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## **A scoping review of non-pharmacological health education provided to families of children with idiopathic childhood constipation within primary health care**

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# A Scoping Review of Non-Pharmacological Health Education Provided to Families of Children With Idiopathic Childhood Constipation Within Primary Health Care

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## Abstract

**Objectives:** Idiopathic childhood constipation is a prevalent condition that initially brings the child under the care of the primary health care team. Although it is acknowledged that health education is crucial to reducing chronicity, the range of evidenced-based non-pharmacological health education provided to families has not previously been reviewed. For this scoping review, 4 research questions sought to identify papers that provide information on the utilization of guidelines, the range of health education, who provides it, and whether any gaps exist. **Methods:** Following a registered protocol and using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews, searches of 10 online databases, reference lists, Google Scholar, and book chapter references were made. Eligible papers were original research published in English between January 2000 and December 2022. **Results:** Twelve worldwide studies (2 qualitative and 10 quantitative) reported that: evidence-based guidelines are not consistently used by primary care providers; the range of non-pharmacological health education provided is inconsistent; the non-pharmacological health education is provided by doctors, nurses, and pharmacists; and that gaps exist in non-pharmacological health education provision. **Conclusion:** This review demonstrates that rather than a lack of guideline-awareness, decreased specific idiopathic childhood constipation knowledge (and possibly time) may be responsible for inconsistent non-pharmacological health education. Inappropriate treatment and management of some children escalates risk for chronicity. Improving health education provision however, may be achieved through: increased collaboration; better utilization of nurses; and through developing the child's health literacy by involving both child and family in all aspects of health education and decision-making.

## Keywords

idiopathic childhood constipation, health education, primary care providers, role of nurse, scoping review

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## Introduction

Idiopathic Childhood Constipation (ICC) is common and is suggested to coincide with 4 life-stages that is, transitioning from breastfeeding to breastmilk substitute (formula),<sup>1</sup> weaning onto solid food,<sup>2</sup> toilet training,<sup>3</sup> and starting either part-time or full-time school.<sup>4,5</sup> ICC may also develop as a result of the child experiencing stressful situations or environments.<sup>6</sup> Children may either involuntarily or voluntarily withhold stools<sup>7</sup> sometimes as a result of pain, which is further exacerbated when more water is absorbed from the retained stool through being held longer in the rectum or

sigmoid colon. This makes the stool more firm and difficult or painful to pass, and the child even less inclined then to pass the stool.<sup>4</sup> Other terms used to describe ICC are

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“functional” childhood constipation (a term that is being discontinued for being too vague,<sup>8</sup> functional gastrointestinal disorders (FGIDs),<sup>9</sup> or “disorders of gut-brain interaction (DGBI).”<sup>10</sup>

The 4 life-stages that ICC is said to coincide, initially brings the child under the care of the primary health care team. Thus Primary Care Providers (PCPs) including doctors, nurses, and retail pharmacists,<sup>11</sup> all have a responsibility to provide collaborative and evidence-based ICC health education to both the child and family, which is considered an extremely important factor in treating and managing ICC.<sup>12-14</sup> However, being unfamiliar with their child’s bowel habits, parents may not initially recognize the signs and symptoms of ICC.<sup>15</sup> Conversely, even if parents are aware of their child being constipated, they may prefer to obtain health advice from retail Pharmacists, and purchase over-the-counter medication<sup>16</sup> in a bid to self-manage the condition before seeking health advice from their PCP.<sup>17</sup>

The concept of primary health care was first established in the Declaration of Alma-Ata, where not only health, but collaborative health education were viewed as human rights.<sup>18</sup> These human rights also apply to children who, as detailed in Article 13 of The United Nations Convention on the Rights of the Child,<sup>19</sup> have the right to request, receive and share information in relation to any issue that affects them. While this placed the child at the center of care,<sup>20</sup> the philosophy for care now emphasizes a need for this to occur within the context of family.<sup>21</sup> While acknowledging that parents may wish to shield their child against negative health discussions, involving children in health education may develop their health literacy.<sup>22</sup> Borzekowski<sup>22</sup> further asserts that children as young as 3 years old should play an active role in learning about their health to enable them to achieve more control over their habits and health decisions.<sup>22</sup> This may empower children to “own” their ICC,<sup>7,23</sup> especially those who are either seeking to be more independent of their parents,<sup>24</sup> or who are transitioning into adult health services.<sup>25</sup>

To assist health professionals in the diagnosis, treatment, and management of ICC (as opposed to constipation originating from an underlying medical, anatomical, or neuropathic condition or disorder), a number of evidence-based guidelines have been developed. These include (but are not limited to) the collaborative European Society for Pediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN) and North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN),<sup>26</sup> the National Institute for Health and Care Excellence (NICE),<sup>27</sup> and Rome II, III, and IV.<sup>28</sup>

In recent years, interest in ICC has grown and studies conducted have shown a prevalence of between 0.5% and 32.2%. This is evidenced through 3 systematic reviews,<sup>17,29,30</sup> which collectively identified 27 countries worldwide that undertook studies on ICC prevalence. ICC is also considered chronic if it lasts for a period of 8 weeks or more and has been declared as a “growing global public health problem.”<sup>31</sup>

The rationale for reviewing the range of evidence-based non-pharmacological health education that is, aspects that help to manage ICC other than medication, provided to families of children diagnosed with ICC within primary health care, is due to its not having previously been comprehensively reviewed, and thus makes undertaking a scoping review particularly suitable.<sup>32</sup> This scoping review has been undertaken systematically through following the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)<sup>33</sup> (Supplemental Appendix A).

The objectives of this scoping review are to identify papers that provide information on the evidence-based non-pharmacological ICC health education provided to families within primary health care, by answering the following research questions: (1) Are the evidence-based guidelines utilized and to what extent? (2) What range of non-pharmacological ICC health education is provided? (3) Who provides the non-pharmacological ICC health education? (4) Are any gaps identified in the ICC health education?

## Methods

With guidance from a librarian an a priori protocol was produced. This protocol included a search strategy with keywords that were assigned to the mnemonic PICO, the inclusion and exclusion criteria, the information sources, the search methods, one search result, and the data extraction process.<sup>32</sup> The protocol was registered with the Open Science Framework (OSF).

## Data Analysis

To fully encompass the potential growth in knowledge, all papers published between January 2000 and December 2022, from any geographical area, were included. However, due to time and resource limitations, papers were restricted to the English language. Any paper detailing information related to ICC health education, treatment, management, or therapy provided to families by either a General Practitioner (GP), Child Health Nurse (CHN), School Health Nurse (SHN) (or their international equivalents), Nurse Practitioner, or retail Pharmacist were eligible.

Papers were excluded if: (a) constipation developed from an underlying organic or congenital medical condition; (b) they focused solely on complementary, quality of life, gut motility, urinary involvement, surgical, pharmacological, dietary, or encopresis/soiling aspects; (c) they focused solely on an adult population; (d) the ICC health education was provided in either a secondary or tertiary health care setting; (e) the ICC health education could not be deduced from the data; or (f) PCP figures were difficult to extract from the data.

In order to maintain the currency of the literature review, 2 searches were undertaken. The first (conducted on 07/01/2021)

searched for papers between December 2020 and January 2021, and the second (a re-run of the first search but with a different date limiter) was conducted on 12/05/2022 and searched for papers between January 2021 and December 2022. The keywords listed in the protocol were used to customize search strategies for 9 computerized databases, and truncations and wildcards were adapted according to the search strategy of each database. The search strategy covering both searches for the CINAHL database is shown in Supplemental Appendix B. Using the same protocol, 4 additional searches of reference lists, eJournals, Google Scholar, and book chapter references (Supplemental Appendix C) were undertaken.

The papers identified as potentially-eligible for inclusion were 104 for the first search and 11 for the second search. These papers were exported from EndNote into Rayyan—a website developed to facilitate title and abstract screening for systematic reviews.<sup>34</sup> Referring to the inclusion and exclusion criteria, 2 reviewers (DH and DI) reviewed the abstracts of all the papers both independently and then collaboratively; assigning reason(s) for exclusion. Conflicts were discussed and included papers (n=13) were read in full, which resulted in one more paper from the first search being excluded. Furthermore, both the included papers from the first search (n=12) (no papers from the second search were included), and the excluded papers from both searches (n=103) were then independently assessed by 2 reviewers (DA and EM) with the final decision for inclusion being made by all 4 authors. No critical appraisal was undertaken. An email sent to one designated correspondence author<sup>35</sup> requesting further information for clarification (with the reply) is shown in Supplemental Appendix D.

Due to the small number of studies, DH appraised the papers independently. To address the research questions and facilitate data extraction, steps were undertaken and the results presented in tabular form. The first step used data items to guide data extraction, and included the author; year of publication; country of origin; context; design; method; research aim(s); participants; data collection tools; key findings; and conclusions. The key findings were limited to non-pharmacological ICC health education only. The second step compared and matched the extracted non-pharmacological ICC health education against aspects recommended in the evidence-based guidelines. The results of the data charting process were verified by the co-authors.

## Results

### Study Characteristics

The screening, inclusion, and exclusion process of the searches are provided in Figure 1. The results of the first search are denoted in round brackets, with square brackets

denoting the results of the second search alongside. The 12 included papers (2 qualitative and 10 quantitative) and 103 excluded papers are listed in Table 1 and Supplemental Appendix E respectively. Including qualitative studies gives the parents a voice regarding the impact that ICC health education provision (or lack of) has on the child and family, which would not be realized from numerical data collected through quantitative studies. For clarity, the term Primary Care Provider (PCP) will encompass all health professionals who practise within primary health care, with differentiation made only between medical and nursing. Although a descriptive data analysis is presented,<sup>32</sup> the data extracted utilizing the data charting process Steps 1 and 2 are shown in Tables 1 and 2, respectively.

The 12 studies listed in Table 1 were published between 2003 and 2021 with 67% (n=8) being published in the last 10 years. Two studies were conducted in the United Kingdom (UK),<sup>36,39</sup> 3 in the United States of America (USA),<sup>38,41,43</sup> one study each was conducted in Canada,<sup>37</sup> Italy,<sup>35</sup> Indonesia,<sup>45</sup> Iran,<sup>44</sup> and Australia<sup>16</sup>; one<sup>40</sup> was conducted across 3 countries; and one<sup>42</sup> was conducted across 9 countries within Europe.

Two studies were qualitative,<sup>36,37</sup> and 10 were quantitative.<sup>16,35,38-45</sup> All but one study<sup>38</sup> used author-developed data collection tools. Four studies<sup>35,41,44,45</sup> cite 1 guideline, and 3<sup>40,42,43</sup> cite 2 guidelines.

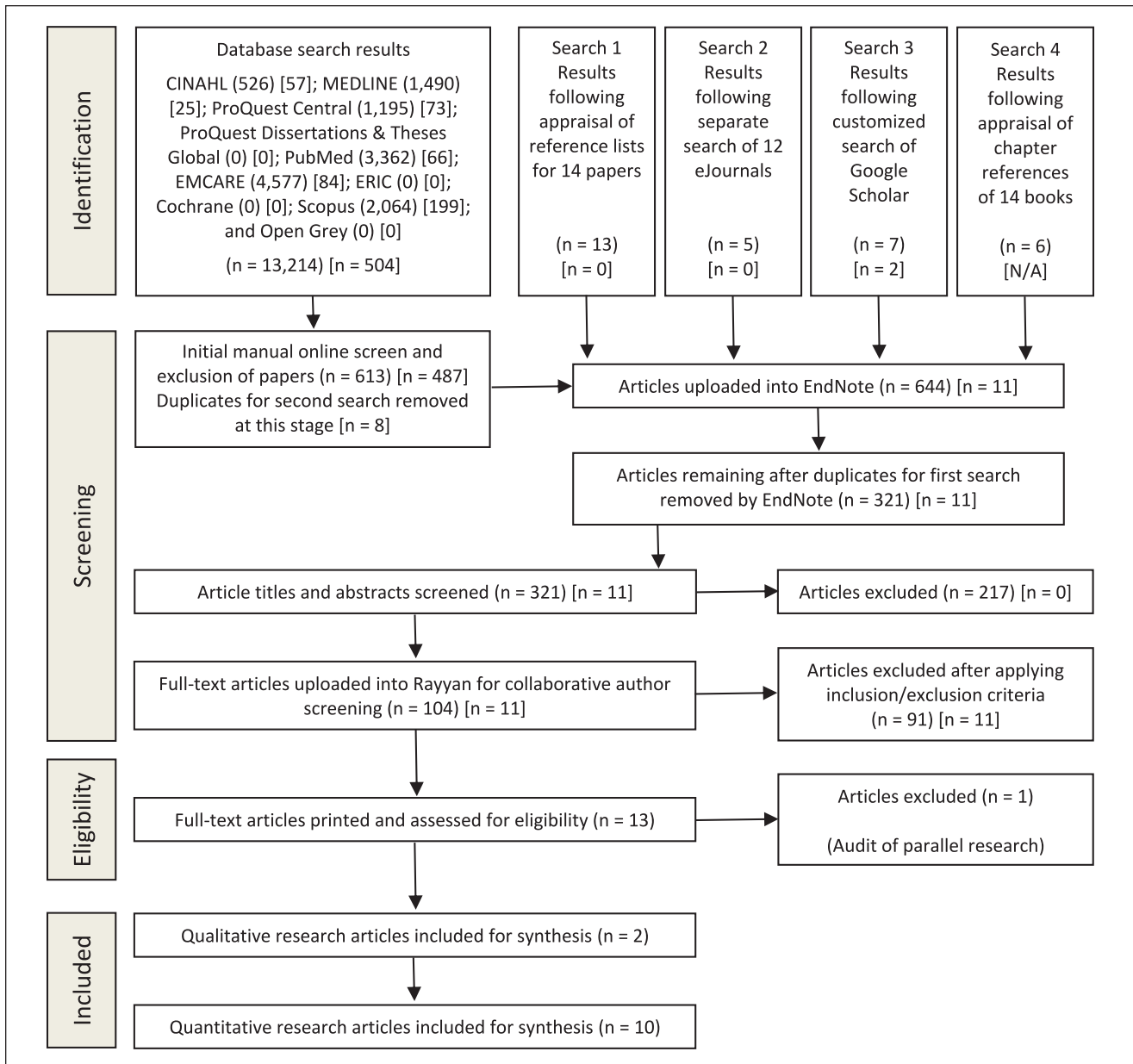
Collectively, the studies reported on 3148 participants (30 parents of children, 509 children, 1163 PCPs/GPs, 771 in-training Pediatricians, 197 Gastroenterologists, 116 Nurse Practitioners/Physician Assistants (NPs/PAs), and 362 retail Pharmacists). The sample size of the qualitative studies ranged from 14 to 16 (mean 15), and from 100 to 771 (mean 328) for the quantitative studies. The ages of the children ranged from 0 to 14 years (mean 7 years).

The studies explored parents' experiences in managing and caring for their child with constipation following consultation with PCPs<sup>36,37</sup>; PCPs' awareness of guidelines and their ability to treat and manage ICC<sup>35,38,40-45</sup>; the role of the nurse in providing care and ICC health education,<sup>39,43,44</sup> and the role of retail Pharmacists in providing care and ICC information.<sup>16</sup>

Using the information extracted from Tables 1 and 2 with reference to the 4 research questions, the results are further synthesized below.

### Q1. Are the Evidence-Based Guidelines Utilized and to What Extent?

Five studies do not cite evidence-based guidelines,<sup>16,36-39</sup> and one<sup>40</sup> makes reference to both the NASPGHAN and NICE guidelines through 2 citations<sup>46,47</sup> respectively. The remaining 6 studies specifically cite evidence-based guidelines that is, NASPGHAN and/or ESPGHAN,<sup>41,43,45</sup> and Rome II and/or Rome III.<sup>35,42,44</sup>



**Figure 1.** Screening, inclusion, and exclusion process.

Results for the first search are given in round brackets, and in square brackets for the second search.

While 3 studies aimed to appraise the approach used by PCPs to diagnose and treat ICC,<sup>40-42</sup> only one<sup>41</sup> specifically aimed to see how the PCP approach adhered to the NASPGHAN guidelines. Furthermore, only one<sup>35</sup> used Rome II to determine participant eligibility before using a predefined protocol to confirm its validity, and one<sup>44</sup> used Rome III to determine participant eligibility and confirm improvement. Citing guidelines (or not) appears to make little difference to the number of aspects provided. For example, of 4 studies that each deliver 6 aspects of ICC

health education, 2 do not cite guidelines,<sup>38,39</sup> 1 cites 2 guidelines,<sup>40</sup> and 1 cites 1 guideline.<sup>44</sup>

In addition, it was found that 76% (n=206) of all PCPs had never heard of the NASPGHAN guidelines and that, even if they had, none of the PCPs surveyed ever used the guidelines to treat or manage children with ICC.<sup>43</sup> Another study found that only 29% (n=278) of PCPs used Rome III and that 11% still used the superseded Rome II.<sup>42</sup> This trend continued with 84.3% (n=967) of PCPs being found to be either unfamiliar or somewhat familiar with the NASPGHAN guidelines.<sup>41</sup>

**Table 1.** Data Extracted from the 12 Included Studies.

Author, country, context	Design, method, research aim	Participants	Data collection tools	Key findings/Conclusions
Qualitative research Farrell et al, <sup>36</sup> UK Diverse clinical settings, including Primary Care	Qualitative, phenomenological Aim: Explore parents' experiences when consulting health professionals about management of children's constipation	Parents of 14 children aged <3 to >5 years (specific ages not detailed)	In-depth interviews Field notes	Six themes identified: 1 enduring and extreme constipation 2 dismissed and fobbed off - child will grow out of it - role of the nurse validated 3 asserting the need for action 4 validation and acknowledgment - role of the nurse validated 5 being vigilant 6 positive responses from health professionals - aspects of care explained - concerns acknowledged Conclusion: Study reveals that health professionals grossly underestimate the impact of childhood constipation Nurses may be in a good position to take a lead role in supporting parents and children
Thompson et al, <sup>37</sup> Canada Primary setting	Qualitative, Interpretive description Aim: Understand and give voice to parents' experiences and information needs when caring for a child with FC	Parents of 16 children aged 3-9 years or older	In-depth interviews Reflexive Journal Field Notes	Four major themes identified: 1 living in the shadows 2 not taken seriously Sub-theme: persevering and advocating 3 missing information and misinformation - child will grow out of it - increase fiber and water - skip junk food - omit dairy, cheese, and bread - increase fruit/vegetables 4 self-doubt and strained relationships One minor theme identified: affirmative influences that foster resilience and hope Conclusion: Parents have significant unmet needs for support and information
Quantitative research Borowitz et al, <sup>38</sup> 2005 USA 26 PCPs: 15 Pediatricians 11 FPs	Quantitative Prospective, non-probability purposive Aim: Stage 1: Coded office records review Stage 2: Parental rating of compliance Aim: Examine treatment types prescribed by PCPs to children when they present with constipation for the first time, and the efficacy of the treatment	(130 children enrolled) 119 children aged 2-7 years	Bowel Diary Stage 1: 5-point ordinal scale checklist Stage 2: 6-point scale	Stage 1: No statistical significance of successful treatment between: • Pediatricians (62%) and FPs (67%) ( $P = .8063$ ) • responders to treatment ( $n = 75$ ) and non-responders ( $n = 44$ ) Statistical significance in: • number of bowel movements per week between responders ( $3.1 \pm 2.3$ ) and non-responders ( $1.8 \pm 1.0$ ) ( $P = .0016$ ) • aggressive therapy and less aggressive therapy ( $P = .0480$ ) Stage 2: No statistical significance between: • responders to treatment ( $5.1 \pm 1.3$ ) and non-responders ( $4.6 \pm 1.8$ ) ( $P = .1380$ )



**Table 1. (continued)**

Author, country, context	Design, method, research aim	Participants	Data collection tools	Key findings/Conclusions
Smith and Derrett and Derrett <sup>39</sup> UK Primary Health Care: 21 HVs	Quantitative Non-probability purposive, Non-experimental, descriptive Aim: Identify types of advice and care provided to young children with constipation, pathways to care and ideas for service improvement	34 children aged 2 weeks to 4.5 years	Author-developed questionnaire	<p>Conclusion: Substantial variability in PCP ICC treatment Approximately 40% of children with ICC remain symptomatic after 2 months of treatment PCPs should consider early, aggressive ICC treatment to reduce chronicity PCPs tend to undertreat constipation</p> <ul style="list-style-type: none"> <li>• Constipation duration ranged from 2 days to 18 months (mean 3 months) and strongly related to age (<math>r = .71, P &lt; .001</math>)</li> <li>• Seven (21%) children were symptomatic for <math>\geq 6</math> months</li> </ul> <p>Types of non-pharmacological advice:</p> <ul style="list-style-type: none"> <li>• Fluids (94%)</li> <li>• Dietary (76%)</li> <li>• Psychological/behavioral (21%)</li> <li>• Formula/bottle feeding (12%)</li> <li>• Breastfeeding (3%)</li> <li>• Orange juice in cooled water (3%)</li> <li>• Herbal remedies (3%)</li> <li>• Exercise (3%)</li> <li>• Education relating to laxatives (6%)</li> <li>• Referral to GP (15%)</li> </ul> <p>Conclusion: Constipation is either not reported or recognized adequately and is poorly managed</p>
Primavera et al, <sup>35</sup> 2010 Italy Primary Health Care: 21 FPs	Quantitative Prospective, open-label, nonrandomized Aim: Assess prevalence of FGIDs Demonstrate that FPs can diagnose and manage FGIDs using Rome II criteria (cyclical vomiting not included) Assess compliance of FPs with predefined diagnostic and therapeutic protocols To evaluate success of education and reassurance in comparison to drug therapy	(929) children enrolled 261 children aged birth to 14 years 10 lost during follow-up	Author-developed questionnaire	<p>Conclusion: Constipation is either not reported or recognized adequately and is poorly managed</p> <ol style="list-style-type: none"> <li>1. FGIDs are prevalent</li> <li>2. 247 (98.4%, n = 251) diagnosed with FGID at 12-month follow-up, thus validating use of guidelines</li> <li>3. Compliance of FPs using protocols &gt;80%</li> <li>4. Not applicable as FC not covered in discussion<sup>a</sup></li> </ol> <p>FC diagnosed in more children across the 8 FGID categories (n = 92, 37.24%, N = 247)</p> <p>At 12-month follow-up, for these 92 children, FC:</p> <ul style="list-style-type: none"> <li>• had disappeared (n = 26, 28.26%)</li> <li>• was much improved (n = 46, 50%)</li> <li>• was mild (n = 12, 13.04%)</li> <li>• remained unchanged (n = 7, 7.6%)</li> <li>• was worse (n = 1, 1.08%)</li> </ul> <p>Conclusion: FPs are capable of diagnosing and managing FC in Primary Health Care Guidelines valid for diagnosis and management of FGIDs CME important</p>

(continued)

**Table 1. (continued)**

Author, country, context	Design, method, research aim	Participants	Data collection tools	Key findings/Conclusions
Burgers et al., <sup>40</sup> Italy, the Netherlands, and USA PCPs	Quantitative Prospective study Aim: Investigate the approach to childhood constipation by PCPs in 3 Western countries	Surveys distributed Italy: 312 The Netherlands: 204 USA: 500 413 surveys returned (response 41%) 383 suitable for data analysis: Italy: 75 The Netherlands: 187 USA: 121	Author-developed survey	(% Italy, Netherlands, USA respectively) Non-procedural diagnostic tools used by PCPs: Bowel diary (80%, 63%, and 53%, $P < .05$ ) PCP treatment strategies provided: <ul style="list-style-type: none"> <li>• Dietary advice (95%)</li> <li>• Education, always (88%)</li> <li>• Increase physical activity, always (58%)</li> <li>• Scheduled toilet training, always (28%); sometimes (54%)</li> </ul> Conclusion: Misconceptions relating to causes and management of childhood constipation are common among PCPs. Significant practice differences exist between countries. National public campaigns and educational programs by benefit patients and healthcare costs
Yang and Punati and Punati <sup>41</sup> USA Primary Health Care: GPs and in-training Pediatricians	Quantitative Survey Aim: Evaluate diagnostic and therapeutic approaches of GPs and in-training Pediatricians toward FC and how closely these approaches adhere to the guidelines	(8223 questionnaires sent electronically: 453 GPs 7770 in-training Pediatricians) 1202 responses, of which 967 were complete: 196 GPs 771 in-training Pediatricians	Author-developed questionnaire	Diagnostic: 84.3% unfamiliar or slightly familiar with guidelines No fecal incontinence Initial therapeutic approach: <ul style="list-style-type: none"> <li>• increasing fluids (92.1%)</li> <li>• increasing fiber (89.5%)</li> <li>• prune/fruit juice (77.7%)</li> <li>• behavioral interventions (71.2%)</li> <li>• regular follow-up (53.4%)</li> <li>• reducing constipating foods (50.1%)</li> </ul> Conclusion: Increasing awareness of guidelines will likely help knowledge deficits, in particular the role of medication Rome diagnostic criteria was used by 110 GPs (40%, n=278): Rome II (30, 11%) Rome III (80, 29%) Therapeutic approach to FC Non-pharmacological: <ul style="list-style-type: none"> <li>• dietary intervention (98%)</li> <li>• increasing fiber and water intake (83%)</li> <li>• reducing milk consumption (3%)</li> <li>• behavioral advice (e.g. toilet training) (6%)</li> </ul> Conclusion: Rome III is not sufficiently widespread among GPs, and a persistent gap exists between guidelines/recommendations and daily practice
Scarpato et al. <sup>42</sup> Europe GPs	Quantitative Prospective multicentre survey Aim: Investigate diagnostic and therapeutic approaches of GPs to children with symptoms suggestive of FGIDs. (Includes children aged 4-18 years presenting with FC)	1107 GPs within 9 countries: Croatia (25), Greece (61), Israel (50), Italy (245), Lebanon (20), Montenegro (24), Serbia (50), Slovenia (100), Spain (532) Response rate 25% (n=278): Croatia (20, 80%), Greece (32, 52.5%), Israel (20, 40%), Italy (64, 26%), Lebanon (5, 25%), Montenegro (25, 62.5%), Serbia (32, 64%), Slovenia (10, 10%), Spain (80, 15%)	Author-developed questionnaires	



**Table 1. (continued)**

Author, country, context	Design, method, research aim	Participants	Data collection tools	Key findings/Conclusions
Barnes et al. <sup>43</sup> USA Includes PCPs defined as: Pediatricians and FPs Alongside Gastroenterologists, and Gastroenterology NPs/ PAs	Quantitative Survey Aim: Investigate practice patterns related to diagnosis and treatment of FC and identify opportunities for CME	(3042 surveys sent electronically): 1185 Pediatricians 1857 Family Physicians 206 PCPs responded 197 Gastroenterologists 116 NPs/PAs	Author-developed patient case-vignette survey Case 1: 3years old Case 2: 6years old <sup>b</sup> Case 3: 16years old	(Gastroenterologists and NPs/PAs respectively %) PCP use of guidelines to aid diagnosis of FC <ul style="list-style-type: none"> <li>• for all patients 0% (12% and 9%)</li> <li>• for most 8% (48% and 59%)</li> <li>• for half 9% (18% and 13%)</li> <li>• for few 6% (15% and 10%)</li> <li>• for none 1% (8% and 9%)</li> <li>• Never heard of guidelines 76% (0% and 0%)</li> </ul> Case 1: PCP treatment (p values given for non-amalgamated groups): Non-pharmacological <ul style="list-style-type: none"> <li>• lifestyle change 94%</li> <li>• (88% and 93%) (P= .057)</li> <li>• fiber supplement 55%</li> <li>• (44% and 34%) (P= .001)</li> <li>• delay toilet training 27%</li> <li>• (39% and 39%) (P= .015)</li> <li>• probiotic 24%</li> <li>• (18% and 27%) (P= .129)</li> <li>• specialist referral 3%</li> <li>• (6% and 5%) (P= .551)</li> <li>• other 1% (2% and 5%) (P= .067)</li> </ul> Case 3: PCP treatment (p values given for non-amalgamated groups): Non-pharmacological <ul style="list-style-type: none"> <li>• lifestyle change 66%</li> <li>• (59% and 62%) (P= .443)</li> <li>• toilet regimen 33%</li> <li>• (50% and 49%) (P= .001)</li> <li>• fiber supplement 41%</li> <li>• (35% and 26%) (P= .021)</li> <li>• probiotic 23%</li> <li>• (14% and 22%) (P= .071)</li> <li>• Specialist referral</li> </ul> Psychologist 56% (72% and 72%) (P= .002) GI motility 11% (28% and 28%) (P< .001) Colonoscopy 6% (5% and 17%) (P< .001) Surgeon 1% (2% and 3%) (P= .522) <ul style="list-style-type: none"> <li>• other 3%</li> <li>• (4% and 8%) (P= .180)</li> </ul> Conclusion: While Gastroenterologists and NPs/PAs have similar practice patterns, unfamiliarity with guidelines may mean PCPs may not always appropriately manage FC. CME may benefit all 3 groups of health professionals

(continued)

**Table 1. (continued)**

Author, country, context	Design, method, research aim	Participants	Data collection tools	Key findings/Conclusions
Faramarzian et al. <sup>44</sup> Iran Imam Reza Clinic Nurses Doctors	Quantitative Pseudo-experimental clinical trial study Aim: Determine impact of nurse-centered strategies on children's chronic functional constipation in relation to improvement Experimental group: In addition to usual treatment, a comprehensive nurse-centered program comprised 3 training sessions (n = 47) Control group: usual treatment given by doctor (n = 48) A notebook (recording daily bowel actions and symptoms), was renewed and reviewed monthly for a period of 3 months	(120 children enrolled, 25 children excluded) 95 children aged 3-14 years	Author-developed Data Gathering Form Notebook	Experimental group: • 3 pamphlets contained training points: - introduction to constipation - nutrition - behavior Control group: • Diet • Brief necessary training No significant improvement at 1 month: 70.2% Experimental group 70.8% Control group (P = .947) No significant improvement at 2 months: 83.0% Experimental group 68.8% Control group (P = .106) No significant improvement at 3 months: 83.0% Experimental group 72.9% Control group (P = .237) Conclusion: Although no significant improvement between the experimental and control, the increasing trend in improvement for the experimental group could be expected to become significant Routine follow-up may result in more children being in remission post treatment
Widodo et al. <sup>45</sup> Indonesia Primary Health Care: GPs in 20 different cities	Quantitative Survey Aim: Assess knowledge of GPs about diagnosis and treatment of childhood constipation in children over 6 months old	(103 GPs enrolled, 3 GPs excluded) 100 GPs	Author-developed questionnaire	In relation to treatments/interventions prescribed/recommended: Non-pharmacologic: • 96% high-fiber diet • 90% increased fluid intake • 74% toilet training (only 15% explained fully and correctly) • 46% abdominal massage Conclusion: Although GPs aware of some important aspects of constipation diagnosis and management, overall knowledge is limited. Confirms difficulties in spreading existing information from guidelines to GPs

(continued)

**Table 1. (continued)**

Author, country, context	Design, method, research aim	Participants	Data collection tools	Key findings/Conclusions
Hinds et al, <sup>16</sup> Australia Primary Health Care: Retail Pharmacists	Quantitative Survey Aim: Determine nature and extent of interactions with families of infants concerned about FGIDs including constipation in relation to: Frequency of interactions with parents who have not seen a GP Recommendations and/or advice given Where retail Pharmacists obtained their information What further information around guidelines/ recommendations would retail Pharmacists value Demographic information	362 retail Pharmacists: NSW (34%) Victoria (28%) Queensland (17%) WA (9%) SA (8%) Tasmania (2%) NT (1%) ACT (1%)	Author-developed questionnaire	In relation to constipation Aim 1: 85% of retail Pharmacists have constipation-related conversations with parents who have not seen a GP at least once a week Aim 2: <ul style="list-style-type: none"> <li>• Increase water consumption (60%)</li> <li>• Physical soothing (48%)</li> <li>• Changing infant formula (42%)</li> <li>• Specific infant formula (28%)</li> <li>• Increase fiber intake (30%)</li> <li>• GP for evaluation and advice (37%)</li> </ul> Aim 3: <ul style="list-style-type: none"> <li>• Based on knowledge, training and experience (84%)</li> <li>• Clinical guidelines (52%)</li> <li>• Colleagues, other medical professionals (40%)</li> <li>• Parents asked for a related product (36%)</li> <li>• Product manufacturer guidelines (25%)</li> </ul> Aim 4: Needs consideration and construction Conclusion: Indicates need for greater emphasis be given to reassurance in education of health care professionals involved in management of FGIDs Consider/construct easily-accessible, evidence-based guidelines as per those that exist for GPs

Abbreviations: ACT, Australian capital territory; CME, continuing medical education; ESPGHAN, European Society for Pediatric Gastroenterology Hepatology, and Nutrition; FPs, family physicians; FC, functional constipation; FGIDs, functional gastrointestinal disorders; GPs, general pediatricians; HVs, health visitors; NSW, New South Wales; NASPGHAN, North American Society for pediatric gastroenterology, hepatology, and nutrition; NT, Northern Territory; NPs/PAs, nurse practitioners/physician assistants; PGC, Pediatric gastroenterology clinic; PCPs, primary care physicians; SA, South Australia; WA, Western Australia.

<sup>a</sup>As constipation therapy was stated as being mandatory, FC was not covered in the discussion in favor of the most demanding sub-group. Therefore, an email was sent to the author (Giuseppe Magazzù, MD) who confirmed FPs provided the following health education/interventions in all cases.

<sup>b</sup>Case 2 not covered in key findings as, exhibiting clinical signs (ie, sacral dimple), excludes this from Scoping Review Protocol.

## Q2. What Range of Non-pharmacological ICC Health Education is Provided?

Collectively, the 4 evidence-based guidelines cited in the studies recommend 16 aspects of non-pharmacological ICC health education, which are matched with that provided across the 12 studies as shown in Table 2. In order of frequency, these aspects relate to fluids (83%, n=10), fiber (67%, n=8), general dietary advice (58%, n=7), demystification/education/explanation (50%, n=6), bowel diary (25%, n=3), regular/scheduled toileting (25%, n=3), toilet training guidance (25%, n=3), physical activity (17%, n=2), tailored follow-up (17%, n=2), point of contact for ongoing support (17%, n=2), action of laxatives (8%, n=1), written/website information (8%, n=1), and rewards systems (8%, n=1). Table 2 also shows that 3 guideline-recommended aspects of ICC health education that is, the use of the Bristol Stool Scale, recognizing withholding behaviors, and excluding cows' milk only on specialist recommendation, appear not to have been provided in any of the 12 studies.

In addition, inconsistencies exist between the guideline-recommended range of ICC health education and that provided across the 12 studies (Table 2) including:

- Studies that do cite guidelines either do not provide all the aspects of ICC health education recommended, or do not conform to the aspect requirement. For example, 6 studies advised families to increase fluids, fiber and/or physical activity (marked with an asterisk) when the guidelines recommend adequate or normal levels only.<sup>35,40-43,45</sup>
- Studies that cite one guideline use aspects recommended by another.<sup>35,41-44</sup>
- Studies that cite no guidelines use aspects that are recommended in guidelines.<sup>16,36-39</sup>
- Some studies provided ICC health education that is not supported by the guidelines.<sup>38,39,41,43,44</sup>
- Some studies provided ICC health education that is not supported by the evidence-base.<sup>16,36-39,41-43,45</sup>

## Q3. Who Provides the Non-Pharmacological ICC Health Education?

Non-pharmacological ICC health education is solely provided by medical PCPs in 8 studies<sup>35-38,40-42,45</sup> – although the role of the nurse is validated in one study.<sup>36</sup> The role of the nurse as providers of ICC health education is the sole focus of one study,<sup>39</sup> and 2 further studies consider the role of nurses alongside medical PCPs.<sup>43,44</sup> One study considers the role of retail Pharmacists in providing ICC health education.<sup>16</sup>

## Q4. Are Any Gaps Identified in the ICC Health Education?

Gaps clearly exist between the ICC health education recommended by the 4 evidence-based guidelines cited and that provided within the 12 studies (Table 2). Specifically, these may be attributable to: (a) unfamiliarity with the guidelines,<sup>16,40-43,45</sup> (b) a need for increasing PCP ICC education,<sup>37,40,43</sup> (c) grossly underestimating, undertreating, and poorly managing ICC,<sup>36,38-40</sup> (d) providing misinformation<sup>36,37</sup>, and (e) not meeting the needs of families.<sup>37</sup>

## Discussion

This scoping review aimed to identify what non-pharmacological ICC health education is provided to families within primary health care. As this subject has not previously been comprehensively reviewed, undertaking a scoping review was particularly suitable. It analyzed 12 studies based on 4 questions.

The first “*are the evidence-based guidelines utilized and to what extent?*” may be answered by Table 2 where 42% of the studies neither cites nor utilizes guidelines. Furthermore, inconsistencies exist in the extent to which they are utilized. For example, studies that do cite guidelines either do not necessarily follow all the recommendations of the guideline or, in the instances where they do, not always as the guideline recommends; studies that cite one guideline, actually use strategies recommended by another; and studies that cite no guidelines use strategies that are recommended in guidelines. This may be due to PCPs being unaware of the guidelines<sup>41,43</sup> from their not being sufficiently publicized.<sup>42</sup> The issue of how to encourage PCPs to use guidelines in daily practice however is unclear,<sup>42</sup> particularly as some PCPs either do not agree with the content of the guidelines due to missing information,<sup>45</sup> do not find the guidelines user-friendly,<sup>48</sup> or have other issues with the guidelines that impede their use.<sup>43</sup> Furthermore, despite up-to-date guideline versions being available online,<sup>28</sup> 2 studies call for the development of guidelines.<sup>16,39</sup>

PCPs being unaware of, or not utilizing the guidelines (and/or lacking ICC knowledge, covered below) may result in children with ICC not being appropriately treated and managed,<sup>42,43</sup> which may consequentially increase the adverse impact of ICC with regard to: (a) children undergoing unnecessary diagnostic testing<sup>49</sup>, (b) the psychological, psychosocial and psycho-emotional health of the child and family,<sup>50-53</sup> (c) increasing the risk of chronicity in society due to the lack of early and aggressive treatment,<sup>11,38,45</sup> and (d) the cost to health services.<sup>54-60</sup>

When considering the second question “*what range of non-pharmacological ICC health education is provided?*”

**Table 2. Guideline-Recommended ICC Health Education Versus That provided within the 12 Studies.**

ICC health education recommended in cited evidence-based guidelines	ICC health education provided and guidelines cited											
	Qualitative						Quantitative					
	Farrell et al, <sup>36</sup>	Thompson et al, <sup>37</sup>	Borowitz et al, <sup>38</sup>	Smith and Derrett <sup>39</sup>	Primavera et al, <sup>35a</sup>	Burgers et al, <sup>40b,c</sup>	Yang and Punati <sup>41b</sup>	Scarpato et al, <sup>42a,d</sup>	Barnes et al, <sup>43b,d</sup>	Faramarzian et al, <sup>44d</sup>	Widodo et al, <sup>45b</sup>	Hinds et al, <sup>16</sup>
<b>Included in guidelines</b>												
Dietary advice <sup>c</sup>	✓	✓	✓	✓	✓	✓		✓*	✓	✓	✓*	✓*
Adequate/normal fluids <sup>a,b,c,d</sup>	✓*	✓*	✓*	✓	✓*	✓	✓*	✓*	✓*		✓*	✓*
Adequate/normal fiber <sup>a,b,c,d</sup>	✓*	✓*	✓*	✓	✓	✓*	✓*	✓*	✓*		✓*	✓*
Normal amount of physical activity <sup>b,c</sup>		✓		✓	✓	✓*			✓			
Demystification, education, explanation <sup>b,c,d</sup>	✓			✓	✓	✓				✓		
Education regarding actions of laxatives <sup>c</sup>				✓								
Provide written/website information <sup>c</sup>									✓	✓		
Bowel diary <sup>c,d</sup>			✓			✓				✓		
Use of Bristol Stool Scale <sup>c</sup>			✓							✓		
Regular/scheduled toileting <sup>c,d</sup>			✓			✓			✓			
Toilet training guidance <sup>a,b,c</sup>								✓	✓		✓	
Rewards systems <sup>c,d</sup>			✓			✓						
Recognizing withholding behaviors <sup>d</sup>												
Tailored follow-up <sup>c</sup>							✓					
Point of contact for ongoing support (PCP, CHN, SHN) <sup>c</sup>				✓								
Exclude cows' milk only on specialist recommendation <sup>f</sup>												
<b>Not supported by guidelines</b>												
Prebiotics <sup>b,d</sup>												
Probiotics <sup>b,d</sup>									✓			
Alternative treatments <sup>d</sup>				✓								
Routine referral for multidisciplinary treatment <sup>b,c</sup>			✓	✓			✓		✓	✓		
<b>Not supported by evidence-base</b>												
Child will grow out of ICC	✓	✓										
Omit dairy, cheese, bread, increase fruit/vegetables		✓						✓				
Breast feeding, breast milk substitute, bottle feeding advice				✓								✓
Reducing constipating foods (including milk/milk products)			✓				✓	✓	✓			
Abdominal massage/soothing											✓	✓

Abbreviations: ESPGHAN/NASPGHAN, European Society for Pediatric Gastroenterology, Hepatology, and Nutrition/North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition; NICE, National Institute for Health and Care Excellence.

<sup>a</sup>Rome II

<sup>b</sup>ESPGHAN/NASPGHAN

<sup>c</sup>NICE.

<sup>d</sup>Rome III

Table 2 shows the comprehensive range of non-pharmacological ICC health education recommended by the evidence-based guidelines. If these were all routinely followed by every PCP, it would ensure equitable, consistent, and age-appropriate non-pharmacological ICC health education regardless of where in the world the family lived. Table 2 also suggests the majority of ICC health education provided is either missing or provided incorrectly.<sup>37</sup> As this occurs regardless of whether PCPs cited the guidelines or not, there may be a need to increase PCP ICC knowledge,<sup>35,40,41,43</sup> especially as ICC knowledge in younger PCPs was found to be weak, with only 15% (n=100) of GPs being able to explain toilet training accurately and in full.<sup>45</sup>

Two options for increasing PCP ICC knowledge are to incorporate it within doctor (or nurse) training,<sup>61</sup> or to include it in Continuing Professional Development (CPD). CPD is a legal requirement for all PCPs as per their respective Codes of Professional Conduct (for example, in Australia these include the Medical Board of Australia,<sup>62</sup> the Nursing and Midwifery Board of Australia,<sup>63</sup> and the Pharmacy Board of Australia.<sup>64</sup> Opportunities for online ICC-specific CPD exist through: educational hyperlinks, completing questionnaires, or writing practice profiles<sup>65,66</sup>; from resources to aid PCPs and families such as the NASPGHAN Constipation Care Package<sup>67</sup>; or through accessing educational games.<sup>68</sup>

Furthermore, while none of the studies specifically mention a lack of time as being a reason for not providing ICC health education, in reality the increasing demands on PCPs' time may prevent them from keeping abreast with new research and CPD topics,<sup>69-71</sup> particularly in practice-specific areas such as ICC. It is feasible that incorporating all the aspects of ICC health education recommended by the evidence-based guidelines (Table 2) may inevitably take longer than the 5- to 20-min PCP consultation time.<sup>72</sup> Notwithstanding, this time-laden and indispensable process of involving both the child and parent in all aspects of the education and collaborative decision-making process, and providing culturally and literacy-appropriate verbal and written explanations and rationales for the treatment regimen<sup>27</sup> is essential. The provision of such ICC health education not only meets the basic human rights of both the parent<sup>18</sup> and child,<sup>19</sup> but is wanted by the parent for both themselves and their child.<sup>56</sup> This would also develop the child's health literacy,<sup>22</sup> which is particularly important as it is they who have to take the medication, sit on the potty or toilet (if toilet-trained), and defaecate. Indeed, anything less may result in ICC health education being misunderstood or forgotten, which would be a gross waste of valuable resources.<sup>73</sup> In addition, as neither the child nor the parents are obliged to utilize the ICC health education<sup>73</sup> if it does not align with how the family actually lives with ICC on a day-to-day basis,<sup>74</sup> it is crucial that all ICC health education is tailored to the existing knowledge and needs of the child and family.<sup>27,56</sup>

When addressing the third question "*who provides the non-pharmacological ICC health education?*" PCPs are identified as medical, nursing, and retail pharmacists. While ICC health education is provided by medical PCPs in the majority of studies, the voice of the parents heard in 2 studies<sup>36,37</sup> imply that doctors are busy with matters more important than ICC. While it is unclear whether this was real or assumed, these 2 studies give the impression that the consultations were swift and superficial and left parents with a sense of being "dismissed and 'fobbed off'"<sup>36</sup> and "not taken seriously."<sup>37</sup> While these swift, superficial consultations may arise from aspects covered previously, some PCPs may also just consider the issue of ICC to be of no great importance (believing that the child will grow out of it). It is surprising to note that the overriding theme of not being listened to has seemingly remained unchanged during the 18-year span of these 2 studies.

Interestingly, Table 2 shows that the ICC health education provided by nursing PCPs<sup>39,43,44</sup> was comparable to, or better than that provided by medical PCPs. Specifically, these studies validated the role of the nurse through: (a) their approachability and understanding<sup>36</sup>; (b) their ability to renew parents' confidence and sense of being able to cope<sup>37</sup>; (c) being best-placed to educate and support families<sup>36</sup>; (d) their providing treatment in accordance with guidelines<sup>43</sup>; and (e) through recognizing that nurse-led ICC health education should become an integral part of ICC management.<sup>44</sup> Uniquely, one study showed that apart from parents self-referring, nurses experienced full bi-directional collaboration with other PCPs, which helped to keep the families within primary health care.<sup>39</sup> Two studies also identified the need for nurse-led ICC clinics.<sup>36,39</sup> Audits of nurse-led ICC clinics have shown their success in improving parental satisfaction and their efficacy in providing collaborative, holistic, and evidence-based ICC health education to both the child and family,<sup>14,75-79</sup> and to PCPs.<sup>80</sup>

Retail Pharmacists are licensed and trusted PCPs with extensive training and knowledge<sup>81</sup> that makes them competent to provide collaborative and evidence-based ICC health education to the child and family. Situated within local shopping areas with no appointment necessary, retail Pharmacists are also easily accessible to parents.<sup>82</sup> While one study<sup>16</sup> found that 85% of retail Pharmacists had at least one constipation-related conversation per week, it can be deduced from the results that these parent-Pharmacist conversations also occur from 2 to 3 times per week to more than 2 per day, thus making them a valuable member of the PCP team.

For the fourth question "*are any gaps identified in the ICC health education?*" it is acknowledged that every study may have provided more ICC health education than was detailed. However, Table 2 suggests that many gaps and inconsistencies in ICC health education exist when guideline-recommended ICC health education is matched across



the 12 studies. In addition, the number of ICC health education aspects provided does not appear to depend on whether PCPs cited the evidence-based guidelines or not and, while this would suggest that awareness of the guidelines has little bearing on health education provision, 3 studies indicate that being aware of the guidelines would help bridge the knowledge gap.<sup>41-43</sup>

## Conclusion

This scoping review shows that, apart from a lack of awareness of the guidelines, a lack of PCP ICC knowledge—and possibly a lack of time—may also be responsible for the patchy and inconsistent non-pharmacological ICC health education identified. The inappropriate treatment and management of some children, escalates the many adverse impacts of ICC and the risk of chronicity. Improving ICC health education provision that covers all of the guideline-recommended aspects may be achieved through: PCP ICC-specific online CPD; increased collaboration between PCPs; better-utilizing nurses (perhaps within nurse-led ICC clinics); and through developing the health literacy of the child by involving both the child and family in all aspects of the education and collaborative decision-making process.

## Limitations

This scoping review has revealed that despite the development of guidelines, the prevalence of ICC is increasing, and that this is likely due to the gaps and inconsistencies in ICC health education provided by PCPs. However, it was often difficult to extract the subject of non-pharmacological ICC health education from abstracts alone, which may have resulted in a number of studies being omitted. The same could be said for only including those studies that were written in English and published from the year 2000.

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DH made substantial contribution to conceptualization, design, data acquisition, analysis and interpretation, and drafting and revising manuscript. DH and DI reviewed abstracts, and all authors reviewed and approved studies for inclusion. DA, DI and EM revised the manuscript for important intellectual content. All authors approved manuscript for publication. DH agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.


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## Supplemental Material

Supplemental material for this article is available online.

## Data Sharing Statement

All data presented in this scoping review was obtained from available published articles.

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