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Abstract

Information booklets for parents of children with Minimal Change Nephrotic syndrome are currently in general circulation in the U.K. This study set out to discover what information parents require in a general information booklet, and whether the present standard of written information is adequate.

Ten sets of parents were interviewed in their homes using a semi-structured interview technique.

Five out of the ten parents interviewed had previously received an information booklet, these parents said they found them very general and basic. The other parents interviewed said that they would have liked some written information.

Some of the parents made some very constructive contributions to the content of the new information booklet. Half the parents interviewed expressed a desire to be informed of current research into minimal change nephrotic syndrome, and some parents were concerned about the adequacy of generalised information.

Introduction

Minimal Change Nephrotic Syndrome is the most common form of glomerulonephritis in children. It usually presents with proteinuria and oedema in the toddler age group. If untreated, ascites and pleural effusions may cause respiratory difficulty, and the child may become very prone to infections. The most common, and usually the most effective form of treatment is with prednisolone, although steroid dependant nephrotic syndrome often requires the use of stronger immunosuppressives to initiate a prolonged remission¹.

Without the correct treatment, Minimal Change Nephrotic Syndrome is potentially a life threatening condition. Nowadays, most of these children's care is given by their families at home. For the care to be effective, the care givers need to be well informed about the condition and how to carry out the treatment².

A booklet 'Childhood Nephrotic Syndrome: A guide to the treatment and management of Childhood Nephrotic Syndrome' (1988), has been compiled by the members of the paediatric renal unit, City Hospital, Nottingham, and published by the British Kidney Patient's Association³. It explains in easy to understand language what Nephrotic Syndrome is, the treatment and its side effects, and other useful information. This is the main booklet presently supplied to parents of children with nephrotic syndrome in the Manchester area.

This study was designed to investigate what information parents require in an information booklet, and whether they feel that the existing standard of written information is adequate. Parents were informally interviewed to discover their views.

Method

Ethical approval was obtained before commencing this study. Questionnaires were sent to the medical and nursing staff in the nephrology department, and the renal dietician and social worker, at the Royal Manchester Children's Hospital to find out what information they give to parents of children with nephrotic syndrome in the out patient's clinic and on the ward. The information from these

questionnaires was used to draw up an informal interview guide to be used with the parents.

Fourteen parents were selected for entry into the study. A letter was written to these parents explaining the object of the study and how it would be conducted. Ten parents replied (71.4%) and all these said that they wished to be interviewed at home. The interviews were recorded using a small cassette tape recorder. All the interviews had the same basic content, but the parents had the freedom to talk about things that were not included in the interview guide. The duration of each interview was between half an hour and three hours, depending on how much the parents wished to say. In five of the interviews, the teenage children with nephrotic syndrome also contributed.

The interviews were transcribed using a word processor, and analysed according to themes⁴.

This is a small opportunist sample and no statistical conclusions can be drawn from it. However, the investigators felt that this qualitative data was sufficient to compile a fairly comprehensive picture of the informational requirements of this group of parents.

Results.

The parents came from a wide variety of backgrounds, they were not asked their occupation but some volunteered the information, of the ones who said what they did, there was a building engineer, a teacher, a manual labourer, a shop assistant, and an unemployed person. Eight of the families were caucasian, two were of Asian origin.

Eight of the ten families said that they got most of their verbal information from the doctors in the out patient's clinic, and mainly the paediatric consultants, of these three said that the nurses didn't really seem to know much about it. The other two families said they had got most of their information from the nurses.

Five of the families had previously been given an information booklet produced by the British Kidney Patient's Association, four of these parents said that they

found the booklet was very general, basic and had little in it that they had not already been told. One family was given a research article but they were disappointed that it did not contain any information about the causes of nephrotic syndrome. Of the five parents who had not been given any written information, one tried to find something in the library, and one looked it up in their family health book, both said that they could not find much.

Nine of the families said that they thought they had understood what had been said to them in the outpatient clinic, the other parent, a mother, said that she did not understand but her father had gone with her, he understood and was able to explain it to her later. One of the parents said it was sometimes difficult to concentrate on what was being said and try to control a hyperactive child at the same time. Another parent said that it depends on the state of mind, a parent who is very distressed about their child will not take much in, and he thought it would be useful in this case to have the information written down so that they could read it later. One parent said it was important to know what questions to ask as she 'got more information when she asked the right questions'.

Nine of the interviewees said they remembered most of the information given to them in clinic, one mother said she remembered the basics but could not remember the technical words "... if I'm trying to explain it to somebody later, it's there but I can't remember the exact words.." , another said that she wrote down the instructions about the treatment while she was in clinic.

Four out of the ten interviewees had been given a possible explanation for the cause of nephrotic syndrome although they said it was basically unknown. Most of the parents were interested in the cause and wanted more information. One father said he felt frustrated because the cause was not yet known, and he did not think enough research was being done.

One of the most striking findings during the interviews was the anxiety caused by the side effects of the steroids. One parent said she thought that this was worse than the disease itself. All the parents reported that their children had experienced behaviour changes, or obesity, or both. Young children became aggressive

and had uncontrollable temper tantrums causing their parents to abandon shopping trips, and disrupting their sleep for weeks at a time, "...we were up all night most nights, he wouldn't go to sleep, he just used to sit in bed throwing things about, jumping, and screaming all night". Older children were moody, but were most affected by their appearance. A teenage boy, who was unable to wear the same trendy clothes as his friends due to obesity, had previously said he wished he could die.

Most of the parents interviewed had some specific ideas about what should be included in the new information booklet:-

"What usually brings it on, what causes it"

"More background to it"

"Do older children get it, can you get it in adult life, are there any other drugs or any other ways of dealing with it"

"What the kidney actually does, how the structure changes, how the proteins attract water, the fluids, why the swelling occurs, diagrams would be good to understand it, the different types of treatment, a glossary"

"How long do they have in remission normally, does it affect girls as well as boys, how many children are affected, is it more prominent up north than down south, what does minimal change mean, if he gets a cold can he take antibiotics or cough medicine while he's on the steroids"

"Would it affect people if they went out for a drink or something, they wouldn't relapse after a few pints would they?"

"The only problem with this book is that each child is different, how are you going to get around that?"

A few of the parents said that they wanted to meet other parents of children with nephrotic syndrome.

"With not knowing anyone else, you don't know what the problems are, and I think if you could get chatting to someone else with a child with the same problem, then you want to know if they're having the same problem with their child, whether it's common, like to have a bad temper".

Some of the parents asked what research was being done into the cause of childhood nephrotic syndrome and asked for an update.

Discussion.

This study not only gave us an idea of the parents satisfaction with the present written information, and their views about what they would like in an information booklet. It also drew our attention to other aspects, such as their desire to be kept up to date with research, the need to meet other parents, individual written information, and the anxiety caused by the side effects of the steroids.

Using the information from the parents and the hospital staff, and current literature^{5 6 7 8}, an information booklet was produced. This contains information in greater depth than the booklet previously used, it has large clear diagrams and a brief glossary of medical terms that the parents may come across. The booklet was sent to the parents who had taken part, for their comments. Seven parents replied, saying that they were satisfied with the new booklet. The new booklet is considerably larger than the booklet used previously, it might be debated whether all parents would read this much information, or whether we should continue to use the British Kidney Patient's Association booklet routinely, and just give the new booklet to parents who ask for more information.

Most parents were very interested to know what happens in childhood nephrotic syndrome and what causes it. Parent's intense desire for information was also found by Korsch et al. (1968)⁹ in a study of doctor-patient interaction in the paediatric out patient clinic. In response to the request for a research update, and so that parents could meet each other, the parents of children with nephrotic syndrome in the Manchester catchment area were invited to an evening meeting. About eighty parents and children attended, this was an amazing show of enthusiasm. The consultants discussed present research and encouraged parents to ask questions. The parents seemed to enjoy the meeting and asked when the next one would be.

In response to the request for individual written information, we are planning to assess parent's understanding and satisfaction with the general information booklet and with individual information letters after the clinic visits, to find out whether all or just some parents would significantly benefit from receiving

individual written information concerning their child's progress.

Parents and children may need more support to cope with the side effects of the steroids. A study may be planned in the near future to investigate the extent of this disturbance.

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