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Gastrostomy Tube Decision-Making Needs of Caregivers of Children with Cystic Fibrosis: A Scoping Review Protocol

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Complete List of Authors:	Zientek, Emily; Texas Tech University Health Sciences Center Rane, Sanika; Baylor College of Medicine Godfrey, Chelsea; Baylor College of Medicine Sisson, Emily; Texas Medical Center Dickinson, Kimberly; Baylor College of Medicine Department of Pediatrics, Pediatrics
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Title: Gastrostomy Tube Decision-Making Needs of Caregivers of Children with Cystic Fibrosis: A Scoping Review Protocol

Authors:

Emily Zientek[1], Sanika R. Rane[2], Chelsea C. Godfrey[2], Amy Sisson[3], Kimberly M. Dickinson[4]

1 *Texas Tech University Health Sciences Center, Paul L. Foster School of Medicine, El Paso, Texas*

2 *Baylor College of Medicine, Houston, TX, USA*

3 Texas Medical Center Library, Houston Academy of Medicine, Houston, Texas, USA.

4 Department of Pediatrics, Pulmonary Section, Baylor College of Medicine and Texas Children's Hospital, Houston, Texas

Corresponding Author: Correspondence and requests for reprints should be addressed to Kimberly M. Dickinson, MD, MPH Department of Pediatrics, Pulmonary Section, Baylor College of Medicine and Texas Children's Hospital, 6701 Fannin Street, Suite 1040 Houston, Texas 77030. Email: kmdickin@texaschildrens.org

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ABSTRACT

Introduction: While ensuring appropriate growth is essential for all children, optimizing nutritional status in children with cystic fibrosis (CF) is critical for improving health outcomes. Nutritional challenges in CF are multifactorial and malnutrition is common. While gastrostomy tubes (G-tubes) can improve weight status in individuals with CF, they also have common and chronic complications resulting in clinical equipoise. To date, factors influencing G-tube decision-making among caregivers of children with CF have not been systematically explored. This review aims to evaluate existing knowledge about caregivers' decisional needs related to G-tube placement, with a focus on caregivers of children with CF, as well as known medical and psychosocial benefits and risks of G-tube feedings in pediatric care.

Methods and analysis: This scoping review will follow the methodological framework of Arksey and O'Malley. We will include articles published between 1985 and 2023 in English and Spanish from six electronic databases, retrieved references from selected articles, and grey literature. Articles will be screened for final eligibility and inclusion according to title and abstract, followed by full texts. Articles will be independently reviewed by two reviewers and any disagreements discussed with a third reviewer for consensus. We will map themes and concepts and data extracted will be presented in tabular, diagrams, and descriptive summaries.

Ethics and Dissemination: As a form of secondary analysis, scoping reviews do not require ethics approval. This review will inform future research with caregivers involved in G-tube decision-making for children with CF. The final review will be submitted to a peer-reviewed scientific journal, disseminated at relevant academic conferences and will be shared with patients and clinicians.

Trial Registration Number https://osf.io/g4pdb

Article Summary

Strengths and Limitations of this study

- The proposed scoping review will be the first review to synthesize existing knowledge related to pediatric caregivers' G-tube decision-making needs.
- A strength of this scoping review protocol is the inclusion of a medical librarian in creating and refining the search strategy and the review of six databases that include peer-reviewed journals as well as a review of grey literature to identify all relevant studies and information.
- This scoping review will follow the Arksey and O'Malley methodological framework. The search will be restricted to articles published between 1985 and 2023 to capture the most recent literature.
- Due to feasibility constraints, another limitation is the exclusion of articles not published in English or Spanish.

INTRODUCTION

Ensuring children grow appropriately is a main tenant of pediatric care. Achieving optimal nutritional status is particularly important for children with chronic medical diseases, which often require additional nutritional support to promote their physical and cognitive development. One such disease is cystic fibrosis (CF), a life-limiting, common recessive genetic disorder characterized by the build-up of viscous mucous in the lungs, pancreas, and intestines. Ultimately, CF results in chronic and progressive obstructive lung disease and exocrine pancreatic insufficiency.[1] Due to malabsorption of nutrients, increased energy expenditure from lung infections, and chronic inflammation, children with CF have increased caloric intake needs.[2] Ensuring children consume their recommended daily caloric intake is critical, as studies demonstrate that achieving higher weight percentiles in childhood is associated with improved long-term lung function and survival.[3–5] However, nearly 10% of children with CF develop nutritional failure, despite medical and behavioral nutritional interventions and significant efforts by caregivers.[6–8] When other strategies are unsuccessful or not sustainable, caregivers (parents and primary guardians) are often recommended to consider initiating enteral tube feedings, including gastrostomy tube (G-tube) placement.[9]

Prior systematic reviews have examined the role of G-tubes in improving weight gain in CF.[10] While there are no randomized trials to inform decisions related to enteral tube feeding in CF, retrospective studies suggest G-tubes are safe and effective at improving weight gain and nutritional status, and have the potential to improve lung function and pulmonary status.[11–17] However, the insertion of a G-tube is not without challenges, including perioperative risk, changes in physical appearance, and common and foreseeable medical complications.[10] Thus, the decision to pursue G-tube placement is highly personalized, as knowledge, values, and perceptions of benefits and risks are unique for each family. While up to 20% of children with CF under the age of 10 years use supplemental tube feedings to augment nutritional intake,[6] it remains unknown what psychosocial and emotional factors influence G-tube decision-making for caregivers of children with CF and nutritional challenges.

To date, most studies of caregiver decision-making related to G-tube placement have focused on children with cognitive impairment or neurodisabilities. Notably, these studies demonstrate that G-tube discussions are associated with 1) intense grief and frustration[18], 2) increased stress and feelings of failure for the caregiver,[19,20] and 3) uncertainty about complications and care burden influence parental acceptance of the procedure.[21] While many factors influencing caregiver decision-making related to G-tube placement are likely universal, these experiences may not fully reflect the experiences of caregivers of children with CF. Within the field of CF, Gunnell *et al.* surveyed caregivers of children with CF with G-tubes and found that most were happy with the decision to pursue G-tube placement, however a lack of objective knowledge about G-tubes was common among surveyed caregivers.[22] Brotherton *et. al* explored parental perceptions of G-tube feedings, including 3 parents of children with CF, and demonstrated the adequacy of information and support received did not meet their expectations.[23]
The purpose of this scoping review is to better describe factors influencing G-tube decision-making among caregivers of children with CF. Given the scarcity of evidence specific to the CF population, we plan to review G-tube decision-making more broadly in the pediatric population, with a focus on determining factors that are universal as well as those that may be unique to caregivers of children with CF. The scoping review design will allow for a systematic approach to searching, selecting and synthesizing existing evidence, including more descriptive elements of the literature, identify knowledge gaps, and provide evidence to inform future recommendations.[24,25] This review will have two main objectives: (1) to evaluate existing knowledge about caregivers' decisional needs related to G-tube placement in children, generally

in pediatrics and for children with CF as well as (2) to evaluate known medical and psychosocial benefits and risks of G-tube feedings in pediatric care.

METHODS AND ANALYSIS

A scoping review design was selected because it is the best suited for descriptively mapping evidence on a topic to identify main concepts, theories, and knowledge gaps.[24] The proposed scoping review will follow the Arksey and O'Malley's methodological framework[26] and will be conducted in accordance with the Joanna Briggs Institute methodology[25,27] to ensure the rigor of the scoping review process. This five-stage process includes: (1) identification of the research question, (2) identification of studies relevant to the research question, (3) selection of studies for inclusion, (4) charting information and data obtained from the included studies, (5) collating, summarizing and reporting the results. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR**)** checklist will be used as a guideline for reporting the results of the scoping review.[28] This scoping review was registered on the Open Science Framework on April 6, 2023 (https: https://osf.io/g4pdb).

Stage 1: Identification of the scoping review research questions

In order to provide a useful and comprehensive review of pediatric caregivers' G-tube decision-making needs, this scoping review aims to identify and present the available information to address the following questions:

1. What is known about caregiver decision-making related to G-tube placement for children including those with CF?
2. What is known about caregiver's experiences living with and caring for a child with a G-tube, particularly for children with CF, including perceived risks and benefits?

Stage 2: Identifying relevant studies

Search Strategy

After reviewing other systematic and scoping reviews on decision-making and in consultation with expert stakeholders and an experienced medical librarian, a comprehensive preliminary search strategy was developed using free-text search terms and Medical Subject Headings related to decision-making, enteral tube feeding, and pediatrics. The search strategy was peer-reviewed by a second medical librarian using the Peer Review of Electronic Search Strategies (PRESS) checklist.[29] An initial limited electronic search of MEDLINE (Ovid) was undertaken to identify potentially relevant articles. The words contained in the titles and abstracts of the relevant articles, and the index terms used to describe the articles were used to develop a final search strategy. Due to lack of funding for translation, the search was limited to articles written in English and Spanish. The timeframe of interest included studies published after 1985 to the present, to ensure studies have relevance to current clinical practice. Post hoc criteria may be included as reviewers become more familiar with the literature. The final MEDLINE search strategy used is detailed in **Appendix 1**. To identify all potentially relevant published studies, the search strategy will be translated using the specific controlled vocabulary and/or syntax for each included database and/or information source: Embase, CINAHL, PsycInfo, Cochrane Database of Systematic Reviews, and Web of Science, which have wide coverage of health publications.

This search yielded 19,729 articles. Sources of unpublished studies and grey literature to be searched include Google Scholar as well as educational information produced by the Cystic Fibrosis Foundation (CFF) and/or CFF-accredited centers.

Stage 3: Study Selection

Following the finalized search parameters, the search results will be exported to EndNote and the medical librarian will remove duplicates. Studies will then be imported into Covidence, a web-based collaboration software platform designed for the creation of literature reviews, to identify duplicate publications and assist with the selection and extraction process outlined in this protocol.[30]

This review will consider studies that describe:

Population
Eligible studies will include the experiences and perspectives of caregivers, defined as parents and guardians of children (<18 years of age), including those with a clinical diagnosis of CF. Studies related to risks and benefits associated with G-tubes in children will also be included.

Concept
The concept of interest is caregiver decision-making needs relative to G-tube placement for children with cystic fibrosis. Given the paucity of knowledge within CF care, this scoping review will explore caregiver decision-making within general pediatric care, with special attention to what is known about caregiver's decision-making needs for children with CF considering G-tube placement. Additionally, the review will include studies that describe the experiences of caregivers related to living with and caring for a child with a G-tube, and how these influence caregiver decision-making.

Context
There will be no geographical limitation applied in relation to this scoping review. Evidence presented from any cultural or geographic context will be eligible.

The review will search all available peer-reviewed literature for studies that contain potentially relevant information; there will be no restrictions on the design of the studies, considering experimental and quasi-experimental studies, including observational and qualitative studies. Primary sources will be excluded if already incorporated into an included evidence synthesis unless the data they contain are not otherwise reported in the evidence synthesis. We will exclude studies that: 1) do not address caregivers' G-tube decision-making in pediatric care 2) do not report results related to risks and benefits associated with G-tubes in children < 18 years of age 3) do not allow full-text access and 4) are published in languages other than English and Spanish or before 1985.

A pilot screening test of 40 potentially relevant articles will be conducted by all four researchers to ensure agreement. Subsequently, the research team will meet to discuss discrepancies and make modifications to the eligibility criteria needed and screening will start once a minimum of 80% agreement is achieved. Thereafter, all studies will be screened independently by two researchers, and the study team will meet regularly throughout the process to refine inclusion criteria. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, and with an additional reviewer when necessary to

reach consensus. Potentially relevant sources will be retrieved in full and their citation details imported into Zotero reference manager. Subsequently, the full-text will be assessed in detail against the inclusion criteria by two independent researchers. The reference list of all included sources of evidence will be screened to capture possible relevant articles not captured in the search strategy and all key authors will be contacted with requests to provide potentially relevant sources. At this point, any studies that are excluded will be reported in the scoping review. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA-ScR flow diagram.[28]

Stage 4: Data Extraction

Data extraction will focus on identifying and charting data relevant to caregiver decision-making needs related to G-tube placement for children with CF. The researchers will chart the data using Covidence and use Microsoft Excel to organize the extracted data. A data extraction form will be developed by the researchers to determine which variables to extract. This tool will capture the relevant information on key study characteristics and detailed information on all metrics used to estimate/describe factors influencing G-tube decision-making. A preliminary charting table with included variables to be abstracted is summarized in **Table 1**. The data extracted will include specific details about the publication, study design, research methodology, as well as study findings and conclusions relevant to the review. Given the objective of the study, the themes will be organized according to factors that influence G-tube decision-making, experiences with G-tubes including medical and psychosocial risks and benefits of G-tube placement and long-term use. As pilot testing and to ensure consistency, all researchers will initially review the same 10 publications, discuss the results and amend the data extraction form in an iterative process during the data charting process. If new themes emerge during data extraction, these will also be included and any modifications will be detailed in the scoping review.

Data extraction of subsequent studies will be undertaken by two independent researchers, and a third reviewer (KMD) will review data extraction templates completed by the other reviewers. This is a quality check to ensure the extracted data from the articles are accurate and executed with rigor. Any disagreements that arise between the reviewers will be resolved through discussion, and with an additional reviewer when necessary. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

Table 1. Data Extraction Template	
Item	**Information**
1. Article Information	Title and Journal
	Author Information
	Year of Publication
	Country
2. Study Information	Study Design
	Study Aims
	Study Outcomes
3. Methodology	Target Population
	Recruitment
	Disease Process
	Tools used to measure outcomes
4. Factors Relevant to Decision-Making	Experiences, perspectives, facilitators, barriers
	Risks and Benefits
5. Future Directions	Research Gaps
	Study limitations

Stage 5: Data analysis and presentation

Results will be summarized both quantitatively and qualitatively to provide a description of the collected data. An analytic framework will be used to provide an overview of the breadth of the literature. This will include both descriptive numerical summary analysis, presented using tables and charts, and qualitative thematic analysis. Patterns and trends (if identified) will be illustrated using figures and or diagrams, and summarized narratively. Each article's summary will include the author(s), year of publication, country of origin, study purpose, participant information and sample size, study design, concept of interest, key findings related to the scoping review questions, study outcomes, and limitations identified by the authors. In keeping with scoping review methodology, an evaluation of study quality will not be performed. Final conclusions will be drawn from the mapped evidence, in addition to consultations with key stakeholders with unique insights into the experience of G-tube decision-making for children to validate and identify any gaps in our findings and ultimately guide recommendations for future research in this field.

Ethics and Dissemination The combined results from this scoping review and interviews with stakeholders will inform the development of a decision aid to support caregivers of children with CF in G-tube decision-making. This scoping review and the decision aid will be published in peer-reviewed journals and disseminated through national/international conference presentations. As this study involves no human participants and data was taken from publicly available publications, approval from a human research ethics committee is not required.

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Author Contributions KD conceived the idea for this scoping review, developed the research questions, objectives, and inclusion criteria. AS and KD contributed to the creation of the search

strategy. EZ and KD contributed to drafting and editing of the scoping review protocol. AS, EZ, SR, CR, and KD reviewed inclusion and exclusion criteria, screened abstracts and full-text papers. All authors read and approved the final manuscript.

Competing Interests: None declared**.**

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Not applicable.

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Appendix 1: Medline OVID search

1. Cystic Fibrosis/
2. "cystic fibrosis*".ti,ab,kw,kf.
3. "cystic fibrosis* ".io,ja,jn,jw,nj,nw,jc.
4. 1 or 2 or 3
5. Enteral Nutrition/ or Gastrostomy/ or Nutritional Requirements/ or Nutritional Status/
6. ((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) adj4 (nutrition* or feed*)).ti,ab,kw,kf.
7. ((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) adj4 (tube or tubes or stoma or stomas or stomy or requir* or status*)).ti,ab,kw,kf.
8. (gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies").ti,ab,kw,kf.
9. (gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes").ti,ab,kw,kf.
10. (gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies").ti,ab,kw,kf.
11. 5 or 6 or 7 or 8 or 9 or 10
12. 4 and 11 13. exp Deglutition Disorders/
14. ((deglutition* or swallow*) adj3 (disorder* or "dis-order*" or problem* or difficult*)).ti,ab,kw,kf.
15. (dysphag* or "gastroesoph* reflux*" or "gastro-esoph* reflux*" or "gastro-oesoph* reflux*" or "laryngopharyng* reflux*" or "laryngo-pharyng* reflux*").ti,ab,kw,kf.
16. 13 or 14 or 15
17. 11 or 16
18. exp Decision Making/ or exp Informed Consent/ or Conflict, Psychological/ or Family Conflict/ or Patient Autonomy/ or Motivation
19. (decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or motivat*).ti,ab,kw,kf.
20. Health Knowledge, Attitudes, Practice/ or Health Literacy/
21. (knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*).ti,ab,kw,kf.
22. Psychological Distress/ or Stress, Psychological/ or Caregiver Burden/ or Patient Satisfaction/

23. (distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*).ti,ab,kw,kf.
24. Risk/ or Risk Assessment/
25. (risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*).ti,ab,kw,kf.
26. Communication/ or Information Seeking Behavior/
27. communicat*.ti,ab,kw,kf.
28. (info* adj3 seek*).ti,ab,kw,kf.
29. Nurse-Patient Relations/ or Physician-Patient Relations/
30. ((nurse* or doctor* or physician*) adj3 patient*).ti,ab,kw.
31. ((nurse* or doctor* or physician* or provider* or patient*) adj3 (relation* or communicat*)).ti,ab,kw,kf.
32. 30 and 31
33. exp Guideline/
34. (guideline* or "guide-line*").ti,ab,kw,kf.
35. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 32 or 33 or 34
36. exp Family/ or exp Parents/ or Caregivers/ or Legal Guardians/
37. (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*).ti,ab,kw,kf.
38. (caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*).ti,ab,kw,kf.
39. 36 or 37 or 38
40. exp Pediatrics/ or exp Infant/ or exp Child/ or exp Adolescent/
41. (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).ti,ab,kw,kf.
42. (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).io,ja,jn,jw,nj,nw,jc.
43. 40 or 41 or 42
44. 17 and 35 and 39 and 43
45. 12 or 44
46. limit 45 to (yr="1985 -Current" and (english or spanish))

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Factors Guiding Gastrostomy Tube Decision-Making for Caregivers of Children with Cystic Fibrosis: A Scoping Review Protocol

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Authors:

Emily Zientek[1], Sanika R. Rane[2], Chelsea C. Godfrey[2], Amy Sisson[3], Kimberly M. Dickinson[4]

1 *Texas Tech University Health Sciences Center, Paul L. Foster School of Medicine, El Paso, Texas*

2 *Baylor College of Medicine, Houston, TX, USA*

3 Texas Medical Center Library, Houston Academy of Medicine, Houston, Texas, USA.

4 Department of Pediatrics, Pulmonary Section, Baylor College of Medicine and Texas Children's Hospital, Houston, Texas

Corresponding Author: Correspondence and requests for reprints should be addressed to Kimberly M. Dickinson, MD, MPH Department of Pediatrics, Pulmonary Section, Baylor College of Medicine and Texas Children's Hospital, 6701 Fannin Street, Suite 1040 Houston, Texas 77030. Email: kmdickin@texaschildrens.org

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ABSTRACT

Introduction: While ensuring appropriate growth is essential for all children, optimizing nutritional status in children with cystic fibrosis (CF) is critical for improving health outcomes. Nutritional challenges in CF are multifactorial and malnutrition is common. While gastrostomy tubes (G-tubes) can improve weight status in individuals with CF, they also have common and chronic complications resulting in clinical equipoise. To date, factors influencing G-tube decision-making among caregivers of children with CF have not been systematically explored. This review aims chart existing knowledge about caregivers' decisional needs related to G-tube placement, with a focus on caregivers of children with CF, as well as known medical and psychosocial benefits and risks of G-tube feedings in pediatric care.

Methods and analysis: This scoping review will follow the JBI methodological framework. We will include articles published between January 1, 1985 and November 1, 2023 in English and Spanish from MEDLINE (Ovid), Embase, CINAHL, PsycInfo, Cochrane Database of Systematic Reviews, and Web of Science related to G-tube decision-making. Articles published in languages besides English and Spanish will be excluded. Articles will be screened for final eligibility and inclusion according to title and abstract, followed by full texts. Articles will be independently reviewed by two reviewers and any disagreements discussed with a third reviewer for consensus. We will map themes and concepts and data extracted will be presented in tabular, diagrams, and descriptive summaries.

Ethics and Dissemination: As a form of secondary analysis, scoping reviews do not require ethics approval. This review will inform future research with caregivers involved in G-tube decision-making for children with CF. The final review will be submitted to a peer-reviewed scientific journal, disseminated at relevant academic conferences and will be shared with patients and clinicians.

Study registration; https://osf.io/g4pdb

Article Summary

Strengths and Limitations of this study

- The proposed scoping review will synthesize existing knowledge related to pediatric caregivers' G-tube decision-making needs, including caregivers of children with cystic fibrosis.
- A strength of this scoping review protocol is the review of six databases that include peer-reviewed journals to identify all relevant studies and information.
- This scoping review will follow the JBI methodological framework.
- Due to feasibility constraints, a limitation is the exclusion of articles not published in English or Spanish.

INTRODUCTION

Ensuring children grow appropriately is a main tenant of pediatric care. Achieving optimal nutritional status is particularly important for children with chronic medical diseases, which often require additional nutritional support to promote their physical and cognitive development. One such disease is cystic fibrosis (CF), a life-limiting, common recessive genetic disorder characterized by the build-up of viscous mucous in the lungs, pancreas, and intestines. Ultimately, CF results in chronic and progressive obstructive lung disease and exocrine pancreatic insufficiency.(1) Due to malabsorption of nutrients, increased energy expenditure from lung infections, and chronic inflammation, children with CF have increased caloric intake needs.(2) Ensuring children consume their recommended daily caloric intake is critical, as studies demonstrate that achieving higher weight percentiles in childhood is associated with improved long-term lung function and survival.(3-5) However, nearly 10% of children with CF develop nutritional failure, despite medical and behavioral nutritional interventions and significant efforts by caregivers.(6-8) When other strategies are unsuccessful or not sustainable, caregivers (parents and primary guardians) are often recommended to consider initiating enteral tube feedings, including gastrostomy tube (G-tube) placement.(9)

Retrospective studies suggest G-tubes are safe and effective at improving weight gain and nutritional status in CF, and have the potential to improve lung function and pulmonary status.(10-16) A prior systematic review has examined the role of G-tubes in improving weight gain in CF,(17) however due to a lack of randomized trials, there is not sufficient data to guide when to start enteral tube feedings in CF to ensure the best results. Notably, the prior systematic review identified several challenges associated with the insertion of a G-tube, including perioperative risk, changes in physical appearance, and common and foreseeable medical complications.(17) These findings highlight the complexity of the highly personalized decision to pursue G-tube placement, as knowledge, values, and perceptions of benefits and risks are unique for each family. While up to 20% of children with CF under the age of 10 years use supplemental tube feedings to augment nutritional intake,(6) it remains unknown what psychosocial and emotional factors influence G-tube decision-making for caregivers of children with CF and nutritional challenges.

To date, most studies of caregiver decision-making related to G-tube placement have focused on children with cognitive impairment or neurodisabilities. Notably, these studies demonstrate that G-tube discussions are associated with 1) intense grief and frustration, 2) increased stress and feelings of failure for the caregiver, and 3) uncertainty about complications and care burden influence parental acceptance of the procedure.(18-21) While many factors influencing caregiver decision-making related to G-tube placement are likely universal, these factors may not fully reflect the experiences of caregivers of children with CF. Within the field of CF, Gunnell *et al.* surveyed caregivers of children with CF with G-tubes and found that most were happy with the decision to pursue G-tube placement, however a lack of objective knowledge about G-tubes was common among surveyed caregivers.(22) Brotherton *et. al* explored parental perceptions of G-tube feedings, including 3 parents of children with CF, and demonstrated the adequacy of information and support received did not meet their expectations.(23)

Given the scarcity of evidence specific to the CF population, we plan to review G-tube decision-making more broadly in the pediatric population, with a focus on determining factors that are universal as well as those that may be unique to caregivers of children with CF. The scoping review design will allow for a systematic approach to searching, selecting and analysis of existing evidence, including more descriptive elements of the literature, identify knowledge gaps, and provide evidence to inform future research.(24,25) This review will have two main

objectives: (1) to chart existing knowledge about factors influencing caregivers' decision-making related to G-tube placement in children, generally in pediatrics and for children with CF as well as (2) to chart known medical and psychosocial benefits and risks of G-tube feedings in pediatric care.

METHODS AND ANALYSIS

Analysis

A scoping review design was selected because it is the best suited for descriptively mapping evidence on a topic to identify main concepts, theories, and knowledge gaps.[24] The proposed scoping review will follow the guidelines of the JBI to ensure the rigor of the scoping review process.(25,26) This five-stage process includes: (1) identification of the research question, (2) identification of studies relevant to the research question, (3) selection of studies for inclusion, (4) charting information and data obtained from the included studies, (5) collating, summarizing and reporting the results. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR**)** checklist will be used as a guideline for reporting the results of the scoping review.(27) This scoping review was registered on the Open Science Framework on April 6, 2023 (https: https://osf.io/g4pdb).

Stage 1: Identification of the scoping review research questions

In order to provide a useful and comprehensive review of pediatric caregivers' G-tube decision-making needs, this scoping review aims to identify and present the available information to address the following questions:

1. What is known about factors influencing caregiver's decision-making related to G-tube placement for children, including those with CF?
2. What is known about the medical and psychosocial benefits and risks of G-tube feedings as it pertains to caregiver's experiences living with and caring for a child with a G-tube, including those with CF?

Stage 2: Identifying relevant studies

Search Strategy

After reviewing other systematic and scoping reviews on decision-making and in consultation with expert stakeholders and an experienced medical librarian, a comprehensive preliminary search strategy was developed using free-text search terms and Medical Subject Headings related to decision-making, enteral tube feeding, and pediatrics. The search strategy was peer-reviewed by a second medical librarian using the Peer Review of Electronic Search Strategies (PRESS) checklist.(28) An initial limited electronic search of MEDLINE (Ovid) was undertaken to identify potentially relevant articles. The words contained in the titles and abstracts of the relevant articles, and the index terms used to describe the articles were used to develop a final search strategy. Due to lack of funding for translation, the search was limited to articles written in English and Spanish. The timeframe of interest included studies published after January 1,1985 to November 1, 2023. This timeframe was selected to encompass studies published after the widespread use of G-tube in pediatrics to ensure studies have relevance to current clinical practice. Post hoc criteria may be included as reviewers become more familiar with the

literature. The final search strategies for all databases used are detailed in **the Supplementary File**. To identify all potentially relevant published studies, the search strategy will be translated using the specific controlled vocabulary and/or syntax for each included database and/or information source: Embase, CINAHL, PsycInfo, Cochrane Database of Systematic Reviews, and Web of Science, which have wide coverage of health publications. This search yielded 19,729 articles.

Stage 3: Study Selection

Following the finalized search parameters, the search results will be exported to EndNote and the medical librarian will remove duplicates. Studies will then be imported into Covidence, a web-based collaboration software platform designed for the creation of literature reviews, to identify duplicate publications and assist with the selection and extraction process outlined in this protocol.(29)

This review will consider studies that describe:

Population
Eligible studies will include the experiences and perspectives of caregivers, defined as parents and guardians of children (<18 years of age), including those with a clinical diagnosis of CF. Studies related to risks and benefits associated with G-tubes in children will also be included.

Concept
The concept of interest is caregiver decision-making needs relative to G-tube placement for children with cystic fibrosis. Given the paucity of knowledge within CF care, this scoping review will explore caregiver decision-making within general pediatric care, with special attention to what is known about caregiver's decision-making needs for children with CF considering G-tube placement. Additionally, the review will include studies that describe the experiences of caregivers related to living with and caring for a child with a G-tube, and how these influence caregiver decision-making.

Context
There will be no geographical limitation applied in relation to this scoping review. Evidence presented from any cultural or geographic context will be eligible.

The review will search all available peer-reviewed literature for studies that contain potentially relevant information; there will be no restrictions on the design of the studies, considering experimental and quasi-experimental studies, including observational and qualitative studies. Primary sources will be excluded if already incorporated into an included evidence synthesis unless the data they contain are not otherwise reported in the evidence synthesis. We will exclude studies that: 1) do not address caregivers' G-tube decision-making in pediatric care 2) do not report results related to risks and benefits associated with G-tubes in children < 18 years of age 3) do not allow full-text access and 4) are published in languages other than English and Spanish or before 1985.

A pilot screening test of 40 potentially relevant articles will be conducted by all four researchers to ensure agreement. Subsequently, the research team will meet to discuss discrepancies and make modifications to the eligibility criteria needed and screening will start once a minimum of 80% agreement is achieved. Thereafter, all studies will be screened independently by two

researchers, and the study team will meet regularly throughout the process to refine inclusion criteria. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, and with an additional reviewer when necessary to reach consensus. Potentially relevant sources will be retrieved in full and their citation details imported into Zotero reference manager. Subsequently, the full-text will be assessed in detail against the inclusion criteria by two independent researchers. The reference list of all included sources of evidence will be screened to capture possible relevant articles not captured in the search strategy and all key authors will be contacted with requests to provide potentially relevant sources. At this point, any studies that are excluded will be reported in the scoping review. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA-ScR flow diagram.(27)

Stage 4: Data Extraction

Data extraction will focus on identifying and charting data relevant to caregiver decision-making needs related to G-tube placement for children with CF. The researchers will chart the data using Covidence and use Microsoft Excel to organize the extracted data. A data extraction form will be developed by the researchers to determine which variables to extract. This tool will capture the relevant information on key study characteristics and detailed information on all metrics used to estimate/describe factors influencing G-tube decision-making. A preliminary charting table with included variables to be abstracted is summarized in **Table 1**. The data extracted will include specific details about the publication, study design, research methodology, as well as study findings and conclusions relevant to the review. Given the objective of the study, the themes will be organized according to factors that influence G-tube decision-making, experiences with G-tubes including medical and psychosocial risks and benefits of G-tube placement and long-term use. As pilot testing and to ensure consistency, all researchers will initially review the same 10 publications, discuss the results and amend the data extraction form in an iterative process during the data charting process. If new themes emerge during data extraction, these will also be included and any modifications will be detailed in the scoping review.

Data extraction of subsequent studies will be undertaken by two independent researchers, and a third reviewer (KMD) will review data extraction templates completed by the other reviewers. This is a quality check to ensure the extracted data from the articles are accurate and executed with rigor. Any disagreements that arise between the reviewers will be resolved through discussion, and with an additional reviewer when necessary. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

Table 1. Data Extraction Template

Item	Information
1. Article Information	Title and Journal
	Author Information
	Year of Publication
	Country
2. Study Information	Study Design
	Study Aims

	Study Outcomes
3. Methodology	Target Population
	Recruitment
	Disease Process
	Tools used to measure outcomes
4. Factors Relevant to Decision-Making	Experiences, perspectives, facilitators, barriers
	Risks and Benefits
5. Future Directions	Research Gaps
	Study limitations

Stage 5: Data analysis and presentation

Results will be summarized both quantitatively and qualitatively to provide a description of the collected data. An analytic framework will be used to provide an overview of the breadth of the literature. This will include both descriptive numerical summary analysis, presented using tables and charts, and qualitative thematic analysis. Patterns and trends (if identified) will be illustrated using figures and or diagrams, and summarized narratively. Each article's summary will include the author(s), year of publication, country of origin, study purpose, participant information and sample size, study design, concept of interest, key findings related to the scoping review questions, study outcomes, and limitations identified by the authors. In keeping with scoping review methodology, an evaluation of study quality will not be performed. Final conclusions will be drawn from the mapped evidence, in addition to consultations with key stakeholders with unique insights into the experience of G-tube decision-making for children to validate and identify any gaps in our findings and ultimately guide recommendations for future research in this field.

Patient and public involvement None

Ethics and Dissemination The results from this scoping review will inform the development of a decision aid to support caregivers of children with CF in G-tube decision-making. This scoping review and the decision aid will be published in peer-reviewed journals and disseminated through national/international conference presentations. As this study involves no human participants and data was taken from publicly available publications, approval from a human research ethics committee is not required.

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Author Contributions KD conceived the idea for this scoping review, developed the research questions, objectives, and inclusion criteria. AS and KD contributed to the creation of the search strategy. EZ and KD contributed to drafting and editing of the scoping review protocol. AS, EZ, SR, CG, and KD reviewed inclusion and exclusion criteria, screened abstracts and full-text papers. All authors read and approved the final manuscript.

Competing Interests None declared.

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Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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Supplementary File: Combined Full Search Strategies of All Databases

1) Medline Search Strategy

#	Query
1	Cystic Fibrosis/
2	"cystic fibrosis*".ti,ab,kw,kf.
3	"cystic fibrosis*".io,ja,jn,jw,nj,nw,jc.
4	1 or 2 or 3
5	Enteral Nutrition/ or Gastrostomy/ or Nutritional Requirements/ or Nutritional Status/
6	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) adj4 (nutrition* or feed*)).ti,ab,kw,kf.
7	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) adj4 (tube or tubes or stoma or stomas or stomy or requir* or status*)).ti,ab,kw,kf.
8	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies").ti,ab,kw,kf.
9	(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes").ti,ab,kw,kf.
10	(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies").ti,ab,kw,kf.
11	5 or 6 or 7 or 8 or 9 or 10
12	4 and 11
13	Deglutition Disorders/ or exp Gastroesophageal Reflux/ or exp Laryngopharyngeal Reflux/
14	((deglutition* or swallow*) adj3 (disorder* or "dis-order*" or problem* or difficult*)).ti,ab,kw,kf.
15	(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*").ti,ab,kw,kf.
16	13 or 14 or 15
17	11 or 16

18	exp Decision Making/ or exp Informed Consent/ or Conflict, Psychological/ or Family Conflict/ or Personal Autonomy/ or Motivation/
19	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*).ti,ab,kw,kf.
20	Health Knowledge, Attitudes, Practice/ or Health Literacy/
21	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*).ti,ab,kw,kf.
22	Psychological Distress/ or Stress, Psychological/ or Caregiver Burden/ or Patient Satisfaction/
23	(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*).ti,ab,kw,kf.
24	Risk/ or Risk Assessment/
25	(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*).ti,ab,kw,kf.
26	Communication/ or Information Seeking Behavior/
27	communicat*.ti,ab,kw,kf.
28	(info* adj3 seek*).ti,ab,kw,kf.
29	Nurse-Patient Relations/ or Physician-Patient Relations/
30	((nurse* or doctor* or physician*) adj3 patient*).ti,ab,kw.
31	((nurse* or doctor* or physician* or provider* or patient*) adj3 (relation* or communicat*)).ti,ab,kw,kf.
32	30 and 31
33	exp Guideline/
34	(guideline* or "guide-line*").ti,ab,kw,kf.
35	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 32 or 33 or 34
36	exp Family/ or exp Parents/ or Caregivers/ or Legal Guardians/
37	(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*).ti,ab,kw,kf.
38	(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*).ti,ab,kw,kf.
39	36 or 37 or 38
40	exp Pediatrics/ or exp Infant/ or exp Child/ or exp Adolescent/

41 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).ti,ab,kw,kf.

42 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).io,ja,jn,jw,nj,nw,jc.

43 40 or 41 or 42

44 17 and 35 and 39 and 43

45 12 or 44

46 limit 45 to (yr="1985 -Current" and (english or spanish))

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2) Embase Search Strategy

#1 'cystic fibrosis'/de

#2 'cystic fibrosis*':ti,ab,kw

#3 'cystic fibrosis*':jt

#4 #1 OR #2 OR #3

#5 'enteric feeding'/de OR 'gastrostomy'/de OR 'nutritional requirement'/de OR 'nutritional status'/de

#6 ((enteral* OR enteric* OR gastr* OR nasogastr* OR gastrojejun* OR jejun* OR peg) NEAR/4 (nutrition* OR feed*)):ti,ab,kw

#7 ((enteral* OR enteric* OR gastr* OR nasogastr* OR gastrojejun* OR jejun* OR peg OR nutrition* OR stomach* OR digestiv* OR feed*) NEAR/4 (tube OR tubes OR stoma OR stomas OR stomy OR requir* OR status*)):ti,ab,kw

#8 gastrostoma:ti,ab,kw OR gastrostomas:ti,ab,kw OR gastrostomy:ti,ab,kw OR gastrostomies:ti,ab,kw OR gastrojejunostoma:ti,ab,kw OR gastrojejunostomas:ti,ab,kw OR gastrojejunostomy:ti,ab,kw OR gastrojejunostomies:ti,ab,kw OR 'gastro jejunostoma':ti,ab,kw OR 'gastro jejunostomas':ti,ab,kw OR 'gastro jejunostomy':ti,ab,kw OR 'gastro jejunostomies':ti,ab,kw

#9 gtube:ti,ab,kw OR gtubes:ti,ab,kw OR 'g-tube':ti,ab,kw OR 'g-tubes':ti,ab,kw OR 'gj-tube':ti,ab,kw OR 'gj-tubes':ti,ab,kw

#10 gstoma:ti,ab,kw OR gstomas:ti,ab,kw OR gstomy:ti,ab,kw OR gstomies:ti,ab,kw OR 'g-stoma':ti,ab,kw OR 'g-stomas':ti,ab,kw OR 'g-stomy':ti,ab,kw OR 'g-stomies':ti,ab,kw OR 'gj-stoma':ti,ab,kw OR 'gj-stomas':ti,ab,kw OR 'gj-stomy':ti,ab,kw OR 'gj-stomies':ti,ab,kw

#11 #5 OR #6 OR #7 OR #8 OR #9 OR #10

#12 #4 AND #11

#13 'dysphagia'/de OR 'gastroesophageal reflux'/exp OR 'laryngopharyngeal reflux'/de

#14 ((deglutition* OR swallow*) NEAR/3 (disorder* OR 'dis-order*' OR problem* OR difficult*)):ti,ab,kw

#15 dysphag*:ti,ab,kw OR 'gastroesoph* reflux*':ti,ab,kw OR 'reflux* gastroesoph*':ti,ab,kw OR 'gastro-esoph* reflux*':ti,ab,kw OR 'reflux* gastro-esoph*':ti,ab,kw OR 'gastro-oesoph* reflux*':ti,ab,kw OR 'reflux* gastro-oesoph*':ti,ab,kw OR 'laryngopharyng* reflux*':ti,ab,kw OR 'reflux* laryngopharyng*':ti,ab,kw OR 'laryngo-pharyng* reflux*':ti,ab,kw OR 'reflux laryngo-pharyng*':ti,ab,kw

#16 #13 OR #14 OR #15

#17 #11 AND #16

#18 'decision making'/de OR 'family decision making'/de OR 'patient decision making'/de OR 'shared decision making'/de OR 'ethical decision making'/de OR 'informed consent'/de OR 'conflict'/de OR 'family conflict'/de OR 'patient autonomy'/de OR 'motivation'/exp

#19 decision*:ti,ab,kw OR decid*:ti,ab,kw OR choice*:ti,ab,kw OR choos*:ti,ab,kw OR consensus*:ti,ab,kw OR consent*:ti,ab,kw OR conflict*:ti,ab,kw OR disagree*:ti,ab,kw OR agree*:ti,ab,kw OR participat*:ti,ab,kw OR prefer*:ti,ab,kw OR involv*:ti,ab,kw OR engag*:ti,ab,kw OR expect*:ti,ab,kw OR autonom*:ti,ab,kw OR motivat*:ti,ab,kw

#20 'attitude to health'/de OR 'health literacy'/de

#21 knowledg*:ti,ab,kw OR attitude*:ti,ab,kw OR literacy*:ti,ab,kw OR believ*:ti,ab,kw OR belief*:ti,ab,kw OR percept*:ti,ab,kw OR perceiv*:ti,ab,kw OR perspectiv*:ti,ab,kw

#22 'distress syndrome'/de OR 'mental stress'/de OR 'caregiver burden'/de OR 'caregiver burnout'/de OR 'emotional stress'/de OR 'ethical dilemma'/de OR 'family stress'/de OR 'home stress'/de OR 'interpersonal stress'/de OR 'life stress'/de OR 'parental stress'/exp OR 'patient satisfaction'/de

#23 distress*:ti,ab,kw OR despair*:ti,ab,kw OR stress*:ti,ab,kw OR burden*:ti,ab,kw OR burnout*:ti,ab,kw OR 'burn* out*':ti,ab,kw OR satisf*:ti,ab,kw OR dissatisf*:ti,ab,kw

#24 'risk'/de OR 'patient risk'/de OR 'risk assessment'/de OR 'health risk assessment'/de OR 'risk attitude'/de OR 'risk aversion'/de OR 'risk denial'/de OR 'risk perception'/exp

#25 risk*:ti,ab,kw OR advantag*:ti,ab,kw OR advers*:ti,ab,kw OR benefit*:ti,ab,kw OR disadvantag*:ti,ab,kw OR 'dis-advantag*':ti,ab,kw OR drawback*:ti,ab,kw OR 'draw-back*':ti,ab,kw OR harm*:ti,ab,kw

#26	'interpersonal communication'/de OR 'information seeking'/de
#27	communicat*:ti,ab,kw
#28	(info* NEAR/3 seek*):ti,ab,kw
#29	'nurse patient relationship'/de OR 'doctor patient relationship'/de
#30	((nurse* OR doctor* OR physician*) NEAR/3 patient*):ti,ab,kw
#31	((nurse* OR doctor* OR physician* OR provider* OR patient*) NEAR/3 (relation* OR communicat*)):ti,ab,kw
#32	#30 AND #31
#33	'guideline'/de
#34	guideline*:ti,ab,kw OR 'guide-line*':ti,ab,kw
#35	#18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #32 OR #33 OR #34
#36	'family'/exp OR 'parent'/exp OR 'caregiver'/de OR 'legal guardian'/de
#37	family*:ti,ab,kw OR families*:ti,ab,kw OR parent:ti,ab,kw OR parents:ti,ab,kw OR mother*:ti,ab,kw OR father*:ti,ab,kw OR grandparent*:ti,ab,kw OR grandmother*:ti,ab,kw OR grandfather*:ti,ab,kw OR guardian*:ti,ab,kw
#38	caregiver*:ti,ab,kw OR 'care-giver*':ti,ab,kw OR caretaker*:ti,ab,kw OR 'care-taker*':ti,ab,kw OR carer*:ti,ab,kw
#39	#36 OR #37 OR #38
#40	'pediatrics'/exp OR 'infant'/exp OR 'child'/exp OR 'adolescent'/exp
#41	pediatri*:ti,ab,kw OR paediatr*:ti,ab,kw OR infan*:ti,ab,kw OR baby*:ti,ab,kw OR babies*:ti,ab,kw OR neonat*:ti,ab,kw OR 'neo-nat*':ti,ab,kw OR newborn*:ti,ab,kw OR 'new-born*':ti,ab,kw OR 'newly born*':ti,ab,kw OR toddler*:ti,ab,kw OR preschool*:ti,ab,kw OR 'pre-school*':ti,ab,kw OR child*:ti,ab,kw OR schoolchild*:ti,ab,kw OR 'school-age*':ti,ab,kw OR girl*:ti,ab,kw OR boy:ti,ab,kw OR boys:ti,ab,kw OR tween*:ti,ab,kw OR teen*:ti,ab,kw OR adolescen*:ti,ab,kw OR kid:ti,ab,kw OR kids:ti,ab,kw OR juvenile*:ti,ab,kw OR youth*:ti,ab,kw
#42	pediatri*:jt OR paediatr*:jt OR infan*:jt OR baby*:jt OR babies*:jt OR neonat*:jt OR 'neo-nat*':jt OR newborn*:jt OR 'new-born*':jt OR 'newly born*':jt OR toddler*:jt OR preschool*:jt OR 'pre-school*':jt OR child*:jt OR schoolchild*:jt OR 'school-age*':jt OR girl*:jt OR boy:jt OR boys:jt OR tween*:jt OR teen*:jt OR adolescen*:jt OR kid:jt OR kids:jt OR juvenile*:jt OR youth*:jt
#43	#40 OR #41 OR #42
#44	#17 AND #35 AND #39 AND #43
#45	#12 OR #44

#46 (#12 OR #44) AND ([english]/lim OR [spanish]/lim) AND [1985-2022]/py

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3) CINAHL

1 (MH "Cystic Fibrosis")

2 TI "cystic fibrosis*" OR AB "cystic fibrosis*"

3 SO "cystic fibrosis*" OR JN "cystic fibrosis*" OR JT "cystic fibrosis*"

4 S1 OR S2 OR S3

5 (MH "Enteral Nutrition") OR (MH "Gastrostomy") OR (MH "Nutritional Requirements") OR (MH "Nutritional Status")

6 TI ((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) N4 (nutrition* or feed*))) OR AB (((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) N4 (nutrition* or feed*))

7 TI ((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) N4 (tube or tubes or stoma or stomas or stomy or requir* or status*))) OR AB (((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) N4 (tube or tubes or stoma or stomas or stomy or requir* or status*))

8 TI (gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies") OR AB (gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies")

9 TI (gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes") OR AB (gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes")

10 TI ((gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies")) OR AB ((gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies"))

11 S5 OR S6 OR S7 OR S8 OR S9 OR S10

12 S4 AND S11

13 MH "Deglutition Disorders") OR (MH "Gastroesophageal Reflux")

14 TI (((deglutition* or swallow*) N3 (disorder* or "dis-order*" or problem* or difficult*))) OR AB (((deglutition* or swallow*) N3 (disorder* or "dis-order*" or problem* or difficult*)))

15	TI ((dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*")) OR AB ((dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*"))
16	S13 OR S14 OR S15
17	S11 OR S16
18	(MH "Decision Making+") OR (MH "Consent+") OR (MH "Conflict (Psychology)") OR (MH "Family Conflict") OR (MH "Patient Autonomy") OR (MH "Motivation")
19	TI ((decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivate*)) OR AB ((decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivate*))
20	(MH "Health Literacy")
21	TI (knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*) OR AB (knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*)
22	(MH "Psychological Distress") OR (MH "Stress, Psychological") OR (MH "Caregiver Burden") OR (MH "Patient Satisfaction")
23	TI (distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*) OR AB (distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*)
24	(MH "Relative Risk") OR (MH "Risk Assessment")
25	TI (risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*) OR AB (risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*)
26	(MH "Communication"") OR (MH "Information Seeking Behavior")
27	TI communicat* OR AB communicat*
28	TI (info* N3 seek*) OR AB (info* N3 seek*)
29	(MH "Nurse-Patient Relations") OR (MH "Physician-Patient Relations")
30	TI ((nurse* or doctor* or physician*) N3 patient*) OR AB ((nurse* or doctor* or physician*) N3 patient*)

31	TI ((nurse* or doctor* or physician* or provider* or patient*) N3 (relation* or communicat*)) OR AB ((nurse* or doctor* or physician* or provider* or patient*) N3 (relation* or communicat*))
32	S30 AND S31
33	(MH "Practice Guidelines")
34	TI (guideline* or "guide-line*") OR AB (guideline* or "guide-line*")
35	S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S32 OR S33 OR S34
36	(MH "Family+") OR (MH "Parents+") OR (MH "Caregivers") OR (MH "Guardianship, Legal")
37	TI (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*) OR AB (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*)
38	TI (caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*) OR AB (caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*)
39	S36 OR S37 OR S38
40	(MH "Pediatrics+") OR (MH "Infant+") OR (MH "Child+") OR (MH "Adolescence+")
41	TI (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR AB (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
42	SO (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR JN (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR JT (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
43	S40 OR S41 OR S42
44	S17 AND S35 AND S39 AND S43
45	S12 OR S44 Limiters - Published Date: 19850101-20231231; English Language

46 s12 or s44

47 s12 or s44 Limiters - Published Date: 19850101-20231231; Language: Spanish

48 S45 OR S47

Limiters - Published Date: 19850101-20231231; Language: Spanish "

48 S45 OR S47

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4) APA PsycInfo

#	Query
1	Cystic Fibrosis/
2	cystic fibrosis.mh.
3	"cystic fibrosis*".tw.
4	cystic fibrosis*.jn,jx,nl,ol.
5	1 or 2 or 3 or 4
6	(enteral nutrition or gastrostomy or nutritional requirements or nutritional status).mh.
7	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) adj4 (nutrition* or feed*)).tw.
8	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) adj4 (tube or tubes or stoma or stomas or stomy or requir* or status*)).tw.
9	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies").tw.
10	(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes").tw.
11	(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies").tw.
12	6 or 7 or 8 or 9 or 10 or 11
13	5 and 12
14	exp Dysphagia/
15	(deglutition disorders or gastroesophageal reflux or laryngopharyngeal reflux).mh.

16	((deglutition* or swallow*) adj3 (disorder* or "dis-order*" or problem* or difficult*)).tw.
17	(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*").tw.
18	14 or 15 or 16 or 17
19	12 or 18
20	exp Decision Making/ or exp Informed Consent/ or Family Conflict/ or exp Autonomy/ or exp Conflict/ or Motivation/
21	(decision making or informed consent or conflict, psychological or family conflict or personal autonomy or motivation).mh.
22	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*).tw.
23	Health Knowledge/ or Health Literacy/
24	(health knowledge, attitudes, practice or health literacy).mh.
25	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*).tw.
26	Psychological Stress/ or Distress/ or Caregiver Burden/ or Client Satisfaction/
27	(psychological distress or stress, psychological or caregiver burden or patient satisfaction).mh.
28	(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*).tw.
29	Risk Factors/ or Risk Assessment/
30	(risk or risk assessment).mh.
31	(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*).tw.
32	Communication/ or Information Seeking/
33	(communication or information seeking behavior).mh.
34	communicat*.tw.
35	(info* adj3 seek*).tw.
36	(nurse-patient relations or physician-patient relations).mh.
37	((nurse* or doctor* or physician*) adj3 patient*).tw.
38	((nurse* or doctor* or physician* or provider* or patient*) adj3 (relation* or communicat*)).tw.

39	37 and 38
40	exp Treatment Guidelines/ or guideline.mh.
41	(guideline* or "guide-line*").tw.
42	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 39 or 40 or 41
43	exp Family/ or exp Parents/ or Caregivers/ or Guardianship/
44	(family or parents or caregivers or legal guardians).mh.
45	(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*).tw.
46	(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*).tw.
47	43 or 44 or 45 or 46
48	exp Pediatrics/ or (pediatrics or infant or child or adolescent).mh.
49	(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).tw.
50	(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).jn,nl,ol,jx.
51	or/48-50
52	19 and 42 and 47
53	51 and 52
54	limit 52 to (childhood or adolescence <13 to 17 years>)
55	53 or 54
56	13 or 55
57	limit 56 to (yr="1985 -Current" and (english or spanish))

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5) Cochrane Database of Systematic Reviews

ID	Search
#1	MeSH descriptor: [Cystic Fibrosis] explode all trees

#2	(cystic NEXT/3 fibrosis*):ti,ab,kw
#3	(cystic NEXT/3 fibrosis*):so
#4	#1 or #2 or #3
#5	MeSH descriptor: [Enteral Nutrition] this term only
#6	MeSH descriptor: [Gastrostomy] this term only
#7	MeSH descriptor: [Nutritional Requirements] this term only
#8	MeSH descriptor: [Nutritional Status] this term only
#9	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) NEXT/4 (nutrition* or feed*)):ti,ab,kw
#10	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) NEXT/4 (tube or tubes or stoma or stomas or stomy or requir* or status*)):ti,ab,kw
#11	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or (gastro NEXT jejunostoma) or (gastro NEXT jejunostomas) or (gastro NEXT jejunostomy) or (gastro NEXT jejunostomies)):ti,ab,kw
#12	(gtube or gtubes or g NEXT tube or g NEXT tubes or gj NEXT tube or gj NEXT tubes)
#13	(gstoma or gstomas or gstomy or gstomies):ti,ab,kw
#14	(stoma or stomas or stomy or stomies) NEAR/3 (g or gi)
#15	#5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14
#16	#4 and #15
#17	MeSH descriptor: [Deglutition Disorders] this term only
#18	MeSH descriptor: [Gastroesophageal Reflux] explode all trees
#19	MeSH descriptor: [Laryngopharyngeal Reflux] explode all trees
#20	((deglutition* or swallow*) NEAR/3 (disorder* or dis-order* or problem* or difficult*)):ti,ab,kw
#21	(dysphag* or (gastroesoph* NEXT reflux*) or (reflux* NEXT gastroesoph*) or (gastro NEXT esoph* NEXT reflux*) or (reflux* NEXT gastro NEXT esoph*) or (gastro NEXT oesoph* NEXT reflux*) or (reflux* NEXT gastro NEXT oesoph*) or (laryngopharyng* NEXT reflux*) or (reflux* NEXT laryngopharyng*) or (laryngo NEXT pharyng* NEXT reflux*) or (reflux NEXT laryngo NEXT pharyng*)):ti,ab,kw
#22	#17 or #18 or #19 or #20 or #21
#23	#15 or #22

#24	MeSH descriptor: [Decision Making] explode all trees
#25	MeSH descriptor: [Informed Consent] explode all trees
#26	MeSH descriptor: [Conflict, Psychological] this term only
#27	MeSH descriptor: [Family Conflict] this term only
#28	MeSH descriptor: [Motivation] this term only
#29	MeSH descriptor: [Personal Autonomy] this term only
#30	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*):ti,ab,kw
#31	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
#32	MeSH descriptor: [Health Literacy] this term only
#33	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*):ti,ab,kw
#34	MeSH descriptor: [Psychological Distress] this term only
#35	MeSH descriptor: [Stress, Psychological] this term only
#36	MeSH descriptor: [Caregiver Burden] this term only
#37	MeSH descriptor: [Patient Satisfaction] this term only
#38	(distress* or despair* or stress* or burden* or burnout* or (burn* NEXT/3 out*) or satisf* or dissatisf*):ti,ab,kw
#39	MeSH descriptor: [Risk] this term only
#40	MeSH descriptor: [Risk Assessment] this term only
#41	(risk* or advantag* or advers* or benefit* or disadvantag* or (dis-advantag*) or drawback* or (draw-back*) or harm*):ti,ab,kw
#42	MeSH descriptor: [Communication] this term only
#43	MeSH descriptor: [Information Seeking Behavior] this term only
#44	(communicat*):ti,ab,kw
#45	((info* NEXT/3 seek*)):ti,ab,kw
#46	MeSH descriptor: [Nurse-Patient Relations] this term only
#47	MeSH descriptor: [Physician-Patient Relations] this term only
#48	((nurse* or doctor* or physician*) NEAR/3 patient*):ti,ab,kw

#49 ((nurse* or doctor* or physician* or provider* or patient*) NEXT/3 (relation* or communicat*)):ti,ab,kw

#50 #48 and #49

#51 MeSH descriptor: [Guideline] explode all trees

#52 (guideline* or guide NEXT line*):ti,ab,kw

#53 #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #50 or #51 or #52

#54 MeSH descriptor: [Family] explode all trees

#55 MeSH descriptor: [Parents] explode all trees

#56 MeSH descriptor: [Caregivers] this term only

#57 MeSH descriptor: [Legal Guardians] this term only

#58 (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*):ti,ab,kw

#59 (caregiver* or care NEXT giver* or caretaker* or care NEXT taker* or carer*):ti,ab,kw

#60 #54 or #55 or #56 or #57 or #58 or #59

#61 MeSH descriptor: [Pediatrics] explode all trees

#62 MeSH descriptor: [Infant] explode all trees

#63 MeSH descriptor: [Child] explode all trees

#64 MeSH descriptor: [Adolescent] explode all trees

#65 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or neo NEXT nat* or newborn* or new NEXT born* or toddler* or preschool* or pre NEXT school* or child* or schoolchild* or school NEXT age* or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*):ti,ab,kw

#66 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or neo NEXT nat* or newborn* or new NEXT born* or toddler* or preschool* or pre NEXT school* or child* or schoolchild* or school NEXT age* or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*):so

#67 #61 or #62 or #63 or #64 or #65 or #66

#68 #23 and #53 and #60 and #67

#69 #16 or #68 with Cochrane Library publication date Between Jan 1985 and Dec 2023, in Cochrane Reviews, Cochrane Protocols, Trials, Clinical Answers, Editorials, Special Collect

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6) Web of Science Search Strategy

1	TS=("cystic fibrosis*")
2	SO=("cystic fibrosis*")
3	#1 OR #2
4	TS=((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) NEAR/4 (nutrition* or feed*))
5	TS=((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) NEAR/4 (tube or tubes or stoma or stomas or stomy or requir* or status*))
6	TS=(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies")
7	TS=(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes")
8	TS=(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies")
9	#4 OR #5 OR #6 OR #7 OR #8
10	#3 and #9
11	TS=((deglutition* or swallow*) NEAR/3 (disorder* or "dis-order*" or problem* or difficult*))
12	TS=(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*")
13	#11 OR #12
14	#9 OR #13
15	TS=(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*)
16	TS=(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*)
17	TS=(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*)
18	TS=(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*)

19	TS=comunicat*
20	TS=(info* NEAR/3 sick*)
21	TS=((nurse* or doctor* or physician*) NEAR/3 patient*)
22	TS=((nurse* or doctor* or physician* or provider* or patient*) NEAR/3 (relation* or communicat*))
23	#21 AND #22
24	TS=(guideline* or "guide-line*")
25	#15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #23 OR #24
26	TS=(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*)
27	TS=(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*)
28	#26 OR #27
29	TS=(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
30	SO=(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
31	#29 OR #30
32	#14 AND #25 AND #28 AND #31
33	#10 OR #32
34	PY=1985-2023
35	#33 and #34
36	(#33 AND #34) and English or Spanish (Languages)

BMJ Open

Factors guiding gastrostomy tube decision-making for caregivers of children with cystic fibrosis: a scoping review protocol

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Title: Factors guiding gastrostomy tube decision-making for caregivers of children with cystic fibrosis: a scoping review protocol

Authors:

Emily Zientek[1], Sanika R. Rane[2], Chelsea C. Godfrey[2], Amy Sisson[3], Kimberly M. Dickinson[4]

1 *Texas Tech University Health Sciences Center, Paul L. Foster School of Medicine, El Paso, Texas*

2 *Baylor College of Medicine, Houston, TX, USA*

3 Texas Medical Center Library, Houston Academy of Medicine, Houston, Texas, USA.

4 Department of Pediatrics, Pulmonary Section, Baylor College of Medicine and Texas Children's Hospital, Houston, Texas

Corresponding Author: Correspondence and requests for reprints should be addressed to Kimberly M. Dickinson, MD, MPH Department of Pediatrics, Pulmonary Section, Baylor College of Medicine and Texas Children's Hospital, 6701 Fannin Street, Suite 1040 Houston, Texas 77030. Email: kimberlymdickinson@gmail.com

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ABSTRACT

Introduction: While ensuring appropriate growth is essential for all children, optimizing nutritional status in children with cystic fibrosis (CF) is critical for improving health outcomes. Nutritional challenges in CF are multifactorial and malnutrition is common. While gastrostomy tubes (G-tubes) can improve weight status in individuals with CF, they also have common and chronic complications resulting in clinical equipoise. To date, factors influencing G-tube decision-making among caregivers of children with CF have not been systematically explored. This review aims to chart existing knowledge about caregivers' decisional needs related to G-tube placement, with a focus on caregivers of children with CF, as well as known medical and psychosocial benefits and risks of G-tube feedings in pediatric care.

Methods and analysis: This scoping review will follow the JBI methodological framework. We will include articles published between January 1, 1985 and November 1, 2023 in English and Spanish from MEDLINE (Ovid), Embase, CINAHL, PsycInfo, Cochrane Database of Systematic Reviews, and Web of Science related to G-tube decision-making. Articles published in languages besides English and Spanish will be excluded. Articles will be screened for final eligibility and inclusion according to title and abstract, followed by full texts. Articles will be independently reviewed by two reviewers and any disagreements discussed with a third reviewer for consensus. We will map themes and concepts and data extracted will be presented in tabular, diagrams, and descriptive summaries.

Ethics and Dissemination: As a form of secondary analysis, scoping reviews do not require ethics approval. This review will inform future research with caregivers involved in G-tube decision-making for children with CF. The final review will be submitted to a peer-reviewed scientific journal, disseminated at relevant academic conferences and will be shared with patients and clinicians.

Study registration: https://osf.io/g4pdb

Article Summary

Strengths and Limitations of this study

- The proposed scoping review will analyze existing knowledge related to pediatric caregivers' G-tube decision-making needs, including caregivers of children with cystic fibrosis.
- A strength of this scoping review protocol is the review of six databases that include peer-reviewed journals to identify all relevant studies and information.
- This scoping review will follow the JBI methodological framework.
- Due to feasibility constraints, a limitation is the exclusion of articles not published in English or Spanish.

INTRODUCTION

Ensuring children grow appropriately is a main tenant of pediatric care. Achieving optimal nutritional status is particularly important for children with chronic medical diseases, which often require additional nutritional support to promote their physical and cognitive development. One such disease is cystic fibrosis (CF), a common recessive genetic disorder characterized by the build-up of viscous mucous in the lungs, pancreas, and intestines. Ultimately, CF results in chronic and progressive obstructive lung disease and exocrine pancreatic insufficiency.(1) Due to malabsorption of nutrients, increased energy expenditure from lung infections, and chronic inflammation, children with CF have increased caloric intake needs.(2) Ensuring children consume their recommended daily caloric intake is critical, as studies demonstrate that achieving higher weight percentiles in childhood is associated with improved long-term lung function and survival.(3-5) However, nearly 10% of children with CF develop nutritional failure, despite medical and behavioral nutritional interventions and significant efforts by caregivers.(6-8) When other strategies are unsuccessful or not sustainable, caregivers (parents and primary guardians) are often advised to consider initiating enteral tube feedings, including gastrostomy tube (G-tube) placement.(9)

Retrospective studies suggest G-tubes are safe and effective at improving weight gain and nutritional status in CF, and have the potential to improve lung function and pulmonary status.(10-16) A prior systematic review has examined the role of G-tubes in improving weight gain in CF,(17) however due to a lack of randomized trials, there is not sufficient data to guide when to start enteral tube feedings in CF to ensure the best results. Notably, the prior systematic review identified several challenges associated with the insertion of a G-tube, including perioperative risk, changes in physical appearance, and common and foreseeable medical complications.(17) These findings highlight the complexity of the highly personalized decision to pursue G-tube placement, as knowledge, values, and perceptions of benefits and risks are unique for each family. While up to 20% of children with CF under the age of 10 years use supplemental tube feedings to augment nutritional intake,(6) it remains unknown what psychosocial and emotional factors influence G-tube decision-making for caregivers of children with CF and nutritional challenges.

To date, most studies of caregiver decision-making related to G-tube placement have focused on children with cognitive impairment or neuro-disabilities. Notably, these studies demonstrate that G-tube discussions are associated with 1) intense grief and frustration, 2) increased stress and feelings of failure for the caregiver, and 3) uncertainty about complications and care burden influence parental acceptance of the procedure.(18-21) While many factors influencing caregiver decision-making related to G-tube placement are likely universal, these factors may not fully reflect the experiences of caregivers of children with CF. Within the field of CF, Gunnell *et al.* surveyed caregivers of children with CF with G-tubes and found that most were happy with the decision to pursue G-tube placement, however a lack of objective knowledge about G-tubes was common among surveyed caregivers.(22) Brotherton *et. al* explored parental perceptions of G-tube feedings, including 3 parents of children with CF, and demonstrated the adequacy of information and support received did not meet their expectations.(23) Notably, the few studies related to G-tube decision-making were conducted prior to the introduction of cystic fibrosis transmembrane conductance regulator (CFTR) modulator therapies, which correct the malfunctioning protein made by the CFTR gene. The advent of highly effective modulator therapies have led to significant improvements in nutritional status for those individuals with specific CFTR mutations.(24) While the need for G-tube recommendations will likely become less common in the modulator era, the importance of these discussion and decision-making for

those caregivers of children with CF and nutritional challenges will continue to be highly personalized. Thus, it is essential to understand how this difficult decision is viewed in early CF care as well as the current risks and benefits of G-tube feedings, with awareness that the balance of risks and benefits may change for caregivers over time.

Given the scarcity of evidence specific to the CF population, we plan to review G-tube decision-making more broadly in the pediatric population, with a focus on determining factors that are universal as well as those that may be unique to caregivers of children with CF. The scoping review design will allow for a systematic approach to searching, selecting and analysis of existing evidence, including more descriptive elements of the literature, identify knowledge gaps, and provide evidence to inform future research.(25,26) This review will have two main objectives: (1) to chart existing knowledge about factors influencing caregivers' decision-making related to G-tube placement for children with CF as well as general pediatric care and (2) to chart known medical and psychosocial benefits and risks of G-tube feedings in CF care as well as general pediatric care.

METHODS

Study Design

A scoping review design was selected because it is the best suited for descriptively mapping evidence on a topic to identify main concepts, theories, and knowledge gaps.[2] The proposed scoping review will follow the guidelines of the JBI to ensure the rigor of the scoping review process.(26,27) This five-stage process includes: (1) identification of the research question, (2) identification of studies relevant to the research question, (3) selection of studies for inclusion, (4) charting information and data obtained from the included studies, (5) collating, summarizing and reporting the results. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) checklist will be used as a guideline for reporting the results of the scoping review.(28) This scoping review was registered on the Open Science Framework on April 6, 2023 (https: https://osf.io/g4pdb).

Stage 1: Identification of the scoping review research questions

The research questions are as follows:

1. What is known about factors influencing caregiver's decision-making related to G-tube placement for children with CF?
2. What is known about the medical and psychosocial benefits and risks of G-tube feedings as it pertains to caregiver's experiences living with and caring for a child with CF and a G-tube?
3. What is known about factors influencing caregiver's decision-making related to G-tube placement and the medical and psychosocial benefits and risks of G-tube feedings in general pediatric care?

Stage 2: Identifying relevant studies

Search Strategy

After reviewing other systematic and scoping reviews on decision-making and in consultation with expert stakeholders and an experienced medical librarian, a comprehensive preliminary search strategy was developed using free-text search terms and Medical Subject Headings related to decision-making, enteral tube feeding, CF, and pediatrics. The search strategy was peer-reviewed by a second medical librarian using the Peer Review of Electronic Search Strategies (PRESS) checklist.(29) An initial limited electronic search of MEDLINE (Ovid) was undertaken to identify potentially relevant articles. The words contained in the titles and abstracts of the relevant articles, and the index terms used to describe the articles were used to develop a final search strategy. Due to lack of funding for translation, the search was limited to articles written in English and Spanish. The timeframe of interest included studies published after January 1,1985 to November 1, 2023. This timeframe was selected to encompass studies published after the widespread use of the G-tube in pediatrics to ensure studies have relevance to current clinical practice. Post hoc criteria may be included as reviewers become more familiar with the literature. The final search strategies for all databases used are detailed in **the Supplementary File**. To identify all potentially relevant published studies, the search strategy will be translated using the specific controlled vocabulary and/or syntax for each included database and/or information source: Embase, CINAHL, PsycInfo, Cochrane Database of Systematic Reviews, and Web of Science, which have wide coverage of health publications.

Stage 3: Study Selection

Following the finalized search parameters, the search results will be exported to EndNote and the medical librarian will remove duplicates. Studies will then be imported into Covidence, a web-based collaboration software platform designed for the creation of literature reviews, to identify duplicate publications and assist with the review, selection and extraction process outlined in this protocol.(30)

This review will consider studies that describe:

Population

Eligible studies will include the experiences and perspectives of caregivers, defined as parents and guardians of children (<18 years of age) with a clinical diagnosis of CF. Additionally, it will include the experiences of caregivers considering G-tube placement in pediatric care. Studies related to risks and benefits associated with G-tubes in children will also be included.

Concept

The concept of interest is caregiver decision-making needs relative to G-tube placement for children with cystic fibrosis. Given the paucity of knowledge within CF care, this scoping review will also explore caregiver decision-making within general pediatric care to better chart existing knowledge on factors that influence caregivers considering G-tube placement and experiences of being a caregiver of a child with a G-tube.

Context

There will be no geographical limitation applied in relation to this scoping review. Evidence presented from any cultural or geographic context will be eligible.

The review will search all available peer-reviewed literature for studies that contain potentially relevant information; there will be no restrictions on the design of the studies, considering experimental and quasi-experimental studies, including observational and qualitative studies. Primary sources will be excluded if already incorporated into an included evidence synthesis unless the data they contain are not otherwise reported in the evidence synthesis. We will exclude studies that: 1) do not address caregivers' G-tube decision-making in pediatric care 2) do not report results related to risks and benefits associated with G-tubes in children < 18 years of age 3) do not allow full-text access and 4) are published in languages other than English and Spanish or before 1985.

A pilot screening test of 40 potentially relevant articles will be conducted by all four researchers to ensure agreement. Subsequently, the research team will meet to discuss discrepancies and make modifications to the eligibility criteria needed and screening will start once a minimum of 80% agreement is achieved. Thereafter, all studies will be screened independently by two researchers, and the study team will meet regularly throughout the process to refine inclusion criteria. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, and with an additional reviewer when necessary to reach consensus. Potentially relevant sources will be retrieved in full and their citation details imported into Zotero reference manager. Subsequently, the full-text will be assessed in detail against the inclusion criteria by two independent researchers. The reference list of all included sources of evidence will be screened to capture possible relevant articles not captured in the search strategy and all key authors will be contacted with requests to provide potentially relevant sources. At this point, any studies that are excluded will be reported in the scoping review. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA-ScR flow diagram.(28)

Stage 4: Data Extraction

Data extraction will focus on identifying and charting data relevant to caregiver decision-making needs related to G-tube placement for children with CF and in general pediatric care. The researchers will chart the data using Covidence and use Microsoft Excel to organize the extracted data. A data extraction form will be developed by the researchers to determine which variables to extract. This tool will capture the relevant information on key study characteristics and detailed information on all metrics used to estimate/describe factors influencing G-tube decision-making and experiences of being a caregiver of a child with a G-tube. A preliminary charting table with included variables to be abstracted is summarized in **Table 1**. The data extracted will include specific details about the publication, study design, research methodology, as well as study findings and conclusions relevant to the review. Given the objective of the study, the themes will be organized according to factors that influence G-tube decision-making, experiences with G-tubes including medical and psychosocial risks and benefits of G-tube placement and long-term use. As pilot testing and to ensure consistency, all researchers will initially review the same 10 publications, discuss the results and amend the data extraction form in an iterative process during the data charting process. If new themes emerge during data extraction, these will also be included and any modifications will be detailed in the scoping review.

Data extraction of subsequent studies will be undertaken by two independent researchers, and a third reviewer (KMD) will review data extraction templates completed by the other reviewers. This is a quality check to ensure the extracted data from the articles are accurate and executed with rigor. Any disagreements that arise between the reviewers will be resolved through discussion, and with an additional reviewer when necessary. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

Table 1. Data Extraction Template

Item	Information
1. Article Information	Title and Journal
	Author Information
	Year of Publication
	Country
2. Study Information	Study Design
	Study Aims
	Study Outcomes
3. Methodology	Target Population
	Recruitment
	Disease Process
	Tools used to measure outcomes
4. Factors Relevant to Decision-Making	Experiences, perspectives, facilitators, barriers
	Risks and Benefits
5. Future Directions	Research Gaps
	Study limitations

Stage 5: Data analysis and presentation

Results will be summarized both quantitatively and qualitatively to provide a description of the collected data. An analytic framework will be used to provide an overview of the breadth of the literature. This will include both descriptive numerical summary analysis, presented using tables and charts, and qualitative thematic analysis. Patterns and trends (if identified) will be illustrated using figures and or diagrams, and summarized narratively. Each article's summary will include the author(s), year of publication, country of origin, study purpose, participant information and sample size, study design, concept of interest, key findings related to the scoping review questions, study outcomes, and limitations identified by the authors. In keeping with scoping review methodology, an evaluation of study quality will not be performed. Final conclusions will be drawn from the mapped evidence, in addition to consultations with key stakeholders with unique insights into the experience of G-tube decision-making for children to validate and identify any gaps in our findings and ultimately guide recommendations for future research in this field.

Patient and public involvement None

Ethics and Dissemination The results from this scoping review will inform the development of a decision aid to support caregivers of children with CF in G-tube decision-making. This scoping review and the decision aid will be published in peer-reviewed journals and disseminated

through national/international conference presentations. As this study involves no human participants and data was taken from publicly available publications, approval from a human research ethics committee is not required.

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Contributions KD conceived the idea for this scoping review, developed the research questions, objectives, and inclusion criteria. AS and KD contributed to the creation of the search strategy. EZ and KD contributed to drafting and editing of the scoping review protocol. AS, EZ, SR, CG, and KD reviewed inclusion and exclusion criteria, screened abstracts and full-text papers. All authors read and approved the final manuscript.

Competing Interests None declared**.**

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Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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Supplementary File: Combined Full Search Strategies of All Databases

1) Medline Search Strategy

#	Query
1	Cystic Fibrosis/
2	"cystic fibrosis*".ti,ab,kw,kf.
3	"cystic fibrosis*".io,ja,jn,jw,nj,nw,jc.
4	1 or 2 or 3
5	Enteral Nutrition/ or Gastrostomy/ or Nutritional Requirements/ or Nutritional Status/
6	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) adj4 (nutrition* or feed*)).ti,ab,kw,kf.
7	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) adj4 (tube or tubes or stoma or stomas or stomy or requir* or status*)).ti,ab,kw,kf.
8	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies").ti,ab,kw,kf.
9	(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes").ti,ab,kw,kf.
10	(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies").ti,ab,kw,kf.
11	5 or 6 or 7 or 8 or 9 or 10
12	4 and 11
13	Deglutition Disorders/ or exp Gastroesophageal Reflux/ or exp Laryngopharyngeal Reflux/
14	((deglutition* or swallow*) adj3 (disorder* or "dis-order*" or problem* or difficult*)).ti,ab,kw,kf.
15	(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*").ti,ab,kw,kf.
16	13 or 14 or 15
17	11 or 16

18	exp Decision Making/ or exp Informed Consent/ or Conflict, Psychological/ or Family Conflict/ or Personal Autonomy/ or Motivation/
19	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*).ti,ab,kw,kf.
20	Health Knowledge, Attitudes, Practice/ or Health Literacy/
21	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*).ti,ab,kw,kf.
22	Psychological Distress/ or Stress, Psychological/ or Caregiver Burden/ or Patient Satisfaction/
23	(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*).ti,ab,kw,kf.
24	Risk/ or Risk Assessment/
25	(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*).ti,ab,kw,kf.
26	Communication/ or Information Seeking Behavior/
27	communicat*.ti,ab,kw,kf.
28	(info* adj3 seek*).ti,ab,kw,kf.
29	Nurse-Patient Relations/ or Physician-Patient Relations/
30	((nurse* or doctor* or physician*) adj3 patient*).ti,ab,kw.
31	((nurse* or doctor* or physician* or provider* or patient*) adj3 (relation* or communicat*)).ti,ab,kw,kf.
32	30 and 31
33	exp Guideline/
34	(guideline* or "guide-line*").ti,ab,kw,kf.
35	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 32 or 33 or 34
36	exp Family/ or exp Parents/ or Caregivers/ or Legal Guardians/
37	(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*).ti,ab,kw,kf.
38	(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*).ti,ab,kw,kf.
39	36 or 37 or 38
40	exp Pediatrics/ or exp Infant/ or exp Child/ or exp Adolescent/

41 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).ti,ab,kw,kf.

42 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).io,ja,jn,jw,nj,nw,jc.

43 40 or 41 or 42

44 17 and 35 and 39 and 43

45 12 or 44

46 limit 45 to (yr="1985 -Current" and (english or spanish))

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2) Embase Search Strategy

#1 'cystic fibrosis'/de

#2 'cystic fibrosis*':ti,ab,kw

#3 'cystic fibrosis*':jt

#4 #1 OR #2 OR #3

#5 'enteric feeding'/de OR 'gastrostomy'/de OR 'nutritional requirement'/de OR 'nutritional status'/de

#6 ((enteral* OR enteric* OR gastr* OR nasogastr* OR gastrojejun* OR jejun* OR peg) NEAR/4 (nutrition* OR feed*)):ti,ab,kw

#7 ((enteral* OR enteric* OR gastr* OR nasogastr* OR gastrojejun* OR jejun* OR peg OR nutrition* OR stomach* OR digestiv* OR feed*) NEAR/4 (tube OR tubes OR stoma OR stomas OR stomy OR requir* OR status*)):ti,ab,kw

#8 gastrostoma:ti,ab,kw OR gastrostomas:ti,ab,kw OR gastrostomy:ti,ab,kw OR gastrostomies:ti,ab,kw OR gastrojejunostoma:ti,ab,kw OR gastrojejunostomas:ti,ab,kw OR gastrojejunostomy:ti,ab,kw OR gastrojejunostomies:ti,ab,kw OR 'gastro jejunostoma':ti,ab,kw OR 'gastro jejunostomas':ti,ab,kw OR 'gastro jejunostomy':ti,ab,kw OR 'gastro jejunostomies':ti,ab,kw

#9 gtube:ti,ab,kw OR gtubes:ti,ab,kw OR 'g-tube':ti,ab,kw OR 'g-tubes':ti,ab,kw OR 'gj-tube':ti,ab,kw OR 'gj-tubes':ti,ab,kw

#10 gstoma:ti,ab,kw OR gstomas:ti,ab,kw OR gstomy:ti,ab,kw OR gstomies:ti,ab,kw OR 'g-stoma':ti,ab,kw OR 'g-stomas':ti,ab,kw OR 'g-stomy':ti,ab,kw OR 'g-stomies':ti,ab,kw OR 'gj-stoma':ti,ab,kw OR 'gj-stomas':ti,ab,kw OR 'gj-stomy':ti,ab,kw OR 'gj-stomies':ti,ab,kw

#11 #5 OR #6 OR #7 OR #8 OR #9 OR #10

#12 #4 AND #11

#13 'dysphagia'/de OR 'gastroesophageal reflux'/exp OR 'laryngopharyngeal reflux'/de

#14 ((deglutition* OR swallow*) NEAR/3 (disorder* OR 'dis-order*' OR problem* OR difficult*)):ti,ab,kw

#15 dysphag*:ti,ab,kw OR 'gastroesoph* reflux*':ti,ab,kw OR 'reflux* gastroesoph*':ti,ab,kw OR 'gastro-esoph* reflux*':ti,ab,kw OR 'reflux* gastro-esoph*':ti,ab,kw OR 'gastro-oesoph* reflux*':ti,ab,kw OR 'reflux* gastro-oesoph*':ti,ab,kw OR 'laryngopharyng* reflux*':ti,ab,kw OR 'reflux* laryngopharyng*':ti,ab,kw OR 'laryngo-pharyng* reflux*':ti,ab,kw OR 'reflux laryngo-pharyng*':ti,ab,kw

#16 #13 OR #14 OR #15

#17 #11 AND #16

#18 'decision making'/de OR 'family decision making'/de OR 'patient decision making'/de OR 'shared decision making'/de OR 'ethical decision making'/de OR 'informed consent'/de OR 'conflict'/de OR 'family conflict'/de OR 'patient autonomy'/de OR 'motivation'/exp

#19 decision*:ti,ab,kw OR decid*:ti,ab,kw OR choice*:ti,ab,kw OR choos*:ti,ab,kw OR consensus*:ti,ab,kw OR consent*:ti,ab,kw OR conflict*:ti,ab,kw OR disagree*:ti,ab,kw OR agree*:ti,ab,kw OR participat*:ti,ab,kw OR prefer*:ti,ab,kw OR involv*:ti,ab,kw OR engag*:ti,ab,kw OR expect*:ti,ab,kw OR autonom*:ti,ab,kw OR motivat*:ti,ab,kw

#20 'attitude to health'/de OR 'health literacy'/de

#21 knowledg*:ti,ab,kw OR attitude*:ti,ab,kw OR literacy*:ti,ab,kw OR believ*:ti,ab,kw OR belief*:ti,ab,kw OR percept*:ti,ab,kw OR perceiv*:ti,ab,kw OR perspectiv*:ti,ab,kw

#22 'distress syndrome'/de OR 'mental stress'/de OR 'caregiver burden'/de OR 'caregiver burnout'/de OR 'emotional stress'/de OR 'ethical dilemma'/de OR 'family stress'/de OR 'home stress'/de OR 'interpersonal stress'/de OR 'life stress'/de OR 'parental stress'/exp OR 'patient satisfaction'/de

#23 distress*:ti,ab,kw OR despair*:ti,ab,kw OR stress*:ti,ab,kw OR burden*:ti,ab,kw OR burnout*:ti,ab,kw OR 'burn* out*':ti,ab,kw OR satisf*:ti,ab,kw OR dissatisf*:ti,ab,kw

#24 'risk'/de OR 'patient risk'/de OR 'risk assessment'/de OR 'health risk assessment'/de OR 'risk attitude'/de OR 'risk aversion'/de OR 'risk denial'/de OR 'risk perception'/exp

#25 risk*:ti,ab,kw OR advantag*:ti,ab,kw OR advers*:ti,ab,kw OR benefit*:ti,ab,kw OR disadvantag*:ti,ab,kw OR 'dis-advantag*':ti,ab,kw OR drawback*:ti,ab,kw OR 'draw-back*':ti,ab,kw OR harm*:ti,ab,kw

#26	'interpersonal communication'/de OR 'information seeking'/de
#27	communicat*:ti,ab,kw
#28	(info* NEAR/3 seek*):ti,ab,kw
#29	'nurse patient relationship'/de OR 'doctor patient relationship'/de
#30	((nurse* OR doctor* OR physician*) NEAR/3 patient*):ti,ab,kw
#31	((nurse* OR doctor* OR physician* OR provider* OR patient*) NEAR/3 (relation* OR communicat*)):ti,ab,kw
#32	#30 AND #31
#33	'guideline'/de
#34	guideline*:ti,ab,kw OR 'guide-line*':ti,ab,kw
#35	#18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #32 OR #33 OR #34
#36	'family'/exp OR 'parent'/exp OR 'caregiver'/de OR 'legal guardian'/de
#37	family*:ti,ab,kw OR families*:ti,ab,kw OR parent:ti,ab,kw OR parents:ti,ab,kw OR mother*:ti,ab,kw OR father*:ti,ab,kw OR grandparent*:ti,ab,kw OR grandmother*:ti,ab,kw OR grandfather*:ti,ab,kw OR guardian*:ti,ab,kw
#38	caregiver*:ti,ab,kw OR 'care-giver*':ti,ab,kw OR caretaker*:ti,ab,kw OR 'care-taker*':ti,ab,kw OR carer*:ti,ab,kw
#39	#36 OR #37 OR #38
#40	'pediatrics'/exp OR 'infant'/exp OR 'child'/exp OR 'adolescent'/exp
#41	pediatri*:ti,ab,kw OR paediatr*:ti,ab,kw OR infan*:ti,ab,kw OR baby*:ti,ab,kw OR babies*:ti,ab,kw OR neonat*:ti,ab,kw OR 'neo-nat*':ti,ab,kw OR newborn*:ti,ab,kw OR 'new-born*':ti,ab,kw OR 'newly born*':ti,ab,kw OR toddler*:ti,ab,kw OR preschool*:ti,ab,kw OR 'pre-school*':ti,ab,kw OR child*:ti,ab,kw OR schoolchild*:ti,ab,kw OR 'school-age*':ti,ab,kw OR girl*:ti,ab,kw OR boy:ti,ab,kw OR boys:ti,ab,kw OR tween*:ti,ab,kw OR teen*:ti,ab,kw OR adolescen*:ti,ab,kw OR kid:ti,ab,kw OR kids:ti,ab,kw OR juvenile*:ti,ab,kw OR youth*:ti,ab,kw
#42	pediatri*:jt OR paediatr*:jt OR infan*:jt OR baby*:jt OR babies*:jt OR neonat*:jt OR 'neo-nat*':jt OR newborn*:jt OR 'new-born*':jt OR 'newly born*':jt OR toddler*:jt OR preschool*:jt OR 'pre-school*':jt OR child*:jt OR schoolchild*:jt OR 'school-age*':jt OR girl*:jt OR boy:jt OR boys:jt OR tween*:jt OR teen*:jt OR adolescen*:jt OR kid:jt OR kids:jt OR juvenile*:jt OR youth*:jt
#43	#40 OR #41 OR #42
#44	#17 AND #35 AND #39 AND #43
#45	#12 OR #44

#46 (#12 OR #44) AND ([english]/lim OR [spanish]/lim) AND [1985-2022]/py

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3) CINAHL

1 (MH "Cystic Fibrosis")

2 TI "cystic fibrosis*" OR AB "cystic fibrosis*"

3 SO "cystic fibrosis*" OR JN "cystic fibrosis*" OR JT "cystic fibrosis*"

4 S1 OR S2 OR S3

5 (MH "Enteral Nutrition") OR (MH "Gastrostomy") OR (MH "Nutritional Requirements") OR (MH "Nutritional Status")

6 TI ((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) N4 (nutrition* or feed*))) OR AB (((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) N4 (nutrition* or feed*))

7 TI ((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) N4 (tube or tubes or stoma or stomas or stomy or requir* or status*))) OR AB (((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) N4 (tube or tubes or stoma or stomas or stomy or requir* or status*))

8 TI (gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies") OR AB (gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies")

9 TI (gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes") OR AB (gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes")

10 TI ((gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies")) OR AB ((gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies"))

11 S5 OR S6 OR S7 OR S8 OR S9 OR S10

12 S4 AND S11

13 MH "Deglutition Disorders") OR (MH "Gastroesophageal Reflux")

14 TI (((deglutition* or swallow*) N3 (disorder* or "dis-order*" or problem* or difficult*))) OR AB (((deglutition* or swallow*) N3 (disorder* or "dis-order*" or problem* or difficult*)))

15	TI ((dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*")) OR AB ((dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*"))
16	S13 OR S14 OR S15
17	S11 OR S16
18	(MH "Decision Making+") OR (MH "Consent+") OR (MH "Conflict (Psychology)") OR (MH "Family Conflict") OR (MH "Patient Autonomy") OR (MH "Motivation")
19	TI ((decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivate*)) OR AB ((decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivate*))
20	(MH "Health Literacy")
21	TI (knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*) OR AB (knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*)
22	(MH "Psychological Distress") OR (MH "Stress, Psychological") OR (MH "Caregiver Burden") OR (MH "Patient Satisfaction")
23	TI (distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*) OR AB (distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*)
24	(MH "Relative Risk") OR (MH "Risk Assessment")
25	TI (risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*) OR AB (risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*)
26	(MH "Communication"") OR (MH "Information Seeking Behavior")
27	TI communicat* OR AB communicat*
28	TI (info* N3 seek*) OR AB (info* N3 seek*)
29	(MH "Nurse-Patient Relations") OR (MH "Physician-Patient Relations")
30	TI ((nurse* or doctor* or physician*) N3 patient*) OR AB ((nurse* or doctor* or physician*) N3 patient*)

31	TI ((nurse* or doctor* or physician* or provider* or patient*) N3 (relation* or communicat*)) OR AB ((nurse* or doctor* or physician* or provider* or patient*) N3 (relation* or communicat*))
32	S30 AND S31
33	(MH "Practice Guidelines")
34	TI (guideline* or "guide-line*") OR AB (guideline* or "guide-line*")
35	S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S32 OR S33 OR S34
36	(MH "Family+") OR (MH "Parents+") OR (MH "Caregivers") OR (MH "Guardianship, Legal")
37	TI (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*) OR AB (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*)
38	TI (caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*) OR AB (caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*)
39	S36 OR S37 OR S38
40	(MH "Pediatrics+") OR (MH "Infant+") OR (MH "Child+") OR (MH "Adolescence+")
41	TI (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR AB (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
42	SO (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR JN (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR JT (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
43	S40 OR S41 OR S42
44	S17 AND S35 AND S39 AND S43
45	S12 OR S44 Limiters - Published Date: 19850101-20231231; English Language

46 s12 or s44

47 s12 or s44 Limiters - Published Date: 19850101-20231231; Language: Spanish

48 S45 OR S47

Limiters - Published Date: 19850101-20231231; Language: Spanish "

48 S45 OR S47

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4) APA PsycInfo

#	Query
1	Cystic Fibrosis/
2	cystic fibrosis.mh.
3	"cystic fibrosis*".tw.
4	cystic fibrosis*.jn,jx,nl,ol.
5	1 or 2 or 3 or 4
6	(enteral nutrition or gastrostomy or nutritional requirements or nutritional status).mh.
7	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) adj4 (nutrition* or feed*)).tw.
8	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) adj4 (tube or tubes or stoma or stomas or stomy or requir* or status*)).tw.
9	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies").tw.
10	(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes").tw.
11	(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies").tw.
12	6 or 7 or 8 or 9 or 10 or 11
13	5 and 12
14	exp Dysphagia/
15	(deglutition disorders or gastroesophageal reflux or laryngopharyngeal reflux).mh.

16	((deglutition* or swallow*) adj3 (disorder* or "dis-order*" or problem* or difficult*)).tw.
17	(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*").tw.
18	14 or 15 or 16 or 17
19	12 or 18
20	exp Decision Making/ or exp Informed Consent/ or Family Conflict/ or exp Autonomy/ or exp Conflict/ or Motivation/
21	(decision making or informed consent or conflict, psychological or family conflict or personal autonomy or motivation).mh.
22	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*).tw.
23	Health Knowledge/ or Health Literacy/
24	(health knowledge, attitudes, practice or health literacy).mh.
25	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*).tw.
26	Psychological Stress/ or Distress/ or Caregiver Burden/ or Client Satisfaction/
27	(psychological distress or stress, psychological or caregiver burden or patient satisfaction).mh.
28	(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*).tw.
29	Risk Factors/ or Risk Assessment/
30	(risk or risk assessment).mh.
31	(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*).tw.
32	Communication/ or Information Seeking/
33	(communication or information seeking behavior).mh.
34	communicat*.tw.
35	(info* adj3 seek*).tw.
36	(nurse-patient relations or physician-patient relations).mh.
37	((nurse* or doctor* or physician*) adj3 patient*).tw.
38	((nurse* or doctor* or physician* or provider* or patient*) adj3 (relation* or communicat*)).tw.

39	37 and 38
40	exp Treatment Guidelines/ or guideline.mh.
41	(guideline* or "guide-line*").tw.
42	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 39 or 40 or 41
43	exp Family/ or exp Parents/ or Caregivers/ or Guardianship/
44	(family or parents or caregivers or legal guardians).mh.
45	(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*).tw.
46	(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*).tw.
47	43 or 44 or 45 or 46
48	exp Pediatrics/ or (pediatrics or infant or child or adolescent).mh.
49	(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).tw.
50	(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).jn,nl,ol,jx.
51	or/48-50
52	19 and 42 and 47
53	51 and 52
54	limit 52 to (childhood or adolescence <13 to 17 years>)
55	53 or 54
56	13 or 55
57	limit 56 to (yr="1985 -Current" and (english or spanish))

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5) Cochrane Database of Systematic Reviews

ID	Search
#1	MeSH descriptor: [Cystic Fibrosis] explode all trees

#2	(cystic NEXT/3 fibrosis*):ti,ab,kw
#3	(cystic NEXT/3 fibrosis*):so
#4	#1 or #2 or #3
#5	MeSH descriptor: [Enteral Nutrition] this term only
#6	MeSH descriptor: [Gastrostomy] this term only
#7	MeSH descriptor: [Nutritional Requirements] this term only
#8	MeSH descriptor: [Nutritional Status] this term only
#9	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) NEXT/4 (nutrition* or feed*)):ti,ab,kw
#10	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) NEXT/4 (tube or tubes or stoma or stomas or stomy or requir* or status*)):ti,ab,kw
#11	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or (gastro NEXT jejunostoma) or (gastro NEXT jejunostomas) or (gastro NEXT jejunostomy) or (gastro NEXT jejunostomies)):ti,ab,kw
#12	(gtube or gtubes or g NEXT tube or g NEXT tubes or gj NEXT tube or gj NEXT tubes)
#13	(gstoma or gstomas or gstomy or gstomies):ti,ab,kw
#14	(stoma or stomas or stomy or stomies) NEAR/3 (g or gi)
#15	#5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14
#16	#4 and #15
#17	MeSH descriptor: [Deglutition Disorders] this term only
#18	MeSH descriptor: [Gastroesophageal Reflux] explode all trees
#19	MeSH descriptor: [Laryngopharyngeal Reflux] explode all trees
#20	((deglutition* or swallow*) NEAR/3 (disorder* or dis-order* or problem* or difficult*)):ti,ab,kw
#21	(dysphag* or (gastroesoph* NEXT reflux*) or (reflux* NEXT gastroesoph*) or (gastro NEXT esoph* NEXT reflux*) or (reflux* NEXT gastro NEXT esoph*) or (gastro NEXT oesoph* NEXT reflux*) or (reflux* NEXT gastro NEXT oesoph*) or (laryngopharyng* NEXT reflux*) or (reflux* NEXT laryngopharyng*) or (laryngo NEXT pharyng* NEXT reflux*) or (reflux NEXT laryngo NEXT pharyng*)):ti,ab,kw
#22	#17 or #18 or #19 or #20 or #21
#23	#15 or #22

#24	MeSH descriptor: [Decision Making] explode all trees
#25	MeSH descriptor: [Informed Consent] explode all trees
#26	MeSH descriptor: [Conflict, Psychological] this term only
#27	MeSH descriptor: [Family Conflict] this term only
#28	MeSH descriptor: [Motivation] this term only
#29	MeSH descriptor: [Personal Autonomy] this term only
#30	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*):ti,ab,kw
#31	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
#32	MeSH descriptor: [Health Literacy] this term only
#33	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*):ti,ab,kw
#34	MeSH descriptor: [Psychological Distress] this term only
#35	MeSH descriptor: [Stress, Psychological] this term only
#36	MeSH descriptor: [Caregiver Burden] this term only
#37	MeSH descriptor: [Patient Satisfaction] this term only
#38	(distress* or despair* or stress* or burden* or burnout* or (burn* NEXT/3 out*) or satisf* or dissatisf*):ti,ab,kw
#39	MeSH descriptor: [Risk] this term only
#40	MeSH descriptor: [Risk Assessment] this term only
#41	(risk* or advantag* or advers* or benefit* or disadvantag* or (dis-advantag*) or drawback* or (draw-back*) or harm*):ti,ab,kw
#42	MeSH descriptor: [Communication] this term only
#43	MeSH descriptor: [Information Seeking Behavior] this term only
#44	(communicat*):ti,ab,kw
#45	((info* NEXT/3 seek*)):ti,ab,kw
#46	MeSH descriptor: [Nurse-Patient Relations] this term only
#47	MeSH descriptor: [Physician-Patient Relations] this term only
#48	((nurse* or doctor* or physician*) NEAR/3 patient*):ti,ab,kw

#49 ((nurse* or doctor* or physician* or provider* or patient*) NEXT/3 (relation* or communicat*)):ti,ab,kw

#50 #48 and #49

#51 MeSH descriptor: [Guideline] explode all trees

#52 (guideline* or guide NEXT line*):ti,ab,kw

#53 #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #50 or #51 or #52

#54 MeSH descriptor: [Family] explode all trees

#55 MeSH descriptor: [Parents] explode all trees

#56 MeSH descriptor: [Caregivers] this term only

#57 MeSH descriptor: [Legal Guardians] this term only

#58 (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*):ti,ab,kw

#59 (caregiver* or care NEXT giver* or caretaker* or care NEXT taker* or carer*):ti,ab,kw

#60 #54 or #55 or #56 or #57 or #58 or #59

#61 MeSH descriptor: [Pediatrics] explode all trees

#62 MeSH descriptor: [Infant] explode all trees

#63 MeSH descriptor: [Child] explode all trees

#64 MeSH descriptor: [Adolescent] explode all trees

#65 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or neo NEXT nat* or newborn* or new NEXT born* or toddler* or preschool* or pre NEXT school* or child* or schoolchild* or school NEXT age* or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*):ti,ab,kw

#66 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or neo NEXT nat* or newborn* or new NEXT born* or toddler* or preschool* or pre NEXT school* or child* or schoolchild* or school NEXT age* or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*):so

#67 #61 or #62 or #63 or #64 or #65 or #66

#68 #23 and #53 and #60 and #67

#69 #16 or #68 with Cochrane Library publication date Between Jan 1985 and Dec 2023, in Cochrane Reviews, Cochrane Protocols, Trials, Clinical Answers, Editorials, Special Collect

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6) Web of Science Search Strategy

1	TS=("cystic fibrosis*")
2	SO=("cystic fibrosis*")
3	#1 OR #2
4	TS=((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) NEAR/4 (nutrition* or feed*))
5	TS=((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) NEAR/4 (tube or tubes or stoma or stomas or stomy or requir* or status*))
6	TS=(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies")
7	TS=(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes")
8	TS=(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies")
9	#4 OR #5 OR #6 OR #7 OR #8
10	#3 and #9
11	TS=((deglutition* or swallow*) NEAR/3 (disorder* or "dis-order*" or problem* or difficult*))
12	TS=(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*")
13	#11 OR #12
14	#9 OR #13
15	TS=(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*)
16	TS=(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*)
17	TS=(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*)
18	TS=(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*)

19	TS=comunicat*
20	TS=(info* NEAR/3 sick*)
21	TS=((nurse* or doctor* or physician*) NEAR/3 patient*)
22	TS=((nurse* or doctor* or physician* or provider* or patient*) NEAR/3 (relation* or communicat*))
23	#21 AND #22
24	TS=(guideline* or "guide-line*")
25	#15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #23 OR #24
26	TS=(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*)
27	TS=(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*)
28	#26 OR #27
29	TS=(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
30	SO=(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
31	#29 OR #30
32	#14 AND #25 AND #28 AND #31
33	#10 OR #32
34	PY=1985-2023
35	#33 and #34
36	(#33 AND #34) and English or Spanish (Languages)

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Factors guiding gastrostomy tube decision-making for caregivers of children with cystic fibrosis: a scoping review protocol

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Factors guiding gastrostomy tube decision-making for caregivers of children with cystic fibrosis: a scoping review protocol

Emily Zientek[1], Sanika R. Rane[2], Chelsea C. Godfrey[2], Amy Sisson[3], Kimberly M. Dickinson[4]

1 *Texas Tech University Health Sciences Center, Paul L. Foster School of Medicine, El Paso, TX, USA*

2 *Baylor College of Medicine, Houston, TX, USA*

3 *Texas Medical Center Library, Houston Academy of Medicine, Houston, TX, USA*

4 *Department of Pediatrics, Pulmonary Section, Baylor College of Medicine and Texas Children's Hospital, Houston, TX, USA*

Correspondence to:

Kimberly M. Dickinson, MD, MPH

Department of Pediatrics, Pulmonary Section, Baylor College of Medicine and Texas Children's Hospital, 6701 Fannin Street, Suite 1040 Houston, Texas 77030, USA

Email: kimberlymdickinson@gmail.com

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ABSTRACT

Introduction: While ensuring appropriate growth is essential for all children, optimizing nutritional status in children with cystic fibrosis (CF) is critical for improving health outcomes. Nutritional challenges in CF are multifactorial and malnutrition is common. While gastrostomy tubes (G-tubes) can improve weight status in individuals with CF, they also have common and chronic complications resulting in clinical equipoise. To date, factors influencing G-tube decision-making among caregivers of children with CF have not been systematically explored. This review aims to chart existing knowledge about caregivers' decisional needs related to G-tube placement, with a focus on caregivers of children with CF, as well as known medical and psychosocial benefits and risks of G-tube feedings in pediatric care.

Methods and analysis: This scoping review will follow the JBI methodological framework. We will include articles published between January 1, 1985 and November 1, 2023 in English and Spanish from MEDLINE (Ovid), Embase, CINAHL, PsycInfo, Cochrane Database of Systematic Reviews, and Web of Science related to G-tube decision-making. Articles published in languages besides English and Spanish will be excluded. Articles will be screened for final eligibility and inclusion according to title and abstract, followed by full texts. Articles will be independently reviewed by two reviewers and any disagreements discussed with a third reviewer for consensus. We will map themes and concepts and data extracted will be presented in tabular, diagrams, and descriptive summaries.

Ethics and dissemination: As a form of secondary analysis, scoping reviews do not require ethics approval. This review will inform future research with caregivers involved in G-tube decision-making for children with CF. The final review will be submitted to a peer-reviewed scientific journal, disseminated at relevant academic conferences and will be shared with patients and clinicians.

Study registration: https://osf.io/g4pdb.

Strengths and limitations of this study

- The proposed scoping review will analyze existing knowledge related to pediatric caregivers' G-tube decision-making needs, including caregivers of children with cystic fibrosis.
- A strength of this scoping review protocol is the review of six databases that include peer-reviewed journals to identify all relevant studies and information.
- This scoping review will follow the JBI methodological framework.
- Due to feasibility constraints, a limitation is the exclusion of articles not published in English or Spanish.

INTRODUCTION

Ensuring children grow appropriately is a main tenant of pediatric care. Achieving optimal nutritional status is particularly important for children with chronic medical diseases, which often require additional nutritional support to promote their physical and cognitive development. One such disease is cystic fibrosis (CF), a common recessive genetic disorder characterized by the build-up of viscous mucous in the lungs, pancreas, and intestines. Ultimately, CF results in chronic and progressive obstructive lung disease and exocrine pancreatic insufficiency.(1) Due to malabsorption of nutrients, increased energy expenditure from lung infections, and chronic inflammation, children with CF have increased caloric intake needs.(2) Ensuring children consume their recommended daily caloric intake is critical, as studies demonstrate that achieving higher weight percentiles in childhood is associated with improved long-term lung function and survival.(3-5) However, nearly 10% of children with CF develop nutritional failure, despite medical and behavioral nutritional interventions and significant efforts by caregivers.(6-8) When other strategies are unsuccessful or not sustainable, caregivers (parents and primary guardians) are often advised to consider initiating enteral tube feedings, including gastrostomy tube (G-tube) placement.(9)

Retrospective studies suggest G-tubes are safe and effective at improving weight gain and nutritional status in CF, and have the potential to improve lung function and pulmonary status.(10-16) A prior systematic review has examined the role of G-tubes in improving weight gain in CF,(17) however due to a lack of randomized trials, there is not sufficient data to guide when to start enteral tube feedings in CF to ensure the best results. Notably, the prior systematic review identified several challenges associated with the insertion of a G-tube, including perioperative risk, changes in physical appearance, and common and foreseeable medical complications.(17) These findings highlight the complexity of the highly personalized decision to pursue G-tube placement, as knowledge, values, and perceptions of benefits and risks are unique for each family. While up to 20% of children with CF under the age of 10 years use supplemental tube feedings to augment nutritional intake,(6) it remains unknown what psychosocial and emotional factors influence G-tube decision-making for caregivers of children with CF and nutritional challenges.

To date, most studies of caregiver decision-making related to G-tube placement have focused on children with cognitive impairment or neuro-disabilities. Notably, these studies demonstrate that G-tube discussions are associated with 1) intense grief and frustration, 2) increased stress and feelings of failure for the caregiver, and 3) uncertainty about complications and care burden influence parental acceptance of the procedure.(18-21) While many factors influencing caregiver decision-making related to G-tube placement are likely universal, these factors may not fully reflect the experiences of caregivers of children with CF. Within the field of CF, Gunnell *et al.* surveyed caregivers of children with CF with G-tubes and found that most were happy with the decision to pursue G-tube placement, however a lack of objective knowledge about G-tubes was common among surveyed caregivers.(22) Brotherton *et. al* explored parental perceptions of G-tube feedings, including 3 parents of children with CF, and demonstrated the adequacy of information and support received did not meet their expectations.(23) Notably, the few studies related to G-tube decision-making were conducted prior to the introduction of cystic fibrosis transmembrane conductance regulator (CFTR) modulator therapies, which correct the malfunctioning protein made by the CFTR gene. The advent of highly effective modulator therapies have led to significant improvements in nutritional status for those individuals with specific CFTR mutations.(24) While the need for G-tube recommendations will likely become less common in the modulator era, the importance of these discussion and decision-making for

those caregivers of children with CF and nutritional challenges will continue to be highly personalized. Thus, it is essential to understand how this difficult decision is viewed in early CF care as well as the current risks and benefits of G-tube feedings, with awareness that the balance of risks and benefits may change for caregivers over time.

Given the scarcity of evidence specific to the CF population, we plan to review G-tube decision-making more broadly in the pediatric population, with a focus on determining factors that are universal as well as those that may be unique to caregivers of children with CF. The scoping review design will allow for a systematic approach to searching, selecting and analysis of existing evidence, including more descriptive elements of the literature, identify knowledge gaps, and provide evidence to inform future research.(25,26) This review will have two main objectives: (1) to chart existing knowledge about factors influencing caregivers' decision-making related to G-tube placement for children with CF as well as general pediatric care and (2) to chart known medical and psychosocial benefits and risks of G-tube feedings in CF care as well as general pediatric care.

METHODS AND ANALYSIS

Study design

A scoping review design was selected because it is the best suited for descriptively mapping evidence on a topic to identify main concepts, theories, and knowledge gaps.[2] The proposed scoping review will follow the guidelines of the JBI to ensure the rigor of the scoping review process.(26,27) This five-stage process includes: (1) identification of the research question, (2) identification of studies relevant to the research question, (3) selection of studies for inclusion, (4) charting information and data obtained from the included studies, (5) collating, summarizing and reporting the results. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) checklist will be used as a guideline for reporting the results of the scoping review.(28) This scoping review was registered on the Open Science Framework on April 6, 2023 (https: https://osf.io/g4pdb).

Stage 1: Identification of the scoping review research questions

The research questions are as follows:

1. What is known about factors influencing caregiver's decision-making related to G-tube placement for children with CF?
2. What is known about the medical and psychosocial benefits and risks of G-tube feedings as it pertains to caregiver's experiences living with and caring for a child with CF and a G-tube?
3. What is known about factors influencing caregiver's decision-making related to G-tube placement and the medical and psychosocial benefits and risks of G-tube feedings in general pediatric care?

Stage 2: Identifying relevant studies

Search strategy
After reviewing other systematic and scoping reviews on decision-making and in consultation with expert stakeholders and an experienced medical librarian, a comprehensive preliminary search strategy was developed using free-text search terms and Medical Subject Headings related to decision-making, enteral tube feeding, CF, and pediatrics. The search strategy was peer-reviewed by a second medical librarian using the Peer Review of Electronic Search Strategies (PRESS) checklist.(29) An initial limited electronic search of MEDLINE (Ovid) was undertaken to identify potentially relevant articles. The words contained in the titles and abstracts of the relevant articles, and the index terms used to describe the articles were used to develop a final search strategy. Due to lack of funding for translation, the search was limited to articles written in English and Spanish. The timeframe of interest included studies published after January 1,1985 to November 1, 2023. This timeframe was selected to encompass studies published after the widespread use of the G-tube in pediatrics to ensure studies have relevance to current clinical practice. Post hoc criteria may be included as reviewers become more familiar with the literature. The final search strategies for all databases used are detailed in the Supplementary File. To identify all potentially relevant published studies, the search strategy will be translated using the specific controlled vocabulary and/or syntax for each included database and/or information source: Embase, CINAHL, PsycInfo, Cochrane Database of Systematic Reviews, and Web of Science, which have wide coverage of health publications.

Stage 3: Study selection

Following the finalized search parameters, the search results will be exported to EndNote and the medical librarian will remove duplicates. Studies will then be imported into Covidence, a web-based collaboration software platform designed to support the process of performing literature reviews, to identify duplicate publications and assist with the review, selection and extraction process outlined in this protocol.(30)

This review will consider studies that describe:

Population
Eligible studies will include the experiences and perspectives of caregivers, defined as parents and guardians of children (<18 years of age) with a clinical diagnosis of CF. Additionally, it will include the experiences of caregivers considering G-tube placement in pediatric care. Studies related to risks and benefits associated with G-tubes in children will also be included.

Concept
The concept of interest is caregiver decision-making needs relative to G-tube placement for children with cystic fibrosis. Given the paucity of knowledge within CF care, this scoping review will also explore caregiver decision-making within general pediatric care to better chart existing knowledge on factors that influence caregivers considering G-tube placement and experiences of being a caregiver of a child with a G-tube.

Context
There will be no geographical limitation applied in relation to this scoping review. Evidence presented from any cultural or geographic context will be eligible.

We will search all available peer-reviewed literature for studies that contain potentially relevant information; there will be no restrictions on the design of the studies, considering experimental and quasi-experimental studies, including observational and qualitative studies. Primary sources will be excluded if already incorporated into an included evidence synthesis unless the data they contain are not otherwise reported in the evidence synthesis. We will exclude studies that: 1) do not address caregivers' G-tube decision-making in pediatric care 2) do not report results related to risks and benefits associated with G-tubes in children < 18 years of age 3) do not allow full-text access and 4) are published in languages other than English and Spanish or before 1985.

A pilot screening test of 40 potentially relevant articles will be conducted by all four researchers to ensure agreement. Subsequently, the research team will meet to discuss discrepancies and make modifications to the eligibility criteria needed and screening will start once a minimum of 80% agreement is achieved. Thereafter, all studies will be screened independently by two researchers, and the study team will meet regularly throughout the process to refine inclusion criteria. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, and with an additional reviewer when necessary to reach consensus. Potentially relevant sources will be retrieved in full and their citation details imported into Zotero reference manager. Subsequently, the full-text will be assessed in detail against the inclusion criteria by two independent researchers. The reference list of all included sources of evidence will be screened to capture possible relevant articles not captured in the search strategy and all key authors will be contacted with requests to provide potentially relevant sources. At this point, any studies that are excluded will be reported in the scoping review. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA-ScR flow diagram.(28)

Stage 4: Data extraction

Data extraction will focus on identifying and charting data relevant to caregiver decision-making needs related to G-tube placement for children with CF and in general pediatric care. The researchers will chart the data using Covidence and use Microsoft Excel to organize the extracted data. A data extraction form will be developed by the researchers to determine which variables/themes to extract. This tool will capture the relevant information on key study characteristics and detailed information on all metrics used to estimate/describe factors influencing G-tube decision-making and experiences of being a caregiver of a child with a G-tube. A preliminary charting table with included variables/themes to be abstracted is summarized in Table 1. The data extracted will include specific details about the publication, study design, research methodology, as well as study findings and conclusions relevant to the review. Given the objective of the study, the variables/themes will be organized according to factors that influence G-tube decision-making, experiences with G-tubes including medical and psychosocial risks and benefits of G-tube placement and long-term use. As pilot testing and to ensure consistency, all researchers will initially review the same 10 publications, discuss the results and amend the data extraction form in an iterative process during the data charting process.

Data extraction of subsequent studies will be undertaken by two independent researchers, and a third reviewer (KMD) will review data extraction templates completed by the other reviewers. This is a quality check to ensure the extracted data from the articles are accurate and executed

with rigor. Any disagreements that arise between the reviewers will be resolved through discussion, and with an additional reviewer when necessary. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

Table 1. Data extraction template

Item	Information
1. Article information	Title and journal
	Author information
	Year of publication
	Country
2. Study information	Study design
	Study aims
	Study outcomes
3. Methodology	Target population
	Recruitment
	Disease process
	Tools used to measure outcomes
4. Factors relevant to decision-making	Experiences, perspectives, facilitators, barriers
	Risks and benefits
5. Future directions	Research gaps
	Study limitations

Stage 5: Data analysis and presentation

Results will be summarized both quantitatively and qualitatively to provide a description of the collected data. An analytic framework will be used to provide an overview of the breadth of the literature. This will include both descriptive numerical summary analysis, presented using tables and charts, and qualitative thematic analysis. Patterns and trends (if identified) will be illustrated using figures and or diagrams, and summarized narratively. Each article's summary will include the author(s), year of publication, country of origin, study purpose, participant information and sample size, study design, concept of interest, key findings related to the scoping review questions, study outcomes, and limitations identified by the authors. In keeping with scoping review methodology, an evaluation of study quality will not be performed. Final conclusions will be drawn from the mapped evidence, in addition to consultations with key stakeholders with unique insights into the experience of G-tube decision-making for children to validate and identify any gaps in our findings.

Patient and public involvement

None.

ETHICS AND DISSEMINATION

The results from this scoping review will inform the development of a decision aid to support caregivers of children with CF in G-tube decision-making. This scoping review and the decision aid will be published in peer-reviewed journals and disseminated through national/international conference presentations. As this study involves no human participants and data will be taken

from publicly available publications, approval from a human research ethics committee is not required.

*** ***

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Contributors KD conceived the idea for this scoping review, developed the research questions, objectives, and inclusion criteria. AS and KD contributed to the creation of the search strategy. EZ and KD contributed to drafting and editing of the scoping review protocol. AS, EZ, SR, CG, and KD reviewed inclusion and exclusion criteria, screened abstracts and full-text papers. All authors read and approved the final manuscript.

Competing interests None declared.

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Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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Supplementary File: Combined Full Search Strategies of All Databases

1) Medline Search Strategy

#	Query
1	Cystic Fibrosis/
2	"cystic fibrosis*".ti,ab,kw,kf.
3	"cystic fibrosis*".io,ja,jn,jw,nj,nw,jc.
4	1 or 2 or 3
5	Enteral Nutrition/ or Gastrostomy/ or Nutritional Requirements/ or Nutritional Status/
6	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) adj4 (nutrition* or feed*)).ti,ab,kw,kf.
7	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) adj4 (tube or tubes or stoma or stomas or stomy or requir* or status*)).ti,ab,kw,kf.
8	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies").ti,ab,kw,kf.
9	(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes").ti,ab,kw,kf.
10	(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies").ti,ab,kw,kf.
11	5 or 6 or 7 or 8 or 9 or 10
12	4 and 11
13	Deglutition Disorders/ or exp Gastroesophageal Reflux/ or exp Laryngopharyngeal Reflux/
14	((deglutition* or swallow*) adj3 (disorder* or "dis-order*" or problem* or difficult*)).ti,ab,kw,kf.
15	(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*").ti,ab,kw,kf.
16	13 or 14 or 15
17	11 or 16

18	exp Decision Making/ or exp Informed Consent/ or Conflict, Psychological/ or Family Conflict/ or Personal Autonomy/ or Motivation/
19	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*).ti,ab,kw,kf.
20	Health Knowledge, Attitudes, Practice/ or Health Literacy/
21	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*).ti,ab,kw,kf.
22	Psychological Distress/ or Stress, Psychological/ or Caregiver Burden/ or Patient Satisfaction/
23	(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*).ti,ab,kw,kf.
24	Risk/ or Risk Assessment/
25	(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*).ti,ab,kw,kf.
26	Communication/ or Information Seeking Behavior/
27	communicat*.ti,ab,kw,kf.
28	(info* adj3 seek*).ti,ab,kw,kf.
29	Nurse-Patient Relations/ or Physician-Patient Relations/
30	((nurse* or doctor* or physician*) adj3 patient*).ti,ab,kw.
31	((nurse* or doctor* or physician* or provider* or patient*) adj3 (relation* or communicat*)).ti,ab,kw,kf.
32	30 and 31
33	exp Guideline/
34	(guideline* or "guide-line*").ti,ab,kw,kf.
35	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 32 or 33 or 34
36	exp Family/ or exp Parents/ or Caregivers/ or Legal Guardians/
37	(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*).ti,ab,kw,kf.
38	(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*).ti,ab,kw,kf.
39	36 or 37 or 38
40	exp Pediatrics/ or exp Infant/ or exp Child/ or exp Adolescent/

41 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).ti,ab,kw,kf.

42 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).io,ja,jn,jw,nj,nw,jc.

43 40 or 41 or 42

44 17 and 35 and 39 and 43

45 12 or 44

46 limit 45 to (yr="1985 -Current" and (english or spanish))

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2) Embase Search Strategy

#1 'cystic fibrosis'/de

#2 'cystic fibrosis*':ti,ab,kw

#3 'cystic fibrosis*':jt

#4 #1 OR #2 OR #3

#5 'enteric feeding'/de OR 'gastrostomy'/de OR 'nutritional requirement'/de OR 'nutritional status'/de

#6 ((enteral* OR enteric* OR gastr* OR nasogastr* OR gastrojejun* OR jejun* OR peg) NEAR/4 (nutrition* OR feed*)):ti,ab,kw

#7 ((enteral* OR enteric* OR gastr* OR nasogastr* OR gastrojejun* OR jejun* OR peg OR nutrition* OR stomach* OR digestiv* OR feed*) NEAR/4 (tube OR tubes OR stoma OR stomas OR stomy OR requir* OR status*)):ti,ab,kw

#8 gastrostoma:ti,ab,kw OR gastrostomas:ti,ab,kw OR gastrostomy:ti,ab,kw OR gastrostomies:ti,ab,kw OR gastrojejunostoma:ti,ab,kw OR gastrojejunostomas:ti,ab,kw OR gastrojejunostomy:ti,ab,kw OR gastrojejunostomies:ti,ab,kw OR 'gastro jejunostoma':ti,ab,kw OR 'gastro jejunostomas':ti,ab,kw OR 'gastro jejunostomy':ti,ab,kw OR 'gastro jejunostomies':ti,ab,kw

#9 gtube:ti,ab,kw OR gtubes:ti,ab,kw OR 'g-tube':ti,ab,kw OR 'g-tubes':ti,ab,kw OR 'gj-tube':ti,ab,kw OR 'gj-tubes':ti,ab,kw

#10 gstoma:ti,ab,kw OR gstomas:ti,ab,kw OR gstomy:ti,ab,kw OR gstomies:ti,ab,kw OR 'g-stoma':ti,ab,kw OR 'g-stomas':ti,ab,kw OR 'g-stomy':ti,ab,kw OR 'g-stomies':ti,ab,kw OR 'gj-stoma':ti,ab,kw OR 'gj-stomas':ti,ab,kw OR 'gj-stomy':ti,ab,kw OR 'gj-stomies':ti,ab,kw

#11 #5 OR #6 OR #7 OR #8 OR #9 OR #10

#12 #4 AND #11

#13 'dysphagia'/de OR 'gastroesophageal reflux'/exp OR 'laryngopharyngeal reflux'/de

#14 ((deglutition* OR swallow*) NEAR/3 (disorder* OR 'dis-order*' OR problem* OR difficult*)):ti,ab,kw

#15 dysphag*:ti,ab,kw OR 'gastroesoph* reflux*':ti,ab,kw OR 'reflux* gastroesoph*':ti,ab,kw OR 'gastro-esoph* reflux*':ti,ab,kw OR 'reflux* gastro-esoph*':ti,ab,kw OR 'gastro-oesoph* reflux*':ti,ab,kw OR 'reflux* gastro-oesoph*':ti,ab,kw OR 'laryngopharyng* reflux*':ti,ab,kw OR 'reflux* laryngopharyng*':ti,ab,kw OR 'laryngo-pharyng* reflux*':ti,ab,kw OR 'reflux laryngo-pharyng*':ti,ab,kw

#16 #13 OR #14 OR #15

#17 #11 AND #16

#18 'decision making'/de OR 'family decision making'/de OR 'patient decision making'/de OR 'shared decision making'/de OR 'ethical decision making'/de OR 'informed consent'/de OR 'conflict'/de OR 'family conflict'/de OR 'patient autonomy'/de OR 'motivation'/exp

#19 decision*:ti,ab,kw OR decid*:ti,ab,kw OR choice*:ti,ab,kw OR choos*:ti,ab,kw OR consensus*:ti,ab,kw OR consent*:ti,ab,kw OR conflict*:ti,ab,kw OR disagree*:ti,ab,kw OR agree*:ti,ab,kw OR participat*:ti,ab,kw OR prefer*:ti,ab,kw OR involv*:ti,ab,kw OR engag*:ti,ab,kw OR expect*:ti,ab,kw OR autonom*:ti,ab,kw OR motivat*:ti,ab,kw

#20 'attitude to health'/de OR 'health literacy'/de

#21 knowledg*:ti,ab,kw OR attitude*:ti,ab,kw OR literacy*:ti,ab,kw OR believ*:ti,ab,kw OR belief*:ti,ab,kw OR percept*:ti,ab,kw OR perceiv*:ti,ab,kw OR perspectiv*:ti,ab,kw

#22 'distress syndrome'/de OR 'mental stress'/de OR 'caregiver burden'/de OR 'caregiver burnout'/de OR 'emotional stress'/de OR 'ethical dilemma'/de OR 'family stress'/de OR 'home stress'/de OR 'interpersonal stress'/de OR 'life stress'/de OR 'parental stress'/exp OR 'patient satisfaction'/de

#23 distress*:ti,ab,kw OR despair*:ti,ab,kw OR stress*:ti,ab,kw OR burden*:ti,ab,kw OR burnout*:ti,ab,kw OR 'burn* out*':ti,ab,kw OR satisf*:ti,ab,kw OR dissatisf*:ti,ab,kw

#24 'risk'/de OR 'patient risk'/de OR 'risk assessment'/de OR 'health risk assessment'/de OR 'risk attitude'/de OR 'risk aversion'/de OR 'risk denial'/de OR 'risk perception'/exp

#25 risk*:ti,ab,kw OR advantag*:ti,ab,kw OR advers*:ti,ab,kw OR benefit*:ti,ab,kw OR disadvantag*:ti,ab,kw OR 'dis-advantag*':ti,ab,kw OR drawback*:ti,ab,kw OR 'draw-back*':ti,ab,kw OR harm*:ti,ab,kw

#26	'interpersonal communication'/de OR 'information seeking'/de
#27	communicat*:ti,ab,kw
#28	(info* NEAR/3 seek*):ti,ab,kw
#29	'nurse patient relationship'/de OR 'doctor patient relationship'/de
#30	((nurse* OR doctor* OR physician*) NEAR/3 patient*):ti,ab,kw
#31	((nurse* OR doctor* OR physician* OR provider* OR patient*) NEAR/3 (relation* OR communicat*)):ti,ab,kw
#32	#30 AND #31
#33	'guideline'/de
#34	guideline*:ti,ab,kw OR 'guide-line*':ti,ab,kw
#35	#18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #32 OR #33 OR #34
#36	'family'/exp OR 'parent'/exp OR 'caregiver'/de OR 'legal guardian'/de
#37	family*:ti,ab,kw OR families*:ti,ab,kw OR parent:ti,ab,kw OR parents:ti,ab,kw OR mother*:ti,ab,kw OR father*:ti,ab,kw OR grandparent*:ti,ab,kw OR grandmother*:ti,ab,kw OR grandfather*:ti,ab,kw OR guardian*:ti,ab,kw
#38	caregiver*:ti,ab,kw OR 'care-giver*':ti,ab,kw OR caretaker*:ti,ab,kw OR 'care-taker*':ti,ab,kw OR carer*:ti,ab,kw
#39	#36 OR #37 OR #38
#40	'pediatrics'/exp OR 'infant'/exp OR 'child'/exp OR 'adolescent'/exp
#41	pediatri*:ti,ab,kw OR paediatr*:ti,ab,kw OR infan*:ti,ab,kw OR baby*:ti,ab,kw OR babies*:ti,ab,kw OR neonat*:ti,ab,kw OR 'neo-nat*':ti,ab,kw OR newborn*:ti,ab,kw OR 'new-born*':ti,ab,kw OR 'newly born*':ti,ab,kw OR toddler*:ti,ab,kw OR preschool*:ti,ab,kw OR 'pre-school*':ti,ab,kw OR child*:ti,ab,kw OR schoolchild*:ti,ab,kw OR 'school-age*':ti,ab,kw OR girl*:ti,ab,kw OR boy:ti,ab,kw OR boys:ti,ab,kw OR tween*:ti,ab,kw OR teen*:ti,ab,kw OR adolescen*:ti,ab,kw OR kid:ti,ab,kw OR kids:ti,ab,kw OR juvenile*:ti,ab,kw OR youth*:ti,ab,kw
#42	pediatri*:jt OR paediatr*:jt OR infan*:jt OR baby*:jt OR babies*:jt OR neonat*:jt OR 'neo-nat*':jt OR newborn*:jt OR 'new-born*':jt OR 'newly born*':jt OR toddler*:jt OR preschool*:jt OR 'pre-school*':jt OR child*:jt OR schoolchild*:jt OR 'school-age*':jt OR girl*:jt OR boy:jt OR boys:jt OR tween*:jt OR teen*:jt OR adolescen*:jt OR kid:jt OR kids:jt OR juvenile*:jt OR youth*:jt
#43	#40 OR #41 OR #42
#44	#17 AND #35 AND #39 AND #43
#45	#12 OR #44

#46 (#12 OR #44) AND ([english]/lim OR [spanish]/lim) AND [1985-2022]/py

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3) CINAHL

1 (MH "Cystic Fibrosis")

2 TI "cystic fibrosis*" OR AB "cystic fibrosis*"

3 SO "cystic fibrosis*" OR JN "cystic fibrosis*" OR JT "cystic fibrosis*"

4 S1 OR S2 OR S3

5 (MH "Enteral Nutrition") OR (MH "Gastrostomy") OR (MH "Nutritional Requirements") OR (MH "Nutritional Status")

6 TI ((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) N4 (nutrition* or feed*))) OR AB (((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) N4 (nutrition* or feed*))

7 TI ((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) N4 (tube or tubes or stoma or stomas or stomy or requir* or status*))) OR AB (((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) N4 (tube or tubes or stoma or stomas or stomy or requir* or status*))

8 TI (gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies") OR AB (gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies")

9 TI (gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes") OR AB (gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes")

10 TI ((gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies")) OR AB ((gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies"))

11 S5 OR S6 OR S7 OR S8 OR S9 OR S10

12 S4 AND S11

13 MH "Deglutition Disorders") OR (MH "Gastroesophageal Reflux")

14 TI (((deglutition* or swallow*) N3 (disorder* or "dis-order*" or problem* or difficult*))) OR AB (((deglutition* or swallow*) N3 (disorder* or "dis-order*" or problem* or difficult*)))

15	TI ((dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*")) OR AB ((dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*"))
16	S13 OR S14 OR S15
17	S11 OR S16
18	(MH "Decision Making+") OR (MH "Consent+") OR (MH "Conflict (Psychology)") OR (MH "Family Conflict") OR (MH "Patient Autonomy") OR (MH "Motivation")
19	TI ((decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivate*)) OR AB ((decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivate*))
20	(MH "Health Literacy")
21	TI (knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*) OR AB (knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*)
22	(MH "Psychological Distress") OR (MH "Stress, Psychological") OR (MH "Caregiver Burden") OR (MH "Patient Satisfaction")
23	TI (distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*) OR AB (distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*)
24	(MH "Relative Risk") OR (MH "Risk Assessment")
25	TI (risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*) OR AB (risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*)
26	(MH "Communication"") OR (MH "Information Seeking Behavior")
27	TI communicat* OR AB communicat*
28	TI (info* N3 seek*) OR AB (info* N3 seek*)
29	(MH "Nurse-Patient Relations") OR (MH "Physician-Patient Relations")
30	TI ((nurse* or doctor* or physician*) N3 patient*) OR AB ((nurse* or doctor* or physician*) N3 patient*)

31	TI ((nurse* or doctor* or physician* or provider* or patient*) N3 (relation* or communicat*)) OR AB ((nurse* or doctor* or physician* or provider* or patient*) N3 (relation* or communicat*))
32	S30 AND S31
33	(MH "Practice Guidelines")
34	TI (guideline* or "guide-line*") OR AB (guideline* or "guide-line*")
35	S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S32 OR S33 OR S34
36	(MH "Family+") OR (MH "Parents+") OR (MH "Caregivers") OR (MH "Guardianship, Legal")
37	TI (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*) OR AB (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*)
38	TI (caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*) OR AB (caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*)
39	S36 OR S37 OR S38
40	(MH "Pediatrics+") OR (MH "Infant+") OR (MH "Child+") OR (MH "Adolescence+")
41	TI (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR AB (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
42	SO (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR JN (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*) OR JT (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
43	S40 OR S41 OR S42
44	S17 AND S35 AND S39 AND S43
45	S12 OR S44 Limiters - Published Date: 19850101-20231231; English Language

46 s12 or s44

47 s12 or s44 Limiters - Published Date: 19850101-20231231; Language: Spanish

48 S45 OR S47

Limiters - Published Date: 19850101-20231231; Language: Spanish "

48 S45 OR S47

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4) APA PsycInfo

#	Query
1	Cystic Fibrosis/
2	cystic fibrosis.mh.
3	"cystic fibrosis*".tw.
4	cystic fibrosis*.jn,jx,nl,ol.
5	1 or 2 or 3 or 4
6	(enteral nutrition or gastrostomy or nutritional requirements or nutritional status).mh.
7	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) adj4 (nutrition* or feed*)).tw.
8	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) adj4 (tube or tubes or stoma or stomas or stomy or requir* or status*)).tw.
9	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies").tw.
10	(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes").tw.
11	(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies").tw.
12	6 or 7 or 8 or 9 or 10 or 11
13	5 and 12
14	exp Dysphagia/
15	(deglutition disorders or gastroesophageal reflux or laryngopharyngeal reflux).mh.

16	((deglutition* or swallow*) adj3 (disorder* or "dis-order*" or problem* or difficult*)).tw.
17	(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*").tw.
18	14 or 15 or 16 or 17
19	12 or 18
20	exp Decision Making/ or exp Informed Consent/ or Family Conflict/ or exp Autonomy/ or exp Conflict/ or Motivation/
21	(decision making or informed consent or conflict, psychological or family conflict or personal autonomy or motivation).mh.
22	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*).tw.
23	Health Knowledge/ or Health Literacy/
24	(health knowledge, attitudes, practice or health literacy).mh.
25	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*).tw.
26	Psychological Stress/ or Distress/ or Caregiver Burden/ or Client Satisfaction/
27	(psychological distress or stress, psychological or caregiver burden or patient satisfaction).mh.
28	(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*).tw.
29	Risk Factors/ or Risk Assessment/
30	(risk or risk assessment).mh.
31	(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*).tw.
32	Communication/ or Information Seeking/
33	(communication or information seeking behavior).mh.
34	communicat*.tw.
35	(info* adj3 seek*).tw.
36	(nurse-patient relations or physician-patient relations).mh.
37	((nurse* or doctor* or physician*) adj3 patient*).tw.
38	((nurse* or doctor* or physician* or provider* or patient*) adj3 (relation* or communicat*)).tw.

39	37 and 38
40	exp Treatment Guidelines/ or guideline.mh.
41	(guideline* or "guide-line*").tw.
42	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 39 or 40 or 41
43	exp Family/ or exp Parents/ or Caregivers/ or Guardianship/
44	(family or parents or caregivers or legal guardians).mh.
45	(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*).tw.
46	(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*).tw.
47	43 or 44 or 45 or 46
48	exp Pediatrics/ or (pediatrics or infant or child or adolescent).mh.
49	(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).tw.
50	(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*).jn,nl,ol,jx.
51	or/48-50
52	19 and 42 and 47
53	51 and 52
54	limit 52 to (childhood or adolescence <13 to 17 years>)
55	53 or 54
56	13 or 55
57	limit 56 to (yr="1985 -Current" and (english or spanish))

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5) Cochrane Database of Systematic Reviews

ID	Search
#1	MeSH descriptor: [Cystic Fibrosis] explode all trees

#2	(cystic NEXT/3 fibrosis*):ti,ab,kw
#3	(cystic NEXT/3 fibrosis*):so
#4	#1 or #2 or #3
#5	MeSH descriptor: [Enteral Nutrition] this term only
#6	MeSH descriptor: [Gastrostomy] this term only
#7	MeSH descriptor: [Nutritional Requirements] this term only
#8	MeSH descriptor: [Nutritional Status] this term only
#9	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) NEXT/4 (nutrition* or feed*)):ti,ab,kw
#10	((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) NEXT/4 (tube or tubes or stoma or stomas or stomy or requir* or status*)):ti,ab,kw
#11	(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or (gastro NEXT jejunostoma) or (gastro NEXT jejunostomas) or (gastro NEXT jejunostomy) or (gastro NEXT jejunostomies)):ti,ab,kw
#12	(gtube or gtubes or g NEXT tube or g NEXT tubes or gj NEXT tube or gj NEXT tubes)
#13	(gstoma or gstomas or gstomy or gstomies):ti,ab,kw
#14	(stoma or stomas or stomy or stomies) NEAR/3 (g or gi)
#15	#5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14
#16	#4 and #15
#17	MeSH descriptor: [Deglutition Disorders] this term only
#18	MeSH descriptor: [Gastroesophageal Reflux] explode all trees
#19	MeSH descriptor: [Laryngopharyngeal Reflux] explode all trees
#20	((deglutition* or swallow*) NEAR/3 (disorder* or dis-order* or problem* or difficult*)):ti,ab,kw
#21	(dysphag* or (gastroesoph* NEXT reflux*) or (reflux* NEXT gastroesoph*) or (gastro NEXT esoph* NEXT reflux*) or (reflux* NEXT gastro NEXT esoph*) or (gastro NEXT oesoph* NEXT reflux*) or (reflux* NEXT gastro NEXT oesoph*) or (laryngopharyng* NEXT reflux*) or (reflux* NEXT laryngopharyng*) or (laryngo NEXT pharyng* NEXT reflux*) or (reflux NEXT laryngo NEXT pharyng*)):ti,ab,kw
#22	#17 or #18 or #19 or #20 or #21
#23	#15 or #22

#24	MeSH descriptor: [Decision Making] explode all trees
#25	MeSH descriptor: [Informed Consent] explode all trees
#26	MeSH descriptor: [Conflict, Psychological] this term only
#27	MeSH descriptor: [Family Conflict] this term only
#28	MeSH descriptor: [Motivation] this term only
#29	MeSH descriptor: [Personal Autonomy] this term only
#30	(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*):ti,ab,kw
#31	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
#32	MeSH descriptor: [Health Literacy] this term only
#33	(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*):ti,ab,kw
#34	MeSH descriptor: [Psychological Distress] this term only
#35	MeSH descriptor: [Stress, Psychological] this term only
#36	MeSH descriptor: [Caregiver Burden] this term only
#37	MeSH descriptor: [Patient Satisfaction] this term only
#38	(distress* or despair* or stress* or burden* or burnout* or (burn* NEXT/3 out*) or satisf* or dissatisf*):ti,ab,kw
#39	MeSH descriptor: [Risk] this term only
#40	MeSH descriptor: [Risk Assessment] this term only
#41	(risk* or advantag* or advers* or benefit* or disadvantag* or (dis-advantag*) or drawback* or (draw-back*) or harm*):ti,ab,kw
#42	MeSH descriptor: [Communication] this term only
#43	MeSH descriptor: [Information Seeking Behavior] this term only
#44	(communicat*):ti,ab,kw
#45	((info* NEXT/3 seek*)):ti,ab,kw
#46	MeSH descriptor: [Nurse-Patient Relations] this term only
#47	MeSH descriptor: [Physician-Patient Relations] this term only
#48	((nurse* or doctor* or physician*) NEAR/3 patient*):ti,ab,kw

#49 ((nurse* or doctor* or physician* or provider* or patient*) NEXT/3 (relation* or communicat*)):ti,ab,kw

#50 #48 and #49

#51 MeSH descriptor: [Guideline] explode all trees

#52 (guideline* or guide NEXT line*):ti,ab,kw

#53 #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #50 or #51 or #52

#54 MeSH descriptor: [Family] explode all trees

#55 MeSH descriptor: [Parents] explode all trees

#56 MeSH descriptor: [Caregivers] this term only

#57 MeSH descriptor: [Legal Guardians] this term only

#58 (family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*):ti,ab,kw

#59 (caregiver* or care NEXT giver* or caretaker* or care NEXT taker* or carer*):ti,ab,kw

#60 #54 or #55 or #56 or #57 or #58 or #59

#61 MeSH descriptor: [Pediatrics] explode all trees

#62 MeSH descriptor: [Infant] explode all trees

#63 MeSH descriptor: [Child] explode all trees

#64 MeSH descriptor: [Adolescent] explode all trees

#65 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or neo NEXT nat* or newborn* or new NEXT born* or toddler* or preschool* or pre NEXT school* or child* or schoolchild* or school NEXT age* or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*):ti,ab,kw

#66 (pediatri* or paediatr* or infan* or baby* or babies* or neonat* or neo NEXT nat* or newborn* or new NEXT born* or toddler* or preschool* or pre NEXT school* or child* or schoolchild* or school NEXT age* or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*):so

#67 #61 or #62 or #63 or #64 or #65 or #66

#68 #23 and #53 and #60 and #67

#69 #16 or #68 with Cochrane Library publication date Between Jan 1985 and Dec 2023, in Cochrane Reviews, Cochrane Protocols, Trials, Clinical Answers, Editorials, Special Collect

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6) Web of Science Search Strategy

1	TS=("cystic fibrosis*")
2	SO=("cystic fibrosis*")
3	#1 OR #2
4	TS=((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG) NEAR/4 (nutrition* or feed*))
5	TS=((enteral* or enteric* or gastr* or nasogastr* or gastrojejun* or jejun* or PEG or nutrition* or stomach* or digestiv* or feed*) NEAR/4 (tube or tubes or stoma or stomas or stomy or requir* or status*))
6	TS=(gastrostoma or gastrostomas or gastrostomy or gastrostomies or gastrojejunostoma or gastrojejunostomas or gastrojejunostomy or gastrojejunostomies or "gastro jejunostoma" or "gastro jejunostomas" or "gastro jejunostomy" or "gastro jejunostomies")
7	TS=(gtube or gtubes or "g-tube" or "g-tubes" or "gj-tube" or "gj-tubes")
8	TS=(gstoma or gstomas or gstomy or gstomies or "g-stoma" or "g-stomas" or "g-stomy" or "g-stomies" or "gj-stoma" or "gj-stomas" or "gj-stomy" or "gj-stomies")
9	#4 OR #5 OR #6 OR #7 OR #8
10	#3 and #9
11	TS=((deglutition* or swallow*) NEAR/3 (disorder* or "dis-order*" or problem* or difficult*))
12	TS=(dysphag* or "gastroesoph* reflux*" or "reflux* gastroesoph*" or "gastro-esoph* reflux*" or "reflux* gastro-esoph*" or "gastro-oesoph* reflux*" or "reflux* gastro-oesoph*" or "laryngopharyng* reflux*" or "reflux* laryngopharyng*" or "laryngo-pharyng* reflux*" or "reflux laryngo-pharyng*")
13	#11 OR #12
14	#9 OR #13
15	TS=(decision* or decid* or choice* or choos* or consensus* or consent* or conflict* or disagree* or agree* or participat* or prefer* or involv* or engag* or expect* or autonom* or motivat*)
16	TS=(knowledg* or attitude* or literacy* or believ* or belief* or percept* or perceiv* or perspectiv*)
17	TS=(distress* or despair* or stress* or burden* or burnout* or "burn* out*" or satisf* or dissatisf*)
18	TS=(risk* or advantag* or advers* or benefit* or disadvantag* or "dis-advantag*" or drawback* or "draw-back*" or harm*)

19	TS=comunicat*
20	TS=(info* NEAR/3 sick*)
21	TS=((nurse* or doctor* or physician*) NEAR/3 patient*)
22	TS=((nurse* or doctor* or physician* or provider* or patient*) NEAR/3 (relation* or communicat*))
23	#21 AND #22
24	TS=(guideline* or "guide-line*")
25	#15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #23 OR #24
26	TS=(family* or families* or parent or parents or mother* or father* or grandparent* or grandmother* or grandfather* or guardian*)
27	TS=(caregiver* or "care-giver*" or caretaker* or "care-taker*" or carer*)
28	#26 OR #27
29	TS=(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
30	SO=(pediatri* or paediatr* or infan* or baby* or babies* or neonat* or "neo-nat*" or newborn* or "new-born*" or toddler* or preschool* or "pre-school*" or child* or schoolchild* or "school-age*" or girl* or boy or boys or tween* or teen* or adolescen* or kid or kids or juvenile* or youth*)
31	#29 OR #30
32	#14 AND #25 AND #28 AND #31
33	#10 OR #32
34	PY=1985-2023
35	#33 and #34
36	(#33 AND #34) and English or Spanish (Languages)