

Comparison of hypoglycaemia and quality of life in patients with cystic fibrosis related diabetes and Type 1 diabetes

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Background: Advances in medical knowledge and treatments have improved prognosis for people with cystic fibrosis (CF). However, adulthood can bring additional complications for these patients, such as the development of cystic fibrosis related diabetes (CFRD). Treatment of CFRD often involves taking insulin, which can result in hypoglycaemia, a common complication also reported among those with type 1 diabetes mellitus (T1DM). Little evidence exists on the differences in experiences of hypoglycaemia between people with CFRD and those with T1DM or on how diabetes affects the quality of life of these two patient groups.



Aims: An investigation was conducted that aimed to:

- a. Describe the experiences of patients living with CFRD or T1DM.
- b. Compare the frequency, severity and symptoms of hypoglycaemia and reduced hypoglycaemic awareness, between patients with CFRD or T1DM.
- c. Identify factors associated with hypoglycaemia and reduced hypoglycaemic awareness in patients with CFRD or T1DM.
- d. Compare quality of life between patients with CFRD or T1DM.
- e. Determine factors that affect quality of life in patients with CFRD or T1DM.

Data collection: Three forms of data collection were employed: questionnaires, diaries and interviews. Questionnaires included:

- Background demographic questions.
- Investigator-developed questions about knowledge and frequency of hypoglycaemia.
- The Edinburgh Hypoglycaemia Scale (EHS), which retrospectively assesses autonomic and neuroglycopenic symptoms associated with hypoglycaemia.
- The Diabetes Quality of Life Measure (DQoL), which explores the following satisfaction with treatment, impact of treatment, worry about future effects of diabetes and about social/vocational issues.

Diaries were sent out with questionnaires, which all patients were asked to complete in order to provide prospective data relating to hypoglycaemia.

Within the diaries, participants were invited to record the following information, over one week, relating to every episode of hypoglycaemia they experienced: Date, time, remedial action taken, warning signs/symptoms and if a third party was needed for assistance.

Semi-structured interviews were conducted with a sub-sample of those completing a questionnaire. During interviews, individuals were asked about their experiences of hypoglycaemia, their response to being diagnosed with diabetes and how they managed this condition. Informed consent was obtained to tape these face to face or telephone conversations.

Patients from the Trust were eligible to participate if: a) aged between 18-60; b) diagnosed with CFRD or T1DM for at least three months and treated with insulin; c) able to read and write English; and d) free of cognitive impairment. Questionnaires were sent to 295 T1DM and 145 CFRD patients, and were returned by 55 T1DM and 52 CFRD patients. Of these, 12 people with T1DM and 11 with CFRD were selected to take part in a semi-structured interview. Individuals invited for interview were chosen in order to provide maximum variation in terms of gender, duration and type of diabetes.

Analysis: Questionnaire data were analysed using t-tests, Mann Whitney U tests or chi square tests as appropriate. Qualitative data were analysed using a framework approach, whereby material was coded and themes derived from this initial stage of analysis.

Findings: *Questionnaires* – Patients with CFRD reported significantly fewer episodes of hypoglycaemia, whilst T1DM respondents were more likely to recall an occurrence that caused them to lose consciousness. There was little difference in the number of autonomic symptoms participants reported having on the EHS, but those with T1DM appeared to have more neuroglycopenic ones. In terms of quality of life, diabetes caused T1DM patients more worry compared to those with CFRD, with the former scoring significantly worse on the total DQoL scale.

Diaries – Comparing prospective data to information given on questionnaires suggested that when asked to recall retrospectively how often they experienced hypoglycaemia, patients underestimated the frequency of such an event. Data from diaries suggested no difference between the number of hypoglycaemia episodes experienced by the two groups.

Interviews - Variation in perceptions recalled during interviews stemmed from diabetes being part of an existing life-threatening chronic illness in people with CFRD, compared to being a new life-threatening condition in those with T1DM. Hence, for patients with CFRD, diagnosis represented a progression in their health status, which called on them to adapt existing treatment regimens. In contrast, interviewees with T1DM had to re-evaluate their previous sense of self as 'healthy' and adjust to managing a long-term complaint. For interviewees with T1DM, a desire to reduce future health risks motivated their self-management efforts, whilst those with CFRD were driven by the negative effect poor control of diabetes had on their chest and weight.