reinforces the importance of including the PwCI, assuming decision-making capacity as a starting point. However, to effectively support this process, the inclusion of caregivers is pivotal to maintaining a collaborative healthcare relationship with all involved.

Organisation elements supporting quality communication, practices such as robust healthcare record systems and multidisciplinary meetings, were identified as important systemic approaches to supporting communication, ensuring HCPs have the tools necessary to work with PwCI [11]. Single-point care navigation or care coordination was also identified as a pivotal strategy for PwCI [29]. This is supported by recent work in brain cancer care, reinforcing the importance of consistent care coordination as a vehicle for quality care and communication [75]. Sourcing and identifying services to enhance care and daily function is a vital role of a care coordinator, ensuring those services are available to support PwCI to better communicate their needs and actively engage in their care. Supporting staff to develop their skills in communication with PwCI through formal training opportunities was seen as a way to embed these strategies into usual practice, ensuring HCPs are comfortable and confident in their ability to tailor their communication for PwCI and their families [14]. Other training priorities for HCPs lie in advanced care planning and principles of shared decision-making, recognising the nuanced practice of working with PwCI and the challenges that changes in cognitive capacity can bring [30].

5.1. Limitations of this review

With an expansive and important topic, it was surprising to see the limited detail regarding specific recommendations for HCPs communicating with PwCI and their families. Many studies discussed the issue in detail, reinforcing the importance of the topic; however, they did not articulate a framework or communication guidelines suitable for data extraction. Studies were not included if they did not articulate a framework, recommendations, or guidelines for improving the quality of HCPs' communication with PwCI. These studies were removed at the full-text review stage. This may have limited the fullness of the review, however, the elements identified were reinforced in multiple studies and resources. The identified elements displayed a consistent and repeated pattern of strategies and recommendations for healthcare communication; we are therefore confident that the key concepts have been comprehensively gathered within this review.

Although the country of origin for the studies was identified during data extraction, no specific details were gathered or identified regarding cultural differences in the application of communication strategies. We recognise that cultural nuances in communication are important and would need to be considered and addressed as part of future work in this area.

We did not include communication strategies for working with people with expressive or receptive aphasia. However, the management of aphasia has some very specific recommendations regarding communication support [76]. While understanding and expressing language is an important part of a person's cognitive capacity, we argue that there are distinct and separate approaches to working with people with

aphasia, and it is in the more subtle cognitive changes and impairment that our review is focused on. There is potential to extend these recommendations in the future to incorporate HCP communication strategies for working with people with aphasia, but it is beyond the scope of this review.

The lived experience perspective was likewise not included in the scoping review. While we recognise the importance of the patient experience, this review focused specifically on identifying strategies used by HCPs; therefore, the consumer perspective fell outside its parameters. There is an opportunity for future work in this area to identify and incorporate a lived-experience perspective, particularly when developing HCP training interventions.

6. Implications for clinical practice

Significant work has been undertaken in the development of communication frameworks and training programs for HCPs working with PwCI and their families across related health areas. One intention of our review was to better understand how HCPs can tailor communication to meet the needs of PwCI, with the plan to create a training resource for use in neuro-oncology.

People diagnosed with primary brain tumour and brain cancer have distinct challenges; they are faced with the life-limiting challenge of a poor prognosis in addition to progressive neuro-cognitive deterioration [77]. For some, cognitive changes are subtle and easily missed, for others, cognitive changes are more evident, with more dramatic consequences for the individual and their families. The communication strategies distilled as part of this review will contribute to developing a targeted training resource, initially, for neuro-oncology HCPs, with potential application across other oncology cancer streams and for HCPs working with people with benign brain tumours. An important part of the next steps is to identify ways to measure the impact of communication skills training, both on HCP behaviour and on patient outcomes and experience. The distinct elements identified to support the tailoring of communication for PwCI and their families as part of this scoping review can be embedded in targeted training to build skills in medical, nursing, and allied HCPs. It has also been vital to recognise the importance of underpinning communication and training strategies with a strong conceptual base aligned with organisational values to embed improvements in communication practice in organisations. Future work also needs to address sustainability and implementation; how can these elements of quality communication be understood, used appropriately and embedded as a part of everyday healthcare practice?

7. Conclusion

This scoping review identified the important elements of communication within healthcare settings for establishing and maintaining quality communication with PwCI. We have identified the important theoretical concepts in communication needed to underpin healthcare communication and the systems within health service organisations that support communication with PwCI. More specifically, we have articulated the person-based elements of presentation, delivery, behaviour, and action, the environmental elements and ways to engage families during healthcare interactions, acknowledging the intersection with basic healthcare communication frameworks. Points of difference and strategy distinction in working with PwCI lie in how information is presented, the environmental set up, and communication behaviour of HCPs. While many of these strategies were relatively straightforward and ‘common-sense’, future challenges lie in how these implicit communication skills become explicit, and part of a conscious choice for HCPs when seeking to tailor communication for a PwCI.

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CRediT authorship contribution statement

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2026.109611](https://doi.org/10.1016/j.pec.2026.109611).

References

- [1] Peppercorn JM, et al. American society of clinical oncology statement: toward individualized care for patients with advanced cancer. *J Clin Oncol* 2011;29(6):755–60.
- [2] Brindley PG. Commentary: communication: the most important “procedure” in healthcare and bioethics: CQ. *Camb Q Health Ethics* 2019;28(3):415–21.
- [3] Clayton JM, et al. Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-Oncol* 2008;17(7):641–59.
- [4] Wittenberg E, et al. Cancer communication and family caregiver quality of life. *Behav Sci* 2017;7(4):12.
- [5] Wang Y, et al. Communication between caregivers of adults with cancer and healthcare professionals: a review of communication experiences, associated factors, outcomes, and interventions. *Curr Oncol Rep* 2024;26(7):773–83.
- [6] Lobb EA, Halkett GK, Nowak AK. Patient and caregiver perceptions of communication of prognosis in high-grade glioma. *J Neuro-Oncol* 2011;104(1):315–22.
- [7] Janda M, et al. Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Educ & Couns* 2008;71(2):251–8.
- [8] Laid Saar-Powell R, et al. Family involvement in cancer treatment decision-making: a qualitative study of patient, family, and clinician attitudes and experiences. *Patient Educ Couns* 2016;99(7):1146–55.
- [9] Sillner A, et al. Influence of changes in memory and thinking on preferences and satisfaction of health care communications. *Innov Aging* 2023;7(ement_1):917–8.
- [10] Bunevicius A, Miller J, Parsons M. Isocitrate dehydrogenase, patient-reported outcomes, and cognitive functioning of glioma patients: a systematic review. *Curr Oncol Rep* 2020;22(12):120. 1–10.
- [11] Dean K, et al. Exploring the experiences of people with mild cognitive impairment and their caregivers with particular reference to healthcare – a qualitative study. *Int Psychogeriatr* 2014;26(3):475–85.

- [12] Paynter C, et al. The impact of communication on healthcare involvement for people living with motor neurone disease and their carers: a longitudinal qualitative study. *Int J Lang & Commun Disord* 2022;57(6):1318–33.
- [13] Boele FW, et al. Long-term wellbeing and neurocognitive functioning of diffuse low-grade glioma patients and their caregivers: a longitudinal study spanning two decades. *Neuro-Oncol* 2023;25(2):351–64.
- [14] Dooley J, Bailey C, McCabe R. Communication in healthcare interactions in dementia: a systematic review of observational studies. *Int Psychogeriatr* 2015;27(8):1277–300.
- [15] Boele FW, et al. Communication in the context of glioblastoma treatment: a qualitative study of what matters most to patients, caregivers and health care professionals. *Palliat Med* 2023;37(6):834–43.
- [16] Laidsaar-Powell R, et al. Facilitating collaborative and effective family involvement in the cancer setting: guidelines for clinicians (TRIO guidelines-1). *Patient Educ Couns* 2018;101:970–82.
- [17] Laidsaar-Powell R, et al. Improving breast cancer nurses' management of challenging situations involving family carers: pilot evaluation of a brief targeted online education module (TRIO-Conflict). *Patient Educ Couns* 2021;104(12):3023–31.
- [18] Halkett GK, et al. RT Prepare: a radiation therapist-delivered intervention reduces psychological distress in women with breast cancer referred for radiotherapy. *Br J Cancer* 2018;118(12):1549–58.
- [19] Butow PN, et al. Increasing oncologists' skills in eliciting and responding to emotional cues: evaluation of a communication skills training program. *Psycho-Oncol* 2008;17:209–18.
- [20] Rimmer B, et al. Health-related quality of life in adults with low-grade gliomas: a systematic review. *Qual Life Res* 2023;32(3):625–51.
- [21] Aromataris, E. and Munn, Z. *JBIM Manual for Evidence Synthesis*. 2020 April 2021; Manual]. Available from: (<https://synthesismanual.jbi.global>).
- [22] Tricco AC, et al. PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 2018;169(7):467–73.
- [23] Munn Z, et al. What are scoping reviews? Providing a formal definition of scoping reviews as a type of evidence synthesis. *JBIM Evid Synth* 2022;20(4):950–2.
- [24] Covidence. Covidence systematic review software. Melbourne, Australia: Veritas Health Innovation; 2024. (www.covidence.org).
- [25] Microsoft Corporation, MS Excel (Microsoft 365 Subscription). 2025, Microsoft Corporation. p. [Computer Software].
- [26] Lucas PJ, et al. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Med Res Methodol* 2007;7(1).
- [27] Ben-Zacharia A, et al. Impact of shared decision making on disease-modifying drug adherence in multiple sclerosis. *Int J MS Care* 2018;20(6):287–97.
- [28] Boykin GV. Strategies for increasing communication with the dysphasic patient. *Dimens Crit Care Nurs* 1984;3(5):279–87.
- [29] Cristian A, et al. Safety considerations for patients with communication disorders in rehabilitation medicine settings. *Phys Med & Rehabil Clin North Am* 2012;23(2):343–7.
- [30] Friedland RP. Strategies for driving cessation in Alzheimer disease. *Alzheimer Dis Assoc Disord* 1997;11(1):73–5.
- [31] Griffin JM, et al. Integrating family caregivers of people with Alzheimer's disease and dementias into clinical appointments: identifying potential best practices. *J Appl Gerontol* 2020;39(11):1184–94.
- [32] Korc-Grodzicki B, et al. Addressing the quality of communication with older cancer patients with cognitive deficits: development of a communication skills training module. *Palliat & Support Care* 2020;18(4):419–24.
- [33] Macchi ZA, Lum HD. Advance care planning in neurologic illness. *Handb Clin Neurol* 2022;190:129–48.
- [34] Michigan Medicine Center for Disability, Health and Wellness. Cognitive Impairment Resource Guide for Staff. 2023 [cited 2024; Available from: (<https://disabilityhealth.medicine.umich.edu/clinical/michart-disability-accommodations-tab/resources-workflow/cognitive-impairment-resource-guide-staff>)].
- [35] Miller CA. Communication difficulties in hospitalized older adults with dementia: try these techniques to make communicating with patients easier and more effective. *Am J Nurs* 2008;108(3):58–66.
- [36] Oyesanya TO, Thomas MA. Strategies nurses use when caring for patients with moderate-to-severe traumatic brain injury who have cognitive impairments. *J Clin Nurs* 2019;28(21-22):4098–109.
- [37] Sharma A. Palliative care and care partner support in neuro-oncology. *CONTINUUM Lifelong Learn Neurol* 2023;29(6):1872–95.
- [38] Vick JB, et al. "Let him speak" a descriptive qualitative study of the roles and behaviors of family companions in primary care visits among older adults with cognitive impairment. *Int J Geriatr Psychiatry* 2018;33(1):e103–12.
- [39] Alsawy S, et al. What is good communication for people living with dementia? A mixed-methods systematic review. *Int Psychogeriatr* 2017;29(11):1785–800.
- [40] Blackhall A, et al. VERA framework: communicating with people who have dementia. *Nurs Stand* 2011;26(10):35–9.
- [41] Collins R, et al. Methods and approaches for enhancing communication with people with moderate-to-severe dementia that can facilitate their inclusion in research and service evaluation: findings from the IDEAL programme. *Dementia* 2022;21(4):1135–53.
- [42] Hancock NJ, Houghton J, Jones F. Integrating an approach to personalised self-management support in stroke and neurorehabilitation service contexts: People1st - a quality improvement initiative. *Disabil & Rehabil* 2023;45(19):3034–45.
- [43] Jack K, Ridley C, Turner S. Effective communication with older people. *Nurs Older People* 2019;34(4).
- [44] National Institute for Health Care and Excellence. Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services. 2011, NICE: United Kingdom.
- [45] Nolan KJ, Keady J. A stitch in time. facilitating proactive interventions with dementia caregivers: the role of community practitioners. *Journal of Psychiatric & Mental Health Nursing*, 2. Wiley-Blackwell; 1995. p. 33–40.
- [46] Page S, Rowett R, Davies-Abbott I. Care to talk? A framework for appreciative conversations about dementia: Innovative practice. *Dementia* 2017;16(8):1069–74.
- [47] Pepper A, Denning KH. Person-centred communication with people with dementia. *Nurs Older People* 2023;35(2).
- [48] Dementia Australia. Managing changes in communication. 2024 [cited 2024; Available from: (<https://www.dementia.org.au/national/support-and-services/carers/managing-changes-in-communication>)].
- [49] Department of Health, Identifying and managing cognitive impairment. 2015. Available from: (<https://www.health.vic.gov.au/patient-care/identifying-and-managing-cognitive-impairment>).
- [50] Naehrig DN, et al. Impact of cognitive function on communication in patients with primary or secondary brain tumours. *J Neuro-Oncol* 2016;126(2):299–307.
- [51] Prescott S, Fleming J, Doig E. Rehabilitation goal setting with community dwelling adults with acquired brain injury: a theoretical framework derived from clinicians' reflections on practice. *Disabil & Rehabil* 2018;40(20):2388–99.
- [52] Smith ER, et al. Memory and communication support in dementia: research-based strategies for caregivers. *Int Psychogeriatr* 2011;23(2):256–63.
- [53] Belfrage M, et al. Best-practice guide to cognitive impairment and dementia care for Aboriginal and Torres Strait Islander people. *Dementia Training Australia*; 2024.
- [54] Togher L. Improving communication for people with brain injury in the 21st century: the value of collaboration. *Brain Impair* 2013;14(1):130–8.
- [55] Bayley M, et al. INCOG 2.0 guidelines for cognitive rehabilitation following traumatic brain injury: methods, overview, and principles. *J Head Trauma Rehabil* 2023;38:7–23.
- [56] Anderson S, Marlett NJ. The language of recovery: how effective communication of information is crucial to restructuring post-stroke life. *Top Stroke Rehabil* 2004;11(4):55–67.
- [57] Alzheimer Society of Canada. Dementia screening and diagnosis tools for health-care providers. 2024 [cited 2024; Available from: (<https://alzheimer.ca/en/help-support/im-healthcare-provider/dementia-diagnosis-screening-tools-health-care-providers>)].
- [58] Hunt AW, et al. Communication during goal-setting in brain injury rehabilitation: what helps and what hinders? *Br J Occup Ther* 2015;78(8):488–98.
- [59] Orange JB, et al. Alzheimer's disease. Physician-patient communication. *Can Fam Physician* 1994;40:1160–8.
- [60] Orange JB, Ryan EB. Alzheimer's disease and other dementias. *Implic Physician Commun Clin Geriatr Med* 2000;16(1):153–73 (xi).
- [61] Vachon M, Veilleux MC, Macoir J. Promoting the maintenance of satisfactory communication: strategies used by caregivers and medical staff with people suffering from Alzheimer's disease. *Geriatr Et Psychol Neuropsychiatr Du Vieil* 2017;15(2):185–95.
- [62] Dorfler E, Kulnik ST. Despite communication and cognitive impairment - person-centred goal-setting after stroke: a qualitative study. *Disabil & Rehabil* 2020;42(25):3628–37.
- [63] Piers R, et al. Advance care planning in dementia: recommendations for healthcare professionals. *BMC Palliat Care* 2018;17(1).
- [64] Siddiqui TG, et al. "What should I do when I get home?" treatment plan discussion at discharge between specialist physicians and older in-patients: mixed method study. *BMC Health Serv Res* 2020;20(1):1002.
- [65] Swiss academy of medical sciences, medical-ethical guidelines: care and treatment of people with dementia. *Swiss Med Wkly* 2018;148:1–12.
- [66] van Eenennaam RM, et al. Discussing personalized prognosis in amyotrophic lateral sclerosis: development of a communication guide. *BMC Neurol* 2020;20(446):1–11.
- [67] Aoki Y. Shared decision making for adults with severe mental illness: a concept analysis. *Japan Journal Nursing Science* JNS 2020;17(4):e12365 (p).
- [68] Peixoto VG, Diniz RV, Godeiro Jnr C. C.d.O.SPIKES-D: a proposal to adapt the SPIKES protocol to deliver the diagnosis of dementia. *Dement & Neuropsychol* 2020;14(4):333–9.
- [69] Better Health Channel. Dementia - communication. 2024; Available from: (<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/dementia-communication>).
- [70] Rasenberg E, Brand G, van Weel-Baumgarten E. Integrating medical and practical skills in communication skills training: do students feel it supports them with transfer from classroom to practice? *PEC Innov* 2023;2:100158.
- [71] Coulter A, Oldham J. Person-centred care: what is it and how do we get there? *Future Hosp J* 2016;3(2):114–6.

- [72] Lloyd M, Bor R, Noble LM. Clinical communication skills for medicine. Fourth edition. Edinburgh: Elsevier; 2019.
- [73] Brown RF, et al. Developing patient-centered communication skills training for oncologists: describing the content and efficacy of training. *Commun Educ* 2010;59(3):235–48.
- [74] Cancer Australia, Optimal care pathway for older people with cancer. Optimal Care pathways, 2025. Available from: (<https://www.cancer.org.au/assets/pdf/optimal-care-pathway-for-older-people-with-cancer>).
- [75] Jeon MS, et al. Identifying components of care coordination for primary brain tumor: a scoping review. *Neuro-Oncol Pract* 2025:357–75.
- [76] Stipinovich AM, Tonsing K, Dada S. Communication strategies to support decision-making by persons with aphasia: a scoping review. *Int J Lang & Commun Disord* 2023;58(6):1955–76.
- [77] Osoba D, et al. Effect of disease burden on health-related quality of life in patients with malignant gliomas. *Neuro-Oncol* 2000;2(4):221–8.