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CLINICAL PRACTICE GUIDELINE OPEN ACCESS

# Clinical Practice Guideline for the Management of Communication and Swallowing in Children Diagnosed With Childhood Brain Tumor or Leukemia

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## ABSTRACT

Childhood brain tumor and leukemia (CBTL) and their treatments can have negative effects on development, including communication and swallowing. Clinical practice guideline recommendations for managing communication and swallowing difficulties in children diagnosed with CBTL were informed by (i) a systematic review using the GRADE approach to rate certainty of evidence; (ii) GRADE Evidence to Decision Framework involving an international panel of experts; and (iii) a Health Professional and Consumer survey. To improve outcomes and quality of life, children with CBLT should have access to communication and swallowing assessment and intervention from cancer diagnosis, throughout and after treatment, and across survivorship.

## 1 | Introduction

The developing brain is extremely fragile and susceptible to the impact of childhood brain tumor and leukemia (CBTL), the leading forms of cancer in children in developed countries worldwide [1–5] and the effects of required treatments [6–8]. Many effects resulting from central nervous system (CNS)-targeted treatments are not realized until many years later [9–13] due to late-occurring structural and functional changes in the brain [14–16]. These deleterious changes can appear any time up to 10–20 years post-treatment, potentially interrupting normal development in children who face the largest proportion of

**Abbreviations:** ANZCHOG, Australian and New Zealand Children's Haematology/Oncology Group; CBTL, childhood brain tumor and leukemia; CNS, central nervous system; EtD, Evidence to Decision; GRADE, Grading of Recommendations, Assessment, Development and Evaluations; NHMRC, National Health and Medical Research Council; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; SWiM, Synthesis Without Meta-analysis guidelines.

their lives post-cancer [8, 17]. While not all negative treatment effects have been avoided, modern treatment protocols have been adapted to minimize side effects whilst maintaining high cure rates [18]. Here, we focus on the impacts seen on communication development and swallowing skills.

Children diagnosed with CBTL are at risk for developing a range of communication difficulties in critical foundation skills, including speech and language skills such as understanding instructions, vocabulary, producing sentences, correct grammar, and reading and writing [9, 10, 14, 19–25]. Cognitive-communication and social language difficulties are also evident, impacting functional abilities such as problem-solving, story-telling, understanding jokes and sarcasm, conversation-level skills, social skills, initiating and maintaining friendships, and job readiness [10, 14, 26–32]. Communication difficulties have been reported for up to 81% of survivors of major childhood cancers [33]. Critically, verbal and nonverbal language skills that are yet to develop are most vulnerable, with young children in particular experiencing difficulty acquiring or developing skills at the expected rate after cancer treatment across developmental milestones [16, 17]. Missed schooling and reduced time spent socializing with peers can also exacerbate communication difficulties for children with CBTL [34–36]. However, early intervention can minimize or prevent communication deficits that occur following treatment for childhood brain cancer or leukemia [37].

Children diagnosed with CBTL commonly experience swallowing difficulties [38]. These challenges may include impairments with biting, chewing, clearing food effectively from the mouth, difficulty with food and fluid consistencies, fatigue during eating, uncoordinated swallowing, and/or the absence of a cough reflex to clear an obstruction [24, 38, 39]. Swallowing difficulties most frequently occur during and as a result of CNS cancer treatments (e.g., due to mouth ulcers). Difficulties may also persist longer term, with impacts to social and mealtime management, as well as potential life-threatening impacts from swallowing related to choking and chest infections [24, 39]. Poor management of swallowing can also lead to malnutrition and compromise development [38].

The long-term burden of CBTL can weigh on families, communities, and the health system, including costs that are associated with primary and ongoing healthcare services [40, 41]. It is vital that cancer cure includes optimization of quality of life for children and families surviving brain cancer and leukemia [9]. To optimize patient care, communication and swallowing management should be tailored to the needs of the child and family, with good coordination between team members [42]. An experienced and highly competent multidisciplinary team involved in the rehabilitation of children with brain tumor or leukemia may contribute to quality assurance of the overall treatment and follow-up programs [43]. Here, we advocate for a systematic, evidence-based approach to the management of communication and swallowing in children diagnosed with CBTL through clinical practice guideline recommendations. Clinical guidelines address the potential inequality of services provided for these children within or across centers, which may be perpetuated when a standardized approach does not exist [44]. Guidelines also assist health professionals to provide and advocate for evidence-based care and management and to educate patient consumers (parents and patients) and support them to advocate for best practice management of communication and swallowing difficulties.

## 2 | Guideline Development

The clinical practice guideline was developed according to the 2016 National Health and Medical Research Council (NHMRC) Standards for Guidelines [45].

### 2.1 | Guideline Development Committee

#### 2.1.1 | Panel of Experts (Steering Committee)

The Panel of Experts (Steering Committee) consisted of five members with research and/or clinical expertise in CBTL (AM, CW, PP, MW, LD), and one consumer (MM; parent of a child diagnosed with CBTL), and the Lead Development Group (Chair [KD], Project Coordinator [RH], and Research and Evidence Consultant [LC]). The role of the Panel of Experts was to provide input and feedback across all phases of guideline development, including clinical question development, systematic review, evidence synthesis, survey development, and development of the recommendations. Members of the Panel of Experts were invited to the role by the Chair or through a call for interest via the Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG).

### 2.2 | Health Professional and Consumer Group

The Health Professional and Consumer Group consisted of 22 multidisciplinary health professionals with experience in CBTL and two consumers (parents of children diagnosed with CBTL). The role of Health Professional and Consumer Group members was to complete an online survey to gather their perspectives and input into the clinical management of communication and swallowing in children diagnosed with CBTL. Recruitment, demographic information, including years of practice, employment, setting/s, disciplines, expertise and experience, and survey procedures are detailed in Chami et al. [46].

### 2.3 | Clinical Questions

Two clinical questions were developed to guide the evidence review for guideline recommendations. The questions were consistent with the PICOTS (population, intervention, comparison, outcome, timing, setting) format [47] (see Table 1).

The population of CBTL is inherently diverse, due to a range of presentation characteristics. Diversity includes differences in cancer diagnoses, cancer treatments, cancer treatment effects (during and after), age at diagnosis, as well as progression of disease, periods of admission, medical complications (e.g., increased intracranial pressure, infections), family circumstances, and values. In this guideline, brain tumor and leukemia were considered as one population (i.e., childhood brain tumor or leukemia) due to the similarities in CNS-targeted cancer treatments and outcomes for these groups. Both cancer

**TABLE 1** | PICOTS[a] clinical questions used to develop clinical practice guideline recommendations.

| Communication outcomes | *What are the communication outcomes associated with childhood brain tumor or leukemia?* |
|---|---|
| **Swallowing outcomes** | *What are the swallowing outcomes associated with childhood brain tumor or leukemia?* |

[a]PICOTS format—population (P): children aged 0–16 with brain tumor or leukemia; intervention (I): any; comparison (C): any; outcome (O): communication/swallowing; timing (T): at diagnosis prior to cancer treatment, during the cancer treatment phase, during the cancer follow-up phase, during the survivorship phase; setting (S): both inpatient and outpatient settings.

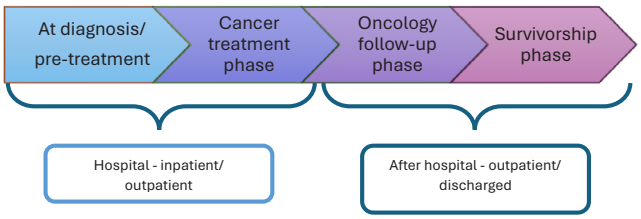


**FIGURE 1** | Framework of timing and setting in childhood brain tumor/leukemia.

groups commonly receive CNS-applied chemotherapy and/or radiotherapy that are reported to impact the developing brain and CNS [18]. However, a majority of the evidence on which the guideline recommendations are based was noted to be more largely represented by reports of children with brain tumor, with a recent increase in the amount of leukemia studies.

The scope of the guideline focuses on children aged 0–16 years. The 16-year age limit represents the upper age limit commonly applied to patients receiving pediatric services in the Australian healthcare system where the guideline originated.

## 2.4 | Timing and Setting Framework in Childhood Brain Tumor or Leukemia

The course of CBTL was conceptualized over time based on a long-term approach to health and well-being. Research focusing on communication and swallowing skills in this population examined outcomes at one or more points in time across a child's cancer journey, from diagnosis through to survivorship. To provide consistency in describing these time points, a framework was developed that identifies four key pediatric oncology phases (see Figure 1):

1. At diagnosis/pretreatment: at cancer diagnosis, prior to the start of cancer treatment
2. Cancer treatment phase: during, or in the weeks after, cancer treatment
3. Follow-up phase: less than 5 years since cancer treatment has finished
4. Survivorship phase: defined here as ≥5 years since cancer treatment has finished

These phases are closely linked with setting, including site-specific, country, and individual care practices. While some studies examine outcomes when children diagnosed with CBTL are still in hospital, others do so in community settings, such as clinics, schools, and at home. For simplicity in the framework, setting was binary classified into: "hospital–inpatient" and "after hospital–outpatient/discharged."

Due to the possibility of cancer recurrence, secondary cancer/s, or multiple primary cancer/s, it is important to recognize that a child may return to an earlier phase in this framework.

## 2.5 | Evidence That Informed the Guideline

The evidence-based recommendations in this guideline as well as the key practice points were informed by three sources of evidence:

1. Systematic review, including Grading of Recommendations, Assessment, Development and Evaluations (GRADE) Certainty of Evidence ratings and outcomes (narrative synthesis methods)
2. International Panel of Experts (Steering Committee) of research/clinical experts and a consumer using the GRADE Evidence to Decision (EtD) Framework
3. Health Professional and Consumer Group survey

## 2.6 | Systematic Review

The systematic review followed reporting guidelines for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statements [48], including the Synthesis Without Meta-analysis (SWiM) guidelines [49].

Systematic review methods are detailed in our original systematic review [50], including materials and methods such as information sources, search strategy, inclusion/exclusion criteria, study selection, data extraction, quality assessment of individual studies, and quality assessment of the body of evidence (certainty of evidence). The date range was expanded to December 19, 2024, and results updated here as follows.

### 2.6.1 | Study Selection

The updated PRISMA flowchart is shown in Figure S1. All 68 included studies and outcomes are detailed in Table S1 (communication) and Table S2 (swallowing).

### 2.6.2 | Characteristics of Included Studies

The characteristics of included studies specific to outcome are detailed, respectively, in Table S1 (communication) and Table S2 (swallowing). Study designs for included studies, participants,

and prognostic factors (cancer diagnoses) by outcome are summarized in Figures S2–S4.

#### 2.6.3 | Data Synthesis

As noted in our original systematic review [50], due to heterogeneity of studies in terms of design and outcome measures, a narrative synthesis, not meta-analysis, was conducted. Narrative synthesis was guided by the SWiM guidelines designed for the reporting of methods and results in narrative systematic reviews [49]. Narrative summaries for each outcome (communication: speech, language, speech+language; and swallowing) were guided by predefined items [50] as shown in Table S3.

#### 2.6.4 | Quality Assessment and GRADE Certainty of Evidence

The Joanna Briggs Institute (JBI) critical appraisal tools were used to assess the quality of each individual study [51, 52], resulting in a numerical score (see Tables S4–S7; individual quality assessment: speech, language, speech+language, swallowing). Individual study appraisal indicated methodological shortcomings in a majority of studies.

The body of evidence (GRADE) certainty rating for all outcomes (communication: speech, language, speech+language; swallowing) was determined by unanimous consensus by all authors as "very low." For each outcome, the GRADE parameters contributing to the GRADE certainty rating were risk of bias and precision, as well as study design (as detailed in Tables S4–S7; GRADE certainty of evidence: speech, language, speech+language, swallowing).

#### 2.6.5 | GRADE Summary of Findings Per Outcome (Narrative Summaries)

The GRADE summary of findings of the systematic review per outcome (communication, swallowing) are presented in Tables S8 and S9.

### 2.7 | GRADE Evidence to Decision Framework

GRADE Evidence to Decision (EtD) frameworks were completed by the Panel of Experts. The completed EtD frameworks and Summary of Judgments to Final Recommendations for Communication and Swallowing are detailed in full in Tables S10 and S11. The GRADE EtD framework provides a structured approach to ensure that judgments are reported transparently [53] (https://www.gradeworkinggroup.org/). The framework aims to determine the strength of recommendation, integrating the systematic review findings with prespecified criteria. This process included question formulation, making an assessment of the evidence, and drawing conclusions [53]. Input from the GRADE EtD Panel of Experts was gathered using a combination of online modes that are reported to be an effective method of engaging experts in the GRADE EtD process [54]. Neutral recommendations were developed based on the clinical questions. These clinical questions were provided by the Lead Development Team to the Panel of Experts to consider. For communication, the neutral recommendation was: "Communication assessment and intervention should/should not be offered to children diagnosed with CBTL." For swallowing, the neutral recommendation was: "Swallowing assessment and management should/should not be offered to children diagnosed with CBTL."

The GRADE EtD framework was presented to the Panel of Experts via an online package developed by the Lead Guideline Development team using the software program, Typeform (https://www.typeform.com/). This online package guided the Panel of Experts through the evidence assessment process. Systematic review methods and findings were presented in two PowerPoint presentations (communication and swallowing) with an audio-recorded voiceover that provided details of the methods and summarized key findings from each of the systematic reviews.

The Panel of Experts were each asked to assess the evidence by providing detailed opinions and judgments about the GRADE EtD criteria in an online questionnaire, which included the GRADE EtD criteria (problem, desirable effects, undesirable effects, values, balance of effects, resources required, cost-effectiveness, equity, acceptability, feasibility) and consisted of both multiple choice and open question/answer formats to capture individual responses.

All nine (100%) Typeform GRADE EtD online questionnaires were returned complete. Responses were collated into the GRADE EtD framework format. All judgments (multiple-choice answers) and full comments from the Panel of Experts were included for each judgment area of the GRADE EtD framework. Multiple-choice judgments were tallied by majority; however, raw numbers (judgment of each member of the Panel of Experts) were also retained.

The GRADE EtD summary of judgments from the Panel of Experts informed the final recommendations and determined the strength of recommendations. The final two recommendations for both communication and swallowing were unanimously agreed upon (as detailed in Tables S10 and S11, GRADE EtD framework and summary of judgments).

### 2.8 | Health Professional and Consumer Group Survey

The final source of evidence that informed the guideline was a survey of health professionals and consumers that also informed guideline development [46]. Health professionals with clinical experience with CBTL were eligible. Eligible consumers were adult (≥18 years old) survivors of CBTL or parents of children/adolescents diagnosed with CBTL. The clinical questions were presented in three sections: (i) assessment and management of communication and swallowing issues in children with CBTL; (ii) multidisciplinary care (health professional involvement); and (iii) risk factors regarding CBTL and when they should

be considered by speech pathologists assessing and managing communication and swallowing disorders in this population [46].

No studies examining risk factors were identified in the systematic review. However, survey findings [46] highlighted the importance of providing comprehensive communication and swallowing assessment and intervention, and the need for this to be offered over time following CBTL diagnosis into the survivorship phase. Findings also supported a multidisciplinary approach to management of communication and swallowing in CBTL, during cancer treatment and beyond. Finally, a range of risk factors was identified, with the findings highlighting the need to provide individualized care that is tailored to the patient in terms of their individual characteristics (child factors), their cancer, and treatment factors (see Table S12; risk factors identified by the Health Professional and Consumer Group).

## 2.9 | Public Consultation and Guideline Approval

The guideline underwent public consultation and consultation with the Director-General, Chief Executive, and Secretary of each State, Territory, and Commonwealth Department of Health in Australia. Independent peer-reviews using the Agree II instrument [55] and methodological review were conducted by the National Health and Medical Research Council (NHMRC). The guideline recommendations were approved by the Chief Executive Officer of the NHMRC, under Section 14A of the National Health and Medical Research Council Act 1992.

# 3 | Evidence-Based Recommendations and Key Practice Points

## 3.1 | Communication Recommendation

The communication recommendation and key practice points are presented in Table 2.

### 3.1.1 | Strength of Communication Recommendation

Based on the GRADE EtD framework, this recommendation was rated as strong. The Panel of Experts was confident that the desirable effects of adherence to the recommendation outweighed the undesirable effects. The implications of a strong recommendation for patients, clinicians, and policymakers as identified by GRADE [56] are:

- for patients—most people in your situation would want the recommended course of action and only a small proportion would not; request discussion if the intervention is not offered;
- for clinicians—most patients should receive the recommended course of action; and
- for policymakers—the recommendation can be adopted as a policy in most situations.

### 3.1.2 | Evidence for Communication Recommendation

The systematic review unambiguously demonstrated the existence of communication difficulties in this population. Communication disorders were frequently reported in children diagnosed with CBTL [50], and may be present at the time of cancer diagnosis [21, 24]) and/or during the cancer treatment phase [20, 57]. However, communication disorders may also be seen in the longer term, months or years after cancer treatment has been completed [22, 58, 59].

Communication disorders were evident across multiple subdomains of speech and language [50]. Dysarthria or specific speech deficits reported in this population included prosodic deficits [19, 21, 60–62], poor articulation/speech intelligibility [19, 21, 25, 61–63], slow rate [19, 25, 60, 63], and voice problems [19, 20, 25, 33, 61–65]. Fluency disorders have also been identified [21, 33, 66]. Mutism and/or dysarthria following surgery for cerebellar tumor surgery are well documented, including postoperative pediatric cerebellar mutism syndrome (pCMS) [19, 24, 25, 33, 57, 60–82]. For some children, mutism may resolve to dysarthria and/or language difficulties [24, 60, 63, 65, 69, 73, 77, 79, 80]. In the leukemia population, specific speech disorders have not been identified, but general disorders in speech have been reported [20, 59]. Identified language disorders included verbal language skills [14, 19–22, 33, 58–60, 69–71, 79, 80, 82–87], word-finding [60, 69, 84], narrative (story-telling) skills [26], and high-level language skills (e.g., inferencing, metaphors, jokes, and problem solving) [14, 23, 58, 85–88]. Literacy difficulties were also reported [19, 23, 33, 58, 89–91].

However, there are a various distinct limitations related to this body of evidence. First, there has been a reliance on descriptive study designs with small sample sizes. Second, heterogeneity across the literature in study design, participant factors, outcome measures, and timing of assessment makes it challenging to determine the prevalence of communication difficulties in this population. Third, there is limited evidence related specifically to children with leukemia as an emerging focus area.

Essential communication assessment and intervention in children diagnosed with CBTL was also recognized in evidence systematically gathered from the Health Professional and Consumer survey [46]. Communication skills were identified as critical foundations for later academic success, social connectedness, and mental health. The potential for cascading effects into adulthood with impacts on employment and participation in society was also highlighted. Outcomes from the Health Professional and Consumer survey study [46] emphasized a tailored and individualized approach as essential to communication management for children with CBTL, due to the heterogeneity in clinical presentations, medical management, and risk factors. Identified risk factors included child factors (e.g., age, socioeconomic background, hospital stay), brain tumor properties (e.g., location, size), and cancer treatment received (e.g., treatment type/combination, frequency) (see Table S12).

The desirable effects of providing communication assessment and intervention were rated by the Panel of Experts as large (see Table S10). The desirable effects focused on the improved communication outcomes that could be achieved if assessment

**TABLE 2** | Communication recommendation and key practice points.

| **Evidence-based recommendation 1: Communication** | |
|---|---|
| **Communication assessment and intervention should be offered to children diagnosed with childhood brain tumor or leukemia** | Strong recommendation[a] |
| **Key practice points** | |
| **Assessment and intervention** | |
| ***When to assess*** | |
| Communication assessment should occur at or as soon as possible after cancer diagnosis | |
| Communication assessment should occur during the cancer treatment phase and oncology follow-up phase. Multiple assessments during these phases may be required if concerns are indicated by the oncology care team and/or family | |
| Regular monitoring of the child's communication development should continue throughout the survivorship phase until the end of adolescence | |
| ***What to assess*** | |
| A comprehensive assessment of speech and language should be conducted. Assessment needs to be tailored to the age and developmental level of the child. Where appropriate, language assessment should include high-level language, discourse-level skills, and literacy | |
| Assessment should include a range of individualized assessment procedures such as norm-referenced assessments, criterion-referenced tools, caregiver report, and clinical observations across environments | |
| ***When to intervene*** | |
| Children diagnosed with CBTL should be provided with early individualized intervention during the cancer treatment phase for identified communication difficulties | |
| Children diagnosed with CBTL should be provided with timely individualized intervention for communication difficulties identified during the oncology follow-up and survivorship phases through until the end of adolescence | |
| **Care team** | |
| Speech pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the cancer treatment and follow-up phases | |
| All members of the oncology care team should be informed about communication difficulties and involved in management throughout the cancer treatment and follow-up phases | |
| Speech pathologists should work in partnership with oncologists, family members, and education professionals to monitor communication development throughout the survivorship phase until the end of adolescence | |
| **Education** | |
| Education about communication development and difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible | |
| Education about communication development and difficulties in CBTL should continue to be provided to families throughout the cancer treatment and follow-up phases | |
| Education about potential long-term communication difficulties in CBTL should be provided to families and education professionals throughout the oncology follow-up and survivorship phases | |

[a]Based on GRADE EtD framework.

and intervention were routinely offered to all children with downstream benefits for improved quality of life, particularly for social and academic participation. The undesirable effects were rated as small. These related to feelings of stress, worry, or frustration that could be experienced by the child or family in relation to testing and communication being *"just one more thing to worry about."* Desirable effects were overwhelmingly rated as outweighing undesirable effects.

### 3.1.3 | Evidence for Key Practice Points: Communication

Evidence for the communication key practice points is detailed in Table S13; including when to assess and when to monitor communication skills in CBTL (Figure S5) and the areas of communication to be considered for assessment in CBTL (Figure S6).

**TABLE 3** | Swallowing recommendation and key practice points.

| **Evidence-based recommendation 2: swallowing** | |
|---|---|
| **Swallowing assessment and management should be offered to children diagnosed with childhood brain tumor or leukemia** | Strong recommendation[a] |
| **Key practice points** | |
| **Assessment and intervention** | |
| ***When to assess*** | |
| Swallowing assessment should occur at or as soon as possible after diagnosis of CBTL | |
| Swallowing assessment should occur during the cancer treatment phase. Multiple assessments may be required where concerns are indicated by the oncology care team and/or family | |
| Regular monitoring of the child's swallowing should continue throughout the oncology follow-up and survivorship phases until the end of adolescence | |
| ***What to assess*** | |
| A comprehensive swallowing assessment should be conducted. Assessment needs to be tailored to the age and developmental level of the child. All phases of the swallow (pre-oral anticipatory, oral-preparatory, oral, and pharyngeal) need to be assessed | |
| Videofluoroscopy should be considered on a case-by-case basis as part of the assessment protocol to examine aspiration | |
| ***When to intervene*** | |
| Children diagnosed with CBTL should be provided with early individualized management for swallowing difficulties during the cancer treatment phase | |
| Children diagnosed with CBTL should be provided with individualized management for swallowing difficulties identified by the oncology care team and/or family in the oncology follow-up and survivorship phases | |
| **Care team** | |
| Speech pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the cancer treatment phase to manage swallowing | |
| All members of the oncology care team should be informed about swallowing difficulties and involved in their management as needed throughout oncology phases | |
| Speech pathologists should work in partnership with oncologists and family members to monitor swallowing throughout the survivorship phase until the end of adolescence | |
| **Education** | |
| Education about swallowing difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible | |
| Education about swallowing difficulties in CBTL should continue to be provided to families throughout the cancer treatment and follow-up phases | |

[a]Based on GRADE EtD framework.

## 3.2 | Swallowing Recommendation

The swallowing recommendation and key practice points are presented in Table 3.

### 3.2.1 | Strength of Swallowing Recommendation

Based on the results of the GRADE EtD framework, this recommendation was rated as strong. The Panel of Experts was confident that the desirable effects of adherence to the recommendation outweighed the undesirable effects. The implications of a strong recommendation for patients, clinicians, and policymakers as identified by GRADE [56] are consistent with those outlined above for communication.

### 3.2.2 | Evidence for Swallowing Recommendation

It was clear from the systematic review that swallowing difficulties are present in children with CBTL and are frequently seen immediately or soon after cancer treatment. Swallowing disorders are frequently reported in children with CBTL [50]. Disorders are most likely to be experienced during cancer treatment [33, 92]. For some children diagnosed with CBTL, particularly children diagnosed with brain tumor, swallowing disorders may continue for longer term [24, 57].

Acute swallowing disorders in children with CBTL are typically characterized by deficits across the oral preparatory and oral phase (e.g., reduced lip seal, food/liquid residue post-swallow,

food spillage/drooling, impaired transfer of food in mouth) and the pharyngeal phase of the swallow (e.g., delayed initiation of swallow, food/liquid residue in pharynx, coughing/gurgly voice, aspiration) [20, 24, 39]. General clinical factors or pre-oral anticipatory factors that can impact swallowing ability, such as fatigue and alertness/awareness may also be affected [24, 39] and therefore need to be assessed. When children are receiving cancer treatment, swallowing disorders can be severe, with aspiration of food or liquids possible [92, 93]. As a result, supplemental tube feeding may be required [20, 24, 38, 39, 57].

However, there are limitations in the body of evidence that need to be considered. To date, studies have relied on descriptive designs and relatively small samples. Heterogeneity across studies in relation to participant factors, outcome measures, and timing of assessments limit the ability to draw conclusions about the prevalence of swallowing difficulties in this population. Furthermore, there is a lack of evidence related specifically to the swallowing outcomes of children with leukemia.

Essential swallowing assessment and management for children diagnosed with CBTL was also reflected in evidence systematically gathered from experts, health professionals, and consumers [46]. The possibility of swallowing difficulties resulting in aspiration and being life-threatening was emphasized. Ensuring adequate nutrition in the acute period was also highlighted. Longer term swallowing difficulties and their potential to influence quality of life were also recognized, such as the impact on independence, family mealtimes, and social eating/fitting in with peers at school.

This source of evidence also emphasized the need to consider the heterogeneity of clinical presentation and medical management in the CBTL population when providing swallowing management [46]. Consideration of risk factors was seen to be particularly important, including child factors (e.g., age, socioeconomic background, hospital stay), swallowing-related factors (e.g., prolonged tube feeding, poor physical positioning), tumor properties (e.g., cancer location, brain tumor size), and cancer treatment (e.g., treatment type/combination, frequency) (outlined in Table S12). Given the inherent diversity in this population, swallowing assessment and management should be offered to all children diagnosed with CBTL in the context of an individualized approach.

Desirable effects of providing swallowing assessment and management were rated as large by the Panel of Experts, such as the safe swallowing of fluids and food and the prevention of aspiration and subsequent health complications such as chest infections and pneumonia (see Table S11). The undesirable effects were rated as small and related to the potential for stress/anxiety related to assessment for children and their families. The desirable effects of providing assessment and management were therefore rated as outweighing undesirable effects.

#### 3.2.3 | Evidence for Key Practice Points: Swallowing

Evidence for swallowing key practice points is detailed in Table S14, and when to assess and when to monitor swallowing skills in CBTL are outlined in Figure S7.

### 3.3 | Implications for Clinical Practice: GRADE EtD Framework

The GRADE EtD framework provided valuable context about the likely impact of recommendations on clinical practice and the health system. As part of the GRADE EtD framework, the Panel of Experts considered the five factors that weigh the risk versus benefit of the guideline recommendations (resources required, costeffectiveness, equity, acceptability, feasibility). The implications for clinical practice per outcome are described, respectively, in Tables 4 and 5.

## 4 | DISCUSSION

This clinical practice guideline has been developed to provide recommendations for multidisciplinary health professionals involved in the management of communication and swallowing disorders for children diagnosed with childhood brain tumor or leukemia, and families of children with CBTL. They are to be used alongside clinician judgment and patient preferences. Given the inherent diversity in this population, communication and swallowing assessment and intervention should be offered to all children diagnosed with CBTL in the context of an individualized approach to management. These recommendations are based on the best available evidence. Relevant health professionals may include, but are not limited to, speech pathologists, oncologists, rehabilitation physicians, nurses, occupational therapists, physiotherapists, dietitians, child life therapists, psychologists, and music therapists. Education providers in educational settings will also benefit from evidence-based guidelines to support CBTL survivors to transition back into the classroom and school community for educational services.

These guidelines will equip parents and families as lifelong advocates in seeking optimal quality-of-life outcomes for their children by providing knowledge about difficulties their child may experience and what these difficulties might look like over the course of development and beyond. This will ensure that families are connected with timely management, early intervention services, and appropriate referral services [94].

The impact of communication and swallowing disorders on quality of life beyond childhood, adolescence, and into adulthood is also acknowledged. Impacts are worse when early intervention and management are not provided. Adult survivors of childhood cancer may experience barriers to educational achievement as well as an impact to mental health, vocational independence, and earning potential [40, 41, 95].

The evidence unambiguously demonstrated the existence of communication disorders in this population. It was also clear that swallowing disorders can affect children with CBTL and are frequently seen immediately or soon after cancer treatment, particularly in children with brain tumor. There are limitations in the body of evidence that need to be considered. Studies have relied on descriptive designs and relatively small samples. There was significant heterogeneity across studies in relation to study design, participant factors, outcome measures, and timing of assessments. These heterogeneous factors limit the ability to draw robust conclusions about the prevalence of communication

**TABLE 4** | Implications of communication recommendation for clinical practice: GRADE EtD framework.

| Implications for clinical practice | Summary of judgments and comments from GRADE EtD framework |
|---|---|
| Resources required | **Costs and savings**<br>The Panel of Experts (Steering Committee) determined it is likely that there would be both costs and savings related to offering communication assessment/intervention to all children diagnosed with CBTL. Possible costs in the short-term may relate to the employment and upskilling of staff. However, there are potential long-term savings for the health sector, disability sector, education sector, and families due to reduced impact of communication difficulties long-term. |
| Cost effectiveness | **Favors providing assessment/intervention**<br>The Panel of Experts (Steering Committee) determined that communication assessment/intervention would be more cost effective compared to no communication assessment/intervention.<br>The short-term costs of offering communication/intervention are likely to be small compared to long-term costs of treating more established disorders later in development. The cost benefits also extend to psychological, educational, and employment outcomes. |
| Equity | **Increased**<br>The Panel of Experts (Steering Committee) determined that equity would likely to be increased if communication assessment/intervention was offered to children diagnosed with CBTL. If the recommended minimum standard via a national guideline was implemented, communication assessment/intervention would become routine. This would allow greater access to communication assessment/intervention, regardless of factors such as cultural and linguistic diversity, non-English-speaking backgrounds, socioeconomic status, geographical location, and education levels. |
| Acceptability | **Yes**<br>The Panel of Experts (Steering Committee) determined that offering communication assessment/intervention would be acceptable to the majority of stakeholders, including families and health professionals. |
| Feasibility | **Yes**<br>The Panel of Experts (Steering Committee) determined that offering communication assessment/intervention would be feasible to incorporate into current services. There are few issues with regards to feasibility, except for funding and staffing resources. |

and swallowing disorders in this population. Furthermore, there is a lack of evidence related specifically to the communication and swallowing outcomes of children with leukemia.

There is a clear need for larger scale studies with prospective longitudinal research designs examining communication and swallowing outcomes and intervention in children diagnosed with CBTL [50]. In particular, additional research focusing on communication outcomes in children diagnosed with leukemia is warranted. This includes further examination of communication disorders longitudinally across all timepoints and settings (e.g., diagnosis, during cancer treatment, oncology-follow-up, and survivorship). It is critical to co-design research with consumer partners, specifically focused on communication and swallowing outcomes of children from culturally, linguistically, socially, and geographically diverse communities. Recognition of diversity will ensure continued progress toward equitable and accessible services across all populations of children diagnosed with CBTL. Greater accuracy in identifying the prevalence of communication and swallowing disorders in children diagnosed with CBTL is also needed, as are larger scale studies focusing on effectiveness of communication and swallowing rehabilitation programs [50].

## 5 | CONCLUSION

The recommendations made in this guideline call for both communication and swallowing assessment and intervention to be offered to children diagnosed with brain tumor or leukemia.

Children diagnosed with brain tumor and leukemia often experience communication disorders such as difficulties producing clear speech, understanding and using language, and literacy skills. Communication disorders are common both at the time of cancer diagnosis and during cancer treatment, but are most commonly seen or arise in the months or years after cancer treatment.

Swallowing disorders are frequently reported during cancer treatment. However, there is evidence that swallowing disorders may continue longer term once cancer treatment has finished, particularly for children diagnosed with brain tumor. Feeding and swallowing contribute to quality of life, socialization, and family bonding, whereas the impaired ability to swallow foods and fluids can also be life-threatening, as it puts the child at risk of chest infections if food/fluid enters the lungs.

**TABLE 5** | Implications of swallowing recommendation for clinical practice: GRADE EtD framework.

| Implications for clinical practice | Summary of judgments and comments from GRADE EtD framework |
|---|---|
| Resources required | **Negligible costs**<br>The Panel of Experts (Steering committee) determined that there were negligible costs related to offering swallowing assessment/management to children diagnosed with CBTL. They recognized that the resources to provide assessment and management in the acute phases were already available; however, longer term follow-up could require additional resources in relation to staff, education, and assessment tools. Health professionals' time was the main resource identified. |
| Cost effectiveness | **Favors providing assessment/management**<br>The Panel of Experts (Steering Committee) determined that swallowing assessment/management would be more cost effective compared to no swallowing assessment/management. Providing management was seen as outweighing the potential negative impacts of swallowing difficulties related to aspiration, chest infection, and hospital stay length. |
| Equity | **Increased**<br>The Panel of Experts (Steering Committee) determined that equity would be likely to be increased if swallowing assessment/management was offered to children diagnosed with CBTL. In particular, equity may be increased for children from non-English-speaking backgrounds or lower socioeconomic backgrounds where families may be less able to identify swallowing difficulties or advocate for needs. One member of the Panel of Experts (Steering Committee) noted that more targeted approaches to identifying which children need swallowing assessment/management would be preferable to the current "status-quo." |
| Acceptability | **Yes**<br>The Panel of Experts (Steering Committee) determined that offering swallowing assessment/management would be acceptable to the majority of stakeholders, including families and health professionals. |
| Feasibility | **Yes**<br>The Panel of Experts (Steering Committee) determined that offering swallowing assessment/management would be feasible to incorporate into current services. However, they did recognize that this would depend on funding and staffing resources. It was recognized that it is not onerous and mostly requires time from the speech pathologist. |

The intended outcome of these evidence-based guideline recommendations is to improve the quality of life for children surviving brain tumor and leukemia. Guideline development has involved translating evidence from the research and clinical/consumer expertise into recommendations to guide improvements in cancer services and quality of clinical care for this population. Implementation of these recommendations will support a systematic and equitable approach to clinical management for communication and swallowing in CBTL, including long-term follow-up. Guidelines will inform targeted early intervention programs and survivorship surveillance planning. These recommendations will support children to keep healthy and lead a fulfilled life, not only during cancer diagnosis and treatment, but critically after cancer survival.


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#### Disclosure

KD and AM were co-authors on a number of studies included in the systematic review that informed guideline development. Potential conflict of interest procedures were conducted, and KD and AM did not conduct appraisal of any individual studies.

#### Conflicts of Interest

The authors declare no conflicts of interest.

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## Supporting Information

Additional supporting information can be found online in the Supporting Information section.