The effect of ‘Go and Grow with CF’ on nutrition and pancreatic enzyme knowledge of children with cystic fibrosis

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Abstract  A randomised clinical trial was conducted to assess the impact of the ‘Go and Grow with CF’ intervention program on nutrition and pancreatic enzyme knowledge and self-management skills. Forty-two children with cystic fibrosis aged six to 11 years and 55 carers of two- to 11-year-old children participated in the program. Separate but similar validated questionnaires were used for face-to-face interviews with children with cystic fibrosis and for telephone interviews with carers on three occasions. The questionnaires were designed to assess nutrition and pancreatic enzyme knowledge and self-management skills. The improvement in knowledge of the children’s intervention group was significant immediately post-intervention ($P = 0.001$) but not at follow-up 12 months later. Children’s knowledge for both the intervention and control groups was associated with their appropriate self-management score immediately ($P = 0.02$ and $P = 0.03$, respectively) and 12 months post-intervention ($P = 0.01$ and $P = 0.00$, respectively). The home-based ‘Go and Grow with CF’ program was found to be effective in increasing children’s knowledge in the short-term. The absence of a long-term effect of the program on nutrition and pancreatic enzyme knowledge and behaviours may be due to the need for regular ongoing education and counselling. (Aust J Nutr Diet 2001;58:164–168)

Key words: nutrition knowledge, questionnaire, cystic fibrosis, behaviour, intervention

Introduction

Cystic fibrosis (CF) is a common, severe autosomal recessive disorder affecting many body systems (1). The nutritional problems and consequences of the disease are multifactorial. Lung function, anorexia, pancreatic insufficiency and intestinal and biliary complications contribute to increased energy needs, inadequate intake and excessive nutrient losses (2). Despite recent advances in the treatment of CF, poor growth and malnutrition continue to be significant problems and affect the length of survival of patients (3–9).

Individuals with CF need to consume a high energy, high fat, high salt diet and up to 90% of patients also require pancreatic enzyme replacement therapy (PERT) (10,11). An adequate level of knowledge is needed by children and their parents in order to be capable of making appropriate food choices and to optimise pancreatic enzyme administration. Children’s knowledge of nutrition and PERT is often poor despite the provision of specialist dietetic advice to families (12,13). Knowledge and subsequent adherence to treatments for CF could possibly be improved by the provision of periodic, structured, age-appropriate education programs (14).

A nutrition education and behaviour intervention program, ‘Go and Grow with CF’, was developed in 1996 with the specific aim of facilitating primary school-aged children and carers of two- to 11-year-olds in the process of translating nutrition and enzyme knowledge into behaviour and action (15). A carer was defined as the adult most responsible for the child’s nutrition and PERT needs. Specific objectives of the intervention program were:

- to increase the nutrition and PERT knowledge and self-management skills of children with CF and their carers; and,
- to increase the number and range of strategies used by carers to cope with food and PERT-related behaviour problems.

A clinical trial was established to assess the impact of the ‘Go and Grow with CF’ intervention program on knowledge, behaviour, dietary intake and nutritional status. The purpose of this paper is to report on the nutrition and enzyme knowledge and self-management results obtained from the clinical trial.

Methods

Study participants

Children eligible for the clinical trial were those attending the Princess Margaret Hospital CF clinic who were aged between two and 11 years at the commencement of baseline data collection and who had pancreatic insufficiency. Exclusion criteria for the clinical trial were pancreatic sufficiency, liver disease requiring drug therapy, short-gut syndrome, enteral tube feeding and marked language delay in children aged six to 11 years.

Of the 88 children in the specified age group attending the CF clinic, 70 were eligible for the clinical trial. Of these, 11 were not enrolled in the study because they did
not attend the clinic regularly or their parents did not consent to their participation. Thus, 59 children aged two to 11 years and their primary carer were enrolled in the clinical trial. Thirty of these children and their carers were randomly assigned (using a random number table) to participate in the intervention program. The carer of one child chose for their family not to participate in the ‘Go and Grow with CF’ intervention program due to time constraints and their data were excluded from the analysis. Another carer and child, who had been randomly allocated to the control group, transferred interstate and were unavailable for follow-up at 12 months after the intervention. Thus, with both groups combined, the respondents interviewed were 42 children aged six to 11 years and 55 carers of children aged two to 11 years (three carers had two children each) except the 12-month follow-up after the intervention, there were 41 children and 54 carers.

Informed written consent was obtained from the child’s carer in accordance with the approval that was obtained from the Human Ethics Committees of Princess Margaret Hospital and Curtin University of Technology, Western Australia.

Procedures

The intervention program, ‘Go and Grow with CF’, was developed by a dietician in consultation with a clinical psychologist and is described in detail elsewhere (15). The program was based on social learning theory constructs (16,17) and desirable behaviours were nurtured through six steps each week to help children apply their nutrition and PERT knowledge. The program included an introductory workshop, a home-based course and a concluding workshop. It was implemented at Princess Margaret Hospital between April and August 1996. Program participants included 21 children aged six to 11 years and 27 carers of 29 children aged two to 11 years.

Separate but similar validated questionnaires for children with CF and for their carers (13), which were based on the learning objectives of the ‘Go and Grow with CF’ program, were used to assess nutrition and enzyme knowledge and self-management skills on three occasions between January 1996 and October 1997, namely Time 1 (pre-intervention), Time 2 (immediately post-intervention) and Time 3 (12 months post-intervention). The questionnaires evaluated knowledge and self-management skills of children regarding pancreatic enzymes, fat, energy and salt, and knowledge and skills of carers only regarding malabsorption and vitamins. Content validity of the questionnaires and reliability of respondents in answering individual questions have been described previously (13). The questionnaires were administered as face-to-face interviews with children aged six to 11 years and by telephone with carers of two-to 11-year-olds.

Knowledge questions were mostly closed, in that respondents selected one of two alternative answers or ‘don’t know’. The alternative response of ‘don’t know’ was provided to discourage guessing.

The self-management questionnaire consisted mostly of scenarios about which the respondents were initially asked an open question. For example, ‘If your child had signs of more than usual malabsorption what would you do?’ Several appropriate and inappropriate responses were possible for each question. When respondents indicated they had finished answering the open question, prompts were read out from a list of possible answers not yet stated in order to assess if respondents knew a range of possible correct responses. An example of a prompt is, ‘If your child had signs of more than usual malabsorption would you: review what he or she has been eating; review the number of enzymes; increase the number of enzyme capsules each day, etc?’ Yes, no or don’t know responses were required for each item on the list. Prompts were not given with the few questions that asked the respondent to recommend the number of pancreatic enzymes that should be taken by the character in the scenario.

The children’s self-management questionnaire also included questions assessing signs of possible malabsorption and communication with their carer about management. The carers’ self-management questionnaire also included questions to assess the age at which they expected children to manage their own PERT.

When participants were recruited for the clinical trial, demographic information was obtained from carers using a questionnaire based on the WA Child Health Survey household record form and family background questionnaire (18).

Statistical analysis

The Statistical Package for Social Sciences 6.1.3, 1995 (SPSS Incorporated, Chicago, Illinois, USA) was used to determine descriptive statistics for the questionnaires and to assess the effects of the intervention using independent t-tests. Total knowledge and appropriate and inappropriate self-management scores were determined for children’s and carers’ questionnaires. This was done by summing the number of correct answers for the knowledge questionnaires and the number of appropriate and inappropriate responses for the self-management questionnaires. The average difference in the scores from Time 1 to Time 2 and Time 1 to Time 3 were calculated for participants within each group to assess both the immediate and long-term changes. The participants’ differences in scores over time were used to compare the difference in the average improvement between the intervention and control groups using independent t-tests.

In addition to calculating an overall score, each question in the children’s and carers’ self-management questionnaires was analysed individually. Changes over time were assessed and the differences in the change between groups were analysed by:

- evaluating the proportion of unprompted alone, and combined unprompted and prompted, responses that were appropriate for the intervention group and determining whether the proportion had improved or declined over time;
- determining by cross-tabulation the proportion of participants who gave only appropriate responses; and,
- performing independent t-tests on the individual differences over time on the total of appropriate and inappropriate responses for each question.

Associations between the knowledge scores of the children and carers, and the changes in the scores, in each group over time, were examined using Pearson’s correlation coefficient. Spearman’s correlation coefficient was used to examine the association between children’s and carers’ knowledge and self-management scores as the
scales of measurement in the questionnaires differed (e.g. children’s maximum possible score for the knowledge questionnaire was 37 and for the self-management questionnaire was 23 appropriate responses and 11 inappropriate responses).

Demographic information (18) was used to assign each subject a socioeconomic index which was one of five levels of socioeconomic status based on their carers’ level of education, household size and total family income. The index was cross–tabulated with group to compare the socioeconomic status of those receiving the ‘Go and Grow with CF’ intervention program with the controls. One-way analysis of variance (ANOVA) was used to compare the mean knowledge and self-management scores between five levels of socioeconomic status.

Sample size calculations for the clinical trial were based on changes in percentage of ideal body weight. It was determined that 20 subjects per group would be sufficient to detect a mean difference in percentage of ideal body weight of 2.5%, with a statistical power of 85% and Type I error of 0.05. In order to account for the possibility of drop-outs the number of subjects recruited was based on the maximum number of children eligible for the clinical trial.

Results

Descriptive statistics for the children’s and carers’ knowledge questionnaires are shown in Table 1. The change in children’s knowledge from Time 1 to Time 2 was statistically significantly different between the intervention and control groups (P = 0.001) (Table 1). This difference in the change between the groups was 3.5 units in favour of the intervention group (where the maximum knowledge score was 37). The improvement in knowledge of the children in the intervention group occurred for all domains, i.e. enzymes, fat, energy and salt, with the greatest improvement being with the fat and enzyme questions.

From Time 2 to Time 3, the knowledge scores of the children in the intervention group decreased and the control group’s knowledge scores improved to a point where the mean knowledge score for each group differed by only 0.3 of a unit at Time 3. As such, the improvement in children’s knowledge from Time 1 to Time 3 was not statistically different between the groups (Table 1).

The improvement in the average response of the carers’ intervention group from Time 1 to Time 2 was slightly greater than that of the control group (Table 1). However, the differences in the change between groups from both Time 1 to Time 2 and Time 1 to Time 3 were not statistically different. It is possible that high baseline scores made it difficult to detect an improvement in carers’ knowledge.

The differences between groups for the children’s and carers’ self-management scores were not statistically significant. Also, there was no overall intervention or time effect noted when individual questions in the self-management questionnaires were analysed.

A separate set of questions in the validated self-management questionnaire assessed children’s reported communication with carers when they experienced signs of possible malabsorption (abdominal pain and loose, fatty, frothy or pale bowel actions). At Time 2, a greater number of children in the intervention group compared to the control group reported communicating with their carers when they experienced signs of possible malabsorption (intervention group: Time 1, 9 and Time 2, 12 out of 21; control group: Time 1, 14 and Time 2, 10 out of 21). The t-test indicated that the difference between the groups in favour of the intervention group continued to Time 3 (P = 0.002), even though less children in each of the groups reported communicating with their carers when they experienced signs of possible malabsorption.

A positive outcome from the intervention for carers was the increase in the number of respondents in the intervention group indicating appropriate management for malabsorption, growth, salt supplementation, enzyme therapy and cooperation with meal times, immediately post-intervention. This difference between groups was not evident at Time 3 because either the difference in the groups was non-discriminatory or the number of respondents in the intervention group indicating appropriate management for these aspects declined.

Analysis of children’s and carers’ knowledge and self-management scores using Spearman’s correlation revealed that the knowledge of the children in each group at Time 2 and Time 3 was associated with their appropriate self-management score (Time 2, intervention group, r = 0.52, P = 0.02; control group, r = 0.46, P = 0.03; Time 3, intervention group, r = 0.53, P = 0.01; control group, r = 0.71, P = 0.00). Correlation coefficients of approximately 0.5 indicate that in a linear regression setting the knowledge scores explain 25% of the variation in self-management scores.

Chi-squared analysis, based on a contingency table, indicated no significant difference in the distribution of the socioeconomic index for the intervention and control groups. One-way ANOVA indicated that the difference between the socioeconomic index categories and the children’s and carers’ mean knowledge and self-management scores was not statistically significant and this persisted whether or not intervention and control status were considered.

Discussion

The nutrition and behaviour intervention program was effective in increasing children’s knowledge in the short-term (Table 1), irrespective of a family’s socioeconomic index. The knowledge of the children’s intervention group improved in the four domains tested by the questionnaire (enzymes, fat, energy and salt), with the greatest improvement being with the fat and enzyme questions. It is difficult to determine whether the mean improvement from pre- to post-intervention of 11% in the knowledge score of the children’s intervention group (representing 3.5 out of 37 units) was of clinical significance. All the questions in the questionnaires were considered by the investigators to be important concepts to be understood by children with CF in order for them to be capable of optimising their nutritional intake. The improved post-intervention mean score of 74% may still be insufficient for achieving CF dietary and PERT recommendations most of the time. An accurate assessment of dietary intake, in conjunction with knowledge, would be advanta-
geous in determining what level of knowledge is necessary for optimising nutritional status.

The knowledge scores of the children’s intervention and control groups were similar to each other 12 months after the intervention program. From Time 2 to Time 3, the knowledge of the intervention group decreased. This result suggests that periodic nutrition and PERT education may be necessary to help children and carers retain knowledge gains achieved by participating in the ‘Go and Grow with CF’ program, and to make further advancements. Interest in dietary and PERT information could be maintained by using a variety of age-appropriate materials and programs on a rotational basis.

The proportion of carers in the intervention group indicating appropriate management regarding several aspects of nutrition and PERT was significantly different from the control group immediately post-intervention, although this result was not duplicated at Time 3. Twelve months after the intervention, knowledge and self-management of both the children’s and carers’ control group also improved, such that the scores of the groups were similar. The improvement in the children’s and carers’ control groups may be a consequence of the respondents actively seeking information about issues they felt they did not answer correctly each time they were interviewed. This positive effect of the study provides further evidence of the need for continuing education.

The short-term improvement in knowledge about fat and enzymes after participation in the pilot program suggests that the 1998 revised version of the program, which includes a fat target (19) and the Australian PERT guidelines (20,21), could assist families in knowing more about the energy and pancreatic enzyme needs of a child who has CF. Although knowledge does not equate with behaviour, there is potential for ‘Go and Grow with CF’ to be an effective program as it teaches families both the ‘what’ and ‘how’ of achieving important nutrition recommendations for children who have CF.

The positive association between knowledge and appropriate self-management at Time 2 and Time 3, for both the children’s intervention and control groups, concurs with social learning theory constructs that maintain that an individual’s ability to perform certain behaviours depends on the acquisition of adequate knowledge (16,17). Children’s responses to questions about reporting signs of possible malabsorption suggested that there was both a short- and long-term improvement in the intervention group’s communication with carers about problems associated with PERT. The improvement in communication about possible malabsorption is an important outcome of the program and possibly indicates that ‘Go and Grow with CF’ equipped families with information to assess and discuss an aspect of the child’s gastrointestinal management, which may in turn improve clinical outcomes.

Process evaluation of ‘Go and Grow with CF’ (15) indicated that carers perceived that they and their children learned a great deal of information from the nutrition and behaviour intervention program. The objective evidence presented in this paper does not support this level of learning, probably due to limitations of the questionnaires, as discussed in detail elsewhere (13). Refinement of the questionnaires, and inclusion of questions with high discriminatory power, would enable the real effects of the program over time, on both children’s and carers’ knowledge and self-management skills, to be established.

Conclusion

The ‘Go and Grow with CF’ home-based program was effective in increasing children’s knowledge in the short-term. Adequate levels of knowledge are required to enable individuals with CF to be capable of achieving nutrition and PERT recommendations, and subsequently to optimise their nutritional status. The apparent absence of a long-term effect of the program, on children’s and carers’ knowledge, and carers’ appropriate management of food and PERT-related behaviour problems, suggests that regular, ongoing education and counselling are required by families to reinforce aspects related to the child’s current

| Table 1. Nutrition and enzyme knowledge scores for children with cystic fibrosis aged six to 11 years and carers of two to 11 year olds |
|-----------------|-----------------|-----------------|
| Time            | Variable        | Children        | Carers           |
|                 |                 | (maximum possible score = 37) | (maximum possible score = 42) |
|                 |                 | Intervention (group 1) | Control (group 2) | Intervention (group 1) | Control (group 2) |
|                 |                 | n = 21 | n = 21(a) | n = 27 | n = 28(b) |
| Pre-intervention | Mean score ± se | 23.3 ± 1.1 | 23.7 ± 1.1 | 35.4 ± 0.92 | 36.0 ± 0.6 |
|                 | Mean percentage of maximum score | 63 | 64 | 84 | 86 |
| Post- minus pre-intervention | Mean score change ± se | 4.2 ± 0.6 | 0.7 ± 0.7 | 1.8 ± 0.8 | 1.1 ± 0.5 |
|                 | Mean score difference(a) group 1 – 2 | 3.5* | 0.7 |
| 12-month follow-up minus pre-intervention | Mean score change ± se | 2.2 ± 1.1 | 2.1 ± 0.9 | 1.6 ± 0.8 | 1.6 ± 0.5 |
|                 | Mean score difference(a) group 1 – 2 | 0.1 | 0.0 |

* Significant difference between groups, P = 0.001.
(a) Except at 12 month follow-up, n = 20.
(b) Except at 12 month follow-up, n = 27.
(c) Statistical significance from independent t-tests for between group changes.
stage of development and disease status. The ‘Go and Grow with CF’ home-based course material has the potential to be used as both a preventative program and to help identify strategies for solving nutrition and PERT-related problems if they arise.

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References