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 people[1] 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

[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.

17,000) in children who required tube feeding within the UK. The majority of these children required naso-gastric tubes, and approximately 33% required gastrostomy tubes[1].

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

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

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

1.1 Scoping Reviews

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

Whereas systematic reviews clearly seek to address a well-defined question, taking into account the type of study designs that may be appropriate to the question, and assessing the quality of the studies, scoping reviews tend to have a broadly defined topic area and include studies with a wide range of designs. The quality of the studies is not generally considered. However, a review of scoping reviews proposed recommendations to enhance consistency of methodology and provide some form of quality assessment of articles included in the review.[12] The study cited an example of researchers who reported that the results of their scoping review could not be used to inform

policy, as the quality of the studies included had not been assessed. An objective of this review is to inform future research and policy around blended diet. Therefore this review will be comprehensive in that it will identify a broad range of literature, exploring the extent, range and nature of research activity related to the use of blended diets regardless of study design, and will provide an overview of the research, summarising the findings, assessing the quality of the studies and identifying gaps in the evidence base. Thus providing direction for researchers, policymakers and practitioners in the field of blended diets.

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

2. Method

2.1 Search Strategy and data synthesis

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

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

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

2.2 Definition and inclusion/exclusion criteria

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

2.3 Quality Assessment

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

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

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

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

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

2.4 Analysis methodology

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

3.3 Contamination concerns

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

3.4 Equipment

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

3.5 Medical/well-being

There have been no clinical trials to determine the impact of blended diet on specific parameters such as height or weight, but studies have considered broader aspects of well-being such as a

reduction in retching [6]. In a discussion report it was suggested that complications and risks might occur as a result of discovering previously unknown food allergies, gastrointestinal challenges or of parent error in food preparation, such as insufficient calories or fluids [39].

Numerous studies describe benefits of blended diet including increased tolerance of feeds, reduction of constipation, and retching and decreased oral feeding aversion. [5,40,41,6,28,42,43]. One such study suggested that the viscosity of blended diet may reduce the rate of gastric emptying and that gastrointestinal motility may be positively influenced by blended diet [6]. A single case study described the case of a 5-year old boy who had a gastrostomy and fundoplication at 8-months due to failure to thrive. The boy did not tolerate formula feeds and instances of vomiting, retching and constipation gradually increased accompanied by poor growth. On the advice of a friend the boy's mother tried putting small amounts of puree and fruit juices down his tube, and he then exhibited no signs of gastrointestinal discomfort and his growth improved [5].

3.6 Views of patients, carers and clinicians

3.61 Patient experience

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

3.62 Carer experience

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

One study describes how the use of a blended diet can enable parents to take a more involved role in providing food for their child[41]. The need to ensure parental education, and a parental desire for more information regarding preparation and nutritional content on blended diet, and the cost implications in terms of time and equipment is also highlighted [39,41].

The psychosocial importance of blended diet was illustrated by a study that described how a UK hospice enabled children to have a blended diet based upon its policy of respecting parental wishes and replicating home conditions as far as possible[42]. As blended diet can be prepared by using family foods, it can lead to the restoration of the psychosocial aspects of feeding, enabling the tube fed patient to be included in family meals [19]. Conversely, another study reported that parental satisfaction with blended diet was 'exceptionally high', primarily due to the decrease in retching and gagging. Although not mentioned by parents, the authors acknowledged that the use of blended diet may add time pressures in terms of preparation. [6] A study in which self-reported parental satisfaction with blended diet was 'excellent', illustrated their findings with examples of parents spending less time on changing and washing as their child's stooling improved which in turn enabled them to work on toilet training that improved their self-esteem [28].

3.63 Clinicians' experience

The review revealed a diversity of experience and opinion regarding blended diet, with a lack of overall consensus. Perceptions and reality did not always match. One study reported that in practice dietitians found there were fewer problems than they had predicted when families used blended diet. It was also found that despite concerns regarding tube blockage and infection more than 50% of dietitians who responded would recommend blended diet to supplement commercial formula [46].

A survey carried out to assess attitudes and experiences of registered dietitians regarding blended diet[47]revealed that 70.2% indicated that parental request was the main reason for using blended diet, and 22.9% cited tube-feeding intolerance as the main reason. Positive outcomes were reported by 76.9% of respondents including less feeding intolerance, improved growth and oral intake. The study also examined differences in relation to the experience of the dietitians. More experienced dietitians were less likely to be familiar with blended diet and wanted no more information about it, whereas less experienced dietitians tended to be more familiar with it and wanted more information. Anecdotally one dietitian with many years experience reported that tube-feeding intolerance was unheard of in her practice prior to the introduction of commercial formulas.

Another dietitian in the same study reported that in her experience families who undertook to use blended diet on their own had poor outcomes. This opinion is further supported in a study that reported on a case of a child developing scurvy as a result of being fed a nutritionally inadequate

blended diet [26]. A discussion report summarised the issues facing clinicians, acknowledging that there are many websites and social media devoted to the promotion of blended diet, and clinicians working with tube fed children are likely to be asked about the use of blended diet. The study recommends that clinicians increase their knowledge of and familiarity with blended diet so that they feel more comfortable when discussing its use with patients[48].

3.7 Other Themes

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

3.7.1 Uncertainty

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

3.7.2 Choice and Compromise

In order to enable viable patient choice there is inevitably a need to compromise;

"The best candidate would be a family who has considered the pros and cons of a blenderized diet" (p22).[39] The same study mentions that parents may be forced to compromise, and use a combination of blended diet and formula if schools will not allow staff to feed a child using a blended diet in school.

3.7.3 Edification

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

4. Discussion

Researchers and practitioners alike acknowledge the paucity of research related to blended diets.[36] As far back as 1985 it was stated *"there is no documented advantage of blenderised 'normal food' over formulas compounded from individual nutrients" (p64)* [17]. Despite dietitians and manufacturers knowing the exact constituents of formula feeds, a question that was not addressed in

any of the studies was that of knowing exactly what is absorbed by a patient. There is also debate about whether there are some micronutrients that cannot be provided by commercial feeds [25].

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

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

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

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

4.1 Limitations of the review

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

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

5. Conclusion

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

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

Transparency Declaration.

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

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