BACKGROUND

- The clinical complications and medical impacts of achondroplasia (ACH) in children and adults are well studied.
- Frequent complications of ACH in childhood include recurrent infections (otitis media, deep sphen, hearing loss; tooth defects/intellectual disabilities), and speech delay or articulation difficulties. An adult with ACH is often included due to diverse tall and short
- Kyphoscoliosis, sleep apnea, and obesity.
- Research has also shown that infants and young children with ACH experience delays in some developmental milestones, including gross motor, fine motor, communication, and cognitive development.
- Various studies have also shown the broader impacts of ACH on children's lives, including impacts on functioning and daily life, emotional well-being, and social well-being.

METHODS

The purpose of the study was to investigate the impacts of ACH on the functioning, daily life, and well-being of children aged 2 to <12 years.

- The study was part of a larger study of parents of children with ACH.
- Individual telephone interviews and 1 parent focus group were conducted in the US and Spain with 36 parents of children aged 2 to <12 years with ACH.
- The interviews/focus group were conducted in English (US) or Spanish (Spain), transcribed verbatim, and translated to English if necessary.
- Telephone interviews lasted approximately 1 hour, with the focus group lasting 2 hours.
- Interview and focus group transcripts were analyzed for content and coded by themes using a qualitative analysis software program.

RESULTS

DEMOGRAPHIC/HEALTH CHARACTERISTICS FOR CHILDREN OF PARENT PARTICIPANTS

Demographic and health characteristics for the children of parent participants are shown in Table 2. The most frequently reported impacts on children's social well-being were:
- Embarrassed/self-conscious (33%, n=12)
- Angry/mad (33%, n=12)
- Being treated as younger than age (83%, n=30)
- Difficulties participating in social activities, such as birthday parties/playdates (64%, n=23)
- Experience of teasing/bullying (64%, n=23)

IMPACTS ON SOCIAL WELL-BEING

The most frequently reported impacts on children's social well-being were:
- Difficulty participating in sports or physical play (47%, n=18)
- Being treated as younger than age (83%, n=30)
- Negative attention in public, such as staring or pointing (46%, n=17)
- Experience of teasing/bullying (64%, n=23)
- Difficulty participating in social activities, such as birthday parties/playdates (46%, n=17)

IMPACTS ON EMOTIONAL WELL-BEING

The most frequently reported impacts on children's emotional well-being related to ACH included:
- Feeling worse off (47%, n=18)
- Feeling physically active (47%, n=18)
- Feeling diferencia (33%, n=12)
- Feeling less well (47%, n=18)

IMPACTS ON FUNCTIONING AND DAILY LIFE

The most frequently reported impacts on children's functioning and daily life were difficulties with:
- Reaching objects high places (88%, n=32)
- Wearing older (67%, n=24)
- Being physically active (47%, n=18)
- Dressing/undressing self (47%, n=18)

STUDY LIMITATIONS

- To our knowledge, this is the first study to investigate the broad impacts of ACH on children's functioning and daily life.
- The findings highlight some of the difficulties that children with ACH experience in their functioning and daily life, as well as challenges to school participation.
- Additionally, the study suggests that children with ACH experience a range of emotional and social impacts.

CONCLUSIONS