

Inconvenience and adaptation in Japanese adult achondroplasia and hypochondroplasia: A cross-sectional study

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Highlights

- A lot of inconveniences were described in adult ACH/HCH patients.
- Individual adaptations by ACH/HCH patients improved only some parts of problems.
- Social supports are needed to resolve inconveniences in ACH/HCH patients.

Abstract. The health-related quality of life is reduced in patients with achondroplasia (ACH) and hypochondroplasia (HCH); however, the detailed inconveniences in the daily living and individual adaptations have not been elucidated. This study aimed to evaluate the inconvenience and adaptation in patients with ACH/HCH. A cross-sectional study was conducted in patients with ACH/HCH aged 20 yr or older. Questionnaires were sent to 567 patients (described 86) with a medical history at the co-authors' institutions or who were registered at the patients' association with ACH in Japan. The questionnaire included a free description format for the inconveniences and adaptations in daily living; a content analysis was performed. The recorded inconveniences included 148 physical, 84 mental, and 52 social problems. Patients who underwent spine surgery had significantly more recorded physical problems than those who did not ($p < 0.05$). Pain and numbness were significantly higher in patients aged ≥ 50 yr ($p < 0.05$). The 160 and 1 adaptations were for physical and social problems, respectively. No patient adaptation was found for mental health problems. Individual adaptations by ACH/HCH patients can improve only some aspects of physical and social problems. Multilateral social support is needed to resolve patients' issues.

Key words: achondroplasia, hypochondroplasia, HRQoL, inconvenience, adaptation

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Introduction

Achondroplasia (ACH) is a common skeletal dysplasia with short-limbed stature caused by a gain-of-function mutation in the fibroblast growth factor receptor 3 (FGFR3) gene (1, 2). In addition, ACH is characterized by frontal bossing, midface hypoplasia, trident hand, elbow contracture, and lumbar lordosis (3). Children with ACH occasionally require surgery for foramen magnum stenosis, which causes severe complications, such as sleep apnea, hydrocephalus, paralysis, and sudden death (4). Spinal canal stenosis is also associated with ACH, and the rate of spinal surgery increases with age (5). Hypochondroplasia (HCH) is a mild skeletal form of ACH; however, patients with HCH also have short stature and spinal canal stenosis (6). Although some FGFR3 inhibitors have been developed for the treatment of ACH/HCH (6–8), growth hormone administration is the only medical treatment for short stature (9, 10). Limb lengthening surgery is another symptomatic therapy; however, it is a major burden for patients (11, 12).

The health-related quality of life (HRQoL) has been assessed in the field of achondroplasia. In the Little People of America (LPA) study, the HRQoL scores of the physical and mental domains in adult patients with ACH were significantly lower than those of the normal population (13). The physical component summary (PCS) was ameliorated in patients with a height of 140 cm or taller; additionally, low PCS and mental component summary (MCS) were found in patients with a past medical history of spine surgery (14). In a Norwegian study, the patients with ACH associated with symptomatic spinal stenosis showed lower scores on the Health Assessment Questionnaire (5). These studies comprehensively assessed the patients' HRQoL based on the scoring system; however, they have a limited knowledge of the specific inconveniences or difficulties in the daily lives of the patients, which seems to be important in determining the patients' support and care (15, 16). Instead of using scores, free descriptions of their inconveniences or difficulties in daily living could have a direct impact on their QoL and also have important implications for the social welfare and support for the patients with ACH. The purpose of this study was to determine the inconvenience and to evaluate the sufficiency of individual adaptations in Japanese patients with ACH/HCH.

Materials and Methods

Study design, setting, and participants

This was a cross-sectional study. A questionnaire with a description of the study rationale and consent form was sent to eligible patients in July 2016. The answered questionnaire and written consent form were collected until March 2018. Although some of the data have already been reported (14), this study specifically

focused on the content of the free description format.

The eligibility criteria were ACH or HCH patients aged 20 yr or older, who had a medical history of ACH at the co-authors' institutions, or who were registered at the patients' associations in Japan (Fig. 1). Some patients received duplicated questionnaires because they had a medical history at the co-authors' institutions and were registered at the patients' associations. If the patients received duplicated questionnaires, they returned only one questionnaire. The patients who were unable to complete the Japanese consent form or questionnaire were excluded. The patients who responded to the questionnaire were given a gift card for 500 yen as a participation incentive.

Questionnaire

The front cover of the questionnaire included entry columns for the signature, date of birth, and the date of registration. The general demographic questionnaire included the recent weight, height, and past surgical history of the participant. The questionnaire included "Inconveniences in daily living or something to be concerned about one's own future" (inconvenience) and "Adaptations to improve inconveniences" (adaptation) as a free description format. The participants were allowed to detail the answers to the inconveniences and adaptations at their will.

Data analysis

Free descriptions of the inconveniences and adaptations were evaluated based on content analysis (17, 18). The patients' inconveniences and adaptations were extracted from the free descriptions after identifying the phrases. The meaning units extracted from the patients' comments were condensed and coded. The same meaning codes were integrated into one subcategory by discussion until a consensus was reached between the two authors. Eventually, the homogeneous subcategories were grouped into one category. Each category was divided into three themes (physical, mental, and social problems).

The inter-rater reliability of category and theme was determined by four authors based on the calculation

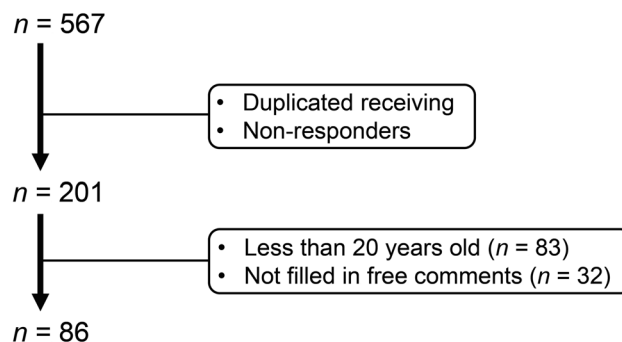


Fig. 1. Flow chart of eligible participants.

formula of Scott (19). The classification was accepted if the inter-rater reliability was greater than or equal to 0.61 (20, 21). Finally, the number of comments grouped into subcategories was counted (22).

In a previous study, we demonstrated that the HRQoL was strongly associated with the past medical history of spine surgery and patient age (14). Both the PCS and role/social component summary (RCS) significantly deteriorated in patients who had a history of spine surgery or who were 50 yr of age or older. Therefore, the participants who described the inconveniences were divided into two groups based on: a past history of spine surgery and no past history of spine surgery; and age less than 50 yr of age and over 50 yr of age. The number of categories and themes were compared between the groups.

Statistical analysis

A chi-square test was performed to compare the number of categories and themes between each group. The Fisher's exact test was used when the sample number was less than five. Statistical significance was set at $p < 0.05$. All the analyses were performed using SPSS version 24 (IBM Corporation, Armonk, NY, USA).

Results

Participants

The total number of eligible patients was 567. Among 201 patients who returned their questionnaires, 83 patients were of age < 20 yr old, and 32 patients did not provide free comments for the inconveniences. Thus, 86 patients were included in the current study (Fig. 1). The participant characteristics are shown in Table 1. There were 78 ACH and four HCH patients, and the remaining four patients were diagnosed with either ACH or HCH. Among them, the FGFR3 mutation was confirmed in 17 patients with ACH. A total of 65 out of 86 patients provided free comments for the adaptations.

Several physical, mental, and social problems were noted in ACH/HCH patients

The contents extracted from the free format were integrated into 22 subcategories (Fig. 2A). The most recorded subcategory was 'Pain and numbness' ($n = 43$), followed by 'Concerning the medical condition and daily living' in the future ($n = 42$), 'Difficulty due to short-limbed short stature' in daily living ($n = 37$), and 'Problems in the office' ($n = 22$). These subcategories were divided into ten categories and three themes. The inter-rater reliability for the categories and themes were 0.81 and 1.0, respectively. There were 148, 84, and 52 participants, who recorded physical, mental, and social problems, respectively.

Table 1. Patient demographics

Characteristics	n (%)
Diagnosis	
ACH	78 (90.7)
HCH	4 (4.7)
ACH or HCH	4 (4.7)
Sex	
Male	31 (36.0)
Female	54 (62.8)
No response	1 (1.2)
Age	
Mean age (SD) (yr)	34.3 (12.1)
Less than 50 yr old	75 (87.2)
50 yr or older	11 (12.8)
BMI	
Mean BMI (SD)	28.4 (5.6)
Past history of spine surgery	
Yes	31 (36.0)
No	53 (61.6)
No response	2 (2.3)
Adaptations	
Answered	65 (75.6)
No answered	21 (24.4)

ACH, Achondroplasia; HCH, Hypochondroplasia; SD, Standard deviation; BMI, body mass index.

Additional physical problems were extracted in the patients who had a past spine surgery

Physical problems were significantly more common in ACH/HCH patients, who had a history of spine surgery compared with those without spine surgery, while there was no statistical difference in the mental and social problems between the groups (Table 2). In the analysis of the comment rate of the category, the patients who underwent spine surgery tended to have additional descriptions regarding daily living, pain, and numbness.

More pain and numbness were described in older patients

Next, the effect of age on the comment rate of each category was evaluated. The comment rate of 'pain and numbness' was significantly increased in the patients aged 50 yr or older compared with those aged < 50 yr (Table 2).

Adaptations in individual ACH/HCH patients improved only some parts of inconveniences

The adaptations to improve the inconveniences were integrated into 11 subcategories (Fig. 2B). These subcategories were categorized as daily living, moving, pain and numbness, and the office. The inter-rater reliability for each category was 0.82. Additional recorded numbers of adaptations rather than inconveniences were observed only in 'Daily living' and 'Moving' (Fig. 2C).

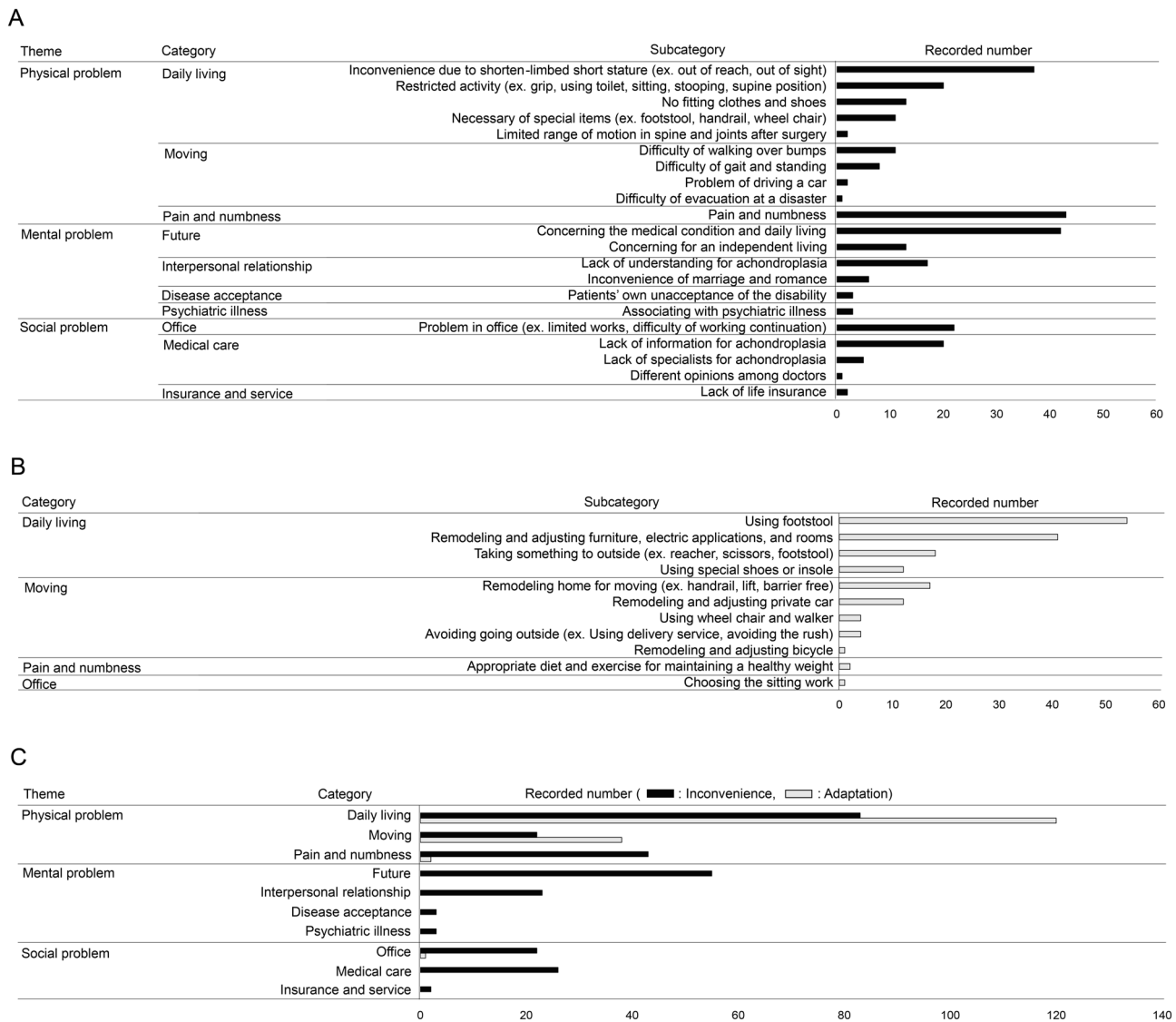


Fig. 2. Inconveniences and adaptations described from ACH/HCH patients: A. Themes, categories, and subcategories of inconvenience. B. Category and subcategory of adaptation. C. Theme and category of patients' inconvenience and adaptation. The recorded number of each subcategory and category was shown as a bar graph.

Discussion

The current study indicated that there were various inconveniences in patients with ACH/HCH categorized as physical, mental, and social problems. 'Difficulty due to short-limbed short stature' was a major physical problem. Pauli (23) reviewed examples of inconveniences due to shortening of the limbs in patients with ACH, such as sitting on a standard chair, bottom wiping, and driving a car. For these adaptations, he indicated a modified chair to allow for back and foot support, bottom wiper used for perineal hygiene, and pedal extenders for driving. The current study also demonstrated several inconveniences and adaptations. However, the adaptations were limited to some physical and social problems.

The majority of the ACH/HCH patients described "pain and numbness". However, there were few individual adaptations for this problem. These symptoms

seem to be mainly caused by spinal canal stenosis, which is a common complication in adult ACH/HCH (5, 24). However, only a few adaptations seem to be available for patients with ACH/HCH to ameliorate pain and numbness. Although spine surgery was occasionally considered when treating pain and numbness, ACH/HCH patients with a history of spine surgery were likely to experience pain and numbness. A previous HRQoL study also demonstrated that the physical component summary score was significantly decreased in the patients with ACH who had a history of spine surgery (14).

The most common mental problem was "concerning the medical condition and daily living in the future". An HRQoL survey among the adult members of the LPA showed that the patients aged 40 yr had a lower physical HRQoL (13). A previous study also demonstrated that aging led to a significant decrease in the physical

Table 2. Comment rate for each group

		Past his- tory of spine surgery (n = 31)	No past his- tory of spine surgery (n = 53)	p	Less than 50 yr old (n = 75)	50 yr or older (n = 11)	p
		n (%)	n (%)		n (%)	n (%)	
Theme	Physical problem	23 (74.2)	27 (50.1)	0.036	42 (56.0)	9 (81.8)	0.104
	Mental problem	22 (71.0)	32 (61.5)	0.329	48 (64.0)	8 (72.7)	0.571
	Social problem	13 (41.9)	21 (39.6)	0.835	30 (40.0)	4 (36.4)	0.818
Category	Daily living	13 (41.9)	14 (26.4)	0.142	25 (33.3)	3 (27.3)	1.000
	Moving	6 (19.4)	8 (15.1)	0.613	12 (16.0)	3 (27.3)	0.397
	Pain and numbness	14 (45.2)	16 (30.2)	0.167	23 (30.7)	8 (72.7)	0.015
	Future	16 (51.6)	25 (47.2)	0.694	37 (49.3)	6 (54.5)	0.747
	Interpersonal relationship	9 (29.0)	10 (18.9)	0.283	16 (21.3)	3 (27.3)	0.701
	Disease acceptance	1 (3.2)	2 (3.8)	1.000	3 (4.0)	0 (0.0)	1.000
	Psychiatric illness	2 (6.5)	1 (1.9)	0.552	2 (2.7)	1 (9.1)	0.340
	Office	7 (22.6)	12 (22.6)	0.995	18 (24.0)	1 (9.1)	0.443
	Medical care	7 (22.6)	11 (20.8)	0.844	15 (20.0)	3 (27.3)	0.692
	Insurance and service	1 (1.9)	1 (3.2)	1.000	1 (1.3)	1 (9.1)	0.241

HRQoL (14). Future age-related deteriorating physical functions may develop in the patients with ACH. Interpersonal relationships are also an issue for mental problems. Similar to the listed subcategories of “Lack of understanding of ACH” in general, the reported disadvantages of ACH included teasing, staring, too much attention, general discrimination, prejudice, inaccurate expectations by others, stigma, difficulties in personal relationships, dating, socializing, inappropriate comments, and rudeness (25). Since no adaptation was described for the mental problems in the current study, the mental problems could not be resolved by the individual efforts of the patients. The LPA study also indicated that there were factors of lower mental HRQoL, including a poor access to health care, short duration of insurance, lack of social support from family and friends, and treatment differently by medical professionals due to height (13). Social support is needed to resolve the mental problems associated with ACH/HCH.

The major social problems for ACH/HCH were “problems in office” and “lack of information for achondroplasia” in the current study. The patients with ACH have limited career choices, issues of unemployment, and reduced income (25). The exercise capacity in ACH/HCH patients was lower than that in the general population (26). Ireland *et al.* (27) indicated that exercise-induced fatigue, decreased muscle mass, and reduced neuromuscular coordination decreased the opportunity for social participation and self-care performance. They also stated that there were fewer opportunities for employment in patients with ACH due to complications, such as spinal canal stenosis and lower limb pain. Although resolving physical problems could lead to a reduction in office problems, medical treatment and individual effort alone could not resolve the physical issues in ACH/HCH. Social support from family, friends,

and colleagues is required (13). Regarding rare diseases, there is less information about patients’ activities (28). Due to the fewer opportunities to obtain information about their own disease for ACH/HCH patients, not only improving the access to health care, but also increasing the number of ACH/HCH specialists is needed.

There has been a lot of therapeutic research on the interventions for physical problems; however, no research has been conducted on social participation (28). Medical intervention and individual adaptations will not provide a comprehensive solution to the problem of ACH/HCH patients. In a survey of adolescents in Nepal, the psychological well-being was observed to be higher when they had support from family and friends (29). In asthma HRQoL studies, a lower HRQoL was found in patients with a lack of reliance on and difficulty in getting help (30, 31). The social environment maintained with unrestricted mobility and networks had an effect on the daily living in patients with a spinal cord injury (32). Multilateral social support is needed to resolve physical, mental, and social problems.

There were potential biases in the free-description format. First, we excluded patients who did not describe the inconveniences in a free-described format. In addition, the patients did not always have any inconveniences. Second, we extracted the subcategories from the two authors. There was a potential risk of missing the recorded content. Third, the diagnoses of ACH or HCH were self-reported based on the questionnaire survey. Fourth, the recovery rate was low. A larger number of participants would be required to draw firm conclusions. Lastly, this was a Japanese study; therefore, the results may not be generally applicable since the social background varies among different countries.

Conclusions

The patients with ACH/HCH have various physical, mental, and social inconveniences. Medical interventions can only ameliorate some physical problems. Notably, the individual adaptations by ACH/HCH patients improved some physical problems and only a few social problems. Multilateral social support is needed to resolve the physical, mental, and social problems of the patients.

Conflicts of Interests: The authors declare no conflicts of interest in connection with the submitted article.

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References

- Rousseau F, Bonaventure J, Legeai-Mallet L, Pelet A, Rozet JM, Maroteaux P, *et al.* Mutations in the gene encoding fibroblast growth factor receptor-3 in achondroplasia. *Nature* 1994;371: 252–4. [[Medline](#)] [[CrossRef](#)]
- Shiang R, Thompson LM, Zhu YZ, Church DM, Fielder TJ, Bocian M, *et al.* Mutations in the transmembrane domain of FGFR3 cause the most common genetic form of dwarfism, achondroplasia. *Cell* 1994;78: 335–42. [[Medline](#)] [[CrossRef](#)]
- Horton WA, Hall JG, Hecht JT. Achondroplasia. *Lancet* 2007;370: 162–72. [[Medline](#)] [[CrossRef](#)]
- Hecht JT, Francomano CA, Horton WA, Annegers JF. Mortality in achondroplasia. *Am J Hum Genet* 1987;41: 454–64. [[Medline](#)]
- Fredwall SO, Steen U, de Vries O, Rustad CF, Eggesbø HB, Weedon-Fekjær H, *et al.* High prevalence of symptomatic spinal stenosis in Norwegian adults with achondroplasia: a population-based study. *Orphanet J Rare Dis* 2020;15: 123. [[Medline](#)] [[CrossRef](#)]
- Ornitz DM, Legeai-Mallet L. Achondroplasia: Development, pathogenesis, and therapy. *Dev Dyn* 2017;246: 291–309. [[Medline](#)] [[CrossRef](#)]
- Kitoh H, Matsushita M, Mishima K, Nagata T, Kamiya Y, Ueda K, *et al.* Pharmacokinetics and safety after once and twice a day doses of meclizine hydrochloride administered to children with achondroplasia. *PLoS One* 2020;15: e0229639. [[Medline](#)] [[CrossRef](#)]
- Savarirayan R, Irving M, Bacino CA, Bostwick B, Charrow J, Cormier-Daire V, *et al.* C-type natriuretic peptide analogue therapy in children with achondroplasia. *N Engl J Med* 2019;381: 25–35. [[Medline](#)] [[CrossRef](#)]
- Harada D, Namba N, Hanioka Y, Ueyama K, Sakamoto N, Nakano Y, *et al.* Final adult height in long-term growth hormone-treated achondroplasia patients. *Eur J Pediatr* 2017;176: 873–9. [[Medline](#)] [[CrossRef](#)]
- Kanaka-Gantenbein C. Present status of the use of growth hormone in short children with bone diseases (diseases of the skeleton). *J Pediatr Endocrinol Metab* 2001;14: 17–26. [[Medline](#)] [[CrossRef](#)]
- Kitoh H, Mishima K, Matsushita M, Nishida Y, Ishiguro N. Early and late fracture following extensive limb lengthening in patients with achondroplasia and hypochondroplasia. *Bone Joint J* 2014;96-B: 1269–73. [[Medline](#)] [[CrossRef](#)]
- Paley D. Problems, obstacles, and complications of limb lengthening by the Ilizarov technique. *Clin Orthop Relat Res* 1990; 81–104. [[Medline](#)]
- Dhiman N, Albaghdadi A, Zogg CK, Sharma M, Hoover-Fong JE, Ain MC, *et al.* Factors associated with health-related quality of life (HRQOL) in adults with short stature skeletal dysplasias. *Qual Life Res* 2017;26: 1337–48. [[Medline](#)] [[CrossRef](#)]
- Matsushita M, Kitoh H, Mishima K, Yamashita S, Haga N, Fujiwara S, *et al.* Physical, mental, and social problems of adolescent and adult patients with achondroplasia. *Calcif Tissue Int* 2019;104: 364–72. [[Medline](#)] [[CrossRef](#)].
- Edwards RD, Brenowitz WD, Portacolone E, Covinsky KE, Bindman A, Glymour MM, *et al.* Difficulty and help with activities of daily living among older adults living alone with cognitive impairment. *Alzheimers Dement* 2020;16: 1125–33. [[Medline](#)] [[CrossRef](#)]
- Río-González Á, Molina-Rueda F, Palacios-Ceña D, Alguacil-Diego IM. Living with lymphoedema-the perspective of cancer patients: a qualitative study. *Support Care Cancer* 2018;26: 2005–13. [[Medline](#)] [[CrossRef](#)]
- Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008;62: 107–15. [[Medline](#)] [[CrossRef](#)]
- Greenfield JA, Kimberly LL, Berman ZP, Ramly EP, Alfonso AR, Lee O, *et al.* Perceptions of Quality of Life among face transplant recipients: A Qualitative content analysis. *Plast Reconstr Surg Glob Open* 2020;8: e2956. 10.1097/GOX.0000000000002956. [[Medline](#)]
- Scott WA. Reliability of content analysis: The case of nominal scale coding. *Public Opin Q* 1955;19: 321–5. [[CrossRef](#)]
- Freitas Á, Santana P, Oliveira MD, Almendra R, Bana E Costa JC, Bana E Costa CA. Indicators for evaluating European population health: a Delphi selection process. *BMC Public Health* 2018;18: 557. [[Medline](#)] [[CrossRef](#)]
- Hallgren KA. Computing inter-rater reliability for observational data: an overview and tutorial. *Tutor Quant Methods Psychol* 2012;8: 23–34. [[Medline](#)] [[CrossRef](#)]
- Pollack LO, McCune AM, Mandal K, Lundgren JD. Quantitative and qualitative analysis of the quality of life of individuals with eating disorders. *Prim Care Companion CNS Disord* 2015;17: 10. 10.4088/PCC.14m01667. [[Medline](#)]
- Pauli RM. Achondroplasia: a comprehensive clinical review. *Orphanet J Rare Dis* 2019;14: 1. [[Medline](#)] [[CrossRef](#)]
- Hunter AG, Bankier A, Rogers JG, Sillence D, Scott Jr CI. Medical complications of achondroplasia: a multicentre patient review. *J Med Genet* 1998;35: 705–12. [[Medline](#)] [[CrossRef](#)]

25. Gollust SE, Thompson RE, Gooding HC, Biesecker BB. Living with achondroplasia in an average-sized world: an assessment of quality of life. *Am J Med Genet A* 2003;120A: 447–58. [[Medline](#)] [[CrossRef](#)]
26. Takken T, van Bergen MW, Sakkars RJ, Helder PJ, Engelbert RH. Cardiopulmonary exercise capacity, muscle strength, and physical activity in children and adolescents with achondroplasia. *J Pediatr* 2007;150: 26–30. [[Medline](#)] [[CrossRef](#)]
27. Ireland PJ, McGill J, Zankl A, Ware RS, Pacey V, Ault J, *et al.* Functional performance in young Australian children with achondroplasia. *Dev Med Child Neurol* 2011;53: 944–50. [[Medline](#)] [[CrossRef](#)]
28. Ireland PJ, Pacey V, Zankl A, Edwards P, Johnston LM, Savarirayan R. Optimal management of complications associated with achondroplasia. *Appl Clin Genet* 2014;7: 117–25. [[Medline](#)] [[CrossRef](#)]
29. Poudel A, Gurung B, Khanal GP. Perceived social support and psychological wellbeing among Nepalese adolescents: the mediating role of self-esteem. *BMC Psychol* 2020;8: 43. [[Medline](#)] [[CrossRef](#)]
30. Adeyeye OO, Adewumi TA, Adewuya AO. Effect of psychological and other factors on quality of life amongst asthma outpatients in Lagos, Nigeria. *Respir Med* 2017;122: 67–70. [[Medline](#)] [[CrossRef](#)]
31. Rashid A, Mohd R. Poor social support as a risk factor for antenatal depressive symptoms among women attending public antenatal clinics in Penang, Malaysia. *Reprod Health* 2017;14: 144. [[Medline](#)] [[CrossRef](#)]
32. Alve YA, Bontje P. Factors influencing participation in daily activities by persons with spinal cord injury: lessons learned from an international scoping review. *Top Spinal Cord Inj Rehabil* 2019;25: 41–61. [[Medline](#)] [[CrossRef](#)]