COMMUNICATION AND EATING DATA COLLECTED BY CEREBRAL PALSY REGISTRIES

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ABSTRACT

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Purpose: Motor impairments in cerebral palsy (CP) can disrupt communication and eating. CP registries were asked for communication and eating definitions and data collection methods.

Methods: CP registries staff answered a 21-question survey. Questions included the types of communication and eating data collected (if any), frequency of collection, registries' operational definitions, and reasons for data not being collected.

Results: Twenty-five of 26 active CP registries responded to the survey. Lack of resources, outside the registry's purpose, and lack of available instruments or data sources were reasons given for no data collection. Most registries' data collection occurred once when children were five-years-old or younger. Communication and eating definitions varied by registries, but most definitions focused on underlying hearing, speech, language, eating, and swallowing skills as well as assistive technology use. Hearing data were collected by 96% (n=25 registries); speech data were collected by 85% (n=22 registries); eating data were collected by 65% (n=17 registries); and language data were collected by 42% (n=11 registries).

Conclusions: To compare or pool data across population-based CP registries, definitions of communication, speech, language, hearing, and eating should be standardized and a consensus minimal data set for communication and eating established. The frequency and timing of data collection need to be explicitly considered in surveillance and clinical research. A working group of CP registry staff and communication and eating clinical researchers should be convened to standardize definitions and data collection methods.

DEDICATION

To my husband Jeff
and daughters Ayla and Mylanie
who always support me.

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CHAPTER 1

Introduction and Review of the Literature

Cerebral palsy (CP) is a congenital, neurological disability, affecting at least one in 500 school-aged children.[1] The most recent consensus definition by internationally-recognized CP experts states that CP "describes a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disturbances of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems."[2] Thus, the hallmark of CP are gross and fine motor problems that can lead to difficulty with walking, use of hands, communication, and eating. The severity of these problems in CP can vary from slight to severe difficulties.[3-7]

Communication and eating issues in cerebral palsy

Despite recognition on the importance of assessing communication and eating in children with CP,[3,8,9] information about the prevalence and nature of communication and eating problems in CP is limited.[10] Few recent studies have adequately measured communication and eating in individuals with CP. Children with CP may have cognitive, visual, speech, hearing, language, and eating impairments that contribute to communication and eating difficulties.[10-12] The reported numbers of CP individuals with different types of communication and eating problems vary widely from 30[13] to 86%,[14] probably due to several factors including the source of cases, operational definitions, and the age of the individual at the time of measurement. For example, in one source, 30% of people with CP were estimated to have at least one speech, language, and/or hearing disorder, but no supporting data were provided to support this estimate.[15]

A recent study from a Norwegian cerebral palsy registry reported 50% of children with CP had speech problems as classified by ratings of “slightly indistinct” (16%), “obviously indistinct” (9%), “severely indistinct” (6%), or “no speech” (19%).[6] Speech problems were found in 92% of children with dyskinetic CP. These population-based speech problems may underestimate CP communication disorders as only speech disorders were included (and not other types of communication problems resulting from hearing or language impairments). The same Norwegian cerebral registry reported 21% of children with CP were “completely dependent on assistance during feeding” and that 14% relied on gastrostomy tube feeding.[16] Better descriptions of communication and eating development and the presence of problems in population-based samples would clarify the need for speech-language pathology and audiology services for individuals with CP.[17] This need for services should lead clinicians to additional research in effective assessment and intervention.[17]

Following the principles proposed by the International Classification of Functioning, Disability and Health (ICF) from the World Health Organization (WHO), communication and eating can be described from several different perspectives: problems in anatomy and physiology which are termed “body structure and function,” problems that limit daily activities, and problems that limit participation in home, school, work, and/or community.[18-23] While activities and participation were defined separately in the ICF, no distinction between activities and participation were made in the ICF headings with detailed definitions.[23,24]

ICF body structure or body function

Verbal communication relies upon adequate body structures and functions for speech, language, and hearing. Speech sound errors with the primary motor speech disorder of dysarthria are likely the most common communication disorder in cerebral palsy.[25-27] Dysarthria is an umbrella term for speech disorders caused by damaged central and/or peripheral motor-sensory loops that interfere with one or more component (i.e., respiration, larynx, resonance, articulators) of the speech production system.

Describing dysarthrias in perceptual,[25,27] acoustic,[28] and/or sensorimotor[11,29-31] terms is needed but does not denote the resulting activity and/or participation limitations that may result from impairments in these aspects of the body's structure and function.[32,33] In addition, other speech, language, and hearing impairments can also affect a person's ability to communicate.

Language development can be described by both what the child with CP understands (i.e., receptive language skills) and what the child says (i.e., expressive language skills). Language is often described by speech-language pathologists in terms of 5 categories: pragmatics, semantics, morphology, syntax, and phonology.[11] Pragmatics concerns language use; semantics include vocabulary knowledge; morphology includes understanding of when to use word parts such as past tense –ed and plural –s; syntax includes the correct use of grammatical rules; and phonology includes knowing which sound combinations are used in one’s language system. Often, communication assessments by speech-language pathologists will include screening and/or assessment in receptive and expressive pragmatics, semantics, morphology, syntax, and phonology.

Hearing assessment through the use of pure tone audiometry or physiological tools[34] such as otoacoustic emissions (OAEs) or auditory brainstem response (ABR) is likely the most commonly reported communication measure in CP studies. However, the simple reporting of the data does not indicate that the role of hearing in communication is well-understood by CP registry staff. This will be explained in the Discussion chapter.

ICF activity and participation levels related to communication

Most professionals recognize that communication problems in individuals with CP can limit the individuals' social interactions, educational attainment, and employment opportunities.[11,35-37] Assessing communication function at the activity level of the WHO model may be captured by formal and informal intelligibility assessment[38,39] as well as normative and criterion-referenced instruments (e.g., Focus on the Outcomes of Communication under Six[40] and Speech Participation and Activity of Children[38]).[41] However, few of these instruments and procedures have been developed specifically for cerebral palsy or explicitly elicited perspectives from people with cerebral palsy about important issues in communication activity and participation.[18,26,32,42,43]

Eating, feeding, and swallowing

Eating, feeding, and swallowing are all terms that describe consumption of food and drink. The act of eating can also be thought of as a timeline of motor actions: getting food and drink into the mouth, oral preparation, oral transport, pharyngeal transport, and/or esophageal transport.[11] People with CP may have trouble with one or more of these motor actions which may make getting adequate nutrition and hydration difficult.[7,44] Some people with CP require an aide to orally feed them or require assistive technology such as the use of tube feeding.[7]

Little has been written about activity and participation limitations that could result from difficulties with eating.[45,46] For example, some individuals with uncoordinated eating skills may not wish to have familiar and/or unfamiliar dining partners watch them eat or drink. If so, this would limit a daily activity that is often shared with other people. Since dining together is an important social ritual in family, school, employment, and community settings, a person with eating difficulties may be more socially isolated.[46,47] Another problem could be someone who needs an extended amount of time to eat safely.[7,46,48] This may decrease a person's opportunities to participate in other desired activities.

Need for accurate data on communication and eating disorders in people with CP

Communication and eating disorders can affect individuals, with CP. Describing the extent of any problems at a body structure/function, activity, and/or participation level would be an important first step in better understanding and intervening in communication and eating problems of individuals with CP. The confusing and conflicting prevalence rates for different communication and eating abilities need to be explained and methods for collecting such data improved.

Cerebral palsy registries

As CP is a relatively rare disorder, collecting population-based data is challenging. One epidemiologic strategy for collecting population-based data is creating and maintaining a registry.[49] A registry is a database of individuals with a known condition within a defined geographical area. By employing strategies to identify all cases born within a defined geographical area, a registry allows for the calculation of CP's prevalence so that public health officials know the extent of the disorder and the likely need for an array of services. (Incidence rate, the number of new CP cases per population in a given time period, has typically not been reported due to CP being caused by prenatal or perinatal brain damage.[2,50] Thus, CP does not "develop" as a child ages although the CP symptoms may change.) In addition, CP registries can follow the natural history, co-morbidities, health care utilization, and treatment outcomes.[49]

Reporting of CP cases by medical and/or educational systems is not mandatory in the United States. No population-based CP registry currently exists in the United States; however, Chicago-area clinicians are creating a clinical CP registry (Msall, personal communication, 2006). In addition, CP surveillance, using a cross-sectional data review of 8-year-old children in selected U.S. regions, is conducted by the Division of Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention.[51]

Population-based CP registries exist in Australia, Canada, and Europe,[49,50,52] although each registry has its own purposes, procedures, and data focus.[53] The earliest CP registries started in Europe: Denmark in 1950, Sweden in 1954, England and Ireland in 1966.[49] Currently, at least 10 European countries (Denmark, France, Germany, Ireland, Italy, Netherlands, Norway, Slovenia, Sweden, and United Kingdom) have or have had CP registries or population-based surveillance efforts.[49,50,52] The Australian and European CP registries have created regional coalitions of existing registries: the Australian Cerebral Palsy Register (ACPR), the Surveillance of Cerebral Palsy in Europe (SCPE), and the United Kingdom Cerebral Palsy (UKCP). [49,50,52,54] These coalitions of registries work with their member registries to forge a common minimum data set to allow for the pooling of data.

In 2009, 22 CP registries respondents reported monitoring CP prevalence as one major purpose of their registry.[53] In addition, 17 (77%) of these registries' missions included service planning and/or long term outcomes.[53] Data sources varied by each registry and included data from health professionals, administrative records, research projects, and family or the individual with CP. [53] The age at which children were entered into their respective registries varied greatly from birth to no upper age limit.[53] The variability may be partially due to the diagnosis of CP, which cannot be made definitively until the child is at least 24 months old.[2] To be certain about the child's qualifying CP diagnosis, many registries have protocols to wait until the child is 4- to 5-years-old to collect data or reconfirm registry inclusion. The age(s) when data were collected varied from the child's birth to 12 years although several registries indicated that data collection was ongoing throughout the child's life.[53] Data ascertainment was considered complete by age 5 for 14 of the 22 registries.[53]

Are cerebral palsy registries collecting communication and eating information?

Not all CP registries list the data that they collect on individuals with CP. (Although at least 2 have websites that contain copies of data collection forms.) Few articles referencing CP registries adequately describe communication and eating information. As communication, speech, and language rapidly change from birth into school years, the child's age when collecting this data is likely to be important variable in describing these development areas.

Communication data were apparently being collected by some of the SCPE registries. However, operational definitions and definition justifications are not often given. For example, a cross-sectional study of 431 children recruited from 8 European registries reported 58% had "communication problems,"[55] but did not describe what the term meant. This vague term is not descriptive of the range of speech, language, and/or hearing problems that may occur with CP. A better classification (i.e., 57% normal, 16% difficulty but uses speech, 12% uses non speech for formal communication, 15% no formal communication) of 818 eight-years-olds with CP recruited from 9 European CP registries was listed in another study[56] but still with no additional information on operational definitions.

Several registries have collected hearing data, apparently in the form of pure tone thresholds by frequencies per each ear. Audiologists typically define hearing loss in children when thresholds are greater than 20 dB HL in an ear at any of the pure tone frequencies that are routinely tested (e.g., 250, 500, 1000, 2000, 3000, 4000, 6000, 8000 Hz) in each ear.[57] Thus, it is puzzling that several reports of hearing loss in CP use a definition of "more than 70 dB in the better ear"[52,56] with no description on how this is calculated nor any justification for a 70 dB cutpoint. This type of hearing loss definition is likely to grossly underreport hearing difficulties in individuals with CP.

In the previously-mentioned study of 818 eight-year-olds with CP recruited from 9 European CP registries, the child's eating was classified (71% no problems, 22% feeds orally with difficulty, 7% partial or complete non oral feeding).[56] This classification system was not operationalized. Understanding which stages of eating (getting food and drink into the mouth, oral preparation, oral transport, pharyngeal transport, and/or esophageal transport) are working would better highlight any eating problems as well as possible interventions.

Research focus

This research surveyed existing CP registries to determine the type, collection frequency, and operational definition of any communication and/or eating data collected by each registry. Registry-provided definitions were then analyzed for common communication and eating concepts and linked to ICF framework.[23,24]

CHAPTER 2

Research Design and Methods

Overview

A 21-question survey of CP registries throughout the world identified what, if any, communication and eating data were collected. Reasons for non-collection were asked. If a registry collected communication and eating data, the frequency of collection and operational definitions were requested.

Design

This cross-sectional study surveyed known CP registries regarding any communication and eating data collected regarding individuals with CP.

Participants

Population source

The population of interest were CP registries that were actively collecting data.

Study participants

Study participants were staff members from each CP registry. Participants for this research were from 26 of 27 active CP registries: 7 in Australia, 1 in Canada, and 18 in Europe. Possible CP registries were identified through literature searches of registry-reported data, snowball recruiting from currently operating registries' suggestions, and the 3 umbrella registries (SCPE, UKCP, and ACPR). Table 1 lists the 27 registries including the 26 that responded. In addition, 2 surveillance research programs, a one-time survey in the Netherlands and an annual cross-sectional project in the United States, participated. The Institutional Review Board (IRB) at Michigan State University deemed that this research did not require IRB approval.

Instrument

A 21-question survey was created to ascertain the type of communication and eating data collected (if any), frequency of collection, and operational definitions. The survey questions are included in the Appendix. The questions, presented in English, were reviewed for clarity by speech-language pathology students and professionals with CP experiences. In addition, 3 individuals who spoke languages other than English read the survey questions to determine if the wording was understandable by speakers of English as a second language.

Procedures

Recruitment phase. Paneth et al. had published the contact information of 25 known CP registries.[50] To obtain enrollment into the study, each of these CP registries was contacted by e-mail to explain the project and to ask for a staff member familiar with the registry's communication and eating data collection to participate in the survey. If no one from the registry responded, the registry was contacted by another email, by phone, or in person. Multiple attempts were made to increase response rate. During the survey, each CP registry staff was asked if he or she were aware of other CP registries. These additionally-identified CP registries were then asked to participate in the survey.

Data collection phase. This 21-question survey was available in a mixed mode (web-based, phone interview, or in-person at conferences) methodology according to the registry staff's preference. The survey could be completed within 15 minutes depending on how many categories of communication and eating data were being collected by the registry. Survey Monkey (http://www.surveymonkey.com), a web-based survey tool, was used to collect data.

In countries where English was not a native language, a bilingual staff member from the CP registry participated. After a registry staff agreed to participate in the survey, information about completing the survey in his or her mode preference (web-based, phone, in-person at CP conferences) was given. (Note: A paper version was not offered due to the complicated skip pattern of the survey.) For the self-administered method (web), e-mail reminders were sent if the staff has not completed the survey within 2 weeks. Data were checked for accuracy by at least 2 undergraduate research assistants. The project coordinator contacted registry's participants to clarify any ambiguous results.

Analysis

Definitions for communication and/or eating data collection were provided by a registry staff member. Results were analyzed using frequency and content analysis of the definitions. Following the principles proposed by the International Classification of Functioning, Disability and Health (ICF) from the World Health Organization (WHO), communication and eating definitions were evaluated for their ICF perspectives: problems in anatomy and physiology which are termed "body structure and function," problems that limit daily activities, problems that limit participation in home, school, work and/or community.[18-22,58] Body structure and function definitions included wording about speech, language, hearing, swallowing. Activity definitions included wording about communication and eating activities. Participation definitions included wording about communicating and eating in life situations.

CHAPTER 3

Results

Results were obtained from 26 of 27 active registries which was an excellent response rate of 96% for population-based cerebral palsy registries. All respondents chose a web/internet mode to complete the survey, providing definitions for any hearing, speech, language, eating, and other communication data collected by their registries. An “other” category was created from respondents’ answers to the last survey question “Does your registry collect other communication data (e.g., non-speech aids, augmentative and alternative communication – AAC, sign language, hearing aids) and/or eating data?” While most of the respondents were registries, one ongoing and one event-specific surveillance efforts’ responses (i.e., H15, H16, S12, L9, E14, O9) are presented at the end of Tables 1 and 2 starting on the next page but are not included in the following analyses of the registries’ results.

Registry-provided definitions in Table 2 are listed in the category that the respondent used. Each definition was coded by a letter indicating to which question the definition was a response: “H” is a response to the hearing question, “S” is a response to the speech question, “L” is a response to the language question, “E” is a response to the eating/feeding/ swallowing question, and “O” is a response to any other communication or swallowing data question. The number following the letter was assigned in the order that the definitions were received.

Individual registries’ responses (e.g., No, Yes, Letter-Number definition code, NR) to data collection questions can be found in Table 1. “No” indicated that the registry did not collect that type of information. “Yes” indicated that the registry collected that type of information but did not provide a definition. A definition code (e.g., H3, S4, L1, E2, O3), as described in the previous paragraph, indicated that the registry collected that type of information and provided a definition or

Table 1. Communication and eating data by registries and surveillance projects.

	Registry Name	Speech	Language	Hearing	Eating	Other
Australia	New South Wales and Australian Capital Territory CP Register	S2, S3	No	H2	No	No
	Queensland CP Register	S2	Yes	H2	No	No
	The South Australian CP Register	Yes	Yes	H2, H6, H9	E1, E6	No
	Tasmanian CP Register	S2, S9	L1 (see S9)	H2, H3	E3	O2
	Victorian CP Register	S2	No	H2	E8	No
	Western Australia CP Register	S2	No	H2	E2	No
	Northern Territory Australian CP Register	S2	No	H2	No	No
Canada	Canada- Quebec	S5	L2	H8	E5	O3, O4
Europe	Cyprus	S1, S2, S3	L7	H1, H2, H6, H9	E1, E6	O8
	National Danish CP Register	No	No	No	No	NR
	Registre des Handicaps de l'Enfant de la Haute-Garonne (France)	S11	No	H7, H10, H14	No	No
	Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP) (France)	S6	No	H7, H10	No	No
	Iceland	S3	L8	H7	E13	No
	Ireland- Eastern Region CP Study	Yes	NR	H12	E10	NR
	Southern Ireland CP Register (SICPR)	*	*	*	*	*
	Central Italy CP Register	No	Yes	H7	No	No
	CP in Kaunas County Lithuania	Yes	NR	Yes	Yes	No
	Norwegian CP Registry (CPRN)	S4	L6	H4	E4	Yes
	Portugal- National Epidemiological Study of CP	S8	L5	H7	E9	Yes
	Registro de Parálisis Cerebral de Madrid – DIMAS (Spain)	No	No	H7, H10	No	NR
	The CP Register of Western Sweden -Gothenberg	S2, S3	L4	H2, H6, H7	E1, E11	O7
	CPUP- Swedish National Health Care Quality Programme for Secondary Prevention in CP	S10	NR	H13	E12	No

Table 1. (cont'd)

	Registry Name	Speech	Language	Hearing	Eating	Other
Europe: United Kingdom & N. Ireland	Cerebral Palsy Register for Scotland	S7	L3	H11	E7	O6
	Mersey and Cheshire Cerebral Palsy Register	No	No	H5	No	No
	North of England Collaborative Cerebral Palsy Survey (NECCPS)	S3	No	H6, H7	E1	No
	Northern Ireland Cerebral Palsy Register (NICPR)	S1, S3	No	Yes	E1, E6	O5
	4Child, Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children	S1	No	H1	E1	O1
Surveillance	Netherlands- Gelderlands	S12	NR (See S12)	H16	E14	NR
	United States, Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)	No	L9	H15	No	O9

Note: ID Letter & Number = registry collected this data & provided definition listed in Table 2
YES = registry collected this data, but no definition provided
NO = registry did not collect this data
NR = registry did not response to this question
* = registry did not respond to the survey

Table 2. Definitions of communication and eating by registries and surveillance projects.

ID	Definitions S=Speech; L=Language, H=Hearing, E= Eating/Feeding/ Swallowing, O=Other
	Speech Definitions
S1	"Is there a problem with articulation of speech?(Developmental age appropriate) Yes; No; Uncertain" *Wording found on Northern Ireland CP Register Form* ; and *on Oxford, UK, 4Child, 3 Yr. Gold Form*
S2	"Presence of associated impairments (please circle one for each of following four): Speech: No impairment; some impairment; non-verbal; unknown" *Wording found on Australia New Cerebral Palsy Record Form*
S3	"Are communication difficulties present? Yes; No; Uncertain. If YES: How does the child usually communicate? Tick one box: Speech; Speech and other formal methods (e.g. signing); Formal systematised methods only; Not communicating by speech of formal." *Wording found on Northern Ireland CP Register Form*
S4	At diagnosis: 1. Interaction with child: Shared focus on play? Yes; No Visual tracking of toys? Yes; No Give/take play, taking turns? Yes; No 2. Language understanding: Understands single words ? Yes; No Understands simple sentences? Yes ; No Understands complex sentences ? Yes; No 3. Speech development: Sounds? Yes; No Babbling? Yes; No Words? Yes; No Sentences? Yes; No At 5 years: 1. Has language understanding been assessed? Yes, formally assessed? ; Yes, clinically assessed?; No; Unknown 2. Which assessment methods were utilized? 3. Language understanding (compared with healthy peers): Normal ; Slightly impaired; Moderately impaired; Does not understand speech; Unknown 4. Speech function: Normal; Slightly difficult to understand; Difficult to understand; Very difficult to understand; No speech; Unknown 5. Does the child communicate by use of graphic communication aids? Printer; Bliss; Pictogram; Pictures; Does not use; Unknown 6. Does the child communicate by use of hand signals, signs or gestures? Yes; No; Unknown
S5	Are there difficulties in communication? If yes, how does the child communicate?
S6	List of associated impairment, including any speech difficulty, then coded with ICD10
S7	Speech assessed on a 5 point scale from appropriate for age to profound
S8	COMMUNICATION / VERBAL EXPRESSION I. Communication without any problem with good verbal expression II. Communication with some difficulties in verbal articulation. Slow speech but understood by strangers. III. Communication with marked difficulties in verbal articulation. Speech only understood by relatives and not by strangers. IV. Unable to communicate by verbal expression, uses symbols. Ability to point symbols. V. Communication only with the eyes / facial expression, Yes / No, or technical aid.

Table 2. (cont'd)

ID	Definitions S=Speech; L=Language, H=Hearing, E= Eating/Feeding/ Swallowing, O=Other
S9	The following questions are answered when children have a 5 year old exam with a paediatric rehabilitation specialist. Speech (select the option that applies) Normal (<3 month delay for age) Delayed Mild delay for age (3-6 months) Moderate delay for age (7-12 months) Severe delay (>12 months) Impaired (dyspraxia, dysarthria, speech and voice disorders) Non speaking Language (select the option that applies) Expressive < 3 month delay for age > 3 month delay for age Receptive < 3 month delay for age > 3 month delay for age Other communication (select all options that apply) Alternative and augmentative technology/device Signing, pictures, other similar methods (also see L1).
S10	ICF b3. Voice and speech functions. (Excluding speech dysfunction due to mental dysfunction) No Disability; Disability; Not known
S11	Is there a problem with acquisition of language? Yes/ No/ not known
S12	Communication options: 1) normal verbal communication 2) same but with light dysarthria or dyslalia 3) obvious expressive and/or receptive restriction in language use 4) some receptive but no expressive; General communication items (using no problems / slight problems, no interference with daily functioning / obvious problems interfering with daily functioning / severe problems or total impossibility to perform the item; or indicate if not known or "irrelevant" as the child's peer could not do it yet either) 1/ understanding spoken word and 2/ speech - in the same chapter 3 hearing 4 seeing and 5 writing were rated; Some behavioural aspects of communication or contactual proficiency were rated
	Language Definitions
L1	Clinical interpretation by paediatric rehabilitation specialist (also see S9).
L2	Are there difficulties in communication? If yes, how does the child communicate?
L3	Expressive language assessed on a 5 point scale from appropriate for age to profound
L4	This is a part of determination of developmental level (IQ), sometimes, in more extensive investigations also a specific language test has been performed regarding impressive and expressive language
L5	Communication / Verbal Expression I. Communication without any problem with good verbal expression II. Communication with some difficulties in verbal articulation. Slow speech but understood by strangers. III. Communication with marked difficulties in verbal articulation. Speech only understood by relatives and not by strangers. IV. Unable to communicate by verbal expression, uses symbols. Ability to point symbols. V. Communication only with the eyes / facial expression, Yes / No, or technical aid.

Table 2. (cont'd)

ID	Definitions S=Speech; L=Language, H=Hearing, E= Eating/Feeding/ Swallowing, O=Other
L6	At diagnosis: 1. Interaction with child: Shared focus on play? Yes; No Visual tracking of toys? Yes; No Give/take play, taking turns? Yes; No 2. Language understanding: Understands single words? Yes; No Understands simple sentences? Yes; No Understands complex sentences? Yes; No 3. Speech development: Sounds? Yes; No Babbling? Yes; No Words? Yes; No Sentences? Yes; No At 5 years: 1. Has language understanding been assessed? Yes, formally assessed?; Yes, clinically assessed?; No; Unknown 2. Which assessment methods were utilized? 3. Language understanding (compared with healthy peers): Normal; Slightly impaired; Moderately impaired; Does not understand speech; Unknown 4. Speech function: Normal; Slightly difficult to understand; Difficult to understand; Very difficult to understand; No speech; Unknown 5. Does the child communicate by use of graphic communication aids? Printer; Bliss; Pictogram; Pictures; Does not use; Unknown 6. Does the child communicate by use of hand signals, signs or gestures? Yes; No; Unknown
L7	Use of spoken language: pre-verbal, single words, sentences comprehension/non verbal communication
L8	Speech and language therapist evaluates most children and applies standardised tests
L9	The standard scores on subtests for select intelligence and adaptive tests include this data
	Hearing Definitions
H1	"Hearing Impairment: Sensorineural loss of 50 dB or more averaged across the range 0.5 to 4 kHz in the better ear. In the absence of a pure-tone audiogram, include all children with a hearing aid / cochlear implant fitted for sensorineural loss."
H2	"Presence of associated impairments (please circle one for each of following four): Hearing: No impairment; some impairment (includes conductive hearing loss); bilateral deafness; unknown" *Wording found on Australia New Cerebral Palsy Record Form*
H3	Children who have the 5 year old exam will have the following questions answered. How was the hearing assessed? Clinical assessment only; Formal testing by audiologist Hearing results (select the most appropriate option): normal; unilateral; sensorineural loss; bilateral sensorineural loss; conductive hearing loss (with or without grommets) currently; conductive hearing loss (with or without grommets) in the past Uses hearing aid/s: yes/no Uses a cochlear implant: yes/no
H4	1. Is the child hearing impaired? Yes; No; Unknown 2. Does the child have a serious hearing impairment (hearing loss >70dB before correction, in best ear)? Yes; No; Unknown
H5	Hearing loss? Yes; No; NR. If yes (tick one).Mod unilateral (50-70db)/ Mod bilateral (50-70 db)/ Severe unilateral (more than 70db)/ Severe bilateral (more than 70db)/ Stills to sound/ Unresponsive

Table 2. (cont'd)

ID	Definitions S=Speech; L=Language, H=Hearing, E= Eating/Feeding/ Swallowing, O=Other
H6	"Is hearing impairment present? Y; N; Uncertain. If YES: does the child use hearing aids? Y; N; Uncertain" *Wording found on Northern Ireland CP Register Form*
H7	"Yes/No, Severe hearing impairment (Severe and profound hearing loss in the better ear before correction) If the level of hearing loss is greater than 70 db in both ears, this will conform to the SCPE criteria" *Wording found on Surveillance of Cerebral Palsy in Europe (SCPE), Data Collection Form for Cerebral Palsy*
H8	Is there an auditory impairment? Severity of the auditory impairment? (severe >70dB)
H9	"Current hearing: Tick one box (two columns of boxes one without aids and one with aids) 1. Normal or near normal <40dB HL 2. Moderately impaired 41-70dB HL 3. Severely impaired 71-95dB HL 4. Profoundly impaired >95dB HL." *Wording found on Northern Ireland CP Register Form*
H10	Include hearing test results when available
H11	Hearing assessed on a 5 point scale from appropriate for age to profound
H12	Hearing impairment: none, mild, moderate (aids), severe/profound
H13	ICF b230 Hearing functions: No Disability; Disability *Not known*; one or double sided deafness or needing hearing aid
H14	Is hearing impairment present? Yes / No; Age at diagnosis Hearing loss (left and right ears) What do you consider to be the likely cause? Does the child use hearing aids? Has cochlear implants?
H15	MADDSP Definition of Hearing Loss Hearing loss is defined as a measured, bilateral, pure-tone hearing loss at frequencies of 500, 1000, and 2000 hertz averaging 40 decibels (dB) or more in the better ear. In the absence of a measured, bilateral hearing loss, children meet the case definition if their source records include a description, by a licensed or certified audiologist or qualified physician, of a hearing loss of 40 dB or more in the better ear (e.g., profound sensorineural hearing loss). Severity is defined on the basis of the following Hearing loss levels (measured in the better ear): moderate (a hearing loss of 40-69 dB), severe (a hearing loss of 70-89 dB), and profound (a hearing loss of >=90 dB).
H16	Hearing levels: no hearing restriction, light or severe hearing restriction, deaf Activity level: no problems, slight problems, no interference with daily functioning, obvious problems interfering with daily functioning, severe problems or total impossibility to perform the item

Table 2. (cont’d)

ID	Definitions S=Speech; L=Language, H=Hearing, E= Eating/Feeding/ Swallowing, O=Other
	Eating/Feeding/Swallowing Definitions
E1	"Is there a swallowing problem either with food or drink? Yes; No; Uncertain"
E2	Swallowing: 1) Normal 2) Modifications required (e.g., special spoon, food thickening) 3) Non-oral feeding 4) Uncertain
E3	Mealtime management (oromotor/swallowing/eating/nutrition) Currently affected? Yes; No Past only? Yes; No If current, is there a swallowing problem with either food or drink? Yes; No Is the swallowing problem (if present) controlled on a special therapy/dietary regime? Yes; No Is there aspiration (proven or high suspicion)? Yes; No Is there associated failure to thrive? Yes; No Is there excessive drooling or dribbling in waking hours? Yes; No Gastro-oesophageal reflux Currently? Yes; No Past only? Yes; No Controlled on medical treatment? Yes; No Uncontrolled on medical treatment? Yes; No Surgical treatment? Yes; No PEG? Yes; No
E4	1. Does the child have eating difficulties? Yes; No; Unknown 2. How is the child fed? Eats without assistance; Eats with assistance; Must be fed (orally); Partially tube fed; Mainly tube fed; Unknown 3. Gastrostomy 4. Age at gastrostomy? Yes; No; months; Unknown
E5	Is the child fed by gavage or gastrostomy tube?
E6	"Is there excessive drooling or dribbling during waking hours? Yes; No; Uncertain" *Wording found on Northern Ireland CP Register Form*
E7	Feeding assessed on a 5 point scale from appropriate for age to profound
E8	Data on whether gastrostomy fed, and date PEG inserted.
E9	ORALMOTOR FUNCTION / FEEDING I. Chews, swallows and drinks without problem, Self-feeding II. Some difficulties in chewing and swallowing. Self-feeding without adaptations or technical aids. Needs only little occasional help and supervision. III. Persistent difficulties in chewing and swallowing for solids and/or liquids with occasionally choking. Self-feeding with adaptations and permanent supervision, or needs to be fed because poor hand function. IV. Poor chewing with marked difficulties in swallowing for solids and liquids, choking occasional. Tongue thrust/ bite/ gag reactions/ oral spasms. Needs to be fed. Time for feeding < 1 hour. (needs adapted food). V. No chewing. Severe difficulties in swallowing for solids and liquids. Tongue thrust and/or bite/ gag reactions, and/or oral spasms. Choking frequently. Totally dependent in feeding. Time for feeding > 1 hour. Gastrostomy or Nasogastric Tube.
E10	Feeding: no problem, some difficulty, severe difficulty, gastrostomy/NG tube
E11	Way of feeding, presence of gastrostomy, enriched food, consistency
E12	ICF b510 Ingestion functions: No Disability; Disability; Not known

Table 2. (cont’d)

ID	Definitions S=Speech; L=Language, H=Hearing, E= Eating/Feeding/ Swallowing, O=Other
E13	We mainly ask if the child can eat or needs a feeding tube
E14	no drooling, sometimes drooling, continuous drooling Food intake: independent, some help needed, only with help, tube feeding Activity: eat/drink rated as 1 no limitation whatsoever , 2 some limitation but independent, 3 obvious limitation, adaptation needed and/or help, 4 impossible, help essential
	Other Definitions
O1	Records use of hearing aids and cochlear implants
O2	Other communication (select all options that apply) Alternative and augmentative technology/device, signing, pictures, other similar methods
O3	Type of communication aid specified
O4	Assisted feeding specified
O5	Other communication: (a) are communication difficulties present (excluding isolated articulation defects)? yes/no/uncertain (b) If yes, how does the child usually communicate? speech or speech and formal methods or formal systemised methods only or not communicating by speech or formal methods.
O6	Other communication: Comprehension and conversation assessed on a 5 point scale from appropriate for age to profound
O7	Types of AAC used, extension of use
O8	Modes of communication other than speech: e.g. PECS, sign language, feeding information: oral vs. gastrostomy or NG tube, swallowing difficulties, drooling
O9	Hearing aids, cochlear implants

a description of the type of data collected. Specific registries' definitions can be found by comparing this definition code in Table 1 to the corresponding coded definition in Table 2. "NR" indicated that the registry did not answer that question. "See" statements were added in Table 2 to indicate definitions judged by the researcher to include concepts from another category. The register definitions also varied by type of questions used in data collection. Thirty-five definitions were based on yes/no or categorical responses (e.g. S1, S3, S8, L2, L4, H2, H4, H6, E1, E3, E4). Eleven definitions used ordinal responses (e.g., S7, S8, L2, H5, H9).

Reasons provided by the registry staff for not collecting communication and/or eating data included adequate data not available, area not considered, not part of registry's minimum data set, and lack of definitions or measurement tools. As seen in Table 3, the reasons varied by type of data. CP registry staff noted that hearing or speech surveillance were more often included as part of the registry's minimum data set when compared to surveillance of language and eating. Due to the data unavailability from its sources, one registry respondent, the National Danish Cerebral Palsy Register, indicated that communication and eating data were not collected.

Table 3. Frequency of reasons for no communication or eating data collection.

Reasons	Speech	Language	Hearing	Eating
Data not available	3	5	1	2
Area not considered	2	2		3
Not part of minimum data set and/or registry purpose	2	6		5
Inadequate definitions and/or measurement tools				2

Type of communication and eating definitions

Hearing data were collected by 96% (n=25 registries) of the 26 registries with 14 different definitions. Eight (i.e., hearing definitions H1, H4, H5, H7, H8, H9, H19, H12 in Table 2) of the 14 definitions included a label (e.g., normal, moderate, severe, profound) and/or a number (e.g., >40 dB, >50 dB, > 70 dB) indicating degree of hearing loss. Three definitions (i.e., hearing definitions H1, H2, and H3) explicitly listed types (e.g., sensorineural, conductive) of hearing loss. None of the definitions included hearing loss configuration (e.g., flat, sloping, rising, trough). Five definitions (i.e., H2, H3, H5, H13 and H14) included ear-specific data. Seven definitions (i.e., H1/O1), H3, H6, H9, H12, H13, and H14) noted the presence of hearing aids, cochlear implants, and/or grommets which are types of hearing loss interventions.

Speech data were collected by 85% (n=22 registries) of reporting registries with 11 differing definitions. Aspects of speech sound production (e.g., articulation, dysarthria, dyspraxia) were mentioned in 4 of 11 speech definitions (i.e., S1, S4 S8, S9 in Table 2). Language data were collected by 42% (n=11 registries) of reporting registries with 8 differing definitions. Aspects of expressive language or communication data were explicitly mentioned in 5 of the 8 language definitions (i.e., L3, L4, L5, L6, L7 in Table 2), and aspects of receptive language or communication data were explicitly mentioned in 3 of the 8 definitions (i.e. L4, L6, L7). However, L1 and L8 definitions referred to unnamed standardized assessments which are likely to include expressive and receptive language measurements. Speech, language, and communication concepts were sometimes entangled in definitions (e.g. definitions S3, S4, S5, S8, S9, S11, L2, L5, L6, L7, O5, O6). Augmentative and alternative communication (AAC), including nonverbal communication, gestures, signs, communication pictures, and speechgenerating devices, were monitored in 9 definitions (e.g., S3, S4/L6, S8/L5, S9, L7, O2, O3, O7, O8)

Eating data were collected by 65% (n=17 registries) of reporting registries with 13 differing definitions. Non-oral (e.g., tube, PEG, gastronomy, and nasogastric) feeding information was requested in 9 of the 13 definitions (i.e., E2, E3, E4, E5, E8, E9, E10, E11, E13 in Table 2) Information about nutrition, growth, and/or adapted diets were included in 4 definitions (i.e., E2, E3, E9, E11). Self-feeding and/or preparing food and drink in the mouth were included in 6 definitions (i.e., E2, E3, E4, E9, E10, E11). Four eating definitions included meal management or need for assistance to eat (i.e., E3, E4, E5, E9,). Drooling was noted in 2 definitions (i.e., E3, E6). Swallowing as a general concept was part of 4 definitions (i.e., E1, E2, E3, E9). Pharyngeal swallowing symptoms (i.e., aspiration, choking) were mentioned in 2 definitions (i.e., E3, E9). Gastrioesophageal reflux (GER) was included in 1 definition, F3.

Results from linking the ICF concepts to registries definitions showed an overall focus on ICF body function headings as described below.[23,24] Some definitions included the ICF activity headings of “communication” or eating under “self-care.” Communication and eating effects on a person’s participation in ICF major life areas of “education,” “employment,” and “community” were not explicitly captured in any of the definitions.

All the hearing definitions were focused on ICF body function heading of “hearing functions” with no reference to hearing’s important contribution to understanding communication.[23,24] Thirteen speech and language definitions (e.g., S1, S2, S4, S5, S6, S8, S9, L1, L3, L4, L5, L6, L7) included concepts from the ICF body structure and/or function including ICF headings of “mental functions of language,” “mental function of sequencing complex movements,” or “voice and speech function.”[23,24] Only 8 registry definitions (e.g. definitions

S3, S4, S5, S8, S9, L2, L5, L6) were focused at least partially on ICF activity concepts of "communication" including "speaking," "using communication devices and techniques," and "producing nonverbal messages" or "formal sign language."[23,24] Nine of the eating/swallowing definitions (e.g., E2, E3, E4, E5, E8, E9, E10, E11, E13 focused on the ICF environmental factor of "products and technology" for assisted feeding while only 6 definitions (e.g., E1, E2, E3, E4, E9, E12) included ICF body function of "ingestion, "digestion," or "weight maintenance" and 4 definitions (e.g., E3, E4, E9, E13) included the ICF activity heading of "eating" or "drinking."[23,24]

Data collection frequency and timing

Reported data collection frequency varied from none to 3 times during the child's life. Table 4 lists the speech and language data collection frequency by registry. Speech data were collected once by 59% (n=13) of registries reporting speech data. Language data were collected once by 45% (n=5) of registries reporting language data. Table 5 lists the hearing and eating data collection frequency by registry. Hearing data were collected once by 64% (n=16) of registries reporting hearing data. Eating data were collected once by 59% (n=10) of registries. While not specifically requested in the survey, several registries reported data collection timing by age of the person with CP. This information is also included in Tables 4 and 5. The ages were generally 5 years old or younger, though ages 8, 12, and 20 were mentioned by a few registers.

Table 4. Speech and language data collection frequency by registry.

	Speech data			Language data		
Registry Name	Once	Annual	Other	Once	Annual	Other
New South Wales and Australian Capital Territory CP Register	x		option to add or change data at age 5			
Queensland CP Register			At referral and confirmed at 5yrs, Plans to confirm data at 20 years			At referral and confirmed at 5yrs
The South Australian CP Register	at age 5			at age 5		
Tasmanian CP Register	x			only for 5 yr olds who undergo examination by a clinician		
Victorian CP Register	x					
Western Australia CP Register			When enrolled and at age 5			
Northern Territory Australian CP Register	x					
Canada- Quebec	x			x		
Cyprus		x				on review in clinic 4-6 monthly- but not in each case
National Danish CP Register						

Table 4. (cont'd)

Registry Name	Speech data			Language data		
	Once	Annual	Other	Once	Annual	Other
Registre des Handicaps de l'Enfant de la Haute-Garonne (France)			At age 5, 8, and 12			
Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP) (France)	x					
Iceland			Most often around age 2 and between ages 5 and 6			Most often around age 2 and between ages 5 & 6
Ireland- Eastern Region CP Study			No Response			No Response
Central Italy CP Register					x	
CP in Kaunas County Lithuania	x					
Norwegian CP Registry (CPRN)			At diagnosis and age 5			At diagnosis and age 5
Portugal- National Epidemiological Study of CP	x			x		
Registro de Parálisis Cerebral de Madrid – DIMAS (Spain)						

Table 4. (cont'd)

Registry Name	Speech data			Language data		
	Once	Annual	Other	Once	Annual	Other
The CP Register of Western Sweden - Gothenberg	x			x		
CPUP- Swedish National Health Care Quality Programme for secondary prevention in CP	x					
CP Register for Scotland			Varies by clinician visits			Varies
Mersey and Cheshire CP Register						
North of England Collaborative CP Survey (NECCPS)	x					
Northern Ireland CP Register (NICPR)	x		If first collected in a young child (i.e. less than 5 years) then collected again (ideally at 5 years.)			
4Child, Four Counties Database of CP, Vision Loss and Hearing Loss in Children			age 3 and age 5			
New South Wales and Australian Capital Territory CP Register	x		option to add or change data at age 5			

Table 5. Hearing and eating data collection frequency by registry.

Registry Name	Hearing data			Eating data		
	Once	Annual	Other	Once	Annual	Other
Queensland CP Register			At referral and confirmed at 5 yrs, Plans to confirm data at 20yrs			
The South Australian CP Register	x			x		
Tasmanian CP Register	x			only for 5 year olds who undergo exam by clinician		
Victorian CP Register	x			x		
Western Australia CP Register			When enrolled and at age 5			
Northern Territory Australian CP Register	x					
Canada- Quebec	x			x		
Cyprus			usually at first appointment and any time later			usually at first contact and sometimes at follow up visits
National Danish CP Register						
Registre des Handicaps de l'Enfant de la Haute-Garonne (France)			At age 5, 8, and 12			

Table 5. (cont'd)

Registry Name	Hearing data			Eating data		
	Once	Annual	Other	Once	Annual	Other
Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP) (France)	x					
Iceland	x		if results unclear, hearing test is repeated			Twice during preschool years
Ireland- Eastern Region CP Study			Initially and at least one medical chart update			Initially and at least one medical chart update
Central Italy CP Register		x				
CP in Kaunas County Lithuania	x			x		
Norwegian CP Registry (CPRN)			At diagnosis and age 5			At diagnosis and age 5
Portugal- National Epidemiological Study of CP	x			x		
Registro de Parálisis Cerebral de Madrid – DIMAS (Spain)	x					
The CP Register of Western Sweden - Gothenberg	x			x		

Table 5. (cont'd)

Registry Name	Hearing data			Eating data		
	Once	Annual	Other	Once	Annual	Other
CPUP- Swedish National Health Care Quality Programme for secondary prevention in CP	x			x		
CP Register for Scotland			Varies			Varies
Mersey and Cheshire CP Register	x					
North of England Collaborative CP Survey (NECCPS)	x			x		
Northern Ireland CP Register (NICPR)	x		If first collected in a young child (i.e. less than 5 years) then collected again (ideally at 5 years.)	x		If first collect < 5 years, then collect again at 5 years.

CHAPTER 4

Discussion

Population-based cerebral palsy registers and cerebral palsy clinical research studies have the potential to provide important data on communication and eating disorders. However, this potential is undermined by several data collection issues: 1) frequency of data collection, 2) timing of data collection, 3) lack of valid and reliable definitions.

Inclusion, frequency, and timing of communication and eating data collection by CP registries varied at least in part due to data sources, registry resources, and registry purposes. Some of the comments by registry staff indicated that this type of data was not available in their data sources, and/or that communication and/or eating surveillance was not a major focus of their registry, A majority of registries reported collecting eating and communication, especially hearing, data only once in a child’s lifetime, often by age 5. This collection timing and frequency does not reflect that speech and language development continues into at least adolescence. In addition, some problems (e.g., conductive hearing loss) may be temporary, and some individuals with communication and eating problems receive interventions to remediate the problems or improve functional outcomes such as through the use of assistive technology.[17,59] Several registry staff noted that the lack of resources limit their registry from expanding the type and frequency of data collection. Permanently impaired gross and fine motor movements are the hallmark symptoms of CP with communication and eating problems considered “associated” impairments of CP.[2] Timing of data collection likely required some balancing of data availability, funding limitations, and registry purposes.

Registries do not have a consensus on valid and reliable definitions for communication and eating issues in CP. Many definitions use speech, language, and communication terms interchangeably. With the adoption of the ICF model within cerebral palsy research and clinical activities, all definitions should be based on the ICF framework and explicitly include its level.

Speech, language, hearing, and communication are distinct, but related terms. Speech is often described by the body structures and functions of the respiratory, laryngeal, nasal/pharyngeal, and oral systems used to produce speech. However, hearing and language skills also play important roles in developing and maintaining adequate speech. Language is often described by how one receives and expresses the language components of pragmatics (e.g., use), semantics (e.g., vocabulary and meaningful concepts), syntax (e.g., sentence construction), morphology (e.g., word constructions such as plurals, past tense, or possessives), and phonology (e.g., permissible sound combinations). Communication is often used as a more global term where one combines the body structures and functions of speech, language, hearing, gestures, and so forth to send and receive messages.

Hearing definitions used by CP registries are primarily at a body function level. None of the definitions explicitly included hearing's role in communication. As presented in Chapter 1, audiologists typically define hearing loss in children when thresholds are greater than 20 dB HL in an ear at any of the pure tone frequencies that are routinely tested.[57] Based on that criteria, most of the CP registries' definitions underreport hearing difficulties in individuals with CP.

Many registries' hearing loss definitions used different minimum cut points than 20 dB HL (i.e., 40 to 70 dB hearing sensitivity thresholds -- presumably measured in dB HL although this decibel reference level was listed in only the H9 definition). Only definition H1 described how to use pure tone thresholds to calculate a sensorineural hearing loss average to be used with its definition. If hearing definitions are based on a single number, they should describe how the single number is obtained and provide justifications for using a number greater than 20 dB HL to quantify hearing loss. These cut points are implied in definitions H2, that use terms of normal, hearing impairment, deafness, mild, moderate, severe, and profound. However, these terms have not been standardized to mean only one range of thresholds.[60] Categorical descriptions such as mild, moderate, severe, and profound hearing loss need to be referenced to a particular audiogram description method.

Types (i.e., sensorineural or conductive) of hearing loss were included in definitions H1, H2, H3. The type of hearing loss can affect communication and should be referenced in the hearing data.[60] For example, conductive hearing losses are due to problems in the outer and middle ear and may be temporary and/or fluctuating in the degree of hearing loss. Sensorineural hearing losses result from permanent problems in the inner ear or auditory nerve. Mixed hearing losses have both a conductive and sensorineural component. Definitions H2, H3, H5, H13 included some indication if one (i.e., unilateral) or both (i.e., bilateral) ears were affected. The number of ears involved and when the hearing loss is acquired during speech and language development can affect a person's communication ability.

Communication can include different methods such as speaking, listening, reading, writing, and using AAC. The current set of definitions needs careful and consistent delineation of these interacting components and a determination of which components can and should be tracked in a minimal universal data set.

Eating definitions (which should consider ingesting both food and fluids) can clarify body structures/functions, compensatory strategies, and activity/participation. For example, sorting out what stages of eating (getting food and drink into the mouth, oral preparation, oral transport, pharyngeal transport, and/or esophageal transport) are working would better highlight any body structure/function problems as well as possible interventions.

The relative amount of time and assistance that eating takes may affect the activity level, life participation in eating and other desired activities, and environmental factors. Eating safely and adequately may take time away from other activities and participation. Eating's possible role in one's participation with family, friends, cultural, vocational, and community life may also be important.[46,47] For example, participating in business lunches or holiday meals may affect business success or cultural connectedness. Environmental factors including diet modifications, adapted equipment, or aide assistance may also interact with activity and participation. The underlying reason(s) for assistive technology such as feeding tubes may also be relevant. For example, the tube may be necessary for the individual to safely ingest food and fluids or the tube may be necessary to ensure the person's adequate nutritional intake due to slow but safe oral eating.

Assistive technology (AT) use (e.g. AAC, hearing aids, feeding tubes) is included in a few data sets. While AT does not usually change the underlying body structure and function, it has the potential to improve activity and/or participation by modifying environmental factors.

At the February 2009 World Congress of CP Registers, held in Sydney, Australia, registries' representatives began a discussion about a possible universal minimum data set. These efforts could improve prevalence data if communication and eating data were included in a universal minimum data set. However, registry representatives need to discuss the purposes for collecting this type of data to make decisions about what communication and eating definitions to use. These decisions would then help registry staff to evaluate the frequency and timing of data collection. Data sources would need to be encouraged or required to use the same definitions.

Most CP registries collect the Gross Motor Function Classification System (GMFCS)[61,62] level and some registries collect the Manual Ability Classification System[63] (MACS) to describe, respectively, mobility and handling objects at an WHO ICF activity/participation level. The Communication Function Classification System[43] (CFCS) has recently been completed as a communication analogue to the GMFCS and MACS. The CFCS is used by a professional or a parent to classify the child's everyday communication with familiar and unfamiliar communication partners into one of five levels: Level I. Effective communicator with familiar and unfamiliar communication partners, Level II. Effective but slower communicator with familiar and unfamiliar communication partners, Level III. Effective communicator with familiar but not unfamiliar communication partners, Level IV. Inconsistent communicator even with familiar communication partners, Level V. Seldom effective communication even with familiar communication partners. All types of communication including AAC are considered in the CFCS classification. SCPE registry members (Virella, personal communication, 2010) are evaluating the feasibility of including the CFCS in SCPE minimum data set.

Limitations of this study

No master list of CP registries exist which made potential participant identification difficult. Registries start and cease operations, apparently due to the availability of funding, staffing, and other necessary resources.

Although the results lists the communication and eating data collected by most of the active population-based CP registries, little is known about how the registries decided upon these definitions. In addition, little is known about decisions on which ages to collect communication and eating data and how data sources may influence these decisions.

Future research needs

The confusing and conflicting prevalence rates for communication and eating must be improved as a first step in understanding the extent of the problem in individuals with CP.

However, no complete set of valid and reliable definitions or measurement tools currently exist for collecting data on communication, speech, language, hearing, and eating throughout a person's life. Research is needed to validate existing definitions or create new measures especially in consideration of the ICF model. This is unlikely to happen without research that clarifies the origins and purposes of CP registries' communication and eating definitions and data as well as rationale for the frequency and timing of data collection. CP registries need clinical and research expertise in CP communication and eating issues to collaborate on developing a consensus minimal data set for communication and eating. A more extensive set of data definitions than this minimal set is needed for clinical research questions about the participation of individuals with communication and/or eating problems in life situations such as family life, education, employment, and community.

Public health concerns to be addressed by prevalence and intervention effectiveness need to be considered including healthy aging in individuals with CP.[64] Research should also consider if one set of definitions are appropriate throughout the life span of individuals with communication and/or eating problems as they transition to adult issues of family, employment, and community participation.[36,37,65]

Conclusions

The motor impairment caused by CP can affect and even disrupt the important daily activities of communication and eating. A range of communication and eating performances is demonstrated among people with CP. CP professionals and researchers should consider communication (including speech, language, and hearing) and eating classifications and assessments as well as possible ramifications of communication and eating problems in daily activities and societal participation by individuals with CP.[37,66]

The confusing and conflicting prevalence rates for different communication and eating abilities need to be improved. Population-based CP registries may be able to help address these needs but are limited by 1) a lack of resources to expand data collection, 2) the lack of a valid, reliable universal data set of communication and eating measures, and 3) a body structure/function focus for hearing definitions. In order to compare or pool data across registries, definitions of communication, speech, language, hearing, and eating should be standardized. A working group of CP registry staff and communication and eating clinical researchers should be convened to standardize definitions and data collection methods.

The possible influences of timing data collection by a person's age need to be explicitly considered in surveillance and clinical research. For example, frequency and timing of data collection is likely to affect prevalence due to both the developmental nature of speech, language, hearing, and eating and possible remediation of these conditions throughout one's lifespan. Researchers and registry staff should report the age(s) of the individuals, operational definitions used, and the source of the data. The resulting improved prevalence estimates could advance both clinical research and service delivery to optimize communication and eating in individuals with cerebral palsy.

APPENDIX

APPENDIX

Registry survey questions

Which Cerebral Palsy Registry do you represent?

Please list the names, locations and any contact information for any other cerebral palsy registries you are award of that are not listed in question one.

Does your registry track any speech data? *Please mark all that apply.*

Dysarthria
Speech sound errors
Intelligibility
Other speech data

Please indicate any questions, definitions and/or categories used for the speech data collection by your registry.

How often are speech data collected?

No speech data are tracked

Why are speech data not collected by your registry? *Please mark all that apply*

Data not available
Not relevant to cerebral palsy
Do not know the reason
Was not considered
Other (please specify)

Does your registry track any language data? *Please mark all that apply.*

Receptive language (amount of language understood)
Expressive language (amount of language spoken)

Please indicate any questions, definitions and/or categories used for the receptive (understood language) and/or expressive (spoken language) data collection by your registry.

How often are language data collected?

No language data are tracked

Why are language data not collected by your registry? *Please mark all that apply*

Data not available
Not relevant to cerebral palsy
Do not know the reason
Was not considered
Other (please specify)

Does your registry track any hearing data? *Please mark all that apply.*

Yes, we track hearing data

Please indicate any questions, definitions and/or categories used for the hearing data collection by your registry.

How often are hearing data collected?

No hearing data are tracked

Why are hearing data not collected by your registry? *Please mark all that apply*

Data not available
Not relevant to cerebral palsy
Do not know the reason
Was not considered
Other (please specify)

Registry survey questions (cont’d)

Does your registry track the following data? *Please mark all that apply.*

Yes, feeding data
Yes, eating data (e.g., tube feeding, by mouth)
Yes, eating data (e.g., tube feeding, by mouth)

Describe any data that are gathered. Please indicate any questions, definitions and/or categories(such as eating by mouth, tube feeding, etc.) used for the feeding, eating, and/or swallowing data collection by your registry..

How often are feeding, eating, and/or swallowing data collected?

No feeding, eating, and/or swallowing data are collected

Why are feeding, eating, and/or swallowing data not collected by your registry? *Please mark all that apply*

Data not available
Not relevant to cerebral palsy
Do not know the reason
Was not considered
Other (please specify)

Does your registry track other communication data (e.g., non-speech aids, augmentative and alternative communication- AAC, sign language, hearing aids) and/or eating data? *Please mark all that apply*.

Yes, other types of communication data
Yes, other types of eating data

Describe the other communication and eating data that are gathered. (Please include any definitions and/or categories used)

How often are other data collected?

No other types of data

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