'It’s Just Food Blended': Exploring Parents’ Experiences of Choosing Blended Diet for their Tube-fed Child

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The use of blended diet is contentious among professionals in the UK.

A recent rapid review identified three distinct viewpoints:

1. It is unsafe and substandard
2. There are particular benefits, for e.g. management of reflux
3. Those that see value but are cautious do to a lack of evidence
Quasi-Systematic Review

The voice of the parent was largely missing!

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Aim and Objectives

Aim:
This research aimed to generate rich data and a deep understanding about individual parents’ experiences of choosing blended diet to feed their long-term tube-fed child.

Objectives:

- To explore the reasons why parents first consider an alternative to commercial formula.
- To understand the benefits of blended diet as perceived by parents who use it to feed their tube-fed child.
- To explore how individual parents have been supported by professional in their choice to use blended diet.
- To identify challenges experienced by parents following their choice to use blended diet.
Methodology

Interpretive Phenomenological Analysis

- Phenomenology- generation of meaning by attempting to understand experience
- Hermeneutics- Theory of interpretation
- Idiographic Approach- Looks at the particular before moving to the general

Smith, Flowers and Larkin 2009
Research Design

- Purposeful Sampling Strategy
- Blended Diet UK Facebook group
- 15 Parents of a tube-fed child or young person between the ages of 1 to 25 years.
- Using blended diet for at least 12 months
- Living in the UK
- Good Grasp of English
- Face to Face, in-depth qualitative, audio recorded interviews
Discussion of Key Findings
1) To explore the reasons why parents first consider an alternative to commercial formula.

- Parents primary motivation was the Health and Wellbeing of their child
- Unacceptability of other treatment options
- Parental assessment of wider risk posed to the child
We were coming to that place, the option of last resort. We had tried everything and she’s not getting better. Now what I have to consider as a parent is; not just the nutrition of my daughter but the health and safety of her because whilst she was on these [commercial] formulas she would vomit, and she would aspirate on that vomit. Nathan
2) To understand the benefits of blended diet as perceived by parents who use it to feed their tube-fed child.

- Rapid improvement of previously debilitating symptoms
- Reduction in medications
- Improved growth
- Perception of improved appearance and health
- Happier child
Once I’d started I actually felt that I’d been let down by the professionals; not telling us about it [blended diet]... I just think what might she have been like? If she’d been on proper food at that point would she have been in hospital all that many times and could I have kept a job down instead of packing in work to care for her? Emily
- Inclusion in social aspects of food
  - Family meal times
  - Special Occasions
  - Inclusion of wider family members
- A plethora of smaller choices
  - Personalisation
  - Variety
- ‘Real Food’ rather than medicine
  - ‘I can be his Mum rather than his nurse’

When this idea, the blended diet came of real food it somehow changed things and made things… actually this is more how life should be, it brought some normality to a household so entrenched with medical stuff.

Fiona
3) To explore how individual parents have been supported by professionals in their choice to use blended diet.

- Inconsistent
  - No one profession seemed more or less supportive
  - Different experiences with members of the same profession
  - Changing attitudes toward blended diet

- Continued focus on risk is perceived to be unhelpful

- Parents want advice on food from their dietitian
My friend, I remember her telling me how great her dietitian was. She’s been given really good nutritional advice about foods to try and why and they’ve gone through all the benefits of this food versus that. Whereas I have to go online, I have to read something and decide whether that is right or wrong. I would like to have someone who can cut through all of that for me and give me some advice about food. My poor dietitian is just so worried that she is not giving me any advice really so I’ve had to go and make guesses myself. Marie
4) To identify challenges experienced by parents following their choice to use blended diet.

- Getting Started
- Additional time and work
- Investment

My head was full of numbers and calculations and when I made it the whole kitchen was a mess it was like the Swedish chef had been at work it was everywhere and that was a challenge and I think it’s important for people to know it doesn’t stay like that you get your routine, you get your rhythm. **Olivia**
• Defending their choice
  • Respite
  • School
  • Hospital

• Peer Support

I’ve tried to level with them as an equal, as a healthcare professional as well. I’m a sensible Mum, I’m not some quack but I think sometimes I’m viewed as this spear heading, single woman campaign, a lentil feeding, sandal wearing type crusader which I’m not I just want to feed him normal food. Laura
Strengths and Limitations

**Strengths**

- Valuable insight and understanding of parents experiences which has been missing from the literature to date.
- Rigorous Methodology
- Array of experiences
- Diversity of opinion
- Wealth of experience

**Limitations**

- A biased group
- Exclusion of non English speakers and those with communication difficulties
- Excluded parents using blended diet for <1 year
Implications for Practice

General HEF

- Consider the language used
- Allow parents flexibility

The Decision to Try Blended Diet

- When should we discuss Blended Diet with Parents?
- Holistic assessment of Risk
- Potential to alleviate feelings of isolation and exclusion

Supporting Parents who have chosen Blended Diet

- Good communication with the MDT
- Continued focus on risk is unhelpful
- Advise on food
- More support initially
- Support needed depends on how they blend
Recommendations for Future Research

- Are perceived risks of blended diet occurring in reality?
- What are the views of tube-fed individuals?
- What are the implications of batch blending and home dehydrators?
- Why does blended diet improve symptoms in some and in how many?
- Longitudinal research looking at use of commercial formula
- Health economics analysis is needed
References

Brown, S. (2014) 'Blended Food for Enteral Feeding Via a Gastrostomy'. Nursing Children and Young People 26 (9), 16-20

Armstrong, J., Buchanan, E., Duncan, H., Ross, K., and Gerasimidis, K. (2017) 'Dietitians’ Perceptions and Experience of Blenderised Feeds for Paediatric Tube-Feeding'. Archives of Disease in Childhood 102 (2), 152-156


Suggestions for Future Research

 Are the perceived risks associated with blended diet occurring in reality?
 Why are symptoms improved and in how many children?
 Longitudinal research is needed which looks at the effects of exclusive feeding using commercial formula.
 Future research into blended diet should include outcomes which are indicative of the child's generally health and wellbeing.

Thank you,
Any Questions?