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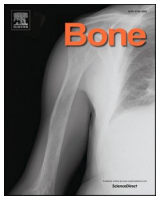

Full Length Article

Limb lengthening in individuals with achondroplasia: Analysis of an international survey

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ABSTRACT

Background: Limb lengthening surgery is a contentious option for individuals with achondroplasia. This study aimed to assess real-world experiences, outcomes, and perspectives on limb lengthening in a multinational cohort of individuals with achondroplasia.
Methods: A cross-sectional, international online survey on limb lengthening experiences and perspectives was conducted in 11 languages across 16 countries from May until July 2024.
Results: Out of 467 responders (229 self-responders, 238 parents/caregivers), 90 (19.3 %) reported undergoing limb lengthening (LL) surgery. The mean age at first surgery was 10.5 years (SD 4.5). On average, respondents underwent 3.7 (SD 2.9) procedures, resulting in 14.5 cm (SD10.4) added and final adult height of 137.1 cm in females and 142.1 cm in males. Significant improvements were described in activities such as car driving, bathing, brushing hair, and wiping after toileting for those who underwent both arm and leg lengthening ($p \leq 0.001$). Among respondents, 23 % would recommend the procedure to others and 28 % would not recommend LL. Nearly half of respondents (49 %) was uncertain about recommending LL.
Conclusions: This is the largest international survey on LL in achondroplasia with results highlighting some of the differences in perspectives and choices of the individual with achondroplasia and their families, providing real-world evidence of the outcomes of this intervention. While significant functional improvements were reported, a reduced percentage of respondents recommended LL intervention. The findings underscore the existence of a triad when considering limb lengthening in achondroplasia as individual choices and life experiences, socio-cultural environment and access to clinical options.

1. Introduction

Achondroplasia is a skeletal dysplasia and the most common form of disproportionate short stature with an estimated incidence of 1 case in 25,000 live births [1]. Characterized by rhizomelic shortening of the limbs, macrocephaly, and distinctive facial features, achondroplasia is caused by a gain-of-function mutation in the fibroblast growth factor receptor 3 (FGFR3) gene [2].

There are different approaches that can facilitate individuals with achondroplasia to function freely and fully in diverse environments which are projected for average stature individuals. Alongside the physical barriers to participation, emotional and social barriers often also need to be overcome, and various strategies have been employed.

While recent advancements in pharmacological treatments developed towards increasing growth velocity for children with achondroplasia [3], limb lengthening surgery remains an option for many individuals. This surgical procedure aims to increase height and improve body proportions, potentially enhancing functional capabilities and quality of life [4,5]. The concept of limb lengthening intervention have evolved in the last 100 years [6]. Significant advancements were made

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in the early 20th century by pioneers like Dr. Ilizarov who developed the Ilizarov method using external fixators to gradually lengthen bones [7,8] with current approaches including intramedullary lengthening nails [9]. However, limb lengthening is a complex multifaceted and time-consuming process that carries risks [10]. Successful lengthening involves medical, psychological, and social considerations alongside good understanding of the process and full commitment from individuals with achondroplasia and their families [11].

While in some countries, limb lengthening is a frequently requested intervention and economically covered treatment option (5,10) [12], in others, its availability is more clinically or economically restricted and less frequently requested.

Despite the importance of this topic, there is a paucity of large-scale, patient-reported data on the experiences and outcomes of limb lengthening in the achondroplasia community.

The International Society of Children's Bone Health (ISCBH) and the European reference network for rare bone diseases (ERN-BOND) [13] organized a series of achondroplasia related workshops. The 3rd workshop took place in June 2024, under the theme "Long bone pathology". In preparation for this workshop, a multinational survey was launched, and preliminary results were presented at the workshop with a request for more participants to be added to the survey [13]. This paper reports the full results of a comprehensive international survey, providing insights into the demographics, surgical experiences, outcomes, and perspectives of individuals with achondroplasia who have undergone limb lengthening surgery and those who did not.

2. Methods

2.1. Study design and participants

We conducted a cross-sectional, international online survey on limb lengthening experiences and perspectives directed to individuals with achondroplasia (self-respondents), and caregivers of children with achondroplasia. The survey was disseminated from May to mid-July 2024 through advocacy organizations, clinical European networks (e.g., ERN BOND, UK Achondroplasia Network), and social media. Eligibility criteria included a self-reported diagnosis of achondroplasia, be aged over 12 years for self-respondents or be a parent of a child with achondroplasia <12 years, and lastly, the ability to complete the survey in one of the available languages.

2.2. Survey instrument

The survey was developed by a multidisciplinary team including patient advocates (two members with achondroplasia, one who had undergone LL, an average stature parent of child with achondroplasia), achondroplasia specialist clinicians, and a medical computer scientist. It included multiple choice options and open text questions, comprising sections on demographics, medical history, surgical experiences (for those who underwent limb lengthening), reasons for not undergoing surgery (when applicable), and overall perspectives on limb lengthening. For this survey, we have applied items related to standardized instruments, as the WeeFim [14]. The survey included quality of life measures and questions on functional abilities before and after surgery, focusing on activities of daily living such as bathing, dressing, driving, and walking up/downstairs. Respondents were asked to rate their ability to perform these tasks on a scale from 1 (very difficult) to 5 (very easy), allowing for a quantitative comparison of pre- and post-surgery functionality.

To mitigate selection bias, the survey was disseminated via neutral channels, as ERN BOND healthcare provider and professionals and translated into 11 languages, reviewed by native speakers, to ensure consistency. The STROBE [15] and Sex and Gender Equity in Research (SAGER) [16] guidelines were followed.

2.3. Data collection and management

Responses were collected anonymously through REDCap (Research Electronic Data Capture) [17,18], a secure, web-based software platform. The study was approved by Leipzig University. All participants provided informed consent before completing the survey. For minors, parental consent was obtained.

Data were cleaned to remove incomplete or duplicate entries, and responses were categorised into three main groups:

- Group 1: Self-respondents aged 12 to <18 years
- Group 2: Self-respondents aged 18 years and above
- Group 3: Parents/caregivers responding for children aged 0 to <12 years

An additional category, "Extra data," included responses from parents/caregivers for children aged 12 to <18 years.

Responses were collected from 24 countries including Argentina, Australia, Austria, Belgium, Brazil, Canada, Denmark, France, Germany, Greece, Honduras, Italy, Japan, Netherlands, Norway, Peru, Poland, Portugal, Romania, South Korea, Spain, Switzerland, United Kingdom, and United States of America. Free-text responses were manually reviewed by two independent people, a physician and a medical computer scientist, and classified into topic groups.

2.4. Statistical analysis

Descriptive statistics were used to summarize demographic and clinical characteristics, using mean and standard deviation. Normal distribution was verified. Fisher's exact-test was used to test for independence of categorical characteristics. In addition, Student's t-test was conducted to verify differences in continuous characteristics. All analyses were conducted using R version 4.2.2 [19]. Significance level was set to 5 %.

3. Results

3.1. Study population

A total of 614 responses were received and after data cleaning, 467 responses were used for analysis. The study population comprised 32 self-respondents aged 12 to <18 years (Group 1), 197 self-respondents aged 18 years and above (Group 2), and 238 parent/caregiver responses for children aged 0 to <12 years (Group 3). A group with extra data was also analysed which included 69 parents who responded for children aged 12 to <18 years. Although respondents from this group didn't follow inclusion criteria, their views were considered relevant for analysis and therefore, the group was labelled "Extra data" and analysed separately from the three included groups. Geographic distribution of respondents is presented in Fig. 1.

Geographical differences were observed in the prevalence of limb lengthening surgery. Among the countries with the highest number of respondents, Germany showed a 16.7 % rate of limb lengthening (27/162). The highest rate of limb lengthening surgery were observed in Italy (12/20) with 60 %, and Spain (21/37) with 56 %. The response rate also reflects the level of dissemination of patient organizations which varied considerably.

3.2. Demographics

The mean age of the overall study population was 19.7 years (SD 17.7). The sex distribution was nearly equal, with 51 % female and 49 % male respondents. The 467 valid responses comprised 229 (49.0 %) responses from self-respondents of which 32 (6.9 %) aged between 12 to <18 years (Group 1) and 197 (42 %) over 18 years (Group 2) and 238 (51 %) responses from parents/caregivers. Most respondents (96 %)

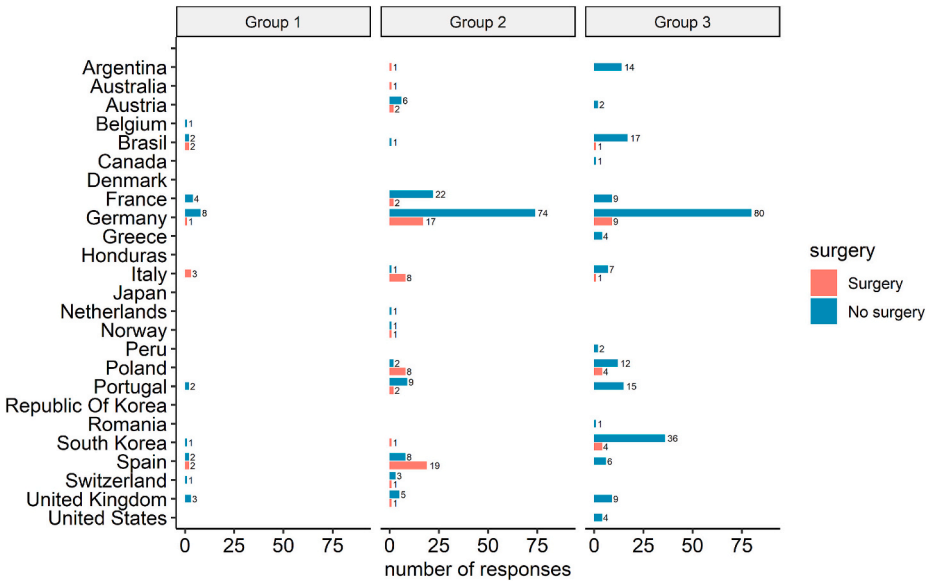

Fig. 1. Geographic distribution of respondents by groups and limb lengthening surgery.

reported that neither parent had achondroplasia and were of average stature, indicating a higher proportion of new cases (de novo), in the sample, than the established percentage of 80 % [20]. Sociodemographic data is presented in Table 1. The highest number of responses came from Germany (162 responses). Responses distribution by group and gender shown in Fig. 2. Of the 313 (67 %), connected to a patient organization, 54 had undergone limb lengthening.

3.3. Limb lengthening surgery

Of the 467 respondents, 91 (19.5 %) had undergone limb lengthening surgery. Among these, the prevalence was higher among self-respondents (Group 1 + 2), with 72 (79 %) reporting LL history compared to 19 (21 %) reported by parents/caregivers. Lengthening on the legs only (legs) was the most common procedure, reported by 53 (11 %), followed by lengthening in both arms and legs, with 36 (7.7 %) responses, and arms-only lengthening (arms) being minimally identified, with only 2 (0.4 %) reports. Respondents reported specific side for lengthening as shown in Fig. 3. Of note only one respondent with a family history of achondroplasia (father) underwent LL (1/91).

The mean age at first limb lengthening surgery was 10.5 years (SD 4.5), with Group 2 reporting a higher mean age of 12 years (SD 4.0) compared to the age reported by parent/caregiver (5.8 years, SD 2.5).

On average, participants underwent 3.7 (SD 2.9) lengthening surgery cycles, with a mean total lengthening of 14.5 cm (SD 10.4) per limb with a total final adult height of 137.1 cm in women and 142.1 cm in men (reported by Group 2). Three self-respondents from Group 2 indicated an added length >40 cm. Group 2 reported 4.2 (SD 3.1) cycles and during these cycles, with Group 1 indicating 3.1 cycles (SD2.0). Only 17 respondents (19 %) had only one limb lengthening cycle. The number of cycles per group is presented in Table 2.

3.4. Quality of life changes

Participants who underwent limb lengthening reported significant improvements in several aspects of daily living with results presented in Fig. 4. Significant improvements were reported by 36 respondents after both legs and arms lengthening in driving ($p < 0.001$), in brushing hair ($p = 0.002$), wiping after toileting ($p = 0.044$), and bathing ($p = 0.031$). Other activities such as bathing, dressing, and walking up/downstairs showed improvements, although these were not statistically significant. In leg lengthening only, 53 respondents informed significant

Table 1
Sociodemographic data of the study participants. Categorical and continuous characteristics are given with n (%) and mean (SD) respectively.

		Overall	Group 1	Group 2	Group 3
		N = 467	*N* = 32	*N* = 197	*N* = 238
Are you the father/ mother/ other caregiver responding on behalf of your child?	Father	38 (8.1 %)	0 (0 %)	0 (0 %)	38 (16 %)
	Mother	196 (42 %)	0 (0 %)	0 (0 %)	196 (82 %)
	Caregiver	4 (0.9 %)	0 (0 %)	0 (0 %)	4 (1.7 %)
	Self	229 (49 %)	32 (100 %)	197 (100 %)	0 (0 %)
What is your sex?	Female	236 (51 %)	16 (50 %)	115 (58 %)	105 (44 %)
	Male	229 (49 %)	16 (50 %)	81 (41 %)	132 (55 %)
	Other	0 (0 %)	0 (0 %)	0 (0 %)	0 (0 %)
	No response	2 (0.4 %)	0 (0 %)	1 (0.5 %)	1 (0.4 %)
Current age (years)		19.7 (17.7)	14.4 (1.6)	37.0 (14.2)	6.0 (3.2)
Age group (years)	0 to <12	238 (51 %)	0 (0 %)	0 (0 %)	238 (100 %)
	12 to <18	32 (6.9 %)	32 (100 %)	0 (0 %)	0 (0 %)
	18+	197 (42 %)	0 (0 %)	197 (100 %)	0 (0 %)
Does your father or mother have achondroplasia	Yes, father	13 (2.8 %)	1 (3.1 %)	6 (3.0 %)	6 (2.5 %)
	Yes, mother	7 (1.5 %)	2 (6.3 %)	5 (2.5 %)	0 (0 %)
	Yes, both parents	1 (0.2 %)	0 (0 %)	0 (0 %)	1 (0.4 %)
	None	446 (96 %)	29 (91 %)	186 (94 %)	231 (97 %)
Current body height (cm)		112.5 (23.7)	126.4 (11.0)	132.5 (10.0)	93.5 (16.9)
Current weight (kg)		36.4 (20.7)	40.0 (8.4)	56.2 (12.6)	19.5 (9.6)

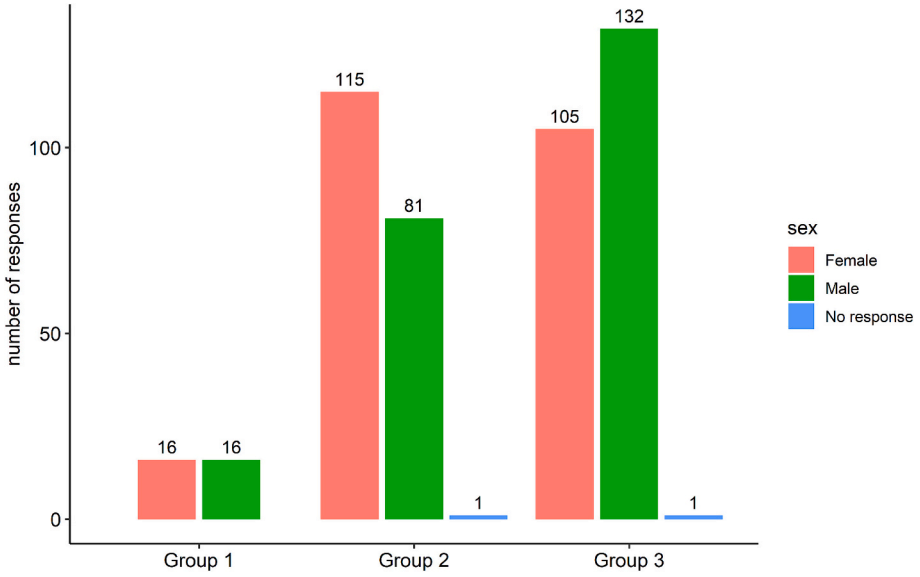

Fig. 2. Number of responses, distributed by groups and gender.

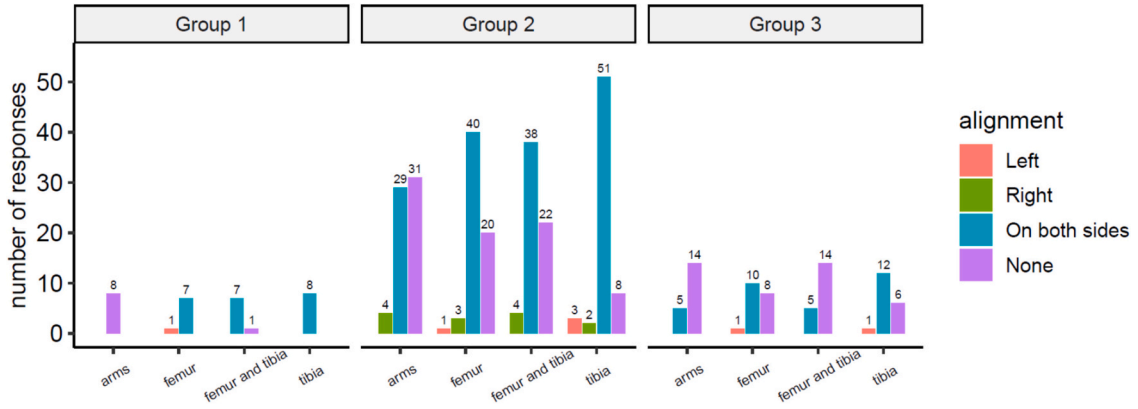

Fig. 3. Location of the lengthening surgery by groups.

Table 2
Number of cycles of limb lengthening reported in total and by groups.

	Total surgery	Group 1	Group 2	Group 3
Limb lengthening surgery cycles	$N = 90$	$N = 32$	N = 197	N = 238
1	17 (19 %)	2 (25 %)	10 (16 %)	5 (28 %)
2	23 (26 %)	1 (13 %)	15 (24 %)	7 (39 %)
3	16 (18 %)	2 (25 %)	10 (16 %)	4 (22 %)
4	6 (6.7 %)	2 (25 %)	3 (4.8 %)	1 (5.6 %)
5+	27 (30 %)	1 (13 %)	25 (40 %)	1 (5.6 %)

improvements in driving ($p = 0.007$).

3.5. Complications and challenges

While limb lengthening surgery led to improvements in various aspects of daily living, complications and challenges were also reported by 91 participants as free text. The responses were categorised into complication categories, with some responses falling into more than one category due to multiple complications being addressed in the response. The most common complications included pin site infections ($n = 25$), joint stiffness ($n = 19$), delayed bone healing ($n = 15$), asymmetrical walking ($n = 14$), and other reasons ($n = 17$), although not mentioned. Respondents from Group 1 reported 4 complications, from Group 2 this number increased to 73 and Group 3 reported 12 complications. Among all groups, 45/114 respondents indicated not having had complications (39 %).

Additionally, 81 respondents highlighted several challenges during the lengthening process including 31.9 months (SD 41.8) between the first and last lengthening surgery with extended periods of immobilization, with a mean time of 11.3 months (SD 15.1) using a wheelchair, post-surgeries.

3.6. Perspectives on limb lengthening

Participants also responded to free text questions about aspects that they considered to have improved (92 responses) or, conversely, worsened (68 responses) following limb lengthening. The responses were categorised as shown in Figs. 5 and 6, with some responses falling into more than one category due to multiple aspects being addressed in the response.

Among all responses, only 91 responded to the question of who the decision maker was to undergo limb lengthening across all three groups

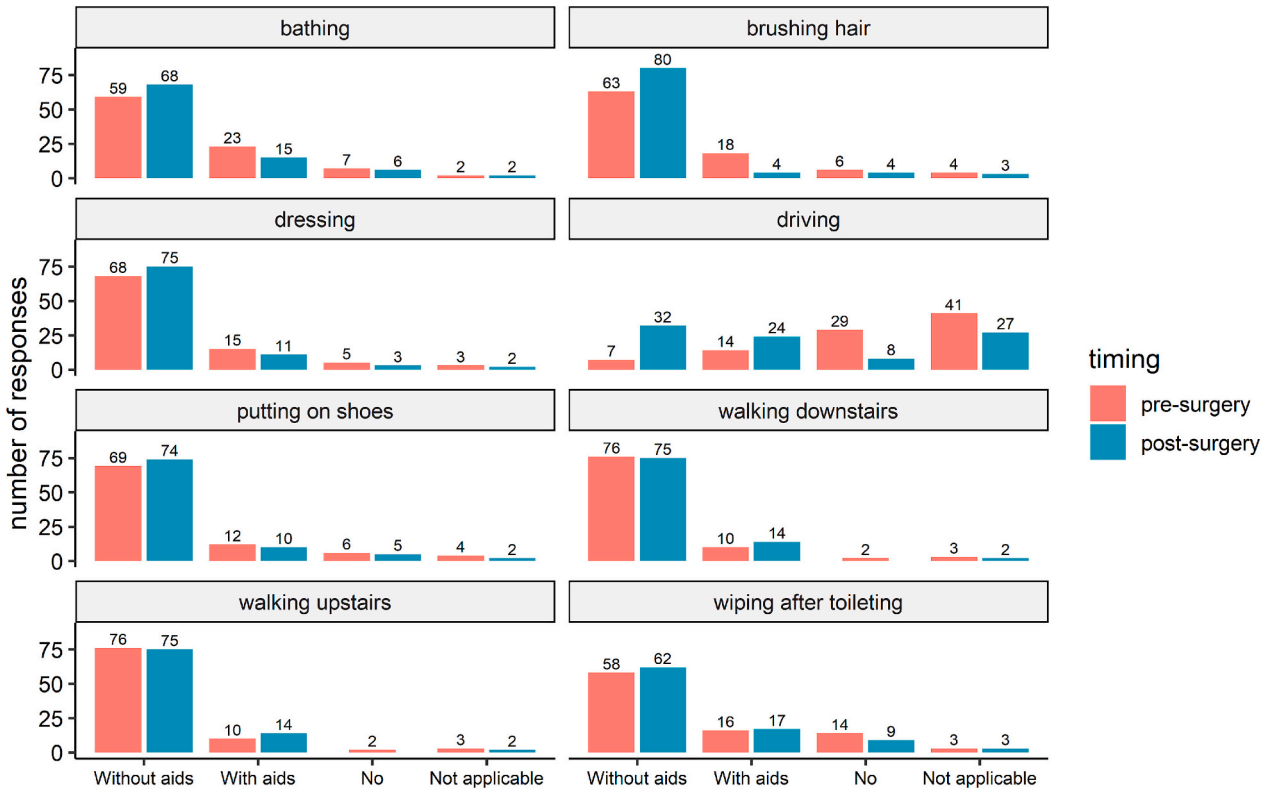

Fig. 4. Quality of life changes pre- and post-surgery for different daily living activities for the total samples (3 groups).

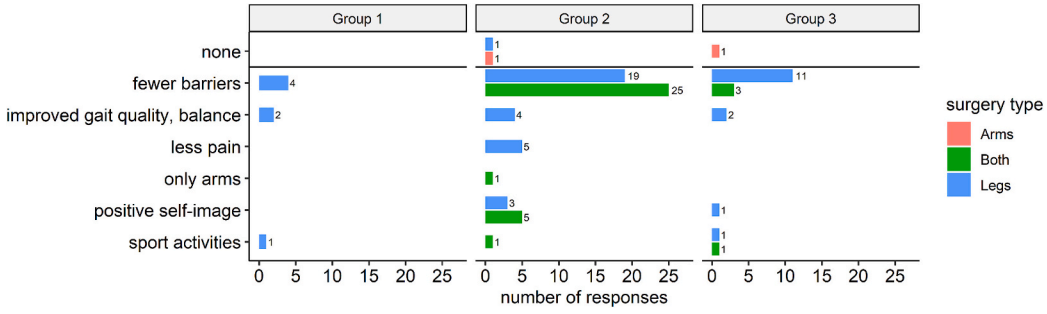

Fig. 5. Improved aspects after limb lengthening. This was a free-text question, and responses were categorised, with some assigned to multiple categories.

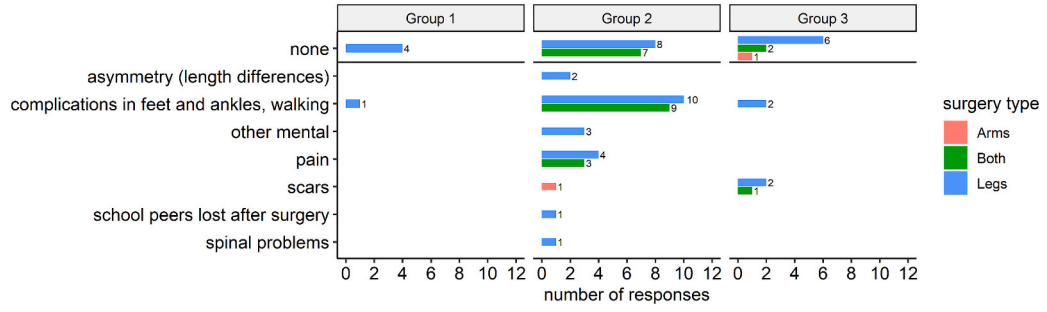

Fig. 6. Worsened aspects after limb lengthening. This was a free-text question, and responses were categorised, with some assigned to multiple categories.

(91/467). However, considering the responses it would appear to predominantly be a joint decision between the individual and their parents (n = 48, 53 %). Group 1 shared very limited information on this topic with only 8 responses in 32 respondents. It was balanced between own decision (25 %), parents' decision (38 %), and joint decision (38 %). For Group 2, consisting in adults with achondroplasia, a joint decision was the most indicated decision process by 35/197 (55 %) followed by own decision (n = 17, 27 %). At last, for Group 3, 19 parents responded and 10 indicated that it was a joint decision (53 %) while 8 informed it was the parents deciding (42 %).

Respondents gave free text reasons for their decision to undergo limb lengthening or not. These answers were organized in main topic groups. The main reasons indicated by Group 1 were "No specific reason" ($n = 7$) and "pain" ($n = 6$) while for Group 2 was acceptance of short stature ($n = 41$), followed by "no specific reason", "not beneficial", and due" time" needed for the full process. For Group 3 (parents, the main reason presented was the child being "too young" ($n = 99$), (Group 3), and "child should decide" ($n = 37$).

3.7. Recommendations

Regarding whether an individual would be recommending limb lengthening or not, 108 (23 %) respondents stated they would recommend limb lengthening while 130 (28 %) would not recommend. A larger portion of respondents (49 %) were uncertain about recommending or not. Interestingly, among the subgroups who underwent limb lengthening, 40 respondents from Group 2 would recommend it versus 9 who would not, while in Group 3, 14 parents would recommend it. There was no negative recommendation in this group when parents had experience of limb lengthening in their children, as presented in Fig. 7.

The most indicated reasons for not recommending were mostly presented by Group 2 and included acceptance of the condition, not being beneficial, pain, and time/social exclusion during the process, as shown in Fig. 8.

3.8. Self-reported versus parent-reported data

The "Extra data" group related to parent-reported data of children and adolescents aged between 12 to <18 years was compared to Group 1, of self-respondents with the same age range. This group comparison included a total of 101 participants: 32 in Group 1 and 69 in the Extra Data group.

Group 1 had a slightly higher mean age (14.4 years) compared to the Extra Data group (13.7 years), which was statistically significant ($p = 0.04$).

Both groups were comparable regarding sex spilt, current height (126 cm) and prevalence of limb lengthening surgery with 25 % of participants in both Group 1 and the Extra Data group had undergone limb lengthening surgery. For those who underwent surgery, some differences were observed, although not statistically significant. Attitudes towards recommending limb lengthening showed some differences between the groups, although not statistically significant. While in Group 1, 41 % would recommend and 31 % would not recommend, these percentages were of 33 % and 17 % respectively in Extra data group.

While many characteristics were similar between self-reported and parent-reported data for adolescents with achondroplasia, some notable differences emerged. Self-reporting adolescents (Group 1) tended to be slightly older, and reported later age at first surgery (10.4, SD 4.1 versus 8.8, SD 3.2), more procedures (3 surgery cycles versus 2 cycles), and greater total lengthening (18 cm, SD7 versus 14 cm, SD7).

4. Discussion

This multinational patient survey provides valuable insights into the real-world experiences of limb lengthening in achondroplasia, offering a comprehensive view of surgical prevalence, outcomes, quality of life changes, and decision-making processes across different countries and cultures. The survey revealed differences in limb lengthening surgery prevalence across groups, which may reflect changing attitudes towards the procedure over time or varying decision-making processes between generations.

Living with achondroplasia encompasses multiple physical, social, and emotional dimensions. Multiple everyday tasks may pose significant physical challenges, and social prejudice and stigma due to physical differences, creating physical and emotional challenges [21–24].

The limb lengthening process aims to restore body proportions, improve daily functioning, and enhance psychological well-being [11,25,26], yet it remains a controversial approach with significant variability in perspectives on limb lengthening across different countries and cultures [27] a high level of physical and emotional demands [28–30].

Improved functional outcome of limb lengthening intervention may be the most important focus for some individuals, while to others, their identity as an individual and as part of a group with short stature, is the focus. In addition, research and development of innovative therapies, are delivering new pharmacologic options. Currently, achondroplasia specific patient reported outcome measures are available [31,32] which can be of use to better understand the effects of therapies use and interventions in overall Quality of life.

The average age at first surgery (10.5 years) and the average total length gained per limb (14.5 cm) align with previous studies. Verdoni et al. (2023) reported a mean age of 11.7 years at first lengthening and Chilbule et al. (2016) noted gains of 10–15 cm per segment in their review of limb lengthening in achondroplasia [10,33]. However, the significant variability in outcomes, complications reported and the

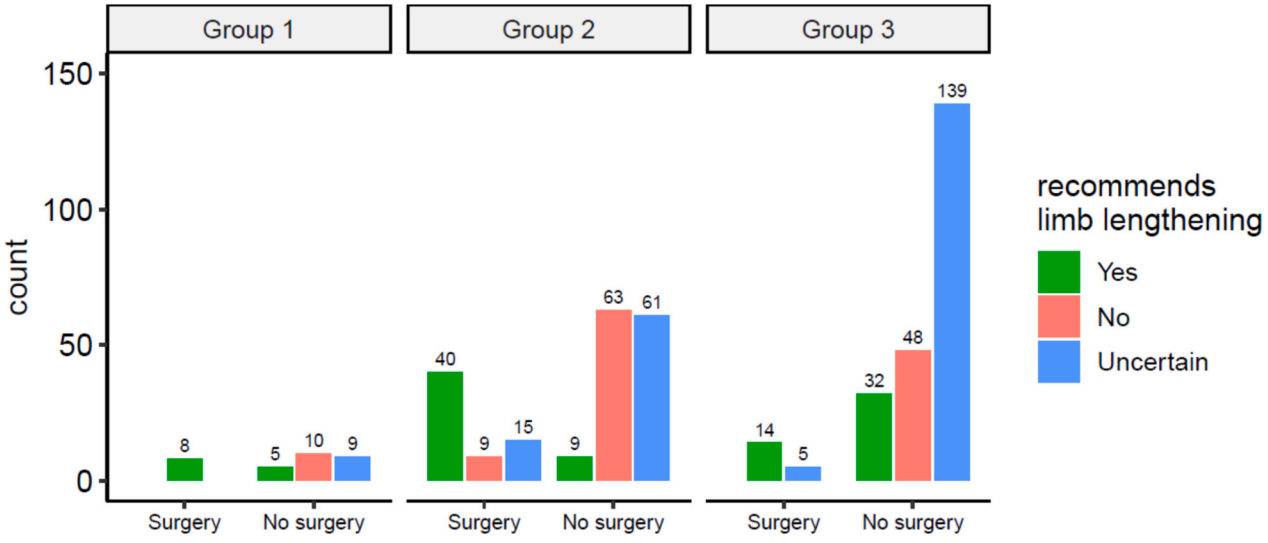

Fig. 7. Number of respondents that recommended or not recommended limb lengthening grouped by previous experience in limb lengthening or not.

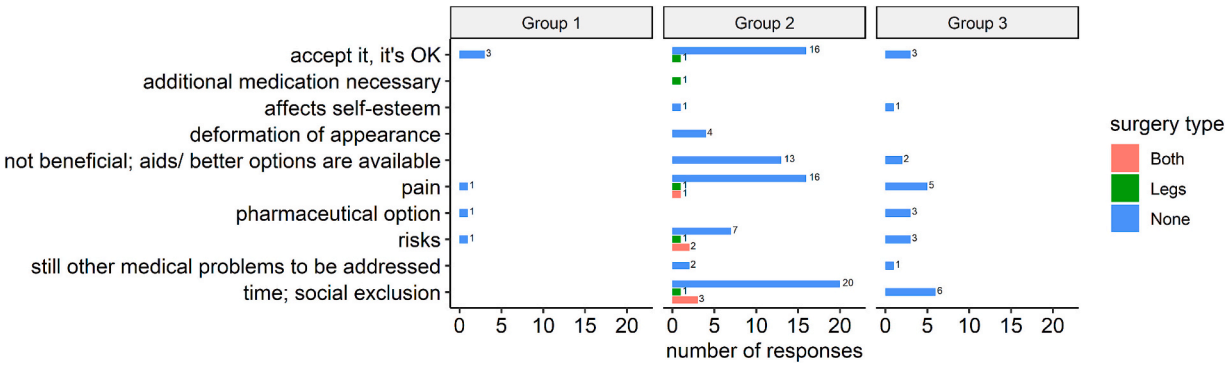

Fig. 8. Reasons for not recommending LL surgery presented by groups. This was a free-text question, and responses were categorised, with some assigned to multiple categories.

complexity of the decision-making process with potential risks involved [30,34], underscore the need for individualized treatment planning and comprehensive pre-operative counselling and post-operative support for individuals with achondroplasia and their families. Also, geographical differences in limb lengthening surgery should be interpreted cautiously due to varying sample sizes across countries.

While limb lengthening resulted in increased mean adult height, it's important to note that the mean reported final adult height (137.1 cm in women and 142.1 cm in men) was still below average population height [35], highlighting that the procedure aims to improve function rather than achieve average stature.

The comparison between self-reported and parent-reported data for adolescents with achondroplasia highlighted differences in attitudes towards recommending limb lengthening, emphasizing the importance of considering both self-reported and parent-reported data when assessing outcomes and perspectives. Self-respondents from Group 2 showed more polarized opinions on recommending limb lengthening, with higher rates for non-recommendation compared to the other two groups.

The survey also revealed that the decision to undergo limb lengthening was predominantly a joint decision between the individual and their parents across groups (38 %–53 %). However, the reasons for undergoing or not undergoing surgery varied significantly between groups. For self-respondents, acceptance of short stature and lack of perceived benefits were common reasons for not undergoing surgery, which may reflect the broader social and cultural contexts in which individuals with achondroplasia live, while for parents, the child's young age was the primary reason, as the surgical process tends to start between 9 and 11 years [6].

Physical limitations also affect movement, mobility, exercise [36], and participation in social activities, educational opportunities, and employment prospects [37]. In this context, limb lengthening surgery has emerged as an option to address some of these challenges, yet the pre- and post-surgery outcomes revealed no significant differences on these aspects. Significant improvements were noted in various activities of daily living, particularly for those who underwent both arm and leg lengthening.

These findings support previous studies that have reported enhanced functional capabilities post-surgery [38,39]. However, activities such as bathing, dressing, and walking up/downstairs showed improvements, were not statistically significant suggesting that some functional challenges may persist post-surgery [40].

Although the survey did not specifically address the impact of extended periods of immobilization, multiple surgical interventions and hospital stays, intensive physical therapy requirements and psychological stress related to the lengthy recovery process, often at an important developmental stage should be explored in future studies.

This survey underscores the complex nature of limb lengthening procedures and the need for comprehensive pre-operative counselling and post-operative support for patients and their families.

The heterogeneity in recommending limb lengthening (23 % recommend, 28 % would not and almost half were uncertain) underscores the complexity of decision-making regarding limb lengthening and reflects individualized risk-benefit considerations. The nuance of this complexity emphasizes the importance of comprehensive, person-centred care that addresses the physical, psychological, and social aspects of living with achondroplasia and warrants further investigation. Future research should explore how new treatments may impact surgical decision-making, optimal timing of interventions, and long-term outcomes when combined with limb lengthening procedures [41]. As new treatments emerge, continued research and open dialogue are essential to define its optimal role in a comprehensive, person-centred approach to achondroplasia care [42].

4.1. *Strengths and limitations*

This study offers several strengths that contribute to its reliability and relevance. The survey includes a large and diverse sample of individuals with achondroplasia and their families, providing a broad perspective on limb lengthening experiences across different countries and cultures. The comprehensive survey instrument, developed by an international multidisciplinary team, allowed for a detailed exploration of demographics, surgical experiences, outcomes, and perspectives. The inclusion of both self-reported and parent-reported data for adolescents with achondroplasia highlighted differences in attitudes towards recommending limb lengthening, emphasizing the importance of considering both self-reported and parent-reported data when assessing outcomes and perspectives.

However, while providing valuable insights, the survey has several limitations that should be considered when interpreting the results.

The cross-sectional nature of our study enabled responses of individuals that underwent surgery at different ages or life stages. While broadening the responses, it precluded time gap and temporal trends with varying experiences and perspectives which could have influenced respondents' recommendation of the surgical intervention.

As the survey collected perspectives from self-responders as from caregivers, it introduces heterogeneity and complexity in interpretation of results. Yet, combining perspectives provides a lifespan view of LL outcomes, which is pivotal for counselling families considering multistage interventions.

Also, as the tool used to collect responses was an online survey, this may have introduced potential for recall bias and inaccuracies. Participants may have over- or underestimated their experiences or outcomes, either intentionally or unintentionally. To mitigate this, we used validated scales where possible and provided clear instructions for reporting objective measures such as height and number of surgeries.

The voluntary nature of participation may have introduced selection bias as noted by Cheung et al. (2024), as individuals interested in or

having undergone limb lengthening may have been more likely to respond, potentially skewing the representation of experiences. To mitigate this, we made efforts to reach a diverse range of participants through various channels, including patient organizations, clinical networks, and social media.

The cross-sectional nature of the survey limits our ability to capture long-term outcomes and complications, which are crucial for a comprehensive understanding of the procedure's impact. Detailed data on complication rates and types were not fully captured, leaving an important aspect of the risk-benefit analysis incomplete. Also, it was not fully explored how the functional changes are perceived by participants in the context of their overall quality of life.

The survey spanned multiple countries, yet differences in individual options and experiences between countries were not analysed. The impact of different healthcare systems and cultural attitudes on decision-making and outcomes also was not explored. The survey did not capture specific data on the use of different surgical techniques or emerging pharmacological treatments which may significantly influence future surgical decisions and outcomes [3].

4.2. Implications for future research

Future research should focus on addressing the limitations identified in this study. Longitudinal studies are needed to capture long-term outcomes and complications. Additionally, studies should explore how new treatments may impact surgical decision-making, optimal timing of interventions, and long-term outcomes when combined with limb lengthening procedures. The development of standardized protocols and long-term follow-up studies will be essential to better understand and optimize outcomes.

Moreover, future studies should aim to capture detailed real-world data and efficacy studies of different surgical techniques and emerging pharmacological options and potential combinations. The impact of different healthcare systems and cultural attitudes on decision-making and outcomes should also be explored in more detail.

5. Conclusions

This multinational survey provides crucial insights into the complex landscape of limb lengthening in achondroplasia. The findings underscore the multifaceted nature of decision-making surrounding this procedure, highlighting both its potential benefits and significant challenges. The varied perspectives on decision-making process, the lived experience of undergoing limb lengthening and recommending or not this intervention reflect the procedure's complexity and the deeply personal nature of this decision. These findings call for enhanced individual and family education and support systems for guidance through the decision-making process considering medical factors as social and cultural considerations.

Furthermore, the findings raise the need for standardized protocols and long-term follow-up studies to better understand and optimize outcomes, particularly as new technologies and pharmacological options emerge.

CRediT authorship contribution statement

Christoph Beger: Writing – review & editing, Visualization, Software, Resources, Formal analysis, Data curation. **Inês Alves:** Writing – review & editing, Writing – original draft, Validation, Methodology, Investigation, Conceptualization. **Patricia Carl-Innig:** Writing – review & editing, Conceptualization. **Marco Sessa:** Writing – review & editing. **Klaus Mohnike:** Writing – review & editing, Conceptualization. **Moira S. Cheung:** Writing – review & editing, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

Data will be made available on request.

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