Collaborative care for the patient with cystic fibrosis-related diabetes

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Introduction

Cystic fibrosis-related diabetes (CFRD) poses both a problem of management and the added burden of secondary chronic disease for patients and their carers. Both the paediatric diabetes specialist nurse (PDSN) and the paediatric cystic fibrosis specialist nurse (PCFSN) have skills to offer patients and carers. This article describes the development of a nurse-led collaborative approach to the care of children with CFRD, supported by written educational material for patients and carers. The aim is to maximise the expertise available and reduce the risk of patients receiving conflicting and/or confusing information.

The Royal Gwent Hospital runs a cystic fibrosis clinic for 36 patients. Over the past 4 years the paediatric diabetes specialist nurse (PDSN) and the paediatric cystic fibrosis specialist nurse (PCFSN) have developed informal cooperative working practices with cystic fibrosis patients.

Their experience during this period highlighted the absence of written educational material, and a lack of formalised collaborative care for patients with these two conditions.

Furthermore, review of the current literature demonstrated no evidence of structured collaborative care between specialist nurses in this field of practice.

In response to this, the two specialist nurses set up an initiative to improve nursing practice and enhance the education of patients and their carers.

The initiative comprised:

- Joint home visits by the PDSN and PCFSN
- Development of a core information document to be used by all team members and to be kept in the medical records
- Production and provision of written information on impaired glucose tolerance (IGT) in cystic fibrosis patients and cystic fibrosis-related diabetes (CFRD) for patients and carers
- Production and provision of written information on CFRD for school teachers.

Background

The incidence and prevalence of impaired glucose tolerance (IGT) and diabetes mellitus in cystic fibrosis patients increases with age (Lanng et al, 1991). As the life expectancy of patients with cystic fibrosis has improved, the number of patients developing CFRD is increasing.

The added complication of cystic fibrosis in people with diabetes warrants further research, particularly regarding its treatment and long-term effects. Internationally, Lanng and colleagues in Copenhagen are leading this research.

In the UK, Hodson has written extensively about CFRD (e.g. Hodson, 1992), including a booklet for the Cystic Fibrosis Trust (Hodson and Lant, 1996). Hodson (1992) reports that:

- 50% of cystic fibrosis patients over the age of 18 years have IGT
- 4% of cystic fibrosis patients between 10 and 14 years of age develop diabetes mellitus
- 15% of cystic fibrosis adults develop diabetes mellitus.

Hyperglycaemia may adversely influence weight, pulmonary function, and the development of microvascular complications. In addition, the adverse effect of IGT on prognosis is increasingly being recognised (Wilson et al, 1996).

ARTICLE POINTS

1 Half of all cystic fibrosis patients over 18 years of age have impaired glucose tolerance (IGT).

2 The incidence and prevalence of IGT and diabetes mellitus in cystic fibrosis patients increases with age.

3 Improved life expectancy of cystic fibrosis patients has led to an increasing number of patients developing cystic fibrosis-related diabetes.

4 There have been no previous reports of collaborative care in these two fields of practice.

5 A nurse-led collaborative care initiative is described which maximises benefits for patients/carers.

KEY WORDS

- **Cystic fibrosis**
- **Impaired glucose tolerance**
- **Diabetes**
- **Collaborative care**

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1 CFRD requires careful management if patients are to adhere to treatment regimens.

2 The presence of a second chronic disease requiring invasive treatment imposes a huge burden on patients and carers.

3 Adolescents find it particularly difficult to comply with treatment.

4 Patients with CFRD will need to adapt their diet and medication appropriately, with careful guidance from the cystic fibrosis dietitian and specialist nurses.

Management issues

CFRD is an added complication of diabetes that requires careful management if patients and family are to adhere to what is already a rigorous daily routine treatment.

Research studies have demonstrated significant rates of psychological and social disturbance in children with chronic disease, their parents and siblings (Elander and Midence, 1997). The presence of a second chronic disease requiring invasive treatment can impose a huge burden on patients and their families, and compliance with treatment may become particularly difficult during adolescence.

Great care and sympathy is needed when instructing patients on their new treatment regimen, to avoid the development of depression in both patients and families. Davis (1993) notes that 'children and their parents have to change and adapt to a set of undesirable and unfortunate circumstances'.

Explanation of the diet required for successful management of CFRD can be difficult, as patients may be aware that individuals with diabetes have to restrict their intake of refined sugar. This contrasts with the need for cystic fibrosis patients to adhere to the high-calorie, high-protein diet that is essential to their survival. To meet this requirement, patients with CFRD will need to adjust their insulin or oral hypoglycaemic agents to maintain normal blood glucose levels, with careful guidance from the cystic fibrosis dietitian and specialist nurses.

Development of the initiative

Ten patients (seven male, three female) from the Royal Gwent Hospital cystic fibrosis clinic who were designated as having either IGT or CFRD were involved in the first stage of the initiative, which ran for 6 months. Their ages ranged from 7 to 18.7 years (mean 11.1 years).

Two of these patients were receiving daily insulin therapy, and one was receiving intermittent treatment with insulin for steroid-induced diabetes. The remaining seven patients were managed using dietary control.

In September 1996, the PDSN and PCFSN met regularly to examine these patients' medical notes. They recorded relevant available data such as:

- Glucose tolerance test date and result

Patient's name.....Date of birth.....Date of referral to diabetes specialist nurse.....

Date						
Glucose tolerance test						
HbA_{1c}						
Insulin						
Blood glucose monitoring						
Urinalysis						
Symptoms						
Comments						

Figure 1. Cystic fibrosis/diabetes clinical nurse specialist review form

- Glycated haemoglobin (HbA_{1c}) level
- Blood glucose monitoring
- Urinalysis result
- Symptoms
- Insulin regimen.

Core information document

During this process, the specialist nurses identified the need for a core information document in a readily accessible form.

A review form was therefore designed as a communication tool, to be kept in the medical notes and updated as appropriate (Figure 1). The aim was to facilitate ready access to the patient's current diabetes status for all medical and nursing staff.

The form also offers a basis for correlation of data, to determine, for example, the relationship between commencement of insulin therapy, lung function and general health at the time.

Written information

In order to support the collaborative care programme, it was necessary to produce written material. With the assistance of the Trust's Patient Information Unit, the two specialist nurses wrote and produced user-friendly information leaflets to be given to patients and their families.

Joint home visits

A programme of joint home visits by the PCFSN and PDSN was initiated (*Figure* 2). The aim was to explain this initiative to all families and children involved, in order to reduce potential confusion among patients and their carers concerning the management of IGT or CFRD.

The format of the joint visits was as follows:

- Introduction to this new nurse-led development
- Assessment of the patient's and family's knowledge of the patient's current diabetic status
- Informal discussion in the relaxed home setting, allowing time and opportunity for families to ask questions and express anxieties
- Teaching of practical skills (e.g. blood glucose monitoring), using the latest available technology

PAGE POINTS

1 A review form was designed, to be kept in the medical notes and updated as necessary.

2 This provided all medical and nursing staff with ready access to the patient's current diabetic status.

3 User-friendly information leaflets were produced for distribution to patients and carers.

4 Joint home visits by the two specialist nurses were arranged to explain the new collaborative approach to care and to educate patients/carers.

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Figure 2. Joint home visits were undertaken with the aim of explaining the collaborative care programme to patients and their families.

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1 Joint home visits enable the two nurse specialists to share their knowledge and skills to their mutual advantage.

2 They also lessen the risk of patients receiving conflicting/confusing advice from different nurse specialists on separate occasions.

3 The burden of a second chronic disease may mean that neither is properly managed in everyday life

4 Responses to this initiative from patients and families confirmed the need for and value of this level of care.

5 The core information document ensures an accurate channel of communication between all medical and nursing staff.

Readers or other care teams requiring further information on the authors' experiences at the Royal Gwent Hospital should contact Jane Bramwell or Jane Buckley (tel. 01633 234525; fax 01633 214930)

- Review of the appropriate patient information leaflet, which was then left with the family.

The care from the PCFSN continued, but with the additional expertise of the PDSN, thus allowing this group of patients to benefit from the service already offered to the general paediatric diabetes caseload.

It also provided a valuable opportunity for the PCFSN and PDSN to share their knowledge and skills to their mutual benefit. Importantly, it reduced the risk of giving the patient and family conflicting/confusing information, which might have been the case if the two specialist nurses had each seen the patient/family separately.

In addition, fact sheets detailing the information provided to patients and families were produced as a teaching and educational resource for colleagues. These have proved invaluable when promoting this new collaborative care approach at meetings, lectures and conferences.

School visits were included as part of the collaborative care programme. At these visits, advice tailored to the individual's specific diabetes needs was offered, supported by written material for schools.

Discussion

There can be little doubt that the management of a chronic illness is challenging to both patient and carer.

As Dodge (1992) stated:

'Perhaps most importantly, compliance with recommended treatment is notoriously low in both cystic fibrosis and diabetic teenagers; and the burden of a second chronic illness may well mean that neither is properly managed in everyday life. The extent to which non-compliance distorts the life expectancy figures is difficult to estimate, but we would guess that it may be considerable.'

Increased awareness of CFRD and its complications, coupled with the lack of structured collaborative nursing care for children with this disorder, prompted the PCFSN and PDSN at the Royal Gwent Hospital to set up this initiative to maximise the expertise available to patients.

Informal evaluation

After the initial six-month period, opinions on the initiative were sought from patients, their families/carers and professionals. Follow-up outpatient clinics provided the opportunity for the PCFSN and PDSN to discuss how useful the families had found the written information and the collaborative nursing care approach.

The uniformly positive response received from patients and their families confirmed the need for and value of this level of care, which is now ongoing in our clinic. This combined approach has maximised the expertise available to these patients. The provision of written educational material was an essential component of the process.

During ward visits, professional colleagues have verbally confirmed the value of the core information document, which ensures an accurate channel of communication between all staff.

The positive response at meetings and conferences suggests that all cystic fibrosis teams should establish a similar working arrangement between diabetes and cystic fibrosis specialist nurses, supported by appropriate written material.

Outcomes

The development of a joint review form, to be kept in the medical notes, and a set of information leaflets and fact sheets enable consistent and accurate information to be provided to patients, carers and other professionals.

This initiative has enhanced communication between all medical/nursing staff involved and improved support and education for patients and carers. ■

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