'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities

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ABBREVIATIONS

ICF	International Classification of Functioning, Disability and Health
QOL	Quality of life
PODCI	Pediatric Outcomes Data Collection Instrument
RCT	Randomized controlled trial

AIM Improving participation of children with disabilities is a priority; however, the participation construct lacks clarity. This systematic review investigated how researchers defined 'participation' and the language used in participation intervention research.
METHOD Nine health and education databases were searched for intervention studies of children with disabilities that included a participation outcome. Quantitative data were extracted using a customized form, and participation text data were extracted verbatim. Themes were derived using a thematic coding approach. These participation themes were applied to the outcome measures used in the included studies to compare participation language with the methods used to quantify participation changes.
RESULTS Of the 2257 articles retrieved, 25 were included in this review. Five participation themes and nine subthemes were developed. Two themes, attendance and involvement, were directly related to the participation construct. Three additional themes described related concepts: preferences, activity competence, and sense of self.
INTERPRETATION Attendance and involvement seem to describe the essence of the participation concept. The related themes may provide important avenues to enhance participation outcomes. This review highlighted the need for researchers to define the construct under investigation clearly and select measures carefully, as measurement choice is the mechanism through which the concept is operationalized in research.

The publication of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) has resulted in an intensification of international interest in 'participation' as the ultimate health outcome.[1,2] The ICF defines participation as 'involvement in a life situation'[2] participation restriction is defined as 'problems an individual may experience in involvement in life situations'.[2] Because there is no universal acceptance of the definition of participation, a discourse in the literature has developed about how to operationalize the concept.[3,4] This is critical, because without clarity about the concept, defining outcome goals and developing scales and measures to assess participation outcomes will remain open to question as to whether the measures are fit for purpose.

One part of the complexity of the conceptual issue is the fact that the World Health Organization did not clearly distinguish between activity and participation within their classification system, offering authors four methods for determining when participation rather than activity was being classified.[1,2] This lack of distinction provides ample opportunity for varied interpretations of the concept under investigation and hence varied approaches to measurement,[5] leading to imprecision and confusion in what is found and reported.

Several authors describe participation as multidimensional or as a family of constructs.[6,7] We see a strong analogy between these approaches and how the concepts associated with 'quality of life' (QOL) have been clarified over the past decade or more.[8] That is, when QOL was first reported in the literature as an important concept within health research, there were varied notions about what it meant. This resulted in confusion and/or disagreement about research findings and difficulties with combining findings from different studies. The complex discourse in QOL literature has been clarified by the introduction of terms such as 'quality of life', 'health-related quality of

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life', and 'health utility', each of which has a distinct meaning.[8] It is possible that the concept of participation will also become clearer through an approach that identifies and parses multiple constructs within the conceptual family. As with the QOL construct, participation is focused on the intersection between the individual and the environment. Participation is, however, more focused on everyday functioning than the QOL focus on well-being and perceptions about life.[9]

We recently completed a systematic review of the effect of randomized controlled trials (RCTs) that aimed to improve participation for children with disabilities.[10] One of the outcomes of that review was the recognition of the lack of consistency and clarity in the definition and measurement of participation in the included trials. The aim of the current study was to extend the findings of the previous review by investigating the construct of participation as applied to children with disabilities and as defined in published intervention research. We chose intervention research as the focus of enquiry because to effect and measure change in participation it was anticipated that researchers would need to define the participation variable and, in the context of their view of the underlying construct, select the most appropriate outcome measure to quantify change.[11]

This investigation of how researchers resolve the issue of participation as a complex construct when designing and reporting intervention research in childhood disability was undertaken to inform the field further about future research design and reporting. The research questions addressed were the following. (1) What participation language do authors use to determine whether interventions under investigation improve participation outcomes? (2) How do authors assessing these interventions define participation? (3) What is the relationship between the definitions or descriptions of participation provided by the authors and the defined construct of the participation measure chosen within the study?

METHOD

Search strategy

The original search for this study was performed in October 2013 in multiple databases using the search strategy previously reported in Adair et al.[10] No update of the search was undertaken because of the large number of articles identified initially, the recurrent themes evident from the data extraction and analysis using the included articles, and the focus on conceptual issues as opposed to a synthesis of intervention effects. The search terminology and an example of the search strategy are provided in Appendices S1 and S2 respectively (online supporting information).

Selection criteria

The inclusion and exclusion criteria for studies in this review are reported in Table I. In contrast to the previous review,[10] this review included all intervention study designs rather than only RCTs and pseudo-RCTs. This broad approach was taken because the research questions in this current study focused on the underlying concepts used within studies rather than the effects of the interventions under investigation. To ensure that selection of studies was not biased by a predetermined definition of participation, the current authors applied no operational definition of participation to the search or selection criteria. Studies that were described by their authors as aiming to address either participation or engagement were sought.

One researcher (BA) performed the initial search and subsequent initial screening of articles. To determine those articles that met the selection criteria, two reviewers (BA and AU) then independently assessed the titles and abstracts of those articles. After review of abstracts, the same two reviewers independently assessed the full text for each remaining article. The complexity of the underlying construct of participation and the breadth of studies retrieved in the search necessitated a full-team discussion to determine the final list of included articles. This helped to address potential selection bias due to the discipline of reviewers or an individual's specific understanding of the participation construct.

What this paper adds

- The language used to describe participation in research is inconsistent.
- There is a disconnection between participation language and outcome measures used in research.
- Two key elements to the participation construct are attendance and involvement.
- Other subthemes are related to, but not synonymous with, participation.

Table I: Study selection criteria

Inclusion criteria	Exclusion criteria
Population	
Mean/median age of participants 5–18y	Studies focussed on children with diabetes
Permanent childhood or developmental disability	
Outcome	
Authors explicitly described an aim of the study intervention was to enhance an aspect of participation AND/OR inclusion of a discrete participation outcome measure or measure with a discrete subsection related to assessing participation	Qualitative studies focused on experiences or outcomes Outcomes defined as 'correct' on-task behaviour as this was determined to be a measure of behavioural/activity skill and not participation Quality of life
Design	
Intervention-based studies including randomized controlled trial, quasi-randomized controlled trial, single-group pre- and post-test studies, single case experimental designs	Other systematic reviews or literature reviews Study design was a case study or case series
Publication type	
Articles published as full texts in peer review journals	Abstracts, conference papers, theses, books, and other grey literature Published in languages other than English

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Data extraction

A customized, predetermined data collection tool (available on request from the authors) was used to extract the relevant data from each article. Extracted data focused on (1) quantitative data, including study and participant characteristics, types of intervention, dependent variables, and outcome measures and (2) qualitative data related to the language used to describe participation. Two reviewers (BA, AU) independently assessed the full texts of included articles and independently performed quantitative data extraction. Measures were deemed to assess participation if the authors stated they were participation measures or when the two independent reviewers identified the measure as a participation measure. Differences were resolved by reference to the literature and discussion to reach consensus.

A subgroup of three reviewers (CI, DK, BA) performed the primary data extraction and analysis of the qualitative data. During the qualitative data extraction process, salient segments of text were sought and extracted verbatim from sections of the manuscript, including the background, purpose statement, outcome measure descriptions, the discussion, and wherever else the authors provided a definition of participation or discussed the participation variable. Although some studies could be interpreted as having provided an implied definition of participation, text was only extracted as a definition when it was preceded by phrases such as 'participation or engagement can be defined as … '. Text that was considered pertinent to the construct of participation was independently extracted verbatim and compared between the reviewers. Where discrepancies existed in extracted data, the pertinent sections of the articles were reviewed and discussed by the reviewers until mutual agreement was reached.

Text data were also sought that described the participation outcome measures included in the studies. Where the study authors developed their own measures, these data were extracted from the included article. Where previously published measures were used, text data were extracted from the original source, such as the instruments' manuals or validation reports.

Data analysis and qualitative data coding

Given the qualitative nature of this review, the authors undertook a narrative synthesis and summary. A thematic coding approach was used to analyse the content of the language associated with participation.[12,13] Three reviewers (CI, DK, BA) immersed themselves in the text data extracted from each paper by reading and re-reading the text to become familiar with the authors' intent and the language used. After this, reviewers independently identified words and phrases that were pertinent to the concept of participation from each study (second round of text extraction). Differences were discussed and consensus reached in this second text extraction. The final extracted words were then compared and contrasted to identify underlying themes represented by groups of words and phrases across all studies. The themes that were relevant to each included study were then identified, providing an overview of the participation themes used by authors when describing their study. Table II provides an example of the extraction, reduction, and interpretation process used to build the themes.

In a second step, two independent authors applied the themes to the extracted text describing the participation outcome measures chosen by the included studies. This assignment of language themes to outcome measures enabled a comparison between participation themes assigned to the description of participation in the article and those assigned to the tools intended to measure participation.

Regular review and discussion of the full texts of the included articles was undertaken throughout coding and analysis to ensure that text was not taken out of context, thus assisting with the credibility and trustworthiness of results. Researcher triangulation and peer examination were other methods used throughout data analysis to ensure the credibility of the results.[14,15]

Quality assessment

The methodological quality and risk of bias assigned to the RCTs and pseudo-RCTs included in the current study have previously been reported.[10] Owing to their research designs, the remaining studies were considered to have low methodological quality and a high risk of bias for measuring the effect of interventions. Considering the research questions addressed by the current review and our focus on language and concepts rather than results of interventions, no further quality assessments were performed.

RESULTS

The initial database search identified 2257 articles; 110 full texts were assessed and 29 articles considered for data extraction. Four articles[16–19] were excluded during the data extraction process after a more comprehensive review of

Table II: Worked example of text data extraction, reduction, and interpretation

Verbatim text	First extraction of pertinent phrases	Second extraction of words and phrases	Subcategory assigned	Conceptual theme
'Enablement of participation of children and their families in activities, which are valued and foster socialization, lead to positive development and emotional well-being.'[21]	Activities, which are valued and foster socialization	Activities which are valued	Meaningful	Preference

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the studies, leaving 25 remaining for data extraction and inclusion in the narrative synthesis and summary (see Fig. 1). The four articles excluded did not explicitly define the outcomes as participation measures, but rather focused on parental perceptions of their child's homework skill[16] and assessment of the competence of a child at performing a skill[17–19] and were therefore considered by the review team to be measures of capacity.

Study characteristics

The characteristics of the 25 included studies are shown in Table SI (online supporting information). Seven studies were RCTs or pseudo-RCTs.[20–26] The remaining 18 were either comparative studies without concurrent control groups (including interrupted time series[27–37] or case series[38–44]). The studies presented data for children aged 2.5 to 22 years. Studies focused on children with cerebral palsy (seven studies),[24,25,29,32,35,38,43] autism (six studies),[22,28,31,33,34,37] other conditions such as myelomeningocele or haemophilia (six studies),[27,30,39,41,44,45] or included mixed groups (six studies).[20,21,26,36,40,42] The context in which the interventions were implemented included private residences, schools/education centres, and hospitals and community health centres.

Participation language

The information relating to the language used by study authors when describing aspects of participation is shown

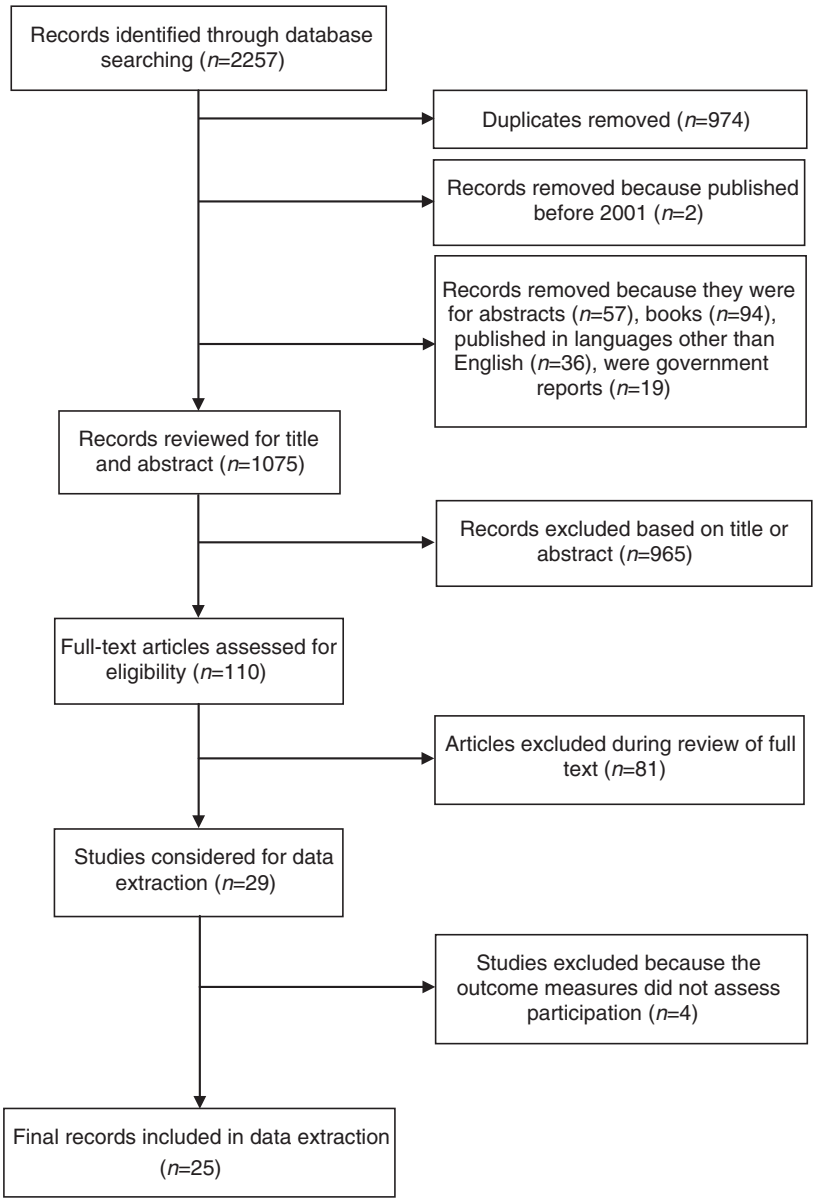

Figure 1: Article yield during review process. This figure has been modified from our previously published and concurrently run systematic review.[10] Permission has been granted from the publishers to reproduce this table.

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in Tables SII and SIII (online supporting information). Five themes and nine subthemes were derived from the text extracted from the articles. Two themes were identified as describing the participation concept: involvement (including subthemes of affect, motivation and social connection), and attendance. Three themes were identified as describing related concepts: preference (including subthemes of meaningfulness and choosing), activity competence (including the subthemes of competence and appropriate actions) and sense of self, which included personal growth or self-perception elements such as self-competence or confidence.

Participation definitions

Most studies (n=15) did not provide either a conceptual or operational definition of participation or engagement (see Table SIII). Twelve studies used the term 'participation', one study the term 'engagement',[33] 11 studies used both terms interchangeably, and one study used neither word.[22] Six studies that did not explicitly define participation did refer to the ICF,[2] and therefore could be considered to have inferred a definition of the construct of participation.[21,24,32,35,39,43] Only four studies provided an explicit definition of participation or engagement:[27,30,38,43] one defined academic engagement;[27] two referred to the ICF with one describing 'life situations' further;[38,43] and the fourth[30] described engagement in a recreational activity.

In 10 studies, participation was considered to be a primary outcome,[22,27–30,33–36,42] in 11 studies a secondary outcome,[21,24,25,31,32,37–41,44] and in four studies the primary outcome was unclear.[20,23,26,43] The definition of the measured construct for each included participation measure is provided in Table SIII. We identified 38 measures used to assess participation in the 25 included studies. Of these, nine were tools previously developed and published, while six were tools developed specifically for the study. Ten studies measured frequency of attendance at activities (an aspect of attendance); 10 measured elements of involvement, including three studies that used the Children's Assessment of Participation and Enjoyment, five that measured elements of social connection, and two that measured affect. Frequency counts of observed behaviours defined by the study, for example 'on-task behaviour' or task completion counts and measures of time to complete tasks, were used in 11 studies.

Relationship between participation language and participation outcome measures

Table SIII provides the participation themes derived from the body of the included articles (column 4) as well as the themes addressed by each of the participation outcome measures (column 7). Only two studies demonstrated clear consistency and coherence between the participation language subthemes derived from the text and those assigned to the measure.[36,37] Both Robb[36] and Woods and Poulson[37] addressed issues related to participating competently and appropriately, while Woods and Poulson[37] also included aspects of social connection. Three studies[25,32,40] showed no overlap between the language subthemes derived from the text and those assigned to the measure and the remaining 20 demonstrated partial overlap.

It was possible to assign all the language themes derived from the text of the included articles to at least one outcome measure, with the exception of the subtheme motivation. Although seven articles described the motivation associated with participation,[27,29,31,40–43] none of the chosen outcome measures assessed this theme. The most common theme discussed by the studies and addressed by the chosen outcome measures was activity competence. Nineteen articles used language related to activity competence[23,25,27–31,34–43] and all but five of these studies included a measure of competence.[23,30,40] A further five studies did not use language related to activity competence in the body of the article but included a measure that addressed this theme.[21,22,24,32,33,44]

DISCUSSION

As a mechanism for gaining conceptual clarity for future research, this review analysed the language used by researchers who aimed to enhance participation outcomes for children with disabilities. Using participation-related text extracts from 25 intervention studies, we identified five themes. One theme, preferences, has previously been shown to be an important predictor of participation,[46,47] and might be considered a precursor to the act of participation. Preferences included activities that were meaningful or important to the individuals concerned, as well as those chosen. Two themes, attendance and involvement, were identified as being consistent with the concept of participation: they relate to the objective 'being there' and the more subjective 'in-the-moment' experience of participation. This finding is consistent with participation as defined within the ICF as 'involvement in a life situation'[2] as well as previous evidence from the literature.[48–50] The final two themes, activity competence and sense of self, relate to gaining skills, or a shift in self-perception that can occur as a result of participation.

The preferences theme, including the subthemes of meaningfulness and choosing, is identified as a precursor to participation. Preferences are related to the person's previous experience or personal history and therefore can act as intrinsic motivation for participation. Meaningfulness is also an aspect of 'sense of coherence', something that is formed throughout childhood[51,52] and has been shown to be a predictor of future everyday functioning in adolescents with attention-deficit–hyperactivity disorder.[53] Thus, previous experiences can act as a predictor for participation and affect the person's sense of self for future actions.

The language coded within the activity competence theme is consistent with the ICF delineation of an activity limitation as ranging 'from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without

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the health condition'[2] Many papers used language that described the quality of the execution of a task and measured participation in relation to performances that were 'independent' or 'appropriate' to the development of the child or situation, or that demonstrated 'correct' interactions with objects or people. The inference associated with this language is that an increase in skill is equal to an increase in participation. This may not be true. Consider, for example, how many people play tennis with varying levels of skill but 'participate' actively for reasons that may range from the need for exercise to the value of friendships with tennis partners. Personal growth, as expressed in increased participation, may also occur as a result of increasing skill.

In contrast to the competence theme, the theme sense of self was derived from language that spoke of the value of participation for enhancing individuals' confidence and self-esteem, and of feelings of satisfaction with participation. Satisfaction, and feeling proud, were deemed the consequences of reflection on performance rather than as part of the 'in-the-moment' experience, and hence were coded within the sense of self theme. The sense of self theme speaks to the possibility of intrapersonal growth associated with participation. Several descriptive studies[54,55] have reported a moderately strong relationship between intrinsic perceptions of competence, such as autonomy and self-efficacy, and high frequency of attendance in activities. A systematic review of school factors and mental health in children[56] reported a strong bi-directional relationship over time between future/forward perceptions of self, such as self-efficacy and locus of control, and achievement in school, which is an indirect indicator of engagement in school activities. It would appear that participating in activities, and intrinsic factors including preferences and sense of self, are closely interrelated. Although commonly discussed and often measured, both activity competence and sense of self were considered a consequence or outcome of participation but might also be important predictors of future participation,[57] or participation restriction. That is, a lack of preferences, skills, or self-confidence might predict lower levels of participation. Therefore activity competence and sense of self provide information important for the development of intervention methods aimed at increasing participation.

The two themes derived from our language analysis that appeared to be explicitly linked with the experience of participation were involvement and attendance. Of the 25 included studies, 20 used language that described participation in relation to one or both of these themes. Of these, 10 studies articulated aspects of the attendance theme, including frequency of taking part or the range of activities that were undertaken, and 19 studies used language related to the affect, motivation, or social connection subthemes of the involvement theme. This suggests that the involvement dimension of participation is considered important, perhaps essential, by researchers aiming to increase participation.

Although there was articulation of the involvement and attendance aspects of participation within the included papers, there was a striking lack of definitional clarity in relation to the participation construct. Only four studies provided a definition of participation, and two of these referenced the ICF. A further six papers made reference to the ICF, but did not present the definition 'involvement in a life situation'.[2] Although 10 papers identified participation as a primary outcome, only three included a definition. No papers explicitly discussed participation restriction. The ICF defines participation restriction as 'problems an individual may experience in involvement in life situations',[2] and the construct is further described as being 'determined by comparing an individual's participation to that which is expected of an individual without disability in that culture or society'.[2] This definition implies that participation restriction is equal to low frequency of attendance, as many researchers in the included studies indicated. However, participation restriction can also be seen as low engagement, or involvement, while being in the activity.

Along with the lack of clarity in the definition of the participation construct, this review found a mismatch between the language and the measures used: the language themes were not necessarily the variables that researchers stated as important to the study. Across the studies, measures that assessed activity competence, including task skill, correct performance, or the degree of independence were most commonly used (in 18 studies). Ten studies assessed changes in aspects of attendance, including frequency of attendance, patterns of attendance, and range of activities undertaken. These are the objective, observable aspects of the participation construct and those that are most amenable to measurement according to the ICF. That is, participation restrictions in attendance can be assessed against a known community or cultural standard. However, at an individual level, focusing on attendance will not provide information about how important the individual perceives it to be to participate.

In contrast to attendance, the involvement theme may be less amenable to assessment against cultural standards, as expectations of involvement might be highly variable within cultures, but it is nonetheless important to assess and address. Ten studies were found to include measures in which the construct could be mapped against one or more of the involvement subthemes. The Children's Assessment of Participation and Enjoyment[58] was used in three studies; this questionnaire explicitly assesses enjoyment while participating, and the social context in which participation occurs. The Pediatric Outcomes Data Collection Instrument (PODCI),[59] used in two studies,[39,43] is predominantly an activity performance and attendance measure; however, it does include 'happiness' in the description of the metric, and thus was also mapped to the affect subtheme of involvement. The PODCI, however, may not be an effective measure of involvement while participating, as this is not its primary intent. In addition,

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positive affect is not necessarily the same as involvement; children can be intensely involved, for example in solving a school problem, but may not enjoy or be happy performing the task at hand. Several of the remaining studies that were identified as assessing aspects of the involvement theme assessed social connections through behavioural counts of social interactions and communicative exchanges and/or intervals of reciprocal play. No study assessed motivation or willingness to continue with a task or persistence, despite the apparent importance of this subtheme. This appears to be an important gap in measurement given that there is some evidence that persistence predicts engagement in activities.[60,61] It is also worth noting here that willingness, persistence, attendance, and involvement, all of which were key participation subthemes, do not require social interaction. Thus, it is possible to participate actively in solo activities (e.g. reading for pleasure) with no social element.

Selecting valid and reliable measures to include in intervention research, and administering them in the manner in which they are intended, is critical to the internal validity of the research undertaken.[62] Having conceptual clarity between the variable under investigation and the measure(s) chosen is critical to the validity of the research and the interpretability of the findings. Although this review did not focus on the effectiveness of the interventions under examination, findings suggest that in the field of participation research, outcome measures are required to tap more effectively into the involvement aspect of participation. If the measures chosen are not reliable and valid for addressing the outcomes of interest, then there remains uncertainty about the effect of the interventions being assessed.

Maxwell et al.[50] provide evidence that an additional ICF qualifier is required that addresses the intensity of participation. New measures, including the Participation and Environment Measure for Children and Youth,[63] and the Young Children's Participation and Environment Measure,[64] include an assessment of both 'how often' as well as 'how involved' a parent perceives their child to be in the assessed activities. In these measures, involvement is operationalized as the child being 'engaged throughout the activity … he or she shows a lot of initiative and/or interest or attention to what he or she and others are doing during the activity'.[49,63] The language in this definition is most closely aligned to the motivation subtheme from this review, but also draws in elements of social connection. Tools such as these are important additions both to research and to practice; however, the need for a proxy response rather than asking the child directly potentially limits this particular tool. Constructs such as those identified in the involvement subtheme – affect, motivation, persistence, and social connection – may best be measured through direct response from the individual whenever possible, and when not possible owing to the child's age or communicative ability, observations of behaviour or proxy respondents may provide an alternative.

This review explicitly sought research from health, psychology, and education to explore potential variations in understanding the construct of participation. There was some evidence that studies undertaken within educational settings (n=10) were more likely to use the term 'engagement' as well as 'participation', as seven out of 12 papers that used the term were conducted in educational settings.[20,27,29,30,33,34,36] Studies that referred to the ICF were all hospital/clinic based or conducted by therapists, suggesting that the ICF remains a framework used predominantly in health-related settings. Although the terms 'engagement' and 'participation' were both used, they tended to be used interchangeably and the setting of the intervention research did not clearly influence the language themes identified.

Limitations of the study

This review focused specifically on developing an in-depth understanding of the concept of participation and as such did not extract and analyse text from the included studies that described environmental supports and barriers to participation. The review authors acknowledge the established importance of the environmental context to participation from the perspective of the opportunities afforded to participate, and as a key focus of participation interventions that aim to enhance participation outcomes.[3] The literature search for this review was completed in late 2013. It is possible that new research would be included in an updated search; however, saturation of language themes was found from analysis of the 25 included studies.

Implications for research and practice

The language analysis from this review suggests a potential relationship among the five themes as depicted in Figure 2. Preference for particular activities is likely to lead to an individual seeking or choosing to attend that activity. Once attendance has been achieved, involvement is possible, and the experience of involvement might include affect, willingness/motivation, and social aspects. Attendance and involvement may lead to competence in the activity and/or shifts in sense of self-confidence or self-esteem, which may in turn influence preferences.

It is critical that a consistent distinction is made between the actual participation phenomenon and related concepts. The participation experience consists of two elements: attendance and involvement, with attendance being a necessary prerequisite to involvement. These two elements or dimensions have also been suggested by other authors.[6,7] The related concepts (preference, activity competence, and sense of self) are also important, as is evident by their frequent inclusion in participation literature, but they are distinct from the participation phenomenon: they are not essential to any particular participation experience. The review of included papers in this study identified that researchers frequently took approaches to measuring participation that focused on activity competence or preferences. It may be very appropriate for researchers,

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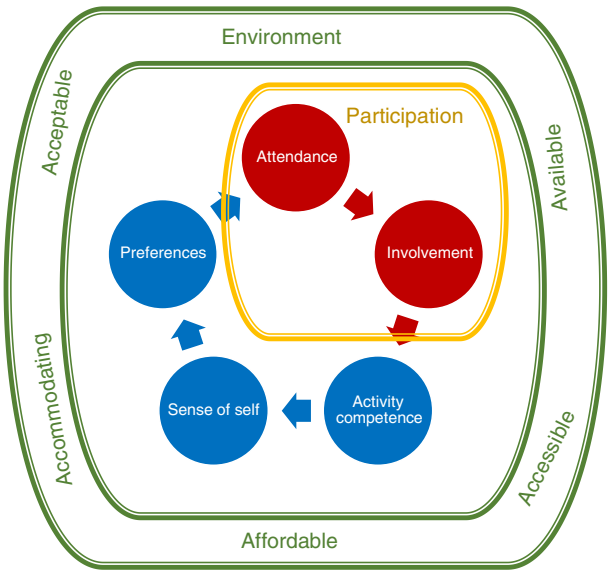

The participation concept:
Attendance: defined as 'being there' and measured as frequency of attending, and/or the range or diversity of activities in which an individual takes part.
Involvement: the experience of participation while attending, including elements of motivation, persistence, social connection, and affect.

Related concepts:
Activity competence: the ability to execute the activity being undertaken according to an expected standard.
Sense of self: intra-personal outcomes of participation related to confidence, satisfaction and self-esteem.
Preferences: the opportunity to choose and to be able to undertake activities that are meaningful or valued.

Environmental dimensions:[3]
Availability: objective provision of activities or services.
Accessibility: ability (or perceived ability) to access the activity or situation.
Affordability: financial, time, energy, and other resource constraints to attending.
Accommodability: the ability of the situation to be adapted or modified.
Acceptability: the person's acceptance of the situation, and other people's acceptance of the individual in the activity setting.

Figure 2: A family of participation and participation-related constructs situated within an environmental context including the five dimensions of the environment as described by Maxwell et al.[3]

clinicians, and educators to focus on competence and preference as methods to increase participation, but the measurement of participation itself should focus on attendance and involvement.

The involvement theme of participation seems to be the 'engine' in a cluster of important intrinsic factors that also include preferences and sense of self. As such, the activities that children attend must be adapted to accommodate the child's activity competence to be experienced as meaningful, and be matched to preferences to be accepted by the child. The 'intrinsic factors' sense of self and to a certain extent preferences can be difficult to interpret because they often are operationalized in a manner that resembles measures of engagement. Although potentially complex to achieve, the field needs to develop measures of sense of self and preference that are distinct to measures of engagement.

The findings of this review support the need for further investigation of proposed relationships between the participation construct and the five central dimensions of the environment described by Maxwell et al.: 'availability, accessibility, affordability, accommodability and acceptability'.[3] We hypothesize that there are strong relationships between the participation themes identified in this study and the environmental dimensions described by Maxwell et al. In particular, we predict that attendance will be positively related to availability, accessibility, and affordability of activities. In addition, involvement is predicted to be positively related to how accommodating and acceptable the activity setting is both to the individual with the disability and to others. These hypotheses are important areas of further investigation both within clinical practice and within research.

CONCLUSION

This review highlighted the need for all researchers to define clearly the construct under investigation and to operationalize the construct through the measurement choices they make. This is essential to ensure that the findings of research are interpretable. The language analysis undertaken in this study found five themes that might be considered as part of a family of participation constructs. Defining each of these participation constructs consistently should promote effective selection/development of measures for use in research and practice that aims to enhance participation outcomes.

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SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Study search terminology.

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Appendix S2: Example of database search strategies.

Table SI: Characteristics of included studies.

Table SII: Participation subthemes and themes derived from language used to describe participation.

Table SIII: Relationship between definition of participation and participation measure chosen.

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