ORIGINAL REPORT

RELEVANT AREAS OF FUNCTIONING IN PEOPLE WITH ADOLESCENT IDIOPATHIC SCOLIOSIS ON THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH: THE PATIENTS' PERSPECTIVE

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Objective: To investigate relevant aspects of functioning and disability, and environmental factors in people with adolescent idiopathic scoliosis according to patients' self-reports based on the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY).
Design: Multicentre, empirical, cross-sectional study.
Setting: Four departments of orthopaedics in 4 hospitals, and 5 departments of rehabilitation medicine in 5 hospitals.
Methods: Semi-structured interviews were conducted with 975 patients with adolescent idiopathic scoliosis from 5 hospitals according to the patients' self-reporting. In addition, patients were divided into 3 groups according to clinical outcome. Participant information included demographic and disease-related characteristics. Three adolescent idiopathic scoliosis groups were then compared with respect to the problems identified. Interviews were transcribed verbatim. Categories identified by qualitative analysis were subsequently mapped to the ICF-CY using established linking rules. In order to enrich these findings, we also translated the Scoliosis Research Society 22 Patient Questionnaire (SRS-22 PQ) into the language of the ICF-CY, based on ICF linking rules.
Results: A total of 1278 themes that linked to 54 ICF-CY categories from 18 chapters were identified. Twenty-two (41%) categories were identified as Body Functions, 7 (13%) as Body Structures, 15 (27%) as Activities and Participation, and 10 (19%) as Environmental Factors. Of the 54 categories, 45 (83%) were second-level, 5 (9%) were third-level, and 4 (7%) were fourth-level. Differences between the SRS-22 PQ results and our findings were observed for several ICF-CY categories.
Conclusion: Patients with AIS reported activity limitations and participation restrictions combined with impaired body structures and functions. Environmental factors may act as a barrier to, or facilitator of, patient functioning in daily life. The ICF-CY provides a valuable framework for representing the complexity and multifaceted impact of AIS, and for comparing and examining the content of the SRS-22 PQ for AIS in children and adolescents. These results will be used to develop ICF Core Sets for AIS in China.

Key words: adolescent idiopathic scoliosis; international classification of functioning, disability and health; patient perspective; qualitative research, Scoliosis Research Society-22 Patient Questionnaire.

INTRODUCTION

Adolescent idiopathic scoliosis (AIS) has been defined as a complex 3-dimensional deformity of the spine and trunk occurring in children and youth (1). Although the precise aetiology of AIS remains unknown, the main causes appear to be genetic predisposition, connective tissue abnormalities, and skeletal, muscular and neurological disturbances during growth (2, 3). AIS may result in significant disturbance of body morphology, reduced thoracic volume, impaired spinal mobility and respiration, decreased trunk balance, increased rates of back pain, and serious aesthetic concerns, activity limitations and decreased quality of life (4, 5).

Early clinical detection of scoliosis relies on careful examination of trunk shape and is subject to screening programmes in some regions (6). Management options in AIS include conservative and operative modalities, e.g. physiotherapy, psychological therapies, corrective bracing, or surgery for mild, moderate, or severe scoliosis (7). These modalities should be fine-tuned to the patient's living circumstances, including education and home environments, as well as to personal factors, such as age, sex, complications, disease prognosis, psychosocial aspects, and physical potential (8). It is therefore important that health professionals recognize that comprehensive and multifaceted assessments vary across both the health domain assessed (e.g. impairment levels vs social participation) and the patients' perspective (patient view/perceptions vs clinician view/perceptions), in order to accurately capture the extent and severity of the unique difficulties faced by children and young people with AIS (9).

The International Classification of Functioning, Disability and Health (ICF) (10) and its paediatric version, the ICF for Children and Youth (ICF-CY) (11) provide a comprehensive description of, and reference for, the components of health (12). In addition, it offers a universal language that is understood by health professionals, researchers, policymakers, patients and patient organizations (13). Although its classifications with more than 1,600 categories can serve as a reference, the ICF-CY is not easily applicable in clinical practice (14). Therefore, ICF-CY-based tools are needed to facilitate its application in the case of AIS.

To improve the utility and application of the ICF framework in clinical and research settings, ICF-based tools, such as the ICF Core Sets, have been developed for some adult health conditions or different situation (15, 16). The Core Sets facilitate the use of ICF terminology to formulate clinical reasoning, describe the results of clinical comprehensive assessment, deliver a patient's needs, determinate goals of interventions and evaluate effects of interventions (17). According to the methodology endorsed by the World Health Organization (WHO) for development of ICF Core Sets, 4 independent studies need to conduct and reflect the perspectives of professionals, researchers, clinical opinion, and patients or (and) caregivers on relevant areas of functioning to gather evidence to support the selection of the categories (18).

However, to our knowledge, no qualitative study has applied the ICF-CY coding system to AIS to describe functioning and disability from the perspective of patients. Our research team explored the ICF Core Sets for children and adolescents with AIS with regard to the Chinese clinical and cultural environment. The data collected was integrated into data from other research. The aim of this study was to investigate relevant aspects of functioning and disability as well as environmental factors in patients with AIS using patients' self-reports based on the ICF-CY in China.

METHODS

Study design

The study was a multi-centre cross-sectional study carried out in 5 hospitals in China and approved by the Zhongnan Hospital of Wuhan University, Wuhan (Department of Orthopaedics and Department of Rehabilitation Medicine), China–Japan Friendship Hospital, Beijing (Department of Orthopaedics and Department of Rehabilitation Medicine), Boai Hospital of Chinese Rehabilitation Research Center, Beijing (Department of Rehabilitation Medicine), Third People Hospital of Beijing University (Department of Orthopaedics and Department of Rehabilitation Medicine), and the West China Hospital of Sichuan University (Department of Orthopaedics and Department of Rehabilitation Medicine) Research Ethics Board. Patients with AIS were recruited from 5 different centres over a period of 12 months (between August 2014 and July 2015). The qualitative study was conducted using semi-structured interviews. Relevant areas of functioning were examined through patients' self-reports, using the ICF-CY framework (11).

Study population

Patients participating in individual interviews had to meet the following inclusion criteria: diagnosis of AIS made by a health professional based on radiography of the spine revealing its deformity (Cobb angle $\geq 10°$), age 12–18 years; and able to communicate effectively. All subjects provided informed written consent. Patients were excluded if they had received primary surgical treatment.

Data collection

Physicians in 5 centres assessed the patients' suitability to enter the study. All eligible patients were scheduled for a face to face interview. The interviews lasted approximately 45–60 min. Before each interview, a brief questionnaire gathering socio-demographic and health information was administered. Five professionals from the 5 centres (JBL from Zhongnan Hospital, RDG from China-Japan Friendship Hospital, DC from Chinese Rehabilitation Research Center, CC from Third People Hospital, HBL from West China Hospital) with many years of experience working with patients with AIS, performed the individual interviews. These 5 professionals had been trained in ICF workshops offered by the ICF Research Branch and our research team according to this study protocol. Each individual interview was digitally recorded and transcribed verbatim.

Participant information

Participant information included demographic and disease-related characteristics: age and sex, height, weight, education, type of scoliosis, Cobb angle, angle of trunk rotation and the region-specific Scoliosis Research Society-22 Patient Questionnaire (SRS-22) (19). Twenty-two questions of SRS-22 cover 5 domains: function (5 items), pain (5 items), mental health (5 items), self-perceived image (5 items), and satisfaction with management (2 items). Five response levels are allowed for each item (scored 1–5, from worst to best), and the results are expressed as the mean score for each domain. The Chinese version was used, which has proved to be reliable and valid (20).

Interview

The semi-structured interviews were based on the components of the ICF-CY (11). The interviewer asked a series of open-ended questions addressing the following 5 domains: (*i*) Body Structures that cause some difficulty in taking part in everyday life activities; (*ii*) Body Functions, which include physiological functions that may affect ability to perform different daily activities; (*iii*) Activities and Participation, which include abilities and limitations in everyday life activities; and (*iv*) Environmental Factors, which include the physical and social environment in which the patient lives.

Data processing and ICF linking

All themes and data from semi-structured interviews was translated to certain ICF-CY categories according to established ICF linking rules carried out by 2 independent health professionals (PW, CPD) who had undertaken ICF workshops provided by the ICF Research Branch (21).

Firstly, all themes were assigned a letter "b", "s", "d" or "e", which represent the components Body Functions, Body Structures, Activities and Participation, and Environmental Factors, respectively. Secondly, a numerical code was assigned starting with the chapter number, followed by a second-, third-, and fourth-level code depending on the specificity of the themes.

The SRS-22 PQ was linked to ICF-CY items, based on ICF linking rules published by Cieza et al. (21) Linking was performed by 2 health professionals (JDY, PW) who have expert knowledge of the conceptual fundamentals of the ICF-CY, as well as of the chapters, domains and categories of the detailed classification, including their definitions. The first step of the linkage process was to derive meaningful concepts to be linked to the ICF-CY categories. This was agreed in a discussion between the 2 raters before the linking process. As a second step, meaningful concepts identified in the SRS-22 PQ were independently linked to the ICF-CY by the 2 raters in a precise and exhaustive fashion. As a consequence, each concept was linked to the most specific ICF-CY category. If an item of the SRS-22 PQ contained more than one concept, each concept was linked separately. According to the linking rules, if the meaningful concept refers to a diagnosis or a health condition, the meaningful concept will be assigned hc (health condition). In the third step, the linking versions were contrasted, and any disagreement about the linkage discussed by the 2 raters. Persistent disagreement was resolved with the help of a third

independent rater. A consent discussion, in which the linked ICF-CY categories were discussed and consent was found, occurred after the linking process.

Statistical analysis

Descriptive statistics were used to display the final list of ICF-CY categories and performed with SPSS 17.0 (SPSS Inc., Chicago, IL, USA). The distribution of categories by participants' characteristics was made at the first-, second-, third- and fourth-level to facilitate the presentation of results.

RESULTS

Participants' characteristics

From August 2014 to July 2015, 975 patients with AIS (704 female; 72%), and a mean age at interview 13.5 years (standard deviation (SD) 1.1) were interviewed. Demographic and disease-related characteristics of patients with AIS are shown in Table I.

Relevant areas of functioning

We identified 1,278 themes that were linked to 54 ICF-CY categories from 18 chapters. Of the 54 categories linked, 22 (41%) were identified as Body Functions, 7 (13%) as Body Structures, 15 (27%) as Activities and Participation, and 10 (19%) as Environmental Factors. Of the 54 categories linked, 45 (83%) were second-level, 5 (9%) were third-level, and 4 (7%) were fourth-level (Table II).

Table I. *Demographic and disease-related characteristics of patients with adolescent idiopathic scoliosis* (n = 975)

Characteristic	Group 1 Cb≤20° (*n*=259)	Group 2 20°<Cb<40° (*n*=380)	Group 3 Cb≥40° (*n*=336)	Total sample (*n*=975)
Age, year, mean (SD)	12.4 (1.2)	12.5 (1.0)	14.3 (1.0)	13.5 (1.1)
Males/females, *n*	90/169	98/282	83/253	271/704
Height, cm, mean (SD)	146.3 (5.7)	147.0 (6.1)	160.5 (5.8)	154.2 (5.9)
Weight, kg, mean (SD)	44.1 (5.1)	43.5 (5.5)	48.3 (4.6)	46.2 (5.0)
Education, *n* (%)				
Primary school (A%)	30 (3)	28 (3)	12 (1)	70 (A=7)
Middle school (A%)	217 (22)	333 (34)	240 (25)	790 (A=81)
High school (A%)	12 (1)	19 (2)	84 (9)	115 (A=12)
Type of scoliosis				
Thoracic curve (A%)	28 (3)	30 (3)	14 (1)	72 (A=7)
Lumbar curve (A%)	84 (9)	99 (10)	90 (9)	273 (A=28)
Thoracolumbar curve (A%)	107 (11)	190 (19)	148 (16)	445 (A=46)
S-shape curve (A%)	40 (4)	61 (6)	84 (9)	185 (A=19)
Cobb angle, °, mean (SD)	15.3 (4.2)	26.8 (6.9)	44.3 (8.1)	25.6 (5.7)
Angle of trunk rotation, °, mean (SD)	10 (2.1)	17.2 (3.2)	25.9 (5.2)	15.6 (2.9)
Risser sign, mean (SD)	3.01 (0.56)	3.23 (1.04)	3.57 (1.23)	3.27 (0.98)
SRS-22[a], mean (SD)				
Function (0–5)	4.2 (0.6)	3.8 (0.4)	2.5 (0.5)	3.5 (0.5)
Pain (0–5)	4.1 (0.4)	3.6 (0.4)	1.5 (0.4)	2.9 (0.4)
Self-perceived image (0–5)	4.0 (0.5)	3.7 (0.6)	1.6 (0.5)	3.5 (0.5)
Mental health (0–5)	3.8 (0.5)	3.1 (0.5)	0.7 (0.1)	2.8 (0.3)

Cb: Cobb angle; SRS-22: Scoliosis Research Society-22 Patient Questionnaire; SD: standard deviation; A: number of patients/number of total patients from 3 groups.

Table II. *Distribution of categories of the International Classification of Functioning, Disability and Health for patients with adolescent idiopathic scoliosis*

	Group 1 *n* (A%)	Group 2 *n* (A%)	Group 3 *n* (A%)	Total *n* (A%)
Body Function (First-level categories = 5, second-level categories = 15, third-level categories = 3, fourth-level categories = 4)				
b1-Mental functions				
b126-Temperament and personality functions	44 (5)	125 (12)	214 (22)	383 (39)
b1300-Energy level	43 (4)	117 (12)	196 (20)	356 (36)
b134-Sleep functions	22 (2)	83 (9)	94 (10)	199 (21)
b152-Emotional functions	41 (4)	224 (23)	249 (26)	514 (53)
b1801-Body image	20 (2)	278 (29)	336 (34)	634 (65)
b2-Sensory functions and pain				
b28010-Pain in head and neck	14 (1)	30 (3)	110 (11)	154 (15)
b28013-Pain in back	76 (8)	227 (23)	270 (28)	573 (59)
b28015-Pain in lower limb	10 (1)	54 (6)	87 (9)	151 (16)
b28016-Pain in joints	9 (1)	43 (4)	109 (11)	161 (16)
b4-Functions of the cardiovascular, hematological, immunological and respiratory systems				
b410-Heart functions	12 (1)	98 (10)	151 (15)	261 (26)
b4152-Functions of veins	8 (1)	53 (5)	69 (7)	130 (13)
b440-Respiration functions	11 (1)	170 (17)	222 (23)	403 (41)
b455-Exercise tolerance function	34 (3)	257 (29)	334 (34)	625 (66)
b5-Functions of the digestive, metabolic and endocrine systems				
b510-Ingestion functions	5 (0.5)	69 (7)	101 (10)	175 (17.5)
b525-Defecation functions	12 (1)	76 (7)	129 (13)	217 (21)
b530-Weight maintenance functions	155 (16)	299 (30)	320 (34)	774 (80)
b7-Neuromusculoskeletal and movement-related functions				
b710-Mobility of joint functions	117 (12)	337 (35)	336 (34)	790 (81)
b715-Stability of joint functions	70 (7)	150 (15)	208 (21)	428 (43)
b730-Muscle power functions	71 (7)	110 (11)	235 (24)	416 (42)
b740-Muscle endurance functions	102 (10)	269 (28)	330 (32)	701 (70)
b760-Control of voluntary movement	10 (1)	95 (10)	157 (16)	262 (27)
b770-Gait pattern functions	25 (3)	288 (30)	328 (33)	641 (66)

Table II *Cont.*

	Group 1 n (A%)	Group 2 n (A%)	Group 3 n (A%)	Total n (A%)
Body structures (First-level categories = 3, second-level categories = 7, third-level categories = 0, fourth-level categories = 0)				
s1-Structures of the nervous system				
s120-Spinal cord and related structures	65 (6)	304 (31)	336 (34)	705 (71)
s4-Structures of the cardiovascular, immunological and respiratory systems.				
s410-Structure of cardiovascular system	11 (1)	97 (10)	114 (12)	222 (23)
s430-Structure of respiratory system	15 (2)	84 (9)	215 (22)	314 (33)
s7-Structures related to movement				
s710-Structure of head and neck region	28 (3)	30 (3)	14 (1)	72 (7)
s740-Structure of pelvic region	35 (4)	34 (3)	235 (24)	304 (31)
s750-Structure of lower extremity	10 (1)	54 (6)	168 (17)	232 (24)
s760-Structure of trunk	14 (1)	115 (12)	268 (27)	397 (40)
Activities and participation (First-level categories = 6, second-level categories = 15, third-level categories = 0, fourth-level categories = 0)				
d2-General tasks and demands				
d220-Undertaking multiple tasks	10 (1)	25 (3)	134 (14)	169 (18)
d230-Carrying out daily routine	9 (1)	24 (3)	155 (16)	188 (20)
d240-Handling stress and other psychological demands	10 (1)	22 (2)	157 (17)	189 (20)
d4-Mobility				
d415-Maintaining a body position	9 (1)	25 (3)	193 (20)	227 (24)
d420-Transferring oneself	10 (1)	22 (2)	124 (13)	156 (16)
d430-Lifting and carrying objects	9 (1)	54 (6)	125 (13)	188 (20)
d450-Walking	9 (1)	98 (10)	215 (22)	322 (33)
d455-Moving around	9 (1)	65 (7)	214 (22)	288 (23)
d5-Self-care				
d510-Washing oneself	9 (1)	23 (2)	164 (17)	196 (20)
d520-Caring for body parts	8 (1)	22 (2)	160 (16)	190 (19)
d530-Toileting	9 (1)	25 (3)	139 (14)	173 (18)
d540-Dressing	10 (1)	23 (2)	157 (16)	190 (19)
d7-Interpersonal interactions and relationships				
d730-relating with strangers	57 (6)	220 (23)	238 (24)	515 (53)
d8-Major life areas				
d880-Join a game	53 (5)	210 (22)	329 (34)	592 (61)
d9-Community, social and civic life				
d920-Recreation and leisure	52 (5)	210 (22)	318 (33)	580 (60)
Environmental factors (First-level categories = 4, second-level categories = 8, third-level categories = 2, fourth-level categories = 0)				
e1-Products and technology				
e110-Products or substance for personal consumption	F 0 (0); B 0 (0)	F 12 (1); B 92 (9)	F 110 (11); B 105 (11)	F 122 (12) B 197 (20)
e1151-Assistive products for personal use in daily living	F 0 (0); B 0 (0)	F 10 (1); B 82 (8)	F 100 (10); B 107 (11)	F 110 (11) B 189 (19)
e3-Supports and relationships				
e310-Immediate family	F 181 (19); B 0 (0)	F 200 (21); B 0 (0)	F 167 (17) B 0 (0)	F 548 (57) B 0 (0)
e320-Friends	F222 (23); B 0 (0)	F158 (16); B 0 (0)	F326 (33) B 0 (0)	F 706 (72) B 0 (0)
e355-Health professionals	F182 (19); B 0 (0)	F254 (26) B 0 (0)	F278 (29) B 0 (0)	F 514 (74) B 0 (0)
e4-Attitudes				
e410-Individual attitudes of immediate family members	F222 (23); B 0 (0)	F158 (42, 16); B 0 (0, 0)	F326 (97, 33) B 0 (0, 0)	F 706 (72) B 0 (0)
e420-Individual attitudes of friends	F222 (23); B 0 (0)	F158 (42, 16); B 0 (0, 0)	F326 (97, 33) B 0 (0, 0)	F 706 (72) B 0 (0)
e450-Individual attitudes of health professionals	F182 (19) B 0 (0)	F254 (67, 26) B 0 (0, 0)	F278 (85, 29) B 0 (0, 0)	F 514 (74) B 0 (0)
e5-Services, systems and policies				
e5800-Health services	F 98 (10) B 87 (9)	F 104 (10) B 76 (8)	F 100 (10) B 106 (11)	F 302 (30) B 269 (28)
e585-Education and training services, systems and policies	F 114 (12) B 80 (8)	F 100 (10) B 89 (9)	F 145 (15) B 79 (8)	F 359 (37) B 248 (25)

A: number of patients/number of total patients from 3 groups. b: Body function; s: Body Sturctures; d: Activities and participation; e: Environmental factors; F: Facilitators; B:barriers.

Body Structures/Body Functions

Body Functions are defined in the ICF as the physiological functions of the body systems (10, 11). Twenty-two categories from the qualitative analysis were linked to 5 Body Functions domains (Table II). These included: mental functions (b1), sensory functions and pain (b2), functions of the cardiovascular, haematological, immunological and respiratory systems (b4), functions of the digestive, metabolic and endocrine systems (b5), and neuromusculoskeletal and movement-related functions (b7). The frequent problems reported by patients with AIS linked with "b710" – mobility of joint functions (81%), and "b530" – weight maintenance functions (80%). In group 3, all patients reported impaired body functions were "b1801" – body image (100%) and "b710" – mobility of joint functions (100%). In group 3, over 50% but less than 90% of the patients were reported with body functions impairment in 11 ICF categories (b126, b1300, b152, b28013, b440, b455, b530, b715, b730, b740 and b770). In group 2, over 50% but less than 90% of the patients were identified with body functions impairment in 8 ICF categories (b152, b1801, b28013, b455, b530, b710, b740 and b770). In group 1, over 50% but less than 90% of the patients were identified in only 1 ICF category (b530).

Body Structures are defined in the ICF as the anatomical parts of the body (10, 11). Seven categories from the qualitative analysis were linked to 3 body structure domains (Table II). These included: structures of the nervous system (s1), structures of the cardiovascular, immunological and respiratory systems (s4) and structures related to movement (s7). The frequent problems reported by all participants with AIS in 3 groups linked with "s120" – spinal cord and related structures (71%). In group 3, all patients described impaired body structures were "s120" – spinal cord and related structures (100%). In group 2, over 50% but less than 90% of the patients were identified with body structures impairment in some ICF category (s120).

Activities and Participation

The ICF defines activities as the execution of a task or action and participation as an individual's involvement in a life situation (10, 11). Fifteen categories from the qualitative analysis were linked to 6 Activities and Participation domains (Table II). These included: general tasks and demands (d2), mobility (d4), self-care (d5), interpersonal interactions and relationships (d7), major life areas (d8), and community, social and civic life (d9). The frequent problems reported by all participants with AIS linked with "d880" – Join a game (61%) and "d920" – Recreation and leisure (60%). In group 3, over 50% but less than 90% of the patients were reported with activities and participation problems in 6 ICF categories (d415, d450, d455, d730, d880 and d920). "d880" – Join a game was frequently indicated by patients from group 3 as being a challenge for them. In group 2, over 50% but less than 90% of the patients were reported with activities and participation problems in 3

ICF categories (d730, d880 and d920). In general, the patients in group 1 indicated that they were able to perform many activities and participation. However, over 20% of patients in group 1 reported activities and participation problems in some 3 ICF categories (d730, d880 and d920).

Environmental Factors

According to the ICF, Environmental Factors make up the physical, social, and attitudinal environment in which people live and conduct their lives (10, 11). Many environmental factors were described as positively influencing functioning, such as e310, e320, e355, e410, e420 and e450. Patients indicated that support and care from medical professionals were the main facilitators. They also acknowledged the love and support of their immediate family members as well as the attitudes of their peers who treat them as equals. However, not every patient had the same positive experience and some listed the same factors as barriers to functioning. Aspects related to "e110" – products or substance for personal consumption, "e1151" – assistive products for personal use in daily living, "e5800" – health services and "e585" – education and training services, systems and policies were some of factors most frequently described as being a hindrance (Table II).

Linking SRS-22 PQ to ICF-CY

As a result of the linking process, 33 meaningful concepts were derived from the 22 items and linked to 34 ICF-CY categories (Table III). Twenty-eight concepts of the questionnaire were linked to the ICF-CY and another 5 meaningful concepts were assigned. Of the meaningful concepts identified, 41.2% could be linked to the ICF-CY component Body Functions. Another 14.7% of meaningful concepts related to Body Structure and 35.2% to Activities and Participation. In total, 8.8% of the meaningful concepts were related to Environmental Factors. Only the item of the scale "back (back condition)" was considered not to be linked to a specific ICF-CY category. Therefore, this item was assigned health condition 5 times. For the ICF-CY Body Functions component, a total of 11 meaningful concepts were linked to 14 categories of this component. The categories "Emotional function"(b152), "Body image" (b1801) and "Pain in back" (b28013) were linked most frequently. As for the Body Structure component, 5 meaningful concepts were linked to 5 categories of ICF-CY. Linkage included "Structure of trunk" (S760), "Structure of head and neck region" (S710), "Structure of upper extremity" (S730) and "Structure of lower extremity" (S750). The component Activities and Participation was represented with categories and 12 linkages. Major categories of activities and participation levels were mapped, such as "a school education" (d850), and "activities and participation (A&P)". The Environmental Factors component was represented with a total of 3 categories and 3 linkages in SRS-22 PQ. These included categories in human environmental functioning, such as "Individual attitudes of health professionals" (e450) and "Drugs" (e1101) (Table III).

Table III. *Linking Scoliosis Research Society 22 Patient Questionnaire (SRS-22 PQ) to International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)*

Items	Meaningful concepts	ICF category	Component	Level
1. Which one of the following best describes the amount of pain you have experienced during the past 6 months? (none, mild, moderate, moderate to severe)	Pain	b280 Sensation of pain	b	2
2. Which one of the following best describes the amount of pain you have experienced over the last month? (none, mild, moderate, moderate to severe, severe)	Pain	b280 Sensation of pain	b	2
3. During the past 6 months have you been a very nervous person? (none of the time, a little of the time some of the time, most of the time, all of the time)	Nervous	b152 Emotional function	b	2
4. If you had to spend the rest of your life with your back shape as it is right now, how would you feel about it? (very happy, somewhat happy, neither happy nor unhappy, somewhat unhappy, very unhappy)	Back shape; Spend the rest of your life; Feeling happy or unhappy	s760 Structure of trunk; A&P; b152 Emotional function	s, b, d	2
5. What is your current level of activity? (bedridden, primarily no activity, light labor and light sports, moderate labor and moderate sports, full activities without restriction)	Activity; Bedridden; Labor; sports	A&P; d4150 Maintaining a lying position d9201 Sports	d	2, 3
6. How do you look in clothes? (very good, good, fair, bad, very bad)	Look in cloth	b1801 Body image	b	2
7. In the past 6 months have you felt so down in the dumps that nothing could cheer you up? (very often, often, sometimes, rarely, never)	Feel down in the dumps;	b152 Emotional functions	b	2
8. Do you experience back pain when at rest? (very often, often, sometimes, rarely, never)	Back pain	b28013 Pain in back;	b	4
9. What is your current level of work/school activity? (100% normal, 75% normal, 50% normal, 25% normal 0% normal)	Work/school activity	d850 Remunerative employment; d820 School education;	d	2, 2
10. Which of the following best describes the appearance of your trunk; defined as the human body except for the head and extremities? (very good, good, fair, poor, very poor)	Appearance of trunk; human body except for the head and extremities	b1801 Body image; s710 Structure of head and neck region s730 Structure of upper extremity s750 Structure of lower extremity s760 Structure of trunk	b, s	3, 2, 2, 2, 2, 2
11. Which one of the following best describes your pain medication use for back pain? (none, non-narcotics weekly or less (e.g., aspirin, tylenol, ibuprofen), non-narcotics daily, narcotics weekly or less (e.g. tylenol III, lorcet, percocet), narcotics daily)	Back pain; Medication	b28013 Pain in back; e1101 Drugs	b, d	4, 3
12. Does your back limit your ability to do things around the house? (never, rarely, sometimes, often, very often)	Back Do things around the house	Hc; d699 Domestic life, unspecified	b, d	4, 2
13. Have you felt calm and peaceful during the past 6 months? (all of the time, most of the time, some of the time, a little of the time, none of the time)	Calm and peaceful	b152 Emotional functions	b	2
14. Do you feel that your back condition affects your personal relationships? (none, slightly, mildly, moderately, severely)	Back condition; personal relationship	Hc; d7 Interpersonal interactions and relationships	d	1
15. Are you and/or your family experiencing financial difficulties because of your back? (severely, moderately, mildly, slightly, none)	Back; financial difficulties	Hc; d870 Economic self-sufficiency	d	2
16. In the past 6 months have you felt down hearted and blue? (never, rarely, sometimes, often, very often)	Down hearted and blue	b152 Emotional functions	b	2
17. In the last 3 months have you taken any days off of work, including household work, or school because of back pain? (0 days, 1 day, 2 days, 3 days, 4 or more days)	Back pain; household work; school	b28013 Pain in back; d820 School education; d 640 Doing housework	b, d	4, 2, 2
18. Does your back condition limit your going out with friends/family? (never, rarely, sometimes, often, very often)	Back condition; Going out with friends/family	Hc; d9205 Socializing	d	1
19. Do you feel attractive with your current back condition? (yes, very; yes, somewhat; neither attractive nor unattractive; no, not very much; no, not at all)	Attractive; Back condition	b1801 Body image; Hc	b	3
20. Have you been a happy person during the past 6 months? (none of the time, a little of the time, some of the time, most of the time, all of the time)	A happy person;	b152 Emotional functions	b	2

Table III *Cont.*

Items	Meaningful concepts	ICF category	Component	Level
21. Are you satisfied with the results of your back management? (very satisfied, satisfied, neither satisfied nor unsatisfied, unsatisfied, very unsatisfied)	Satisfied; Back management	e450 Individual attitudes of health professionals	b, d	2, 2
22. Would you have the same management again if you had the same condition? (Definitely yes, Probably yes, Not sure, Probably not, Definitely not)	Same condition management	e450 Individual attitudes of health professionals	d	2

A&P: Activities and Participation; Hc: health condition.

DISCUSSION

This cross-sectional study identified relevant areas of functioning and disability among patients with AIS based on the perspective of the patients. To our knowledge, it is the first study to explore functioning and disability among a sample of patients with untreated scoliosis from low to high severity in China (22). The most common issues raised by patients were related to mobility of joint functions, body image, spinal cord and related structures, joining in a game and recreation and leisure. The main contextual factors identified in the study were related to products and technology, supports and relationships, attitude and policies related to health, education, and social services. A comprehensive list of categories covering ICF-CY components was identified, which will provide key aspects for professionals to consider when assessing the population of patients with AIS. Furthermore, these findings provide further evidence to support the development of the ICF Core Sets for patients with AIS in China. Meanwhile, our data could be integrated into international data to develop the ICF Core Sets for AIS.

In our study, patients with a Cobb angle ≥40° had a negative view of their body function, body structure and described limitation in their activity and restriction in participation. Conversely, patients with a Cobb angle ≤20° had a positive view of their ability and reported their strengths and facilitating factors. The discordance between the perspectives of the 3 groups in this study may be due to the severity of scoliosis resulting in a different expectation of ability (23, 24). In the component Body Functions, most patients' problems were identified as mobility of joint functions and weight maintenance functions disorders, especially in group 3. These are the most common problems in patients with AIS and lead to a significant negative effect on patients' daily lives and quality of life (25, 26). In addition, the majority of patients focused more on decreased exercise tolerance, low muscle endurance, body image, pain in back and gait disorders, which were the common symptoms and problems in patients with AIS (27–32). Interestingly, our result found that all patients with a Cobb angle ≥40° have a negative view of their body image, which may be lead to a higher impairment of temperament and personality disorders and emotional disorders than others groups. In the component Body Structure, not all patients described impaired body structures in the spinal cord. Scoliosis was not identified as a problem area for some patients with a Cobb angle ≤20°. This inconformity between Body Structures and presentation of

patients was described in other studies (33). In the component Activities and Participation, most patients talked about a lack of enjoyment in games, recreation and leisure. Our result is in accord with a previously reported study that identified that most patients with AIS have lower social participation than healthy peers (34). In addition, some patients with severe scoliosis reported that they felt awkward, shy or embarrassed with some strangers. Families and physiotherapists should provide more support and help to patients with embarrassment (35). In the component Environmental Factors, the support and assistance of immediate family and health professionals could impact on the recovery and rehabilitation of patients. Barrier factors could encourage government, policy decision-makers and the relevant departments to change existing environmental conditions according to survey data and national conditions. Environmental conditions may change with time and depend on government policies, socioeconomic status and personal attitude, thus they can act to improve or decrease the individual's level of functioning over time (36).

The SRS-22 PQ is the most common and available tool for assessing the functioning condition of people with AIS. When comparing of the content of SRS-22 PQ with our findings, some differences were found. For Body Functions and Structure, SRS-22 PQ focused on the function and structure related to the spine, whereas our finding showed that patients may also pay attention to other systems, such as cardiovascular function. In addition, the SRS-22 PQ does not include any item about body-weight management, which is problem frequently reported by our subjects. For Activities and Participation, we found that our subjects focussed on interests and leisure, which may partly be due to their age. However, the SRS-22 PQ is not a specific tool for children and adolescents. Furthermore, the SRS-22 PQ does not include any information about environmental factors, which, according to our findings, is also a crucial focus of our subjects. Therefore, our semi-structured interviews are more systematic and can capture most patients' problems based on components of the ICF-CY.

Study limitations

This study has some limitations. First, the sample was drawn from clinical settings in China. Thus, although China has a multicultural population, these findings may not represent the perspectives of international patients with AIS. Secondly, selecting patients from 5 hospitals may have biased the study towards those patients with more severe symptoms or more chronic conditions. However, our findings have high face validity and are in

line with the studies conducted in this field. Thirdly, the selection of patients for interviews might be biased towards individuals with AIS who are capable of undergoing the interview procedure. The final limitation, within the current version of the ICF, is the lack of ability to represent issues that relate to Personal Factors. Altogether, our study gives a first impression from the patients' perspective using the ICF, regardless of potential selection bias.

In Conclusion, patients with AIS reported activity limitations and participation restrictions combined with impaired body structures and functions. Environmental factors may act as a barrier to, or facilitator of, patient functioning in daily life. These results will be used to help develop ICF Core Sets for AIS in China. The ICF-CY provides a valuable framework for representing the complexity and multifaceted impact of AIS, in terms of body function, body structures, activities and participation, and environmental factors. The perspectives of patients with AIS on relevant areas of functioning and disability based on the ICF-CY could develop the ICF Core Sets for AIS according to the Chinese clinical and cultural environment.

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