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ORIGINAL ARTICLE

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Estimated energy and nutrient intake for infants following baby-led and traditional weaning approaches

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Abstract

Background: Baby-led weaning (BLW), where infants self-feed without the use of spoon-feeding by a caregiver, continues to be a popular approach for starting solids. However, concerns remain amongst health professionals that infants using this method may not consume sufficient energy or nutrients from solid foods. Little research has examined how different weaning approaches shape dietary intake. The present study aimed to use a 3-day weighed diet diary to measure estimated energy and nutrient intake in infants aged 6–12 months.

Methods: Diet diaries were completed by 71 parents and analysed to compare estimated infant intake from milk and solid foods for those either following a BLW or traditional spoon-feeding approach (TW). Intake was analysed for each weaning group in two age groups: 26–39 and 40–52 weeks, to account for different eating patterns at the start and end of the weaning process.

Results: For the younger infants, significant differences in estimated energy intake were found, with TW infants consuming 285 kcal from solid foods compared with 120 kcal for BLW infants. Conversely, BLW infants consumed more calories and nutrients from breast or formula milk, consistent with a slower transition to solid foods. No differences were found in estimated intake amongst older infants, suggesting that BLW infants had 'caught up' with their spoon-fed peers.

Conclusions: Overall, few infants regardless of weaning group met recommended intake guidelines for energy (either over or under consuming) with many deficient in iron and zinc intake. The findings are important for those supporting parents through the transition to solid foods.

KEYWORDS

baby-led weaning, complementary feeding, energy intake, infant feeding, nutrient intake, weighed diet diary

Key points

- At 6–9 months, infants following a baby-led weaning (BLW) consumed less energy from solid foods compared to traditionally weaned (TW) infants with over three-quarters of TW infants consuming more than World Health Organisation (WHO) guidelines.
- Infants following a BLW approach had a more gradual transition to solid foods than those following a TW approach more closely supporting WHO guidelines. However, some parents may need further support with respect to offering more solid food exposures. No differences were found in energy, macro- or micronutrient intake for infants aged 10–12 months for infants following BLW or TW approaches, suggesting a convergence of intake towards later infancy.
- Many infants, regardless of weaning approach, did not meet the recommended guidelines for iron or zinc intake, suggesting that there is a need to focus on promoting the intake of these micronutrients.

INTRODUCTION

Baby-led weaning (BLW), where infants self-feed solid foods rather than being traditionally weaned (TW) using spoon-fed purees, remains popular in the UK. Parents are often drawn to BLW because they consider that it will promote healthier eating behaviour and weight,[1] but some health professionals are concerned that it may promote undernutrition.[2,3] Although research exploring the impact of BLW is building particularly around eating behaviour and weight,[4] evidence is often based on parental report, with a clear gap in our understanding of its impact upon infant dietary intake, particularly in the UK.

In New Zealand, the Baby-Led Introduction to SolidS (BLISS) randomised controlled trial of a 'baby-led' vs. TW approach upon child weight and intake, as assessed using a weighed 3-day food diary, utilised a modified form of BLW and offered a wider variety of high energy and iron rich foods.[5] Baby-led infants consumed less saturated fat at 12 months, but no difference was found by 24 months.[6] Meanwhile, for micronutrient intake, there was no significant difference in zinc or intake at 7 and 12 months.[7] Overall, although energy intake was similar, baby-led infants consumed more sodium, but less iron, zinc, calcium, vitamin C, vitamin B_{12} and fibre, than TW infants.[8] Another trial in Turkey compared iron intakes and serum levels from 280 infants following BLW or spoon-feeding. No differences were found between weaning groups at 12 months for serum iron markers or iron consumption; however, iron intake in both groups was lower than the Turkish recommended daily allowance for infants aged 12 months.[9]

In the UK, three studies have explored nutrient intake between BLW and spoon-fed infants using a 24-h dietary recall. One study found no significant difference in energy, carbohydrates, protein saturated fat or zinc intake,[10] but found the spoon-fed group consumed more free sugars at 6–8 months of age, whereas the BLW group consumed more fat and sodium. Neither group met the reference nutrient intake (RNI) for iron but the BLW consumed significantly less than the spoon-fed group. Another study found several significant differences between weaning groups,[11] with strict BLW infants being more likely to consume vegetables and protein foods than TW infants at 6–8 months, less likely to have dairy at 9–10 months, and less likely to have savoury snacks, dairy and composite meals at 11–12 months. There was no difference between weaning groups in consumption of iron-containing foods.

In the third recent study, infant intake was estimated using a multiple-pass researcher led 24-h recall.[12] In this type of study, participants are asked to recall the diet for the day before details of individual foods/drinks, portion sizes and recipes are collected. This method collects a greater detail and depth of intake, allowing energy and micronutrients to be estimated more accurately. Overall, 96 mother–infant dyads completed the 24-h recall (60 TW and 36 BLW). Although no difference in energy intake was found between the weaning groups, BLW infants consumed more energy from milk and TW infants more energy from solid foods at 6–8 months. At 6–8 months, TW infants consumed higher levels of iron, zinc, iodine, vitamin B_{12} and vitamin D than BLW infants, although 44% of TW and 63% of BLW consumed below the lower reference nutrient intake for iron. However, most differences disappeared by 9–12 months, when most infants had transitioned to self-feeding and eating a family diet. There were few differences in food exposure between the groups, although TW infants consumed higher levels of commercial products.

However, there are limitations to 24-h recall, such as participant error, failure to remember quantities of food correctly or desire to alter reported food intake. Given the sparsity of research in this area, coupled with concerns regarding nutrient intake expressed by health professionals,[2,3] the present study aimed to conduct a detailed examination of estimated infant nutrient intake, comparing those following a BLW or TW introduction to solid foods, using a 3-day weighed diet diary. Specifically, the aim was to compare whether overall estimated energy, macronutrients and micronutrients differed between the two weaning approaches at the start (26–39 weeks) and end (40–52 weeks) of the weaning process.

METHODS

Participants

Parents with an infant aged 6–12 months were eligible to complete the study. All respondents were female, aged ≥18 years, living in the UK, and had started the weaning process. Exclusion criteria included infant prematurity (gestation < 37 weeks), low birth weight (<2.5 kg) and multiple food allergies, failure to thrive or other complex health issues that might affect diet.

Approval for this study was granted by Swansea University College of Human and Health Research Ethics Committee. All mothers gave informed consent prior to inclusion in the study.

Measures

Alongside a 3-day weighed food diary for their infant, respondents completed a questionnaire, including demographic background (age, sex, education and employment status), infant characteristics (sex, age in weeks and parent-reported weight) and the method of introducing solid foods.

They were also asked how they identified with the following statement in terms of how closely they were

following a baby-led method of introducing solid foods: strictly, loosely, not at all:

> *BLW is the process of placing foods in front of your baby and letting them feed themselves – picking the food up themselves and putting it in their mouths unassisted, rather than being spoon-fed by a parent. This could involve them using a spoon themselves. BLW tends to involve offering the baby family foods rather than offering pureed foods.*

This self-identification was then verified by asking two follow up questions on how frequently they used spoon-feeding with their infant or used purees. Each scale had a seven-point response option from 100% spoon feeding/puree use to 100% self-feeding/whole foods.

Respondents were asked to complete a weighed 3-day food diary. Weighed food records involve recording the weight of each item before eating, then weighing leftovers to provide an accurate picture of what is ingested rather than offered. From this record, an assessment of the caloric and nutrient content of the diet is made. Weighed food records are considered an accurate measure of estimated energy intake and more reliable than food frequency questionnaires and 24-h recall.[13] They have been validated as being comparable to physiological measures of energy intake, such as the doubly labelled water method,[14] and have been used in a number of studies examining estimated nutrient intake in infants[15,16] including the BLISS study.[17] However, they do have limitations, including a degree of under-reporting, which we consider in the discussion.

Parents were asked to weigh and note all of the foods they gave their baby over three selected days, which did not have to be consecutive. Parents were asked not to complete diaries when their child was at day care as a result of the practical limitations for childcare workers completing the diary, introduction of another participant into the study and the risk of inaccuracies between different individuals completing the diaries.

To complete the weighed food diary, parents were provided with portable but accurate scales (Salter Arc 1066l accurate to 1 g), which have been used in similar research.[11] To record each entry, parents were given detailed instructions about how to weigh each food offered and how to record brand, type, preparation and consistency: pureed, mashed, chopped or whole (Figure 1). Parents were asked to weigh leftovers, whether dropped on the floor or in a bowl or bib, although the complexity of this and its impact on intake accuracy is recognised. Breastfeeding mothers were asked to estimate the number and duration of feeds, whereas those formula feeding were asked to note the amounts offered and remaining in the bottle after each feed.

Procedure

Adverts for the study containing brief information, inclusion criteria and researcher details were shared online in baby and feeding groups on social media and in local baby groups. Potential participants contacted the lead researcher and were given full study information. Those who wished to take part and met inclusion criteria were sent a study pack containing scales, demographic questionnaire, consent form and diet diary. A debrief at the end of the diet diary encouraged participants to seek advice from a healthcare provider if the survey had raised any concerns alongside a reminder of researcher contact details.

Data analysis

The initial data analysis plan included analysing three types of weaning approach (strict BLW, loose BLW and TW), which had been used in previous research[11] for two infant age groups (26–39 and 40–52 weeks). However, as the diaries and forms clarifying feeding style were returned, it was clear that two main weaning groups were emerging: a stricter BLW approach and an approach based on a mixture of self and spoon feeding. Given that the UK Department of Health guidelines now encourage finger foods alongside purees, the decision was made to switch to two main weaning groups for analysis. The final sample size was similar to those used in previous New Zealand studies.[5,8]

Measuring intake

Diet diaries were analysed using Nutritics dietary analysis software (Nutritics Professional Plus, version 5.099; Nutritics), which uses multiple nutrition databases including the UK Composition of Foods Integrated Dataset (COFIDS).[18] Generic food items can be entered individually (e.g., 50 g of banana), although the database contains many branded items with information supplied by the manufacturer. If using homemade meals, parents were asked to supply a recipe, which was manually entered, using standard ingredients listed in the database, such as pasta, tomato sauce and courgette. The weight change factor in Nutritics was applied if appropriate. This function changes the data for foods that have been cooked to take into account any weight changes and nutrient losses during preparation. For example, vitamin and mineral content in particular might reduce during the cooking process.

If not supplied, the researcher used the database's standard meal function, for example, 'homemade tomato and vegetable pasta sauce' or, if a branded product not listed in the database was reported, the researcher manually created a new database entry using the manufacturer's standard nutrition labelling, including calories,

carbohydrates, protein, fats, sugars, fibre, sodium and other nutrients, if stated. Branded infant food data already included in Nutritics were used even if incomplete, rather than being substituted for alternative foods by the researcher to minimise errors in nutrients already assessed by the manufacturer.

The majority of diet diaries contained specific weights for foods offered, but, where parents had used less accurate portion sizes (e.g., a tablespoon), the weights reported in Nutritics for these items were used. Clearly, the nutritional data from these meals is not as accurate as it might have been if the participant had supplied a recipe, but, given the small quantities of foods often eaten by infants and the similarity of many common, family style recipes, this was an acceptable substitute.

Finally, to measure the total amount eaten, leftovers were subtracted from the amount offered. For mixed meals where it was hard to remeasure individual ingredients left by the infant, remainders were recorded in proportion with the amounts offered.

Measuring breastmilk intake

Measuring breastmilk intake is complex. Potential options include weighing before and after feeds or measuring salivary/urine isotopes, which are accurate methods, but impractical for such a study.

A more practical method in similar research has used infant age to estimate intake based on studies that have calculated intake figures from total breast milk consumption measured by test weighing or stable isotopes.[15,19] This approach was used by the BLISS study to estimate breastmilk intake in infants age 7 and 12 months.[17] Using this method, they included quantities of 708 g of milk per day for 26–39 weeks and 547 g for 40–52 weeks.[20] Although, initially, we hoped to calculate breastmilk intake by asking mothers to record frequency and duration of feeds, as a result of limitations of this approach and incomplete maternal data, we chose to adopt the same methodology used in the BLISS study.

Analysing overall intake

A Nutritics report was generated for the average estimated intake over three days for overall energy intake, macronutrients (e.g., carbohydrate, fat) and micronutrients (e.g., iron, zinc). Estimated intakes were compared for the two weaning groups for infants aged 26–39 and 40–52 weeks to represent the earlier and later stages of weaning. Intakes were calculated for solid foods alone and then solid foods plus milk.

Estimated intakes were also examined where possible in relation to dietary reference values from the World Health Organisation (WHO) or UK Scientific Advisory Committee on Nutrition (SACN) infant intake recommendations. However, for infants under aged <2 years, there are no official recommendations for carbohydrates, sugar or fibre (or fats below 5 years of age) because of a lack of data on optimal intakes. The RNI is the average daily intake of a nutrient sufficient to meet the needs of 97.5% of a healthy population. Energy intake was considered in relation to the estimated average requirement (EAR). The EAR for energy or a nutrient is the mean intake that a group of people will need, with half of a defined population usually needing more than the EAR, and half less.

Statistical analysis was performed using SPSS, version 25 (IBM Corp.). Differences in demographic background by weaning group were analysed using *t* tests or the ch-squared test. Only a difference in timing of solid foods was found and therefore used as a covariate throughout analyses. We tested the distribution of estimated nutrient intakes for normality using Kolmogorov–Smirnov tests and found all measures to be skewed. Nutrient data was therefore transformed and the natural logarithms computed used to correct for the skewed distribution. Multivariate analysis of covariance (MANCOVA) was then used to compare estimated energy, macronutrient intake and micronutrient intake between the two weaning groups, with separate analyses for the two age groups. Analyses were conducted considering estimated intake from solid food alone followed by intake combining both solids and milk foods. We used the non-transformed data to present median intake scores for this to be logically comparative with other studies.

RESULTS

Seventy one mothers completed the study, with a mean (SD) age of 32.8 (5.0) years, ranging from 22 to 43 years of age. Infants in the study ranged from 27 to 52 weeks of age, with a mean (SD) age of 40 (7.9) weeks; 35 were female and 36 male. Full demographic information for mothers taking part is shown in Table 1.

Twenty six infants were introduced to solids in a strict BLW manner, whereas 45 followed a TW approach. Thirty five infants were in the 26–39 week group (14 BLW/21 TW) and 36 in the 40–52 week group (12 BLW/24 TW). No significant differences in maternal age, education, marital status or employment were found between weaning groups. For infants, no significant differences in sex or age in weeks were found between weaning groups. However, infants in the BLW group were introduced to solid foods at a mean (SD) age of 25.4 (1.5) weeks compared to 24.3 (2.8) weeks in the TW group ($t_{66.080} = 2.314$, $p = 0.024$).

When considering parent-reported infant weight, there was no significant difference in between weaning groups at either age group. In the 26–39 week age group, the strict BLW group had a mean parent-reported weight of 8.6 kg, whereas the TW group weighed an average of 8.4 kg. In the older group (40–52 weeks), the mean weight of the strict BLW group was 9.6 kg, whereas the TW group mean was

TABLE 1 Maternal demographic information: whole sample

Indicator	Subgroup	Whole sample		Baby-led weaning		Traditional	
		n	%	*n*	%	*n*	%
Maternal age (years)	22–24	3	4.2	2	7.7	1	2.2
	25–29	16	22.5	3	11.5	13	28.9
	30–34	24	33.8	10	38.5	14	31.1
	35–39	22	31.0	8	30.8	14	31.1
	40–43	6	8.5	3	11.5	3	6.7
Education level	GCSE	2	2.8	1	3.8	1	2.2
	A Level	11	15.5	5	19.2	6	13.3
	Degree or equivalent	23	32.4	7	26.9	16	35.6
	Postgraduate or equivalent	35	49.3	13	50.0	22	48.9
Marital status	Married	49	69	17	65.4	32	71.1
	Widowed	–	31	9	34.6	13	28.9
	Divorced	–					
	Separated	–					
	Living with partner	22					
	Single	–					
Employment status	Full time	4	5.6	–	–	4	8.9
	Part time	14	19.8	4	15.4	10	22.2
	Maternity leave (will return)	40	56.3	15	57.7	25	55.6
	Maternity leave (won't return)	7	9.8	2	7.7	5	11.1
	Not working	6	8.5	5	19.2	1	2.2
Infant feeding style	Breastfeeding	49	69.0	23	88.4	26	57.8
	Formula feeding	12	16.9	2	7.8	10	22.2
	Mixed feeding	8	11.3	1	3.8	7	15.6
	Expressed breast milk	1	1.4	0	0.0	1	2.2
	Cow's milk	1	1.4	0	0.0	1	2.2

9.8 kg. None of the infants was underweight according to the WHO centile charts for age/weight.

As shown in Table 1, with regard to milk feeding in the BLW group, 23 mothers were breast feeding, two used formula and one used mixed feeding. In the TW group, 26 were breastfeeding, 10 used formula and seven used mixed methods. After excluding two infants fed using expressed breast milk and cow's milk in the older age group, when comparing milk feeding methods using a chi-squared analysis, there was a significant association between milk feeding style and weaning group ($\chi^2 = 6.205$, $df = 2,69$, $p = 0.045$), with BLW infants more likely to be exclusively breastfed.

Age group 1: 26–39 weeks old

Differences in overall estimated energy intake, macronutrients and micronutrients were analysed using MANCOVA controlling for timing of solid foods. As shown in Table 2, for solid foods alone, infants in the TW group had a median estimated intake 2.2 times that of the BLW group, which was significantly different ($p < 0.001$). This gap reduced but was still significant when milk was taken into account. In both age groups, BLW were more likely to eat under the WHO EAR and TW infants over the WHO EAR.

TABLE 2 Comparison of estimated energy intake between weaning groups from solid foods and milk at 26–39 weeks using multivariate analysis of covariance

		WHO EAR	Median intake (25th, 75th percentile)	% < WHO EAR	% > WHO EAR	Comparison of energy intake between groups
Solid food	BLW ($n = 14$)	820 kJ	506.0 (280.0, 678.0) kJ	13 (92.9%)	1 (7.1%)	$F_{1,32} = 11.102$, $p < 0.001$
		196 kcal	121.0 (69.0, 162.0) kcal			
	TW ($n = 21$)		1117.0 (839.0, 1498.0) kJ	5 (23.8%)	16 (76.2%)	
			267.0 (200.5, 358.0) kcal			
Solid food + milk	BLW ($n = 14$)	2855 kJ	2607.0 (2268.0, 2751.0) kJ	12 (85.7%)	2 (14.3%)	$F_{1,32} = 6.448$, $p = 0.04$
		682 kcal	623.0 (542.0, 657.5) kcal			
	TW ($n = 21$)		3105.0 (2701.0, 3333.0) kJ	6 (28.6%)	15 (71.4%)	
			742.0 (645.5, 796.5) kcal			

Abbreviations: BLW, baby-led weaning; EAR, estimated average requirement; TW, traditional weaning; WHO, World Health Organization.

TABLE 3 Comparison of estimated nutrient intake between groups from solid foods alone and solid foods and milk at 26–39 weeks using multivariate analysis of covariance and transformed data

		Solids foods only			Solids and milk		
		BLW ($n = 14$)	TW ($n = 21$)		BLW ($n = 14$)	TW ($n = 21$)	
	RNI	Median (25th, 75th percentile)		p	Median (25th, 75th percentile)		p
Carbohydrate (g)	No RNI < 2 years	12.6 (7.9, 18.0)	36.3 (28.2, 48.0)	$p < 0.001$	63.5 (54.7, 70.0)	82.0 (77.0, 94.5)	$p < 0.001$
Protein (g)	12.7–13.7[a,b]	4.6 (2.5, 5.9)	9.7 (7.7, 15.6)	$p < 0.001$	13.9 (11.7, 15.9)	18.9 (17.1, 23.8)	$p < 0.001$
Fat (g)	No RNI < 5 years	4.9 (2.6, 6.1)	8.5 (4.8, 11.7)	$p < 0.005$	34.4 (31.0, 35.1)	34.41 (31.9, 37.3)	$p = 0.774$
Saturated fat (g)	No RNI < 5 years	1.6 (0.7, 2.5)	2.9 (1.6, 4.2)	$p = 0.011$	15.5 (14.1, 16.2)	15.1 (14.0, 16.8)	$p = 0.662$
Sugar (g)	No RNI < 2 years	3.4 (1.8, 7.5)	12.8 (7.8, 17.4)	$p < 0.001$	53.0 (50.0, 56.5)	59.0 (53.5, 64.0)	$p = 0.249$
Free sugars	No RNI < 2 years	1.0 (0.4, 2.4)	1.6 (0.5, 3.6)	$p = 0.03$	0.4 (0.1, 1.0)	1.6 (0.5, 3.6)	$p = 0.03$
Fibre (g)	No RNI < 2 years	1.8 (1.1, 2.2)	4.0 (3.4, 6.1)	$p < 0.001$	2.1 (1.2, 2.5)	5.5 (3.6, 6.5)	$p < .001$
Iron (mg)	4.3–7.8[a,b]	0.6 (0.4, 7)	2.0 (0.8, 2.7)	$p = 0.005$	1.1 (0.91, 1.5)	3.0 (1.7, 5.8)	$p = 0.003$
Zinc (mg)	5[b]	0.5 (0.3, 7)	0.81 (0.4, 1.5)	$p = 0.058$	2.6 (2.4, 2.8)	3.2 (2.6, 4.5)	$p = 0.057$
Sodium (mg)	320[b]	112 (65.3, 215.0)	200 (128.0, 312.0)	$p = 0.065$	218 (153.3, 345.3)	306 (236.0, 404.5)	$p = 0.031$
Calcium (mg)	525[b]	42.3 (18.0, 73.7)	135. (55.0, 240.1)	$p = 0.002$	288 (254.5, 324.0)	378 (306.5, 493.5)	$p = 0.023$
Vitamin D (μg)	8.5–10[c,d]	0.1 (0.02, 3)	0.3 (0.1, 9)	$p = 0.041$	0.2 (0.1, 4)	0.99 (0.2, 5.2)	$p = 0.009$
Vitamin C (mg)	25[b]	6.8 (1.9, 14.5)	8.6 (5.1, 21.7)	$p = 0.698$	35.4 (30.3, 45.5)	43.0 (35.8, 65.5)	$p = 0.229$
Vitamin B_{12} (μg)	0.3–0.4[a,b]	0.2 (0.1, 4)	0.34 (0.2, 9)	$p = 0.060$	0.2 (0.1, 4)	0.6 (0.2, 1.3)	$p = 0.616$
Folate (μg)	50[b]	15.8 (5.8, 23.2)	26.0 (11.9, 52.0)	$p = 0.113$	52.5 (40.7, 62.5)	67.0 (50.5, 97.5)	$p = 0.083$

Abbreviations: BLW, baby-led weaning; TW, traditional weaning; RNI, recommended nutrient intake.
[a]Dependent on age.
[b]COMA 1991.
[c]Safe intake.
[d]SACN 2016.

Table 3 shows the mean estimated macro- and micronutrient intake for infants in the two weaning groups. For macronutrient intake for solid foods alone, a number of significant differences were found. TW infants consumed significantly more carbohydrate, fibre and protein than the BLW infants, although most of these differences disappeared once milk was also taken into account.

For micronutrients, iron intake was significantly higher in the TW group both with and without milk intake included. However, neither group met the RNI for iron. Calcium and vitamin D intake from solid foods

and the combined diet was significantly higher in the TW group. The only other difference in nutrient intake was noted for sodium, where intake was slightly higher in the BLW group when milk and solids were combined. Intake for all other nutrients was higher in the TW group. Both groups met the RNI for vitamins C, B_{12} and folate.

Age group 2: 40–52 weeks old

Differences in overall estimated energy intake, macronutrients and micronutrients were analysed using MANCOVA controlling for timing of solid foods. Table 4 shows the WHO EAR for energy intake and the median estimated intake for infants in the two weaning groups for both solid foods and the combined diet. No significant difference was found in estimated intake between groups for either energy from solid foods alone or for solid foods and milk combined. In both calculations, both groups had an estimated median intake under the WHO EAR, although approxinately one-third of infants consumed over the EAR.

Table 5 shows the estimated intake of macro- and micronutrients for the two weaning groups. For both estimated macro- and micronutrient intake, no significant differences were found between groups either for solid foods alone or solid foods plus milk. Neither group met the RNI for iron, zinc, calcium or vitamin D, but both groups met the recommended intake for protein, sodium, vitamin C, B_{12} and folate and the intake of sodium was not at unhealthy levels.

DISCUSSION

Using 3-day weighed diet records, the present study examined differences in the estimated energy and nutrient intake of babies aged 6–12 months dependent on their weaning approach. Overall, the findings showed the TW group consumed significantly more energy, carbohydrates and protein, alongside key micronutrients such as iron, calcium and vitamin D at 26–39 weeks, although there were no significant differences in estimated intake for infants 40–52 weeks of age in the two weaning groups. This suggests that, although differences in estimated energy and nutrient intake might be present at the start of weaning, they disappear as infants become more competent and start eating a larger proportion of solid foods in their diet. Notably, differences were more frequent when considering solid food alone compared to the cumulation of milk and solids together. Taken together, these findings have important considerations for health professionals supporting parents through the transition to solid foods and demonstrate the suitability of BLW as a method of complementary feeding as long as milk intake is maintained.

When looking at energy from complementary foods alone, the 26–39-week TW group was consuming more than twice the calories of the strict BLW group from complementary foods, although a high degree of variability was seen. Most infants that were weaned using a strict BLW approach were eating under the recommended WHO guideline for complementary foods at the start of the weaning process, whereas the majority of TW babies were eating more than recommended. When solid foods and milk were considered together, the difference between the two groups was smaller yet still significant, with TW infants consuming around 10% more calories than BLW infants.

Comparatively, no significant differences were found in estimated energy intake between weaning groups for infants aged 40–52 weeks, either for solid foods alone or milk and solid foods taken together. Median consumption for both groups was under the WHO recommendation of 830 calories from milk and solids for infants of 9–11 months with one-third of babies in each group consuming over the EAR. Likewise, this converging of energy intakes between BLW and TW infants was

TABLE 4 Comparison of estimated energy intake between weaning groups from solid foods and milk at 40−52 weeks using multivariate analysis of covariance and transformed data

		WHO EAR	Median intake (25th, 75th percentile)	% < WHO EAR	% > WHO EAR	Comparison of energy intake between groups
Solid food	BLW ($n = 12$)	1904 kJ	1427.0 (703.0, 1865.0) kJ	9 (75.0%)	3 (25.0%)	$F_{1,31} = 830$, $p = 0.369$
		455 kcal	341.0 (168.0, 445.8) kcal			
	TW ($n = 24$)		1674.0 (1152.0, 2198.0) kJ	16 (66.7)	8 (33.3%)	
			400.0 (275.3, 525.3) kcal			
Solid food + milk	BLW ($n = 12$)	3473 kJ	3117.0 (2298.0, 3646.0) kJ	8 (66.7%)	4 (33.3%)	$F_{1,31} = 0.268$, $p = 0.608$
		830 kcal	745.0 (549.3, 871.5) kcal			
	TW ($n = 24$)		3105.0 (2701.0, 3328.0)	16 (66.7%)	8 (33.3%)	
			742.0 (645.5, 795.5) kcal			

Abbreviations: BLW, baby-led weaning; EAR, estimated average requirement; TW, traditional weaning; WHO, World Health Organization.

TABLE 5 Comparison of estimated nutrient intake between weaning groups from solid foods alone and solid foods and milk at 40–52 week using multivariate analysis of covariance and transformed data

		Solids only			Solids and milk		
		BLW ($n = 12$)	TW ($n = 24$)		BLW ($n = 12$)	TW ($n = 24$)	
	RNI	Median (25th, 75th percentile)		p	Median (25th, 75th percentile)		p
Carbohydrate (g)	No RNI < 2 years	37.6 (21.9, 62.0)	50.5 (33.4, 68.8)	$p = 0.367$	84.0 (59.2, 100.5)	87.0 (71.7, 99.0)	$p = 0.202$
Protein (g)	12.7–13.7[a,b]	14.3 (6.8, 16.6)	16.5 (10.5, 20.8)	$p = 0.351$	21.3 (13.9, 23.4)	22.5 (17.6, 26.9)	$p = 0.437$
Fat (g)	No RNI < 5 years	12.2 (5.8, 18.1)	11.9 (9.6, 16.6)	$p = 0.652$	35.3 (28.2, 41.5)	31.9 (28.8, 38.8)	$p = 0.667$
Saturated fat (g)	No RNI < 5 years	4.55 (2.4, 6.75)	4.8 (2.9, 7.5)	$p = 0.517$	15.01 (12.9, 17.3)	13.6 (12.2, 17.5)	$p = 0.771$
Sugar (g)	No RNI < 2 years	11.8 (7.1, 26.7)	20.3 (15.7, 26.1)	$p = 0.066$	50.5 (44.5, 67.2)	57.5 (48.2, 66.0)	$p = 0.390$
Free sugars	No RNI < 2 years	1.0 (0.5, 2.4)	1.5 (0.5, 2.5)	$p = 0.715$	1.0 (0.5, 2.4)	1.5 (0.5, 2.5)	$p = 0.715$
Fibre (g)	No RNI < 2 years	5.2 (2.1, 7.12)	5.8 (3.8, 7.4)	$p = 0.771$	6.1 (2.1, 8.6)	6.0 (3.6, 7.6)	$p = 0.968$
Iron (mg)	7.8[b]	1.8 (0.8, 2.6)	1.8 (1.1, 3.1)	$p = 0.599$	2.15 (1.2, 3.2)	3.1 (1.4, 4.9)	$p = 0.525$
Zinc (mg)	5[b]	1.6 (0.6, 2.2)	1.5 (0.87, 2.3)	$p = 0.882$	3.2 (2.2, 3.9)	3.3 (2.5, 4.1)	$p = 0.890$
Sodium (mg)	320–350[a,b]	305 (205.5, 343.5)	288 (152.7, 398.5)	$p = 0.605$	396 (287.5, 469.2)	365 (246.3, 483.2)	$p = 0.522$
Calcium (mg)	525[b]	152 (61.7, 219.5)	205 (112.3, 278.7)	$p = 0.108$	332 (247.8, 405.5)	416 (353.8, 487.0)	$p = 0.153$
Vitamin D (μg)	8.5–10[c,d]	0.34 (0.21, 44)	0.47 (0.1, 1.7)	$p = 0.631$	0.4 (0.2, 1.7)	1.3 (0.2, 4.0)	$p = 0.608$
Vitamin C (mg))	25[b]	14.7 (3.1, 32.1)	16.4 (9.3, 29.6)	$p = 0.939$	36.6 (24.7, 69.0)	45.5 (31.1, 58.5)	$p = 0.923$
Vitamin B_{12} (μg)	0.4[b]	0.65 (0.33, 1.1)	0.7 (0.4, 1.1)	$p = 0.883$	0.6 (0.3, 1.3)	0.9 (0.4, 1.2)	$p = 0.933$
Folate (μg)	50[b]	53.5 (19.8, 77.6)	38.2 (21.7, 65.0)	$p = 0.336$	91.0 (47.2, 117.3)	74.5 (51.2, 102.3)	$p = 0.441$

Abbreviations: BLW, baby-led weaning; RNI, recommended nutrient intake; TW, traditional weaning.

[a]Dependent on age.

[b]COMA 1991.

[c]Safe intake.

[d]SACN 2016.

also found in the 24-h recall reported by Pearce and Langley-Evans.[12]

However, it is important to note that all infants were within healthy weight ranges, such that no infants were underweight despite a lower than recommended intake, which suggests that infants have a sufficient intake to meet their energy needs.[21] Given the difficulty in estimating breastmilk (see below), it could well be that breastfed infants are consuming more than estimations used, and BLW were more likely to be breastfed. Likewise, no infant was overweight even when consuming more than recommended. However, weight can take time to incrementally increase and the longer term weight gain trajectories of infants consuming over the EAR would be useful to track. Notably, the BLISS study found that infants at 12 months consumed close to the WHO recommendations for infants aged 9–11months.[22]

Overall, BLW infants may on average be starting their transition to solid foods a little too slowly by WHO standards and the TW group too fast, but estimated intakes converge when infants are 40–52 weeks old. However, given the process of introducing solid foods to infants should be gradual, with an emphasis on continued milk intake, particularly in the early months, the findings highlight how BLW may support a gradual transition to solid foods. A slower transition to solid foods reduces the risk of the overconsumption of energy and macronutrients such as protein, or too fast a reduction in milk, which still provides significant nutrients and, in the case of breastmilk, antibodies and other protective factors.[23] The baby-led nature of feeding, where infants have greater control over intake, is likely responsible for this, alongside potentially a slower pace of meal as a result of self-feeding.[24] This may support infants in eating according to energy need rather than parental perceptions of need. However, parents should be supported practically to ensure that their infants *are* gradually making that transition and are not being offered *too few* solid foods.

There is little existing literature available describing energy intake of infants weaned using BLW for comparison. Neither of two New Zealand studies looking at infant weight[8,25] reported significant differences in energy intake between weaning groups. However, intention-to-treat analyses were used in the BLISS trial, with not all participants adhering to their allocated method, which could have affected intake. Also, potentially, the intake amongst BLW infants in the BLISS study could be affected by the trial protocol with respect to offering higher fat foods every day.

In the most recent UK 24-h recall study,[12] the results echoed our data in that TW infants aged 6–8 months had a higher energy intake from solid foods than BLW infants of the same age. However, in that study, there were no significant differences in overall energy intake (from milk and solid foods) at 6–8 months. Additionally, infants in both weaning groups on average consumed much greater amounts of energy from both milk and solid foods than in our study, notably at rates above the WHO EAR for all weaning groups. Likewise, in the other UK 24-recall study, no difference in energy intake was found between weaning groups at either 6–8 or 9–12 months, although infants consumed a lower amount of energy from solid foods for both age groups than in the multiple pass recall study, again greater than the WHO EAR for all groups. Notably, however, in both these studies and as indicated in our data here, no differences in energy intake were seen at 9–12 months between weaning groups.

Why might infants in these two 24-h recall studies be consuming more calories from solid foods than in the present study? Potentially, differences may arise as a result of the methods used. Weighed food diaries are likely to more accurately capture intake than recalls, which have been shown to overestimate intakes in infants and toddlers compared with weighed records.[26] Indeed, infants in our study were eating a comparably closer amount to infants in the BLISS RCT study which also used a weighed food diary.[27] Directly measuring and weighing foods may also make a difference particularly for infants at this age because the amounts consumed are relatively small to begin with.[13,14]

For macronutrient intake, several differences occurred between the two younger weaning groups although these disappeared towards the end of the weaning process, following the same pattern as in the recent 24-h recall study.[12] These initial differences can partly be explained by disparities in overall intake between the two groups. If the overall food intake is higher, levels of macronutrients in that food will also be higher; thus, the TW group took in over twice the median energy of the BLW group when solid foods alone were examined, with the expectation that they would also have a similarly increased intake of macronutrients.

For both milk and solids together, at 26–39 weeks, the TW group had a median estimated carbohydrate intake 29% higher than the BLW group and a protein intake that was 36% higher. However, similar to the BLISS study,[8,22] the BLW group had a median estimated fat intake almost identical to the TW group, meaning their diet was more fat dense given the lower volume of solid foods consumed. Higher fat intake in BLW infants could be attributed to a higher milk intake because breast and formula milk have relatively high fat contents compared to many weaning foods. This was the case in the recent UK 24-h recall study[12] with a higher milk intake raising fat content consumption in younger BLW infants.

However, it could also be a result of the type of food consumed, particularly in the older age group, where estimated fat intake matched the TW group for solid foods alone. Previous research has shown that TW infants eat more commercially prepared composite infant meals, whereas BLW infants are more likely to eat family foods.[11,28,29] Commercial infant meals tend to be higher in sugars and starchy carbohydrates but lower in fat compared to average family meals.[30] It may also be a consequence of health professional concerns that infants may not eat sufficient energy if parents are using BLW,[2,3] leading parents to potentially offer higher fat foods. Indeed, in the BLISS study, the protocol was designed to meet these concerns, encouraging parents to offer healthy fat-rich foods every day.

However, given that only overall estimated fat intake was significantly different and not saturated fat, as well as the small amounts involved and the importance of fats in growth and development,[31,32] this should not be viewed as a negative finding, especially because the difference disappeared in the older group. Estimated intake of fat was also weighted towards unsaturated fats found in avocado and fish rather than saturated fats found in processed foods. Indeed, the higher estimated protein intake of the TW infants may be more problematic as a result of its association with rapid growth and increased fat deposition.[33] In this instance, although the estimated protein intakes of both groups of older infants were in excess of recommendations, when considered as a percentage of energy intake, neither groups consumed more than 13% of their energy from protein, which is not a risk factor for later obesity according to prior research.[34] This was also seen in the younger age group, where, although estimated intake was above UK government recommendation, the mean estimated intake of protein as a percentage of energy was not concerning.

Turning to micronutrients, estimated iron intake was significantly lower in the BLW group at 26–39 weeks. This could be a result of the increased use of iron-fortified formula or cereals in the TW group, although both groups consumed less than the RNI. However, iron *intake* does not necessarily equate to differences in iron *absorption*. Infant formula is fortified with iron to levels above those seen naturally in breast milk, but it is absorbed at a lower rate,[35] as is the non-haem iron in infant cereal.[36,37] Meanwhile, meat, fish or poultry in a mixed meal increases the absorption of any non-haem iron present,[37,38] whereas phytates (found in whole grains) and calcium inhibit absorption.[36] The lower dietary calcium in the BLW group may thus have had a positive impact on iron absorption.

Research examining iron intake by weaning approach is mixed. Although one New Zealand study found a lower iron intake in BLW infants,[8] the BLISS study did not.[22] However, both studies found that infants were consuming below recommended levels. Conversely, in the Turkish randomised controlled trial, no difference was found at

12 months with respect to iron intake from complementary foods or hematologic markers.[9] However, parents who were randomised to the BLW group received advice on high-iron and energy-dense foods and recipes, highlighting the importance of messaging for parents following the approach. Finally, both UK 24-h recall studies found low levels of iron consumption, with BLW infants consuming lower amounts than TW infants. This was attributed to a lower intake of iron fortified cereal in BLW infants, although it was also noted that lower levels of iron in breastmilk may skew this issue.[10,12] As noted above, amounts may be lower but absorption occurs at a greater level. Further research is needed into iron status of infants rather than considering intake alone.

There are limitations to the present study. The sample used was self-selecting both in terms of participation and weaning approach and, in all likelihood, comprised a highly motivated and well-educated cohort with over 80% of the respondents holding at least a University degree. Further research is needed within a more diverse sample. We also excluded those infants with developmental or health issues, meaning that our findings are not applicable to all and caution should be applied in following a BLW method for those infants who are not thriving or able to self-feed.[39]

Other limitations include possible participant error or inaccuracy with respect to measuring or recording foods, particularly left overs when foods are self-fed. This is a common limitation of any diet diary or food recall study. Although detailed instructions were given, some parents simply stated that their infant had eaten a family meal such as "Spaghetti Bolognese" without giving the exact recipe, such that estimates had to be made using the Nutritics database. We also did not collect or record vitamin supplements because it is difficult to estimate absorption/efficacy rates. There are also limitations to the Nutritics software, which has some missing data on micronutrients for manufactured foods. Together, this means that micronutrient amongst infants may have been underestimated.

Another important limitation is the attempt to accurately measure breastmilk intake. We initially asked mothers to record how many feeds they gave and to estimate duration. However, the returned data was very patchy, especially for night feeds. It also did not take into account variation in energy density of milk between mothers and speed of milk delivery (i.e., milk ejection speed, strength of suck), which could alter how much milk two infants receive within the same period of time.[40] As per the BLISS study, we used average intake calculated in previous studies based on test weighing and isotopes,[15,41] although it is likely that these intakes were based on infants who were spoon-fed. Breastmilk intake may be different for infants who are self-feeding and further research is needed. Furthermore, as noted above, given that no infant in the study was underweight, it was likely that breastfed infants consuming a lower level of energy from solid foods were meeting their energy needs from increased breastmilk consumption.

Overall, this is the first study of its kind in the UK to investigate a weighed food record and the detailed estimated nutrient intake of babies weaned using a strict form of BLW. It illustrates that few differences occur in overall nutrient intakes between BLW and TW infants, especially in the later stages of weaning. It also highlights that all parents may need further support, particularly around offering iron rich foods, regardless of weaning approach.

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CONFLICT OF INTERESTS
The authors declare that there are no conflicts of interest.

ETHICS STATEMENT
Approval for this study was granted by Swansea University College of Human and Health Research Ethics Committee. All mothers gave informed consent prior to inclusion in the study.

TRANSPARENCY DECLARATION
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 STROBE. 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.

AUTHOR CONTRIBUTIONS
Hannah Rowan was responsible for the study design, data collection, data analysis, draft report writing and critical revisions. Michelle Lee was responsible for critical revisions. Amy Brown was responsible for study design, data analysis support and critical revisions.

DATA AVAILABILITY
Data are available upon reasonable request from the authors.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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CHRONIC DISEASE

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Dietary strategies for remission of type 2 diabetes: A narrative review

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Abstract

Type 2 diabetes (T2DM) is a growing health issue globally, which, until recently, was considered to be both chronic and progressive. Although having lifestyle and dietary changes as core components, treatments have focused on optimising glycaemic control using pharmaceutical agents. With data from bariatric surgery and, more recently, total diet replacement (TDR) studies that have set out to achieve remission, remission of T2DM has emerged as a treatment goal. A group of specialist dietitians and medical practitioners was convened, supported by the British Dietetic Association and Diabetes UK, to discuss dietary approaches to T2DM and consequently undertook a review of the available clinical trial and practice audit data regarding dietary approaches to remission of T2DM. Current available evidence suggests that a range of dietary approaches, including low energy diets (mostly using TDR) and low carbohydrate diets, can be used to support the achievement of euglycaemia and potentially remission. The most significant predictor of remission is weight loss and, although euglycaemia may occur on a low carbohydrate diet without weight loss, which does not meet some definitions of remission, it may rather constitute a 'state of mitigation' of T2DM. This technical point may not be considered as important for people living with T2DM, aside from that it may only last as long as the carbohydrate restriction is maintained. The possibility of actively treating T2DM along with the possibility of achieving remission should be discussed by healthcare professionals with people living with T2DM, along with a range of different dietary approaches that can help to achieve this.

KEYWORDS

cellular and physiological function, diabetes, dietary intervention, disease, endocrinology, food intake, therapeutic areas

Practice points

- Type 2 diabetes (T2DM) remission should be considered as a treatment goal for people living with T2DM (especially for those within 6 years from being diagnosed). The ability to achieve this may be influenced by duration of diabetes, weight loss and gender. Therefore, it should be positively discussed with this in mind.
- Based on the evidence from clinical trials weight loss (typically 15 kg or greater) is the main driver and predictor of remission. However, more data are needed so that it is more reflective of an ethnically diverse population.

[Correction added on 27 December 2021, after first online publication: Peer review history statement has been added.]

- Based on evidence from clinical trials, maintenance of weight loss appears to be the main driver of continued remission, and this therefore needs to be a key focus of the planning and delivery of all services designed to achieve remission. If a diet low in carbohydrate is sustainable to the individual, normoglycaemia may be maintained in the absence of weight loss, although evidence is limited and loss of remission is likely to occur if carbohydrate restriction ceases.
- Total dietary replacements (TDR) and low carbohydrate diets have been demonstrated as being effective in facilitating weight loss and remission of T2DM. Evidence of effectiveness beyond 2 years is limited. The dietary approach should be one which the individual can maintain for the long term.
- TDR and low carbohydrate diets, if appropriately supported, are considered safe and should not be avoided in suitable individuals who find these approaches acceptable. Clinicians should therefore aim to support their use within clinical practice as part of person-centred diabetes care.
- Programmes supporting people toward achieving remission need to be structured and offer continued, regular support, including the involvement of dietitians (mandated by the National Health Service England).

INTRODUCTION

In recent years, the focus on supporting people with type 2 diabetes (T2DM) has shifted from an upward titration of medication to manage what has been considered to be a progressive life-long condition[1] to one that can be potentially (at least for a period of time) put into remission. The predominant view has been that T2DM care has focused upon risk reduction with respect to both macrovascular and microvascular complications,[2] which has been seen to exist with deterioration of metabolic and primarily glycaemic control, thus justifying the need to escalate pharmaceutical management, including eventually progressing to exogenous insulin therapy (IT).[3] The use of IT in the management of T2DM has changed in the last two decades with the introduction of incretin-based medications and sodium glucose transporter 2 inhibitors, which have potentially extended the time before IT is offered to individuals requiring improved glycaemic control.[3] The focus on titrating and adding additional agents remains the core of glycaemic management in T2DM,[4] despite the emergence of remission as a possible treatment target,[5,6] especially related to sustained weight loss.

A group from the British Dietetic Association's Diabetes and Obesity Specialist Interest Groups, in addition to medical doctors with an interest in low carbohydrate dietary approaches and academic dietitians with research interests in diabetes and obesity management, along with a representative from Diabetes UK, formed a focus group in June 2019. Part of the initial outcome from this group was to undertake a critical review of dietary approaches and interventions that support people with T2DM being able to achieve remission of their diabetes. This review considers both the nutritional strategies and their mode of delivery, utilising data derived from both clinical trials and reported case series.

The focus in clinical practice on T2DM being a progressive disease (at least with respect to rate of progression and β-cell decline) has begun to decrease, with the publication of a number of studies showing the potential of educational, behavioural and lifestyle interventions suggesting that T2DM is not necessarily progressive but rather is potentially, transiently at least, metabolically reversible.[7] However, this concept remains to be the focus in practice, with the majority of newly diagnosed people with T2DM being referred to structured education to help manage their blood glucose. Moreover, several systematic reviews and meta-analyses have demonstrated that self-management education is effective at reducing glycated haemoglobin (HbA1c).[8–10] The clinical impact of structured education varies, with some resulting in no difference in HbA1c at 1 year,[11] whereas others maintain a reduction in HbA1c after 1 year in addition to a reduced requirement for prescribed medication compared to standard care.[12] Despite the potential of education to help improve glycaemic control, the focus of much of the management of glycaemia in T2DM has focused on algorithms that facilitate the prescribing and dose escalation of pharmaceutical therapies, with a near sole focus of achieving optimal glycaemic control.

Despite most guidelines primarily focusing on the pharmaceutical management of hyperglycaemia in T2DM, weight loss has continued to be a core part of management guidelines.[13] This focus on weight loss perhaps has been incongruent with the parallel recommendations of upward titration of either IT or sulphonylurea, which risk the side effect of inducing iatrogenic weight gain. Systematic reviews of bariatric surgery cohorts[14,15] not only demonstrated acute improvements in glycaemic control, but also revealed that T2DM could be put into remission for between 58% and 95% of people.[14,16] The mechanism and latterly the formalisation of definitions of remission have subsequently emerged over the past decade; however, an international consensus definition is still awaited.

Perhaps the most widely accepted mechanism of remission is based upon Taylor's 'Twin Cycle' hypothesis.[17]

This hypothesis is based on the basic principle that excess intake of dietary energy, occurring in conjunction with insulin resistance, results in ectopic fat accumulation (both exogenous from the diet and de novo triglycerides synthesised in the liver) in hepatocytes and the islets of Langerhans of the pancreas. This results in increased hepatic insulin resistance and reduced first phase insulin secretion respectively. The long-term glycaemic benefits of bariatric surgery are multifaceted, although primarily associated with facilitating a significant reduction in body weight and adipose tissue.[18] Mechanistically, this is considered to be associated with the reduction of the amount of lipids accumulated in the liver and pancreas and therefore has the dual effect of reducing insulin resistance and enhancing insulin secretion.[17] More recently, the mechanisms around the rapid glycaemic benefit following bariatric surgery have been associated with a significant reduction in acute energy (calorie) intake and hence an intermediary metabolism substrate deficit following surgery.[19] This would suggest that interventions that can mimic this energy deficit might help to drive similar acute changes in glycaemia, preventing the physiological rise in plasma glucose seen in the immediate postprandial state based on the meal composition.

APPROACH TO THE REVIEW

The review group, using their expertise from both clinical practice and research, undertook to critically review the literature. PubMed, Scopus and Medline were searched for original research articles using combinations of terms 'remission', 'reversal' 'type 2 diabetes', 'very low energy', 'low energy', 'very low calorie', 'low calorie', 'very low carbohydrate', 'low carbohydrate' and 'ketogenic' until 21 December 2020.

A pragmatic narrative approach was used, which considered how data from clinical trials can be interpreted alongside data from clinical practice and case series. A critical analysis of the available data was undertaken to update clinical recommendations and help inform clinical practice. Heterogeneity of studies was considered as a potential source of bias, in that some studies, such as the Diabetes Remission Clinical Trial (DiRECT),[5,20] were designed to achieve T2DM remission, whereas other studies did not have this as a primary aim, did not have a control arm or were audits of clinical practice rather than controlled trials. Alongside the use of bariatric surgery[21] and low energy formula approaches,[5] analysis of clinical practice[22,23] and trials using very low carbohydrate, ketogenic diets,[24] which have reported achieving T2DM remission as their outcome goal, were be considered as part of this review.

Additionally, data from other dietary approaches, including intermittent fasting, were also initially considered because these have been suggested as a potential approach by at least one healthcare provider.[25] However, to date, only limited data are available for intermittent fasting and currently only pilot study data are available that relates to reduction in medication use and not remission[26]; therefore, these were not considered further as part of this review. Therefore, with the significant interest the potential of remission offers people living with T2DM, a practical, evidence-informed review can support practitioners in providing individualised advice and care in a clinical setting.

DEFINING REMISSION

The concept of remission in T2DM is relatively new, despite spontaneous remission being reported in the literature in the 1960s.[27] A challenge in the interpretation of the literature is the heterogeneity in the definition of remission of T2DM, with variation in three main areas: discontinuation of glucose lowering medication, glycaemic thresholds and duration.[28] Additionally, the Association of British Clinical Endocrinologists and Primary Care Diabetes Society (ABCD/PCDS) definition includes a requirement of weight loss as one of its criteria.[29]

Despite the variety in definitions of remission, the most common definitions used are those from the American Diabetes Association (ADA),[30] used in DiRECT[5] and Diabetes Intervention Accentuating Diet and Enhancing Metabolism (DIADEM-I).[31] This defined remission as an HbA1c < 48 mmol mol^{-1}. Other definitions used in studies were that of Virta Health[24] which, along with the ABCD/PCDS definition,[29] are summarised in Table 1. A proposed international consensus definitions from diabetes professional bodies is currently awaiting publication.

The addition of weight loss as a defining feature of remission by the ABCD/PCDS definition[29] could potentially mean that it would exclude euglycaemia achieved following a low carbohydrate/ketogenic diet in the absence of weight loss, even when all diabetes medication is discontinued. The necessity of weight loss in the ABCD/PCDS definition potentially leaves euglycaemia without weight loss on a low carbohydrate/ketogenic diet without a classification, a point which is seemingly not concordant with the historic observations of O'Sullivan and Hurtwitz.[27] Weight loss has been reported as a common feature associated with achieving remission of T2DM, with a target weight loss of 15 kg being highly predictive of achieving success.[5,14,16,32] However, weight loss has not been universally reported in individuals achieving euglycaemia and therefore remission and, as such, a potential alternative definition or status of below diagnostic levels of glycaemia maintained by a dietary approach such as a ketogenic or low carbohydrate diet have been excluded by this definition. Therefore, this group proposed the introduction of the term 'T2DM mitigation' for euglycaemia without weight loss because this acknowledges its potential dependence on continued carbohydrate restriction and lack of the physiological changes associated with T2DM remission that occur with weight loss.[33–35]

Within this review, as a result of the heterogeneous nature of the data, it was necessary to use multiple definitions depending on the intervention used; for example, for

TABLE 1 Summary of the definitions of remission from type 2 diabetes

Guideline for remission	Partial or complete?	Glucose lowering agents	Glycaemic parameters	Duration	Notes
American Diabetes Association[30]	Partial	No diabetes medication	HbA1c < 48 mmol mol^{-1} (<6.5%)	>1 year	
	Complete	No diabetes medication	Fasting glucose <5.6 mmol L^{-1}	>1 year	
DiRECT (5)/DIADEM-1[31]	Remission	No diabetes medication for > 2–3 months in previous 12 months	HbA1c < 48 mmol mol^{-1} (<6.5%)	>1 year	
Virta Health[24,59]	Reversal	No medication or metformin alone	HbA1c < 48 mmol mol^{-1} (<6.5%)	>1 year	
	Remission	No medication	HbA1c < 48 mmol mol^{-1} (<6.5%)	>1 year	
ABCD/PCDS[29]	Remission	Cessation of all diabetes medication	Fasting glucose <7.0 mmol L^{-1} HbA1c < 48 mmol mol^{-1}	>6 months	Occurs along with weight loss

bariatric surgery, the ADA definition of partial remission will be used,[30] whereas, for formula low energy diets (LED) also described as total diet replacement (TDR), the DiRECT definition will be applied.[5] If alternative definitions are used, we have highlighted these along with the potential implications that this could have for implementation of these approaches in routine clinical management of people with T2DM.

BARIATRIC SURGERY AND REMISSION OF T2DM

The first indication that remission of T2DM was achievable came from patients' experiences following bariatric surgery. It was observed that people with T2DM were able to omit all diabetes medications including exogenous IT, with blood glucose concentrations returned to target range within 24–48 h following surgery, well before any significant weight loss.[36] This posed the question: what was driving this change? Remission rates particularly following a Roux-en-Y gastric bypass or biliopancreatic diversion are far greater than those achieved by traditional best medical care.[14–16] These values, however, are reduced in individuals with T2DM managed with insulin.[37]

The exact mechanisms by which bariatric surgery elicits these improvements to glycaemia are not completely understood, although energy restriction,[38] vagal tone,[39] gut hormones,[40] bile acid metabolism[41] and reprogramming intestinal glucose metabolism have all been implicated.[42] To date, the data on durability appears to favour bariatric surgery because this is the only approach to remission that has data demonstrating its effect for up to 10 years.[43]

REMISSION WITH CLINICALLY SIGNIFICANT WEIGHT LOSS FROM CLINICAL TRIALS

Studies have confirmed that marked energy restriction and weight loss can favourably alter key aspects of the pathophysiology of T2DM, resulting in normoglycaemia despite not specifically focussing on achieving remission.[44–46] These studies showed that both a marked energy deficit[36,47,48] and an associated weight loss[47,48] result in a return to normoglycaemia in people with T2DM. However, in all of these studies, the follow-up tests were carried out immediately following the energy restriction, and therefore it was unclear whether hyperglycaemia would return with resumption of usual dietary and lifestyle behaviours.

The landmark Counterpoint study[33] demonstrated that a formula very low energy diet (VLED) led to significant weight loss, which may have a durable effect on the key pathophysiology underlying T2DM and provided evidence for the 'Twin Cycle' hypothesis.[17] In this study, 11 people with T2DM of less than 4 years duration consumed a formula VLED (600 kcal day^{-1}) for 8 weeks. Using this

intervention, subjects achieved normal glycaemia, liver insulin sensitivity was restored and the first-phase insulin response returned to levels of weight-matched controls without T2DM. After the VLED period, the subjects were followed up for 12 weeks, and a mean weight gain of 3.1 kg was found. The fasting and 2-h glucose concentrations also increased marginally, with three subjects having reoccurrence of theirT2DM. This study provided data suggesting that restoring the underlying pathophysiology could help manage glycaemia independently of calorie restriction alone. A further study by the same group examined the longer-term effects of a VLED and reported that remission of T2DM was sustained for up to 6 months.[34]

Importantly, remission in the studies described did not occur in all individuals.[34] Those who responded had higher fasting plasma insulin, lower fasting plasma glucose, shorter duration of T2DM, were younger, and were on fewer medications. Importantly, they also had lower pancreatic and total body fat, although there were no differences in hepatic triglyceride content.[34] However, the primary factor distinguishing responders from non-responders was the return of the first-phase insulin response. The first-phase insulin response improved further in responders, whereas there was no change or little change in non-responders.

The larger DiRECT study confirmed these findings,[5,20] providing high-quality evidence that remission is possible within a primary care setting using a formula LED (approximately 826–850 kcal day^{-1}). The restoration of β-cell function and the export of very low-density lipoprotein from the liver were key in achieving remission.[35,45] In this cluster randomised controlled trial involving 149 subjects per group, individuals with T2DM diagnosed in the last 6 years and a body mass index of 27–45 kg m^{-2} were randomised to either an intensive weight management programme using a LED or standard care. The primary outcomes were two-fold, achieving 15 kg or more weight loss and/or remission of T2DM (Table 1). Although this comprises a successful approach, caution needs to be taken as a result of the limited diversity of the population and the relatively high initial attrition in this study.

At 12 months, 46% of patients in the intervention group and 4% in the control group achieved remission. The proportion of patients achieving remission increased with greater weight loss, with those achieving a weight loss of 15 kg or more having a remission rate of 86% at 12 months (odds ratio per kg weight loss = 1.32).[5] Mean weight loss achieved was 10.0 kg within the intervention group and 1.0 kg within the control group, showing that formula LED is an effective treatment in achieving T2DM remission and weight loss in this patient population. The 2-year data have shown that many of the benefits were sustained in relation to both weight loss and T2DM remission, although the percentage in remission fell from 46% to 36%. Mean weight loss was still significantly greater following the LED (7.6 kg) compared to the control group (2.3 kg), despite a mean weight regain of 2.3 kg, whereas 36% of the subjects sustained diabetes remission in the intervention group (compared to 3% in the control group), similar to the results at 12 months. Greater weight loss was again associated with a higher rate of remission (odds ratio per kg weight loss = 1.25),[5] showing that this is the key driver to remission.

More recently, data from Qatar (DIADEM-1)[31] has demonstrated that a TDR approach can be highly effective in achieving remission in a cohort of patients with a Middle Eastern and North African origin. In this study, also delivered in primary care, 61% of participants achieved remission, whereas 33% achieved normoglycaemia [Hba1c < 5.7% (<39 mmol mol^{-1})]. The mean body weight loss was 11.98 kg compared to 3.98 kg in the control group, with 21% of participants achieving more than 15% weight loss at 12 months. The differences between DiRECT and DIADEM-1 may have been partly driven by the characteristics of the study population being predominantly male, younger, with a diagnosis of T2DM within the last 24 months, and demonstrating mostly good glycaemic control, which has been shown to predict remission.[32]

Therefore, high-quality data are available supporting the use of formula diets to support achieving remission of T2DM, with significant weight loss and a return of the first-phase insulin response. Althogh a reduction of ectopic fat and normalisation of hepatic insulin sensitivity are important in achieving remission, restoration of β-cell function appears to be essential for durable remission.[35] Furthermore, there appears to be a point at which β-cell function declines to a degree from which it cannot recover (although lifestyle interventions aimed at inducing remission are still likely to result in significant clinical and quality of life benefits). Recently, a post-hoc analysis of the DIRECT study investigating predictors of remission confirmed weight loss to be the strongest predictor of remission at both 12 and 24 months. In addition, baseline predictors for both 12- and 24-month remission were fewer anti-diabetes medication, lower gamma-glutamyl transferase levels and better quality of life. A lower baseline HbA1c predicted 12-month remission and older age and being male predicted 24-month remission.[32] Combining these data, this might suggest that a targeted use of these dietary interventions is more likely to be effective within a clinical setting if implemented within 6 years of diagnosis of T2DM and ideally within 2 years, in those on less medication, with better mental health, male and with better glycaemic control.[32,49]

CARBOHYDRATE RESTRICTION AS A MEANS TO ACHIEVING REMISSION OF T2DM AND GLYCAEMIC MITIGATION

The role of carbohydrate restriction in the remission of T2DM has come to the forefront of dietary management with high-profile patient stories of 'remission' being achieved with a very low-carbohydrate diet and the publication of clinical audits resonating the same outcomes.[22,24] At present, there remains a lack of consensus on the definition of a

very-low or low-carbohydrate diet within the literature,[50] although the definitions proposed by Feinman et al.[51] have become commonly used in practice (Table 2). A key issue in this area is that there is significant heterogeneity in the methods used between studies, hindering the drawing of firm conclusions and adding further confusion to both clinicians and patients, with respect to target levels of dietary carbohydrate. Furthermore, most studies have achieved substantial weight loss, and it is therefore not possible to determine the independent effect of adjusting any one macronutrient, including carbohydrate restriction on glycaemia and the ability to achieve T2DM remission.

Several meta-analyses have reviewed the effect of carbohydrate restriction (usually compared to low-fat diets) on glucose homeostasis and weight loss, typically using fasting glucose or HbA1c as the primary outcome, although T2DM remission has not been the focus and has rarely been reported.[52–55] In general, these studies have found that low carbohydrate diets and particularly very low carbohydrate diets are associated with greater improvement of HbA1c at least in the short term (up to 6 months) but no difference has been found over the long-term (12 months).[52–54] It is highly likely that at least some of the apparent lack of effect is the result of a drop-off in ability to continue the level of carbohydrate restriction necessary over time to maintain these improvements. Supporting this, participants assigned to the low-carbohydrate arm of studies have shown increased carbohydrate intake over the course of the year,[54–57] with a review of this phenomena suggesting the change in carbohydrate intake can vary from a 20% decrease to a six-fold increase at follow up.[58] These reviews are also limited by a failure to consider the influence of changes in medication requirements. Within the trials included in meta-analyses, it is common for the low-carbohydrate groups to reduce anti-hyperglycaemic medications to a greater degree than those in the control arms, and so a failure to consider this may result in the benefits of low carbohydrate diets being underestimated in some instances.

Although randomisation is considered to be important in trials to control and account for confounding factors, one of the key disadvantages in dietary trials is that participants rarely adhere to the prescribed diet over a long period. Therefore, non-randomised trials, in which individuals are supported to choose the dietary approach they wish to adopt can be useful in providing an indication of what might be achievable within routine diabetes care. One example of this approach is a recent open-label, non-randomised trial by Virta Health[24,59] which compared the effect of a well-formulated very low carbohydrate, ketogenic diet to usual diabetes care. In total, 349 patients with T2DM were enrolled, with 262 self-selecting the ketogenic diet. The care was delivered remotely, with one-to-one support using biomarkers (capillary β-hydroxybutyrate) to monitor the ability to achieve and maintain nutritional ketosis. Participants had access to a web-based software application providing tele-medicine access to a care team, consisting of a health coach and a medical practitioner (physician or nurse), social support was provided by an online peer community. All participants maintained their existing primary healthcare provision. Each education session lasted 90 min, with 26 sessions being delivered over the 12-month period. At 12 months, for those on the continuous care usual care arm 0.20% (2.19 mmol mol^{-1}), the adjusted mean weight loss was 13.8 kg at 12 months, with the usual care losing only 1.1 kg. At 24 months, weight loss was 11.7 kg with usual care. As with DiRECT,[5] this study focused on individuals who were clinically living with obesity. More research is needed with respect to individuals with T2DM who are not living with obesity.

Although the primary endpoints of this study did not focus on achieving remission, a post-hoc analysis was conducted to assess this outcome. Using the definition of T2DM remission used in DiRECT, 25% of participants achieved remission using an intention-to-treat analysis. The study protocol, however, intended for participants to remain on metformin (which would preclude them achieving remission based on the DiRECT criteria) because of the proposed benefits.[3] A further 35% of participants met the criteria for remission at 12 months if the prescription of metformin was not considered, although, given that the glucose-lowering effect of metformin can be in the order of 9–11 mmol mol^{-1},[53] it can be hypothesised that a number of these individuals would not have remained in T2DM remission if metformin were removed. At 24 months, remission remained significantly better in the continuous care intervention arm, with 17.6% achieving remission compared to 2.4% in usual care. Similar to the results in DiRECT, there was a slight decline in remission rates over time despite substantial weight loss.[59]

Although the direct comparison of DiRECT and Virta is challenging because of methodological differences, it should be noted that the mean duration of T2DM in this study was 8.4 years[24] compared to 3.0 years in DiRECT.[5] In addition, in Virta, 57% were prescribed a diabetes medication other than metformin and 46% were prescribed insulin.[24] This is in contrast to the DiRECT study[5] which excluded people taking IT and only included people with T2DM diagnosed within the previous 6 years. Given the tendency for β-cell function to decline with duration of T2DM, this might partly explain the differences in the rates of remission at 12 and 24 months.

Despite impressive outcomes, there are several limitations that have to be appreciated when interpreting the Virta Health data. The study used β-hydroxybutyrate as a marker for the ability to follow the diet. The ketone data at

TABLE 2 Suggested consensus for carbohydrate restriction[50,51]

Definition	Carbohydrate (g day^{-1})	Carbohydrate (% of energy)[a]
Very low carbohydrate or ketogenic diet	20–50 g	6%–10%
Low carbohydrate	<130 g	<26%
Moderate carbohydrate	130–225 g	26%–45%
High carbohydrate	>225 g	>45%

[a]Based on 2000 kcal day^{-1} diet.

both 12 and 24 months show that patients struggled to maintain nutritional ketosis, with concentrations rarely exceeding the recommended 0.5 mmol L^{-1}, with a mean of 0.3 mmol L^{-1}.[24,59] This suggests that adherence to the diet deteriorated over time. Therefore, given the marked weight loss achieved, it cannot be concluded that the ketogenic diet *per se* was the exclusive driver of improved glycaemia and T2DM remission. In addition, it is also worth noting that the level of contact was much higher than found within traditional clinical practice, and so replication of this model in primary care would be extremely challenging at present. Furthermore, the monthly cost of accessing the programme could impact on accessibility to only those with medical insurance or in the higher socio-economic classes. Therefore, questions remain about the generalisability to a public healthcare setting [such as the UK National Health Service (NHS)], although the use of a digital platform may at least in part mitigate this as an issue.

Finally, there is growing interest in the use of carbohydrate restriction in primary care. Several clinical audits have been published that used carbohydrate restriction and weight loss to manage T2DM, in an attempt to achieve remission.[22,23,60] These data can be challenging to interpret because often there are no published dietary protocols, and participants vary in terms of baseline characteristics, including the duration of T2DM, initial HbA1c, and type and amounts of medications, with much of the data being self-reported. However, these clinical audits also show that, for some patients, glycaemia in the normal range can be achieved in conjunction with medication de-prescribing.

An example of this approach comes from the Norwood Surgery (9500 patients in Merseyside, UK), who reported that 27% ($n = 128$) of individuals with T2DM registered with the practice engaged with their carbohydrate restriction-based programme.[61] This has been achieved using a mixture of 10-min clinical visits; patient-friendly physiological explanations of how changing dietary carbohydrate choices can positively impact on blood glucose, diabetes and health; and group consultations. Utilising this approach, this NHS practice has demonstrated, on average, a median improvement using routine clinical measurements of HbA1c of 17.5 mmol mol^{-1} and 46% remission rate at 23 months for those choosing the low carbohydrate approach. Surprisingly a subcohort ($n = 45$) of participants who had T2DM longer than 6 years did better with an average improvement in HbA1c of 24 mmol mol^{-1}, which did not appear to be associated with a change in weight ($r^2 = 0.0058$, $p = 0.402$) The practice spends £50,000 per year less than the local Clinical Commissioning Group average on drugs for diabetes, offering hope of novel revenue streams for better clinical care. Their approach goes beyond a single lifestyle intervention strategy and is grounded in the behavioural principle that centres on the concept of 'hope' (of what better health could be like),[62] along with peer support and social connectivity. The effectiveness of this approach is supported by observational data, which suggests that individuals who believe that they can achieve remission are more likely to achieve this goal. To date, Norwood reports 87 individuals being in T2DM remission at an average of 30 months.[63] This model and approach has been successfully replicated in online platforms.[64]

Carbohydrate restriction-based approaches in primary care have been shown to be a safe and acceptable way for individuals with T2DM to optimise their glycaemic control.[61] The ability, however, of carbohydrate restriction specifically to produce T2DM remission is less clear because weight loss is often also reported, making the attribution of causality difficult. This leads to the possibility that optimising T2DM control using carbohydrate restriction may be 'diabetes mitigation' rather than a physiological remission because the underlying pathology may not be being altered if weight loss is not present, and a return to a normal dietary pattern may therefore lead to the return of dysglycaemia. Although this may be physiologically accurate, clinically, it might not be significant, and could be of little or no importance to an individual who can and is willing to maintain carbohydrate restriction, and who also benefits from reduced risks of complications as a result of optimal glycaemic control regardless of the underlying mechanism of effect.

CAN CURRENT DIETARY ADVICE FOR PATIENTS WITH T2DM RESULT IN DIABETES REMISSION?

Although there is increasing interest and evidence to support dietary approaches aimed at supporting T2DM remission, mainly from studies and use of TDR and carbohydrate restriction, practice is still largely focused on recommendations linked to the wider public health nutrition messages. Nutritional management of T2DM has historically focussed on improving blood glucose concentrations and promoting weight loss, without specifically aiming to achieve remission.[13,65] Although significant weight loss can help improve and even normalise glycaemia and aid T2DM remission, moderate weight loss (e.g., 5% body weight), more commonly seen in clinical practice, is usually not sufficient to achieve similar outcomes. Supporting this, a retrospective cohort study of people with T2DM receiving typical ADA care (including dietary advice) reported a 7-year cumulative incidence of partial remission of only 1.47% and a complete remission rate of just 0.14%.[66] This shows that although remission was achievable following usual care, it was very rare.

Data from the Look AHEAD trial, which used a combination of meal replacements and an energy restricted, low-fat diet, showed in a post-hoc analysis that remission occurred in 11.5% of people at 12 months in the intensive lifestyle group (ILI), despite an impressive weight loss of 8.6%.[44] The prevalence of remission decreased during the follow-up period and reduced to 7.3% at year 4, with approximately one-third in the ILI group returning to a clinical diagnosis of T2DM each year.[44] The mean duration of T2DM in the cohort was only 5 years, similar to that seen within DiRECT. However, more than 80% of the Look AHEAD subjects were taking two or more hypoglycaemic medications, with 15% taking

insulin, which, similar to the Virta Health results, may have affected remission rates.[24,59] Indeed, multivariate analysis confirmed that shorter diabetes duration, lower HbA1c, not taking insulin and a greater weight loss at 1 year were associated with greater remission.[44]

The potential of the Mediterranean diet has also been explored, with a lower carbohydrate Mediterranean diet being compared against a low-fat diet. Participants following a Mediterranean diet achieved greater remission rates across all years over a 6-year follow-up.[67] At the end of the first year, any remission (partial or complete, according to the ADA definition[30]) was 14.7% in the Mediterranean diet group compared to 4.1% in the low-fat group. These figures reduced year on year, with 5% of participants on the Mediterranean diet still being in remission at 6 years compared to 0% in the low-fat group.[5,67] This reduction in remission appears to be parly related to the weight regain observed over the study period. These data are difficult to directly compare with other remission studies because the initial aim was the introduction of anti-hyperglycaemia medications in people with newly diagnosed T2DM specifically and not remission. Furthermore, the degree of carbohydrate restriction was modest, at 40% of dietary energy from carbohydrate, compared to other studies that adopted a low carbohydrate approach.[67]

More recently, several other studies have been conducted looking at intensive lifestyle interventions, which have included supervised exercise programmes with low-fat, energy restricted diets[45,46] and additional education sessions[68] to achieve T2DM remission. These have been conducted in a variety of different patient populations and show that T2DM remission is achievable with intensive intervention, with 17.8%–53.3% of patients achieving partial or complete remission at 12 months.[46,68] However, because these studies utilised weight loss to facilitate remission, this provides evidence for intensive education supporting dietary energy restriction as an effective strategy for improving glycaemia and inducing T2DM remission.

PRACTICAL CONSIDERATIONS WHEN SUPPORTING PEOPLE TOWARDS ACHIEVING REMISSION

Although the use of formula TDR and low carbohydrate diets in T2DM and obesity are not novel concepts, the implementation and delivery of specific remission-focused services for T2DM is an emerging area and is therefore largely under-researched as part of routine diabetes care. The limited use of TDR, despite good evidence for their safety and efficacy,[69] could be related to a lack of confidence from healthcare professionals regarding these approaches, as well as a negative view of their palatability, safety and side effects.[70] Although the potential lack of use of low carbohydrate diet use might have been driven by the lack of recognition within international guideline, related to the concerns regarding the long-term safety and impact on cardiovascular risk, this has now started to change, with a number of guidelines starting to recommend their use.[3,13]

At present, there remains a dearth of guideline recommendations regarding mode of delivery of intervention components needed to help people achieve T2DM remission. In reviewing the studies describing interventions that led to remission, there was significant heterogeneity in the intervention components meaning that firm conclusions are difficult to define[5,18,20,55,59–64,66–68,71–74] However, there are several areas that should be discussed and considered when supporting people to achieve remission.

Currently, there is limited evidence, if any, that allows direct assessment of whether the intensity of the intervention (primarily based on contact time) has a positively impact on T2DM remission rates. When comparing total number of hours of dietary education within different interventions, there appears to be no apparent difference in remission rates at 1 year (25% and 23%) between interventions delivering a total of 36 h[73] compared to 46 h,[46] respectively. However, remission rates of 46% have also been reported within in a real-world setting[22,60] with a low intensity intervention of approximately 5 h in total over a 2-year period. These data might suggest that variables, other than contact time *per se*, may be influencing remission rates; however, without direct comparison, it is difficult to make a definitive conclusion.

Importantly, the amount of contact may vary between the different stages of T2DM remission, with requirements for initially achieving T2DM remission being different from those needed to maintain remission and weight loss. Although not directly investigating the correlation between intensity of intervention and remission, the number of contacts in the first year of the Look AHEAD trial predicted a greater likelihood of maintaining a 10-kg weight loss at 4 years.[75] Because weight loss appears to be the primary driver of T2DM remission,[32] this may imply that contact time is a key component to achieving remission.

With the advent of COVID-19, the mode of delivery is now of key importance, with digital delivery models being used effectively to support programmes remotely and able to increase the intensity of the intervention. Virta Health, for example, utilises continuous care through intensive digital support, including access to telemedicine, health coaching, behavioural education, biometric feedback and peer support via an online community,[24] which has been reported to be key to the success of the programme. In addition, a small service evaluation of nine people of a remote digitally enabled T2DM remission programme[74] using a TDR intervention showed promising outcomes. Patients achieved aweight loss of 16.6 kg and a reduction in HbA1c of 24.3 mmol mol^{-1}, with 44% of patients being reported to have achieved remission. On further review, because they were continued on metformin (as a result of advice from a general practitioner), they did not met remission criteria (Table 1) but, instead, met the Virta criteria for T2DM 'reversal'. However, similar to contact time, there is a lack of studies directly comparing delivery methods to enable the suggestion that one mode of delivery (i.e. group-based sessions, individual appointments or online/digital provision) is more effective than another.

This lack of evidence of superiority might suggest that a more flexible approach should be offered instead.

The cost of the TDR product could present a barrier to wider use, with self-funding being highlighted as a barrier.[76] These qualitative data revealed that some participants following the initial period where the TDR was free reported that, despite wanting to lose more weight with the TDR, cost was a barrier to continued access. Furthermore, more participants reported that the need to purchase TDR along with a reduced sense of duty to follow the study protocol would impact their ability to continue following this approach. With this in mind, it is sensible pragmatic approach taken by NHS England pilot sites[77] to offer the TDR products to the participants free of charge, which should address these concerns. However, it remains to be seen what will happen following the TDR phase of the pilot and during the weight maintenance phase and whether continued formula product will be provided to enable further weight loss and support weight loss maintenance.

It is possible that using food-based approaches instead of or in partial combination with formula products may be more affordable and acceptable to some, although, currently, there is a lack of evidence to support this approach. However, recent evidence from The Dietary Approaches to the Management Of type 2 Diabetes (DIAMOND) trial demonstrated that it is feasible to implement a short-term (12 week) intervention with a food-based, low-energy (800 kcal day^{-1}), low carbohydrate diet with behavioural support delivered by practice nurses. Although this study demonstrated significant weight loss and improved glycaemic control, it did not investigate the efficacy of this approach in achieving remission.[71] Wider implementation of a food-based LED may be more time-consuming and require greater skilled dietary intervention to ensure nutritional adequacy, which are two clear benefits of using a TDR, but could be a potential development for future clinical practice.

Self-efficacy may also play a role in an individual's likelihood to adhere to a new dietary regimen.[78] Behaviour change counselling is an integral part of successful dietary interventions.[79] The DiRECT study was based on behaviour change models delivered by trained dietitians and practice nurses with the aim of achieving long-term weight loss maintenance.[80] An alternative to models based on high levels of healthcare professional input is to consider that the individualised support facilitating success can be achieved in a virtual platform if well designed,[81] as discussed above. It is likely that providers of services undertaking the NHS England low calorie pilot would need to train their team to deliver this support, although this one-off cost is less than 1 year of T2DM medications for an individual[80] and thus represents a worthwhile investment.

Most remission interventions have been developed and delivered by a multidisciplinary team that is either already experienced in the delivery of the dietary approach being assessed or is trained to do so. The professional background of educators reported in the literature comprised either general practitioners, physicians, dietitians, nurses, health coaches, psychologists or lay educators. Although, to date, there is a lack of evidence to advocate for the essential professional disciplines involved in delivering programmes aimed at achieve T2DM remission, the majority of trials conducted have reported the inclusion of a dietitian as a core team member, and this principle has been retained in emerging clinical guidelines.[13]

A history of eating disorders is an exclusion criterion for many TRD programmes. Where available, clinical psychologists have been used to facilitate this screening. However, many services may not have access to psychological support. Use of screening questionnaires such as the Eating Disorder Examination Questionnaire (EDE-Q)[82] should be used as part of the screening process not only prior to using formula TDR programmes, but also for any planned dietary intervention that has the potential to reduce body weight or alter a patient's relationship with food. If carefully supported by a healthcare team, ideally including a dietitian and clinical psychologist, a systematic review of the data suggests that these approaches can be beneficial and does not appear to trigger binge eating behaviour.[82] Additionally, TDRs can be considered in those who have been treated for and also can effectively manage their binge eating tendencies.[83]

A key consideration when looking to achieve remission, especially when looking to follow either a low carbohydrate diet or a TDR, is that medication will need to be adjusted. In the case of DiRECT, oral hypoglycaemic agents, antihypertensive agents and diuretics were withdrawn on commencing the TDR.[84] If the approach is one involving a low carbohydrate diet, insulins, sulphonylureas and meglitinides will usually need to be reduced or stopped to avoid hypoglycaemia.[85] Sodium-glucose cotransporter 2 inhibitors may carry a risk of causing ketoacidosis and should usually be stopped. Other diabetes medications do not require immediate adjustment; however, once a low carbohydrate diet has been commenced, they may become unnecessary. Additionally, a low carbohydrate diet can lead to an improvement in blood pressure, and so antihypertensive medication may also need to be lowered or stopped.[85]

Another implication to consider is that of the cultural beliefs and practices of individuals and, although ethnicity and culture are not synonymous, there are limited published data in diverse populations, with evidence on remission using TDR mainly being in White populations.[20] Further trials would therefore need to engage a wider ethnic background to assess whether a TDR would be acceptable and achievable to individuals still wishing to engage in the eating, drinking and social activities associated with their belief, religion and/or culture.[86] Recent data from Qatar demonstrated that a TDR approach can be effective in achieving remission (61%) and normoglycaemia [Hba1c < 5.7% (<39 mmol mol^{-1}); 33%] in a cohort of Middle Eastern and North African origin. This population was predominantly male, was younger (than in DiRECT), and had recent diagnosis of T2DM and mostly good glycaemic control, which may not be representative of the general UK multi-ethnic population that would be seen in a routine healthcare setting.[31]

The cost effectiveness of any programme is key to its implementation within clinical practice. Currently, only three interventions have analysed and reported cost effectiveness[87,88] or cost savings.[67,89] Although independent economic evaluations have previously shown T2DM self-management group education to be cost effective, these did not have remission as a primary goal.[90] However, because all the interventions reported remission rates, savings from de-prescribing would be evident. Also, because the remission of T2DM has the potential to reduce the risk of longer-term complications, achieving remission is likely to prove cost-effective long-term, regardless of the method used to achieve it; particularly if it is feasible to implement it as part of current care pathways. Based on the cost analysis from DiRECT,[87,88] the cost per intervention [largely consisting (95%) of TDR formula costs and clinic visits] was £1223,[87] with each case of T2DM remission costing on average £2564. Costs in the control group were substantially lower (£846); however, with remission rate only being 4% at 1 year, this is not a clinically effective option. This compares favourably with data from Look AHEAD, where lifestyle interventions cost 2865 USD per intensive lifestyle intervention, resulting in a 11.5% (partial or complete) remission rate,[75,90] and bariatric surgery, where the estimated cost per remission is 14,389 USD.[91] At 2 years, the healthcare costs in DiRECT were reported to increase to £3036 and £2420 for the intervention and control group, respectively, per remission. To date, studies have not shown overall healthcare cost savings, although modelling suggests this could be achieved at 6 years, assuming that remission can be maintained.[88]

DiRECT report that a high proportion of the participants were from socially deprived circumstances, despite being ethnically homogeneous.[5] Yau et al.[92] emphasise that low socio-economic status has a strong, positive correlation with non-adherence to dietary advice. Cost has also been cited as a possible reason for the low uptake in using TDR. Because the meal replacement products were provided free of charge for DiRECT participants, this may partly explain the enhanced adherence to the intervention compared to other studies. However, despite this, almost one-third of participants in the intervention arm still withdrew by 24 months.[30] It is therefore important that measures to increase retention are explored. The advance in digital technology and digital programmes with in-built support functionalities, which have already been demonstrated to enable cost effective scaling of self- management education in an open-label single arm convenience sampled cohort of people with T2DM,[63] may help on this front, although more data from better controlled implementation studies are required.

LIMITATIONS OF EVIDENCE FOR DIETARY APPROACHES TO REMISSION

The literature suggests that both the availability (both current and future) of TDR product and the perceived duty to follow the study protocol may influence an individual's willingness and ability to follow a LED aimed at achieving remission. This represents a potential challenge when translating findings from clinical trials into routine practice, which is in part overcome by providing TDR product free of charge. This, to a point, is contrasted by the evidence from primary care practitioners who have used low carbohydrate approaches with good success.[22,61] This apparent difference should be treated with caution because it is not possible to quantify the sense of duty and attachment to the practitioner with respect to a potential 'practitioner effect' in those using a low carbohydrate approach. It cannot therefore be ruled out that how remission is approached, as well as by whom, will have an impact on the effectiveness of an intervention beyond that of the dietary approach applied.

As previously highlighted within this review, caution needs to be taken when considering how interventions have been delivered and with regard to which aspects are integral to their overall success. The variable definitions used to define remission are an additional challenge when interpreting the data, especially if reported outcomes use definitions that permit continued prescribing of metformin. This may impact on the reported remission rates as a result of differences in de-prescribing protocols rather than differences in the effectiveness of the intervention. For example, in one study, metformin was only discontinued because of contra-indication, intolerance or patient request.[24]

Further limitations that are likely to impact on reported remission rates are that some clinical trials have made use of run-in periods to assess adherence, with only participants who have confirmed compliance to the diet being included.[44,68] The effect of variability in reporting is also seen in analyses of routine clinical practice data, where some groups report the remission rate only in those who have adopted a low carbohydrate diet,[22] whereas others reported the remission rate for the entire list of diabetes patients in their practice cohort.[61] The overall impact of these could potentially overestimate remission rates in some interventions and cohorts.

CONCLUSIONS

From the available evidence, it appears that a wide range of options have the potential to bring about T2DM remission. The published clinical trials and real-life examples for both LED and low carbohydrate vary with respect to robustness, numbers of participants, education strategies, intensity of intervention and lengths of follow up. With no direct comparison of these two dietary methods to date, it is challenging to determine which dietary intervention is the most successful in relation to T2DM remission.

Similar to many healthcare interventions, one size does not fit all, and individualisation needs to be considered. This may mean that a mixture of different levels of follow-up intensity and mode of delivery (virtual compared to face to face) is likely to be necessary to maximise remission rates, with a more blended approach being taken. There is also a need for longer-term evidence for all of these approaches,

with data from high quality controlled trials limited to outcomes of at most 2–4 years, although there are some data from 5 years plus for uncontrolled and observational evidence. Based on this, patients who would like to achieve T2DM remission should be offered a 'menu' of options with respect to educational and dietary approaches if they wish to attempt to achieve remission. This may be key to driving forward remission in a primary care setting.

Lifestyle, including dietary interventions, has not historically been viewed as a form of treatment in the same way as pharmaceuticals. The emerging data with respect to T2DM remission challenges this viewpoint and could lead to the idea that individuals ought to be supported to balance the choice between using diet as an active treatment with one that is compatible with an enjoyable way of living. Therefore, the dietary approach that brings about T2DM remission should be seen as an active treatment and, unless the individual finds this approach sustainable in the long term, it might be considered only a partial remission of their condition.

Several of the points about the physiological effect of low carbohydrate or TDR diets on remission could be considered to be academic, and the importance or lack thereof of these factors to people with T2DM should be respected. However, the potential for diet, either LED (with or without TDR) or low carbohydrate, to dramatically improve glycaemic control and bring about remission needs to be fully embraced within dietetics and wider diabetes care. This should then be used to support people with T2DM to achieve their goals and initiate the conversation about the potential of T2DM remission, wherever it is appropriate.

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AUTHOR CONTRIBUTIONS

DM was responsible for the study conceptualisation. AB, PMcA, JT, DU, JU, TD, CM, AM and DM were responsible for the methodology. AB, PMcA, JT, DU, JU, TD, SW, CM, AM and DM were responsible for original draft. AB PMcA and DM were responsible for the reviewing and editing. JT, DU, SW, CM and AM contributed to the reviewing and editing.

CONFLICT OF INTERESTS

AB has worked as an investigator on TDR studies which have had commercial support. JT works for Medtronic, a company which manufactures and supplies diabetes pumps. CM and DU are advisors for Diabetes Digital Media who have developed the Low Carb app. TD and SW work for XPERT Health which is a charity providing diabetes education. DM has worked as an investigator on meal replacement studies which have had commercial support.

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UK Dietitians' views on communication skills for behaviour change: A 10 year follow-up survey

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Abstract

Background: In 2007, a survey of UK dietitians identified that dietitians were positive about the use of Communication Skills for Behaviour Change (CSBC) in practice, although barriers to the implementation of skills were acknowledged. This follow-up survey aimed to explore current perceptions of CSBC and compare them with the previous survey.

Methods: A cross-sectional online survey of British Dietetic Association (BDA) members' views of CSBC was undertaken. The results for full members are presented. Quantitative data were analysed descriptively. Qualitative data were subject to either content, or inductive thematic analysis.

Results: A response rate of 9.4% (n = 729) was achieved. Respondents were predominately female (n = 684; 95.1%) and worked in the National Health Service (n = 634; 87.4%). They were positive about the importance of CSBC in practice (n = 714; 99.5%). Pre-registration training had been completed by 346 respondents (48.7%).

Post-registration training had been undertaken by 520 (74.7%) respondents and 514 of these (99.6%) had implemented training into practice, with few barriers identified. Perception of ability to use skills had increased, with 513 (83.6%) respondents rating their skills as excellent/very good compared to 62% previously. The majority (n = 594; 93.7%) reported that post-registration training was necessary, with the need for skills to be regularly reviewed (n = 456; 74.5%), and 235 (51.9%) respondents suggested this be mandatory. By contrast, some suggested that a skill review was not a priority, and would be difficult to administer and stressful.

Conclusions: Perception of the importance of CSBC remains high. Although the perceived ability to apply CSBC has increased, the perceived need for post-registration training is high, with respondents' favouring mandatory training.

KEYWORDS
behaviour change, communication skills, cross-sectional survey, dietetics, training

Key points

1. This survey provides information about current views of the UKdietetic profession in relation to communication skills for behaviour change, and as a follow up to one

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undertaken in 2007, offers some comparisons andidentifies changes in views and practice.
2. 729 full members completed the survey (response rate 9.4%).
3. 99.5% respondents rated communication skills for behaviourchange as important.
4. Those who had trained within the last 10 years weresignificantly more likely to report dedicated pre-registration training incommunication skills for behaviour change ($p < 0.001$).
5. Fewer barriers to implementation of skills in practice wereidentified than in the previous survey.
6. Opportunities for post-registration training are limited byfinancial constraints and time.
7. There is support for mandatory skill reviewpost-registration.

INTRODUCTION

Patient-centred care has been referred to as a set of skills that activate patient participation, promote shared decision-making, seek patient views and opinions, and facilitate a collaborative and supportive approach to care.[1–4] Patient-centred care is essential to support health-related behaviour change.[5] The literature remains ambiguous on what specific communication skills are required to support patient-centred care[6–7]; however, recently, a tool designed to measure patient-centred care in dietetic practice has been developed, based on review of the literature, as well as patient and dietitian views.[8] Further testing is required but this tool may provide the clarity needed to support training and development of these skills in dietitians. A survey of UK dietitians conducted in 2007 provided insight into the communication skills for behaviour change (CSBC) dietitians deemed necessary to support patient-centred care.[9] CSBC were defined as including, but not limited to, 'skills which enable clients to make appropriate choices, express their thoughts and feelings, feel heard and understood, feel valued, respected and supported'. The survey revealed a high level of perceived importance attached to CSBC, but respondents indicated that more training to support skill development was required.[9] Pre-registration education standards and training documents reflect the importance of CSBC as a core competency requirement for dietitians[10–11]; however, individual Higher Education Institutions (HEIs) may teach these skills differently leading to variation in patient-centred care. The survey also identified barriers to applying skills in practice, including a lack of time to implement skills, lack of confidence in skill use and lack of support from colleagues/management,[9] suggesting that additional support is required in the workplace.

Patient perceptions of dietetic care support the importance of CSBC and patient-centred care, including the adoption of a flexible approach, allowing individual preferences to be considered.[12–21] Lack of CSBC contributes to patients' perceptions of lack of empathy, resulting in lower agreement on choices made and potentially contributing to poor engagement.[6,21–22] Dietitians' inability to support patients in making their own decisions appears to have a negative impact on shared decision-making,[23] creating a power imbalance that requires addressing whether patient self-care is to improve.[7,23,24] By contrast, supportive collaborative approaches result in greater adherence,[25] enhanced self-care and improved health outcomes.[25–28]

Overall, patient views suggest that there is a range of practice, but that improvements could still be made in the delivery of patient-centred care in dietetics.[16–17] Dietitians' awareness of their communication style and its impact on patient outcomes must therefore be enhanced, from pre-registration education (both at HEIs and on placement) and into practice. How best to support skill development remains unclear. Some evidence indicates that positive attitudes towards learning communication skills declines as student dietetic training progresses[29] but, recently, a study has suggested that student attitudes to experiential learning with simulated patients is more positive.[30] There have also been developments in the use of technology to support learning[31] that may impact on skill development, although more data are required to substantiate how best to deliver training to support skill enhancement.

Dietitians perceive their ability to deliver CSBC to be high[9,32]; however, perceived skill can vary considerably from true proficiency[33–37] and may contribute to variations seen in patient outcomes.[38] Validated tools to assess CSBC are therefore required to identify skill level, as well as support skill development and application in practice.[7,39] Cultural norms[6,40] and time constraints[7,9,41–42] have been highlighted as potential barriers to the implementation of CSBC in the workplace. This suggests that further training and support is required to establish and develop CSBC skills once qualified.

The literature indicates that patient-centred care remains important to dietitians and patients. Understanding of what patient-centred care means in dietetic practice is developing. Where there is lack of patient-centred care there may be negative impacts on patients, and dietitians have expressed a desire for further training in CSBC to support their delivery of patient-centred care.

Since 2007, there have been many developments in policy, standards and evidence base, all indicating the importance of improved communication skills and patient-centred approach in healthcare. It is not known how much of this has been implemented into pre- and post-registration training of dietitians or whether barriers have changed. The present

follow-up survey therefore aimed to explore current perceptions of UK dietitians towards CSBC training and use of these skills in practice, as well as to determine whether barriers to implementation of skills have changed since 2007.[9] Identifying what barriers, if any, exist, may help direct future training in CSBC and the development of patient-centred care in practice.

METHODS

This cross-sectional survey of British Dietetic Association (BDA) members utilised the questionnaire from the previous BDA members' survey completed in October 2007.[9] The survey was divided into sections including demographic information, experiences of both pre- and post-registration training, views on what pre- and post-registration training should include, the importance of CSBC and the impact of these skills on practice, barriers to their implementation, personal training needs and views on post-registration review of skills. Small revisions to the original questionnaire included the creation of more pre-coded responses, based both on previous responses, and recent developments, such as web-based training packages. Most questions required tick box answers, although there were some open questions requiring respondents to write their views. Although open questions require greater respondent effort, and not all will respond,[42] they can provide an explanation for closed question responses and deeper insight into respondent views that may not otherwise be captured. The revised questionnaire was converted into a web-based survey using Survey Monkey (https://www.surveymonkey.co.uk). Skip logic was also applied (for survey questions, see Supporting information, Table S1).

Information about the survey, including the link, was sent electronically, with a covering email, in January 2018, via the BDA, to all members (n = 9116, all members; n = 7743, full members). One reminder was sent, and the survey remained open for 1 month. The results for full members are presented.

Data were downloaded from Survey Monkey and analysed using SPSS, version 24 (IBM Corp.). Quantitative data were checked for errors and any items that could not be validated were removed. Chi-squared tests were used to idenitfy differences in categorical data. Five-point Likert scales were used to ascertain importance (i.e., 1 was very important, 5 was not at all important) and responses were dichotomised to give an overall positive (1 and 2 combined) or negative (4 and 5 combined) view of importance. Qualitative data were analysed in one of two ways. Content analysis was applied to short responses, for example, when respondents were asked to list skills included in CSBC. Responses to individual open questions encouraging more expansive answers; for example, 'How do you feel personally about having your communication skills for behaviour change assessed?' were analysed manually, using inductive thematic analysis[43] as a result of the volume and depth of the data obtained. Answers to each specific question were combined into one document and then were read, reread and coded systematically. Themes were developed, refined and discussed between two researchers (TP and KW) to achieve agreement. Qualitative data for open questions are presented alongside quantitative data relating to the same section of the questionnaire.

Funding for survey administration was received from the BDA General Education Trust (October 2017). Ethical approval was received from the School of Sociology and Social Policy, University of Nottingham (BIO-1718-0001).

RESULTS

The survey was completed by 729/7743 full BDA members, giving a response rate of 9.4%. Because some respondents did not complete every question, pairwise deletion was applied. Percentages refer to the number of respondents who completed that specific question. Numbers in parenthesis after quotes comprise the respondent survey number.

Respondent characteristics

Respondents were from across the UK, most commonly England (n = 551; 76.6%), Scotland (n = 89; 12.4%), Northern Ireland (n = 43; 6.0%), Wales (n = 34; 4.7%) and other (n = 2; 0.3%) (10 missing data). The majority were female (n = 684; 95.1%) with 31 males (4.3%) and four (0.6%) preferring not to say (10 missing data).

Respondents' experience ranged from < 5 years qualified (n = 144; 19.9%) to 40 years or more (n = 7; 1.0%) since qualification, the most common group being those who had worked between 10 and 20 years (n = 192; 26.5%). Most worked in the National Health Service (NHS) (n = 634; 87.4%) (four missing data). Additional work areas included freelance (n = 24; 3.3%), public health (n = 19; 2.6%), education (n = 14; 1.9%) and industry (n = 7; 1.0%). Others (n = 27; 3.7%) worked in training, media, nursing homes, private companies, research and third sector organisations.

Of the 632 respondents, most were employed as band 6 (n = 263; 41.6%) and band 7 (n = 241; 38.1%) dietitians, with fewer band 8 (n = 67; 10.6%) and band 5 (n = 60; 9.5%). The most common specialisms were paediatrics (n = 97; 15.3%), diabetes (n = 86; 13.5%) and mental health (n = 71; 11.2%) with 82 (12.9%) having a non-specialist caseload. Many (n = 453; 63.0%) estimated that they spent between 26% and 75% of their time with one-to-one client contact, but 55 (7.6%) had none (10 missing data). Most respondents worked 0.81–1 whole time equivalents (n = 454; 63.2%) (11 missing data).

Importance of communication skills for behaviour change

Respondents were positive about the importance of CSBC, with 714 (99.5%) rating them as being important and no-one rating them as not important (n = 3; 0.5% neutral) (12 missing data). They were positive about the importance of

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TABLE 1 Importance of Communication Skills for Behaviour Change (CSBC) for different aspects of practice

	Important		3 (neutral)		Not important		Not applicable		Missing data
Aspect of practice	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***
Relationship with clients	610	98.7	6	1	1	0.2	1	0.2	111
Relationship with colleagues	498	81.4	85	13.9	19	3.1	10	1.6	117
Job satisfaction	544	88.8	60	9.8	4	0.7	5	0.8	116
Client satisfaction	606	98.7	6	1.0	1	0.2	1	0.2	115
Client DNA[a] rates	439	71.7	120	19.6	33	5.3	20	3.3	117
Client clinical outcomes	587	95.6	24	3.9	2	0.3	1	0.2	115
Confidence in client interviews	588	95.9	21	3.4	0	0	4	0.7	116
Time keeping in client interviews	409	66.6	148	24.1	43	7.0	14	2.3	115
Ability to cope with challenging clients	602	97.9	9	1.5	2	0.4	2	0.3	114

[a]Did not attend.

CSBC for undertaking an accurate assessment of the client (n = 588; 95.3%) and for taking a diet history (n = 539; 87.4%).

A few respondents reported that CSBC were not applicable to some parts of practice; however, the majority were positive about the impact of CSBC in many aspects, including relationship with clients (n = 610; 98.7%), client satisfaction (n = 606; 98.7%), ability to cope with challenging clients (n = 602; 97.9%), confidence with client interviews (n = 588; 95.9%) and perceiving improvements in client clinical outcomes (n = 587; 95.6%) (Table 1). The least positive was 409 (66.6%) respondents considering CSBC to be important for time keeping in client interviews. There were 15 comments relating to concern with time keeping; for example, 'Using communication skills for behaviour change takes significantly longer and does not fit into NHS allocated appointment times' [465].

Over 96% respondents also reported that CSBC were important for different components of consultations. These included being able to communicate at an appropriate level for individual clients (n = 612; 100%), listening attentively (n = 613; 100%), recognising and responding appropriately to verbal communication (n = 609; 99.8%) and greeting clients appropriately at the same time as putting them at ease (n = 612; 99.7%). Most respondents were positive regarding their own CSBC skills, with 513 (83.6%) rating them as one or two on a five-point rating scale (i.e., 1 is excellent, 5 is very poor). No-one rated themselves as very poor, although 101 (16.5%) were less confident about their skill level, rating them as three or four.

Pre-registration training undertaken

Dedicated training in CSBC as part of pre-registration education had been received by 346 respondents (48.7%), 268 (37.7%) respondents had not received training and 97 (13.6%) respondents did not recall (18 missing data). The length of time since qualifying was significantly related to report of pre-registration training in CSBC (χ^2 = 56.122, df = 2, n = 711, $p < 0.001$), with 76.8% of those graduating < 10 years ago indicating that training had been received compared to 41.7% who trained > 10 years ago.

The predominant methods of teaching experienced at university were lectures, observation of a skill demonstration and role-play, including those observed by peers or tutors, with feedback (Table 2). On clinical placement, teaching methods were mostly consultations with real patients, with some observations of skill demonstration.

Preferences for pre-registration training

Pre-registration preferences varied (Table 3). Consultations with real patients were thought more appropriate for placement (n = 370; 57.7%) (88 missing data). Apart from role-play with a real patient, other methods were considered to be more appropriate in university, or for both settings, rather than placement only. Some respondents stated that the training methods indicated were inappropriate in either setting, most commonly role-play with a real patient (n = 109, 17.4%), role-play with formal assessment [Objective Structured Clinical Examination (OSCE)] (n = 59, 9.6%), audio-recorded role-play with playback (n = 53, 8.4%) and online training packages such as DIET-COMMS[31] (n = 44, 7.6%). There were 42 other highly variable comments, which included reference to using a variety of methods in both locations; for example, 'Currently I think a number of techniques can be employed but practice and feedback to provide guidance is essential. Some lectures are needed to help set

TABLE 2 Methods of teaching Communication Skills for Behaviour Change (CSBC) experienced pre-registration

Method	A lot		Some		None		Missing data
	n	%	*n*	%	*n*	%	*n*
At university							
Lectures	47	14.5	267	82.2	11	3.4	21
Observing a demonstration of skill (either by video or live)	36	11.1	253	78.3	34	10.5	23
DIET-COMMS online training package	3	1.0	19	6.1	289	92.9	35
Role-play (an opportunity to practice skills)	84	25.9	226	69.8	14	4.3	22
Role-play: audio-recorded and listened back	13	4.1	88	27.8	215	68	30
Role-play: video-recorded and watched back	11	3.5	145	45.6	162	50.9	28
Role-play: observed by peers, followed by information feedback	61	18.9	210	65.2	51	15.8	24
Role-play: observed by tutor, followed by informal feedback	39	12.4	222	70.5	54	17.1	31
Role-play with formal assessment [e.g., Objective Structured Clinical Examination (OSCE)]	23	7.3	133	42.1	160	50.6	30
On clinical placement							
Lectures/tutorials	8	2.6	83	26.9	217	70.5	38
Observing a demonstration of skill (either a video or live)	76	24.5	91	29.4	143	46.1	36
Consultations with real patients	228	70.6	80	24.8	15	4.6	23
DIET-COMMS online training package	0	0	7	2.3	303	97.7	36
Role-play (an opportunity to practice skills)	21	6.8	110	35.4	180	57.9	35
Role-play: audio-recorded and listened back	1	0.3	6	1.9	301	97.7	38
Role-play: video-recorded and watched back	0	0	6	1.9	303	98.1	37
Role-play: observed by peers, followed by informal feedback	17	5.5	53	17.0	241	77.5	35
Role-play: observed by tutor, followed by informal feedback	30	9.7	59	19.0	221	71.3	36
Role-play with formal assessment (e.g., OSCE)	8	2.6	14	4.6	285	92.8	39

the scene' [264]. Additionally, responses suggested ensuring that tutors are skilled before assessing students; for example, 'Perhaps tutors need peer assessing in their delivery of feedback on role-play/communications skills courses?' [568]. Some respondents were unaware of online training packages such as DIET-COMMS (n = 6); for example, 'I can't comment on DIET-COMMS training package I haven't seen it' [600]. Most respondents (n = 386; 60.7%) conveyed that the responsibility for teaching CSBC in pre-registration education should be 50:50 between HEI and placement.

Dietitians were asked to identify, in their own words, the core communication skills that should be included in pre-registration education (558 comments). Three themes were identified. First, the majority of responses related to naming specific communication skills important for building relationships with patients, such as active listening, reflections, paraphrasing, open questions and empathy; for example, 'Reflective listening/paraphrasing to allow build-up of rapport with the patient' [673] (for terms included and counts of skills identified, see Supporting information, Table S2). Second, approaches, techniques and strategies that can be used to support behaviour change were identified, such as confidence scaling, readiness to change and working with resistance; for example, '… assessing readiness to change, exploring and explaining skills, compare ideal with actual, rolling with resistance and negotiation' [559]. Third, personal attributes and interpersonal skills were highlighted; for example 'Qualities including being non-judgemental, accepting, empathic, compassionate' [606].

Post-registration training undertaken

When asked about post-registration training undertaken in CSBC, 520 (74.7%) had received training, 162 (23.3%) had not and 14 (2.0%) had no recollection. Those who trained > 10 years ago were significantly more likely to have had post-registration (84.1%) than those who had trained within the last 10 years (37.0%) (χ^2 = 141.696, df = 2, n = 696, p < 0.001). The types of training received were predominantly attending a formal training session or course (n = 497), self-directed learning (n = 228), observing/shadowing colleagues (n = 226) and having a consultation observed by peers with informal feedback (n = 181). Fewer people had audio-/video-recorded consultations for self-reflection (n = 90), consultations observed by tutors with informal feedback (n = 89) or used any kind of online training programme (n = 9).

Of those who had accessed post-registration training (n = 520), the majority (n = 514; 99.6%), stated they had applied some of their learning into practice and two (0.4%) said

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TABLE 3 Respondents' views on teaching methods to use in pre-registration education

	Setting for delivery of teaching						Teaching method inappropriate		Missing data
	Both		University		Placement				
Teaching method	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*
Lectures	166	26.2	431	69.1	3	0.5	33	5.2	96
Consultations with real patients	256	39.9	2	0.3	370	57.7	13	2.0	88
Observing a demonstration of skill (video or live)	477	74.1	151	23.4	15	2.3	1	0.2	85
Online training packages (e.g., DIET-COMMS)	360	62.0	165	28.4	12	2.1	44	7.6	148
Role-play (an opportunity to practice skills)	468	73.0	161	25.1	7	1.1	5	0.7	88
Role-play: with a real patient	241	38.4	85	13.5	193	30.7	109	17.4	101
Role-play: audio-recorded and listened back	258	41.0	306	48.6	12	1.9	53	8.4	100
Role-play: video-recorded and watched back	253	39.9	357	56.3	13	2.1	11	1.7	95
Role-play: observed by peers, followed by informal feedback	349	55.6	222	35.4	33	5.3	24	3.8	101
Role-play: observed by tutor, followed by informal feedback	336	52.8	276	43.4	16	2.5	8	1.3	93
Role-play with formal assessment [e.g., Objective Structured Clinical Examination (OSCE)]	177	28.7	366	59.4	14	2.3	59	9.6	113

they had not (four missing data). There was no difference between those qualified < 10 years (98.8%) and those < 10 years ago (100%) (Fisher's exact, $p = 0.112$). The only reason identified for being unable to implement training ($n = 1$) was that the training undertaken did not equip the dietitian to change practice. The perceived impacts of post-registration training on practice (Table 4) were positive, although some respondents stated that post-registration training in CSBC was inapplicable to specific aspects of practice.

Recommendations for post-registration training

Most respondents ($n = 594$; 93.7%) stated that post-registration training in CSBC was needed (95 missing data). Those who trained < 10 years ago were significantly less likely to state that most dietitians needed post-registration (89.7%) than those who had trained > 10 years ago (94.7%) ($\chi^2 = 4.274$, $df = 1$, $n = 634$, $p = 0.039$). A range of advanced skills and strategies were deemed appropriate for post-registration training, including motivational interviewing ($n = 495$), cognitive behavioural strategies ($n = 421$) and mindfulness ($n = 346$). Work-based learning was highly rated ($n = 416$) and training incorporating both theory and skills ($n = 433$) was more highly rated than either theory-based ($n = 58$) or skills-based ($n = 283$) learning.

Half of the respondents ($n = 318$; 50.9%) stated that CSBC were more relevant to specific dietetic roles than others and 307 (49.1%) disagreed. Those who had trained < 10 years ago were more likely to consider that these skills were more relevant to some roles than others (58.9%) in comparison to those who trained >10 years ago (48.9%) ($\chi^2 = 3.952$, $df = 1$, $n = 625$, $p = 0.047$). When asked to explain their answers, three themes were identified (56 comments). First, that individual training needs differ; for example, 'The type of post-registration training required is dependent on the individual and the amount of training received pre-registration as well as the area of work (i.e., oncology) requires highly specialised communication skills where CBT, mindfulness and motivational interviewing is key whereas CBT may be less relevant to paediatrics' [476]. Second, these skills were described as so important that they should be incorporated into all post-registration training, for example, 'I believe that communication skills should be weaved through every

TABLE 4 Impact of post-registration training on practice

Aspect of practice	Improved		No change		Got worse		Not applicable		Missing data
	n	%	*n*	%	*n*	%	*n*	%	
Your relationship with clients	475	95.0	20	4.0	0	0	5	1.0	14
Your relationship with colleagues	322	64.4	171	34.2	1	0.2	6	1.2	14
Your job satisfaction	421	84.2	77	15.4	0	0	2	0.4	14
Client satisfaction	457	92.4	26	5.3	0	0	12	2.4	19
Client DNA[a] rates	168	34.0	219	44.3	2	0.4	105	21.3	20
Client clinical outcomes	397	80.7	62	12.6	0	0	33	6.7	22
Your confidence in client interviews	459	92.0	34	6.8	1	0.2	5	1.0	15
Your time keeping in client interviews	226	45.4	178	35.7	82	16.5	12	2.4	16
Your ability to cope with challenging clients	466	93.4	28	5.6	0	0	5	1.0	15

[a]Did not attend.

aspect of post-graduate training to increase client adherence to therapeutic nutritional diets' [73]. Third, the need for constant review or refresher sessions was highlighted, with some suggesting these should be formal or mandatory; for example, 'I think that it should be mandatory that updates/refreshers are undertaken every few years to ensure 'competency' and sharpening of skills as it is easy to slip into bad habits. The refreshers would re-focus peoples' attention on their communication skills' [226], and 'I think there should be a baseline level of skill that should be maintained permanently post registration with the option to increase skill level as job role requires but alongside support to maintain these higher level skills year on year' [55].

Respondents who stated that dietitians do not need post-registration training in CSBC were asked to explain their reasoning. Two key themes were identified (40 comments). First, that it should be covered in pre-registration education; for example, 'This should be part of the dietetic training at university' [548]. Second, that skills are learned on the job and by experience, rather than by going on courses; for example 'Because we learn the basic skills during pre-registration and then these skills are developed through experience and practice, not formal training' [133].

Respondents (n = 513; 83.6%) reported they would personally benefit from further training, particularly in more advanced skills such as cognitive behavioural strategies (n = 417), motivational interviewing (n = 402) and mindfulness (n = 362). Those who had trained > 10 years ago were less likely to feel that they would benefit from further training (81.12%) than those who trained < 10 years ago (93.4%) (χ^2 = 10.612, df = 1, n = 614, p = 0.001). The most popular type of training desired (in line with what they stated post-registration training should include) was mixed (theory with opportunities for skill practice) (n = 332) as opposed to solely skills-based (n = 211) or theory-based (n = 52) learning. The most popular options for training delivery methods were external courses (n = 365) and work-based learning (n = 347), followed by online training packages (n = 299) and self-directed learning (n = 190). Comments (n = 16) were variable and included personal preferences for options, but the main theme was being unable to secure time or funding for external courses, even though face-to-face training was preferred; for example, 'Difficult to get external courses funded and agreed to but better if it could be that route. Just have to be realistic in the current NHS financial situation' [516].

When asked if individual practitioners should have their CSBC reviewed regularly post-registration, the majority 456 (74.5%) agreed they should (117 missing data). There was no significant difference in views depending on when respondents qualified (p = 0.755). Of those who supported skill review, 218 (48.1%) stated that it should be voluntary and 235 (51.9%) that it should be mandatory (three missing data). Those more recently qualified were more likely to support voluntary (62.9%) than those qualified > 10 years ago (44.5%) (χ^2 = 9.715, df = 1, n = 453, p = 0.002). The most popular timeframes for skill review were every 2 (n = 145, 32.0%), 3 (n = 133, 29.4%) or 5 (n = 109. 24.1%) years (276 missing data).

There were 148 comments relating to why there should not be regular post-registration review of skills and three main themes were identified. First, that review of skills should be (or already is) part of existing supervision or performance review, where outcomes may indicate a training

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need, and that individuals are responsible, as professionals, for identifying their training needs. For example, 'I think you pick this up at annual reviews with staff as how they communicate is reflected in outcomes, complaints and compliments' [89] and 'I believe that it is the individual's responsibility to maintain all aspects of CPD, seeking support with this where necessary' [504]. The second theme relates to considerations about how training and/or review of skills could or should be incorporated in a supportive and objective way, particularly when time and money are so short in the workplace. For example, 'Regular training updates are important to allow the individual to feel confident with their practice, rather than regular review' [243], 'They're quite subjective things to review' [182] and 'It's difficult enough undertaking all the CPD and mandatory training we require as it is'. [518]. Third, teaching and learning of CSBC post-registration are not seen as a priority. These respondents stated that it should be covered pre-registration and, once learnt, the skills are not lost. They questioned why dietitians should have the stress and anxiety of skill review and being told they are no good, when they have so many other skills and knowledge to keep up to date with. For example, 'Expect a certain level of ability on qualification and would not expect this to deteriorate significantly and believe that presently other priorities more important' [569] and 'it's a lot of pressure on top of an already pressured job' [149] (for further details, see Supporting information, Table S3).

DISCUSSION

This survey of BDA members provides insight into UK dietitians' current views on the importance of CSBC in dietetic practice and enables some comparisons to views reported 10 years ago. The respondents were from all UK countries, mainly worked in the NHS over a range of specialities, and ranged from recently qualified to highly experienced dietitians. The majority spent much of their working life directly in contact with patients and perceived CSBC as being relevant to their practice. Respondents were positive about the importance of CSBC for delivering patient-centred care in dietetic practice. This is as expected because of the consistent emphasis in curricula, policy documents and Standards of Proficiency.[5,10,11] These findings are consistent with the previous survey.[9]

Pre-registration training

All UK pre-registration courses are accredited by the BDA and must meet the Health and Care Professions Council Standards of Proficiency.[11] The curriculum and graduate capabilities include specific aspects of communication, patient-centred care and values-based care, consistent with CSBC.[10] HEIs train students in these skills, although the methods vary. HEIs are continually updating course structures, content and teaching methods, with new courses having been established, and there have been reported developments in CSBC training over the last 10 years. This may explain why those qualified more recently report a much higher level of dedicated training in CSBC. A cross-sectional survey of UK pharmacists (n = 109) found similar results, with more than half reporting not receiving CSBC training as undergraduates or being dissatisfied with the training they had received,[44] whereas more recently qualified staff reported more training and greater satisfaction. These results suggest that pharmacy educators are also developing educational approaches to support development of CSBC and delivery of patient-centred care.

Dietitians' views on how CSBC should be taught pre-registration varied but, importantly, they were open to different methods being used, including new technologies. Those teaching and assessing these skills, both at HEIs and in practice education, must keep informed and explore new options. This may be challenging, with new graduates having received more pre-registration CSBC training than more experienced staff. Post-registration training, which many dietitians have accessed, is essential for ensuring that experienced staff have the appropriate skills, particularly if they assess students. Some of the negative experiences reported with pre-registration training of CSBC are related to the lack of constructive feedback provided.

A systematic review of medical training suggests that a mix of educational methods is required to develop communication skills.[45] Recently, in dietetics, students have reported positive experiences within communication skills training, which included formal teaching, skills practice with simulated patients, observation, feedback and reflection, and OSCE.[30] There was also increased confidence in their skill level, although this was not related to an objective measure of skill or subsequent performance. Although performance at OSCEs has been related to placement outcome,[46] details on the specific communication skills assessed were not provided.

Views of own skills

Although some respondents lacked confidence, more respondents were positive about their skill level than previously (83.6% vs. 62%), which may be related to the increase in pre-registration training reported. A review of interventions designed to enhance communication skills in allied health professionals found that there was no clear relationship between perception of ability and what was observed in practice.[37] The recommendation was that independent observations, using validated tools, were needed to assess skill level, and that patient outcomes such as satisfaction and health-related behaviours were also needed.

There was also a view expressed in the present study that skills are developed through experience and practice rather than attending training. A validation study for DIET-COMMS,[47] an assessment tool for CSBC, showed that median scores for qualified staff were higher than for final year

students, although the range of scores was wide and some qualified staff had lower scores than students. This suggests that assuming skills will automatically improve over time may be incorrect, as has been reported elsewhere.[48] Independent observation of CSBC is not routine in UK dietetic practice,[9] but objective measures of skill are important to ensure that patient-centred care is being delivered and to support those who are lacking skill or confidence.

Post-registration

The proportion of respondents who had undertaken post-registration training was similar to the previous survey (73% in 2007 vs. 74.7% in 2018). The key difference was the perceived ability to translate training into practice. Previously common barriers identified (436 comments) included lack of support from management and colleagues, lack of confidence in skills and insufficient time for consultations. In 2018, there was just one comment. This change may be a result of differences in amount of training and type of training methods, wider culture changes within work environments, or the continual emphasis on both patient-centred care and values-based care.[5,49–51] A combination of these factors may be contributing to the embedding of patient-centred care as the only acceptable way to work in practice.

The impact of post-registration training on practice was positive. The only aspect some identified as worsening was time keeping in client interviews, although this has improved since the previous survey (45.4% vs. 31.7%). This concern about CSBC taking more time in consultations has been reported more widely[6–7,9] and, for some, is a barrier to implementing further behaviour change skills into practice. Further work is needed to support training transfer into the workplace.

Fewer dietitians indicated the need for post-registration training in advanced communication skills and strategies than previously (92% in 2007 vs. 83.6% in 2018). This may reflect their confidence and training already received. However, barriers to taking time out of the work environment and obtaining funding for external courses remain. Many wanted access to online training resources, which would be more flexible, easier to access and less costly, although few were aware of, or using those currently available. This suggests a need for increasing awareness and further development and evaluation of such resources.

Some respondents stated that post-registration training was not required and that pre-registration training was sufficient. This may reflect the view expressed by some that CSBC training was not a priority. It may also reflect increasing levels of anxiety in the general population and in healthcare students, particularly in relation to skill review.[52] In Australia, dietitians have recognised the basic level of competence achieved in pre-registration training and the need for mandatory review to support the development of CSBC further.[53] Still remaining, though, are practical questions regarding how this could be achieved, how effective it would be and what tools could be used to assess skill attainment. Specific validated tools such as DIET-COMMS have been successfully utilised to support peer review in dietetics.[54] Nevertheless, training is required to support the effective use of any assessment tool and to ensure the correct use and provision of supportive feedback, a concern raised in this survey. A literature review and synthesis of relevant guidance and regulations, across a range of healthcare professions, has found that the use of video-recording healthcare communication, as already happens routinely in medicine, is acceptable and worthwhile, although ethical issues need to be considered.[55] Recommendations on good practice have been developed supporting this method in research and practice. The present survey was not designed to assess skills but has shown mixed views regarding whether assessment of CSBC should be considered in practice or not. Although over half of respondents indicated that it should be mandatory, there were almost as many resistant to the idea, which may be a barrier to its implementation. Video recording, although facilitating objective assessment and reflection, may lead to a higher level of anxiety for some dietitians; however, there is little evidence to say that video recording has a detrimental impact on consultations, with patients reporting positive attitudes if the goal is improved healthcare communication.[55] Importantly, video recording enables fidelity checking, to assess whether training received has led to the desired changes in skill use in practice.[56,57] With concerns being raised about cost of training, both financial and with time, further evaluation of training options to ascertain the most effective, and cost-effective options is needed.

Future studies could ascertain the most effective and acceptable training methods, both pre- and post-registration, that are practical, affordable and supportive. Understanding the graduate skill level across HEIs with different teaching methods and course structures would provide an insight into the effectiveness of pre-registration CSBC training. To provide robust data, validated tools should be used to measure CSBC and/or patient-centred care alongside patient outcomes such as satisfaction, adherence to agreed goals and clinical outcomes. Research in settings, including secondary care, telehealth, group education and non-NHS areas of practice, is needed to reflect the broadening scope of dietetics.

Strengths and limitations

The survey targeted all BDA members and many responded, although the response rate was only 9.4%. Respondents may have been interested in CSBC, therefore biasing the sample. It was not possible, however, to make further contacts aiming to increase the response rate. Cross-sectional surveys are also subject to recall bias, but they enable large numbers of people to be accessed and are relatively economical in relation to time and resources.[42]

A paper survey may have achieved a greater response, whereas online surveys are less costly, easier to administer,

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accessible, decrease time required for data entry and decrease the risk of data entry error by researchers.

Missing data may also have affected the results obtained. Why some respondents failed to answer all questions is unknown, but the questionnaire took 15–20 minutes to complete, which may have lead to fatigue towards the end.[58] Because the aim was to repeat the previous survey, shortening the questionnaire was inappropriate.

Both of the investigators in the present study have undertaken teaching and research in the area of CSBC that will have impacted on the interpretation of the qualitative data.[59] To reduce this, the investigators reviewed qualitative data independently before discussing and reaching agreement on the identified themes. Reflexivity, however, must be acknowledged.

Statistical analysis between the two surveys was not attempted as a result of the cross-sectional survey design and resultant differences in the survey population. However, as a proxy, comparisons were made between those qualified since the previous survey (< 10 years) and those who would have been qualified when the previous survey was undertaken (> 10 years ago). Comparisons, although less robust, do provide some insight into trends over the 10-year period.

This survey has only considered dietitians views and is therefore not providing a true picture of skill level or, importantly, patient views.[60] Patient views would provide greater insight into how skills should be delivered in practice and their impact on outcomes[27–28] and further research is needed in this area.

CONCLUSIONS

This survey has identified that dietitians continue to view CSBC as being important in dietetic practice. There appears to have been a shift since the previous survey, with perceived ability to apply CSBC increasing, alongside a reported increase in pre-registration training in CSBC. Fewer barriers to implementation of skills were identified. There is support for mandatory skill review post-registration. However, financial constraints and time barriers continue to be perceived as barriers to post-registration training. Questions regarding the best way to implement evidence-based pre- and post-registration training in CSBC remain, and cost-effective, pragmatic methods that enhance dietitians' skill development in a supportive way are required.

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CONFLICT OF INTERESTS

The authors have no conflicts of interest.

AUTHOR CONTRIBUTIONS

KW, TP and JS revised the survey. TP and KW analysed the data. Both KW and TP wrote the first draft, reviewed and commented on the subsequent drafts of the manuscript, and approved the final version submitted for publication.

ETHICAL APPROVAL

Ethical approval was received from the School of Sociology and Social Policy, University of Nottingham (BIO-1718-0001).

TRANSPARENCY DECLARATION

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 STROBE 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.

PEER REVIEW

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AUTHOR BIOGRAPHIES

Kirsten Whitehead qualified as a dietitian in 1985. She worked in both hospital and community NHS dietetic posts for over 20 years. Her roles covered a variety of clinical conditions including specialist roles in HIV, cardiovascular disease, obesity and public health. She completed a Masters in Public Health in 2000.Kirsten moved into higher education in 2002 and taught on the Master of Nutrition and Dietetics degree at the University of Nottingham until 2019. During that time she completed her PhD on communication skills in dietetics. That work included a survey of BDA members views on communication skills which has recently been repeated. The PhD also included the development and validation of the DIET-COMMS tool which is designed to assess communication skills within the context of a dietetic consultation. Subsequently this led to the development of an open access training package to support the use of DIET-COMMS in practice https://www.nottingham.ac.uk/dietcomms/. Kirsten is now working freelance as a dietetic educator and is continuing with some research into communication skills in dietetics.

Tracey Parkin qualified as a dietitian in 1990, she worked in the NHS covering a range of specialities before specialising in diabetes. Where she worked for 14 years supporting the development of structured education programmes and researching behaviour change and communication skills to support self-care management. In 2006 she joined the BSc (Hons) Dietetics programme at the University of Plymouth, she became the programme lead in 2016. Her doctorate focuses on "empathy" and "information exchange" within the dietetic consultation for chronic disease management, this was completed in 2012. Tracey has continued researching this area, developing education to support competency in skill attainment when communicating for behaviour change. More recently she has been focusing on motivation to support behaviour change and has been working with psychologists using functional imagery training (FIT) in the area of weight management. She is passionate about researching and developing behaviour change and communication skills in dietitians and other health care professionals, and contributes to teaching in this area across a variety of undergraduate and postgraduate healthcare programmes.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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Competency-based assessment in nutrition education: A systematic literature review

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Abstract

Background: A suitably prepared and qualified nutrition and dietetics workforce is part of the solution to combating the burden of disease. Competency-based assessment is a key part of the education of future workforces. Although there has been recent attention on competency-based assessment in dietetics, there is little exploration of competency-based education for the preparation of nutritionists. The present study aimed to understand how competency-based assessment is implemented and evaluated in nutrition education.

Methods: A systematic literature review was carried out according to PRISMA guidelines. Four databases were initially searched in February 2020 using key words related to *competenc** in combination with *nutrition* or *dietetic* and their synonyms. An updated search was completed again in March 2021. Studies that met eligibility criteria where the focus was on nutrition and involved a method of competency-based assessment were synthesised narratively.

Results: From a total of 6262 titles and abstracts, six studies on competency assessment in nutrition education were identified. The assessments focused on the development of key skills, including motivational interviewing and nutrition assessment, changes to knowledge and attitudes on food and culture, and self-perceived development of communication, collaboration, management, advocacy, scholarship and professional capabilities. No studies were found that assessed promotion of health and wellbeing or the food chain competencies.

Conclusions: The lack of research in competency-based assessment must be addressed to ensure we are effectively preparing future nutritionists for work such that they can impact health outcomes.

KEYWORDS

assessment, competency, nutrition education

Highlights

- Competency-based assessment (CBA) is a key part of the education of future nutrition workforces.
- This systematic literature review highlights that there are few publications of competency-based education for the preparation of nutritionists.
- There is a need to encourage the development of a programme of research that supports the progression and evaluation of credible, dependable and feasible CBA systems in nutrition education.

[Correction added on 27 December 2021, after first online publication: Peer review history statement has been added.]

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INTRODUCTION

Dietary risk factors account for much of the burden of ill health and death across the world.[1] A suitably prepared and qualified nutrition and dietetics workforce is part of the solution to combating the improvements needed to address this burden of disease. Competency-based education frameworks ensure the workforce meets current and future health and, in this context, nutrition needs.[2] Competency standards or frameworks are a key part of competency-based education. Competency-standards describe the skills and abilities required of the workforce which guide curricula supporting the preparation of graduates for the workforce. Competency-based assessment (CBA) involves measurement of a student's competence by analysing their performance and achievements against competence standards[3] or the processes used to measure a student's ability to apply theory into practice,[4] and is a key part of educating future workforces. Although there has been recent attention on CBA in dietetics,[4–8] there is little exploration of competency-based education for the preparation of nutritionists.

Nutritionists are nutrition science experts. In Ireland and the UK, the role of a nutritionist is to provide scientific evidence-based information on food and healthy eating to individuals or the larger public outside of hospital settings,[9] mainly working in preventative roles, across multiple sectors, predominately with healthy people and populations.[10] Although the definition and function vary across the world, primarily as a result of a lack of regulation of the title 'Nutritionist', in the UK, nutritionists can apply for registration. Implicit in this registration system the five core nutritionist competency areas are science, food/feed chain, professional conduct, social/behavioural, and health/well-being.[11] There is an accreditation system based on these five core competencies and set accreditation standards to educate nutritionists. This is a voluntary accreditation system carried out by the Association for Nutrition (AfN), for both individuals and courses. The process for accreditation includes mapping a program's curriculum and modules to these core competencies and the standards for ethics and conduct. Evidence of assessment for each competence is required to show that the level of competencies acquired upon completion of the degree meet the high standards expected. Registering as a nutritionist with the AfN provides assurance to future employers and clients that high standards of competence and professionalism have been met,[9] as well as offering a guarantee to the public about the quality of the nutritionist. Yet, there has been no examination of the CBA processes or methods used in the preparation of nutritionists for the workforce in the UK or beyond.

Ensuring future nutritionist graduates are adequately prepared for the workforce is essential to improve population health and nutrition. Understanding how CBA of nutritionists is carried out will provide insight into the adequacy of this preparation. Therefore, the primary aim of this systematic review is to understand how CBA is implemented and evaluated in the preparation of nutritionists internationally.

METHODS

Search strategy

A systematic review (PROSPERO registration: CRD420 21237951) was carried out according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[12] The PICO (Participant, Intervention, Comparator, Outcome) framework was used to define the research question: How is competence assessed in nutritionist training? A systematic literature search was carried out in February 2020 using the databases: PubMed, CINAHL Complete, Web of Knowledge and Science Direct. Following an initial search of the databases to identify key search terms, a comprehensive search was completed to gather all relevant studies. Key words used included *competenc** in combination with *nutrition* or *dietetic* and their relevant synonyms. Searches were exported for screening (see Supporting information, Appendix S1). An updated search was carried out in March 2021 to capture any new research meeting the PICO criteria.

Study selection

A three-stage screening process was carried out. The first and second stages were completed by the first investigator (SOD) to remove all duplicates and review titles, and then abstracts. Over 10% of abstracts were screened by all investigators (SOD, CP, LR) and differences were discussed to reach agreement. The third stage involved all authors reviewing the studies in full against the criteria (Table 1) to identify those eligible for inclusion. Any disagreement about the eligibility of studies was resolved by consensus between three investigators. Only empirical research studies of any study design, focused on implementation and evaluation of competency assessment in nutrition education, and written in English, were included. Studies focussed on CBA in dietetics education, opinion pieces or editorials were excluded.

Data synthesis

A data extraction template was developed and included authors, year of publication, location, sample population, competency assessment method, method of evaluating the competency assessment, results and competency assessed based on AfN Competency Standards (see Supporting information, Appendix S2). The Critical Appraisal Skills Program (CASP) Qualitative Research Checklist (10 questions),[13] was used to assess the quality of the qualitative studies included. The CASP Cohort Study Checklist

TABLE 1 Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Population	Humans Adults ≥ 18 years Students/graduates of nutrition degree	Animals Children Courses on nutritional therapy Degree programs < third level Dietetics only
Intervention	Implementation of competency-based assessment Evaluation of competency-based assessment	No mention of competency-based assessment or its evaluation
Comparator	NA	
Outcome	Opinion on competency-based assessment Analysis of effectiveness/pre- and post-analysis of competency	No measure of competency analysis
Study design	Primary empirical research (all study designs) English language only	All other study designs and non-English publications

Abbreviation: NA, not applicable.

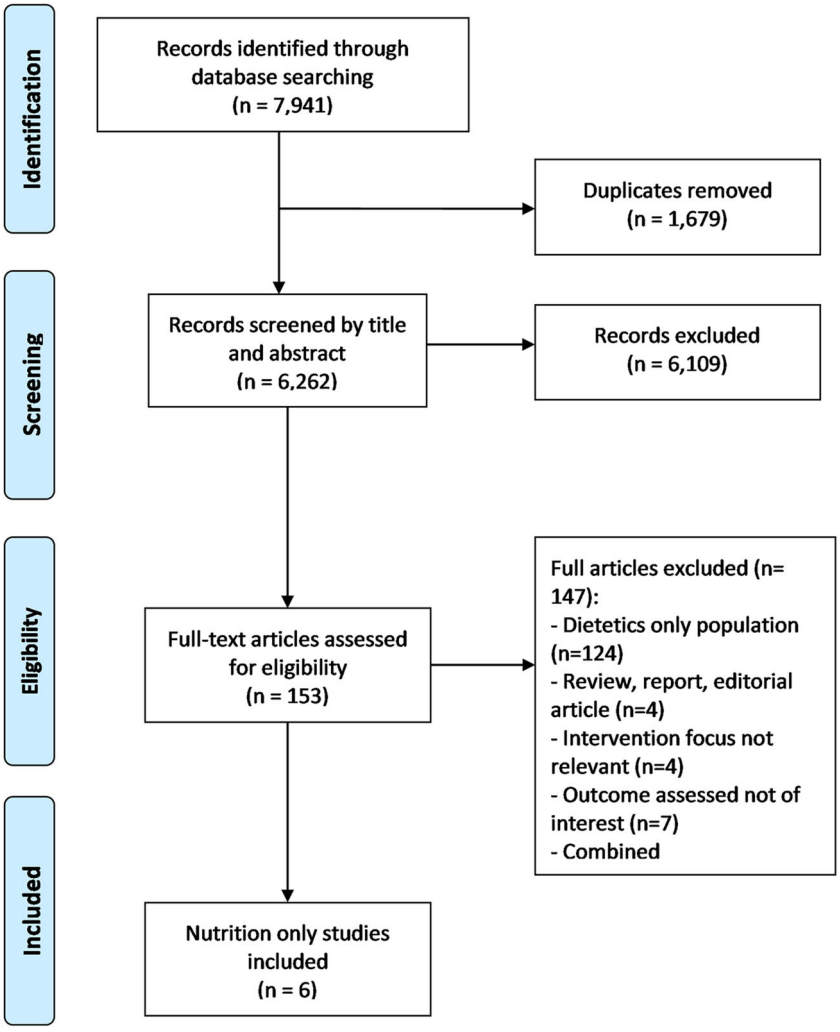

FIGURE 1 PRISMA flow diagram illustrating the process of reviewing and identifying eligible studies which meet the outlined PICO (Participant, Intervention, Comparator, Outcome) criteria

(12 questions)[13] was used to assess the quality of the quantitative studies. A three-point rating system of low, medium or high indicated the quality of each article. Studies were rated as low (≤40%) ≤4/10 or 5/12; low–moderate methodological issues), medium (between 40% and 70%; minor methodological issues) and high (≥70%) (≥7/10 or 9/12; high–robust). Extracted data were synthesised using a narrative approach where all elements of each of the included studies were summarised narratively.[14] All studies, regardless of quality, were weighted equally in the synthesis.

RESULTS

In total, 7941 records were identified through the database searches. After removal of 1679 duplicates, six nutrition only studies were eligible for inclusion (Figure 1). Of the six included nutrition studies, four were qualitative[15–18] and two were quantitative.[19,20] Mapping these to the AfN areas of core competency highlighted that a different competency area was assessed within each of the studies. These included, cultural competence,[17,19,20] behaviour change counselling,[15] self-reflection[16] and nutritional assessment skills.[18] The Feed/Food Chain (C2) and the Health/Wellbeing (C4) competencies were not covered by any of the included studies (Table 2). The methods used to gain feedback on the assessment approaches included face-to-face interviews, portfolio analysis, pre- and post-analysis questionnaires, and video assessments. Of the six studies analysed using the CASP checklists, four were of high quality and two were of medium quality as a result of a lack of details surrounding the research design and recruitment strategies

Synthesis of results

The sample populations of the studies ranged from 20 to 52 students of nutrition specific degrees (Table 3). The geographical locations of the studies included Africa,[16] Europe,[15,16,18] North America,[19] Australia[20] and South America.[17] In five studies, performance was assessed using objective ($n = 5$) tests of knowledge.[15,17–20] Marais et al.[16] was the only study that implemented a subjective assessment using self-reflection via an interview.

An interactive course exposing students to theoretical and practical knowledge about cultural competence was implemented in the study by Bauer and Bai.[19] They used the Campinha–Bacote model to design, implement and evaluate the effectiveness of this course along with a pre- and post-test comparison using the Inventory for Assessing the Process of Cultural Competence among Healthcare Professionals – Revised (IAPCC-R).[19] The Campinha–Bacote model is described as a process made up of five components that healthcare staff must learn to develop in order to deliver high-quality care to patients in culturally diverse environments.[21] These five components are cultural awareness, cultural knowledge, cultural skill, cultural desire and cultural encounter. Total competence scores significantly improved from 'culturally aware' (score of 68.7 at pre-test) to 'culturally competent' (score of 78.7 at post-test) ($p < 0.001$) after the interactive course. Cultural desire was the only one out of five constructs not to increase significantly after the course.

Similarly, McCartan et al.[20] evaluated the effect an Aboriginal health curriculum had on the cultural capabilities of a cohort of first-year students enrolled in a Bachelor level nutrition science program. A survey was created incorporating a 25-item Cultural Capability Measurement Tool (CCMT). This tool measures five learning domains including respect, communication, safety and quality, reflection and advocacy.[22] Students completed the survey in Semester 1 (T1) before receiving the Aboriginal health curriculum, and again during Semester 2 (T2) after completing the curriculum. Students' total CCMT scores increased significantly from the T1 to T2 surveys ($p = 0.001$) indicating an increase in rating of their cultural capabilities after exposure to the curriculum. They were also asked to assess their attitude towards the importance of an Aboriginal health module. A statistically significant increase was found from T1 compared to T2 ($p = 0.020$) for the rating of importance, with the T2 median of 4.93 out of 5 showing almost complete agreement.[20]

In Brazil, Sabatini et al.[17] used portfolio construction and focus groups to assess knowledge of food and culture. Three focus groups were conducted 1 year after the development of the portfolios to assess if they had a long-term effect on the student's knowledge. Students felt that the portfolio had been demanding but instilled a curiosity and autonomy for learning in them to seek more information on

TABLE 2 Included studies mapped against the Association for Nutrition (AfN) core competencies

AfN core competency	Competency sub-group covered
Science (C1)	Garcia de Diego et al.[18]: *CC1g – Nutrient analysis: calculating nutrient contents of foods, feeds and diets of an individual or group of individuals or animals, justifying choice of a method of dietary assessment for a specific stated purpose*
	Sabatini et al.[17]: *CC1o – Prepare, process, interpret and present data, using appropriate qualitative and quantitative techniques, statistical programmes, spreadsheets and programs for presenting data visually*
Food/feed chain (C2)	
Social/behavioural (C3)	Bauer and Bai[19] and McCartan et al.[20]: *CC3d – Religious and cultural beliefs and practices that impact on food, nutrition and health*
	Simper et al.[15]: *CC3f – Theories and application of methods of improving health, behaviour and change for either human or animal systems*
Health/wellbeing (C4)	
Professional conduct (C5)	Marais et al.[16]: *CC5c – Legal context of nutrition practice; including current relevant legislation and guidelines to providing information to individuals*

TABLE 3 Summary of the main information extracted from the studies included in the systematic literature review

Author, date, setting	Sample population	CBA method	Method of evaluating CBA	Main results	Quality analysis (CASP) rating[13]
Simper et al.,[15] Sheffield Hallam University, UK	52 students from final year undergraduate nutrition cohort	Behaviour change counselling competence following 5 × 3 h motivational interviewing training sessions, two recorded practice sessions (at beginning and end) with an actor portraying a client and one feedback session	Video assessment at baseline and follow-up after training sessions	• Significant improvement seen for all six of the behaviours coded. A decrease in closed questions and non-adherent behaviour and an increase in open questions, complex and simple reflections, etc. • Talk time ratio also improved with nutritionists allowing more time for the client to talk and elaborate • Baseline proficiency was seen to be below where it should be for all clinician-behaviour counts. At follow-up, these were above beginning proficiency showing an improvement for all students to being on the way to becoming competent. Improvement was significant for all counts with $p < 0.001$	8/10
Marais et al.,[16] Universities in Norway, Uganda and South Africa	20 students completing master's degree in Nutrition in universities in Norway, South Africa and Uganda, 16 were female, Mean age (SD) was 30.2 (6.0) years	Self-reflection interviews following 18-week NOMA track module	Interviews themed by CanMEDS competency framework	Themes suggest students developed competency: • As communicators • As collaborators, health and nutrition professional effectively work within a team to achieve optimal service-user care • As managers • As health and nutrition advocates • As scholars • As professionals	5/10
Sabatini et al.,[17] UNIFESP, Sao Paulo, Brazil	29 (of 49) students majoring in nutrition submitted portfolios for analysis 11/29 attended focus groups evaluating the portfolio	Construction of portfolio about food and culture	Focus group and analysis of portfolios one year after development	• Significant manifestation of how the portfolio stimulated curiosity and autonomy for learning, and fostered greater interest in food and culture • Greater sociocultural appreciation of eating observed • Students perceived the creation of the portfolio as an exciting and engaging process, although demanding • Similarity between messages recorded in portfolios and opinions expressed in	7/10

TABLE 3 (Continued)

Author, date, setting	Sample population	CBA method	Method of evaluating CBA	Main results	Quality analysis (CASP) rating[13]
				focus groups conducted after 1 year, suggesting portfolio had a long-term reach, promoting reflection and autonomy	
Garcia de Diego et al.,[18] University of Navarra, Spain	30 volunteers: 14 students of master's degree in Food Science, Nutrition and Metabolism; 12 health sciences graduates; and 4 PhDs in nutritional sciences	Ability to use new computer assisted instruction (CAI) tool to carry out dietary nutritional assessments	Questionnaires assessing students' knowledge of clinical assessment tools, functionality of new CAI, usefulness in improving nutritional assessment skills	• Students completed simulations using the tool and found it easy to use, comprehensive and detailed in its content; however, they wished it had a search engine integrated and it lacked the ability to extrapolate the data to a statistical software • Compared to other assessment tools students found it to be more intuitive and 'more complete in the area of diagnosis'[18] • New tool was useful and 97.7% found it helped in identifying diseases and monitoring patients' progress • Overall score of 8.28 on scale of 1–10 for usefulness, functionality, and applicability	5/10
Bauer and Bai,[19] 2015, Montclair State University, New Jersey, USA	34 students completing Master's in Nutrition and Food Science with a concentration on nutrition education across 2010 and 2011 cohorts	Interactive course on cultural competence exposing students to theoretical and practical knowledge about cultural competence	Pre- and post-test comparison using IAPCC-R 2002 and the five constructs from Campinha–Bacote model	• Total competence score improved from 'culturally aware' (score of 68.7 at pre-) to 'culturally competent' (score of 78.7 at post-), $p < 0.001$ • Scores for each construct of the model also improved after completion of the course, $p < 0.001$, except for desire $p = 0.09$ • Students perceived that a course providing multiple interactive activities addressing constructs of this model was very useful • Journals kept by students allowed the instructor to observe trends or changes in student opinions and reactions. For example: 'I did not cringe or squirm (as I thought I might) when I read about the pig's throat being slit because I began to understand the practice as	11/12

(Continues)

TABLE 3 (Continued)

Author, date, setting	Sample population	CBA method	Method of evaluating CBA	Main results	Quality analysis (CASP) rating[13]
				something very special and sacred to the Hmong'. I ask myself, 'Who am I to judge the beliefs and practices of other people?'[19]	
McCartan et al.,[20] Monash University, Melbourne, Australia	22 first-year Bachelor of Nutrition Science students. Mean age (SD) was 20 (7) years. 77% had previous experience meeting an Australian Aboriginal person and 73% had received Indigenous education at school	Evaluation surveys incorporating the CCMT to measure students' self-rating of cultural capability before and after exposure to Aboriginal health curriculum	Pre- and post-comparison of survey using 25-item CCMT measuring cultural capability	• Students' total CCMT scores increased significantly from T1 to T2 surveys ($p = .001$). • Differences in CCMT scores between T1 and T2 were significant in five out of 25 items ($p < .005$). Two of these were in the respect learning domain and the other three were in communication, reflection, and advocacy learning domains. No items in the safety and quality learning domain were significantly different from T1 to T2. • A statistically significant increase was found from T1 compared to T2 ($p = .020$) for rating of importance of an Aboriginal health curriculum in nutrition education, with the T2 median of 4.93 out of a possible 5 showing almost complete agreement	11/12

Note: CanMEDS is a Canadian framework that identifies and describes the abilities physicians require to effectively meet the health care needs of the people they serve.

Abbreviations: CASP, Critical Appraisal Skills Programme; CBA, competency-based assessment; CCMT, Cultural Capability Measurement Tool; IAPCC-R, Inventory for Assessing the Process of Cultural Competence among Healthcare Professionals – Revised; NOMA, NOrwegian MAsters (track module on nutrition, human rights and governance).

food and culture. Greater appreciation of eating as a social and cultural act was observed following the completion of the task. The opinions expressed in the portfolios and during focus groups 1 year later suggest that the portfolio had a lasting effect in promoting autonomy and reflection.[17]

Simper et al.[15] utilised pre- and post-test comparison of motivational interview training with a cohort of final year nutrition undergraduates assessing their competence in behaviour change counselling. Video recordings of student–client counselling sessions were taken at baseline and following completion of the training to observe changes in counselling technique. Six behaviours were coded and significant improvements were seen for each across the cohort. These included a decrease in closed questions and non-adherent behaviour that hinder behaviour change, and also an increase in open questions as well as complex and simple reflections. Students also improved their talking to listening time ratio, allowing clients to elaborate more before moving on to the next question. Proficiency at baseline was below where it should have been for all clinician-behaviour counts. At follow-up, these were above beginning proficiency showing an improvement for all students to being on the way to becoming competent. Improvement was significant for all counts ($p < 0.001$).[15]

Post-test only outcomes were used to measure effectiveness in the remaining studies. Marais et al.[16] evaluated the effectiveness of a module in increasing knowledge and awareness around the relationship between human rights, governance and nutrition. The module lasted for 18 weeks, after which self-reflection interviews were carried out with students.[16] The interviews found that students gained insight and increased their competence level as nutritionists in different roles, including communicator, collaborator, manager, health and nutrition advocate, and professional.

In 2015, Garcia de Diego et al.[18] carried out an evaluation of a new computer assisted instruction tool for nutritional assessment. Thirty student volunteers completed the simulations and found the new tool user friendly, with 97.7% of the students finding it helpful for identifying diseases and monitoring patients progress.

DISCUSSION

This systematic literature review aimed to understand how CBA is implemented and evaluated in nutrition education. The assessments focused on the development of key skills, including motivational interviewing[15] and nutrition assessment,[18] changes to knowledge and attitudes on food and culture,[17,20] and self-perceived development of communication, collaboration, management, advocacy, scholarship and professional capabilities.[16] Our results show that there is limited empirical literature describing CBA in nutrition education, with only six studies identified compared to a similar review recently completed in dietetics that identified 37 studies.

Given that there are currently 57 undergraduate degrees and 38 postgraduate degrees accredited with the AfN, it is surprising to see a lack of published literature on credibility, dependability or feasibility of CBA approaches in nutrition. This finding highlights a lack of focus in nutrition education research. It was, however, reassuring to see the focus of assessment on issues such as behaviour change and cultural understanding in some of the included studies. Ensuring that nutritionists are culturally appropriate in their practice is vitally important as populations diversify across the world. An effective nutrition workforce not only understands cultural traditions and reasons for choosing foods, diets, and lifestyles, but also is able to critically examine how their own cultural beliefs, values and implicit biases impact on their practice. Addressing racism and discrimination is a challenge in the preparation of other healthcare professionals.[23] The lack of published literature with respect to assessment supporting competency in the promotion of health and wellbeing, and on the food chain system, was concerning. This was similar to a recent review conducted on CBA in dietetics where the focus was on assessment of individual patient assessment and management skills.[5] The focus on pre-post knowledge and self-rated capability also limits the strength of the assessment outcome evidence.

None of the included studies reported a programmatic approach to assessment of competence where competence was viewed holistically but rather focused on individual competencies. Given that competencies are 'an observable ability… integrating… knowledge, skills, values and attitudes.'[2] and that competence is demonstrating the ability to draw together different skills and attributes to perform in complex settings, there is a need to work towards a more holistic view of CBA in nutrition. This holistic view of CBA in nutrition would move assessment towards authentic tasks that replicate the work required in current and future practice and ensure that nutritionists are prepared to be at the forefront of improving population health and nutrition.

The findings may appear to infer that nutrition education programs across the world are not implementing CBA. This was not the intention of the review but rather highlights the lack of published research in nutrition education. It is possible that nutrition degrees have robust CBA. However, because the scholarship of teaching and learning is in its infancy in nutrition, such work has not been published. We encourage educators to evaluate and publish their work, especially those implementing programmatic approaches that are positioned as best-practice in CBA. This study is limited given the inclusion of English only studies, with studies from non-English speaking countries not being represented.

Preparation of nutritionists for the work and jobs that will support improvements to population health and nutrition is a key part to reducing disease burden. Although competency standards have been articulated for this profession, this literature review provides evidence of a limited number of peer-reviewed research papers in assessments of performance against these competency standards. There is a

need to encourage the development of a program of research that supports the development and evaluation of credible, dependable and feasible CBA systems in nutrition education, or other dietetics or health profession assessments that may be applicable. This system will provide confidence that nutritionists are competent to meet current and future workforce needs.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

All authors conceptualised the study. SOD was responsible for the study searches. LR supported the database search. CP was responsible for duplicate screening of abstracts. SOD and LR were responsible for data extraction. SOD, LR and CP were responsible for evidence synthesis. SOD drafted the manuscript. LR and CP contributed to manuscript preparation.

TRANSPARENCY DECLARATION

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 (submitted for registration with PROSPERO: CRD42021237951) have been explained.

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PEER REVIEW

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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NUTRITIONAL SUPPORT AND ASSESSMENT

A meta-synthesis exploring caregiver experiences of home enteral tube feeding

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Abstract

Background: It is estimated that 18,232 people received home enteral tube feeding (HETF) in the UK in 2013 and HETF often requires reliance on a caregiver. Caregivers are an essential resource, and so research is needed to explore their perspectives to inform how best to support them. Therefore, this meta-synthesis aimed to explore caregiver experiences of HETF.

Methods: A systematic search and a meta-synthesis of the literature relating to caregiver experiences of HETF were undertaken. Ethical approval was obtained from Coventry University Ethics. A comprehensive search of CINAHL, MEDLINE, Academic Search Complete and SCOPUS databases was conducted, followed by a reference list search of included studies. Studies were screened for eligibility using *a priori* inclusion criteria. Included studies used qualitative methodology, were in English, and explored caregivers' experiences of supporting an adult or child receiving HETF for at least 1 month. The meta-synthesis was conducted using a thematic-synthesis method. Included studies were assessed for quality, and rigour was ensured via transparent reporting of methodology, peer review and reflexivity.

Results: In total, 328 records were screened, with 10 studies included and a total of 97 caregivers' experiences were reported. Four analytical themes were developed: loss of a normal life, psychological impact, practical challenges and becoming the 'expert'. Overall quality of the included studies was assessed as good.

Conclusions: This meta-synthesis highlighted the challenges experienced by caregivers, and revealed the need for improved HETF training for caregivers and psychological support from healthcare professionals, with the aim of providing personalised advice and regimes as part of holistic care.

KEYWORDS
home enteral feeding, feeding tube, enteral nutrition, caregiver experiences, meta-synthesis, qualitative

INTRODUCTION

The National Institute for Health and Care Excellence[1] (NICE) recommends enteral feeding for those with a functioning and accessible gastrointestinal tract, but who are malnourished (or at risk of malnutrition) and struggling to meet their nutritional requirements orally, as a result of inadequate or unsafe intake. If long-term nutrition support

is required, a person can be discharged home with an enteral feeding tube.[2]

There is scarce up-to-date information regarding numbers of people receiving home enteral tube feeding (HETF) in the UK at present. The latest British Artificial Nutrition Survey (BANS) reported that 18,232 people were receiving HETF in the UK in 2013.[3] More recent data report that, in 2015, there were 3216 new HETF registrants.[4] Data regarding children has not been updated since 2011, when 448 children were newly registered in the UK in 2010.[5] These figures are now outdated, and the BANS has recently closed its database as a result of a decline in data submission; therefore, it is likely that the actual numbers of those receiving HETF are higher than estimated.

Guidelines state that anyone receiving HETF requires support from a multidisciplinary team (MDT); including dietitians, nurses and general practitioners.[1] The underlying conditions associated with HETF mean many patients also rely on a caregiver. The BANS[4] report found that 59% of newly registered adults required 'some' or 'total' help, meaning that, without this support, they could either not manage to live independently or their health or wellbeing would deteriorate.[6]

Most research into HETF is quantitative, focusing on clinical issues, such as tube dislodgement, blockage and leakage, stoma site infection, over-granulation, diarrhoea, vomiting, and pneumonia.[7] Patients receiving enteral feeding have reported the negative psychological impact that percutaneous endoscopic gastrostomy (PEG) tubes can have: impairing body image, which affects relationships, restricting freedom, and symbolising illness.[8] As the majority of HETF recipients require caregiver input,[4] enteral feeding is likely to also impact caregivers.

Recommendations for effective support for caregivers is highly relevant because it is estimated that caregivers provide around £119 billion of care costs per year,[9] making them an essential resource that should be supported. Therefore, this meta-synthesis aimed to investigate the impact of HETF through the synthesis of caregiver experiences, with the aim of providing a deeper understanding of their perspectives.

METHODS

Design

A qualitative approach was utilised to provide rich insights into the lived experiences of caregivers. A meta-synthesis was considered appropriate because it allows for deep conceptual exploration of the findings of multiple studies[10] to develop an understanding of the collective caregiver experience. Ethical approval for this study was granted by Coventry University Ethics (reference number P61614).

Searches and study selection

Eligibility criteria were defined *a priori* and included studies were qualitative, English language and provided an exploration of caregivers' experiences of HETF an adult or child for at least 1 month. For the purpose of this study, a 'caregiver' was defined as a layperson who 'provides unpaid support to a partner, child, relative or friend' who is reliant on their help with HETF.[6]

Data were collected online via a systematic search of the literature. The search strategy was informed by the PICO framework, adapted for qualitative use: (P) population (caregivers), phenomenon of (I) interest (HETF) and (CO) context (experiences) (see Supporting information, Table S1). Searches were initially conducted by the lead researcher (SS) during February 2018, then updated using the same search strategy in January 2020 (see Supporting information, Table S2 and S3). CINAHL, MEDLINE, Academic Search Complete and SCOPUS were searched because these databases are relevant for healthcare research. Reference lists of included studies were searched to identify any additional relevant studies. A summary of the study selection process is presented in a Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) Flow Diagram,[11] Figure 1.

The literature from the searches was assessed by the lead researcher against eligibility criteria. Studies including both quantitative and qualitative data, or experiences of caregivers along with patients or HCPs were only included if findings could be clearly differentiated.

All included studies were appraised using the Critical Appraisal Skills Programme[12] (CASP) checklist for qualitative research, allowing discussion of the strengths and weaknesses of the body of evidence.[13] Quality was not used as a threshold for inclusion because lower quality studies can still provide new insights.[14]

Data extraction and synthesis

A study summary sheet and data extraction tool were created and piloted by the lead researcher in accordance with the PRISMA checklist,[11] using one qualitative study.[15] The data extraction tool was adapted, based on feedback from the second researcher (BT). Data from the included studies were then extracted by the lead researcher.

The meta-synthesis was based on the results of the six originally included studies via an iterative process. It was conducted by the lead researcher using the 'thematic-synthesis' method, specifically created for qualitative systematic reviews.[16] This involved three stages: line-by-line coding of the results of primary studies, organising the 'free codes' by developing 'descriptive themes' and then generating 'analytical themes'.

Line-by-line coding of results from included studies produced 289 meaningful free codes. Across the included studies, 53 descriptive categories were created, then combined and grouped into 12 descriptive themes. Throughout this process, the categories and themes were re-assessed, re-organised and refined by the lead researcher. Peer review with the second researcher reduced the descriptive themes to 10, which were discussed further to synthesise four analytical themes (see Supporting information, Figure S1).

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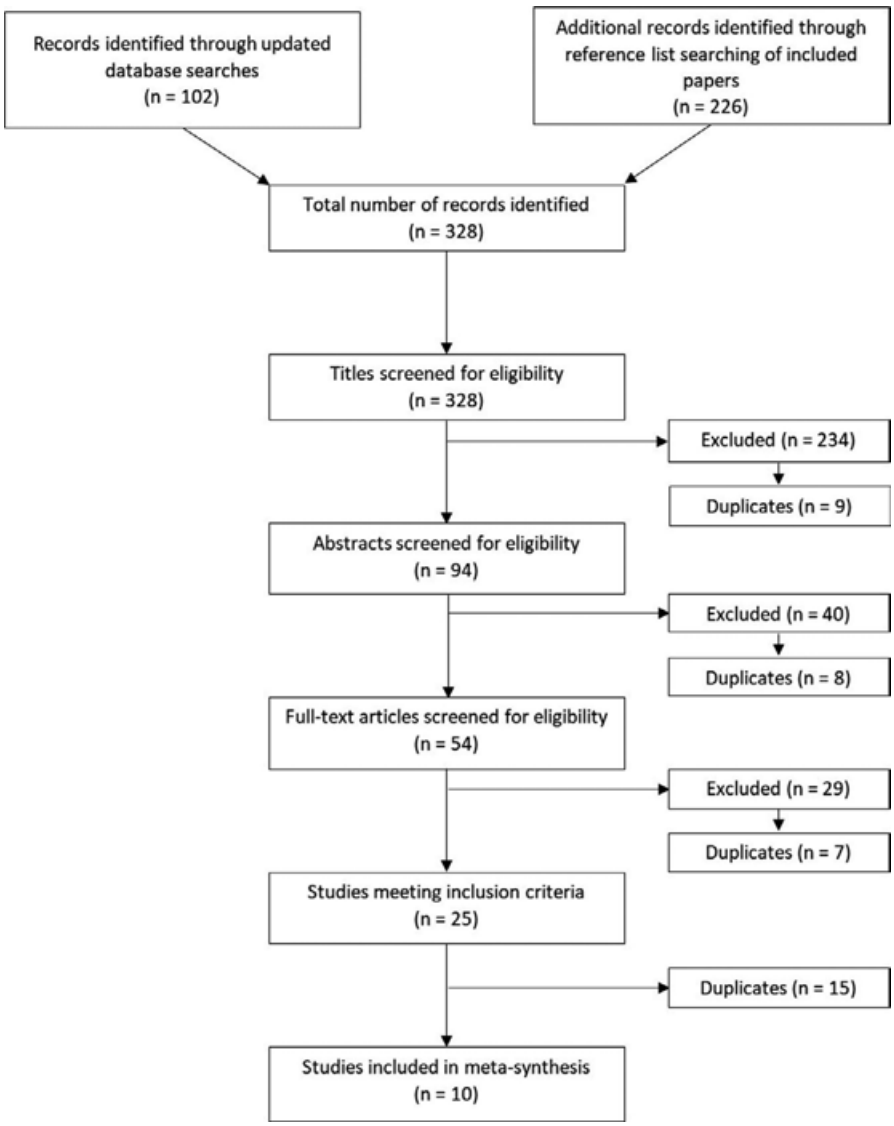

FIGURE 1 Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow diagram

When the searches were updated in 2020, the four new included studies were felt to fit with the existing themes, and so were incorporated into these as appropriate. These were peer-reviewed by the second researcher.

RESULTS

Study characteristics and sample demographics

In total, the experiences of 97 caregivers were reported. A table summarising the study characteristics and sample demographics of the 10 included studies is shown in Table 1.

Statement of quality

Appraisal of the included studies with the CASP checklist[12] revealed the overall quality of the body of evidence to be good, and the results are considered to be credible. A summary table is provided in the Supporting Information (Table S4).

Overarching themes

Four analytical themes were synthesised: loss of a normal life, psychological impact, practical challenges and becoming the 'expert' (Figure 2). The terms 'parent caregiver' and 'adult caregiver' are used to distinguish between mothers and fathers caring for children (parent caregivers), and spouses, partners, sons and daughters caring for adults (adult caregivers). Each theme and subtheme is described below.

Loss of a normal life

The experience of losing a normal life was a prominent issue for many caregivers, particularly parents.

TABLE 1 Study characteristics and sample demographics

Year	Authors	Country	Method of data collection	Number of caregivers	Age of caregivers	Relationship to patient
1997	Thorne, Radford & McCormick[17]	Canada	Interviews	7	Unspecified	4 foster parents 3 biological parents
1998	Spalding & McKeever[18]	Canada	Face-to-face interviews	12	30–49 years	Mothers
2003	Liley & Manthorpe[19]	UK	Face-to-face interviews	5	Unspecified	Family members/spouse
2005	Sleigh[21]	UK	Face-to-face interviews	6	Unspecified	Mothers
2006	Brotherton, Abbott & Aggett[23]	UK	Face-to-face interviews	19	Unspecified	5 wives, 7 husbands, 1 partner, 3 mothers, 1 daughter, 2 sons
2007	Brotherton, Abbott & Aggett[20]	UK	Face-to-face interviews	24	Unspecified	21 mothers, 3 fathers
2011	Mayre-Chilton, Talwar & Goff[25]	UK	Focus groups	3	40 - 70 years	2 partners, 1 child
2018	Russell, Jewell, Poskey et al.[24]	US	Telephone interviews	6	Unspecified	5 mothers, 1 father
2019	Ang, Lim, Ng et al.[22]	Singapore	Face-to-face interviews	9	44–74 years	Family members
2019	Phillips[26]	UK	Face-to-face interviews	6	Unspecified	Mothers

Abbreviations: NGT, nasogastric tube; PEG, percutaneous endoscopic gastrostomy.

Stigma

Perceived stigma was one reason for HETF leading to loss of a normal life. Some came from professionals, as several parents experienced:

> … overt disapproval from … teachers and psychologists, who perceived the gastrostomy as an impediment to mainstreaming the child[17]

Another aspect of stigma was the abnormality of the gastrostomy itself; several parents described it as a 'hole' in their child, and there was repeated use of the words 'unnatural' and 'abnormal' throughout the parents' accounts. One mother's particularly vehement description revealed the intense stigma she felt was attached to her child's gastrostomy and the impact this had, as her understanding of what was 'normal' had to shift:

> [The gastrostomy tube] … was the most horrific, outdated, terrible thing to put in a child. It was an awful looking thing and most awful thing to deal with that we ever, ever experienced in our lives. It changed our lives. It had such an impact, it was so permanent for her, it was a hole in her, it was like this gaping hole in her abdomen. I mean, the way I had to touch her, treat her and position her changed. Everything changed for us …[18]

One adult caregiver mentioned the stigma of enteral tube feeding, and her husband's embarrassment of his gastrostomy, resulted in isolation from her normal life:

> He doesn't want anyone to know and so we can't go out [for a meal]. He even gets bad tempered if I want anyone around, he can't find a reason for not eating in front of them, not even a cup of tea. We always used to be out …[19]

Mother/child bond

Caregiving mothers demonstrated a specific loss of normal life. There was overwhelming consensus that feeding one's child was intrinsic to mothering, and its loss engendered

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Time HETF	Reason for HETF	Age of patient	Type of enteral tube
Several years (specific timeframe unspecified)	Children with disabilities (specific diagnoses unspecified)	Unspecified	Gastrostomy
1.5–8.5 years	9 congenital chronic illnesses, 3 severe acquired brain injuries	3–12 years	Gastrostomy
≥12 weeks	Neurological damage, stroke, underweight from respiratory disease	45–84 years	PEG
6 months - 3 years	Cerebral palsy	2–16 years	4 PEG, 2 gastrostomy with fundoplication
2 months - 9 years and 4 months	Oesophageal cancer, multiple sclerosis, motor neurone disease, cerebrovascular accident, cerebral palsy	20–84 years	PEG
2 months - 7 years and 8 months	3 cystic fibrosis, 2 failure to thrive, 3 schizencephaly, 6 global developmental delay, 4 cerebral palsy, 6 other rare conditions	1 year and 10 months - 14 years and 8 months	PEG
Minimum of 3 months	Head and neck cancer	Unspecified	Gastrostomy
At least 1 month	Cerebral palsy	1–28 years	Gastrostomy
'Long-term'	5 malignancy, 1 functional decline, 2 Parkinson's disease, 1 stroke-related	Unspecified	6 PEG, 3 NGT
< 1 year - > 5 years (using blended diet)	Unspecified	6–31 years	Button gastrostomy

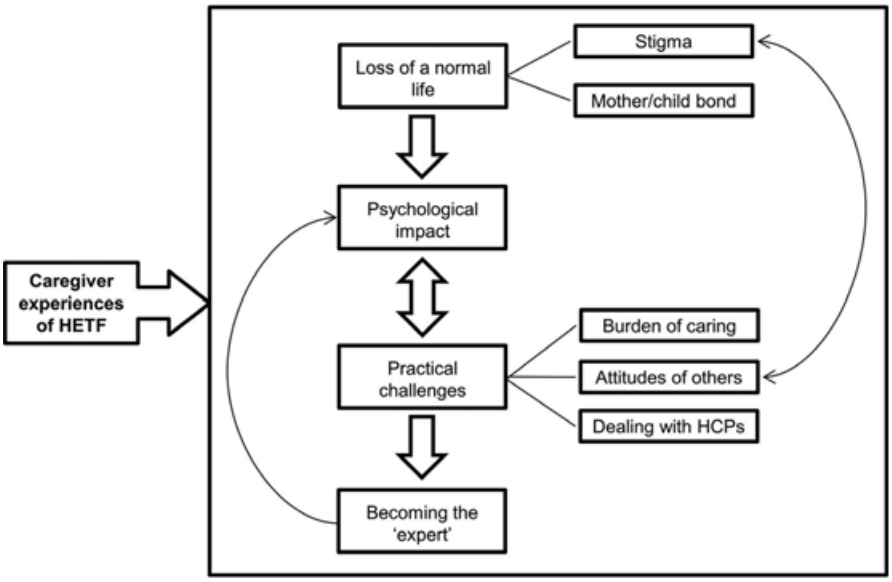

FIGURE 2 Concept map. HCP, healthcare professional; HETF, home enteral tube feeding

feelings of maternal failure. Many mothers missed the closeness that came with feeding their child, stating enteral feeding lacked the emotion of nurturing:

> I think you do lose that closeness with your child because there is no physical contact, it is not a pleasant experience …[20]

Several parents left their child alone when they were pump feeding, which further disrupted bonding:

> When she is on the pump having a feed it's all too easy to go off and do, and get something done[21]

Psychological impact

Across the included studies emerged a sense of caregivers' mixed feelings. Despite mourning the loss of a normal life, once caregivers saw the benefits of tube feeding, they felt a sense of acceptance:

> … it is a necessary evil that has to be done[20]

> We just … we usually internalise it as part of the process and we just accept it[22]

However, for some parents, seeing the physical improvements in their children produced guilt, as they regretted not taking this action earlier:

> … I look back in retrospect, it should have been done far earlier … So then I feel guilty because I didn't push harder at the time …[17]

Caregivers also experienced feelings of guilt when eating in front of their loved one who could not participate, and this altered their behaviours and enjoyment of food:

> I only cook dishes that I know he didn't like. I couldn't sit and eat his favourite meal while he cannot even have one mouthful[23]

Practical challenges

The general consensus from caregivers was that HETF had benefits and was essential for their loved one, though they acknowledged this involved difficulties. Caregiver experiences of dealing with the practical challenges of HETF were revealed and, unfortunately, most reports were negative.

The burden of caring

The main practical challenge faced by caregivers was adapting to the routine and equipment involved with HETF, making HETF feel burdensome. Several caregivers commented on the volume of equipment that arrived at their houses:

> I had no idea how much stuff would be arriving and it was all left on my kitchen floor …[19]

Many caregivers reported difficulties integrating HETF into their daily lives, finding it time consuming and inhibitive:

> … If we are eating out to dinner somewhere, we have to make sure we have food for later, so that she is not missing a meal. So it ends up being a lot of planning[24]

Caregivers described their experience of sleep disturbance from overnight feeds and resulting family conflict because of tiredness. Parent caregivers likened this disruption to caring for a newborn baby:

> In the middle of the night we are saying to each other 'it's your turn to feed her'; 'no it's your turn', like you do with new born babies, it's like being stuck in a time warp at that feeding stage[20]

Dealing with the practicalities of HETF left many caregivers feeling they were providing 24-hour care for their loved one. Caregivers took full responsibility and struggled to come to terms with the social isolation they experienced due to demanding feed regimes, creating feelings of resentment:

> We don't have a social life. I did earlier on … but my normal social life stopped existing 14 months ago. I had lots of interests that have all stopped. I miss them an awful lot[23]

This not only impacted on caregivers' time for themselves, but also on family time due to restrictions of the feed regime:

> It is not good for the family, I don't think other people really understand … we have to plan and then two of us would stay at home whilst the other two go. It is splitting the family[20]

Parent caregivers reported abandoning family holidays as the feeding organisation was prohibitive; other families had tried going away and regretted it as a result of the burden of feeding:

> We would love to go abroad on holiday, and my other child would love to go, but because of her situation [feeding every four hours], we daren't risk it so that stops a holiday abroad[20]

Conversely, several parents reported a more positive experience, stating:

> Wherever we go, he comes. And we just make sure we've got his chair and his feeding pole and his pump and his food, and it's just, instead of packing for a baby, you're packing for him … you

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> just get used to it. It's just a part of something that you do. Yeah, it's called life[17]

Attitudes of others

The attitudes of others exacerbated the practical challenges of HETF. There were many accounts of caregivers providing enteral feeds in public and experiencing negative reactions:

> I have asked the manager if it is ok to feed her and he has made me go and sit in the disabled toilet and feed her in there …[20]

This deterred caregivers from feeding in public, which further limited the caregivers' social interaction as the feed regime was restricted to the home:

> I always make sure I feed her before we go out. I wouldn't feed her outside again[20]

Negative attitudes of family members added to the practical challenges of HETF. Extended family were unwilling or nervous to be involved with the child, placing greater strain on the caregivers:

> My mother-in-law has a problem with him; she finds it difficult. She walks out of the room, I have offered to show her how to feed him but she has declined[20]

Dealing with healthcare professionals (HCPs)

Dealing with HCPs was another practical challenge experienced by caregivers. Some of this was negative because caregivers felt that HCPs had taken control of their lives. Caregivers reported feeling confused by HCPs because they received mixed messages. It seemed ridiculous to caregivers following years of variable intake pre-gastrostomy that dietitians were obsessed over the daily feed intakes.[17] Other caregivers reported receiving conflicting advice:

> I think all you professionals have learned in different places and when you are all saying different things I don't know who I am supposed to listen to[23]

Although HETF training included demonstrations of techniques by HCPs, it 'did not always extend to support in integrating the process of HETF into other household routines and spaces'.[19] It was also suggested that a psychological aspect was missing from the training:

> Very important for the carer is to understand the psychology … sometimes carers feel totally isolated[25]

Becoming the 'expert'

Despite these challenges, caregivers worked relentlessly to overcome difficulties and make HETF work because it was essential for their loved ones' survival. As their confidence increased, caregivers described how they became skilled at HETF, regarding themselves as the 'experts'. Caregivers wanted recognition for their skills and vital role, and lost confidence in HCPs if they sensed inexperience, which further promoted caregivers' self-reliance. Many, particularly parents, adapted prescribed feed regimes to suit their lifestyles and routines after finding the professional's recommendations unrealistic:

> You just have to work with your experience on your own child … You have to experiment, and respect yourself, because each child is different.[17]

Many parents questioned the nutritional value of the feed, with one caregiver describing prescription feeds as 'chemical milkshake'.[26] This led to many caregivers going against recommendations at the time and putting liquidised home-cooked food through the gastrostomy tube, now known as a 'blended diet':

> It just seems healthier and it just feels like a more natural way for [name] to … have her food[26]

Many caregivers (particularly parents) believed HCPs should provide more support and guidance for blended diets and wanted it offered as an alternative. This desire partnered with lack of advice and support from HCPs often led to caregivers working it out for themselves or consulting the internet. Many also believed HCPs should devise means to reinstate oral feeding because they wanted the tube to be temporary. Some tried starting oral feeding by themselves, without professional support:

> We offer him whatever we are eating … if there's something that's hard … he can't chew it, I will chew it for him and give it to him in his mouth so he can taste it, and experience it, and smell it … We have never deprived him[17]

Caregivers reflected that to achieve the normal life they desired they needed to become skilled in HETF and integrate it into daily living, creating a new normal.

> … A lot of it though, was just finally recognising that this is her normal and this is the normal for our family[24].

DISCUSSION

This meta-synthesis is the first to investigate caregiver experiences of HETF, exploring this perspective to inform the

MDT and improve holistic practice. The results have revealed rich descriptions of experiences, showing the journey and challenges of becoming caregivers.

Overall, the caregiver experience of HETF revealed a process of mixed emotions. For many, there was initially a period of distress, facing the loss of their normal lifestyle and the stigma attached to enteral feeding. For mothers, this a had profound impact because they missed the closeness associated with breast or bottle feeding. These losses had a psychological impact on caregivers; however, this developed to acceptance as they came to acknowledge that their loved ones' survival depended on it. Sometimes, a sense of guilt emerged regarding whether a tube should have been placed sooner or their enjoyment of food isolating their loved one. Caregivers acknowledged that, although HETF was essential, it involved many practical challenges they had not expected, including the burden of caring, the impact of attitudes of others (influenced by stigma), and dealing with HCPs. The relationship between psychological impact and practical challenges was two-way because the psychological state influenced the ability to cope with challenges, and challenges impacted the psychological state. Caregivers put great effort into overcoming challenges, eventually becoming confident with HETF, even taking feed regimes into their own hands. Eventually many defined a new normal, which influenced their psychological state and aided acceptance.

One of the most striking caregiver experiences in the present study was that HETF was a burden because prescribed feed regimes did not fit into caregivers' lifestyles and were unrealistic to manage. Caregivers reported feeling unprepared for dealing with the practicalities of HETF. A UK study by Brotherton and Abbott[27] interviewed patients and caregivers dealing with PEG tubes and identified that only 37% felt the information provided during PEG training was useful and 33% felt it was sufficient. Patients and caregivers reported that training provided information on the feeding pump itself but left unanswered questions about the practicalities of HETF, which was what they really wanted to know, reflecting the caregiver experiences revealed in this meta-synthesis.

A 2019 meta-synthesis by Thomas *et al.*,[28] exploring the impact of HETF on the daily lives of patients with head and neck cancer, reveals similar themes to those in the present study. Mourning the loss of one's previous life and the difficulties adjusting to a life now defined by HETF appear to be challenges faced by both patients and caregivers. The present study and this meta-synthesis[28] have both described the experience of HETF as a 'journey' and the importance of creating and accepting 'a new normal' to manage the changes.

Caregivers in this meta-synthesis reported experiencing a significant emotional journey and psychological impact. NICE[1] guidance states that HCPs should ensure caregivers are able to discuss social and psychological needs; however this meta-synthesis has raised questions regarding whether psychological support is available. It is crucial for HCPs to ask about caregiver experiences in HETF consultations and follow this with appropriate support, to prevent caregiver burnout. New ESPEN guidelines[29] now acknowledge the impact of HETF and need for support, recommending that quality of life of both the patient and caregiver should be measured periodically to minimise the impact of HETF on daily life.

Strengths and limitations

A strength of this meta-synthesis is that it breaks new ground exploring caregiver experiences of HETF. Reflexivity (see Supporting information, Table S5) and risk of researcher bias were considered throughout, and the use of a validated method to conduct the meta-synthesis and transparent reporting reduces the influence of the researchers. The data summary sheet and extraction tool were piloted, following PRISMA[11] best practice. These tools helped to ensure consistent recording of relevant information and maintained researcher objectivity. A range of databases were searched, along with reference list searching, as per Centre for Reviews and Dissemination[13] guidance, ensuring a comprehensive search. However, unpublished studies and non-English language studies were excluded, posing the risk of both publication and language bias.

Because this was secondary research, the quality of the included studies affects the quality of the synthesis.[10] As illustrated by the summary table (see Supporting information, Table S4), the two oldest studies[17,18] have the poorest quality. A possible explanation could be changes in the standards of reporting since the 1990s. It is also important to acknowledge the developments in HETF provision that have occurred since this time, such as improved pump technology and the availability of specialist products. However, lower quality and older studies were not excluded because their results reflected the higher quality and more recent studies, suggesting that they still provide valuable insights into the caregiver experience.

To ensure the themes conveyed the collective experience and reduce risk of reporting bias, quotes from all 10 included studies were incorporated to illustrate the themes. Six of the 10 included studies were conducted in the UK, meaning that the results are valuable for challenging and informing UK practice.

Although there are likely to be different experiences between parent and adult caregivers, there is currently a lack of evidence on this topic because only 10 of the 289 records identified met eligibility criteria for this meta-synthesis. Therefore, a focus on only one caregiver group would not have produced sufficient data to form a rich and in-depth understanding of the topic. Experiences of caregivers could also vary depending on the underlying reason for the patient receiving HETF (e.g., stroke, cerebral palsy, motor neurone disease, etc.) because different conditions require varying levels of caregiver input. Although this could influence caregiver perceptions of the HETF experience, currently, there are insufficient numbers of primary studies focusing on one specific underlying condition to be able to synthesise data in this way.

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CONCLUSIONS

This research has achieved its aim because it has revealed new insights into caregiver experiences of HETF, demonstrating an emotional process of learning as caregivers strived to overcome challenges and create a new normal.

Implications for practice

This research identifies that current training may insufficiently prepare caregivers for managing the practicalities of HETF. If training included information on logistics, alongside planning how the feed regime could be integrated into normal life, caregivers should feel better prepared. Creation of a 'best practice' standardised training programme could be useful for facilitating high-quality training across different hospital trusts, aiming to ensure that training is fit for purpose and meets the needs of caregivers, as well as patients. This recommendation for standardisation of training is now also reflected in the new ESPEN guidelines[29] aiming to improve quality of HETF care.

If health professionals could offer group sessions as training updates for caregivers, this may reduce their experience of mixed messages, check safe practice and promote peer support to aid mental wellbeing. Extending this training to include extended family members and friends could help to alleviate caregiver burden and reduce stigma.

This meta-synthesis also highlighted caregiver interest in blended diets; therefore, dietitians need to be prepared to discuss this and provide evidence-based advice. The British Dietetic Association produced a policy statement[30] for this in 2019 and now suggest blended diets as an option where there are potential physiological, social or emotional benefits to the patient and their family, recognising the needs of caregivers alongside the needs of patients.

The guilt felt by caregivers when unable to share food with their loved one was also revealed, and it was identified that oral feeding may be taking place against recommendations because of this. Greater MDT focus on reinstating some aspect of oral feeding, even if only tastes of certain 'safe' foods, could help reduce unsafe practice from caregivers and alleviate any feelings of guilt around the enjoyment of food.

HCPs also need to affirm the role of caregivers, acknowledging their experience by seeking input during assessments and discussing their social and psychological needs to prevent caregiver burnout.

Recommendations for future research

New research into this topic could compare the experiences of different caregivers based on their relationship to the patient or the underlying condition requiring HETF, aiming to determine whether this affects the experiences and needs of caregivers. Future qualitative studies into this topic need to ensure transparent reporting to facilitate a high-quality body of evidence.

TRANSPARENCY DECLARATION

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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CONFLICT OF INTERESTS

The authors have no conflicts of interest.

AUTHOR CONTRIBUTIONS

SS and BT were involved with study design, screening against eligibility criteria, interpretation of results and study write-up. Database searching, data extraction and data analysis were completed by SS as lead researcher.

ETHICAL APPROVAL

Ethical approval was granted by Coventry University Ethics.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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NUTRITIONAL SUPPORT AND ASSESSMENT

The experience of family caregivers of patients receiving home nasogastric tube feeding in China: A descriptive qualitative study

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Abstract

Background: The value of caregivers with respect to ensuring safety during home nasogastric tube (NGT) feeding is increasingly acknowledged. However, little attention has been given to the experience of caregivers.

Methods: A qualitative descriptive design using semi-structured interviews via purposive sampling at a comprehensive hospital in China was employed. Family caregivers of patients with home NGT feeding were recruited. Interviews were recorded, transcribed verbatim and analysed qualitatively using inductive content analysis.

Results: Thirteen family caregivers of patients with home NGT feeding were interviewed. Four main themes were generated: negative experience (uncertainty and ambivalence, transition gaps between hospitals and home care services), new role: adapting to the lifestyle (participating in decision-making, being responsible for everything, adjusting own life to NGT feeding), perceived benefit of caregiving (personal growth, development of positive attitudes and achievements) and expectations (expectations from continuity health system services, expectations from social support).

Conclusions: The present study highlights the vulnerability and perceived benefits embedded in the role of a family caregiver. Improving communication and standardising practices between home and hospitals should be considered.

KEYWORDS
family caregivers, home nutritional support, nasogastric tube, qualitative research

INTRODUCTION

Home enteral tube feeding (HETF), a life-sustaining therapy, is commonly used as a treatment modality for patients with dysphagia.[1] With a shift in focus of providing care from acute to community care settings during recent decades, the number of people receiving HETF has increased globally over recent years.[2] Percutaneous endoscopic gastrostomy (PEG) and nasogastric tubes (NGTs) are commonly placed for nutritional support as reported in the literature.[3] Although PEG was associated with improvements in long-term nutritional requirements, increased motivation to return to eating orally was reported in NGTs.[4] The clinical guidelines suggest that NGT feeding is recommended for 4–6 weeks and PEG is truly suited to patients who require long-term nutritional requirements.[5] However, consensus guidance for selection criteria is not universally applied and there is variability in the uptake of this practice.[6] Most patients in Asian countries, such as in Malaysia[7] and Singapore,[8] were put on NGT for long-term HETF compared to those in Western countries, although the literature has shown more complications with the use of NGT.[9] In Taiwan, 84%–93% of patients who needed home enteral feeding were fed via NGT, which was used for 1 year or more.[10] The high acceptability of NGT in Asia might be related to cultural and religious backgrounds.[9] Family members were reluctant for patients to undergo further surgical procedures in addition to current disabilities and diseases. The importance of 'keeping your body intact' was another reason to use NGT feeding.[8]

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Although HETF has been described as a lifeline,[11] it also means transferring responsibilities and risks from the hospital to the home. Studies found that actively engaging family caregivers is important in nutritional care to achieve positive outcomes.[12] Patients have a limited ability for self-management and can receive therapy at home only if caregivers can guarantee the safety and efficacy of HETF.[13] However, caregivers have described the new lifestyle as a struggle and the hazards of caregiving can convert them into hidden patients.[14] Culture crucially influences the use of support or resources, the motives of caregivers and the coping strategies used in caregiving.[15] In China, as a result of the predominant cultures of Confucianism and collectivism, individuals are perceived to be obligated to take care of family members and are strongly advised to make sacrifices for the sake of family harmony and demands. Yeung *et al.*[16] indicated that Chinese American caregivers pay special attention to 'filial piety' originating from Confucian philosophy, which integrates 'responsibility' with caregiving from family members. Although it is praised in China, there is no government or community social service assistance, which leads to a greater burden on caregivers.[17,18]

Health policy-makers' attention is increasingly directed toward the social challenges of caregiver burden and burnout.[19] It is essential for home medical care to include caregiver perspectives and needs as a standard component of its assessment and plan.[20] Studies have mostly explored the caring experience of PEG and found that it is more convenient than NGT for caregivers.[6,21,22] Despite reporting challenges of managing NGT, there is limited understanding of the experience of family caregivers who manage and live with patients with NGT in developing countries, such as China.[23] Understanding the experience of family caregivers is important for knowing how best to support and work with them in the context of home medical care. Therefore, the present study aimed to gain an understanding of the experience of family caregivers, caring for patients with NGT, in China.

METHODS

Design

A qualitative descriptive study design was conducted to allow participants to voice their opinions and share their experiences through in-depth interviews.

Participants

A purposive sample of participants were recruited from October 2019 to July 2020 from a tertiary comprehensive hospital in Jinan City, Shandong Province, China. The family caregivers were chosen based on gender, age, level of education, relative relationship and duration of caring, providing a diverse sample of experiences for analysis. The inclusion criteria were: (i) being the main caregiver of patients who needed HETF and who were fed via NGT; (b) aged 18 years or over; (iii) caregivers with a family relationship with care recipient (such as spouse, adult children, siblings, or relatives); and (iv) understanding of and fluency in Mandarin. Family caregivers with cognitive impairment or those who were unable to give written consent were excluded. Inclusion of participants continued until new interviews no longer provided additional information, which was understood as a sign of saturation.

Data collection

Face-to-face, semi-structured interviews were conducted by the primary researchers and were audio-recorded. The time and location of interviews were arranged in accordance with the convenience of participants. The interview guideline originating from the review of literature and the researchers' clinical experience within the field was adjusted by conducting pre-interviews with two participants. After group discussion, the interview guide included open-ended questions (see Supporting information, Table S1). Before conducting the interviews, participants were explained the aim of the study and their written informed consent was obtained. Both interviewers were registered nurses who were trained in qualitative interview techniques. Field notes were taken, and clarification was sought from the participants during the interview whenever speech was difficult to understand. No repeat interviews were undertaken in this study. The interview was complete when the participant had nothing further to add. The duration of the interviews ranged from 26 to 75 min. Privacy was assured at all interview venues, hence enabling the participants to talk freely about their caregiving experience without any disruption or concern.

Data analysis

The interviews were transcribed verbatim into transcripts by researchers and then anonymised. These were analysed using inductive content analysis approach.[24] The first step was to gain familiarity with the data by repeatedly reviewing the transcripts, which required the researchers to practice complete immersion in the data. Subsequently, meaningful word patterns and recurring concepts were extracted through thorough discussion with the team. Following the initial coding, themes were developed using a process of constant comparison, applying the emerging codes and themes to the entire data set until data saturation was achieved. The researchers consulted with one another to address any ambiguities or disagreement on methodological issues or data analysis. The final set of themes and subthemes was agreed upon by all of the investigators.

Rigor

The interview transcripts were checked and coded by two researchers, and the second researcher validated the analysis. The fact that the researchers who analysed the data did not have any previous contact with the patients and family caregivers

minimised a potential bias from previous observations, conclusions or prejudices. Concurrently, memos were written about thoughts, ideas and reflections, helping the researcher to focus on and understand the phenomenon during data analysis. The themes extracted from the collected data were repeated to the participants via telephone. Substantial descriptions and direct quotes from the interviews were also provided.

RESULTS

In total, 13 family caregivers completed the interviews (15 were approached; two declined with reasons of no time or no interest). Four were interviewed alone, whereas nine family caregivers were interviewed in the presence of patients because they had to care for them. The participant characteristics are provide in Table 1. Participants were aged between 29–67 years (male = 51.1). Table 2 shows the four themes and nine subthemes that emerged.

Negative experience

Uncertainty and ambivalence

Uncertainty and ambivalence were two feelings mentioned by most caregivers, which is related to the importance of tube feeding for patient survival and to the ever-changing and complex situations to which they were exposed as caregivers. The feeding tube was considered to be an advantage because it ensured that adequate nutrition was provided. However, they described the challenges of managing and living with an NGT, which exhausted all their time and energy. Moreover, they expressed great appreciation for the fact that the use of NGT relieved patients of the pressure of painful or difficult oral eating. They also described that they were not confident taking care of patients:

> It is a good choice for us that she can stay at home, but I'm worried I can't handle the problems we face when taking care of our loved ones. There may be a lot more that can happen and … and … it's too much and so overwhelming. I think I will really panic
>
> (C6)

> I am deeply convinced that the tube can make him stronger and speed up his recovery time […] I'm really afraid, afraid … I don't know how to care for the tube and what's going to happen in the future
>
> (C7)

> We don't know anything about how long this tube is going to last, and when we can feed him (the patient) through his mouth
>
> (C9)

TABLE 1 Description of the participants

Participant characteristic	Number of participants
Age (years)	
> 20 to ≤30	2
> 30 to ≤40	1
> 40 to ≤50	2
> 50 to ≤60	5
> 60 to ≤70	3
Mean (SD) age	51.1 (12.7)
Gender	
Male	6
Female	7
Length of time with the tube (months)	
≥ 1 to < 6	6
≥ 6 to < 12	5
≥ 12 to < 18	1
≥ 18 to < 24	1
Mean (SD) time	7.1 (5.0)
Relationship	
Spouse	6
Parents	3
Adult children	3
Siblings	1

Transition gaps between hospitals and home care services

Most participants mentioned that they learned some skills with respect to taking care of patients. However, over half the participants felt they were left to deal with issues with little or no support and expressed that they did not know who to contact for help with tube management. Some participants noted that information and tube-related education on the management of NGT was inconsistent across hospitals:

> One hospital told us to replace the tube every 2 months, now another hospital suggests changing it every month. I don't know what to do … I'm afraid I always did the wrong thing
>
> (C13)

New role: Adapting to the lifestyle

Participation in decision-making

Caregivers were not familiar with the different modalities of enteral feeding. When faced with a choice they were often caught in a dilemma. Some participants expressed that they weigh up the benefits and concerns, and then choose NGT, because the perceived positive outcomes far outweigh the potential negative consequences:

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TABLE 2 Themes and subthemes from semi-structured interviews

Themes	Subthemes
Negative experience	Uncertainty and ambivalence Transition gaps between hospital and home care services
New role: adapting to the lifestyle	Participation in the decision-making Being responsible for everything Adjusting own life to NGT feeding
Perceived benefit of caregiving	Personal growth Development of a sense of positive attitudes and achievements
Expectations	Expectations from continuity health system services Expectations from social support

Abbreviations: NGT, nasogastric tube.

> For my wife, the process of inserting the tube (NGT) was very uncomfortable, as she experienced nausea […] I was worried … as changing the tube was not as smooth as expected. If there were other methods (PEG or other route) for nutritional support, I would choose them …
>
> (C10)

Another participant reported being distressed when they were involved in decision-making:

> I've thought a lot about this. Did I do the right thing or not? I understood that we were asked to consent, and I am very distressed and confused about what I should do
>
> (C1)

Being responsible for everything

Participants reported that the commitment is closely related to traditional cultural values. Some participants spoke about how caring for their loved one meant making sacrifices, which was seen as something that was done without question. They had to take great responsibility to make daily life workable as a result of the patient's decreased ability to handle tube feeding:

> When you look at her and you see her so helpless, so dependent … After so many years of marriage, well, you feel this affection, so you will get on with it … Despite the greatest or overwhelming difficulties, we chose to endure and never thought of giving up
>
> (C11)

> Like we all know, when we were young, we saw our parents taking care of their sick parents and it is just like a natural thing you just saw all the time. He is my father. I must take good care of him. No matter how, I will try my best to do
>
> (C2)

Some participants emphasised caregiving as an obligation and strongly expressed the commitment and sense of obligation of caregivers:

> We must help each other when there is adversity. I can't leave my sick spouse or pass her on to anyone else. It's unacceptable. I am her husband. This is my obligation to take care of her
>
> (C6)

Adjusting own life to NGT feeding

Several participants described that they experienced shifts in daily routines and struggled to adjust to the new life situation. They gradually integrated tube feeding into their lifestyle and viewed caregiving as a normal part of life:

> In the beginning, the situation was experienced as chaotic, but as time went by, things settled down. Now, I'm used to it, that it is OK. Without having feelings about it
>
> (C12)

> Anyway, we do the same thing every day, you know, everything has its own tactics and once you get used to it, it becomes nothing
>
> (C5)

Perceived benefits of caregiving

Personal growth

Most participants mentioned that they not only acquired knowledge and skills, but also raised healthy awareness and action through caring. They described having grown intrinsically as a result of their role including increased patience and self-awareness:

> I had learned online and read lots of books about nutrition, and I recognised the importance

of feeding appropriately (Evidence-based nutrition and dietary guidance, such as disease-specific enteral formula) since he had an NGT. Now I often use nutritional supplements (e.g., nutrition powder)

(C1)

I supervised my mother's nutrition and exercise; also, for myself and other family members, now health is the most important thing in our life, and we give priority to health

(C7)

I am more careful than before; I often check the tube. I used to be careless, but after she fell sick, I care about everything, I am careful. I'm afraid of making mistakes (e.g., blockage)

(C6)

Other participants emphasised that they acknowledged the importance of self-management abilities, but they usually ignored their own health issues:

We were aware of the importance of having knowledge about how to eat, how to exercise, and how to keep healthy. But now everything goes on as before. It doesn't alter anything

(C5)

Development of positive attitudes and achievements

Some participants stated that they began to look on the bright side and cherish the things that they do have. Meanwhile, they also referred to a growing dependency strengthening their relationship and bringing greater emotional closeness. The sense of achievement went beyond simply carrying out caregiving duties, to a feeling that they had achieved something they did not think they were capable of. This held a significant amount of social value for caregivers:

Nothing can alter the fact that she relies on tube feeding. You have the option to live a life happily or sadly. So why not stay with your loved ones and live a happy life

(C8)

He sits by himself watching television when I cook alone in the kitchen, we have each other, and we live together. I treasure what I have

(C11)

Caregiving includes experiencing a sense of pride in carrying out care-related activities. Participants found a new sense of purpose in the caring role:

You really have a sense of accomplishment when you see that everything is going well. My relatives and neighbours respect me, and they think what I am doing is great

(C6).

The biggest goal of my life now is taking good care of her

(C8)

Expectations

Expectations from continuity health system services

Additional practice and time were needed for caregivers to be competent in caregiving. Participants described support, including follow-up contacts, and emotional and practical support from the health system, as being very limited. Others described a chaotic and uncoordinated response to urgent situations:

As first-time caregivers, we were not ready to manage the patients with tube at home … They [nurses] showed me how to do it at the hospital, but I was not asked to try it. If I did, I would feel more confident …

(C6)

I wish they had followed up with phone calls, home visits by the hospital, and consultancy services related to their problems, once in a while, like, once a month. Now there's nothing

(C12)

I do not always have confidence in primary healthcare institutions, I don't think they can handle it

(C1)

Only in the emergency department can we change the tube. Not anywhere else

(C10)

Expectations from social support

Some participants felt slightly helpless and isolated, which was associated with the low social support they accepted:

I worry about the cost. I have no money and I don't know what will happen to him if we can't afford it

(C13)

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> I'm on the go all day long … I have to wash and rinse the syringe between each meal. There is so much I have to do … everything! She can't do anything and I'm there for her 24 hours a day. I haven't had any help
>
> (C11)

DISCUSSION

The present study provides new evidence about the experiences and needs of family caregivers of patients with NGT feeding within the Chinese cultural context. The findings highlight the uncertainty around potential future problems and benefits from practical aspects of tube care. Access to health professionals or services in transitional care was often described, and support to manage routine and urgent problems was considered particularly limited. This highlights the importance of improvements in this area.

In line with previous research,[23,25,26] a negative effect on caregivers' well-being and daily life was evident. Yang *et al.*[27] indicated that the positive quality of the caregiver–care receiver relationship could buffer family caregivers from negative emotions; however, this was not investigated in the present study. The feeling of uncertainty arises from the imprecision of the prognosis related to the illness, for the future that they have to face, and for the lack of information and preparation for the situation; all of which are aspects mentioned by the caregivers we interviewed. It should be emphasised that this uncertainty may affect the provision of care and produce worries and insecurities in the caregiver.[28] According to Oishi *et al.*,[29] one of the factors that increases uncertainty among caregivers is a lack of coordination between healthcare professionals. More recently, Abrahamson *et al.*[30] pointed out that the transition in moving from the hospital to the home tends to be harder than they expect as a result of a lack of preparation with respect to providing necessary care to their family member. Hurried discharge teaching,[31] planning[32] and inadequate communication[12] were also reported to be associated with negative experiences. Therefore, a comprehensive discharge care plan is essential so that caregivers feel confident and safe. More adaptation and learning time for caregivers should be considered when performing discharge planning.

The acceptance and normalisation of caregivers' new role, as found in previous research,[32] is related to readjustment in their lives in search of new stability, and parallels can be drawn with patients receiving HETF.[11,33] This may involve regaining control over their daily lives.[33] Understanding the effectiveness of nutrition and its role in disease contributed to caregivers participating in decision-making.[34] Information-giving needs to include the associated evidence to ensure that a decision is made in line with their own values,[35] which facilitates decision-making involving caregiver input. Important findings showed that family caregivers begin to realise the difficulty of this task and the responsibility of well-being of patients being in their hands.[32] Some participants claimed that they will silently endure the greatest caregiving difficulties and never consider giving up caregiving even if it results in their exhaustion. This could be interpreted as cultural influences mediating how caregivers fulfil and cope with their role and maintain their motivation.[36] Caregivers perceived the caregiving experience as a normal and anticipated course of life as a result of family obligations and role models, which is in line with a culturally prescribed obligation and expression of reciprocal love.[37] In this context, overload, distress and overwhelming responsibility are well-known factors associated with depression and a reduced health-related quality of life among caregivers.[38] Therefore, the healthcare system's responsibility for providing relevant information and support is crucial to minimise the risk of illness within caregivers and build capacity to promote better health outcomes.

A prominent phenomenon in the present study was the intrinsic growth and sense of achievement in caregivers, which is an emerging area with respect to positive aspects of caregiving.[39,40] One possible reason for this benefit relates to values originating from culture. Yanhong *et al.*[41] explained that there was an intrinsic reward in upholding their commitment: they expressed pride in being able to uphold the cultural values of caregiving. Although increases in knowledge and the development of a sense of achievement interact to promote the maintenance of healthy behaviours, caregivers described ignoring their own health status, which could be attributable to a lack of information about self-care and lower efficiency.[42,43] This highlightSSs the importance of practical suggestions to promote self-care and constant medical monitoring offered by health professionals. In addition, caregivers spoke of focusing more on relationships, gaining a broader perspective on life and finding their lives to have new meaning as a result of caregiving. The wider literature reveals that perceived benefit could play a moderating or mediating role in the relationship between caregiver burden and depression.[44,45] According to Geng *et al.*,[46] focusing on mindful interventions by family caregivers of cancer patients increased their positive experiences. In this context, practicing a positive attitude, as well as the ongoing implications of this, appeared to be an important step. In particular, caregivers appeared to be empowered to continue to face the challenges of their role by a personal choice to focus on the positives, such as cherishing what remained or choosing to use humour.[47] Previous research had indicated that the benefits to caregivers and patients are mutual.[48] Therefore, gaining an understanding of the factors that maintain a higher perception of these benefits may provide a new direction for interventions for caregivers from the positive view.

The results of the present study also highlight the expectations of caregivers in relation to urgent and routine continuity service support for the health system.

The importance of support has been identified previously.[33] Insecurity and a lack of emotional, practical, and information-related support have also been found to increase the vulnerability of caregivers, as well as their sense of loneliness.[23] It is noteworthy that caregivers' ability to handle their situation was also strongly related to the amount and quality of information and support received.[25] One finding concurs with previous studies[49] and suggests that caregivers do not always have confidence in their primary care practitioner. This is closely related to insufficient hospital referral information and a lack of standardisation and consistency among the community and hospitals, leading to frequent misunderstandings and distrust.[50] This suggested that health professionals focused on connecting caregivers to community resources that develop their competencies to meet both the patient's and their own needs. Additionally, substantial evidence suggests that a home enteral nutrition care team linking caregivers to information and resources increased the caregivers' sense of security[51] and reduced the hospital admission rate, as well as the costs associated with enteral tube feedings,[52,53] which could easily put in practice evidence-based best practices. A recent study indicated a lack of extended community caregiving support services and insufficient delivery of home care programmes in China.[36] There is an ardent need to develop national guidelines for home enteral nutrition services that care for patients with NGT feeding, such that they can be carried out effectively and efficiently.

Strengths and limitations

One of the limitations of the present study is that it was carried out in a tertiary hospital for caregivers, and, hence, the experience of our participants may not be generalisable to other centres and countries. Our findings echo the international literature on the experience of caregivers of individuals with other similar diseases, including the burden and benefit of caregiving. Perceived benefit should be a positive intervention to support them in managing this complex and life-changing problem when services vary across regions. During these interviews, the presence of patients resulted in a discussion of whether this restricted what was discussed. In addition, data saturation was a relative concept that was limited only to the findings of the present study and this might change over time.

CONCLUSIONS

This qualitative study underlines the experience and needs of caregivers who assist with NGT feeding of patients at home. It has revealed several key aspects, including negative experiences of caregiving, adaptation to lifestyle, and perceived benefits and expectations. These should be considered when defining clinical protocols and supporting caregivers. Moreover, focusing only on the negative experiences may limit researchers from understanding the holistic experience of caregivers. The methods targeted at creating or enhancing the perceived benefits of caring would likely have a proactive ripple effect throughout the entirety of the caring trajectory and the care network. We suggest that the organisation of home enteral services should be guided by national standards for the provision of services for patients and caregivers, informed by caregivers and the regional context, aiming to ensure equitable and supportive services.

TRANSPARENCY DECLARATION

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 SRQR 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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CONFLICT OF INTERESTS

The authors have no conflicts of interest.

AUTHOR CONTRIBUTIONS

MX was responsible for the study conception, design, data collection, validation and drafting of the article. MZ was responsible for the methodology, project administration, resources, supervision, validation, draft review and editing. XZ and SL contributed to the study conception, data collection and draft review. NX and JH contributed to the data analysis, validation and draft review. All authors critically reviewed the final version of the manuscript submitted for publication.

ETHICAL APPROVAL

Ethical approval for this study was obtained from the Nursing and Rehabilitation ethics committee of the University of Shandong (No:2020-R-041). The study conformed to the principles outlined in the Declaration of Helsinki. Participants were informed about their voluntary participation and could drop out from the study at any time without penalty. Oral and written consent was obtained from the participants. We also guaranteed the confidentiality of their personal information.

PEER REVIEW

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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