Factors Influencing Family Participation in a Longitudinal Study: Comparison of Pediatric and Healthy Samples

Magdalena Janus and Susan Goldberg
Hospital for Sick Children, Toronto

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Compared participation levels in a longitudinal study of parent-child relationships from infancy to 4 years in families of children with cystic fibrosis, congenital heart disease, and with no chronic illness. Demographic (parent's age, education) and child, parent, and family variables (medical status, family environment) were investigated for their predictive value of families' participation. 34% of families (71/209) were lost to the study at a later date. Families of children with cystic fibrosis were the least likely to be lost. Parents' age and/or education predicted participation in all groups. Families in both pediatric samples participated less when parental well-being was less optimal, and the level of mother-infant attachment organization was lower. Unlike demographic factors, family factors have differential impact on participation in families in pediatric and nonpediatric samples.

KEY WORDS: chronic illness; longitudinal study; severity of illness; attachment; family environment; participation; attrition.

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All correspondence should be sent to Magdalena Janus, Psychiatry Research, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario M5G 1X8, Canada.
Although longitudinal studies are time-consuming and expensive, many questions require prospective longitudinal data for definitive answers. A key element in the success of longitudinal studies is minimizing withdrawal as well as evaluating its effects when interpreting the data. Thus, it is important to know which participants do not complete studies and the reasons for their incomplete participation. Such information can also be valuable in developing strategies for increasing participation in subsequent longitudinal work. In fact, if it were possible to identify participants most likely to withdraw from a study before its completion, focused staff efforts might be directed toward increasing retention. The present paper analyzes data from a longitudinal study of the effects of early chronic illness on social development to identify factors which influence two types of participant loss: (a) leaving the study at some point prior to completion ("lost"); (b) continuing to completion with missing data for one or more assessment points. The participants were families of three groups of children identified in infancy: those diagnosed with cystic fibrosis, congenital heart disease, and a healthy comparison group.

Discontinuing participation between data collection points in longitudinal studies has been well documented (e.g., Cordray & Polk, 1983; Winefield, Tiggeman, & Winefield, 1991). With few exceptions (Kokes, Fremouw, & Strauss, 1977; Rambo, Scott, & Llorente, 1992), the impact of refusal and the potential resulting biased data has rarely been studied. It is common practice to compare retained and lost participants with respect to demographic characteristics. Demographic similarity can increase our confidence in generalizing longitudinal findings to the full sample. However, it does not guarantee similarity of retained and lost participants with respect to the measured outcomes. Cordray and Polk (1983) found that attrition was associated not only with social class and ethnicity but with deviant behavior which was the outcome measure of their study. Loss of participants with specific characteristics relevant to outcome variables is an important source of bias in longitudinal research (Green, Navratil, Loeber, & Lahey, 1994), yet systematic analyses of participant refusal and loss have been limited. In general, such studies have been more frequent for adults (Kokes et al., 1977; Rambo et al., 1992) and adolescents (Cordray & Polk, 1983; Green et al., 1994; Snow, Tebes, & Arthur, 1992; Winefield et al., 1991) than for infants and young children and their families. Demographic characteristics relevant to loss of participants are rarely reported (Woollett, White, & Lyon, 1982) and even less information is available regarding reasons for dropping out or withdrawal (Ashurst, de la Rocha, & Tobis, 1992). In the present paper we examine patterns of participation in relation to child, parent, and family characteristics in a 4-year longitudinal study of the impact of chronic illness on early social development. We studied four domains as potential contributors to the development of behavior problems: medical status, child temperament, family environment (e.g., parenting stress, life events), and parent–child relationships.

There was a conscious effort in the course of this research project to involve
fathers: Questionnaires were provided for both parents, communications were to both, appointments were scheduled on Saturdays and evenings if necessary, and each assessment contained a segment for father and child. Therefore, a unique contribution of our analyses includes information from fathers, comparison between mother and father involvement, as well as comparison of fathers in the families who were lost to the study with those who stayed.

Three major questions are addressed:
1. Why are some families lost in the course of a longitudinal study? Do their reasons differ according to the medical status of the target child?
2. Which demographic factors (socioeconomic status, ages of parents, size of family, birth order of the target child, etc.) predict the family’s “lost” status and level of participation in the study?
3. Which study measures in the four domains assessed at 1 year of target child’s age (medical status, child temperament, family environment, and mother–child relationship) predict the family’s further participation?

METHOD

Participants

A more detailed description of the study is provided elsewhere (Goldberg, Gotowiec, & Simmons, 1995). Three groups of families participated: those with (a) an infant diagnosed with cystic fibrosis (CF), (b) an infant diagnosed with congenital heart disease (CHD), and (c) a healthy infant (comparison). The first two groups were recruited from the appropriate clinics and wards at a major children’s hospital; the third group from volunteers in the offices of pediatricians and families approached in walk-in clinics.

Due to the relatively low incidence of CF, all available families were approached for participation. In the CHD group, four diagnoses were selected and all available families were approached. The sex of the target child, ages of parents, and socioeconomic status (SES) in those two groups were monitored, and families for the comparison group were selected to match those from the diagnosed groups. Since it appeared that parents in the CF and CHD groups were younger and less educated, extra efforts were made to target younger and working-class comparison families.

General Procedures

All families were recruited when the target child was under 1 year, interviewed, and informed that they would be asked to complete questionnaires and visit the laboratory for a yearly behavioral assessment with the child. The inclusion criteria required a two-parent family at the time of the recruitment, and
parents' ability to read and write in English. Two families withdrew because completion of questionnaires and communicating with the staff in English proved too demanding. Several couples subsequently separated, but most of the noncustodial parents (usually fathers) continued to participate.

Sample Maintenance Procedures

Each family was contacted by telephone close to the time of the target child's birthday for the yearly assessment. An appointment was scheduled, and questionnaires were sent. Appointments were confirmed the day before, and rescheduled if necessary. Families that did not show up without prior cancellation were called as soon as possible and rescheduled. Those who were contacted were rescheduled up to three times or 6 months after the expected assessment date. (At such an early age it was vital for the accuracy of measures to ensure that children were seen as close to the actual birthday as possible.) At the next assessment date they were recontacted when possible. The exception was families who missed the 1-year visit. Because the 1-year infant attachment assessment was pivotal to the study, those who did not participate in that assessment between 12–18 months were not pursued further.

Whenever possible, we maintained a second contact for each family. For the CF and CHD groups this was the clinic they regularly attend. For the comparison group, this was another family member. At each visit, the costs of parking were covered, and children received small gifts. In addition, an annual holiday letter with information on our progress with the study was mailed to all families.

If a parent indicated that s/he no longer wished to participate, a reason was requested and recorded. When the family could not be reached and no other explanation was available, the reason was recorded as “unknown.” Because we had access to clinic records for families in the pediatric samples, the reasons were more often known for those than for the families in the comparison sample.

Measures

A family was defined as “lost” if parents agreed to participate, came to the initial interview, but did not come for the 4-year visit. Fifteen (7.2%) of the families were lost before completing the first-year assessment, and 59 (28.2%) after the 1-year visit.

Reasons for Loss of Participation

Reasons for withdrawal were coded into one of 9 categories, comprising unknown, 4 situational (objective conditions preventing participation), and 4 personal (voluntary choices). Situational reasons were moving away from the
city, child diagnosed with an additional medical problem, lack of sufficient English to participate, and child's death. Personal reasons included lack of interest, too busy (usually happened when there was no further need for the child to be seen at the CF or CHD clinic every year), difficult to schedule, financial and/or family problems (including separation, divorce, and loss of employment leading to lack of means of transport).

**Participation Outcome**

At each child age (1, 2, 3, and 4), both parents were expected to come to the laboratory, and to complete questionnaires. A participation score was assigned to each parent at each age, based on the number of steps in the study each completed: 1 or 0 for coming (or not) to the laboratory visit; 0, 1, or 2 for not completing any, some, or all questionnaires, respectively. Thus, if a parent came to the laboratory visit and returned all questionnaires, a score of 3 was given for that year (1 for visit, 2 for questionnaires). A parent who came to the laboratory, but did not complete all the questionnaires, was given 2 (1 for visit, 1 for some questionnaires), and so forth. If a parent missed the assessment (no visit, no questionnaire), the score was 0. Since there was a maximum of 4 visits, each parent's score could range from 0 to 12, and the family could score from 0–24. The summary participation score including data from all 4 years was the outcome variable in regression analyses.

**Loss and Participation Predictors**

The following variables, collected at the time of recruitment, were investigated for their relation to family lost status: sex and birth order of the target child, parental age, education, and country of birth. The latter was included to measure acculturation: It was assumed that parents not born in Canada would have less social support available than those born in Canada, even if they immigrated from affluent Western and/or English-speaking countries. With the exception of maternal age, which was higher in the comparison group than the others, $F(2, 206) = 5.76, p < .05$, none of the above measures differed among the three groups.

Two types of predictors of participation were used in regression analyses. First, demographic measures, collected at recruitment, included mother's age and years of education, father's age and years of education, child's birth order, and...
and number of people in the household. Second, the child–parent study measures in four domains, assessed at 1 year of age were as follows:

Child's Medical Status. Severity of illness was assessed with a 10-point severity scale devised to include children with and without chronic illness (see Appendix), where a score of 0 was assigned to a child who had no chronic illness and no other illnesses and 8–9 to children who had more than one severe chronic illness. In the diagnosed groups, severity of illness was based on data from medical files: Shwachman scores (Shwachman & Kulczycki, 1958) for the CF group and a scale devised by a cardiologist for our study (for details, see Goldberg, Simmons, Newman, Campbell, & Fowler, 1991) for the CHD group. Routine illnesses (e.g., colds, earaches) for all children were included on the basis of an illness diary completed by parents. Developmental level was measured by the Mental Developmental Index (MDI) and the Motor Development Index (PDI) obtained from the Bayley Scales of Infant Development (Bayley, 1969) administered at the 1-year assessment. Reliabilities for the 12–18-month-olds on the Bayley are .82 (MDI) and .92 (PDI).

Child Temperament. Parents completed the 97-item Toddler Temperament Scale (Fullard, McDevitt, & Carey, 1984) which has a reported Cronbach α (median for 9 subscales) of .70, and test–retest reliability of r = .81. We used the global measure of difficulty ranging from 1 (easy) to 5 (difficult), computed by a standard algorithm.

Family Environment. Parenting stress was assessed by the Parenting Stress Index (Abidin, 1986), a 120-item parent report that yields an index of stress arising from the parental role and from parenting the specific child. The total score, which sums these two indices, was used for analyses. Cronbach α for PSI total score is .95, with test–retest reliability of r = .88 (Abidin, 1986). Parental Well-Being was considered an important family environment variable. This was measured on a 24-item symptom checklist, combining symptoms of both physical and mental health (Rutter Health Questionnaire; Rutter & Tizard, 1970) with a test–retest reliability of r = .91.

Mother–Child Relationship. Infant–mother attachment status was coded by trained observers from videotapes of the standardized Strange Situation procedure into one of the three categories: secure, insecure-avoidant, and insecure-resistant (Ainsworth, Blehar, Waters, & Wall, 1978). Interrater agreement between 2 independent coders, based on half the sample was 78%. In addition, attachment organization (Main & Solomon, 1986) was coded on a scale from 1 (well organized) to 9 (severely disorganized). The salient elements of disorganized attachment are exhibiting odd and inexplicable behaviors (e.g., signs of fear while approaching the mother, behavioral stilling), and lack of a clear strategy for handling separations and reunions with the caregiver. While every infant receives a score on the disorganization scale, scores above 5.5 are indication of a primarily disorganized and insecure attachment with the caregiver.
ANALYSES

An $\alpha$ level of .05 was used throughout the analyses to determine significant differences. The lost and not-lost groups were compared with respect to demographics and study measures using $t$-tests and chi-square tests where appropriate. A series of stepwise regression analyses, with the entry criterion of .05 and participation level as the dependent variable was conducted for demographic predictors and study measures separately, first for the full sample, and then for each study group.

RESULTS

Reasons for Loss of Participation

Among those who completed the initial interview, 74 out of 209 families (35.4%) were lost in the course of the 4-year study. Table I shows the breakdown of reasons for loss, for all 74 families, and within each study group. Reasons were known for 58 families. Reasons for the loss in the comparison group tended to be situational (10/14, 71%) more frequently than among families of children with CF (3/10, 33%), or with CHD (15/34, 45%), $\chi^2(2, N = 58) = 4.78, p = .09$.

Predictors of Loss

Demographic Predictors

$T$-tests were used to compare demographic characteristics for the lost and not-lost groups. Lost families tended to have parents who were younger and had

<table>
<thead>
<tr>
<th>Reason</th>
<th>Full Sample</th>
<th></th>
<th>Control</th>
<th></th>
<th>CF</th>
<th></th>
<th>CHD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$</td>
<td>%</td>
<td>$n$</td>
<td>%</td>
<td>$n$</td>
<td>%</td>
<td>$n$</td>
<td>%</td>
</tr>
<tr>
<td><strong>Internal</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No interest</td>
<td>7</td>
<td>9.5</td>
<td>3</td>
<td>10.7</td>
<td>0</td>
<td>4</td>
<td>11.4</td>
<td>0</td>
</tr>
<tr>
<td>Family problems</td>
<td>5</td>
<td>6.8</td>
<td>0</td>
<td>7.1</td>
<td>2</td>
<td>18.2</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Too busy</td>
<td>13</td>
<td>17.6</td>
<td>1</td>
<td>3.6</td>
<td>4</td>
<td>36.4</td>
<td>8</td>
<td>22.9</td>
</tr>
<tr>
<td>Difficult to schedule</td>
<td>5</td>
<td>6.8</td>
<td>0</td>
<td>7.1</td>
<td>1</td>
<td>9.1</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td><strong>External</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moved</td>
<td>19</td>
<td>25.7</td>
<td>9</td>
<td>32.1</td>
<td>3</td>
<td>27.3</td>
<td>7</td>
<td>20.0</td>
</tr>
<tr>
<td>Additional diagnosis</td>
<td>3</td>
<td>4.1</td>
<td>1</td>
<td>3.6</td>
<td>0</td>
<td>2</td>
<td>5.7</td>
<td>1</td>
</tr>
<tr>
<td>No English</td>
<td>2</td>
<td>2.7</td>
<td>0</td>
<td>1.8</td>
<td>0</td>
<td>2</td>
<td>5.7</td>
<td>1</td>
</tr>
<tr>
<td>Child died</td>
<td>4</td>
<td>5.4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0.7</td>
<td>1</td>
</tr>
<tr>
<td>Not known</td>
<td>16</td>
<td>21.6</td>
<td>14</td>
<td>50</td>
<td>1</td>
<td>9.1</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>74</td>
<td>28</td>
<td>11</td>
<td>35</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
less education, but most differences did not reach conventional levels of significance. However, father's education was significantly lower among the lost than the not-lost group ($M_{lost} = 13.0 \pm 2.9; M_{not\ lost} = 14.0 \pm 2.9$) $t(197) = 2.16, p < .05$.

Chi-square tests were used for between-groups comparisons for dichotomous demographic variables (e.g., sex of the child, parents' country of birth). Sex of the target child did not differ between lost and not-lost participants. Families were more likely to be lost if the father was not born in Canada (52 vs. 29%), $\chi^2(1, N = 209) = 8.97, p < .01$. This happened most frequently in the CHD group, where 60% of non-Canadian versus 32% of families with Canadian-born fathers ceased participation. Pediatric status of the child had an uneven impact on the loss of participants: The smallest percentage loss was in the CF group (17%), followed by the CHD group (41%), and comparison group (46%), $\chi^2(2, N = 209) = 13.33, p < .01$.

**Study Measures**

A series of $t$-tests was used to compare study measures from the 1-year assessment (severity of illness, developmental indices, child temperament, PSI, parental well-being, and attachment disorganization) between lost versus not-lost families. No significant differences were found. There were also no differences in the distribution of infant attachment categories (avoidant, secure, and resistant; Ainsworth et al., 1978) between lost and not-lost families.

**Level of Participation**

A second common problem in longitudinal studies is that of missing data even when the family continues to participate. To determine factors predicting level of participation, participation scores were the outcomes in a series of regression analyses.

**Demographic Predictors**

The continuous variables investigated for their predictive value in regression analyses were mother’s age and years of education, father’s age and years of education, child’s birth order, and number of people in the household. Maternal age explained 6% of variance and father’s education an additional 2% in participation scores (Table II): families with older mothers and more educated fathers participated more consistently in the study than those with younger mothers and less educated fathers. When regression analyses were repeated for each group
Table II. Regression Analyses with Demographic Variables as Independent Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total sample (n = 193)</th>
<th>Comparison (n = 57)</th>
<th>CF (n = 58)</th>
<th>CHD (n = 78)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE B</td>
<td>β</td>
<td>B</td>
</tr>
<tr>
<td>Mother's age</td>
<td>.70</td>
<td>.18</td>
<td>.27*</td>
<td>.71</td>
</tr>
<tr>
<td>(ΔR² = .06)</td>
<td></td>
<td></td>
<td></td>
<td>(ΔR² = .15)</td>
</tr>
<tr>
<td>Mother's education</td>
<td>.09</td>
<td>.28</td>
<td>.03</td>
<td>-.50</td>
</tr>
<tr>
<td>Father's age</td>
<td>.07</td>
<td>.12</td>
<td>.05</td>
<td>-.20</td>
</tr>
<tr>
<td>(ΔR² = .08)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father's education</td>
<td>.24</td>
<td>.11</td>
<td>.20*</td>
<td>.56</td>
</tr>
<tr>
<td>(ΔR² = .02)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth order</td>
<td>-.58</td>
<td>.86</td>
<td>-.06</td>
<td>2.48</td>
</tr>
<tr>
<td>No. of people in household</td>
<td>.30</td>
<td>.49</td>
<td>.04</td>
<td>-1.20</td>
</tr>
</tbody>
</table>

*p < .001.

* * p < .01.
separately, mother's age was the only statistically significant predictor of participation in the comparison and CHD groups (explaining 15 and 6% of variance, respectively). In the CF group, father's age contributed most to the participation level (8%).

**Study Measures**

Regression analyses with participation score as the dependent variable, and study measures from the 1-year assessment as predictors, were carried out for the families who completed the 1-year assessment. Families who were lost because of situational reasons (e.g., child's death or moving to another country) were omitted from the analysis. Because the PSI had not been administered in the first year of the study to all participating families, the PSI scores were excluded from this analysis. This resulted in a total \( n \) of 112 (36 comparison, 20 CF, and 56 CHD). Each of the four domains of interest was represented by at least one variable: medical status by MDI, PDI, and severity of illness score; child's temperament by the difficulty index from the Toddler Temperament Scale; family environment by scores on the Rutter Health Questionnaire, and mother–child relationship by attachment disorganization scores.

Parental well-being, severity of illness, and disorganization of attachment made significant contributions to family participation (Table III). Parental well-being explained 6% of variance, severity a further 2%, and disorganization a further 2%. Families participated less when parents reported more psychosomatic symptoms, when the child's medical condition was less severe, and when the disorganization score was higher. Child temperament did not contribute to the prediction.

Regression analyses were repeated for each study group (43 families in the comparison, 30 in the CF, and 59 in the CHD group). However, only the three variables significant for the full sample were entered (Table III). This selection was dictated by the need to curb the number of variables for smaller samples. None of the measures predicted participation levels in the comparison group. Rutter Health Questionnaire Scores predicted participation in families with chronically ill children. For families of children with CF, it explained 13% of variance. In the CHD group, it explained 11% of the variance, and disorganization of attachment a further 10%.

^Regression analyses allow only the subjects with nonmissing data on all regression variables. Thus, the reduction of variables for the regression analyses by group also resulted in more subjects in each, because those who had missing data on variables no longer in regression were included.
Table III. Regression Analyses with Study Measures in Parent–Child Domains as Independent Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total sample (n = 112)</th>
<th>Comparison (n = 43)</th>
<th>CF (n = 30)</th>
<th>CHD (n = 59)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE B</td>
<td>β</td>
<td>B</td>
</tr>
<tr>
<td>Parental well-being</td>
<td>-.48</td>
<td>.18</td>
<td>-.24b</td>
<td>-.49</td>
</tr>
<tr>
<td>(ΔR² = .05)</td>
<td></td>
<td></td>
<td></td>
<td>(ΔR² = .13)</td>
</tr>
<tr>
<td>Temperament</td>
<td>-.68</td>
<td>.53</td>
<td>-.12</td>
<td>-1.79</td>
</tr>
<tr>
<td>(ΔR² = .02)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severity of illness</td>
<td>.74</td>
<td>.29</td>
<td>-.25b</td>
<td></td>
</tr>
<tr>
<td>MDI</td>
<td>.02</td>
<td>.05</td>
<td>.05</td>
<td></td>
</tr>
<tr>
<td>PDI</td>
<td>.05</td>
<td>.05</td>
<td>.11</td>
<td></td>
</tr>
<tr>
<td>Disorganization of attachment</td>
<td>-.60</td>
<td>.30</td>
<td>-.19c</td>
<td>.13</td>
</tr>
<tr>
<td>(ΔR² = .01)</td>
<td></td>
<td></td>
<td></td>
<td>(ΔR² = .10)</td>
</tr>
</tbody>
</table>

*Only the three variables significant for the Total sample were entered into the regressions for each group.

*p < .01.

*p < .05.

*p < .001.
Mother and Father Participation Levels

One-way analysis of variance was computed to compare mother and father participation levels among the three study groups. Mothers in the CF and CHD groups tended to participate more than mothers in the comparison group, $F(2, 206) = 2.68$, $p = .07$. Fathers' participation scores did not differ significantly among the groups. Participation scores were compared between mothers and fathers for 62 pairs in the CF group, 86 in the CHD group, and 61 in the comparison group. In each group, mothers participated significantly more than fathers, matched $t$-test, $t(61) = -5.65$, $t(85) = -5.35$, $t(60) = -4.70$, for CF, CHD, and comparison groups, respectively, $ps < .001$.

DISCUSSION

This exploration of patterns of participation in a longitudinal study demonstrates some marked differences between pediatric and nonpediatric populations. Even though the self-volunteering families of non-ill children were most likely to withdraw from the study, they were also the ones whose reasons for withdrawal were most likely to be beyond their immediate control. Families of children with CF were most likely to stay in the study. This may reflect the fact that the treatment of CF in young children includes a quarterly visit to the hospital CF Clinic, and laboratory assessments for the research project were usually carried out on the day of these visits. Thus, most of these families did not make additional trips to participate in the study. Children with CHD did not come for medical checkups as frequently, and so arrangements for visits were often made separately. Hence, their participation was more likely to require extra trips, as did participation for comparison families. The relative percentages of families lost support this interpretation. Furthermore, the CF population is small, their clinic is a small unit, with limited staff, many with long service to the clinic. Thus patients with CF receive individual attention, and develop close loyal relationships with the medical team. While the quality of medical care for children with CHD is excellent, the cardiology team of necessity is much larger with more frequent staff turnover and family relationships with this team are of a less personal nature. The difference in retention between CF and CHD groups reflects this discrepancy in care patterns.

Previous research into correlates of attrition has shown it to be related to SES (e.g., Capaldi & Patterson, 1987; Winefield et al., 1991), high substance use (Snow et al., 1992), depression and life events (Robles, Flaherty, & Day, 1994), but not to the requested length of involvement in a study (Freese, Thoman, & Becker, 1980). In concordance with expectations, demographic and socioeconomic factors played an important role in a family's stable participation.
Mother's age at the target child's birth, and father's education were the most reliable predictors of participation in the present analyses. Parents' ages continued to reliably predict participation within each of the three groups, suggesting that this is a general phenomenon. Families with parents not born in Canada were more likely to withdraw than those with parents born in Canada. Similar patterns were found by Winefield et al. (1991) in a longitudinal study of employment among Australian adolescents.

Fathers are notoriously difficult to recruit for research (Woollett et al., 1982). Our analyses suggest that even when fathers participate, their involvement is significantly lower than that of mothers. Efforts to increase fathers' participation are evident in current research on family issues (Cowan & Cowan, 1987; Lamb, 1986). However, research on the father's role in infancy suggests a relatively low involvement (Lewis, 1986) and limited impact of increased involvement on the quality of father–infant relationship (Bailey, 1994). In our study, fathers were treated as full participants but chose to participate less than mothers. They may have assumed participation to be a component of child care, hence primarily the mother's role. Father participation in child care increases beyond infancy but is qualitatively different from maternal involvement (Lamb, 1986).

The role of fathers in families with chronically ill children is not well understood. Some reports indicate lower involvement of fathers where there is a child with illness (Stewart, Stein, Forrest, & Clark, 1992), others show no difference (Darke & Goldberg, 1994). Improving our knowledge and understanding of the role of the father in the care of a chronically ill child is of paramount importance for both clinical and research perspectives. Data from our study suggest that representative father participation requires more active efforts than were made here.

Families who continued participation through the fourth year did not differ significantly from those who withdrew on any measures from the 1-year assessment. This increases our confidence in the generalizability of data interpretation. Parental well-being turned out to be the strongest predictor of a family's stable participation, but only in the pediatric samples. This may reflect the fact that parents of non-ill children deal with fewer stressors, and thus there is less variation in their well-being than among parents of chronically ill children. In more practical terms, the association of parental well-being with participation levels should alert researchers to recognize families for whom research participation may be complicated, despite good intentions. Sensitivity to this issue, coupled with improved identification of families at such risk, will undoubtedly improve the retention rate.

Nevertheless, medical status of the target child, a solely child-related variable, accounted for a small proportion of variance in participation. Thus, presence of children's medical problems improved participation. This may be partly
accounted for by feelings of indebtedness to the hospital among parents of chronically ill children. A further reflection of this is the higher level of participation associated with increased severity of illness. Severity of illness is usually related to the amount of care the child received in the hospital. There are also more practical consequences of the association between severity and participation. In view of the fact that severity of illness has been associated with psychosocial adjustment outcome (e.g., Daniels, Miller, Billings, & Moos, 1986; Jessop & Stein, 1985), increased representation of families with more seriously ill children in longitudinal projects may yield inflated estimates of maladjustment in pediatric populations.

The most intriguing finding in our analysis was that disorganization of attachment significantly predicted participation in the study. Since the attachment relationship was a major focus of this project, decreased participation in families of infants with high disorganization influences a key component of the study. This highlights the need for careful interpretation of results when withdrawal is related to the phenomenon being studied (Cordray & Polk, 1983). Why would disorganization influence participation? One explanation is that socioemotional measures in our study (those concerning child, parenting issues, or the parent–child relationship) may have been more uncomfortable (and thus not completed) in families where mother–infant attachment was more disorganized. Main and Hesse (1990) found that disorganized infant–parent attachment was often associated with an unresolved loss of attachment figures by the parent. In our study, disorganization was a more salient factor in families of children with CHD. The lack of match between parental expectation regarding the infant, and the actual experience of a serious illness, as well as uncertainty of outcome could significantly disrupt the developing infant–parent attachment (Goldberg, 1988). Further investigation of the development of attachment, its relation to adult intimacy styles and to family coping with illness are necessary to improve our understanding of disorganized attachment.

The present analysis of participation patterns in the 4-year longitudinal study of parent–child relationship carries several practical implications. Although current statistical procedures allow for missing data, there is no better alternative to sound research than high participant retention (Stouthamer-Loeber & van Kammen, 1995). In family-based research, especially of infants and preschoolers, there are fewer sources for keeping track of study participants than in school-aged or adolescent samples (see Capaldi & Patterson, 1987; Navratil, Green, Loeber, & Lahey, 1994; Robles et al., 1994). Several avenues for improving participant retention are suggested by our experience. An exploratory analysis of the first-year data, identifying families at risk for attrition, who then could be pursued with more determination, and more sensitive strategies, might improve retention rates. Families with a history of repeated rescheduling could be contacted much earlier before the assessment date to ensure a longer scheduling
period. Finally, the importance of commitment to the study could be emphasized. Since connection to hospital visits enhanced participation, connecting study assessments with a routine pediatric health checkup could be beneficial. However, in all attempts to increase staff engagement in maintaining the sample, the costs in staff effort have to be balanced with the benefits of having a large and representative sample (Navratil et al., 1994).

In conclusion, two findings important to pediatric psychology research are reiterated: (a) The patterns of participation of families with young children in longitudinal studies differ not only between the families of ill and non-ill children but also between pediatric populations; (b) participation patterns are related to severity of illness. The fact that more severely ill children are more likely to participate should alert researchers to consider a measure of severity of illness when comparing nonparticipants and participants in pediatric studies. Limitation in the range of severity among participants may limit the interpretative value of research.

APPENDIX

Medical Severity Scale

0: No health problems
   No chronic illness; no other illnesses
1: Generally healthy, with minor problems (childhood illnesses)
   No chronic illness, no hospitalization, no prolonged illnesses. Occasional fever/earache/cold/may include visit at the doctor’s and short-term prescribed medication, but not medical intervention. 1 to 2 visits at the doctor’s.
2: Generally healthy, with a major health problem, or many minor illnesses
   No chronic illness, one or two major illness, or many minor illnesses necessitating doctor’s visit. Has to involve medical intervention, in the shape of a long-term medication (i.e., no aspirin, tempra, or cough drops), outpatient procedure or hospitalization (e.g., broken limb). 3 to 6 visits at the doctor’s.
3: Chronically ill, mild
   For Healthy group: when a chronic problem has developed, but is of mild intensity (e.g., mild asthma); more than 6 visits at the doctor’s. For CF group: when Shwachman score > 95. For CHD group: when cardiac severity score 4–6.
4: Chronically ill, mild, plus other nonchronic health problems
   For Healthy group: when a chronic problem has developed, but is of mild intensity (e.g., mild asthma) and there are many minor illnesses. For CF group: when Shwachman score > 95 and there are many minor illnesses. For CHD group: when cardiac severity score 4–6 and there are many minor illnesses
5: Chronically ill, moderate
For Healthy group: when a chronic problem has developed, and is of moderate intensity (e.g., moderate asthma). For CF group: when Shwachman score 80–95; or Shwachman > 95 and a major nonchronic problem present. For CHD group: when cardiac severity score 7–9; or cardiac severity 4–6 and a major nonchronic problem present.

6: Chronically ill, moderate, plus other nonchronic health problems
For Healthy group: when a chronic problem has developed, and is of moderate intensity (e.g., moderate asthma) and there are many minor illnesses. For CF group: when Shwachman score 80–95; or Shwachman > 95 and a major nonchronic problem present and there are many minor illnesses. For CHD group: when cardiac severity score 7–9; or cardiac severity 4–6 and a major nonchronic problem present and there are many minor illnesses.

7: Chronically ill, severe
For Healthy group: when a chronic problem has developed, and is of serious intensity (e.g., severe asthma). For CF group: when Shwachman score < 80; or Shwachman > 80, but there is another chronic health problem. For CHD group: when cardiac severity 10–12; or cardiac severity < 10, but there is another chronic health problem.

8: Chronically ill, severe, plus other nonchronic health problems
For Healthy group: when a chronic problem has developed, and is of a serious intensity (e.g., severe asthma) and there are many minor illnesses. For CF group: when Shwachman score < 80; or Shwachman > 80, but there is another chronic health problem and there are many minor illnesses. For CHD group: when cardiac severity 10–12; or cardiac severity < 10, but there is another chronic health problem and there are many minor illnesses.

9: Chronically ill, very severe
For all groups: two or more chronic problems of any severity.

REFERENCES


