Experiences of Parents of Children With Achondroplasia: Impacts on Quality of Life

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BACKGROUND

The clinical complications and medical impacts of achondroplasia (ACH) in children are well studied and frequently include recurrent ear infections, sleep apnea, hearing loss, tooth crowding, speech delay, and delayed developmental milestones, including gross motor and fine motor delays. Little is known about how having a child with ACH impacts parents’ experiences and quality of life.

OBJECTIVE

The purpose of the study was to investigate the impacts of having a child aged 2 to <12 years with ACH on parents’ general quality of life, including parents’ caretaking and work responsibilities, emotional well-being, and social well-being.

METHODS

The qualitative research study design was based on an adapted grounded theory approach. Based on a literature review and clinical expert interviews, a semi-structured interview guide was developed to elicit parents’ experiences related to ACH. It should be noted that this study was part of a larger study of parents of children with ACH under 12 years of age, and this study focused only on parents of children aged 2 to <12 years.

RESULTS

Parent Participant Sample Description

1. Average age of parents was 41.5 years (SD, 6.6; range, 32-68)
2. Most parents were married (80.6%, n=29), 8.3% were partners (n=3), 5.6% were divorced (n=2), and 5.6% were single (33.3%)
3. 14 reported as “very good” (38.9%), 7 (19.4%) as “good”, and 3 (8.3%) as “fair”

Table 1. Parent participant demographic characteristics

| Demographic/Health Characteristics for Children of Parent Participants | Age, mean(SD) | Female (%) | Relationship to child (%) | Medical issues (%) | Work status, n(%)
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<tbody>
<tr>
<td>Child age, n=25</td>
<td>4.1(3.6)</td>
<td>52.0</td>
<td>47.0</td>
<td>4(16.0)</td>
<td>8(32.0)</td>
</tr>
<tr>
<td>Child gender, n=22</td>
<td>Male</td>
<td>Female</td>
<td>4(18.2)</td>
<td>0</td>
<td>2(25.0)</td>
</tr>
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</table>
| Health status (parent reported), n=18 | Excellent | Very good | Good | Fair | Unknown
| Parent participant health status | Excellent | Very good | Good | Fair | Unknown |
| Health status of child, n=20 | Excellent | Very good | Good | Fair | Unknown |
| Age(s) of child, n=22 | 2 to <5 years | 5 to <9 years | 9 to <12 years |
| Experience with child’s medical care/treatment, n=21 | Providing assistance to child (eg, reaching objects) | Providing support/guidance to child for managing ACH | Providing assistance to child (eg, toileting, bathing, dressing) | Providing assistance to child (eg, feeding objects) |

Demographic/Health characteristics for children of parent participants

1. 30.6% of parent participants (n=11) had children aged 2 to <5 years with ACH, 36.1% of participants (n=13) had children aged 5 to <9 years, and 33.3% of parents (n=12) had children aged 9 to <12 years.

2. Nineteen children were female (52.8%) and 17 were male (47.2%)

3. Twelve parents reported child’s health status as “excellent” (33.3%), 14 reported as “very good” (38.9%), 7 (19.4%) reported as “good,” and 3 (8.3%) reported as “fair”

Impacts on Parents’ Caretaking Responsibilities

1. Managing child’s medical care and treatment, help with self-care, and advocating for child

2. For example, helping child with self-care was more frequently reported by parents of younger children (2 to <5 years; 75%; n=18) than parents of older children (9 to <12 years; 50%; n=6)

3. The findings suggest that there may be some sub-group differences among parents, but significance tests could not be conducted due to small sample sizes.

STUDY LIMITATIONS

1. Given the relatively small sample sizes, results should be interpreted with caution. Percentage differences in parents’ reported impacts may not reflect actual differences in the population. Results may not be generalizable to other groups/populations. For example, parents’ experiences related to having a child with ACH may vary in different countries, cultures, and healthcare systems.

2. To our knowledge, this is the first study of how having a child with ACH affects parents’ general quality of life and well-being.

3. The findings indicate that parents have a range of caretaking responsibilities for their children with ACH, including managing medical care, helping with self-care, and advocating for child care.

CONCLUSIONS

1. Additional studies are needed to explore some of the sub-group differences among parents.

2. Parents also frequently expressed worries about their child’s physical health, safety concerns, worries about child’s social well-being, and feelings of being stressed/overwhelmed.

3. Despite these challenges, a majority of parents reported making social connections and friendships through dwarfism advocacy organizations, which were an important source of education and support.

Figure 1. Impacts on Parents’ Caretaking Responsibilities

Figure 2. Impacts on Parents’ Work or Employment

Figure 3. Impacts on Parents’ Emotional Well-being

Figure 4. Impacts on Parents’ Social Well-being

Figure 5. Impacts on Families

Figure 6. Impacts on Families

A NOTE ON SUB-GROUP DIFFERENCES

The findings suggest that there may be some sub-group differences among parents, but significance tests could not be conducted due to small sample sizes.

Among parents with and without ACH, results were generally similar, though parents with ACH were less likely to report some impacts compared to parents without ACH.

Additionally, the results suggested that there may be some differences by child age group:

1. For example, helping child with self-care was more frequently reported by parents of younger children (2 to <5 years; 75%; n=18) than parents of older children (9 to <12 years; 50%; n=6)

2. Results were generally similar for parents in the US and Spain.