A STUDY OF THE PSYCHOLOGICAL CONCOMITANTS
OF A CHRONIC ILLNESS IN CHILDHOOD

VOLUME II: APPENDICES

ANN M. CULL

Ph.D.
UNIVERSITY OF EDINBURGH
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**VOLUME II**

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APPENDIX I

QUESTIONNAIRE FOR PARENTS OF CHILDREN WITH CYSTIC FIBROSIS

<table>
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<tr>
<th>Identification number</th>
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<tbody>
<tr>
<td>Card number</td>
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<tr>
<td>M1</td>
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<tr>
<td>F2</td>
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</tbody>
</table>

Date of interview.........................

1. Patient's name..............................................Sex..............

2. Patient's address..........................................

3. Patient's date of birth.........................

4. Patient's schooling (with appropriate dates) if any

   a. (if special school indicated) Was this your choice of
      school or were you forced to send him there by the L.E.A.?

5. Mother's name..............................................

6. Mother's date of birth..............................

7. Mother's occupation ......................................
   (state full/part time if in outside employment)

8. Mother's former occupation..........................

9. At what age did you leave school?..................

10. Did you have any special training after school?
    a. (If YES) What was that?..............................

11. Father's name and date of birth..................

12. Father's occupation.................................

13. At what age did he leave school?..................

14. Did he have any special training after school?
    a. (If YES) What was that?..............................

15. Does he have to be away from home at all, except during
    the day?
    a. (If YES) Variable amount/up to 2 nights per week/3 nights
       per week normally away/separated or divorced/dead (circle one)

16. Is he on shift work?
    a. (If YES) What shifts?.................................

   610
17. Were you and your husband related to each other?
cousins/second cousins

18. Date of marriage..........................

19. How many living children are there in the family? Are they all well? (Note whether any siblings have physical or mental handicaps or ill health)

<table>
<thead>
<tr>
<th>Name</th>
<th>D.O.B.</th>
<th>School (if any) or occupation</th>
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</thead>
<tbody>
<tr>
<td>1</td>
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<tr>
<td>6</td>
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</tbody>
</table>

20. Have you had any children who have died?
a. (If YES) Specify D.O.B. and age at death..........................

21. Do any other adults, apart from your husband, live in the house with you and N?
a. (If YES) State relationship - if any - to child..................

22. How many people live in the house altogether?..................

HOUSING

23. Is the house: rented/owned/other (Circle)

24. How many rooms are there?..........................
(not counting bathroom or working kitchen)

25. Do you have to share a toilet?
a. (If YES) With how many other people?..........................

26. Have you: Running water

A hot water system
A bath
An inside flush lavatory
A washing machine
Clothes drying facilities
Telephone
Use of a car in emergency

<table>
<thead>
<tr>
<th>State of repair</th>
<th>by observation only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exterior repair</td>
<td>Good Moderate Poor</td>
</tr>
<tr>
<td>Interior repair</td>
<td>Good Moderate Poor</td>
</tr>
<tr>
<td>Interior comfort</td>
<td>Good Moderate Poor</td>
</tr>
<tr>
<td>Garden facilities</td>
<td>Good Moderate Poor</td>
</tr>
<tr>
<td>Apparent play facilities</td>
<td>Good Moderate Poor</td>
</tr>
</tbody>
</table>

27. How many rooms are used as bedrooms?..............

29. Does N sleep in a room of his own?
   a. (If NO) With whom does he share a room?...........

30. Do you get any complaints about that?
   a. (If YES) Specify from whom and what..............

31. Do you find that you need more space with N?
    (If YES) Specify for what.........................

32. Do you and your husband have to share your bedroom with anyone else?
    a. (If YES) Is this because of N?
    b. (If NO ) Give reason..........................

33. In your view, does this house meet your family's needs?
    a. (If NO ) In what way is it unsatisfactory?.....

34. Have you had to modify the house in any way because of N?
    a. (If YES) In what way?.........................
43b. (If YES) How much did this cost? .........................................

c. (If YES) How did you finance it? ..........................................

35. Has there been any damage to the house from equipment used by N?

a. (If YES) What sort of damage? ...........................................

b. (If YES) Have you had it repaired?

c. (If YES) How much did this cost? ..........................................

d. (If YES) How did you finance it? ..........................................

36. Has the local Council helped you in any way, for example, with repairs or by installing a telephone?

a. (If YES) What did they do? ..............................................

b. (If NO) Were you aware that the Local Authority had power to assist you in this way?

FAMILY AND NEIGHBOURHOOD SUPPORT

37. How long have you lived in this neighbourhood? ......................

38. Do you like it?

a. (If NO) Why is that? .....................................................

39. Do you have any domestic help?

40. Do you have any family living in this area?

a. (If YES) Specify .........................................................

b. (If NO) Does your family ever come to see you?

41. (If YES to either question) How often do you see them?

every day more than once a week more than once a month less than once a month

42. Do they give you emotional support?
    i.e. will they share your worries with you?

a. (If YES) In what way? ...................................................

b. (If NO) Why is that? ....................................................

43. Do they give you practical help?
44. Would they help care for N?
   a. *(If YES)* In what way?..............................

45.Would they babysit the other children if you had to take N to the doctor?
46. Would they mind the family if you wanted to stay with N in hospital?
47. Do they help you with transporting N to hospital or clinic?
48. Would they babysit for you if you wanted a break?
49. Are there any other ways in which they help you?
   a. *(If YES)* Specify.................................
50. Do you go out and see them at all?
   a. *(If YES)* How often?
      every day  more than  more than  less than
      once a week once a month once a month
51. What do you normally do together? *(specify)*

52. Do you think having a sick child has affected your ability to see your family in any way?
   a. *(If YES)* How is that?.................................

53. Do you have any friends living near?
   a. *(If NO)* Do any friends come and visit you?
   b. *(If YES to either)* How often do you see them?
      every day  more than  more than  less than
      once a week once a month once a month
54. Do they give you emotional support?
    i.e. will they share your worries with you?
   a. *(If YES)* In what way?.................................

55. Do they give you practical help?
56. Would they help care for N?
   a. *(If YES)* In what way?.................................
57. Would they babysit the other children if you had to take N to the doctor?
58. Would they mind the family if you wanted to stay with N in hospital?

59. Do they help you with transporting N to the hospital or clinic?

60. Would they babysit for you if you wanted a break?

61. Are there any other ways in which they help you?
   a. *(If YES) Specify.*

62. Do you think having a C.F. child has affected your ability to maintain friendships?
   a. *(If YES) How is that?*

63. Do you need any extra help in caring for N and his treatment?
   a. *(If YES) What would you like to have?*

64. Do you need any extra help in caring for the other children at home?
   a. *(If YES) What would you like to have?*

65. Do you need any extra help with babysitting?
   a. *(If YES) To meet what sort of needs?*

66. Now I'd like to know about other sorts of help that you have had with N. Does the Health Visitor from the local health clinic call on you to see how he is getting on?
   a. *(If YES) How often?*
   b. *(If NO ) Has she called in the past?*
   c. Have you found these visits helpful?
   d. Why was that?

67. Has anyone else come to see you about N from the Cystic Fibrosis Research Trust, for instance, or the local welfare department/hospital social worker/physiotherapist/dietitian/local education/health department/sister from the hospital? (circle where applicable)
   a. How often?
69. Have you found them helpful?
   a. Why was that?.................................................................

70. (If NO visits) Have you asked them not to?
   a. (If YES) Did you have any particular reason for not wanting them to call?
      .................................................................................................

71. Could you do with more visiting?
   a. (If YES) Specify what kind....................................................

72. What sort of visits do you think could be most helpful — advice about special problems or just a friendly chat?
   a. If the hospital provided help of this sort — perhaps coming out to see you every couple of months, would you welcome this?

73. Do you belong to the local group of the Cystic Fibrosis Research Trust?
   a. (If YES) How did you hear about it?.................................
   b. How often do you manage to attend meetings?....................
   c. (If NO) Did you know about these groups?
   d. (If knows) But you still didn't want to join. Can you say why?.................................................................
   e. (If doesn't know) Would you have joined if you had known about it?

74. Do/would you find the company of parents of other C.F. children helpful to you?
   a. Why is that?.................................................................

75. Do you belong to any other group or club?
   (e.g. W.I., Church Organisation)
   a. (If YES) Specify.................................................................

76. Which clinic do you attend with N?
   .................................................................................................
   a. Is this in a special C.F. clinic or a normal hospital clinic?
      .................................................................................................

77. How far are you from the C.F. clinic?.................................

78. TRANSPORT TO CLINIC

79. How far do you have to travel to get to the C.F. clinic?
   .................................................................................................

80. How often do you travel to the C.F. clinic?
   .................................................................................................

81. How long does it take you to travel to the C.F. clinic?
   .................................................................................................

82. Are you able to travel to the C.F. clinic on your own?
   .................................................................................................
78. How do you travel there? .............................................
79. How much does this cost? ...........................................
80. Who pays? ............................................................... 
81. Do you need any extra help with transport? 

FINANCIAL PRESSURES (Transport and housing should already have been discussed and if hardship has already been noted, this section can be introduced as follows:)

We have already talked about the extra cost of___________

82. Are there any (other) ways in which N's illness has placed an extra strain on the family budget?
   a. (If YES) Specify ......................................................

83. Do you have to buy any special foods?
   a. (If YES) Do these cost more?
      b. (If YES) How much more per week? - specify .........
          (If YES to 83)

84. Do you buy them for all the family?

85. Does N need any special clothes?
   a. (If YES) Do these cost more than you would normally spend?
      b. (If YES) How much more per year? .........................

86. Have you or your husband ever had to give up work to nurse N?
   a. (If YES) Specify ..................................................
      b. How often? .....................................................
      c. When? .........................................................
      d. How much loss of pay did this involve? .................

87. How much money do you have for housekeeping each week? ......

88. Is this only for food?
   a. (If NO) What else does it pay for? .......................... 

89. Does this make it possible for you to feed all the family adequately?
   a. (If NO) How much more per week do you feel you would require to do this?.............

90. Do you think either you, your husband or the other children miss out on anything because of the cost of N's illness?
91. Do you and the children ever get a holiday away from home?
   a. (If NO) Is this because of the cost of the illness?

92. Do you and the children ever get outings or treats of any sort?
   a. (If NO) Is this because of the cost of the illness?

ILLNESS HISTORY

93. I am asking all the mothers I talk to how they first came to know that their children had cystic fibrosis. Can you tell me when you were first told that N had cystic fibrosis?

94. How old was he?

95. Who told you?
   a. Were you and your husband both present at the time of diagnosis?
   b. After Dr. had told you the diagnosis was he accessible to you for further questioning?
   c. (If YES) Did you avail yourselves of the facility and go and visit him?
   d. (If NO) Why was this?

96. Had you any idea before the time of diagnosis that he could be seriously unwell?
   a. (If YES) What made you think that?
   b. (If YES) Did you take him to a doctor at this stage?
   c. (If YES) Who was this? G.P./Specialist
   d. What did he say was wrong? (Prompt in order to obtain complete history to diagnosis)

   (If any evidence of delay in diagnosis because mother failed to go for assessment ask) -

97. Do you ever blame yourself for this delay in seeking help for N?
a. (If YES) Can you tell me how you feel?..............................

..................................................................................

(If any evidence of misdiagnosis or incorrect treatment ask)-

98. Do you blame the doctors for not recognising C.F. straight away?

a. Can you tell me more about how you feel?..............................

..................................................................................

99. Did the diagnosis come as a terrible shock to you?

a. Can you tell me more about how you felt?..............................

..................................................................................
100. Did you resent the doctor telling you?
   a. (If YES) Why was that? ........................................
      (If YES to question 100)

101. Was there any way in which the doctor could have got
      over that?
   a. (If YES) How? ........................................

102. Do you think this has changed your attitude to the
      medical profession in any way?
   a. (If YES) Can you explain? .............................

PARENTS UNDERSTANDING OF ILLNESS

103. When the doctor told you about N's C.F., what did he
      actually say to you? ........................................

104. Did he tell you this immediately?
   a. (If NO) Did you have to ask about it?

105. (Unless already mentioned) Did he tell you this was an
      inherited condition, passed from parents to children?
   a. (If YES) How did you feel about this? ...............  

106. Did he tell you the child would always have the illness
      and need treatment?
   a. (If YES) How did you feel about this? ...............  

107. Did he tell you the illness might get worse in the future?
   a. (If YES) What did he say? .............................  

108. How did you feel about this? .............................  

109. What do you understand of the chances of your children's
      children having it?  ........................................  

110. Has either your own doctor or the specialist taken a lot of 
      trouble to explain N's illness or treatment to you?
      1 2
      YES NO
11. (If YES) Specify which doctor? 

Do you feel you understand his illness as well as you want to, or would you be glad to have it explained more fully?

112 How did you feel about the way in which you were told that he had C.F.? (Prompt, if necessary, was this tactful and kindly or lacking in tact?)

113 What do you think is the right moment to be told about these things? (Prompt) Do you think the doctor should tell the parents as soon as he suspects something is wrong or should he wait till he is quite sure?

114 After you knew N had C.F. did you try and find out more about the illness?

115 Have you read any of the pamphlets put out for parents by the Cystic Fibrosis Foundation Trust?

116 (Unless Dr. specified as giver of pamphlets) Would you have liked Dr. ______ to give you something to read about C.F. at the time of diagnosis?

117 Have you read any articles in the press or watched any T.V. programme on C.F.?

118 How much have the following helped you in understanding C.F.? 

<table>
<thead>
<tr>
<th>Source</th>
<th>Very much</th>
<th>Mod.</th>
<th>Very little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinic doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other parents</td>
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<tr>
<td>Books</td>
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<tr>
<td>Friends</td>
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<td></td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
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</tbody>
</table>
C.F. parents assoc.  Very much Mod.  Very little Not at all
Clergy                     "  "  "  "
Social worker               "  "  "  "
Others (specify)            "  "  "  "

119. Has the doctor discussed the question of having more children with you?

120. Have you discussed this with anyone else?
   (Prompt if necessary - husband)
   a.  (If YES) With whom?.................................

121. Do you think having N has changed your feelings about having more children in any way?
   a.  What is that?........................................

122. If it were possible for you to predict accurately whether or not a baby you were carrying had C.F., and if you could safely terminate your pregnancy, would you risk further pregnancies in the hope of having a well child?

123. Have you done anything about birth control?
   a.  (If NO) Would you like help with this?

124. Does this create any religious conflicts for you?
   a.  (If YES) Can you tell me more about this?...........

MEDICAL SUPERVISION

125. If you want help or advice about N's C.F., who would you go to?
   G.P./Specialist/Other (specify)

126. How often do you consult your family doctor about your child's C.F.?
   more than once every once every 6 never
   once a month two months months or longer

127. Would you say your own family doctor has been a lot of help to you?
   a.  Why is that?.........................................
   b.  Does your G.P. really understand N's illness?

128. How often do you attend the clinic?
   more than once every once every 6
   once a month two months months or longer

129. Has this always been so?
   a.  (If NO) Specify........................................

130. Do you always see the same doctor in the clinic?
131. How long are you normally away from home when you go to the clinic? (Door to door)

132. How long do you usually wait before you see the doctor?

133. How long do you spend with the doctor?

134. Would you like to spend longer talking to him?

a. Why is this?

135. Do you feel you can tell him all your worries?

a. (If NO) Why is this?

136. Do you feel that he really understands the child?

a. (If NO) Why is this?

137. Do you feel he can really help you with treatment?

a. (If NO) Why is this?

138. Can you always get in touch with the doctor when you want?

a. (If NO) Why is that?

139. Do you like the way in which the clinic is run?

a. (If NO) Why is that?

140. Do you like meeting mothers of other C.F. children in the clinic?

a. For what reason?

141. Do you think N likes meeting the other C.F. children?

a. Why is that?

142. Have you ever felt angry towards the doctors in the clinic?

a. (If YES) For what reason?

b. (If YES) Could they have helped you to get over your anger in any way?

c. (If YES) How?

143. Would you say the clinic doctor has been a lot of help to you?

a. Why is that?

144. When the clinic doctor recommends a change in treatment, does the family doctor always know about it?

a. (If NO) Why is that?
145. Have you had any problems concerning N's treatment because of confusion or lack of agreement between the clinic doctor or the G.P.?
   a. (If YES) Could you tell me about them?..............................

146. Does your husband ever take N to the clinic without you?
   a. (If YES) How often? Usually/Often/Seldom

147. Does he ever go with you?
   a. (If YES) How often? Usually/Often/Seldom

148. Would you like to change the clinic arrangements in any way to improve them?
   a. (If YES) How?................................................................

149. How do you feel about being asked to cooperate in research projects organised by the clinic? (Prompt - do you feel they are an intrusion or are you glad to help?)..............

150. Have you ever come in contact with the social worker in the hospital?
   a. (If YES) For what reason?.................................
   b. (If YES) Was she able to help you?

TREATMENT

151. Which of the following kinds of treatment has N required?

   COTAZYME/PANCREX
   Alterations in diet
   Antibiotics
   Nebulizer
   Mist tent
   Postural drainage

   a. (If YES) Are these intermittent or continuous (circle)
   (These sections to be completed if parent said 'yes' to above)

   Cotazyme/Pancrex

152. At what age was it started?..............

153. How did N first react to it?......................
154. What did you tell him about it - if anything? .................................................

155. Has he ever protested against using it?
   a. (If YES) At what age?.....................  
   b. (If YES) What do you think was the reason for his protest? .................................................

156. Does he try to help himself with the treatment?
   a. (If YES) How successful is he?.....................  
   b. (If YES) At what age did he begin to help himself?...........  
   c. (If YES) Did this change his attitude to it in any way?..  
   d. (If YES) Specify.................................................

157. Do you supervise the treatment?  

158. Do you find any difficulty with it?  
   a. (If YES) Specify.................................................

ALTERATIONS IN DIET

159. At what age were these started?.....................

160. How did N first react to them?........................

161. What did you tell him about them - if anything?........................

162. Has he ever protested against them?
   a. (If YES) At what age?.....................  
   b. (If YES) What do you think was the reason for his protest? .................................................

163. Has he changed his attitude to them since?
   a. (If YES) Specify.................................................

164. Do you find any difficulty with these alterations in diet?  
   (If YES) In What way?........................

ANTIBIOTICS

167. At what age was it started?.....................
168. How did N first react to it?

169. What did you tell him about it - if anything?

170. Has he ever protested against using it?
   a. (If YES) At what age?
   b. (If YES) What do you think was the reason for his protest?

171. Does he try to help himself with the treatment?
   a. (If YES) How successful is he?
   b. (If YES) At what age did he begin to help himself?
   c. (If YES) Did this change his attitude to it in any way?
   d. (If YES) Specify

172. Do you supervise the treatment?

173. Do you find any difficulty with it?
   a. (If YES) Specify

NEBULIZER

174. At what age was it started?

175. How did N first react to it?

176. What did you tell him about it - if anything?

177. Has he ever protested against using it?
   a. (If YES) At what age?
   b. (If YES) What do you think was the reason for his protest?

178. Does he try to help himself with the treatment?
   a. (If YES) How successful is he?
   b. At what age did he begin to help himself?
   c. Did this change his attitude to it in any way?
   d. (If YES) Specify
179. Do you supervise the treatment?

180. Do you find any difficulty with it?
   a. (If YES) Specify

MIST TENT

181. At what age was it started?

182. How did N first react to it?

183. What did you tell him about it - if anything?

184. Has he ever protested against using it?
   a. (If YES) At what age?
   b. (If YES) What do you think was the reason for his protest?

185. Does he try to help himself with the treatment?
   a. (If YES) How successful is he?
   b. At what age did he begin to help himself?
   c. Did this change his attitude to it in any way?
   d. (If YES) Specify

186. Do you supervise the treatment?

187. Do you find any difficulty with it?
   a. (If YES) Specify

POSTURAL DRAINAGE

188. At what age was it started?

189. How did N first react to it?

190. What did you tell him about it - if anything?

191. Has he ever protested against using it?
   a. (If YES) At what age?
   b. (If YES) What do you think was the reason for his protest?
192. Does he try to help himself with the treatment?
   a. (If YES) How successful is he?..........................
   b. At what age did he begin to help himself?..............
   c. Did this change his attitude to it in any way?
   d. (If YES) Specify..........................................

193. Do you supervise the treatment?

194. Do you find any difficulty with it?
   a. (If YES) Specify..........................................

195. Do other people beside yourself take responsibility for N's treatment? (Tick YES answers)

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<th>Cotazyme</th>
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<th>Antibiotics</th>
<th>Nebulizer</th>
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196. How often do the others take responsibility?

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197. Can you estimate how much time is spent in any average week maintaining and preparing equipment and administering all the treatments?
   By you  ..............
   By other parent........
198. Do you resent spending so much of your time this way?
   a. Tell me more about your feelings.................................
199. Can you trust your own judgment in caring for N?
   a. (If NO) What are the problems?.................................

HOSPITALISATION

200. Has the child ever been hospitalised for C.F.?
   (If NO) Omit questions 200 a - 208 inclusive
   a. (If YES) At what ages?........................................
      b. For what length of time?..................................

201. (If YES) Were you very worried by this?
   a. Why was this?...................................................

202. (If YES) Was it possible to prepare the child in any way for the hospitalisation?
   a. (If YES) What was he told?..................................
   b. By whom?......................................................
   c. Was it possible for you to stay with N in hospital?
   d. (If NO) How often did you visit N?
      Daily     More than    Less than
      1 a week    1 a week

203. How did your child respond to hospitalisation? (Specify)

204. In hospital did he tend to:
    Cry excessively
    Cling to you
    Withdraw from you
    Refuse to speak to you
    Become very passive and listless
    Become very angry with you
    Become very angry with brothers and sisters
    Suck his thumb
    Rock or bang his head on the bed

1 2
YES NO
1 2
YES NO
1 2
YES NO
1 2
YES NO
1 2
YES NO
1 2
YES NO
1 2
YES NO
1 2
YES NO
205. (If YES to any of these ask 'What did you do about______?' at the end of series.)

206. After he came home did he become extra demanding?
   a. (If YES) What did you do about this?.............................

207. Did he show any other changes in behaviour?
   a. (If YES) Specify........................................
   b. What did you do about this?..............................

208. If you could alter the hospital arrangements in any way to benefit N, how would you do this?

209. Has your child had any other illnesses or hospitalisations?
   a. (If YES) Specify........................................
   b. At what age?............................
   c. How long did he spend in hospital/bed?..................

210. (If applicable) Were you able to prepare him in any way for these hospitalisations?
   a. How did he respond to them?..............................

211. Have you ever been able to discuss any of the hospital procedures with him afterwards?

212. What do you think he disliked most about hospital - specify

213. Was there anything he specially liked about hospital?
   a. (If YES) Specify........................................

**COMMUNICATION**

214. Most parents of a child with C.F. need opportunities to talk out their problems and worries. Have you ever been able to do this fully with:

   Spouse
   Relative
   Friend
   G.P.
   Clinic doctor
Clergyman
Social worker
C.F. Parents Association
Other (specify)

a. (If YES) to spouse, can you and your husband talk about everything together?

b. (If No) What can you not talk about with your husband?

215. Can you talk about most things with N?

a. (If NO) Why is that?

216. Can you talk naturally about his illness?

a. (If NO to any of these) Why can you not talk about?

220. Can N talk naturally about his illness?

a. (If NO) Why do you think that is?

b. (If YES) Does he talk to you?
   Does he talk to his daddy?
   Does he talk to his brothers/sisters?
   Does he talk to your family?
   Does he talk to friends?

221. Does he tell you if he is in pain?

222. Does he tell you if he is sad?

223. Does he tell you if he is worried?

224. At what age did N become aware that he had an illness which he will always have?

a. Who informed him?

b. How did he react?
225. At what age did he learn the name of the illness?..............
a. Who informed him?...................................................
b. How did he react?...................................................

226. Does he know he was born with it?
   a. (If YES) At what age was he told?..........................
b. By whom?..............................................................

227. Does he know the illness is inherited, passed from parents to child?
   a. (If YES) At what age was he told?..........................
b. By whom?..............................................................

228. Does he know how C.F. affects the workings of his body?
   a. (If YES) At what age was he told?..........................
b. By whom?..............................................................

229. Does he know that his illness may get worse in the future?
   a. (If YES) At what age was he told?..........................
b. By whom?..............................................................

230. Has he been told anything else about the illness and its treatment?
   a. (If YES) What was that?...........................................
b. At what age and by whom?...........................................

231. At what age did N begin asking the following questions?

   What made me sick?
   When will I get better?
   What is my sickness called?
   What is wrong in my inside?
   When I'm older will I be able to get married?
   When I'm older will I be able to have children?
   Will my children have the sickness?

   a. What did you tell him when he asked you about..............

232. Has he asked any other questions besides these?
   (If YES) What were these?...........................................

   a. What did you tell him when he asked this?........................

233. Do you think it will be/find it easy or difficult to answer her questions?

1 2
YES NO
23. Can you tell me more about how you feel?

CHILD'S REACTIONS TO ILLNESS

234. Has N ever shown alarm at how C.F. might affect him in the future?
   a. (If YES) Was this: considerable/moderate/slight
   b. At what age?
   c. Did you talk this over with him?
   d. (If YES) What did you say?
   e. How does he feel now?

235. Has N ever seemed pleased at getting special attention?
   a. (If YES) Was this: considerable/moderate/slight
   b. At what age?
   c. Did you talk about this with him?
   d. (If YES) What did you say?
   e. How does he feel now?

236. Has N ever paid much attention to his physical sensations and symptoms?
   a. (If YES) Was this: considerable/moderate/slight
   b. At what age?
   c. Did you ever talk this over with him?
   d. (If YES) What did you say?
   e. How does he feel now?

237. Has N ever felt self conscious or worried about the reactions of others?
   a. (If YES) Was this: considerable/moderate/slight
   b. At what age?
   c. Did you talk this over with him?
   d. (If YES) What did you say?
   e. How does he feel now?

238. Has N ever felt frightened, resentful or sad that he was different from others?
239. Has N ever been worried about his size or shape?
   a. (If YES) Was this: considerable/moderate/slight
   b. At what age?...............................
   c. Did you talk this over with him?.........
   d. (If YES) What did you say?................
   e. How does he feel now?....................

240. Has N shown any other reactions to the illness not already mentioned?
   a. (If YES) At what age?......................
   b. What were these?..........................
   c. How did you cope with these?............

241. Have there been periods when N has shown increased worry about his illness?
   a. (If YES) At what ages have these periods occurred?........
   b. Can you explain his increased worry in any way? (Prompt, for example, because his symptoms were worse at this time or because he was worried by something else, e.g. school problems)

242. When N is worried or upset about experiences in his life (tests in school, new baby, etc.) do any of his C.F. symptoms become more severe?
   a. (If YES) Can you tell me more about this?............

243. Have there been periods when you have been particularly worried about N's emotional adjustment to his illness?
244. Does N have much nasal discharge?
  a. (If YES) Did this produce any fear, worry or shame on his part?

245. Has N got a bad cough?
  a. (If YES) Does this produce any fear or worry on his part?

246. How does N feel about passing foul stools?

247. When N is hungry what does he do?

248. When N has a pain in his tummy what does he do?

249. Does N suffer from prolapse of rectum?
  a. (If YES) How does he react to this?

250. Does N turn to anyone for comfort when he is worried?
  a. (If YES) Who?
  b. (If NO) Why is that do you think?

251. Will N come to you for affection?
  a. Will he go to his daddy for affection?
  b. (If NO to either) Why is that?

PARENTS REACTION TO, AND EXPECTATIONS FOR CHILD WITH ILLNESS

252. We are interested in understanding the ways in which a child's C.F. may influence the way in which his parents take care of him. It may be that parents handle the child with C.F. differently from their other children - would you say this was true?
  a. (If YES) Why is that do you think?

253. Do you think you/expect less from him in the way of personal responsibility for clothing, cleanliness or neatness?
  a. (If YES) Is this: Much less/Moderately less/only a little less (Circle)

254. Would you say that you/expect less from him in the way of responsibility for household chores?
a. (If YES) Is this: Much less/moderately less/very little less (circle)

Will you

255. Would you say that you expect less from him in the way of school achievement?

a. (If YES) Is this: Much less/moderately less/only a little less (circle)

b. (If YES) Is this because you feel you have to protect him?

c. Can you explain? ........................................

d. (If NO ) Is this because you feel you have to push him to compensate for the illness?

e. Can you explain? ........................................

Will you

256. Would you say that you expect less of him in his relationships with other children?

a. (If YES) Is this: Much less/moderately less/only a little less (circle)

257. Would you say that you (will) permit him less independence in making his own decisions?

a. (If YES) Is this: Much less/moderately less/only a little less

258. Would you say that you (will) permit him less independence in joining in activities away from home?

a. (If YES) Is this: Much less/moderately less/very little less

259. Would you say that you (will be) more cautious about permitting him to join in physical activities?

a. (If YES) Is this: Much less/moderately less/only a little less

260. Would you say that you are less likely to punish him?

a. (If YES) Is this: Much less/moderately less/only a little less

261. When he is naughty, how do you punish him? ........................................

(Unless mentioned, prompt)

262. Do you ever smack him? ........................................

263. Do you ever send him to bed or put him in his room?

264. Do you ever deprive him of something he likes, e.g. television, comics, sweets, pocket money?

265. Do you ever say you won't love him if he is bad?

266. Do you ever say you'll send him away if he is bad?

267. Do you ever threaten him with somebody else, e.g. daddy, doctor, teacher?
268. Do you experience any worry or guilt after punishing him?
   a. (If YES) Why is that? ...........................................

269. On the whole, are you happy about the way you handle N's behaviour or do you sometimes find yourself doing things you really don't approve of?

270. Do you agree with your husband about this or is he a lot more strict or less strict than you are?

271. Do you and your husband always agree about how N should be brought up generally or do you feel differently about some things?

272. Apart from treatment or going to the clinic, does your husband help with N at all?
   a. (If YES) How? ...............................................

273. Does he help with the other children?
   a. (If NO to either) Is that because he doesn't want to or because you don't want him to?
   b. Is there anything your husband won't do - that he draws the line at?

274. Is N treated in any special way by your mother and father?
   a. (If YES) Tell me about it? ..................................
   b. (If YES) Is this due to his illness?

275. Is N treated in any special way by your husband's mother or father?
   a. (If YES) Tell me about it? ..................................
   b. (If YES) Is this due to his illness?

276. Is N treated in any special way by family friends or other relatives?
   a. (If YES) Tell me about it? ..................................
   b. Is this due to his illness?
Do you feel that the attitudes of your other children towards the child with C.F. have been influenced by the C.F. in any way? Perhaps we could consider each child in turn:

**TABLE - ELDEST 1st**

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<td>b. Is less aggressive than otherwise?</td>
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<td>c. Does feel protective to N?</td>
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<td>d. Does feel responsible for N's wellbeing?</td>
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<td>e. Does feel jealous of attention given to N?</td>
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<td>g. Does ever talk to N about his illness?</td>
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<td>h. What does say about it to him?</td>
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278. Do you think that when there is one child in the family who needs extra attention the others feel left out? Do you find this?

a. (If YES) What do you do about this? ..........................................

279. Have you ever explained to the other children why it is necessary for you to devote as much time to N?

a. (If NO) Why is this? ...............................................................
280. I have already asked you a lot of questions about N's illness and treatment and your reaction to the illness, but may I now ask you about his general development?

281. Where was he born? Home/Hospital.

282. What did he weigh? ..............

283. Did you have any complications in labour?
   a. (If YES) Specify.........................

284. How long did your labour last? ....

285. Was the baby full term?
   a. (If NO) Specify........................

286. Were there any complications during pregnancy?
   a. (If YES) Specify.........................

287. Were you at all emotionally upset during your pregnancy?
   a. (If YES) Specify.........................

288. How did your husband feel about the pregnancy - was he pleased or displeased?

289. Had you sustained any miscarriages or lost any babies before this pregnancy?
   a. (If YES) Specify........................

290. Did you know about C.F. at this stage?

291. Did you expect N might be a C.F. child?

292. Did you lose anyone close to you during pregnancy?
   a. (If YES) Specify........................

293. Have you lost anyone close to you since then?
   a. (If YES) Specify........................

294. Did you move house during pregnancy?
   a. (If YES) Specify: Why, how many times, etc.
295. Have you moved house since?
   a. (If YES) Elaborate.................................

296. Was your husband in full employment during this pregnancy?
   a. (If NO) Specify.................................

**FEEDING**

297. How did you feed N? Breast/Bottle/Both
   (Elaborate if necessary)

298. Did you feed him at a fixed time or when he seemed hungry?
   Fixed/Hungry/Both

299. At what age did you begin to wean N from the bottle?............

300. At what age was weaning complete? During day.......... At night ....

301. During the first 3 months of life did N have any feeding problems?
   a. (If YES) What were these?............................

302. Did this upset you?..................................

303. What did you do?..................................

304. Did he seem to gain weight satisfactorily during the first 3 months of life?
   a. (If NO) What did you feel was the reason?..............

305. Did this upset you?..................................

306. What did you do about it?..................................

307. During the next 9 months of life - that is up to a year, did N have feeding problems?

308. What were these?..................................

309. Did this upset you?..................................

310. What did you do?..................................

311. During the 1st year of life did he gain weight satisfactorily?

   YES NO
a. (If NO) What did you feel was the reason?.................

312. Did this upset you?

313. What did you do about it?..............................

314. During the 1st year how did you find N generally?

315. How would you describe him as a baby?................

316. Have there been periods after the 1st year when you have been worried about N's eating?

a. (If YES) Give ages and describe........................

TOILET TRAINING

317. At what age did you begin sitting N on a potty for toilet or bowel movements?......................

318. At what age did he begin going to the toilet on his own?....

319. Was training: Easy/Difficult/Stormy (Circle one)

320. At present do you check N's bowel motion before it is flushed away?

321. At what age was N dry all day?...... all night?........

322. After N was toilet trained, have there ever been periods when?

a. he wet during the daytime (give age)...........

b. he wet the bed? (give age)......................

c. he soiled himself during the day? (give age)......

d. he soiled himself at night? (give age)...........

e. (If YES to any of above) Was there any reason for this?

f. What did you do about it?..............................

323. Has the odour of N's bowel movements ever been a problem to you or N?

a. (If YES) In what way?.................................

324. (Prompt) Has he ever experienced any problems in school because of it?
325. What have you done about this?

326. Do you have to help N with toileting during the night?
   a. (If YES) How often?

**GENERAL DEVELOPMENT**

327. At what age did N:
   - Sit alone?
   - Walk alone?
   - Use words to name objects?
   - Put words together into simple sentences?

**GENERAL WELLBEING**

328. During the 1st five years of his life how did you find N. generally?

329. Did he have any problems in his early days (1-5) not directly associated with the illness?
   a. (If YES) Specify.

330. How would you describe him at this stage?

331. Does he have any problems now not directly associated with the illness?
   a. (If YES) Specify.

332. How is his appetite now? Good/Moderate/Poor
   a. Does N ever experience any pain
   b. How often is this?
   c. What do you do about it?

333. Is he generally happy?
   a. (If NO) Why is that?

334. What do you do about it?

**SLEEP**

335. At what age did N begin to sleep through the night regularly?

336. Has N ever had any problems connected with sleep or getting to sleep?

337. (Prompt unless specified) Has he ever taken more than ½ hour to fall asleep?

338. Has he ever seemed fearful at bed time?
339. Has he ever woken up regularly during the night?
340. Has he ever had nightmares?
341. (If YES to any of above) How old was he at the time?......
342. How often did this happen?........................................
343. Were his C.F. symptoms worse at these times?
344. What did you do to get over it?.................................
345. Do you ever get up during the night to make sure N is alright?
   a. How often do you do this: every night more than more than
      once a week once a month
346. What do you do if you find him awake?.......................
347. Do any of your other children ever get up in the night to
      make sure N is alright?
   a. How often do they do this: every night more than more than
      once a week once a month
348. What do they do if they find him awake?.....................
349. Has N ever wanted to sleep with you in your bed?
   a. How often: every night more than more than
      once a week once a month
350. Were his C.F. symptoms worse at this time?
351. What did you do about it?........................................

FEARS
352 All children are frightened or worried by something from
      time to time. Can you tell me what N is frightened by?
      ...........................................................................
353. Has this always been so?
   a. (If NO) When did it begin?........................................
354. Do you associate this with anything special?
   a. (If YES) Specify......................................................
355. How would you describe N? very fearful moderately showing
   fearful very
      little fear

PLAY
356. What is N's favourite type of play?.........................
357. Does he do this alone?

358. Has he always liked to play this way?

359. Does he like to play at home or away? Home/Away

a. (If 'away') Where does he go?

b. With whom?

360. Do you encourage him to bring his friends into the house?

361. Do you allow the other children to bring their friends home?

a. (If NO) Why is that?

362. What do you do if N gets into a disagreement or quarrel?

363. In general do you find it possible to leave N to settle his own differences at this age?

a. (If NO) Why is that?

364. Suppose N complains to you of another child, what do you do?

365. Does he ever hit another child back?

366. Do you encourage him to stick up for himself in this sort of way?

a. (If NO) Why is that?

SPORT

367. Does N engage in any sports?

368. What are these?

369. Why did he decide to take them up?

370. Do they help in any way?

371. How is this?

372. What do they cost? (specify exactly)

373. How do you pay for them?

374. Does this cause you any financial hardship?
### SCHOOL EXPERIENCE

**375.** At what age did N first go to school? ..............................

**376.** Did he have any problems settling in?

a. *(If YES)* Can you tell me about them?..........................

**377.** Has he ever had any problems in school since then?

(Unless mentioned prompt)

**378.** Has he ever seemed clinging or worried about leaving you?

**379.** Has he ever felt sick before leaving for school?

**380.** Has he ever dawdled or invented reasons to stay away?

**381.** Has he ever complained about the other children?

**382.** Has he ever complained that the work was too hard?

a. *(If YES to any of above)* Can you tell me more about.....?

b. At what age was this?..........

c. What do you think were the reasons for this?.............

d. What did you do about it?..........................

**383.** Have the teachers ever complained that N disturbed his classmates or was restless and day dreamed in class?

**384.** Has N any friends at school?

a. *(If NO)* Why is that do you think?..........................

**385.** Has N ever had any teachers he specially liked?

a. *(If YES)* Was there any special reason for his liking?....

**386.** Do you think N differs from (your) other children in his approach to school?

a. *(If YES)* Why is this do you think?..........................

**387.** How many days is he normally absent from school in any one term?

**388.** What causes these absences?..........................
389. Is there any difference between winter and summer in his attendance?
   a. (If YES) Why?.................................

390. Do you think he worries about missing school?
   a. (If YES) What do you do about it?.................................

391. Are you apprehensive about his catching other children's germs?
   a. (If YES) Do you think this encourages you to keep him at home sometimes?

392. Would you like any other educational provision made for him?
   a. (If YES) What? (Give reason).................................

### ATTITUDE OF TEACHERS TO CHILD

#### 393. Have any of your child's teachers worried unduly about having a child with C.F. in class?
   a. (If YES) How many?.................................
   b. For what reason?.................................

#### 394. Have any of your child's teachers expected less from him because of the C.F., do you think?
   a. (If YES) How many?.................................
   b. At what ages?.................................

#### 395. Have any of your child's teachers given him more attention than other children?
   a. (If YES) How many?.................................
   b. At what ages?.................................
   c. Why was this?.................................

#### 396. Have any of your child's teachers picked on him?
   a. (If YES) How often? Frequently/moderately/very little
   b. At what ages?.................................
   c. For what reason?.................................

#### 397. Have any of your child's teachers been bothered by his symptoms?
   a. (If YES) How often? Frequently/moderately/very little
   b. At what ages?.................................
   c. What specially worried them?.................................
MOTHER'S OPINION OF HANDICAP

398. Talking generally now - what do you feel is N's greatest handicap from his point of view?

399. And from your point of view - what is it about him that you find hardest to cope with?

400. Have you any suggestions to make that might be helpful to other mothers of C.F. children - either pratical suggestions for looking after their children, or how you manage to face this and come to terms with it?

401. What or who do you think has most helped N to come to terms with his illness?

a. What or who has most helped you to come to terms with his illness?

402. And what about the future - do you ever try to look ahead or make plans for N, or do you face each day as it comes?

403. (Probe if necessary) Have you any ideas at all about N's future?

404. Does N ever talk about his own future?

405. (Probe if necessary) Has he given you any idea of his hopes or plans for the future?

406. What do you think is the right attitude for a parent to take towards a C.F. child?

407. (If any services already requested, e.g. birth control, more information, etc. note these - then ask) Is there anything else that the clinic doctor could help you with?
APPENDIX II

SUPPLEMENTARY QUESTIONNAIRE TO BE GIVEN TO MOTHERS OF C.F. CHILDREN

The other day I asked you a lot of questions about N and his response to his illness. Now if I may I would like to put a few questions to you about your own responses to illness, both his and other illnesses you may have encountered.

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<tr>
<th>Identification No.</th>
<th>Card No.</th>
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</table>

**MOTHER'S PRESENT HEALTH**

1. First, can I ask you about your present health? Has this been fairly good since N was born

2. (Prompt if necessary) Do you sleep well?
   a. (If NO) Do you require sleeping pills?

3. Is your appetite good?

4. Have you ever been run down or depressed?
   a. (If YES) Have you needed a tonic?

5. Are you nervous?
   a. (If YES) Have you been given tranquillisers/nerve pills?

(If any problems mentioned) Have you always found difficulty

With........................................

When did it start?..........................

For what reason do you think?...........

................................................................

**MOTHER'S PREVIOUS HEALTH**

6. Were you ever seriously ill as a child?
   a. (If YES) Specify..........................

7. As a child did you require hospitalisation?
   a. (If YES) Can you recall anything about it?
   b. (If YES) What did you feel about it then?

8. Do you think your own experience of childhood ailments has affected your handling of N in any way?
   a. (If YES) How............................

9. Have you had any illnesses—either physical or mental—in adult life?
   a. (If YES) Could you tell me about them?..........................
b. (Where appropriate) Do you attribute anything of this to do with N's illness and its effect on you? 

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<th>1</th>
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<tr>
<td>YES</td>
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c. (Where applicable) How did N cope with your being ill. Did this disturb him in any way? 

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<td>YES</td>
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**ILLNESS IN MOTHER'S FAMILY**

10. How many brothers and sisters did you have? (Prompt - did any die in childhood, or at birth) 

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<tr>
<td>YES</td>
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11. And how many brothers and sisters did your parents have? (Prompt - did any die in childhood, or at birth) 

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<tr>
<td>YES</td>
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12. Were any of your brothers and sisters ill during their lifetime? (Prompt, of what do you know) 

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<tr>
<td>YES</td>
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13. Were your parents or your aunts or uncles ever seriously ill? 

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<tr>
<td>YES</td>
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a. (Prompt) Of what? 

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<tr>
<td>YES</td>
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14. As a child, were you brought into contact much with illness? 

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<td>YES</td>
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15. Did experience with these illnesses effect your own view of illness in any way? 

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<td>YES</td>
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a. (If YES) How was that? 

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<tr>
<td>YES</td>
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**FAMILY HEALTH**

16. Apart from N's illness, have you had to cope with any illnesses in your other children, or has your husband ever been seriously ill? 

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<tbody>
<tr>
<td>YES</td>
<td>NO</td>
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a. (If YES) Can you tell me about them? 

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<tr>
<td>YES</td>
<td>NO</td>
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b. Did these worry you in any way? 

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<tr>
<td>YES</td>
<td>NO</td>
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c. (If YES) How was that? 

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<tbody>
<tr>
<td>YES</td>
<td>NO</td>
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**MOTHER'S ATTITUDE AND REACTIONS TO C.F. CHILD'S ILLNESS**

17. Mothers of children with cystic fibrosis approach the illness in different ways, for example, some don't talk about it and make as little as possible of it, whilst others discuss it openly and share treatment procedures with all the family. How would you think you have reacted to it? 

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<tbody>
<tr>
<td>YES</td>
<td>NO</td>
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</tbody>
</table>
a. Why was this?

18. What are your chief worries in relation to the illness?

19. Have you ever doubted the diagnosis?
   a. (If YES) At what point was this?
   b. (If YES) What helped you to come to terms with your doubts?

20. Have you ever felt the burden of caring for a C.F. child was too great?
   a. (If YES) At what times was this?
   b. (If YES) What or who helped you to come to terms with these feelings?

21. Do you ever feel worried that you are unable to fulfil all your responsibilities to your family?
   a. (If YES) Can you tell me more about this?
   b. (If YES to 21) Have there been certain times when this has been more worrying than others?
   c. (If YES) Can you tell me more about this?
   d. Who or what has helped you with these feelings?

22. Do you ever feel discouraged by N's illness
   a. Why is this?
   b. (If discouraged) Who or what helps you to come to terms with your feelings?

23. Do you ever feel optimistic about N's future progress?
a. Why is this?  

b. (If NO) What or who helps you to come to terms with your depression?

24. Many parents of sick children feel responsible for the illness in some way. Have you ever felt like this?

a. (If YES) Can you tell me more about it?  

b. (If YES) Who or what helped you to get over these feelings?

25. Have you ever felt that you should experiment with your C.F. child’s treatment to see if he really requires it?

a. Why is that?  

b. (If YES) What did you do?

c. (If YES) How did it work out?

26. What do you resent most about having a chronically ill child?

(Indent)

a. How do you cope with these problems?

27. Do you ever feel that having a C.F. child has isolated you in any way?

a. (If YES) How is this?

b. How do you cope with these feelings?

DOMESTIC PURSUITS

28. Caring for N takes a lot of your time, how do you manage to fit in your housework with looking after him and helping him with his treatment?
29. Do any of the family, or friends of yours ever help with the housework?
   a. (If YES) Who is that?...........................................

30. Do you have to let some things slide, e.g. mending or ironing?

31. What about shopping - do you take N with you when you go to the shops?
   a. (If YES) Always or only sometimes?............................
   b. (If NO) How do you manage your shopping - do you just slip out or does someone else do it for you?

GAINFUL EMPLOYMENT

32. (If mother works out) How do you manage to hold down a job and look after N?

33. Have you ever had any work problems, because of N's illness?
   a. (If YES) What were these?........................................
   b. How did you cope?..............................................

34. (If mother housebound) Have you ever wanted an outside job?
   a. (If YES) Did N's illness prevent your taking one?........
   b. (If YES) Did you resent this?
   c. How did you come to terms with your feelings?.............

MATERNAL EXPECTATIONS RE MARRIAGE AND FAMILY

35. Before you were married, how did you think you and your husband would live together. (Prompt) Did you think you would go out a lot together or how did you imagine you would spend your time together?

36. Has N's illness prevented you from doing these things?
6.

a. (If YES) How? ....................................................

b. (If YES) Do you resent this? ............................

c. (If YES) How do you come to terms with your resentment? ............................

37. What do you think a mother should do for her children? ........

38. Does N's illness make it especially difficult for you to do these things?

a. (If YES) Do you resent this?

b. (If YES) How do you come to terms with your resentment? ....

39. What are your basic aims in life? ..........................................

40. Are you satisfied that you are accomplishing these? 1 2

a. (If NO) Is this because of N's illness ....

41. Many mothers find that having a C.F. child causes them hardship in some way. Would you say that you have:

less spare time because of N's illness 1 2

less energy because of N's illness 1 2

less money to spend on yourself because of N's illness? YES NO

less money to spend on your other children because of N's illness? 1 2

less time alone with your husband because of N's illness? 1 2

less time to play with all your children because of N's illness? 1 2

less fun in life because of N's illness? 1 2

a. (If YES to more than 1 of above) Which is the most serious deprivation for you? ....

b. How do you come to terms with this? ..........
42. Some mothers find that having a C.F. child in the family puts a great strain on their marital relationship. Have you and your husband ever found any special difficulties because of it?
   a. (If YES) Can you tell me about these?
   b. (If YES) Have you managed to overcome these problems?
   c. (If YES) How did you accomplish this?

43. Have you ever resented or been angry with your husband because there was a tendency to C.F. in his family?
   a. Can you tell me about how you feel?
   b. (If YES) Have you managed to overcome your resentment?
   c. (If YES) How did you accomplish this?

44. Do you and your husband ever go out together?
   a. (If YES) How often: 1 per week/1 per month/seldom/1 or less per annum

45. Does your husband ever babysit and let you go out without him?
   a. (If YES) How often: 1 per week/1 per month/seldom/1 or less per annum
   b. Does this help you?

46. Does your husband ever go out without you?
   a. (If YES) How often: 1 per week/1 per month/seldom/1 or less per annum

47. Do you and your husband enjoy a happy physical relationship?
   a. (If NO) Is this because of N's illness
   b. (If NO) Why is this?

48. Are you afraid of further pregnancies?
   a. (If YES) Is this because of C.F.?
   b. (If NO) Why is this?
49. Have you found that having a sick child has drawn you and your husband together in any way?
   a. (Prompt) Do you think your relationship is better because of it?
   b. (If YES) Can you tell me about this?

RELATIONSHIP WITH OTHER CHILDREN

50. Do you ever have any problems with your other children?
   a. (If YES) What are these?
   b. (If YES) How do you cope with these?

51. What sort of questions do your other children ask about N's illness?

52. How do you answer these?

53. Which of your children do you get the most pleasure from?

RELIGIOUS BELIEFS

54. Some mothers of children with C.F. have found that their religious beliefs have altered because of it. Have you found this?
   a. (If YES) In what way?

55. Have your beliefs helped you in any way to accept and cope with the illness?
   a. (If YES) Can you explain?

FOR NORTHERN IRISH MOTHERS ONLY

56. Have the present political troubles affected N's illness or treatment in any way?
   a. (Prompt unless mentioned) Do they make getting to the clinic more difficult?
   b. Do they upset N in any way?
c. (If YES) How?..............................

d. Does this make his symptoms worse?

e. How do you cope with this?....................

FOR ALL MOTHERS

57. If you had a day in which you were free to do anything you wanted to do, what would you do?

58. Is there anything else, which I have not mentioned, which you would like to talk to me about?
### SUPPLEMENTARY QUESTIONNAIRE TO BE GIVEN TO FATHERS OF C.F. CHILDREN

I have already talked about N's illness with your wife and asked her a lot of questions about his treatment and her attitude to the illness. May I now put a few questions to you about your experience of illness, both N's and any other illnesses you may have encountered.

<table>
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<th>Identification No.</th>
<th>Card No.</th>
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</table>

#### FATHER'S PRESENT HEALTH

1. First, can I ask about your present health and has this been fairly good since N was born? (Prompt if necessary)  
   - 1 2
   - YES NO

2. Do you sleep well?  
   a. (If NO ) Do you require sleeping pills?  
      - 1 2  
      - YES NO

3. Is your appetite good?  
   - 1 2  
   - YES NO

4. Have you ever been run down or depressed?  
   a. (If YES) Have you needed a tonic?  
      - 1 2  
      - YES NO

5. Are your nervous?  
   a. (If YES) Have you been given tranquillisers/nerve pills?  
      - 1 2  
      - YES NO
   b. (If any problems mentioned) Have you always found difficulty with ...............................................................  
      - 1 2  
      - YES NO
   c. when did it start? ...............................................................  
   d. For what reason do you think? ...............................................................  

#### FATHER'S PREVIOUS HEALTH

6. Were you ever seriously ill as a child?  
   - 1 2  
   - YES NO
   a. (If YES) Specify ...............................................................  
      - 1 2

7. As a child did you require hospitalisation?  
   a. Can you recall anything about it?  
      - 1 2  
      - YES NO
   b. (If YES) What did you feel about it then? ...............................................................  

8. Do you think your own experience of childhood ailments has affected your handling of N in any way?  
   a. (If YES) How? ...............................................................  
      - 1 2  
      - YES NO

9. Have you had any illnesses - either physical or mental - in adult life?  
   - 1 2  
   - YES NO
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
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<tr>
<td>a. (If YES) Could you tell me about them?</td>
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<tr>
<td>b. (Where appropriate) Do you attribute anything of this to N's illness and its effect on you?</td>
<td>YES NO</td>
</tr>
<tr>
<td>c. (Where applicable) How did N cope with your being ill - did this disturb him in any way?</td>
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<tr>
<td>ILLNESS IN FATHER'S FAMILY</td>
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</tr>
<tr>
<td>10. How many brothers and sisters did you have? (Prompt - did any die in childhood or at birth)?</td>
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</tr>
<tr>
<td>11. And how many brothers and sisters did your parents have? (Prompt - did any die in childhood, or at birth)?</td>
<td></td>
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<tr>
<td>12. Were any of your brothers and sisters ill during their life time?</td>
<td>YES NO</td>
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<tr>
<td>a. (If YES) Of what, do you know.</td>
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<tr>
<td>13. Were your parents or your aunts and uncles ever seriously ill?</td>
<td>YES NO</td>
</tr>
<tr>
<td>a. (If YES) Of what?</td>
<td></td>
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<tr>
<td>14. As a child, were you brought into contact much with illness?</td>
<td>YES NO</td>
</tr>
<tr>
<td>15. (Where applicable) Did experience with these illnesses affect your own view of illness in any way?</td>
<td>YES NO</td>
</tr>
<tr>
<td>a. (If YES) How was that?</td>
<td></td>
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<tr>
<td>FATHER'S EMPLOYMENT HISTORY</td>
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<tr>
<td>16. Can I now ask you about your work. What do you do?</td>
<td></td>
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<tr>
<td>17. How long have you done this?</td>
<td></td>
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<tr>
<td>18. What did you do before?</td>
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<td>19. Approximately how much do you earn?</td>
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<tr>
<td>20. Has N's illness ever interfered with or influenced your work in any way?</td>
<td>YES NO</td>
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<tr>
<td>a. (If YES) How was that?</td>
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<tr>
<td>21. (Unless already mentioned prompt) Have you ever had to give up work to care for N or to care for your other children whilst N was in hospital?</td>
<td>YES NO</td>
</tr>
</tbody>
</table>
a. When was that? ..............................................................

b. For how long were you off? .................................

22. Have you ever had to give up promotion because of N’s illnesses, e.g. if promotion necessitated moving?
   a. (If YES) Did you resent this?
   b. (If YES) How did you come to terms with your feelings?

PARENTS UNDERSTANDING OF ILLNESS

23. I wonder could I ask you a little about N’s illness now. When the doctor told you about N’s C.F., what did he actually say to you?

24. (Unless already mentioned) Did he tell you this was an inherited condition, passed from parents to children?
   a. (If YES) How did you feel about this? ..............

25. Did he tell you the child would always have the illness and need treatment?
   a. (If YES) How did you feel about this? ..............

26. Did he tell you the illness might get worse in the future?
   a. (If YES) What did he say? ..............................
   b. How did you feel about this? ........................

27. What do you understand of the chances of your children’s children having it?

28. Has either your own doctor or the specialist taken a lot of trouble to explain N’s illness and treatment to you?
   a. (If YES) Specify which doctor .........................

29. Do you feel you understand his illness as well as you want to, or would you be glad to have it explained more fully?

30. How did you feel about the way in which you were told that he had C.F.? (Prompt, if necessary. Was this tactful and kindly or lacking in tact?)
31. What do you think is the right moment to be told about these things?

(Prompt) Do you think the doctor should tell the parents as soon as he suspects something is wrong or should he wait till he's quite sure?

32. After you knew N had C.F. did you try and find out more about the illness?

(IF YES) How?

33. Have you read any of the pamphlets put out for parents by the Cystic Fibrosis Foundation Trust?

(IF YES) Who gave you these?

Did you find them helpful?

(IF NO) Why was that?

34. (Unless doctor specified as giver of pamphlets) Would you have liked Dr. to give you something to read about C.F. at the time of diagnosis?

(IF NO) Why is that?

35. Have you read any articles in the press or watched any T.V. programme on C.F.?

(IF YES) How did you find them?

36. How much have the following helped you in understanding C.F.?

<table>
<thead>
<tr>
<th></th>
<th>Very much</th>
<th>Mod.</th>
<th>Very little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family doctor</td>
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<tr>
<td>Clinic doctor</td>
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<tr>
<td>Other parents</td>
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<td>Books</td>
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<td>Friends</td>
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<tr>
<td>Family</td>
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<tr>
<td>C.F. Parents Association</td>
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<tr>
<td>Clergy</td>
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<tr>
<td>Social Worker</td>
<td></td>
<td></td>
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<tr>
<td>Others (specify)</td>
<td></td>
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</table>

37. Has the doctor discussed the question of having more children with you?

38. Have you discussed this with anyone else?

(Prompt if necessary - wife)

(Specify - with whom)

39. Do you think having N has changed your feelings about having more children in any way?
a. Why is that? .................................................................

COMMUNICATION

40. Most parents of a child with C.F. need opportunities to talk out their problems and worries. Have you ever been able to do this fully with:

    Wife
    Relative
    Friend
    G.P.
    Clinic doctor
    Clergyman
    Social worker
    C.F. Parents Association
    Others (specify)

a. (If YES to wife) Can you and your wife talk about everything together? 1 2

b. (If NO ) What can you not talk about with your wife?

-------------------------------------------------------------------------

41. Can you talk about most things with N? 1 2

a. (If NO ) Why is that? .................................................... 1 2

42. Can you talk naturally about his illness? 1 2

a. (If NO to any of these) Why can you not talk about...........? 1 2

46. Can N talk naturally about his illness? 1 2

a. (If NO ) Why do you think that is? ................................. 1 2

b. (If YES) Does he talk to you?

   Does he talk to his mummy? 1 2
   Does he talk to his brothers/sisters? 1 2
   Does he talk to your family? 1 2
   Does he talk to friends? 1 2

6 6 3
47. Does he tell you if he is in pain?
48. Does he tell you if he is sad?
49. Does he tell you if he is worried?
50. When N asks questions about his illness, do you find it easy or difficult to answer them?

<p>| | |</p>
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<td>1</td>
<td>2</td>
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<tr>
<td>YES</td>
<td>NO</td>
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</tbody>
</table>

a. Can you tell me more about how you feel?

FATHER'S PERCEPTION OF CHILD'S REACTIONS TO ILLNESS

51. Has N ever shown alarm at how C.F. might affect him in the future?

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<td>1</td>
<td>2</td>
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<tr>
<td>YES</td>
<td>NO</td>
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</table>

a. (If YES) Was this: considerable/moderate/slight
b. At what age?

c. Did you ever talk this over with him?

d. (If YES) What did you say?

e. How does he feel now?

52. Has N ever seemed pleased at getting special attention?

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<td>1</td>
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<tr>
<td>YES</td>
<td>NO</td>
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</table>

a. (If YES) Was this: considerable/moderate/slight
b. At what age?

c. Did you talk about this with him?

d. (If YES) What did you say?

e. How does he feel now?

53. Has N ever paid much attention to his physical sensations and symptoms?

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<td>1</td>
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<td>YES</td>
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</table>

a. (If YES) Was this: considerable/moderate/slight
b. At what age?

c. Did you talk this over with him?

d. (If YES) What did you say?

e. How does he feel now?

54. Has N ever felt self conscious or worried about the reactions of others?

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<td>1</td>
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<tr>
<td>YES</td>
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a. (If YES) Was this: considerable/moderate/slight
<table>
<thead>
<tr>
<th>Question</th>
<th>YES</th>
<th>NO</th>
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<tr>
<td>b. At what age?</td>
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<tr>
<td>c. Did you talk this over with him?</td>
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<td>d. (If YES) What did you say?</td>
<td></td>
<td></td>
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<tr>
<td>How does he feel now?</td>
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<tr>
<td>55. Has N ever felt frightened, resentful or sad that he was different from others?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. (If YES) Specify</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. (If YES) Was this: considerable/moderate/slight</td>
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<td></td>
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<tr>
<td>c. At what age?</td>
<td></td>
<td></td>
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<tr>
<td>d. Did you talk this over with him?</td>
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<tr>
<td>e. (If YES) What did you say?</td>
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<td></td>
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<tr>
<td>f. How does he feel now?</td>
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<tr>
<td>56. Has N ever been worried about his size or shape?</td>
<td></td>
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</tr>
<tr>
<td>a. (If YES) Was this: considerable/moderate/slight</td>
<td></td>
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<tr>
<td>b. At what age?</td>
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<tr>
<td>c. Did you talk this over with him?</td>
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<tr>
<td>d. (If YES) What did you say?</td>
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<td></td>
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<tr>
<td>e. How does he feel now?</td>
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<tr>
<td>57. Has N shown any other reactions to the illness not already mentioned?</td>
<td></td>
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</tr>
<tr>
<td>a. (If YES) At what age?</td>
<td></td>
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<tr>
<td>b. What were these?</td>
<td></td>
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<tr>
<td>c. How did you cope with these?</td>
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<tr>
<td>58. Have there been periods when N has shown increased worry about his illness?</td>
<td></td>
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</tr>
<tr>
<td>a. (If YES) At what ages have these periods occurred?</td>
<td></td>
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<tr>
<td>b. Can you explain his increased worry in any way? (Prompt for example - because his symptoms were worse at this time or because he was worried by something else, e.g. school problems)</td>
<td></td>
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<tr>
<td>59. When N is worried or upset about experiences in his life (tests in school, new baby, etc.) do any of his C.F. symptoms become more severe?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. (If YES) Can you tell me more about this?</td>
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</table>
PARENTS REACTIONS TO, AND EXPECTATIONS FOR CHILD WITH ILLNESS

We are interested in understanding the ways in which a child's C.F. may influence the way in which his parents take care of him. It may be that parents handle the child with C.F. differently from their other children - would you say this was true?

a. (If YES) Why is that do you think?..................

Do you think you expect less from him in the way of personal responsibility for clothing, cleanliness or neatness?

a. (If YES) Is this: much less/moderately less/only a little less (Circle)

Would you say that you expect less from him in the way of responsibility for household chores?

a. (If YES) Is this: Much less/moderately less/very little less

Would you say that you expect less from him in the way of school achievement?

a. (If YES) Is this: Much less/moderately less/very little less

b. (If YES) Is this because you feel you have to protect him?

c. Can you explain?..........................................

d. (If NO) Is this because you feel you have to push him to compensate for the illness?

e. Can you explain?..........................................

Would you say that you expect less of him in his relationships with other children?

a. (If YES) Is this: Much less/moderately less/very little less

Would you say that you permit him less independence in making his own decisions?

a. (If YES) Is this: Much less/moderately less/very little less

Would you say that you permit him less independence in joining in activities away from home?

a. (If YES) Is this: Much less/moderately less/very little less
68. Would you say that you are more cautious about permitting him to join in physical activities?
   a. (If YES) Is this: Much less/moderately less/very little less

69. Would you say that you are less likely to punish him?
   a. (If YES) Is this: Much less/moderately less/very little less

70. When he is naughty, how do you punish him?.................
   a. (Unless mentioned, prompt) Do you ever smack him?
   b. Do you ever send him to bed or put him in his room?
   c. Do you ever deprive him of something he likes, e.g. television, comics, sweets, pocket money?
   d. Do you ever say you won't love him if he is bad?
   e. Do you ever say you'll send him away if he is bad?
   f. Do you ever threaten him with somebody else, e.g. doctor, teacher?
   g. Do you experience any worry or guilt after punishing him?
   h. (If YES) Why is that?........................................

71. On the whole, are you happy about the way you handle N's behaviour or do you sometimes find yourself doing things you really don't approve of?

72. Do you agree with your wife about this or is she a lot more strict or less strict than you are?

73. Do you and your wife always agree about how N should be brought up generally or do you feel differently about some things?

OPINION OF HANDICAP

74. Talking generally now - what do you feel is N's greatest handicap, from his point of view?

75. And from your point of view - what is it about him that you find hardest to cope with?

76. Have you any suggestions to make that might be helpful to other fathers of C.F. children - either practical suggestions for looking after their children, or on how you manage to face this and come to terms with it?
77. What or who do you think has most helped N to come to terms with his illness?

78. And what about the future - do you ever try to look ahead and make plans for N, or do you face each day as it comes?

   a. (Probe if necessary) Have you any ideas at all about N's future?

79. Does N ever talk about his own future?

   a. (Probe if necessary) Has he given you any idea of his hopes or fears for the future?

FATHER'S ATTITUDE TO C.F. CHILD'S ILLNESS

80. Have you ever doubted the diagnosis?

   a. (If YES) At what point was this?

   b. (If YES) What or who helped you to come to terms with your doubts?

81. Have you ever felt the burden of caring for a C.F. child was too great?

   a. (If YES) At what times was this?

   b. What or who helped you to come to terms with your feelings?

82. Do you ever feel worried that you are unable to fulfil all your responsibilities to your family?

   a. (If YES) Can you tell me more about this?

   b. (If YES to 82) Have there been certain times when this has been more worrying than others?

   c. (If YES) Can you tell me more about this?

   d. (If YES) Who or what helped you with your feelings?

83. Do you ever feel discouraged by N's illness?
a. Why is this

b. (If discouraged) Who or what helps you to come to terms with your feelings?

84. Do you ever feel optimistic about N's future progress?

a. Why is this?

b. (If NO to question 84) What or who helps you to come to terms with your depression?

85. Many parents of sick children feel responsible for the illness in some way. Have you ever felt like this?

a. (If YES) Can you tell me more about it?

b. Who or what helped you to get over these feelings?

86. Have you ever felt that you should experiment with N's treatment to see if he really requires it?

a. Why is that?

b. (If YES) What did you do?

c. (If YES) How did it work out?

87. Do you ever wish you could participate more in his care and treatment?

a. Can you tell me more about how you feel?

88. What do you resent most about having a chronically ill child? (Itemise)

a. How do you cope with these problems?

89. Do you ever feel that having a C.P. child has isolated you in any way?

a. (If YES) How is this?

b. How do you cope with these feelings?
90. Before you were married, how did you think you and your wife would live together - did you think you would go out a lot together or how did you imagine you would spend your time together?

91. Has N's illness prevented you from doing these things?
   a. (If YES) How?
   b. (If YES to question 91) Do you resent this?
   c. How do you come to terms with your resentment?

92. What do you think a father should do for his children?

93. Does N's illness make it especially difficult for you to do these things?
   a. (If YES) Do you resent this?
   b. (If YES) How do you come to terms with your resentment?

94. What are your basic aims in life?
   a. Are you satisfied that you are accomplishing these?
   b. (If NO) Is this because of N's illness?

95. Many parents find that having a C.F. child causes them hardship in some way. Would you say that you have:
   a. less spare time because of N's illness?
   b. less energy because of N's illness?
   c. less money to spend on yourself because of N's illness?
   d. less money to spend on your wife because of N's illness?
   e. less money to spend on your other children because of N's illness?
   f. less money to spend on your other children because of N's illness?
   g. less time alone with your wife because of N's illness?
   h. less time to play with all your children because of N's illness?
   i. less fun in life because of N's illness?
   j. (If YES to more than 1 of above) Which is the most serious deprivation for you?
How do you come to terms with this?

**MARITAL RELATIONSHIP**

96. Some fathers find that having a C.F. child in the family puts a great strain on their marital relationship. Have you and your wife ever found any special difficulties because of this?

   a. (If YES) Can you tell me about these?
   
   b. (If YES) Have you managed to overcome these problems?
   
   c. (If YES) How did you accomplish this?

97. Have you ever resented or been angry with your wife because there was a tendency to C.F. in her family?

   a. Can you tell me about how you feel?
   
   b. (If YES) Have you managed to overcome your resentment?
   
   c. (If YES) How did you accomplish this?

98. Do you and your wife ever go out together?

   a. (If YES) How often?
      1 per week/1 per month/seldom/1 or less per annum

99. Do you ever go out alone?

   a. (If YES) How often?
      1 per week/1 per month/seldom/1 or less per annum

100. Does your wife ever go out without you?

   a. (If YES) How often?
      1 per week/1 per month/seldom/1 or less per annum

101. Do you and your wife enjoy a happy physical relationship?

   a. (If NO) Is this because of N's illness?
   
   b. (If NO) Why is this?

102. Have you found that having a sick child has drawn you and your wife together in any way? Do you think your relationship is better because of it?

   a. (If YES) Can you tell me about this?
103. Do you experience any problems with your other children?
   a. (If YES) What are these?
   b. (If YES) How do you cope with these?

104. What sort of questions do your other children ask you about N's illness?

105. How do you answer these?

106. Do you think your other children resent all the time you and your wife have to spend on N?
   a. Can you tell me more about this?

107. Which of your children do you get the most pleasure from?

RECOMMENDATIONS

108. Some fathers of children with C.F. have found that their religious beliefs have altered because of it. Have you found this?
   a. (If YES) In what way?

109. Have your beliefs helped you in any way to accept and cope with the illness?
   a. (If YES) Can you explain?

110. If you had a day in which you were free to do anything you wanted to do, what would you do?

111. Is there anything else, which I have not mentioned, which you would like to talk to me about?
THE INTERVIEW SCHEDULE FOR THE CHILD WITH C.F.

deals with the subsections listed below. If a clinical interview is preferred, care should be taken to elicit information about all these topics.

1. **School** - school worries, school friends, fears of missing school and school work.
2. **Play** - companions, location of play, worries in connection with play companions.
3. **Other children's response to child's C.F.** - questions relating to it, worries caused by questions.
4. **Ideal person** - who would the child like to be and why.
5. **Teachers** - reactions to teachers, teachers reaction to child.
6. **Communication** - in whom does the child confide when he is worried.
7. **Family** - mother, father, sibs, likes and dislikes.
8. **Clinic** - response to other children there, mothers of other children, doctor.
9. **Hospital** - length of stay, type of treatment, fears there and fears on returning home, preparation for, dreams of.
10. **Illness** - does the child know name, what does he know of nature of illness, how does he feel about treatment - now and in the future.
11. **Feelings** - sadness, anger, worry, happiness - what causes them.
12. **Fears** - of what.
13. **Fantasies** - nice dreams, 3 magic wishes, first memories, a fantasy day, the future.
INTERVIEW SCHEDULE FOR THE CHILD WITH C.F.

(Questions may need slight rephrasing according to age, but in most instances - except for the first section - should be attempted with all children over 3-6 years)

Now I want to talk about you.

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<th>Identification No.</th>
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<tbody>
<tr>
<td>Sex</td>
<td>1 2 YES NO</td>
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</table>

<table>
<thead>
<tr>
<th>1. Do you go to school?</th>
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<tbody>
<tr>
<td>2. Do you like going to school?</td>
</tr>
<tr>
<td>a. Why is that?</td>
</tr>
<tr>
<td>(Omit complete section if child not at school)</td>
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<tr>
<td>3. Is there anything about school that you really dislike?</td>
</tr>
<tr>
<td>a. (If YES) Tell me about it?</td>
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<tr>
<td>4. Do you ever get scared or worried when you are there?</td>
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<tr>
<td>a. (If YES) What about?</td>
</tr>
<tr>
<td>5. Have you got any friends in school?</td>
</tr>
<tr>
<td>a. (If YES) What do you do with them?</td>
</tr>
<tr>
<td>b. (If NO ) Why is that, do you think?</td>
</tr>
<tr>
<td>6. Do you ever bring any children home to play?</td>
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<tr>
<td>a. (If NO ) Why is that?</td>
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<tr>
<td>b. (If NO ) Do you mind about that?</td>
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<tr>
<td>7. Do you ever go to play in other children's homes?</td>
</tr>
<tr>
<td>a. (If NO ) Why is that?</td>
</tr>
<tr>
<td>b. (If NO ) Do you mind about that?</td>
</tr>
<tr>
<td>8. Do you ever feel different from other children in any way?</td>
</tr>
<tr>
<td>a. (If YES) Tell me about it?</td>
</tr>
<tr>
<td>b. (If YES) How do you feel about this?</td>
</tr>
<tr>
<td>9. Do other children ever talk or ask questions about your illness?</td>
</tr>
<tr>
<td>a. (If YES) What do they say or ask?</td>
</tr>
<tr>
<td>b. (If YES) Do you mind them saying/assembling these things?</td>
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<tr>
<td>c. Tell me how do you feel about it?</td>
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</tbody>
</table>

674
10. What do you like most about the other children you meet in school?
   ....................................................................................................................
   a. Why is this?............................................................................................... 1 2

11. What do you dislike most about other children?........................................
   ....................................................................................................................
   a. Why is this?............................................................................................... 1 2

12. If you weren't you, but could be someone else, who would you be?
   ....................................................................................................................
   a. Tell me about him?....................................................................................
   b. Why do you want to be like him?............................................................

(For Primary Children only)

13. Tell me about your teacher - what is he called?.................................
   ....................................................................................................................
   a. Do you like him?
   b. Why is that?.............................................................................................

14. Tell me about the (other) teachers you've had in school - have you ever liked any of them?
   ....................................................................................................................
   a. Why was that?............................................................................................

15. Do you ever think any of them have been specially kind to you when you're not well?
   ....................................................................................................................
   a. Why is that?............................................................................................... 1 2

16. Do you ever think any of them are specially unkind to you when you're not well?
   ....................................................................................................................
   a. Why is that?............................................................................................... 1 2
   b. (If YES) Does that make you upset?......................................................
   c. (If YES) Tell me how you feel?............................................................... 1 2
   d. (If YES) Do you do anything about it?.................................................. 1 2

17. When you miss school does this worry you?
   ....................................................................................................................
   a. Tell me about how you feel?....................................................................

1 2
YES NO

1 2
YES NO

1 2
YES NO

1 2
YES NO

1 2
YES NO

1 2
YES NO
18. Do you ever try specially hard to make up for the work you've missed?
   a. (If YES) Tell me what you do?.........................

19. Do you stay for school dinner?
   a. (If YES) Do you have to take your capsules before dinner?
   b. (If YES) Does this embarrass/worry you at all?
   c. (If YES) What do you do about it?......................

20. Do any (other) things worry you at school, for example going to the toilet, coughing, or having a runny nose?
   a. (If YES) Tell me about them?.........................
   b. (If YES) What do you do about them?...................

**COMMUNICATION**
(If has school worries)

21. Have you ever talked these worries over with anyone?
   a. (If talked) What did they say?.........................
   b. (If talked) Did this help at all?.......................
   c. (If talked) Why was that?.........................

22. If you are worried by anything (else) can you talk this over with anyone?
   a. (If YES) With whom?.................................
   b. (If YES) Does that help?
   c. (If NO ) Why is that?

23. Do you ever keep secrets from other people?
   a. (If YES) From whom?.................................
   b. (If YES) What sort of secrets?.........................

**FAMILY**

24. Tell me about your mummy - what is she like?...........

25. Does she ever do anything good for you
   a. (If YES) What is that?.................................

26. Does she ever annoy you in any way?
   a. (If YES) How is that?.................................

27. Tell me about your daddy - what is he like?.............
28. Does he ever do anything good for you?
   a. (If YES) What is that?.................................

29. Does he ever annoy you in any way?
   a. (If YES) How is that?.................................

30. Have you any brothers or sisters?
   a. How many?............................................
   b. (If YES) What are / they called?..................
   c. (If YES) Tell me about him/them?

**FOR CHILDREN WITH MORE THAN 1 SIB.**

31. Which do you like best?...............................
   a. Why is that?...........................................

32. Who do you like least?..............................
   a. Why is that?...........................................

**FOR CHILDREN WITH 1 SIB.**

33. Do you like him?........................................
   a. Why?...................................................

**CLINIC**

34. Do you like going to the clinic?..................
   a. Why is that?...........................................

35. What do you like least about going to the clinic?

36. Do you ever talk to the other boys or girls in the clinic?
   a. (If YES) What about?.................................

37. Do you like meeting them or do they annoy you?

38. Does your mother ever talk to the other mothers at the clinic?
   a. (If YES) What do they talk about?..................
   b. (If YES) How do you feel about this?.............

39. Tell me about the doctor who sees you in the clinic - what is he like?
40. Could you tell him about anything that worried you?
   a. (If NO) Why is that? ........................................

41. Have you ever had to stay in hospital?
   a. (If YES) How many times? ..................................
   b. (If YES) How long did you stay there? .................
   c. (If YES) How old were you then? .......................

42. What did they do to you whilst you were there? ........
   a. Were you worried by this/any of these things? .......
      (If several procedures mentioned)
   b. What worried you most? .................................
   c. Tell me about it?  .......................................

43. Before you went into hospital did anyone tell you what was going to happen?
   a. (If YES) Who was that? ..................................
   b. (If YES) What did they say? ............................
   c. (If YES) Did this help at all when you were in hospital? 
      Why was that? ...........................................

44. Tell me what it was like when you got home from hospital? (Prompt - Did anything worry you when you came home?) .................................................................

45. Have you ever had any dreams about hospital since then?
   a. (If YES) Tell me about them? ..........................

46. Can you tell me why you have to go to the clinic? ....

47. Either/Or What do you think is wrong with/How does C.F. affect your inside - can you tell me?

<table>
<thead>
<tr>
<th>1 2</th>
<th>YES NO</th>
</tr>
</thead>
</table>
6.

a. Does this every worry you?

b. Why is that?

48. What are the worst things about being ill/having C.F?

a. Do these ever make you sad or worried?

b. Tell me how you feel?

49. (Unless already mentioned) How do you feel about taking medicines every day?

50. How do you feel about having physiotherapy?

51. (Where applicable) How do you feel about sleeping in a mist tent?

52. (Where applicable) How do you feel about having to miss out on some foods?

53. Why do you think you need so many different kinds of treatment?

54. Do you ever think you should experiment to find out why they are necessary?

a. Tell me about how you feel?

55. And in the future, what do you imagine you'll have to do by way of treatment?

a. How do you feel about that?

FEELINGS

56. Are you ever specially happy?

a. (If YES) What about - tell me.

b. (If NO) Why is that?

57. Are you ever very angry?

a. (If YES) With whom, or about what?

58. Are you ever very sad?

a. (If YES) What about?
59. Are you ever very worried?
   a. (IF YES) Tell me about it................................. 1 2

60. Could you talk about these things with anyone?
   a. (IF YES) With whom?........................................ 1 2
   b. (IF NO ) Why is that?........................................ 1 2

FEARS

61. Are you ever really frightened by anything?
   a. What frightens you?........................................... 1 2
   b. (IF alternative given) Which is the most frightening?

(Unless already mentioned)

   c. Are you afraid of going to the clinic?
   d. Are you afraid of going into hospital?
   e. Are you afraid of nurses?
   f. Are you afraid of doctors?
   g. Are you afraid of being ill?
   h. Are you afraid of being hurt?
   i. Are you afraid of the dark?
   j. Are you afraid of missing school?
   k. Are you afraid of other children?
   l. Are you afraid of growing up?
   m. (IF YES to any of these) Tell me why you’re frightened of

.................................................................

   n. (IF several alternatives given) Which is most frightening to you?

.................................................................

FANTASIES

62. Do you ever have any really nice dreams?
   a. (IF YES) Tell me about them?.............................. 1 2

63. If I could give you 3 magic wishes, what would you wish for?

.................................................................
64. Can you remember back to when you were very little, tell me what happened to you then?

(Prompt, if necessary. Tell me about the first things that happened to you)

.................................................................

.................................................................

65. If you had a day in which you were free to do anything you wanted to do, what would you do?

.................................................................

66. What would you like to be in the future?

...........................

67. Is there anything else you want to tell me about, which we haven't talked about so far?

.................................................................
A. FOR PARENTS

This interview schedule was constructed for the control study of coeliac children and their families. For simplicity of reference then, the system of numbering of items of the original schedule has been retained as far as possible. As a result some gaps may occur in the numbering of the questions in this schedule, where items relevant only to C.F. families have been dropped from this part of the investigation, and not replaced by substitute items.

Amendments should be particularly noted in the section of the schedule dealing with "Treatment" since this is a major point of difference between the structures of the two schedules.
QUESTIONNAIRE FOR PARENTS OF CHILDREN WITH COELIAC DISEASE

Identification number

Card number M1 F2

Date of interview

1. Patient's name

2. Patient's address

3. Patient's date of birth

4. Patient's schooling (with appropriate dates) if any

a. (If special school indicated) Was this your choice of school or were you forced to send him there by the L.E.A.?

5. Mother's name

6. Mother's date of birth

7. Mother's occupation (state full/part time if in outside employment)

8. Mother's former occupation

9. At what age did you leave school?

10. Did you have any special training after school?

a. (If YES) What was that?

11. Father's name and date of birth

12. Father's occupation

13. At what age did he leave school?

14. Did he have any special training after school?

a. (If YES) What was that?

15. Does he have to be away from home at all, except during the day?

a. (If YES) Variable amount/up to 2 nights per week/3 nights per week/normally away/separated or divorced/dead (circle one)

16. Is he on shift work?

a. (If YES) What shifts?
17. Were you and your husband related to each other? cousin/second cousin

18. Date of marriage..............................

19. How many living children are there in the family? Are they all well? (Note whether any siblings have physical or mental handicaps or ill health)

<table>
<thead>
<tr>
<th>Name</th>
<th>D.O.B.</th>
<th>School (if any) or occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
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<tr>
<td>2.</td>
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<tr>
<td>3.</td>
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<tr>
<td>4.</td>
<td></td>
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<tr>
<td>5.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20. Have you had any children who have died?
   a. (If YES) Specify D.O.B. and age at death..........................

21. Do any other adults, apart from your husband, live in the house with you and N?
   a. (If YES) State relationship - if any - to child................

22. How many people live in the house altogether?....................

**Housing**

23. Is the house: rented/owned/other (Circle)

24. How many rooms are there?...........................................
    (not counting bathroom or working kitchen)

25. Do you have to share a toilet?
   a. (If YES) With how many other people?.........................

26. Have you: Running water
    A hot water system
A bath
An inside flush lavatory
A washing machine
Clothes drying facilities
Telephone
Use of a car in emergency

<table>
<thead>
<tr>
<th>State of repair - by observation only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exterior repair</td>
</tr>
<tr>
<td>Interior repair</td>
</tr>
<tr>
<td>Interior comfort</td>
</tr>
<tr>
<td>Garden facilities</td>
</tr>
<tr>
<td>Apparent play facilities</td>
</tr>
</tbody>
</table>

27. How many rooms are used as bedrooms?.................................

28. Does N sleep in a room of his own?
   a. (If NO) With whom does he share a room?...........................

29. Do you get any complaints about that?
   a. (If YES) Specify from whom and what?...............................

30. Do you find that you need more space with N?
    (If YES) Specify for what..............................................

31. In your view, does this house meet your family's needs
    a. (If NO) In what way is it unsatisfactory?........................

32. Do you and your husband have to share your bedroom with anyone else?
   a. (If YES) Is this because of N?
   b. (If NO) Give reason..................................................
FAMILY AND NEIGHBOURHOOD SUPPORT

37. How long have you lived in this neighbourhood? ......................... 1 2

38. Do you like it?

a. (If NO) Why is that? ......................................................... 1 2

39. Do you have any domestic help?

40. Do you have any family living in this area?

  a. (If YES) Specify, ............................................................. 1 2
  b. (If NO) Does your family ever come to see you? ................. 1 2

41. (If YES to either question) How often do you see them?

   more than  more than  less than  
   every day  once a week  once a month  once a month

42. Do they give you emotional support?
   i.e. will they share your worries with you?

  a. (If YES) In what way? ....................................................... 1 2
  b. (If NO) Why is that? ....................................................... 1 2

43. Do they give you practical help?

44. Would they help care for N?

  a. (If YES) In what way? ....................................................... 1 2

45. Would they babysit the other children if you had to take N to the doctor?

46. Would they mind the family if you wanted to stay with N in hospital?

47. Do they help you with transporting N to hospital or clinic?

48. Would they babysit for you if you wanted a break?

49. Are there any other ways in which they help you?

  a. (If YES) Specify ............................................................. 1 2

50. Do you go out and see them at all?

  a. (If YES) How often?
      every day  more than  more than  less than
      once a week  once a month  once a month
51. What do you normally do together? (specify).................................

52. Do you think having a sick child has affected your ability
to see your family in any way?
   a. (If YES) How is that?.............................

53. Do you have any friends living near?
   a. (If NO) Do any friends come and visit you?
   b. (If YES to either) How often do you see them?
      every day more than once a week more than once a month
      less than once a month

54. Do they give you emotional support?
   a. (If YES) In what way?..........................

55. Do they give you practical help?

56. Would they help care for N?
   a. (If YES) In what way?..........................

57. Would they babysit the other children if you had to take
   N to the doctor?

58. Would they mind the family if you wanted to stay with
   N in hospital?

59. Do they help you with transporting N to the hospital
   or clinic?

60. Would they babysit for you if you wanted a break?

61. Are there any other ways in which they help you?
   a. (If YES) Specify.................................

62. Do you think having a coeliac child has affected your
    ability to maintain friendships?
   a. (If YES) How is that?..........................

63. Do you need any extra help in caring for N and his treatment?
   a. (If YES) What would you like to have?.................

   1 2
   YES NO
64. Do you need any extra help in caring for the other children at home?
   a. (If YES) What would you like to have?  
       ........................................................................................................

65. Do you need any extra help with babysitting?
   a. (If YES) To meet what sort of needs?  
       ........................................................................................................

CONTACTS WITH SOCIAL SERVICE AGENCIES

66. Now I'd like to know about other sorts of help that you have had with N. Does the Health Visitor from the local health clinic call on you to see how he is getting on?
   a. (If YES) How often?  
       ........................................................................................................
   b. (If NO) Has she called in the past?
   c. Have you found these visits helpful?
   d. Why was that?  
       ........................................................................................................

67. Has anyone else come to see you about N from the Coeliac Society, for instance, or the local welfare department/hospital social worker/physiotherapist/dietitian/local education/health department/sister from the hospital? (circle where applicable)
   a. How often?  
       ........................................................................................................

68. (If any visits) How do you feel about these visits?  
       ........................................................................................................

69. Have you found them helpful?
   a. Why was that?  
       ........................................................................................................

70. (If NO visits) Have you asked them not to?
   a. (If YES) Did you have any particular reason for not wanting them to call?  
       ........................................................................................................

71. Could you do with more visiting?
   a. (If YES) Specify what kind.  
       ........................................................................................................

72. What sort of visits do you think could be most helpful - advice about special problems or just a friendly chat?  
       ........................................................................................................
a. If the hospital provided help of this sort - perhaps someone coming out to see you every couple of months, would you welcome this?

Do you belong to the Coeliac Society?

a. (If YES) How did you hear about it? ........................................

c. (If NO) Did you know about it?

d. (If knows) But you still didn't want to join. Can you say why?

...........................................................

e. (If doesn't know) Would you have joined if you had known about it?

Do/would you find the company of parents of other coeliac children helpful to you?

a. Why is that? ........................................................................

Do you belong to any other group or club? (e.g. W.I., Church Organisation)

a. (If YES) Specify.................................................................

Which clinic do you attend with N? ................................................

...........................................................

TRANSPORT TO CLINIC

How far are you from the clinic? ..................................................

How do you travel there? ..............................................................

How much does this cost? ............................................................

Who pays? .............................................................................

Do you need any extra help with transport?

FINANCIAL PRESSURES (Transport and housing should already have been discussed and if hardship has already been noted, this section can be introduced as follows:)

We have already talked about the extra cost of

Are there any (other) ways in which N's illness has placed an extra strain on the family budget?

a. (If YES) Specify ....................................................................

...........................................................
83. Do you have to buy any special foods?
   a. (If YES) Do these cost more?
   b. (If YES) How much more per week? - specify.
      (If YES to 83)
84. Do you buy them for all the family?
85. Which foodstuffs do you get on prescription?
   a. Has there ever been any difficulty about this?
   b. (If YES) What was the problem?
86. Have you or your husband ever had to give up work to nurse N?
   a. (If YES) Specify.
   b. How often?
   c. When?
   d. How much loss of pay did this involve?
87. How much money do you have for housekeeping each week?
88. Is this only for food?
   a. (If NO) What else does it pay for?
89. Does this make it possible for you to feed all the family adequately?
   a. (If NO) How much more per week do you feel you would require to do this?
90. Do you think either you, your husband or the other children miss out on anything because of the cost of N's illness?
   a. (If YES) Specify.
91. Do you and the children ever get a holiday away from home?
   a. (If NO) Is this because of the cost of the illness?
92. Do you and the children ever get outings or treats of any sort?
   a. (If NO) Is this because of the cost of the illness?
ILLNESS HISTORY

93. I am asking all the mothers I talk to how they first came to know that their children had coeliac disease. Can you tell me when you were first told that N had coeliac disease?

94. How old was he?

95. Who told you?

a. Were you and your husband both present at the time of diagnosis?

b. After Dr. had told you the diagnosis was he accessible to you for further questioning?

c. (If YES) Did you avail yourselves of the facility and go and visit him?

d. (If NO) Why was this?

96. Had you any idea before the time of diagnosis that he could be seriously unwell?

a. (If YES) What made you think that?

b. (If YES) Did you take him to a doctor at this stage?

c. (If YES) Who was this? G.P./Specialist

d. What did he say was wrong? (Prompt in order to obtain complete history to diagnosis)

97. Do you ever blame yourself for this delay in seeking help for N?
a. (If YES) Can you tell me how you feel?..................

...........................................................................

(If any evidence of misdiagnosis or incorrect treatment ask) -

98. Do you blame the doctors for not recognising coeliac disease straight away?

a. Can you tell me more about how you feel?..................

...........................................................................

99. Did the diagnosis come as a terrible shock to you?

a. Can you tell me more about how you felt?..................

...........................................................................
100. Did you resent the doctor telling you?
   a. (If YES) Why was that? .........................
      (If YES to question 100)
101. Was there any way in which the doctor could have got over that?
   a. (If YES) How? ...................................
102. Do you think this has changed your attitude to the medical profession in any way?
   a. (If YES) Can you explain? ....................

PARENTS UNDERSTANDING OF ILLNESS
103. When the doctor told you about coeliac disease, what did he actually say to you?

104. Did he tell you this immediately?
   a. (If NO) Did you have to ask about it?
105. Did he say that coeliac disease was an inherited condition?
   a. (If YES) What did he say? ....................
   b. (If YES) How did you feel about this? ....
106. Did he tell you the child would always have the illness and need to be on this special diet?
   a. (If YES) How did you feel about this? ....
107. Did he say anything about N's future health?
   a. (If YES) What did he say? ....................
108. How did you feel about this? ..................
110. Has either your own doctor or the specialist taken a lot of trouble to explain N's illness or treatment to you?
11. Do you feel you understand his illness as well as you want to, or would you be glad to have it explained more fully?

112. How did you feel about the way in which you were told that he had coeliac disease? (Prompt, if necessary, was this tactful and kindly or lacking in tact?)

113. What do you think is the right moment to be told about these things? (Prompt) Do you think the doctor should tell the parents as soon as he suspects something is wrong or should he wait till he is quite sure?

114. After you knew N had coeliac disease did you try and find out more about the illness?

115. Have you read the handbook put out for parents by the Coeliac Society?

116. (Unless Dr. specified as giver of handbook) Would you have liked Dr. _______ to give you something to read about coeliac disease at the time of diagnosis?

118. How much have the following helped you in understanding coeliac disease?

<table>
<thead>
<tr>
<th>Family doctor</th>
<th>Very much</th>
<th>Mod.</th>
<th>Very little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic doctor</td>
<td>&quot;</td>
<td>&quot;</td>
<td>&quot;</td>
<td>&quot;</td>
</tr>
<tr>
<td>Other parents</td>
<td>&quot;</td>
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<td>Books</td>
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<td>Friends</td>
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<td>&quot;</td>
</tr>
<tr>
<td>Family</td>
<td>&quot;</td>
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</tr>
</tbody>
</table>
119. Has the doctor discussed the question of having more children with you?

120. Have you discussed this with anyone else?
   (Prompt if necessary - husband)
   a. (If YES) With whom?

121. Do you think having N has changed your feelings about having more children in any way?
   a. Why is that?

MEDICAL SUPERVISION

125. If you want help or advice about coeliac disease, who would you go to? G.P./Specialist/Other (specify)

126. How often do you consult your family doctor about your child's coeliac disease?
   more than once a month once every two months once every 6 months or longer never

127. Would you say your own family doctor has been a lot of help to you?
   a. Why is that?
   b. Does your G.P. really understand N's illness?

128. How often do you attend the clinic?
   more than once a month once every two months once every 6 months or longer

129. Has this always been so?
   a. (If NO) Specify

130. Do you always see the same doctor in the clinic?
   a. (If NO) Do you find this confusing?

131. How long are you normally away from home when you go to the clinic? (Door to door)
132. How long do you usually wait before you see the doctor?

133. How long do you spend with the doctor?

134. Would you like to spend longer talking to him?

135. Do you feel you can tell him all your worries?

136. Do you feel that he really understands the child?

137. Do you feel he can really help you with treatment?

138. Can you always get in touch with the doctor when you want?

139. Do you like the way in which the clinic is run?

140. Do you like meeting mothers of other coeliac children in the clinic?

141. Do you think N likes meeting the other coeliac children?

142. Have you ever felt angry towards the doctors in the clinic?

143. Would you say the clinic doctor has been a lot of help to you?

144. Does your family doctor always know what the clinic doctor has said about N's progress?
145. Have you had any problems concerning N's treatment because of confusion or lack of agreement between the clinic doctor or the G.P.?

a. (If YES) Could you tell me about them?........................................

146. Does your husband ever take N to the clinic without you?

a. (If YES) How often? Usually/Often/Seldom

147. Does he ever go with you?

a. (If YES) How often? Usually/Often/Seldom

148. Would you change the clinic arrangements in any way to improve them?

a. (If YES) How?.................................................................

149. How do you feel about being asked to cooperate in research projects organised by the clinic? (Prompt - do you feel they are an intrusion or are you glad to help?)

150. Have you ever come in contact with the social worker in the hospital?

a. (If YES) For what reason?....................................................

b. (If YES) Was she able to help you?

TREATMENT

151. At what age was the diet begun?...........................................

152. How did N first react to it?....................................................

153. What have you told him/her about it?....................................

154. Will N stick to the diet, even if you are not there to supervise?

a. (If YES) From what age was N reliable?................................

b. (If NO) What are the problems?...........................................
155. Has N ever protested against his diet?
   a. (If YES) At what age?.................................
   b. What do you think was the reason for his protest?.................................

156. Has N ever been off his diet since it was first begun?
   (If YES) When was this?.................................

   For what reason?.................................

   For how long was he off the diet then?...........

157. Did you notice any changes in N while he was off his diet?
   (If YES) What were these?
   What happened when the gluten-free diet was resumed?.................................

158. What do you find most difficult to cope with about N's diet?.................................

159. Have you had any other difficulties with it?
   (If YES) What are these?.................................

160. Has N had any other treatments prescribed as a result of his coeliac disease?
   a. (If YES) What was this?.................................
   b. How did N react to it?.................................
   c. At what age was he then?.................................
   d. Were you able to tell him anything about it?
   e. (If YES) What did you say?.................................
16. (If YES to Q.160)

161. Did he ever protest against these other treatments?
   (If YES) At what age?.............................................
   For what reason, do you think?..............................
   .................................................................
   (If YES to Q.160)

162. Did you have any difficulty with these treatments?
   (If YES) What was the problem?..............................
   .................................................................

163. Can anyone else, besides yourself, cope with N’s diet?
   (If YES) Other parent  YES  NO
   Patient’s sibling  YES  NO
   Relatives  YES  NO
   Friends  YES  NO
   Babysitter  YES  NO
   School  YES  NO

164. Would they be reliable or would you worry in case they gave N something he should not have?...........
   .................................................................
   a. (If not reliable) What seems to be the problem?.....
   .................................................................

165. Does it take extra time to prepare special food for N?
   a. (If YES) About how much time would you say is involved?...
   .................................................................

166. Do you resent spending so much of your time in this way?
   a. Can you tell me how you feel about this?..............
   .................................................................

167. Can you trust your own judgment in caring for N
   (If NO) What are the problems?.........................
   .................................................................
HOSPITALISATION

200. Has the child even been hospitalised for coeliac disease
    (If NO) Omit questions 200 a - 208 inclusive
    a. (If YES) At what ages?..............
    b. For what length of time?...........

201. (If YES) Were you very worried by this?........
    a. Why was this?..........................

202. (If YES) Was it possible to prepare the child in any way for the hospitalisation?
    a. (If YES) What was he told?.......... 
    b. By whom?............................
    c. Was it possible for you to stay with N in hospital?
    d. (If NO) How often did you visit N?

Daily More than Less than
1 a week 1 a week

203. How did your child respond to hospitalisation? (Specify)

204. In hospital did he tend to:

Cry excessively
Cling to you
Withdraw from you
Refuse to speak to you
Become very passive and listless
Become very angry with you
Become very angry with brothers and sisters
Suck his thumb
Rock or bang his head on the bed
205. (If YES to any of these ask 'What did you do about _______ ' at the end of series).

206. After he came home did he become extra demanding?
   a. (If YES) What did you do about this?..........................

207. Did he show any other changes in behaviour?
   a. (If YES) Specify.............................................
   b. What did you do about this?..............................

208. If you could alter the hospital arrangements in any way to benefit N, how would you do this?

209. Has your child had any other illnesses or hospitalisations?
   a. (If YES) Specify.............................................
   b. At what age?.................................................
   c. How long did he spend in hospital/bed?..................

210. (If applicable) Were you able to prepare him in any way for these hospitalisations?
   a. How did he respond to them?..............................

211. Have you ever been able to discuss any of the hospital procedure with him afterwards?

212. What do you think he disliked most about hospital – specify

213. Was there anything he specially liked about hospital?
   a. (If YES) Specify.............................................

COMMUNICATION

214. If you have a problem or are worried about N, do you find you can talk it over with:

   Spouse
   Relative
   Friend
   G.P.
   Clinic doctor

   1  2
   YES NO
   YES NO
   YES NO
   YES NO
   YES NO
### Clergyman

- **Social Worker**
- **Other (specify)**

#### a. (If YES to spouse) Can you and your husband talk about everything together?

#### b. (If NO) What can you not talk about with your husband?

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#### 215. Can you talk about most things with N?

#### a. (If NO) Why is that?

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#### 216. Can you talk naturally about his illness?

#### a. (If NO to any of these) Why can you not talk about ___________?

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#### 220. Can N talk naturally about his illness?

#### a. (If NO) Why do you think that is?

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#### b. (If YES) Does he talk to you?

- Does he talk to his daddy?
- Does he talk to his brothers/sisters?
- Does he talk to your family?
- Does he talk to friends?

#### 221. Does he tell you if he is in pain?

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#### 222. Does he tell you if he is sad?

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#### 223. Does he tell you if he is worried?

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#### 224. At what age did N become aware that he had an illness which he will always have?

- **Who informed him?**
- **How did he react?**
225. At what age did he learn the name of the illness?...........
   a. Who informed him?........................................
   b. How did he react?........................................

226. Does he know he was born with it?
   a. (If YES) At what age was he told?......................
   b. By whom?.................................................

228. Does he know how coeliac disease affects the workings of his body?
   a. (If YES) At what age was he told?......................
   b. By whom?.................................................

230. Has he been told anything else about the illness and its treatment?
   a. (If YES) What was that?................................
   b. At what age and by whom?.................................

232. Has he asked any questions about coeliac disease or the diet?
   (If YES) What were these?................................
       .................................................................
   a. What did you tell him when he asked this?...........
       .................................................................

233. Do you think it will/find it easy or difficult to answer her questions?
   a. Can you tell me more about how you feel?.............
       .................................................................
### Child's Reactions to Illness

#### 234. Has N ever shown alarm at how coeliac disease might affect him in the future?
- (If YES) Was this: considerable/moderate slight
- At what age?..............................
- Did you talk this over with him?
- (If YES) What did you say?....................
- How does he feel now?........................

#### 235. Has N ever seemed pleased at getting special attention?
- (If YES) At what age?..........................
- Did you talk about this with him?
- (If YES) What did you say?....................
- How does he feel now?........................

#### 236. Has N ever paid much attention to his physical sensations and symptoms?
- (If YES) Was this: considerable/moderate slight
- At what age?..............................
- Did you talk this over with him?
- (If YES) What did you say?....................
- How does he feel now?........................

#### 237. Has N ever felt self-conscious or worried about the reactions of others?
- (If YES) Was this: considerable/moderate slight
- At what age?..............................
- Did you talk this over with him?
- (If YES) What did you say?....................
- How does he feel now?........................

#### 238. Has N ever felt frightened, resentful or sad that he was different from others?

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</table>
a. (IF YES) Specify which.................................

b. (IF YES) Was this: considerable/moderate/slight

c. At what age?...........................................

d. Did you talk this over with him?

e. (IF YES) What did you say?..........................

f. How does he feel now?..............................

239. Has N ever been worried about his size or shape?

a. (IF YES) Was this: considerable/moderate/slight

b. At what age?...........................................

c. Did you talk this over with him?

d. (IF YES) What did you say?..........................

e. How does he feel now?..............................

240. Has N shown any other reactions to the illness not already mentioned?

a. (IF YES) At what age?.................................

b. What were these?....................................

c. How did you cope with these?.....................

241. Have there been periods when N has shown increased worry about his illness?

a. (IF YES) At what ages have these periods occurred?

b. Can you explain his increased worry in any way? (Prompt, for example, because his symptoms were worse at this time or because he was worried by something else, e.g., school problems)

242. When N is worried or upset about experiences in his life (tests in school, new baby, etc.) do any of his symptoms recur?

a. (IF YES) Can you tell me more about this?

243. Have there been periods when you have been particularly worried about N's emotional adjustment to his illness?
a. (If YES) Could you tell me about this? .................................................................

246. How does N feel about passing foul stools? .........................................................

247. When N is hungry what does he do? .................................................................

248. When N has a pain in his tummy what does he do? ...........................................

249. Does N suffer from prolapse of rectum?
   a. (If YES) How does he react to this? .................................................................

250. Does N turn to anyone for comfort when he is worried?
   a. (If YES) Who? ...................................................................................
   b. (If NO) Why is that do you think? .................................................................

251. Will N come to you for affection?
   a. Will he go to his daddy for affection?
   b. (If NO to either) Why is that? ...........................................................................

PARENTS REACTION TO, AND EXPECTATIONS FOR, CHILD WITH ILLNESS

252. We are interested in understanding the ways in which a child's coeliac disease may influence the way in which his parents take care of him. It may be that parents handle the child with coeliac disease differently from their other children - would you say this was true? 
   a. (If YES) Why is that do you think? .................................................................

253. Do you think you/expect less from him in the way of personal responsibility for clothing, cleanliness or neatness?
   a. (If YES) Is this: Much less/Moderately less/only a little less (Circle)

254. Would you say that you/expect less from him in the way of responsibility for household chores?
   a. (If YES) Is this: Much less/moderately less/very little less (Circle)
Will you

255. Would you say that you/expect less from him in the way of school achievement?

a. (If YES) Is this: Much less/only a little less (Circle)

b. (If YES) Is this because you feel you have to protect him?

c. Can you explain?

d. (If NO) Is this because you feel you have to push him to compensate for the illness?

e. Can you explain?

256. Would you say that you/expect less of him in his relationships with other children?

a. (If YES) Is this: Much less/only a little less (Circle)

257. Would you say that you/permit him less independence in making his own decisions?

a. (If YES) Is this: Much less/only a little less will

258. Would you say that you/permit him less independence in joining in activities away from home?

a. (If YES) Is this: Much less/only a little less will be

259. Would you say that you/are more cautious about permitting him to join in physical activities?

a. (If YES) Is this: Much less/only a little less

260. Would you say that you are less likely to punish him?

a. (If YES) Is this: Much less/only a little less

261. When he is naughty, how do you punish him? (Unless mentioned, prompt)

262. Do you ever smack him?

263. Do you ever send him to bed or put him in his room?

264. Do you ever deprive him of something he likes, e.g. Television, comics, sweets, pocket money?

265. Do you ever say you won't love him if he is bad?

266. Do you ever say you'll send him away if he is bad?

267. Do you ever threaten him with somebody else, e.g. daddy, doctor, teacher?
268. Do you experience any worry or guilt after punishing him?
   a. (If YES) Why is that?...........................................

269. On the whole, are you happy about the way you handle N's behaviour or do you sometimes find yourself doing things you really don't approve of?

270. Do you agree with your husband about this or is he a lot more strict or less strict that you are?

271. Do you and your husband always agree about how N should be brought up generally or do you feel differently about some things?

272. Apart from treatment or going to the clinic, does your husband help with N at all?
   a. (If YES) How?..................................................

273. Does he help with the other children?
   a. (If NO to either) Is that because he doesn't want to or because you don't want him to?

274. Is N treated in any special way by your mother and father?
   a. (If YES) Tell me about it?.................................
   b. (If YES) Is this due to his illness?

275. Is N treated in any special way by your husband's mother or father?
   a. (If YES) Tell me about it?.................................
   b. (If YES) Is this due to his illness?

276. Is N treated in any special way by family friends or other relatives?
   a. (If YES) Tell me about it?.................................
   b. Is this due to his illness?
Do you feel that the attitudes of your other children towards the child with coeliac disease have been influenced by the coeliac disease in any way? Perhaps we could consider each child in turn:

**TABLE - ELDEST 1st**

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<th>Very Not at all</th>
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<td>Does..........give in more easily to N?</td>
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<td>b.</td>
<td>Is..........less aggressive than otherwise?</td>
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<td>c.</td>
<td>Does..........feel protective to N?</td>
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<td>d.</td>
<td>Does..........feel responsible for N's wellbeing?</td>
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<td>e.</td>
<td>Does..........feel jealous of attention given to N?</td>
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<td>f.</td>
<td>Does..........feel worried about N's illness?</td>
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<td>g.</td>
<td>Does..........ever talk to N about his illness?</td>
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<td>h.</td>
<td>What does..........say about it to him</td>
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**TABLE - 2nd ELDEST**

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<td>a.</td>
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<td>h. What does. . . . . . say about it to him?</td>
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<td>b. Is. . . . . . . less aggressive than otherwise?</td>
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<td>c. Does. . . . . . . feel protective to N?</td>
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278. Do you think that when there is one child in the family who needs extra attention the others feel left out? Do you find this?

a. (If YES) What do you do about this?...............

279. Have you ever explained to the other children why it is necessary for N to have a special diet

a. (If NO ) Why is this?..........................
GENERAL DEVELOPMENTAL HISTORY

280. I have already asked you a lot of questions about N's illness and treatment and your reaction to the illness, but may I now ask you about his general development.

281. Where was he born? Homé/Hospital

282. What did he weigh? ..............

283. Did you have any complications in labour?
   a. (If YES) Specify........................

284. How long did your labour last?..............

285. Was the baby full term?
   a. (If NO) Specify........................

286. Were there any complications during pregnancy?
   a. (If YES) Specify........................

287. Were you at all emotionally upset during your pregnancy?
   a. (If YES) Specify........................

288. How did your husband feel about the pregnancy - was he pleased or displeased?

289. Had you sustained any miscarriages or lost any babies before this pregnancy?
   a. (If YES) Specify........................

290. Did you know about coeliac disease at this stage?

291. Did you expect N might be a coeliac child?

292. Did you lose anyone close to you during pregnancy?
   a. (If YES) Specify........................

293. Have you lost anyone close to you since then?
   a. (If YES) Specify........................

294. Did you move house during pregnancy?
   a. (If YES) Specify: Why, how many times, etc.
295. Have you moved house since?  
   a. (If YES) Elaborate.................................

296. Was your husband in full employment during this pregnancy?  
   a. (If NO ) Specify.................................

**FEEDING**

297. How did you feed N? Breast/Bottle/Both  
   (Elaborate if necessary)

298. Did you feed him at a fixed time or when he seemed hungry?  
   Fixed/Hungry/Both

299. At what age did you begin to wean N from the bottle?.....

300. At what age was weaning complete? During day.............
   At night.............

301. During the first 3 months of life did N have any feeding problems?  
   a. (If YES) What were these?........................

302. Did this upset you?  

303. What did you do?.................................

304. Did he seem to gain weight satisfactorily during the first 3 months of life?  
   a. (If NO) What did you feel was the reason?..............

305. Did this upset you?  

306. What did you do about it?..........................

307. During the next 9 months of life - that is up to a year did N have feeding problems?  

308. What were these?.................................

309. Did this upset you?  

310. What did you do?.................................

311. During the 1st year of life did he gain weight satisfactorily?
a. (If NO) What did you feel was the reason?

312. Did this upset you?

313. What did you do about it?

314. During the 1st year how did you find N generally?

315. How would you describe him as a baby?

316. Have there been periods after the 1st year when you have been worried about N's eating?
   a. (If YES) Give ages and describe.

TOILET TRAINING

317. At what age did you begin sitting N on a potty for toilet or bowel movements?

318. At what age did he begin going to the toilet on his own?

319. Was training: Easy/difficult/stormy (Circle one)

320. At present do you check N's bowel motion before it is flushed away?

321. At what age was N dry all day? all night?

322. After N was toilet trained, have there ever been periods when:
   a. he wet during the daytime (give age)
   b. he wet the bed? (give age)
   c. he soiled himself during the day? (give age)
   d. he soiled himself at night? (give age)
   e. (If YES to any of above) Was there any reason for this?
   f. What did you do about it?

323. Has the odour of N's bowel movements ever been a problem to you or N?
   a. (If YES) In what way?

324. (Prompt) Has he ever experienced any problems in school because of it?
325. What have you done about this?.................................

326. Do you have to help N with toileting during the night?
   a. (If YES) How often?........................................

GENERAL DEVELOPMENT

327. At what age did N:
   sit alone?.........................
   walk alone?......................
   use words to name objects?......
   put words together into simple sentences?.........

GENERAL WELLBEING

328. During the first five years of his life how did you find N generally?

329. Did he have any problems in his early days (1-5) not directly associated with the illness?
   a. (If YES) Specify...........................................

330. How would you describe him at this stage?..........................

331. Does he have any problems now not directly associated with the illness?
   a. (If YES) Specify...........................................

332. How is his appetite now? Good/Moderate/Poor
   a. Does N ever experience any pain
   b. How often is this?.................................
   c. What do you do about it?......................

333. Is he generally happy?
   a. (If NO ) Why is that?.................................

334. What do you do about it?..................................

SLEEP

335. At what age did N begin to sleep through the night regularly?

336. Has N ever had any problems connected with sleep or getting to sleep?

337. (Prompt unless specified) Has he ever taken more than 1/2 hour to fall asleep?

338. Has he ever seemed fearful at bed time?
339. Has he ever woken up regularly during the night?
340. Has he ever had nightmares?
341. (If YES) to any of above) How old was he at the time?........
342. How often did this happen?.....................................
343. Were his coeliac disease symptoms worse at these times? 1 2 YES NO
344. What did you do to get over it?..................................
345. Do you ever get up during the night to make sure N is alright? 1 2 YES NO
   a. How often do you do this: night once a week once a month
346. What do you do if you find him awake?..........
347. Do any of your other children ever get up in the night to make sure N is alright? 1 2 YES NO
   a. How often do they do this: night once a week once a month
348. What do they do if they find him awake?..........
349. Has N ever wanted to sleep with you in your bed? 1 2 YES NO
   a. How often: night once a week once a month

FEARS
352. All children are frightened or worried by something from time to time. Can you tell me what N is frightened by?
353. Has this always been so?
   a. (If NO) When did it begin?..................................
354. Do you associate this with anything special?
   a. (If YES) Specify.............................................
355. How would you describe N? very moderately showing very fearful fearful little fear

PLAY
356. What is N's favourite type of play?..................
357. Does he do this alone?

358. Has he always liked to play this way?

359. Does he like to play at home or away?  
   a. (If 'away') Where does he go?
   b. With whom?

360. Do you encourage him to bring his friends into the house?
   a. (If NO) Why is that?

361. Do you allow the other children to bring their friends home?
   a. (If NO) Why is that?

362. What do you do if N gets into a disagreement or quarrel?

363. In general do you find it possible to leave N to settle his own differences at this age?
   a. (If NO) Why is that?

364. Suppose N complains to you of another child, what do you do?

365. Does he ever hit another child back?

366. Do you encourage him to stick up for himself in this sort of way?
   a. (If NO) Why is that?

**SPORT**

367. Does N engage in any sports?

368. What are these?

369. Why did he decide to take them up?

370. Do they help him in any way?

371. How is this?

372. What do they cost? (specify exactly)

373. How do you pay for them?

374. Does this cause you any financial hardship?
SCHOOL EXPERIENCE

375. At what age did N first go to school?

376. Did he have any problems settling in?
   a. (If YES) Can you tell me about them?

377. Has he ever had any problems in school since then?
   (Unless mentioned prompt)

378. Has he ever seemed clinging or worried about leaving you?

379. Has he ever felt sick before leaving for school?

380. Has he ever dawdled or invented reasons to stay away?

381. Has he ever complained about the other children?

382. Has he ever complained that the work was too hard?
   a. (If YES to any of above) Can you tell me more about?
   b. At what age was this?
   c. What do you think were the reasons for this?
   d. What did you do about it?

383. Have the teachers ever complained that N disturbed his classmates or was restless and daydreamed in class?

384. Has N any friends at school?
   a. (If NO) Why is that do you think?

385. Has N ever had any teachers he specially liked?
   a. (If YES) Was there any special reason for his liking?

386. Do you think N differs from (your) other children in his approach to school?
   a. (If YES) Why is this do you think?

387. How many days is he normally absent from school in any one term?

388. What causes these absences?
389. Is there any difference between winter and summer in his attendance?
   a. (If YES) Why?.................................

390. Do you think he worries about missing school?
   a. (If YES) What do you do about it?..............

391. Are you apprehensive about his catching other children's germs?
   a. (If YES) Do you think this encourages you to keep him at home sometimes?

ATTITUDE OF TEACHERS TO CHILD

393. Have any of your child's teachers worried unduly about having a child with coeliac disease in class?
   a. (If YES) How many?..............................
      b. For what reason?...............................

394. Have any of your child's teachers expected less from him because of the coeliac disease, do you think?
   a. (If YES) How many?..............................
      b. At what ages?.................................

395. Have any of your child's teachers given him more attention than other children?
   a. (If YES) How many?..............................
      b. At what ages?.................................
      c. Why was this?.................................

396. Have any of your child's teachers picked on him?
   a. (If YES) How often? Frequently/moderately/very little
      b. At what ages?.................................
      c. For what reason?..............................

397. Have any of your child's teachers been bothered by his symptoms?
   a. (If YES) How often? Frequently/moderately/very little
      b. At what ages?.................................
      c. What specially worried them?....................
MOTHER'S OPINION OF HANDICAP

398. Talking generally now - what do you feel is N's greatest handicap from his point of view?

399. And from your point of view - what is it about him that you find hardest to cope with?

400. Have you any suggestions to make that might be helpful to other mothers of coeliac children - either practical suggestions for looking after their children, or how you manage to face this and come to terms with it?

401. What or who do you think has most helped N to come to terms with his illness?
   a. What or who has most helped you to come to terms with his illness?

402. And what about the future - do you ever try to look ahead or make plans for N, or do you face each day as it comes?

403. (Probe if necessary) Have you any ideas at all about N's future?

404. Does N ever talk about his own future?

405. (Probe if necessary) Has he given you any idea of his hopes or plans for the future?

406. What do you think is the right attitude for a parent to take towards a coeliac child?

407. (If any services already requested, e.g. more information, etc. note these - then ask) Is there anything else that the clinic doctor could help you with?
B. FOR MOTHERS AND FATHERS

The interview schedules prepared for use with mothers and fathers individually, in the study of parents of C.F. children, were also employed in the control study. Since the same matters were at issue, the main amendments which were required to make the original schedules relevant for this purpose were of the order of substituting the words "coeliac disease" for "cystic fibrosis" throughout. It was not, therefore, deemed necessary to reproduce these questionnaires in their amended form in this part of the Appendix. The interested reader is referred to Parts II and III of this Appendix from which the form of the interview schedules used in the study of the mothers and fathers of children with coeliac disease, may be appreciated.
C. FOR CHILDREN

Once again the interviews conducted with the coeliac children followed a schedule very similar to that used in the original C.F. study. Some amendments were necessary in view of the different nature of the symptoms of these children and of the treatment thereby prescribed and the interview schedule which was used to guide these interviews is presented here in its amended form.

Although it was in any case, much less easy to be rigidly systematic in the interviews with children, the operative principle of the compilation of control questionnaires, suggested in Appendix V.A., was also employed here. That is, gaps in the numbering of items in the control schedule were tolerated in order to maximise the opportunities for cross-reference of responses to any given question, appearing in interviews with both groups.
THE INTERVIEW SCHEDULE FOR THE CHILD WITH COELIAC DISEASE

deals with the subsections listed below. If a clinical interview
is preferred, care should be taken to elicit information about
all these topics.

1. **School** - school worries, school friends, fears of missing school
   and school work.

2. **Play** - companions, location of play, worries in connection with
   play companions.

3. **Other children's responses to child's coeliac disease** - questions
   relating to it, worries caused by questions.

4. **Ideal Person** - who would the child like to be and why.

5. **Teachers** - reactions to teachers, teachers reaction to child.

6. **Communication** - in whom does the child confide when he is worried.

7. **Family** - mother, father, sibs, likes and dislikes.

8. **Clinic** - response to other children there, mothers of
   children, doctor.

9. **Hospital** - length of stay, type of treatment, fears there and
   fears on returning home, preparation for, dreams of.

10. **Illness** - does the child know name, what does he know of nature
    of illness, how does he feel about treatment - now and in the
    future.

11. **Feelings** - sadness, anger, worry, happiness - what causes them.

12. **Fears** - of what.

13. **Fantasies** - nice dreams, 3 magic wishes, first memories, a
    fantasy day, the future.
**INTERVIEW SCHEDULE FOR THE CHILD WITH COELIAC DISEASE**

(Questions may need slight rephrasing according to age, but in most instances - except for the first section - should be attempted with all children over 3-6 years)

Now I want to talk about you.

<table>
<thead>
<tr>
<th>Identification number</th>
<th>Sex</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2</td>
</tr>
<tr>
<td></td>
<td>YES NO</td>
</tr>
</tbody>
</table>

1. Do you go to school?

2. Do you like going to school?
   a. Why is that?.............................

(Omit 3. Is there anything about school that you really complete dislike? section if child a. (If YES) Tell me about it?.............................)

4. Do you ever get scared or worried when you are there?
   a. (If YES) What about?..........................

5. Have you got any friends in school?
   a. (If YES) What do you do with them?.............................
   b. (If NO) Why is that, do you think?.............................

6. Do you ever bring any children home to play?
   a. (If NO) Why is that?.............................
   b. (If NO) Do you mind about that?.............................

7. Do you ever go to play in other children's homes?
   a. (If NO) Why is that?.............................
   b. (If NO) Do you mind about that?

8. Do you ever feel different from other children in any way?
   a. (If YES) Tell me about it.............................
   b. (If YES) How do you feel about this?.............................

9. Do other children ever talk or ask questions about your special diet?
   a. (If YES) What do they say or ask?.............................
   b. (If YES) Do you mind them saying/asking these things?
   c. Tell me how do you feel about it?.............................
10. What do you like most about the other children you meet in school?

.................................................................................................................................

a. Why is this?..............................................................................................................

11. What do you dislike most about other children?..............................................

.................................................................................................................................

a. Why is this?..............................................................................................................

12. If you weren't you, but could be someone else, who would you be?

.................................................................................................................................

a. Tell me about him?...................................................................................................

b. Why do you want to be like him?............................................................................

(For Primary Children only)

13. Tell me about your teacher - what is he called?............................................

.................................................................................................................................

a. Do you like him?

b. Why is that?............................................................................................................

14. Tell me about the (other) teachers you've had in school - have you ever liked any of them?

.................................................................................................................................

a. Why was that?...........................................................................................................

15. Do you ever think any of them have been specially kind to you when you're not well?

.................................................................................................................................

a. Why is that?............................................................................................................

16. Do you ever think any of them are specially unkind to you when you're not well?

.................................................................................................................................

a. Why is that?............................................................................................................

b. (If YES) Does that make you upset?

c. (If YES) Tell me how you feel?..............................................................................

d. (If YES) Do you do anything about it?.................................................................

17. When you miss school does this worry you?

.................................................................................................................................

a. Tell me about how you feel?..................................................................................
18. Do you ever try specially hard to make up for the work you've missed?
   a. (If YES) Tell me what you do?.........................

19. Do you stay for school dinner?
   a. (If YES) Do you have something different to eat from the other girls and boys?
   b. (If YES) Does this embarrass/worry you at all?
   c. (If YES) What do you do about it?.........................

20. Do any (other) things worry you at school, for example going to the toilet?
   a. (If YES) Tell me about them?..............................
   b. (If YES) What do you do about them?.........................

COMMUNICATION
   (If has school worries)

21. Have you ever talked these worries over with anyone?
   a. (If talked) What did they say?..............................
   b. (If talked) Did this help at all?.........................
   c. (If talked) Why was that?.................................

22. If you are worried by anything (else) can you talk this over with anyone?
   a. (If YES) With whom?.................................
   b. (If YES) Does that help?...
   c. (If NO ) Why is that?.................................

23. Do you ever keep secrets from other people?
   a. (If YES) From whom?.................................
   b. (If YES) What sort of secrets?...........................

FAMILY

24. Tell me about your mummy - what is she like?..............

25. Does she ever do anything good for you
   a. (If YES) What is that?.................................

26. Does she ever annoy you in any way?
   a. (If YES) How is that?.................................

27. Tell me about your daddy - what is he like?................
28. Does he ever do anything good for you?
   a. (If YES) What is that?..............................

29. Does he ever annoy you in any way?
   a. (If YES) How is that?..............................

30. Have you any brothers or sisters?
   a. How many?.................................
   b. (If YES) What are/they called?............... 
   c. (If YES) Tell me about him/them?..............

FOR CHILDREN WITH MORE THAN 1 SIB.

31. Which do you like best?..............................
   a. Why is that?.................................

32. Who do you like least?..............................
   a. Why is that?.................................

FOR CHILDREN WITH 1 SIB.

33. Do you like him?.................................
   a. Why?...........................................

CLINIC

34. Do you like going to the clinic?
   a. Why is that?.................................

35. What do you like least about going to the clinic?

36. Do you ever talk to the other boys or girls in the clinic?
   a. (If YES) What about?.........................

37. Do you like meeting them or do they annoy you?

38. Does your mother ever talk to the other mothers at the clinic?
   a. (If YES) What do they talk about?...........
   b. (If YES) How do you feel about this?

39. Tell me about the doctor who sees you in the clinic - what is he like?
40. Could you tell him about anything that worried you?
   a. (If NO) Why is that?.................................

HOSPITAL

41. Have you ever had to stay in hospital?
   a. (If YES) How many times?............................
   b. (If YES) How long did you stay there?..............
   c. (If YES) How old were you then?.....................

42. What did they do to you whilst you were there?
   a. Were you worried by this/any of these things?
      (if several procedures mentioned)
   b. What worried you most?
   c. Tell me about it?.................................

43. Before you went into hospital did anyone tell you what was going to happen?
   a. (If YES) Who was that?.................................
   b. (If YES) What did they say?...........................
   c. (If YES) Did this help at all when you were in hospital?
   d. Why was that?.................................

44. Tell me what it was like when you got home from hospital? (Prompt – Did anything worry you when you came home?)

45. Have you ever had any dreams about hospital since then?
   a. (If YES) Tell me about them?.........................

ILLNESS

46. Can you tell me why you have to go to the clinic?...........
   a. (Unless mentioned) Do you know what your sickness is called?

   YES NO

   1 2
47. What do you think is the matter with your tummy?........

48. Does this ever worry you?
   a. Why is that?

49. What are the worst things about having coeliac disease/ having to have a special diet?
   a. Do these things ever make you feel sad or worried?
   b. Tell me how you feel?

50. Why do you think the special diet is necessary?

51. Do you ever have things which are not in your diet, just to see what will happen?
   a. Tell me about it? (if necessary, prompt, What do you have? When do you eat it? What happens then? Do you do that often?)

52. What do you think will happen when you have grown up, do you think you will still need to have your special diet then?
   a. How do you feel about that?

FEELINGS

56. Are you ever specially happy?
   a. (If YES) What about, tell me?
   b. (If NO) Why is that?

57. Are you ever very angry?
   a. (If YES) With whom or about what?

58. Are you ever very sad?
   a. (If YES) What about?
59. Are you ever very worried?
   a. (If YES) Tell me about it.

60. Could you talk about these things with anyone?
   a. (If YES) With whom?
   b. (If NO) Why is that?

PEARS

61. Are you ever really frightened by anything?
   a. What frightens you?
   b. (If alternatives given) Which is the most frightening?

(Unless already mentioned)
   c. Are you afraid of going to the clinic?
   d. Are you afraid of going into hospital?
   e. Are you afraid of nurses?
   f. Are you afraid of doctors?
   g. Are you afraid of being ill?
   h. Are you afraid of being hurt?
   i. Are you afraid of the dark?
   j. Are you afraid of missing school?
   k. Are you afraid of other children?
   l. Are you afraid of growing up?
   m. (If YES to any of these) Tell me why you're frightened of.
   n. (If several alternatives given) Which is most frightening to you?

FANTASIES

62. Do you ever have any really nice dreams?
   a. (If YES) Tell me about them?

63. If I could give you 3 magic wishes, what would you wish for?
64. Can you remember back to when you were very little, tell me what happened to you then?

(Prompt, if necessary. Tell me about the first things that happened to you)

65. If you had a day in which you were free to do anything you wanted to do, what would you do?

66. What would you like to be in the future?

67. Is there anything else you want to tell me about, which we haven't talked about so far?
APPENDIX VI - PUBLICATIONS

One paper was published, jointly by the four original contributors to this study, during the course of this study. It was prepared by the author and amended by Dr. W.M. McCrae to make it more suitable for publication in a medical journal. Drs. Burton and Dodge approved the contents prior to publication. This paper is reproduced here from The Lancet (1973) 2, 141 - 143.

CYSTIC FIBROSIS: PARENTS' RESPONSE TO THE GENETIC BASIS OF THE DISEASE

W. MORRICE McCRAE       ANN M CULL

Department of Child Life and Health,  
University of Edinburgh

LINDY BURTON             JOHN DODGE

Nuffield Department of Child Health,  
Queen's University of Belfast

SUMMARY

The parents of one hundred families (fifty in Scotland and fifty in Northern Ireland) affected by cystic fibrosis were interviewed. It was found that their understanding of the genetics of the disease was unsatisfactory. Poor education and low intellectual ability were factors, but the principal causes were psychological barriers to understanding in the parents
and inadequate and badly timed instruction by the diagnosing physician. Lack of understanding contributed to the unhappiness of these families, in which the incidence of guilt, anxiety, and depression was high, especially among the mothers. In both countries over 70% of the parents wished to have no further children following the diagnosis of cystic fibrosis in one of their children. In Ireland the principal reason was fear of conceiving a further affected child. This was the reason given by only 36% of couples in Scotland, where the size of family already reached was an equally important consideration in deciding to limit the family. In those families in which a decision had been made to have no further children, the incidence of unintended pregnancies was high. Although only one of these pregnancies resulted in a child suffering from cystic fibrosis, more active steps should be taken to provide adequate family-planning advice for the parents of cystic fibrosis patients.

INTRODUCTION

The parents of an infant with cystic fibrosis need to understand how the disease is inherited and to weigh the risks involved in undertaking further pregnancies. We have sought to discover (a) the parents' intellectual awareness of the genetics of the disease, (b) their emotional reaction to this information, and (c) their behavioural response.

SUBJECTS AND METHODS

Information was gathered from one hundred families visited
in their homes; fifty of these families lived in the East of Scotland and fifty in Northern Ireland. The parents interviewed were ninety-nine mothers and eighty-seven fathers (three of whom were stepfathers). Social class was recorded with reference to the father’s occupation. A limited assessment of parental intelligence was made by means of a brief questionary. The groups studied in Scotland and in Ireland were found to be very similar: skilled manual workers predominated in both groups.

In the Northern Ireland group the average family size was 4.0 children, compared with 2.9 children in the Scottish group; and in Ireland twenty-eight of the two hundred and two children born to families interviewed had died following illness recognised as being due to cystic fibrosis, compared with only three such deaths among one hundred and forty-nine children born to the families in Scotland. In Scotland a further ten children had died, but all in very early infancy, and cystic fibrosis was diagnosed either in retrospect or at the time of death. Family size and composition are shown in Table I.

<table>
<thead>
<tr>
<th>Group</th>
<th>Cystic fibrosis patients</th>
<th>Sibs</th>
<th>Total children</th>
<th>Average Family Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>58</td>
<td>78</td>
<td>149</td>
<td>2.9</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>55</td>
<td>111</td>
<td>202</td>
<td>4.0</td>
</tr>
</tbody>
</table>
In the survey the interval between the taking of decisions on limitation of family size and family recording of decisions varied from eight months to twelve years six months; and this long interval may have weakened the parents' recall of the events discussed.

RESULTS

COMPREHENSION

At the time of the survey the parents, with few exceptions, had some degree of comprehension that cystic fibrosis is an inherited disease. Nevertheless, the majority claimed that at the time they were informed of the diagnosis they were given no information about the genetic nature of the disease, or, alternatively, that the information given was inadequate (Table II).

Although all parents believed that their understanding of the genetic nature of the disease had improved since the time of the diagnosis, many reported that they would welcome further information and detailed discussion (Table III).

TABLE II - REPORT OF INSTRUCTION AT DIAGNOSIS

<table>
<thead>
<tr>
<th>Instruction</th>
<th>Scotland</th>
<th>N. Ireland</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers (N=49)</td>
<td>Fathers (N=44)</td>
</tr>
<tr>
<td>Not told C.F. inherited</td>
<td>12%</td>
<td>23%</td>
</tr>
<tr>
<td>Genetics not fully explained</td>
<td>39%</td>
<td>43%</td>
</tr>
</tbody>
</table>
TABLE III - PARENTS' WISH FOR FURTHER INFORMATION

<table>
<thead>
<tr>
<th>Wish</th>
<th>Scotland</th>
<th>N. Ireland</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers (N=49)</td>
<td>Fathers (N=44)</td>
</tr>
<tr>
<td></td>
<td>Mothers (N=50)</td>
<td>Fathers (N=43)</td>
</tr>
<tr>
<td>Did not wish more information</td>
<td>22%</td>
<td>32%</td>
</tr>
<tr>
<td></td>
<td>26%</td>
<td>40%</td>
</tr>
<tr>
<td>Wished more information</td>
<td>64%</td>
<td>59%</td>
</tr>
<tr>
<td></td>
<td>56%</td>
<td>35%</td>
</tr>
</tbody>
</table>

The parents' actual understanding of the genetic nature of the disease was gauged from the response to the question: What do you understand of the chances of your children's children having cystic fibrosis? Understanding was rated as excellent when the parents appreciated fully the nature of recessive inheritance, that their affected sons were probably sterile, that their affected daughters had an increased chance of bearing an affected child, and that their phenotypically well children could be carriers of cystic fibrosis. Moderate understanding was credited when some, but not all, of this information had been grasped. Understanding was rated as poor when the parents knew simply that their child's illness had been inherited and that there was some chance that any other child conceived in the future might also be affected. (Table IV).

TABLE IV - PARENTS' UNDERSTANDING OF INHERITANCE OF CYSTIC FIBROSIS

<table>
<thead>
<tr>
<th>Group</th>
<th>Excellent (N = 39)</th>
<th>Moderate (N = 79)</th>
<th>Poor (N = 71)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>22%</td>
<td>23%</td>
<td>55%</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>20%</td>
<td>60%</td>
<td>20%</td>
</tr>
</tbody>
</table>
Many of the Scottish parents qualified their answer by saying that they had no wish to look to the future in these terms.

Only about a third of all the parents in the sample had ever had family planning discussed with them by a doctor (Table V). In Scotland the likelihood of medical advice on this aspect was related to social class: family planning had been omitted from discussions with 64% of the families in social classes I and II, but with only 28% of the families in classes III-V. (Comparable figures are not available for Northern Ireland.)

In approximately half the cases where there had been no discussion of family planning with a doctor, there had been no discussion of this subject with anyone – not even between the spouses (Table VI). In Scotland discussion of this subject occurred in all but one of the families of the higher social classes (the exception being the case of a child with cystic fibrosis born as a very late baby; a further pregnancy was assumed to be impossible). In the homes of manual workers, if family planning was not discussed by the doctor it seemed unlikely to be discussed at all.

**TABLE V - NO MEDICAL EVIDENCE ON FAMILY PLANNING**

<table>
<thead>
<tr>
<th></th>
<th>Mother (N = 99)</th>
<th>Fathers (N = 87)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>36%</td>
<td>32%</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>34%</td>
<td>28%</td>
</tr>
</tbody>
</table>
**TABLE VI** - NO DISCUSSION OF FAMILY PLANNING WITH ANYONE
(EVEN SPOUSE)

<table>
<thead>
<tr>
<th>Group</th>
<th>Mothers (N = 99)</th>
<th>Fathers (N = 87)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>18%</td>
<td>16%</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>16%</td>
<td>16%</td>
</tr>
</tbody>
</table>

**TABLE VII** - BLAME ON SPOUSE

<table>
<thead>
<tr>
<th>Group</th>
<th>Mothers (N = 99)</th>
<th>Fathers (N = 87)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>4%</td>
<td>9%</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>10%</td>
<td>5%</td>
</tr>
</tbody>
</table>

**TABLE VIII** - PARENTAL FEELINGS OF GUILT

<table>
<thead>
<tr>
<th>Group</th>
<th>Mothers (N = 99)</th>
<th>Fathers (N = 87)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>40%</td>
<td>38%</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>36%</td>
<td>24%</td>
</tr>
</tbody>
</table>
EMOTIONAL REACTIONS

Blame - Parents were asked if they had ever experienced anger or resentment as the result of a mistaken belief that their child's condition had originated solely in the spouse's pedigree. Such blame was found to be unusual (Table VII).

Guilt - Many parents reported feelings of guilt or responsibility for their part in transmission of disease to their children (Table VIII).

TABLE IX - FAMILY PLANNING AFTER DIAGNOSIS OF CYSTIC FIBROSIS

<table>
<thead>
<tr>
<th>Intention</th>
<th>Scotland</th>
<th>N. Ireland</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family to be limited because of cystic fibrosis</td>
<td>36%</td>
<td>70%</td>
</tr>
<tr>
<td>Family to be limited because of family size</td>
<td>36%</td>
<td>8%</td>
</tr>
<tr>
<td>Further pregnancies intended</td>
<td>28%</td>
<td>16%</td>
</tr>
<tr>
<td>Ambivalent</td>
<td>0%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Depression - This was reportedly extremely common among the mothers of affected children, both in Scotland and in Ireland. 79% of the mothers described themselves as "run down or depressed" and 42% had felt the need to seek medical help because of this depression and were receiving anti-depressant drug therapy.

Continuing fear of further pregnancy - In Scotland 16% of the mothers reported that they were in continuing fear of
becoming pregnant because of the risk that a further child might be affected by cystic fibrosis. This fear persisted despite the use of adequate methods of contraception. In Ireland this fear was much more common, being reported by 44% of the mothers; of the twenty-two mothers in this state of anxiety, only thirteen were using adequate contraceptive techniques.

**Marital stress** - The majority of the couples interviewed reported that cystic fibrosis in the family had not affected the marriage adversely, and indeed many claimed that family ties had been strengthened by the need to cope with this difficulty. Nevertheless, in the fifty families studied in Scotland there had been one divorce and eight separations. In Ireland, perhaps owing to different attitudes, there were no divorces and only two separations, but five couples seemed to be completely lacking in any emotional or physical relationship. In all of these broken marriages cystic fibrosis was an important, but never the sole, factor.
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**TABLE X - OUTCOME FOLLOWING FAMILY-PLANNING DECISION**
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<table>
<thead>
<tr>
<th>Outcome</th>
<th>Scotland (36 families)</th>
<th>N. Ireland (39 families)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Families intending to have no further children:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sterilisations</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Vasectomies</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Accidental pregnancies ending:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miscarriage</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Termination</td>
<td>4</td>
<td>0*</td>
</tr>
<tr>
<td>At term</td>
<td>2</td>
<td>9‡</td>
</tr>
<tr>
<td><strong>Families intending to have further children:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of further children</td>
<td>21</td>
<td>5</td>
</tr>
<tr>
<td>No. of C.F.s</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*Two requests for termination were refused
‡One child affected by cystic fibrosis

### BEHAVIOURAL RESPONSE

Following the diagnosis of cystic fibrosis in the family, the majority of couples decided that they should have no further children (Table IX). In Ireland the diagnosis of cystic fibrosis was by far the most important reason for this decision. In Scotland family size was of equal importance, 36% of the couples having already decided that they had the desired number of children.
There were eighteen "accidental" pregnancies; four terminations of pregnancy were carried out in Scotland but none in Ireland. Of the eleven pregnancies going to term, only one resulted in the birth of a child affected by cystic fibrosis (Table X).

Twenty-seven of the couples in this study decided not to limit their families. A total of twenty-six other children were born to these families, of whom seven were subsequently diagnosed as having cystic fibrosis.

DISCUSSION

It must be assumed that some account of the genetics of the disease was given to the parents at the time of the original diagnosis; but clearly in many cases this explanation did not achieve the desired result. Emery et al have pointed out that one major obstacle in genetic counselling is lack of public knowledge of basic biology and genetics. In the present survey language problems clearly contributed to poor understanding. Parents of higher intelligence and those who had had more years of formal education were significantly more likely to understand genetic risks. Psychological defence mechanisms are a further barrier to comprehension. In Scotland a small number of mothers (4%) completely refused to accept cystic fibrosis as an inherited disease despite all evidence and argument; and by no means all the parents who realised that they did not fully understand the inheritance of the disease wished to seek or receive more information (Table II).
This survey suggests that the diagnosing physician often mishandled the initial interview with the parents when the diagnosis was explained. The name of the disease, an account of its likely course, and the ultimate prognosis along with a discussion of the genetics were often given at one single, brief interview. Not infrequently, this interview was with the mother alone, and this must account for the large number of fathers who claim that they were not initially told that cystic fibrosis is an inherited condition (Table II). The parents' lack of understanding becomes more understandable when it is recognised that the only explanation was so often provided when they were suffering from the extreme distress of learning of their child's poor ultimate prognosis.

Lack of full understanding of the inheritance of cystic fibrosis undoubtedly contributes to the parents unhappiness. Where, for example, it is believed that the affected child's condition originated solely in the spouse's pedigree, then feelings of anger and resentment may occur. This was observed in a few parents who, knowing that no such disease had ever occurred in their own families, assumed that the disease had been inherited from the spouse (Table IV). A feeling of guilt was much less evident among those parents who had a sound understanding of the genetics. Parents disclaiming feelings of guilt often attributed their outlook to physicians who, in their case, had spelled out explicitly that it was inappropriate for them to feel guilty.
In Scotland, only 36% of parents felt obliged to have fewer children than they had intended because of the risk of conceiving a further child affected by cystic fibrosis. The situation was different in Ireland, where the risk of cystic fibrosis was much more commonly the reason given for limiting family size. In part, this may be because Irish parents are less likely to limit their families for reasons other than inherited disease; but the difference between the two groups in their experience of mortality and morbidity from the disease (see Subjects and Methods) may have been a further factor. Experience of morbidity associated with the disease may influence parents more than knowledge of the likelihood of early death.

There was some suggestion that, when the original decision to limit family size because of cystic fibrosis was made easily and without conflict, the parents maintained this position. Where, however, the parents originally accepted advice and thus were more likely to view the situation in terms of their own subsequent experience of the disease and to base further decisions on the observation of the burden which would be imposed on them by the birth of another cystic fibrosis child.

It was disappointing to find that the outcome of family planning did not always match the parents' original intention. The incidence of accidental contraception was high, indicating that better contraceptive advice is required. As a result of the experience of this survey, parents at the cystic fibrosis clinic in Edinburgh are now offered family planning advice, and a suitable appointment is arranged for the parents at a family planning clinic.