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Blended diets for gastrostomy fed children and young people: A scoping review

Abstract

Objective: The objective of the review was to identify what is known about the use of blended diets with gastrostomy fed children and young people¹ and to identify gaps in the literature on this topic in order to inform future research and policy.

Method: A scoping review methodology was used; searching online databases PUBMED, PsychINFO, CINAHL, SCOPUS and AMED, EMBASE for articles that addressed issues pertaining to blended diets. The review identified a broad range of literature regardless of study design and described and evaluated the quality, range and nature of research activity related to the use of blenderised diets.

Results: Forty-three studies were included in the review. The studies focused on nutrition, equipment, views of carers and patients and views of professionals. Several studies described the lack of evidence regarding pros and cons of blended diets and highlighted the need for further research into the field.

Conclusions: There were gaps in the evidence base regarding the impact of blended diets on health and well-being of the children who are given them and upon the carers who feed them. The nutritional impact of blended diets is not fully understood, and the knowledge and views of professionals involved in the care of those receiving blended diets varies.

Key Words: Blended diet, blenderized diet, blenderised diet, pureed diet, homemade diet, gastrostomy, scoping review.

1. Introduction

Children, who are unable to swallow safely, have gastric problems or neurological difficulties may be unable to gain sufficient calories and nutrients by oral intake alone and may require tube feeding via a gastrostomy. Between 2005 and 2010 there was an estimated 41.5% increase (11,800 to 17,000)

¹ Children and young people refer to those up to 25 years of age with special educational needs or a disability in accordance with Part 3 of the Children and Family Act 2014. Within the review the word children will be used for simplicity but encompasses young people too.

31 in children who required tube feeding within the UK. The majority of these children required naso-
32 gastric tubes, and approximately 33% required gastrostomy tubes⁽¹⁾.

33 Tube feeding is not a new concept. Accounts exist dating back 3500 years of people who could not
34 eat orally being fed through tubes via the mouth, nose or rectum into the stomach⁽²⁾. However, in the
35 mid 19th century a surgical technique known as a gastrostomy was developed that enabled feeding
36 tubes to be sited directly into the stomach. Consequently tube feeding became a more medically
37 managed means of feeding, which in turn led to the development of nutritional and calorific controlled
38 formula feeds in the late 1970s. Commercial manufacturers continue to develop formulas to the extent
39 that in 2001 Sullivan et al wrote " *commercial feeds have virtually eliminated blenderized feedings in*
40 *the developed nations of North America and Europe*" ⁽³⁾(p271).

41 However, some patient groups and clinicians, have begun to question the practice of using formula
42 feeds in terms of impact on the patient's digestive system, their health and well-being, and from a
43 psychosocial perspective.^[4,5,6,7]

44 There is a growing interest in blended diets with 27 of the 43 studies, reviewed having been published
45 between 2013-2016. There is no definitive definition of a blended diet; for some it may be deemed
46 as only blending family foods and giving no commercial formula, whilst others may combine the use
47 of blended family foods and commercial formula. This scoping review takes a broader remit than
48 other reviews,^(8,9,7,10) examining blended diets in relation to the mechanics of blended diet; equipment,
49 contamination and nutrition, and describing patient, carer and clinician perspectives.

50

51 1.1 Scoping Reviews

52 Scoping reviews may consist of a brief listing of articles on the topic in question or a more
53 comprehensive breakdown of articles in which information/data from the articles are charted and
54 collated into a report⁽¹¹⁾. Although the methodology of scoping reviews is imprecisely defined, they
55 are particularly suited to summarising and disseminating researching findings and identifying gaps in
56 literature in areas which are complex or poorly defined.⁽¹¹⁾

57 Whereas systematic reviews clearly seek to address a well-defined question, taking into account the
58 type of study designs that may be appropriate to the question, and assessing the quality of the studies,
59 scoping reviews tend to have a broadly defined topic area and include studies with a wide range of
60 designs. The quality of the studies is not generally considered. However, a review of scoping reviews
61 proposed recommendations to enhance consistency of methodology and provide some form of quality
62 assessment of articles included in the review.⁽¹²⁾ The study cited an example of researchers who
63 reported that the results of their scoping review could not be used to inform policy, as the quality of
64 the studies included had not been assessed. An objective of this review is to inform future research

65 and policy around blended diet. Therefore this review will be comprehensive in that it will identify
66 a broad range of literature, exploring the extent, range and nature of research activity related to the
67 use of blended diets regardless of study design,
68 and will provide an overview of the research, summarising the findings, assessing the quality of the
69 studies and identifying gaps in the evidence base. Thus providing direction for researchers,
70 policymakers and practitioners in the field of blended diets.

71 The research question for the scoping review is “What is known from the existing literature about the
72 use of blended diets by parents to feed their gastrostomy-fed children and young people”?

73

74 **2. Method**

75 *2.1 Search Strategy and data synthesis*

76 The author performed the search using Pubmed, PsycINFO, Scopus, Embase, AMED and CINAHL.
77 All articles published in peer-reviewed journals up until October 2016 were considered for inclusion
78 in the study. As one of the objectives of the review was to inform policy, grey literature (such as
79 unvalidated posts on the internet) was not included.

80 The keywords and Medical Subject Headings (MeSH) used were: “blended diet OR blenderized diet
81 OR liquidised diet OR homemade diet OR pureed diet” AND “gastrostomy”. Initially a search on
82 child* OR infant OR paediatric OR pediatric was added to the first search but it narrowed the field to
83 the extent that no matches were found so it was removed. However, the studies included are relevant
84 to the paediatric population. Details of the search strategy can be found in Appendix 1.

85 In addition to the database search, to gain a comprehensive picture of the literature, a search of
86 specific journals in the field of gastrostomy feeding, nutrition and paediatrics was undertaken.

87 *2.2 Definition and inclusion/exclusion criteria*

88 The review included studies that evaluated any aspect of blended diets with gastrostomy feeding in
89 children. It should be acknowledged that only 17 of the studies focussed specifically on children
90 However, the finding of all the studies included (such as those investigating nutritional content or
91 contamination issues) were applicable to children. The search identified studies that reported on
92 pureed and blended diets that were fed orally as opposed to via a gastrostomy; these were not included
93 in the study. Discussion/ reviews, educational studies, poster presentations and new research articles
94 from peer-reviewed journals were included.

95

96

97 *2.3 Quality Assessment*

98 Although scoping reviews do not necessarily consider the quality of the articles included, due to the
99 concerns expressed by researchers ⁽¹¹⁾ a quality rating was used in this scoping review.

100 A range of tools was considered including the Consolidated criteria for reporting qualitative research
101 (COREQ), the PRISMA, the CASP Qualitative research checklist. However, the methodological
102 checklist published in the UK by the National Institute for Clinical Excellence (NICE) guidelines
103 manual ⁽¹³⁾ was selected as a basis for assessing the quality of the studies. Although intended for use
104 with qualitative studies, 8 of the 14 criteria were applicable to qualitative and quantitative research
105 and review studies.

106 The following eight quality criteria were selected. One point was awarded for each criterion,
107 providing a total quality score in the final column of Table 1.

108

- 109 1. Is the approach appropriate for the stated purpose of the paper?
- 110 2. Is the study clear in what it seeks to do?
- 111 3. Is the method of data collection appropriate and clearly described?
- 112 4. Are the methods reliable; could the study be replicated?
- 113 5. Is the data analysis sufficiently rigorous for the purpose of the paper?
- 114 6. Are the findings convincing, clearly presented, referenced and discussed?
- 115 7. Are the findings relevant to the aims of the study?
- 116 8. Are the conclusions adequate?

117

118 In order to enhance the level of rigour of the ratings, a second researcher also rated the quality of 11
119 of the 43 studies. Both ratings were then compared. There was a high level of agreement in 91% of
120 studies, defined as being rated the same level or one point different. The second researcher also
121 categorised each paper by type of study and methodology, and there was 100% agreement. Nineteen
122 of the studies were categorised as discussion/review studies, four as education (i.e. providing
123 systematic instruction) and 20 as new research.

124 *2.4 Analysis methodology*

125 Content analysis described as a means of making inferences by objectively and systematically
126 identifying specified characteristics ⁽¹⁴⁾, was used to provide an overview of the articles. In this study
127 specified characteristics are themes, both deductive and inductive in nature. Deductive in that the
128 authors are aware of key issues regarding blended diet and can specify themes that are likely to be
129 present, and inductive in that other more latent themes may be discovered within a document. Listed
130 below are deductive themes that formed the basis of the framework onto which the articles were
131 charted.

- Nutrition
- Contamination
- Equipment
- Medical/well-being
- Patient experience
- Carer experience
- Clinician experience

3. Results

3.1 Search results and analysis of themes

Table 2 provides a summary of the aims and findings of each of the studies, and the sections below illustrate the results of the content analysis.

For each of the studies included in the scoping review, data relating to year, country and areas of focus have been summarised in Table 3. Four of the studies were published before 2000, but the majority (27) were published after 2013, 27 of the studies were from the USA, 37 had an area of focus on nutrition and contamination, 16 on equipment, 13 on clinicians' experience, 24 on patient/carers experience and 17 on medical/well-being.

3.2 Nutritional value

Several studies ^(15,16,17,18,19,20,21,22,23,24) investigated the nutritional content both of commercial feeds and blended diet. A cross-sectional study of 64 children who were enterally fed with commercial formulas reported that 94% were deficient in at least one micronutrient ⁽²⁵⁾. Conversely other researchers reported on a case of a child receiving a blended diet who went on to be diagnosed with scurvy due to a lack of vitamin C ⁽²⁶⁾. Both studies concluded that close monitoring of a diet's nutritional content was important whether it was a formula or blended diet. An investigation of the fibre content of commercial enteral feeds highlighted concerns about mineral retention in fibre used in formula and other effects of formula fibre including bloating, gas and cramps ⁽²⁷⁾. More recently researchers suggested that a blended diet may improve stooling patterns by incorporating complex whole food nutrients and varying types and quantities of fibres and fats ⁽²⁸⁾. A study investigating properties of commercial formulas found that they did not have the necessary bacteria found in a normal diet that help maintain normal gut function, and that antioxidants and bioflavonoids required for long term prevention of disease were also absent ⁽²⁹⁾.

165 3.3 Contamination concerns

166 Several studies in the review focused upon issues concerning contamination of blended diet. ^(3,30,31).
167 The studies were carried out in hospital settings. One such study in the Philippines analysed 96
168 samples of blended diets from four hospitals and found 100% had unacceptably high levels of
169 bacterial contamination, compared to 33% of commercial formula (reconstituted powder form). They
170 concluded that commercial feeds from prefilled or closed systems are safest in terms of microbial
171 contamination ⁽³⁾. Another also concluded that closed system (i.e. ready prepared formula) were
172 safest in terms of levels of contamination, whilst acknowledging that there was “ample opportunity”
173 for commercial products to become contaminated in a hospital environment ⁽³¹⁾.
174

175 3.4 Equipment

176 The effect of blended diet on feeding equipment (tubes, connectors, pumps) was examined.
177 ^(32,34,9,29,35,36,37). One reported that the viscosity of blended diet might render it unsuitable for infusion
178 through feeding tubes ⁽³²⁾. As a result of 33 patient incidents involving oral medicines being
179 incorrectly delivered intravenously the EnFit[®] system was introduced. This system improved patient
180 safety by ensuring that an enteral plastics device will only connect to another enteral device and
181 cannot be connected to an intravenous device ⁽³³⁾. However, the EnFit[®] design may negatively impact
182 patients, as the force required to dispense a blended diet is higher than the previously used syringes
183 ⁽³⁰⁾. Studies report that there is an increased risk of feeding tubes becoming blocked by blended diet,
184 and that the bore of the feeding tube should be no less than French -14 (a measure of the internal
185 diameter of the tube). However, one study found that none of the five different handmade formulas
186 tested in their study blocked tubes of 10-French ⁽¹⁹⁾. None of the studies in this review presented
187 evidence that blended diet caused more blockages than formula feeds. Indeed an increased
188 occurrence of tube occlusion was reported when patients changed from blended diet to commercial
189 feeds which they surmised was ‘probably due’ to the lack of experience of families in using
190 reconstituted powder commercial feeds ⁽³⁸⁾. A discussion report suggested that care for the
191 gastrostomy site is the same whether using blended diet or formula but suggest that the extension
192 tubing may need to be changed more frequently although no studies have been carried out to prove
193 or disprove this ⁽³⁹⁾.
194

195 3.5 Medical/well-being

196 There have been no clinical trials to determine the impact of blended diet on specific parameters such
197 as height or weight, but studies have considered broader aspects of well-being such as a reduction in
198 retching ⁽⁶⁾. In a discussion report it was suggested that complications and risks might occur as a result

199 of discovering previously unknown food allergies, gastrointestinal challenges or of parent error in
200 food preparation, such as insufficient calories or fluids ⁽³⁹⁾.
201 Numerous studies describe benefits of blended diet including increased tolerance of feeds, reduction
202 of constipation, and retching and decreased oral feeding aversion. ^(5,40,41,6,28,42,43). One such study
203 suggested that the viscosity of blended diet may reduce the rate of gastric emptying and that
204 gastrointestinal motility may be positively influenced by blended diet ⁽⁶⁾. A single case study
205 described the case of a 5-year old boy who had a gastrostomy and fundoplication at 8-months due to
206 failure to thrive. The boy did not tolerate formula feeds and instances of vomiting, retching and
207 constipation gradually increased accompanied by poor growth. On the advice of a friend the boy's
208 mother tried putting small amounts of puree and fruit juices down his tube, and he then exhibited no
209 signs of gastrointestinal discomfort and his growth improved ⁽⁵⁾.

210

211 *3.6 Views of patients, carers and clinicians*

212 *3.61 Patient experience*

213 Studies in the scoping review discuss the clinical impact and well-being of patients using blended
214 diet, ^(41,6) such as the intimacy of the feeding act between a child and parent, and the importance of
215 providing a tube-fed child with the same meal as others in the family ⁽³⁹⁾. They also explain how
216 using blended food can enable children who are able to have some oral intake to receive the same
217 food by mouth as by the gastrostomy. The Graz clinic in Austria also recommends that parents use
218 blended tube feeds when under-going tube weaning ⁽⁴⁵⁾. A negative effect of the new EnFit[®] tubing
219 on patients' well-being was that they make it more difficult for patients to vent their gastrostomy (i.e.
220 to stop uncomfortable build up of gas) ⁽³⁴⁾. A study of 33 children who had a gastrostomy with
221 fundoplication described improvements following the introduction of blended diet. More than half
222 of the children experienced a significant reduction (76-100%) in gagging and retching ⁽⁶⁾. A study
223 of 10 children with intestinal failure was carried out to investigate the effect of using blended diet.
224 They found that 90% of the nine children who successfully transitioned to blended diet showed an
225 improvement in diarrhoea and inconsistent stooling, and prescribed supplementary fibres were able
226 to be discontinued in 100% of the children who transitioned to blended diet ⁽²⁸⁾.

227

228 *3.62 Carer experience*

229 Carers' views focused on the need for information/knowledge, the psychosocial impact and more
230 overt practical implications.

231 One study describes how the use of a blended diet can enable parents to take a more involved role in
232 providing food for their child ⁽⁴¹⁾. The need to ensure parental education, and a parental desire for

233 more information regarding preparation and nutritional content on blended diet, and the cost
234 implications in terms of time and equipment is also highlighted ^(39,41).
235 The psychosocial importance of blended diet was illustrated by a study that described how a UK
236 hospice enabled children to have a blended diet based upon its policy of respecting parental wishes
237 and replicating home conditions as far as possible⁽⁴²⁾. As blended diet can be prepared by using family
238 foods, it can lead to the restoration of the psychosocial aspects of feeding, enabling the tube fed
239 patient to be included in family meals ⁽¹⁹⁾. Conversely, another study reported that parental
240 satisfaction with blended diet was ‘exceptionally high’, primarily due to the decrease in retching and
241 gagging. Although not mentioned by parents, the authors acknowledged that the use of blended diet
242 may add time pressures in terms of preparation. ⁽⁶⁾ A study in which self-reported parental satisfaction
243 with blended diet was ‘excellent’, illustrated their findings with examples of parents spending less
244 time on changing and washing as their child’s stooling improved which in turn enabled them to work
245 on toilet training that improved their self-esteem ⁽²⁸⁾.

246

247 *3.63 Clinicians’ experience*

248 The review revealed a diversity of experience and opinion regarding blended diet, with a lack of
249 overall consensus. Perceptions and reality did not always match. One study reported that in practice
250 dietitians found there were fewer problems than they had predicted when families used blended diet.
251 It was also found that despite concerns regarding tube blockage and infection more than 50% of
252 dietitians who responded would recommend blended diet to supplement commercial formula ⁽⁴⁶⁾. A
253 survey carried out to assess attitudes and experiences of registered dietitians regarding blended
254 diet⁽⁴⁷⁾ revealed that 70.2% indicated that parental request was the main reason for using blended diet,
255 and 22.9% cited tube-feeding intolerance as the main reason. Positive outcomes were reported by
256 76.9% of respondents including less feeding intolerance, improved growth and oral intake. The study
257 also examined differences in relation to the experience of the dietitians. More experienced dietitians
258 were less likely to be familiar with blended diet and wanted no more information about it, whereas
259 less experienced dietitians tended to be more familiar with it and wanted more information.
260 Anecdotally one dietitian with many years experience reported that tube-feeding intolerance was
261 unheard of in her practice prior to the introduction of commercial formulas.
262 Another dietitian in the same study reported that in her experience families who undertook to use
263 blended diet on their own had poor outcomes. This opinion is further supported in a study that
264 reported on a case of a child developing scurvy as a result of being fed a nutritionally inadequate
265 blended diet ⁽²⁶⁾. A discussion report summarised the issues facing clinicians, acknowledging that
266 there are many websites and social media devoted to the promotion of blended diet, and clinicians

267 working with tube fed children are likely to be asked about the use of blended diet. The study
268 recommends that clinicians increase their knowledge of and familiarity with blended diet so that they
269 feel more comfortable when discussing its use with patients⁽⁴⁸⁾.

270

271 3.7 Other Themes

272 The themes in the previous section related to the safety of blended diet, in terms of contamination,
273 equipment and nutrition, and to the opinions of practitioners, carers and patients. This section
274 highlights more latent overarching themes.

275 3.7.1 Uncertainty

276 This was found to permeate several of the studies, and perhaps reflects the lack of evidence. For
277 example uncertainty about the potential impact of allergies,⁽³⁹⁾ the effect of using pumps for blended
278 diets, and using blended diets for jejunostomy fed patients⁽⁴⁸⁾. Further uncertainty comes from the
279 fact that commercial formulas are exempt from labelling and health claim regulations in the US, and
280 can be used in patient care without undergoing efficacy trials⁽²⁰⁾

281 3.7.2 Choice and Compromise

282 In order to enable viable patient choice there is inevitably a need to compromise;
283 “*The best candidate would be a family who has considered the pros and cons of a blenderized diet*”
284 (p22).⁽³⁹⁾ The same study mentions that parents may be forced to compromise, and use a combination
285 of blended diet and formula if schools will not allow staff to feed a child using a blended diet in
286 school.

287 3.7.3 Edification

288 This theme relates to both carers and clinicians. Clinicians need to consider the carer’s preferences
289 and level of health literacy⁽⁴⁹⁾ and to increase their knowledge and understanding of blended diet.⁽³⁴⁾
290 A clinical decision-making tree was created to aid practitioners in their clinical practice⁽⁴⁰⁾. Carers
291 must also be aware of the potential risks relating to inadequate nutrient intake⁽²⁶⁾. This lack of
292 knowledge or awareness highlights the need for further research into blended diet.

293

294 4. Discussion

295 Researchers and practitioners alike acknowledge the paucity of research related to blended diets.⁽³⁶⁾
296 As far back as 1985 it was stated “*there is no documented advantage of blenderised ‘normal food’*
297 *over formulas compounded from individual nutrients*” (p64)⁽¹⁷⁾. Despite dietitians and manufacturers
298 knowing the exact constituents of formula feeds, a question that was not addressed in any of the
299 studies was that of knowing exactly what is absorbed by a patient. There is also debate about whether
300 there are some micronutrients that cannot be provided by commercial feeds⁽²⁵⁾.

301 There still remains a lack of evidence regarding the incidence of tube blockages with blended diet
302 and whether there are groups of patients who have less negative symptoms such as gagging and
303 retching when using blended diet. Other research questions concern whether blended diet can lead
304 to a reduction in medications required for constipation⁽⁴⁰⁾, and whether there is an improvement in
305 health status when a child is fed a blended diet ⁽⁴¹⁾.

306 The need for increased knowledge about blended diets was a recurring theme, with studies
307 highlighting the importance of clinicians considering the carer's/family's food preferences and health
308 literacy when contemplating the introduction of a blended diet ^(49,50,52), and recommending that
309 clinicians increase their knowledge of issues relating to blended diets in order to be able to provide
310 appropriate care.⁽⁵¹⁾.

311 The quality ratings (Table 1) showed that on average new research studies had the highest quality
312 score. This may assist policy makers when considering the type of evidence that may best inform
313 their decisions.

314 Further empirical research regarding the overall impact of blended diets will increase the evidence
315 base. This increased knowledge may provide clinicians and families alike with the resources upon
316 which to discuss the potential use of blended diets with individuals and thus to make informed
317 choices. We have reported that 37 of the 43 studies in the review examined issues related to
318 contamination and nutrition, whereas only 17 considered those related to the medical/well-being of
319 patients. This, and the acknowledgement that many families are turning to social media for support
320 and information, ⁽⁴⁾ may imply that there is a mismatch between the priorities of patients /carers and
321 those of clinicians/researchers. The importance of involving patients in their care is reiterated by both
322 research evidence and Government policy ⁽⁵³⁾; researchers should consider greater patient
323 participation and focus when developing research questions.

324

325 *4.1 Limitations of the review*

326 Scoping reviews are a relatively new way of synthesizing research evidence. There is still
327 considerable debate about the methodology, particularly with regards to quality assessment of the
328 evidence. The authors noted in excess of ten articles in non peer-reviewed publications regarding the
329 use of blended diets but these were not included. There are also active online groups that generate
330 regular debate regarding the use of blended diets both in the USA and in the UK, with membership
331 of over 2200 and 1600 respectively.

332 It is also acknowledged that reviews can only consider the evidence at a single point in time, and that
333 new studies may have been missed by setting end date parameters. Similarly, studies may have been
334 missed through selecting certain databases for the search.

335

336 5. Conclusion

337 This scoping review provides an overview of the literature regarding the use of blended diet. Data
338 from studies were charted and emerging themes were described. By providing a degree of quality
339 evaluation of the studies and synthesis of the findings it is anticipated that the review will be of use
340 to policymakers, and to those carrying out or commissioning research.

341 Regardless of the views of clinicians, it is evident that some families are using blended diets. Overall,
342 the paper revealed a picture of divergent opinions, a patient/carer led move towards the use of blended
343 diets and a lack of evidence to refute or substantiate opinions and anecdotal evidence as to the impact
344 of blended diet on the nutritional, clinical and psychosocial well being of patients and their families.

345 Transparency Declaration.

346 *Anne Breaks, the lead author affirms that this manuscript is an honest, accurate, and transparent*
347 *account of the study being reported. The reporting of this work is compliant with PRISMA*
348 *guidelines. The lead author affirms that no important aspects of the study have been omitted and*
349 *that any discrepancies from the study as planned have been explained.*

350

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