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ORIGINAL PAPER

Parents' and Child Health Professionals' Attitudes Towards Dietary Interventions for Children with Autism Spectrum Disorders

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Abstract Parents of children with autism spectrum disorders (ASD) use a wide range of interventions including poorly evidenced dietary interventions. To investigate parents' and professionals' experience of dietary interventions and attitudes towards a proposed trial to evaluate the gluten free casein free diet (GFCFD). Survey of UK parents of children with ASD, and professionals. 258 parents and 244 professionals participated. 83 % of children had received a range of dietary manipulations; three quarters of professionals have been asked for advice about GFCFD. Respondents identified an inadequate evidence base for dietary interventions in ASD and suggested modifications to a proposed trial design. Both parents and professionals supported the need for further evaluation of dietary interventions in ASD.

Keywords Autism · ASD · Dietary interventions · Gluten · Casein

Introduction

Recent ASD studies have reported a prevalence of at least 1 % of the child population (Baird et al. 2006; Kogan et al. 2009). Although there is no cure for ASD, there is general agreement that early diagnosis and access to appropriate therapeutic interventions may improve outcome (Dawson et al. 2010; Green et al. 2010; Reaven 2011; Volkmar et al. 2004). A variety of interventions have been proposed but there is little evidence to inform parents and professionals about which intervention or combination of interventions might benefit an individual child at any particular time (Carter et al. 2011a; Lord et al. 2006; Ospina et al. 2008). Many interventions are time consuming and costly with little information about their efficacy, effectiveness or their potential to do harm. Parents report a lack of advice from professionals about which interventions to choose,

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and look to alternative sources for information: usually other parents, the media and the internet (Mackintosh et al. 2005).

The US Interagency Autism Coordinating Committee (IACC) Strategic Plan has called for a balance between rigorous evaluation of existing interventions (large-scale randomized controlled trials, including comparative studies) and research into novel, targeted treatments (Interagency Autism Coordinating Committee 2010). In the UK, the need to support autism intervention research has been identified as a key priority, with both researchers and parents agreeing that dietary interventions should be a particular research focus (Charman and Clare 2004; Medical Research Council 2001; Rutter 2011).

Despite the lack of evidence, parents understandably pursue a range of different types of interventions. Several recent surveys have identified that on average children are receiving between four and six interventions, with younger children more likely to be using dietary and behavioral/educational/alternative interventions, and pharmacological interventions being more widely used for adolescents (Green et al. 2006; Carter et al. 2011b; Goin-Kochel et al. 2007). Dietary interventions, such as restrictive diets and dietary supplements are used, with many parents falsely believing that such interventions are likely to be free of adverse effects, and safer than medications (Goin-Kochel et al. 2007; Hanson et al. 2007). However the use of restrictive diets is likely to pose additional risks for children with ASD who may already have feeding problems including a 'self-imposed' restrictive diet. Previous studies have found that children with ASD have more amino acid deficiencies and lower bone density than age matched controls, and in these studies there was a greater problem in those children on restricted diets (Arnold et al. 2003; Hediger et al. 2008; Keen 2008). However although several authors have reported that children with ASD have more restricted diets than age matched controls without ASD (Ahearn et al. 2001; Keen 2008), a recent general population study (using the Avon Longitudinal sample—ALSPAC sample) reported no differences in energy intake or growth for children with ASD (Emond et al. 2010). A further study compared food records and body mass index (BMI) of children with ASD aged 2–11 with matched controls (Hyman et al. 2012). No differences in nutritional intake were found between groups, but children with ASD were more likely to be overweight in the aged 2–5 group, and underweight in the aged 5–11 group.

The most commonly used restrictive dietary intervention is the gluten free casein free diet (GFCFD; Elder 2008; Carter et al. 2011b). This diet can place a substantial burden on families, and has considerable resource implications for healthcare services (Bowers 2002; Parr 2010). Parental reports make claims for high rates of success using the GFCFD as an intervention in ASD. For example (Goin-Kochel et al. 2009), reported that 51 % of parents said that their children improved while on the GFCFD. However in their online survey it was difficult to know how parents attributed their efficacy ratings to individual treatments since most of the children were receiving multiple treatments. Further since parents used the same Likert-like four point rating for each intervention, it was not possible to identify what specific behavioral outcomes parents saw as changed. (Goin-Kochel et al. 2007).

There have been a number of small scale exploratory studies of the effectiveness of the GFCFD (Knivsberg et al. 2002; Elder et al. 2006; Johnson et al. 2011). Knivsberg et al. (2002) was a small (10 subjects per group) single blind Randomised Controlled Trial of the GFCFD implemented by parents for 12 months. Subjects were selected if they had a diagnosis of autism and urinary peptide abnormalities (believed to reflect incomplete breakdown of gliadin, gluten and casein). The diet intervention group showed significant improvements in 'autistic traits' as reported from parent interviews. Compliance with the diet was not measured. Elder et al. (2006) was a pilot study of GFCFD for 6 weeks in a heterogeneous sample that reported no effect. Johnson et al. (2011)reported a 3-month, open label, randomised, parallel group design using the GFCFD and a healthy, low sugar diet thus controlling for the increased time and attention that is required to implement a diet such as the GFCFD. No significant differences were noted between the groups but the authors questioned whether the GFCFD might need to be implemented for a longer period of time before gains can be observed. No significant nutritional differences or side effects were reported but the authors identified that adherence to the GFCFD was difficult. The largest study to date used a single blind, non-placebo controlled design, involved 72 children, and found improvements in core autism symptomatology for those using the GFCFD (Whiteley et al. 2010). Initially in the first 12 months there was a placebo control, however all participants were assigned to GFCFD in the second phase of the trial. In the first phase 21 % withdrew from the study. Reasons for withdrawal included lack of time to support the GFCFD, children not wanting to be on the diet or no reported intervention effect. In the second 12 month phase when all children were offered the GFCFD more than a third of the remaining sample withdrew (Whiteley et al. 2010).

There is no plausible biological mechanism for the GFCFD. The 'opioid-excess theory' proposed that some individuals cannot digest gluten and casein leading to the absorption of excess peptides into the blood and then the brain, resulting in a range of autistic behaviours. An abnormal urinary pattern of proteins has also been reported (Panksepp et al. 1979; Reichelt et al. 1981; Shattock et al. 1990; Whiteley et al. 1999), but these findings have not replicated by independent groups (Alcorn et al. 2004; Cass et al. 2008; D'Eufemia et al. 1996; Horvath and Perman 2002; Le Couteur et al. 1988; van Elburg et al. 1995).

As there has been no large-scale randomized controlled trial of the GFCFD, its effectiveness remains unknown (Millward et al. 2008). We report the findings of a UK online survey designed to investigate current attitudes to dietary interventions, and potential support for a proposed design for a randomized controlled trial (RCT) of the GFCFD in young children with ASD.

Methods

Sample Size Estimation

We aimed to survey 246 UK parents of children with an ASD and 246 UK child health professionals working with children with ASD. The sample size was calculated to allow us to report with 95 % confidence the 'true' rate of agreement in the underlying population, to within ±5 %, for survey findings/statements with approximately an 80 % rate of agreement in our sample www.berrie.dds.nl/calcss.htm (Woodall et al. 2010).

The study received approval from a UK research ethics committee and the local (Northumberland, Tyne and Wear) NHS Trust.

Participants

To achieve the recruitment targets and gain a broad range of views, pediatricians, pediatric neurologists, pediatric gastroenterologists, child psychiatrists and pediatric dietitians were contacted. The aim was to recruit UK-wide. Through the relevant National Royal Colleges, professional bodies, national professional newsletters and UK multidisciplinary Child Development Centers email or postal invitations to participate in the study were sent to the majority of relevant professionals. Parents were recruited through two regional databases, online parent support fora and national parent support organizations.

Materials

Two versions of a survey questionnaire (parent and professional) were designed and piloted. Questionnaire development was undertaken in consultation with parents and child health professionals. Most questions required fixed-choice responses, though for some items there was the facility for brief free-text responses. The questionnaire was presented in four sections: demographic characteristics; experience and use of interventions for treatment of ASD in young children; research priorities; and a final section contained a summary description ('vignette') of the design for a proposed double-blind, multi-site randomized controlled trial (RCT) to evaluate the impact of GFCFD in young pre-school children with ASD together with an illustrative flow chart (see "Appendix").

The vignette included an explanation of the need for randomization and the procedures for access to proposed levels of additional professional support (dietitian and pediatrician). The vignette also included a description of 'Test Foods' (two versions of food products such as biscuits, muffins or porridge), manufactured to be either GFCF or containing precise quantities of gluten and casein) that would be included in the children's diet for the duration of the RCT, so that all parents and researchers remained 'blind' to the introduction of gluten and casein to half the children in the trial. Once survey participants had read the vignette and flowchart, they were asked a series of questions with fixed-choice responses (with space for brief free text comments) to ascertain opinions about the proposed trial design and levels of clinical support. This section of the questionnaire was devised to investigate possible barriers and facilitators to recruitment and retention of families within the proposed research design. Other details about the trial (such as the inclusion/exclusion criteria and safety plan) were not included, in order to keep the vignette brief.

Paper forms of the survey questionnaires were available for respondents who did not have web access or expressed a preference for a paper version (Copies of the questionnaires are available from the corresponding author on request).

Procedure

The study took place over 10 months between April 2009 and February 2010. Participants initially accessed the Newcastle University PADIA (Parents' and Professionals' Attitudes towards Dietary Intervention in Autism) research website (http://research.ncl.ac.uk/cargo-ne/PADIA.html) to express their interest in the survey, completed a short series of questions regarding their status (parent or professional), email address, postcode (zip code) and source from which they heard about the study. Each participant was allocated a unique identification (ID) number to access an information sheet and consent form before completing the full survey anonymously. All respondents were given the opportunity to enter a free prize draw to win a laptop (separate draws for parents and professionals). The two stage recruitment procedure was used to ensure collection of consent and socio-demographic information, protect confidentiality and reduce risk of repeated responses.

Once a unique ID had been allocated, if the questionnaire had not been completed, automatic reminders were sent to the associated email address at 2 and 4 weeks after registration (Edwards et al. 2007; McColl et al. 2001).

All survey responses were transferred to SPPS 15.0 for Windows software package for analysis. Descriptive statistics were used to summarize the experiences and attitudes of parents and professionals.

Results

Sample Composition

Two hundred and fifty eight of 361 (71 %) parents and 244 of 317 (77 %) professionals who expressed an interest completed relevant versions of the questionnaires. 41 % (105) of parents were recruited from two regional databases (North East England and Edinburgh Scotland). 80 % of parents and 89 % of professionals completed the survey online, with the remainder using a paper copy. Completeness of the data set for individual questions ranged from 90.3 to 99.6 % (parents) and from 86.8 to 100 % (professionals). For descriptive statistics the denominator was adjusted for individual questions as necessary.

Most parents who completed the survey were white British birth mothers of a child with an ASD (75 %). 80 % of mothers were homeowners and over half were employed (54 %) and educated to degree level (57 %). Child characteristics are detailed in Table 1. 65 % of parents reported that their child experienced three or more problem behaviors per week. There was no significant relationship between age of child and frequency of problem behaviors. The most frequent behaviors were selective eating (51 %), sensory reactions (52 %) together with temper tantrums (41 %), hyperactivity (40 %) and sleep problems (40 %). These rates of parent reported child problem behaviors are similar to a UK representative database sample (Maskey et al. 2012).

Considering professionals who completed the survey, 42 % were Pediatricians (including 10 % Pediatric Neurodisability Specialists), 32 % Child and Adolescent Psychiatrists, 17 % Dietitians and 9 % Psychologists.

Table 1 Child characteristics ($n = 258$)

Child characteristic	% (n =)
Gender	
Male:female	84.16 (216:42) (ratio 4:1)
Age at survey completion	
<2 years 11 months	2 (5)
3–5 years 11 months	31 (81)
6–11 years	67 (172)
ASD diagnosis	
Autism	27 (70)
Asperger's syndrome	20 (52)
Autism spectrum disorder	49 (127)
PDD-NOS/atypical autism	4 (9)
Age at diagnosis	
<2 years 11 months	27 (70)
3–5 years 11 months	57 (146)
6–11 years	16 (42)
Language level	
No meaningful speech	19 (50)
Single words and phrases	28 (70)
Sentences with good grammar	51 (132)
Other (no details)	1 (5)
Learning disability	31 (81)
Type of educational establishment attended	
Mainstream (school, nursery, unit attached)	71 (179)
Specialist provision	28 (70)
Home ed.	2 (4)
Educational support	
Individual education plan[a]	57 (150)
Statement of special educational needs[b]	55 (144)

[a] An Individual Education Plan (IEP) is a teaching and learning plan devised to identify the targets, provision and outcomes for a child identified with special educational needs

[b] Statement of Special Educational Needs is a legal document issued by the Local Authority responsible for education, following an in-depth multidisciplinary assessment of the child's needs

ASD Intervention Use

Parents reported (from a list of 21 possible interventions) that they were currently implementing a median of four interventions (range 0–15) with their child. Current intervention type and rates are detailed in Fig. 1. The use of speech/communication, and educational interventions and some form of dietary manipulation were all reported by over 80 % of parents. Dietary manipulation included use of special diets such as the GFCFD and dietary supplements (these were grouped as a single category within the fixed response format, with the descriptor 'micronutrients, vitamins, minerals, fish oils).

Although 75 % of professionals reported that they had been approached by families for information about the GFCFD, most (the majority of whom were Child and Adolescent Psychiatrists) estimated that fewer than 10 % of the children with ASD on their current caseload were using the GFCFD. However 26 % of professionals (mostly Pediatric Dietitians and Pediatricians) reported that 10–20 % of the children with ASD they see are using the GFCFD. A smaller number of Pediatric Neurodisability specialists and Child and Adolescent Psychiatrists reported that at least 20 % of their ASD caseload were on the GFCFD.

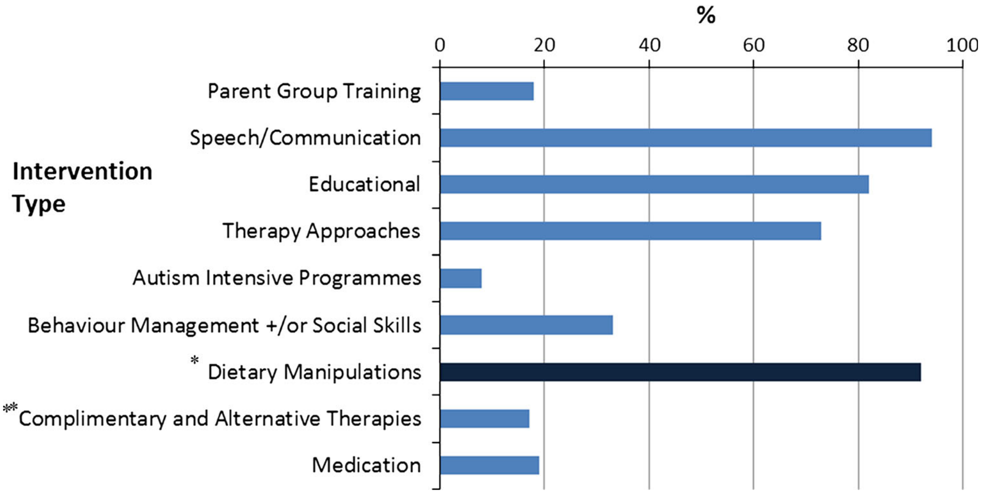

Fig. 1 Interventions currently used by parents. *Single asterisk* Dietary manipulations included use of special diets such as the GFCFD and dietary supplements (micronutrients, vitamins, minerals, fish oils). *Double asterisk* complementary and Alternative Therapies included homeopathy, acupuncture and massage

Table 2 Parent reports of current use of dietary interventions (special diets and supplements)

Age	Dietary Supplement % (*n*)	Special Diet % (*n*)	GFCF Diet % (*n*)	3 or more behaviour problems % (*n*)
<2 year 11 months	40 (2)	20 (1)	20 (1)	40 (2)
3–5 year–11 months	41 (33)	37 (30)	31 (25)	66 (54)
6–11 years	50 (86)	34 (59)	29 (50)	67 (115)
Total	47 (121)	35 (90)	29 (76)	66 (171)

Attitudes Towards Dietary Interventions

Eighty three percent of parents had tried a range of dietary manipulations (including any special diet and use of dietary supplements) with their child. 35 % were currently using a special diet and 46 % were currently using dietary supplements. There was no significant relationship between age of child and rate of dietary intervention use. The majority (86 %) of parents were aware of the GFCFD and 29 % were currently implementing it. For the small number of parents implementing other diets, there was no consistent pattern discernable from the few free-text descriptors provided by parents (examples included the CHO (carbohydrate) diet and soya diet).

For the 76 children currently on the GFCFD, most parents reported a change in their child's behavior with 'significant improvements' (5 point scale: significant decline, decline, no change, improvement, significant improvement) most frequently reported for gastrointestinal symptoms (54 %). Other symptoms reported to 'significantly improve' included concentration and attention (42 %), communication (29 %), social interaction (25 %) and repetitive interests and behaviors (20 %). A further 22 parents (29 % of children on the GFCFD) reported 'some improvement' in gastrointestinal symptoms. Thus the majority of children (83 %, $n = 63$) on the GFCFD experienced at least some improvement in gastrointestinal symptoms. Only 8 of these 63 children had no reported change in social interaction and 13 had no reported change in communication. A higher figure of 20 children were reported to show no change in repetitive interests and behaviors.

For 10 children there was worsening anxiety and aggression (Table 2).

Seventy three percent of professionals stated that there was 'insufficient evidence about the benefits or otherwise' of the GFCFD. Nearly two thirds of professionals felt that they had sufficient knowledge about the GFCFD to discuss it with families. Most reported that they would support families wishing to pursue the GFCFD but would not specifically recommend it to families. 19 % stated that they would advise parents *against* the use of the GFCFD.

Research Priorities

Parents and professionals were asked to rate their top 3 priorities from a list of 22 ASD research topics. The option topics were based on previous surveys (Charman and Clare 2004; Mills and Wing 2005) and findings from consultation with parents and professionals during the questionnaire development. 16 % (the second largest grouping) of professionals and just under 10 % of parents (by fourth largest group of parents) rated dietary interventions and behavioral difficulties as their top priority for ASD research (data available from last author). Parents with children under the age of 3 (only 5 children) prioritized research into causes and early intervention; aged 3–5 years 11 months—communication, causes, early intervention, behavior difficulties and dietary interventions. For children aged 6 years–11 years, parents were most interested in research into causes, communication, dietary interventions and behavior difficulties. For children talking in sentences, parents rated causes, behavioral difficulties, communication, early intervention, dietary interventions and anxiety as their top priorities.

Professionals top 5 research priorities were: behavioral difficulties (17 %), dietary interventions (16 %), causes (14 %), early intervention (just under 12 %) and diagnosis (8 %) (further details available from last author).

Barriers and Facilitators Towards Participation in a Proposed Randomized Controlled Trial of the GFCFD

Seventy eight percent of parents reported they would consider taking part in the proposed RCT. Of these, the majority 109 (85 %) answered 'yes' and a further 13 (10 %) 'maybe' when asked if they would be prepared for their child to be randomly allocated to a 'Test Food group with a 50 % chance of being in the gluten and casein free group'. Of the parents who suggested they would 'agree' to take part, nearly half (45 %) answered a subsequent item by scoring that 'yes' they would be more likely to do so if they were not 'blind' to group allocation. For parents who would not take part, most (63 %) would be no more likely to take part if they were not blind. to group allocation.

Parents were more likely to agree to take part if they were not currently implementing the GFCFD for their child ($\chi^2 = 11.670$, $df = 2$, $p = <0.01$). Of the 60 parents who had previously taken part in an autism research project, most responded positively to considering the proposed trial but 19 who had taken part in previous research, indicated they would definitely not take part ($\chi^2 = 7.287$, $df = 2$, $p = 0.026$). All these parents expressed concerns about the proposed study—citing for example concerns about the impact of the research on their child's existing limited diet, or that their child was already on the GFCFD and they would be reluctant to discontinue this intervention.

Considering the trial protocol, 77 % of parents thought there was sufficient dietitian support and this was significantly associated with likelihood to take part ($\chi^2 = 30.539$, $df = 2$, $p < 0.001$). Despite this, when asked what might be the most difficult part of the study, 44 % of parents expressed concern about getting their child to eat the range of 'Test' foods that would be included in the child's diet for the duration of the trial to maintain blinding.

Professionals' Views

Seventy five percent of professionals reported that they would be prepared to recruit children to the proposed GFCFD trial. Just under one third (31 %) had previously referred families to ASD research studies. Professionals highlighted a need for parents to have reliable access to dietitians (telephone and face-to-face). Perceived barriers to participation included that 'the child's diet may be too limited to take part in the trial, and whether families would be able to follow the procedure for the duration of the trial (i.e. 6 months).

Discussion

This study has identified that most parents of children with ASD who responded to this UK survey use a variety of interventions (most frequently speech/communication, educational and a mixture of dietary manipulations) and are usually implementing several interventions at the same time. These findings are in keeping with other recent surveys of parents of children with ASD conducted in US and Australia and highlight the multimodal approaches adopted by parents as they combine different types of interventions for their children (Carter et al. 2011b; Goin-Kochel et al. 2007; Green et al. 2006). The majority of respondents (parents and professionals) were aware of the GFCFD and indeed many parents had considered and/or tried the GFCFD. The most popular dietary manipulations (again often used in combination) were a range of dietary supplements and use of special diets (usually the GFCFD). The number of parents who reported that they were currently implementing the GFCFD was at the higher end of previously reported surveys (Levy and Hyman 2003; Perrin et al. 2012).

When parents were asked to specify the observed effects of the GFCFD, in line with other surveys, they reported improvement across a wide range of behaviors. Most parents reported at least some improvement in gastrointestinal symptoms often in combination with other behaviors. Some parents reported significant improvements in other behaviors (including concentration, attention and less frequently in some of the core ASD behaviors). The parents' preference for combinations of dietary manipulations, and the lack of specificity in reported improved behaviors (but usually including GI symptoms); add complexity to decisions about appropriate research design and choice of primary outcome measure(s) for evaluation of the impact of a complex intervention such as the GFCFD as an intervention for ASD.

There was general agreement from both parent and professional respondents for the need for more information about, and for more research on, a range of interventions including dietary supplements and the use of ‘special’ diets. Professionals considered that they had sufficient knowledge to discuss the GFCFD with parents who are considering implementing the diet. These discussions may well include issues such as the lack of a robust evidence base for the GFCFD (Isherwood et al. 2011).

Dietary interventions were not the number one priority for the majority of parents, but for parents with children of different ages it was in the top 4–5 research topics. For professionals, research into dietary intervention was the second highest rated research priority. Many professionals also indicated that they would appreciate further training in dietary and other biomedical interventions. Since all professionals who participated in this study indicated that they saw a varying number of children with ASD whose parents were considering and/or implementing the GFCFD, this training would be relevant to all professional groups. Indeed in the light of the professionals’ reported experience (irrespective of their discipline), all professional groups do need to be aware that at any one time at least some families on their caseload may be contemplating/implementing the GFCFD.

These findings may reflect the bias of those who completed the survey but, in keeping with previous research recommendations (Medical Research Council 2001), it also suggests that the dilemma of whether or not to attempt to implement dietary interventions (such as the GFCFD) in the absence of a robust evidence base continues to be a relevant topic for both research and current clinical practice, with the inevitable resource implications for affected families, research funding and service providers.

The novel use of a vignette protocol and flow chart to illustrate the proposed design for an RCT within the survey format appeared to be a successful way of investigating attitudes to and identifying potential facilitators and barriers for, a proposed trial to investigate the impact of the GFCFD in young children with ASD. Respondents were able to complete the sections of the questionnaire dedicated to the proposed trial design. Over three-quarters of parents and professionals stated their preparedness to be involved in a proposed RCT of the GFCFD and provided valuable feedback in response to structured questions about the trial design. This reported willingness of both parents and practitioners to engage in robustly designed research to investigate a ‘controversial’ dietary intervention, where there is a lack of scientific evidence, is encouraging for potential researchers and grant funding organizations. However, for an intervention such as the GFCFD, what is the likelihood that funding one or more fully powered RCTs will alter patterns of demand and uptake for the intervention? An example of another ‘controversial’ biomedical but non-dietary intervention previously reported as a treatment for ASD was the use of secretin (a gastrointestinal hormone). Following the publication of a series of RCTs that reported an important and significant placebo effect, but a lack of response to secretin, there has been a consistent decline in and now virtual absence of parents’ requests for this hormone as a treatment for ASD (Sandler 2005; Williams et al. 2005).

From the parents’ and professionals’ responses, three factors (current use of GFCFD, previous experience of research and level of professional support) were identified as potential barriers to recruitment and retention for the proposed trial.

For some parents currently implementing the GFCFD it might be that if they have already identified that their child is benefitting or hope that there will be benefit from the GFCFD, they may not want to risk allocation to the control group. However for the majority of the parents neither previous use of the GFCFD nor the consideration of future implementation of the GFCFD appeared to affect potential for successful recruitment. Further consideration is needed to clarify for parents who may be particularly committed to this intervention, what might be the circumstances in which they would be prepared to support the evaluation of the GFCFD in their own child and in the wider ASD population.

There was a small subgroup of parents with prior experience of taking part in research who were not prepared for their child to take part in this proposed trial. All gave reasons related to their child’s diet and/or other constraints about the study—such as that their child was already on the GFCFD and they would be reluctant to discontinue this intervention. No parents cited their previous experience of research as a barrier to taking part. However understanding service user attitudes to research, their knowledge of research methodologies and minimizing any potential longer term adverse impact of taking part in research are important considerations. Linked to this consideration of participants’ knowledge and understanding of research design is another intriguing and unexpected result that, amongst the parents who agreed that they would be prepared to take part in the proposed RCT, 45 % also indicated that they would be more likely to take part if they were not ‘blind’ to group allocation. Whether this finding indicated a lack of understanding about the proposed research design, ambivalence about randomization or an ambiguity in the design of the question is unclear. This finding highlights the importance of detailed explanation and a probable need for ongoing discussion to maximise understanding at time of recruitment and to support compliance and retention of participants. In the UK organizations such as INVOLVE funded by the National Institute for Health Research promote knowledge and learning on public engagement, partnership and involvement in research (INVOLVE 2010).

Parents agreed that the proposed levels of professional support within the trial design presented would be sufficient, but in common with the professionals they were concerned about following the diet protocol for 6 months. Consideration of reducing the duration of the GFCFD protocol to 3 months might have been more acceptable to parents and professionals but other authors have queried whether this would then be a sufficient duration to detect a beneficial effect (Johnson et al. 2011). Professionals recommended the need for additional professional support in the form of 'reliable' telephone access with the dietitian. This would allow parents to access urgent advice in addition to planned appointments with professionals. However professionals also had specific concerns about the risks of including children with very restricted diets (despite the proposed funded availability of additional professional support). A small feasibility study has already been undertaken by our multisite collaboration which has demonstrated that young children with ASD are prepared to eat the Test Foods products (Adams et al. 2008).

Understanding the barriers and facilitators that impact on recruitment and retention to evaluation studies is important to the successful outcome of intervention research (Friedman et al. 2010; Woodall et al. 2010). Most of the factors identified in this study appear specific to the complexity of research involving young children with ASD. This information will be useful for refining the research design and protocol for the evaluation of complex interventions such as the GFCFD and other ASD interventions for which there is no firm evidence base.

The survey had a number of limitations, and also strengths. The survey has a large sample of parents and professionals. A two stage recruitment procedure was used to allow collection of information about respondent characteristics and minimize risk of multiple responses. These strategies were successful—there was no evidence of systematic reporting bias from any particular group. Although inevitably the survey respondents are likely to be those parents and professionals with a particular interest in this topic, parents reported a range of experiences with respect to the GFCFD and professionals also expressed a spread of opinions from those who wanted more information about dietary interventions through to a smaller number who would actively discourage parents from attempting to implement the GFCFD. This allows us to have confidence in the reported findings.

As with other internet surveys, parent respondents had higher educational qualifications and were predominantly from higher socio-economic groups. The child characteristics were in keeping with other surveys of early years and primary school aged children, with just under half having a diagnosis of ASD, and most also reported to have a range of additional problems. In this survey the majority of children were attending mainstream educational provision a consequence of UK education inclusion policy for children with special needs to attend mainstream schools. Professionals were distributed across the professional groups which in turn reflects current UK clinical practice (Bowers 2002; Scottish Intercollegiate Guidelines Network 2009; National Institute for Health and Clinical Excellence 2010).

Less than half the parents (41 %) were recruited from the two regional databases but, as with previous electronic survey studies, fathers, unemployed parents and those with low educational attainment and low incomes were underrepresented. Further the two stage recruitment process was a more time consuming process and almost certainly contributed to the study attrition. Just over a quarter of parents (29 %) and just under a quarter (23 %) of professionals who registered on the PADIA website did not then use their allocated unique ID number to access and complete the questionnaires, despite up to two reminders. However no systematic bias was identified between the respondents who completed the whole process and those that only registered an expression of interest. The predominantly fixed-choice response format of the questionnaire limited the amount of detailed information obtained from individual respondents, for example little detail was obtained about the range of dietary supplements given to children.

Conclusion

Despite lack of evidence, most parents of children with ASD continue to implement several interventions at the same time. Parents of children with ASD, and the professionals who work in this area, strongly endorse the need for accurate information about a variety of interventions and would be prepared to consider taking part in a proposed RCT design to evaluate the GFCFD. The information provided by the respondents will be used to improve future research proposals with the aim to increase the scientific evidence in this controversial area.

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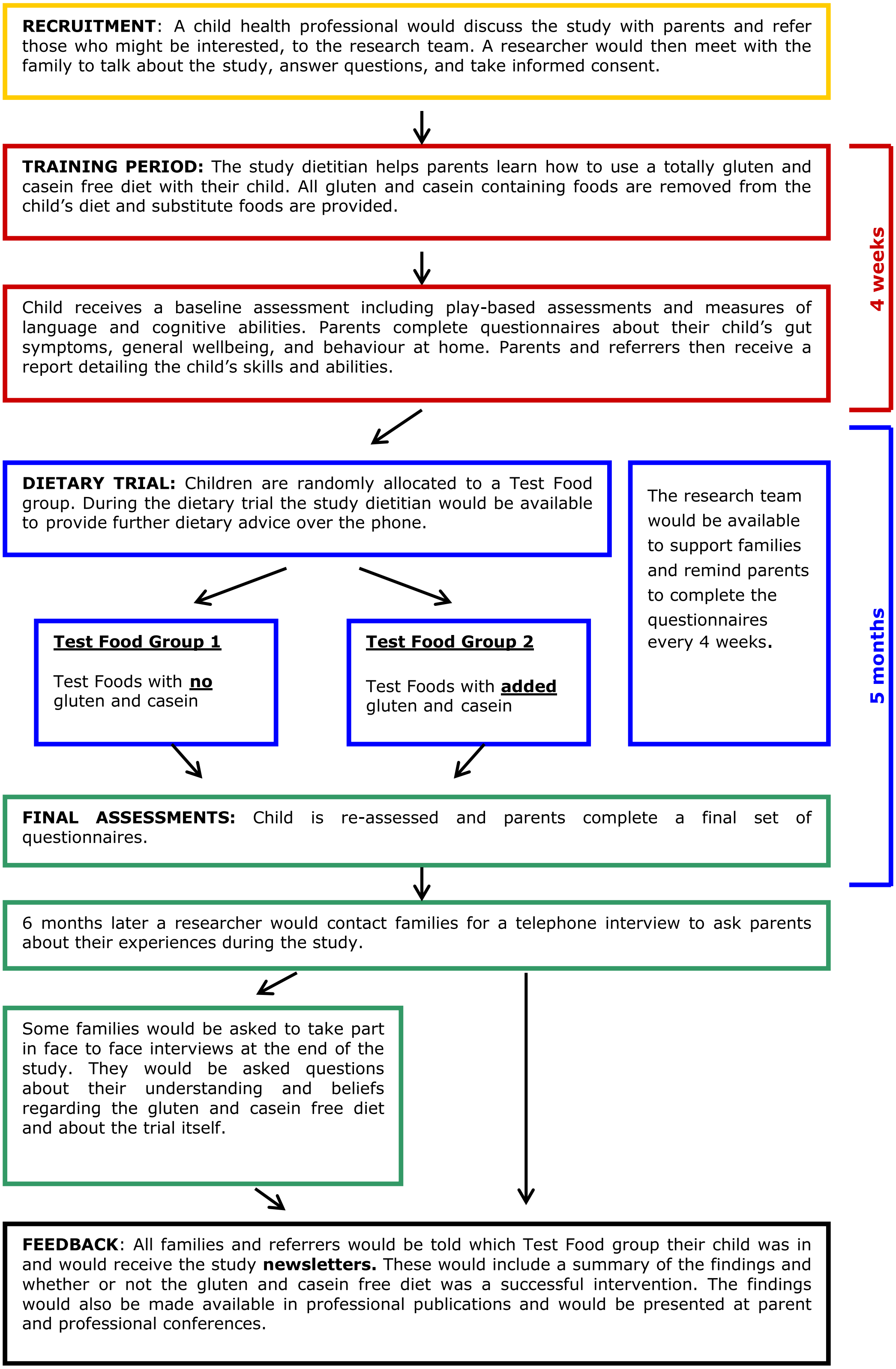
Conflict of interest The authors declare that they have no conflicts of interest.

Appendix

Flowchart of proposed RCT



RECRUITMENT: A child health professional would discuss the study with parents and refer those who might be interested, to the research team. A researcher would then meet with the family to talk about the study, answer questions, and take informed consent.

TRAINING PERIOD: The study dietitian helps parents learn how to use a totally gluten and casein free diet with their child. All gluten and casein containing foods are removed from the child's diet and substitute foods are provided.

Child receives a baseline assessment including play-based assessments and measures of language and cognitive abilities. Parents complete questionnaires about their child's gut symptoms, general wellbeing, and behaviour at home. Parents and referrers then receive a report detailing the child's skills and abilities.

DIETARY TRIAL: Children are randomly allocated to a Test Food group. During the dietary trial the study dietitian would be available to provide further dietary advice over the phone.

Test Food Group 1

Test Foods with **no** gluten and casein

Test Food Group 2

Test Foods with **added** gluten and casein

The research team would be available to support families and remind parents to complete the questionnaires every 4 weeks.

FINAL ASSESSMENTS: Child is re-assessed and parents complete a final set of questionnaires.

6 months later a researcher would contact families for a telephone interview to ask parents about their experiences during the study.

Some families would be asked to take part in face to face interviews at the end of the study. They would be asked questions about their understanding and beliefs regarding the gluten and casein free diet and about the trial itself.

FEEDBACK: All families and referrers would be told which Test Food group their child was in and would receive the study **newsletters.** These would include a summary of the findings and whether or not the gluten and casein free diet was a successful intervention. The findings would also be made available in professional publications and would be presented at parent and professional conferences.

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