

Assessments Used to Measure Participation in Life Activities in Individuals with Cancer: A Scoping Review

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Abstract

Background There is a critical need to facilitate return to work, school, and life activities among individuals with and surviving cancer. Each of these areas is a component of participation, defined by the International Classification of Functioning, Disability, and Health (ICF) as involvement in a life situation. Before developing interventions to address participation, we must first understand how this concept is measured. This scoping review investigates what assessments are currently used to measure participation in life activities in individuals with cancer. **Methods** Six databases were systematically searched using keywords and controlled vocabulary through February 2019. Eligible studies used the term participation in the context of life situations and had an assessment with at least 5 participation-specific questions. **Results** More than 4,000 references were identified and screened for eligibility. Twenty-seven studies were included; 18 unique assessments of participation were identified. Assessments were 1) developed with the primary purpose of measuring participation (n= 8); 2) measured global or physical function (n=8; 4 had a domain specific to participation); or 3) measured community integration (n=1) or social activity (n=1). Most assessments (10/18) were not developed with the purpose of measuring participation and only 4 assessments measured key components of participation (e.g. satisfaction) other than frequency. **Discussion** Measuring participation in life activities is a developing area in oncology research. Most studies do not accurately or comprehensively measure this construct. The heterogeneity in the assessments used indicates no clear consensus on a gold-standard participation measure for use among individuals with cancer. Comprehensively measuring participation is an essential first step to helping individuals with and surviving cancer lead productive and meaningful lives during and after treatment. By identifying deficits in participation, healthcare providers can better understand what activities are most important to their patients and provide necessary interventions. To facilitate the development of targeted interventions, a comprehensive measure of participation needs to be validated for use with individuals with cancer.

Background

Approximately 38% of individuals in the United States will be diagnosed with cancer during their lifetime [1]. Medical advances improved survival trends from 1999 to 2016 for men and women with the majority of the most common cancer diagnoses [2]. While survival rates vary widely depending on cancer type, 67% of individuals with cancer survive 5 or more years after diagnosis [1].

Individuals with cancer typically undergo an assortment of intensive medical treatments such as surgery, chemotherapy, and radiation therapy in an effort to eradicate the disease. Common side effects of treatment include cardiovascular disease, reproductive complications, secondary cancers, neurocognitive impairments, obesity, fatigue, and psychosocial challenges [3–5]. There is substantial evidence describing the negative impact of cancer and its treatment side effects on physical, social, and emotional functioning [6, 7], cognitive performance [8], employment [9], quality of life (QOL) [10], and finances [11, 12]. However, little is known about how these factors interplay to impact participation in life activities in individuals with cancer.

The World Health Organization (WHO) developed the International Classification of Functioning, Disability and Health (ICF) as a universal classification system for health and disability [13]. The ICF identified participation restrictions as one of the key components by which disability should be classified [13]. Participation was originally defined by the ICF as involvement in a life situation [13]. More recent definitions of participation refer to a person's satisfaction with and ability to fulfill social roles within the home, community, and society [14, 15]. Given the many side effects of cancer treatment and the challenges survivors face gaining or returning to employment [9, 16], engaging in basic (e.g. dressing, showering) and instrumental (e.g. housework, shopping) activities of daily living [17, 18], and the cost of treatment [12], evaluating participation is critical. Assessing participation will assist researchers and healthcare

providers to gain a more holistic understanding of the societal impact of cancer and its treatment on an individual's ability to live a meaningful and productive life.

There has been a call to action for the promotion of strategies that facilitate return to work, school, and life for survivors of cancer [19]. However, evaluating participation in life activities in individuals with cancer is an underdeveloped component of cancer rehabilitation programs [20]. With the push to integrate this concept into the continuum of cancer care [20], understanding how participation is currently measured in this population is essential.

Conceptually, there are both objective and subjective dimensions of participation [15]. Objectively, one can describe the frequency of various role-relevant activities and the settings in which they occur [15, 21]. Subjectively, one can describe an individual's satisfaction, desire for change, perceived difficulty, and importance of participation in specific activities [21–23]. Because there is no standard for what is considered better or worse participation, personal preferences have an important role in the measurement of participation [14, 23]. The ultimate goal of measuring this construct is to assess if an individual can do the things that are meaningful to them, to the extent they wish, and in a way that is satisfactory to them.

To accurately measure and track participation in individuals with cancer, we must first investigate what assessments have been used to measure participation in this population. A scoping review on participation in individuals with cancer is a necessary first step to clarify the concept and determine best practices for measurement. Scoping reviews are conducted to investigate broad topics that tend to require conceptual clarity, have not been comprehensively reviewed, and have high variability in how they are presented in the literature [24–26]. We conducted a scoping review to systematically examine the current research in this area and to identify gaps in knowledge. The objective of this review was to determine what assessment tools are currently used to investigate participation in life activities in individuals with cancer. For the purpose of this study, we referred to Chang and Coster's (2014) definition of participation *as active involvement in activities that are intrinsically social and occur in a societally defined context* [15].

Methods

The methods for conducting systematic scoping reviews recommended by the Joanna Briggs Institute and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines were used in this study [25, 26].

Protocol

The study protocol was developed based on the PRISMA-P guideline for protocols. The study protocol is available on request from the corresponding author.

Eligibility criteria

Inclusion and exclusion criteria were established prior to database searches. Studies were eligible for inclusion if they (1) used the term participation or participate in the context of involvement in a life situation; (2) included individuals with cancer (any type of cancer, age, phase of treatment, or survivorship); (3) defined a specific assessment as a measure of participation and/or if the assessment contained at least 5 questions pertaining to participation; (4) reported results or conclusions about participation based on assessment results; (5) were published in any year or language; and (6) were peer-reviewed articles, dissertations, or book chapters.

Studies were excluded if (1) participation was not discussed in the context of a life situation; (2) participation was discussed in the context of life situations, but the focus was too narrow (e.g. only physical activity participation); (3) the term participation was only used in an assessment domain title or within an assessment item; (4) no results were provided related to participation; (5) the population did not include individuals with cancer; (6) the assessment was a questionnaire or survey developed only for the specific study; (7) participants were a duplicate cohort represented in separate studies; (8) the assessment had fewer than 5 questions pertaining to participation; (9) findings were qualitative as the focus of this study was to identify and describe specific assessments used; and (10) only conference abstracts were available as this did not allow us to gain enough in-depth information on the study.

Information sources

Search strategies were generated by a medical librarian (L. S.) to locate published literature on the measurement of participation among individuals with cancer. A combination of keywords and controlled vocabulary were used to search the following databases: Ovid Medline, Embase, Scopus, Cochrane Database of Systematic Reviews (CDSR), and Database of Abstracts of Reviews of Effects (DARE). Additionally, instrumentation fields were used to search in EBSCOhost PsycINFO and EBSCOhost PSYCtests.

During the project planning phase, we identified three articles [21, 22, 27] that conducted similar studies synthesizing and evaluating tools used to measure participation. However, these studies did not focus on the use of these tools in individuals with cancer. Therefore, we conducted an additional search in each of the databases to find literature mentioning the assessments listed in these three review articles with individuals with cancer. Reference and citation information for each of the non-cancer measurement tool studies was created using the Scopus database.

All databases were searched from their inception through February 2019. Retrieved records for each of the three searches were exported into separate EndNote libraries. Duplicate records were removed by the medical librarian following specific de-duplication methodology [28].

Search

Fully reproducible search strategies for each database and search are available in Additional file 1.

Selection of sources of evidence

Titles and abstracts were screened by a single reviewer. Articles identified as needing full-text review were independently screened by two reviewers to determine if they met eligibility criteria. Discrepancies in studies identified for inclusion or in data charting (discussed below) were resolved through discussion and consultation with a third reviewer.

To establish consistent screening guidelines, a list of study inclusion criteria was created with specific examples provided for more abstract components (e.g., the context in which participation was discussed). The list was tested by a single reviewer for 50 full-text articles. Modifications were made for improved clarity and a decision tree was made. The decision tree was used to guide reviewers in identifying articles to include in the study. The two reviewers trialed use of the decision tree for article inclusion with 15 articles and had 100% agreement.

Data charting process

A data charting form was developed in Microsoft Excel specific to the needs of this study. The form was pilot-tested by a single reviewer on 20 full-text articles. Modifications were made to include more specific questions about how participation was discussed in the article, the number of participation-type questions in the assessment, number of study participants, and to include more detailed descriptive terms on how to chart information. A second pilot test was performed with both reviewers on the modified form with five articles. Neither reviewer identified a need for additional modifications to the form. The two reviewers independently charted data from all included studies and compared results.

Data items

Data were charted on article (title, year, and first author) and participant characteristics (sample size, specific cancer population, and age), how participation was discussed (the definition provided, if at all, where participation was discussed in the article, and what participation conclusions were made), the study's primary objective, and information on the assessment used (name, how the study characterized the purpose of the measure, and methods for measuring participation).

Critical appraisal of individual sources of evidence

Because scoping reviews provide a broader overview of the evidence, they do not typically assess studies for quality [29]. This is an optional item in the PRISMA-ScR guidelines and was not completed for this study.

Synthesis of results

Summary statistics were generated for assessment and study characteristics. A bubble plot was created to represent the frequency of assessment use over time. Original articles were identified describing the development of each of the assessments included in the review were identified and reviewed to better understand the intended purpose of each assessment. A summary chart of assessment characteristics was created. A summary table of studies included in the review is provided in Additional file 2.

Results

Over 4,000 articles were identified using broad search terms. After initial screening, 446 full-text articles were reviewed for inclusion. Following full-text review, 27 studies were included in this review. The majority of full-text articles determined to be ineligible for the review did not discuss participation (n = 237). Other excluded articles discussed participation, but in a context different from involvement in life situations, such as exclusively measuring participation in physical activity, examining participation in cancer screening programs, or participation in decision making in medical care (n = 52). Articles were also excluded if participation was discussed briefly, but there were no measures (n = 59) or results (n = 43) pertaining to participation. Details on study selection are described in Figure 1.

While one study was published in 2000, all other studies were published between 2006 and 2019. Time trends, frequency of assessment use, and sample size are illustrated in Figure 2. In the 28 included studies, 18 different assessments were used to measure or draw conclusions about participation. The Patient-Reported Outcomes

Measurement Information System (PROMIS) battery was most frequently used (4 of 27 studies, all published in the last 5 years). The Reintegration to Normal Living Index (RNL) was used in 3 studies across a wider timespan, from 2006 to 2014. All other assessments were used in only 1–2 studies. Only 4 of the 18 assessments evaluated the meaning, satisfaction, or value of participation, which are key components to evaluate when measuring participation [14].

Eighty-one percent of studies characterized the identified assessment as a measure of participation. However, after reviewing the intended purpose of the assessment when it was developed, only 33% of studies used a tool that was developed with the primary purpose of measuring participation. For example, the RNL was described in all 3 studies as a measure of participation, but the assessment was developed with the purpose of measuring global function status, a distinct and separate construct from participation.

Differences in sample size were apparent when comparing studies that used one of the eight assessments developed with the purpose of measuring participation versus those that were not developed for that purpose. Sample size ranged from 8 to 192 participants (median: 30, interquartile range [IQR]: 19.5–128.5) for studies using a participation measure. Studies that used more general assessments not specific to participation ranged from 17 to more than 5,000 participants (median: 104, IQR: 77–249.25). Three studies [30–32] focused on participation in children; all other studies included only adults. Breast cancer was the most frequently studied group as the population of interest in one-third ($n = 9$) of studies. Study and assessment summary characteristics are further described in Table 1.

Table 1. Study and Participation Measure Characteristics

Assessments demonstrated high variability in domains measured (0–12), methods for administration, and number of items (between 5 and 240). Detailed information about assessment properties are provided in Table 2.

Discussion

Summary of Evidence

In this scoping review 27 studies were identified that used assessments to measure, describe, and draw conclusions about participation in individuals with cancer. The large majority of studies (25 of 27) were published in the last 10 years. This likely relates to the publication of the ICF in 2001 in which participation was originally defined. After this time, the term participation became more commonly used in research across a variety of disciplines. The results of this review indicate it took approximately 8 years from the publication of the ICF for the term participation to be more consistently used in published oncology research.

Many assessment tools have been used to measure this construct. The heterogeneity in assessments used to measure participation indicates no clear consensus on an ideal assessment to measure participation in individuals with cancer. Additionally, the variability in assessments used makes it difficult to compare results across studies.

The majority of assessments identified through this review were not comprehensive measures of participation. Studies frequently classified assessments as measures of participation that did not comprehensively measure this construct and were not developed with this purpose. Because many studies potentially mis-classified assessments as measures of participation or drew conclusions about participation without truly measuring this construct, conclusions of such studies should be cautiously interpreted. Researchers and clinicians must understand what questions are asked in these assessments to determine if a study's conclusions can truly be supported by the data collected from the assessment. For example, one of the most widely cited publications describing participation in cancer survivors [6] drew conclusions about participation based on 7 questions, several of which were not truly investigating this concept

(e.g. difficulty using fork, knife, cup; difficulty dressing). This limited number of questions is not adequate to draw conclusions about participation in life situations. Such trends are common in the oncology and participation literature.

Additionally, only 4 of the 8 participation-specific assessments had questions that asked about the value, satisfaction, or meaning of participation, which are essential components of comprehensive participation assessments [33]. All other assessments asked only about the frequency of participation, which in isolation is hard to interpret without the context of the subjective components of participation (e.g. meaning, desire for change). Because participation is specific to each individual based on their interests and values [14], understanding if an individual has a desire for change or is satisfied with their current participation is essential. This is particularly important among individuals with cancer whose general life priorities and meaningful activities may have changed due to their cancer diagnosis. Individuals may take on new roles due to their diagnosis or stop doing activities due to their lack of enjoyment in an activity [34], the side effects of treatment, or time commitments required to travel to and attend medical appointments. Comprehensively measuring participation in individuals with cancer can help researchers and healthcare providers gain a greater understanding of what is truly important to each individual with cancer. Results from participation assessment can help individuals identify areas of their life that may benefit from further support and inform intervention planning. Surviving cancer is a massive feat; incorporating the concept of participation into oncology care can help survivors live a fulfilling and meaningful life during and after cancer and find ways to reduce the societal cost of cancer.

Utilizing assessments designed with the purpose of measuring participation is essential, but few participation-specific measures are currently used with individuals with cancer [35]. The greatest number of studies, and those with the largest sample sizes, used the PROMIS battery, a global health assessment with just one domain specific to participation. Studies using PROMIS also provided minimal interpretation of participation specific-results. When aiming to measure participation, assessments focusing on different (i.e. QOL) or multiple (i.e. in a global health assessment) constructs should be avoided. While cancer-specific QOL assessments include questions that pertain to the construct of participation, they do not comprehensively reflect all areas of an individual's participation in daily life [36]. Using general assessments can provide an overview of participation, but conclusions should not be made about participation in individuals with cancer based on these assessments because the items provide only a limited evaluation of this complex construct [36].

A first step in advancing the current state of the science is developing an in-depth understanding of how participation is impacted in individuals with a variety of cancer diagnoses [20] across the lifespan. In such studies, using a comprehensive measure of participation that evaluates not only the frequency of participation, but additional subjective evaluative components (e.g. satisfaction) is necessary. The findings of such studies can identify focus areas for the development of targeted interventions.

The current lack of consistency in the literature makes it difficult to develop an understanding of participation in individuals with cancer. There is a need for larger scale studies in individuals with a variety of cancer diagnoses and across the lifespan using comprehensive and validated assessments developed with the primary purpose of measuring participation in life situations.

Limitations

The specificity of our research question led to several potential limitations. Because we aimed to understand what assessment tools were used to measure participation in individuals with cancer, we excluded studies that described participation qualitatively or used surveys developed only for the purpose of their study. Additionally, review articles

and position papers recommending assessments for use were excluded as these assessments had not yet been used with individuals with cancer. These strict eligibility criteria were necessary to appropriately answer our research question.

The abstract nature of participation was another potential limitation as this made it difficult to determine what assessments measured participation comprehensively. Measuring participation is a challenge in the field of rehabilitation overall, not just in the area of oncology. As this is the current state of the science, we sought to describe what assessments are currently used and identified areas for future research in the field.

Conclusions

With over 16 million cancer survivors in the United States [37] alone, understanding survivors' participation in activities that are meaningful to them is crucial to improving their daily experiences. Qualitative and survey data demonstrate that survivors want to engage in typical life activities, such as work and school, because these activities are a natural part of daily life, can help establish a sense of normalcy, provide opportunities for socialization, and promote feelings of accomplishment [38, 39]. Being unable to participate in meaningful activities leads some to feel as if they have lost part of their identity [39]. With measurement tools that capture these important life activities, researchers and clinicians can better assess participation and develop interventions to improve survivors' participation. Participation has a widespread impact on individuals' lives and needs to be comprehensively measured and included in outcome assessments of cancer survivors.

Declarations

Ethics approval and consent to participate: Not applicable

Consent for publication: Not applicable

Availability of data and materials: All data generated and analyzed in the current study are available from the corresponding author on request.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: AL screened all articles, extracted data, and prepared the manuscript. TV was the secondary article reviewer, reviewing all full-text articles and assisted in writing the manuscript. KL assisted in writing the manuscript. LS generated and executed the search strategy and assisted in writing the methods section of the manuscript. AK guided the conceptualization of the research question, served as the third reviewer when discrepancies occurred, and assisted in writing the manuscript.

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Tables

Table 1. Study and Participation Measure Characteristics

Study (n= 27) & Assessment (n= 18) Characteristics	n (%)
Study defined participation	9 (33)
Primary objective of study included measuring participation	11 (41)
Study characterized assessment as a measure of participation	22 (81)
Purpose of assessment when developed	8 (44)
Main purpose was to measure participation	9 (33)
+Studies in which these assessments were used	4 (22)
Specific domain(s) assessed participation	8 (44)
Measured global function/health or physical function	8 (44)
Assessment measured satisfaction, meaning, and/or value of participation	4 (22)

Table 2. Properties of Assessments used to Measure Participation in Individuals with Cancer

Name	Purpose was to Measure/Evaluate	Domains	Total # of Items	Methods for Evaluating/Scoring Participation	Population(s) Evaluated with Assessment (Studies in Scoping Review)
Assessments Developed with the Primary Purpose of Measuring Participation					
ACSm [40, 41]	Activity participation of adults in instrumental, leisure, and social activities.	4 categories: instrumental, low-physical-demand leisure, high-physical-demand leisure, and social activities	89	<p>ACS was designed as a semi-structured interview but use in included studies was a modified checklist version.</p> <p>Categorize items as: never done prior to transplant/diagnosis; do now (as often as before transplant/diagnosis); do less or differently than before transplant/diagnosis; not done since transplant/diagnosis; or new activity since transplant/diagnosis.</p>	Breast cancer survivors [42] & various cancer diagnoses [34]
AACS [30, 43] (Now AYAPS)	Participation and activities	8 domains: self-care, sedentary leisure, vigorous leisure, education, work, chores, social interaction, and community access and mobility.	94	Semi-structured interview; asked "Do you participate in this activity?" If yes, provide level of assistance needed, if any. If not, provide personal, family, or environmental reason why.	Childhood cancer survivors with various diagnoses [30]
LIFE-H [44]	Quality of social participation	12 categories of life habits: nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal relationships, community life, education, employment, & recreation	240 (69 item short-form)	Asked about accomplishment (degree of difficulty, types of assistance required) and level of satisfaction	Breast cancer [45]
LIFE-H (children) [46]	Social participation of children with	11 categories: all in Life-H for adults except employment	197 (64 item short-form)	Level of difficulty, type of assistance required; level of satisfaction	Childhood craniopharyngioma [32]

disabilities from 5-13 years of age

IPA [47]	Person-perceived handicaps, which authors state is participation according to the ICDH-2	8 subscales: self-care and appearance, mobility, leisure, social relationships, work, education, family role, and financial independence	41	Rate items from excellent (1) to very poor (5). Most items asked about the possibility of doing activities the way an individual wished. Other items asked about frequency, ability, respect, contribution to activities, and contact with others.	Cancer survivors in Turkey [48]
ICPAS [49]	Participation of children in Iranian context	8 sub-categories: ADL, IADL, play, leisure, social participation, work, education, and sleep/rest.	71	Child and parent-report assessments. Frequency of activities, with whom the activity was done, how enjoyable it is for the child to do the activity, and how much the parent is satisfied (parent-report version only).	Children with various types of cancer undergoing chemotherapy [31]
MAPA [50]	Degree of meaning through participation in activities	N/A	28	Frequency of participation (in the last few months) and degree of personal meaningfulness experienced with each activity (0= not at all meaningful to 4= extremely meaningful).	Various cancer diagnoses [51]
PActS [52]	What older adults feel they should be and could be doing to understand participation from a social perspective	7 activity categories: creative activities, spiritual activities, getting around town, communicating with others, doing physical exercise, keeping up with traditional media, and doing service activities	14	For each activity, asked "How much do you believe that a person of your age and diagnosis should be..." (1= very little to 5= quite a lot) and "How much confidence do you have..." (1= very little to 5= quite a lot)	Various cancer diagnoses [51, 53]
Assessments with Domain(s) Specific to Participation					
Lymph-ICF [54]	Impairment in function, activity limitations, and	5 domains. Impairments in Function: physical &	29	Scored on visual analog scale from 0 (very well) to 100 (not at all). Asked how	Breast cancer with arm lymphedema [54]

	participation restrictions	mental. Activity Limitations & Participation Restrictions: household, mobility, and life and social activities.		well person is able to perform or participate in various activities.	
PIPP [55]	Impact and distress of health conditions from the individuals' perspective	5 subscales: self-care, mobility, participation, relationships, psychological well-being.	23	6-point scale; asked about the amount of impact current health problems had on function (no impact to extreme impact) and how much distress has been caused by the impact of their health problem on function (no distress to extreme distress)	Breast cancer [56] & brain tumor survivors [57]
PROMIS [58]	Global health focusing on physical, mental, and social components	Communicative participation item bank & ability to participate in social roles. Also has items about satisfaction with participation, but not yet used with cancer.	Variable. Profile: 29; CPIB: 46; short form: 10; CAT varies	CPIB: rate how much their condition interferes with participation in a range of daily speech communication activities using Likert scale. Profile & short form: rate ability to participate on Likert scale (never to always)	Head and neck cancer [59], early-stage breast cancer [60], breast cancer [61], & various cancer types [62]
WHODAS 2.0 [63]	General functioning and disability in major life domains	6 major life domains: cognition, mobility, self-care, getting along, life activities, and participation in society.	36 (also has a 12-item short form)	Asked about level of difficulty in activities over the last 30 days or how much problem an individual had (participation domain)	Head and neck cancer survivors [64] & breast cancer [65]
Global Function and Physical Function Assessments					
DASH [66]	Symptoms and functional status at the level of disability; emphasis on physical function	Concepts of symptoms and functional status (3 dimensions: physical, social, psychological)	78 + 5 optional items	Scored on Likert scales with a recall period of 1 week. Items were framed to reflect capacity and performance of activities.	Breast cancer [67]
PASE [68, 69]	Age-specific physical activity questionnaire	N/A	10	Items are weighted. Items weights are multiplied by the amount of time spent in each activity (hours per day over a 7-day	Community-dwelling Mexican-American elders with various cancer diagnoses [70]

				period) and summed for an overall score.	
RNL [71, 72]	Global function status	Two subscales: daily functioning and perception of self.	11	Self or interviewer-administered. Scored on visual analog scale. 1= minimal integration, 10= complete reintegration	Extremity soft tissue sarcoma [73, 74] & primary bone tumor of lower extremity [75]
WSAS [76]	Functional impairment	N/A	5	0 (no impairment) to 8 (very severe impairment) Likert scale scoring. Asks about impairments in work, home management, social leisure activities, private leisure activities, and relationships.	Breast cancer survivors [77]
Other Assessments					
CIQ [78]	Reduced handicap; community integration	Home integration, social integration, and productive activities subscales	15	Asks who usually performs activities in the home, frequency of activities, or with whom an individual performs activities.	Digestive tract cancer [79] & brain tumor [80]
Social Activity Log [81]	Frequency and diversity of social activities outside of daily responsibilities.	N/A	17	Asks how many days in the past 7 days or month an individual participated in certain social activities.	Long-term cancer survivors who received hematopoietic stem cell transplantation [81]

Note. Abbreviations: ACSm: Activity Card Sort, modified; AACS: Adolescent Activity Card Sort; AYAPS: Adolescent and Young Adult Participation Sort; LIFE-H: Assessment of Life Habits; IPA: Impact on Participation and Autonomy Scale; ICPAS: Iranian Children Participation Assessment Scale; MAPA: Meaningful Activity Participation Assessment; PActS: Possibilities for Activity Scale ; DASH: Disability of the Arm, Shoulder, and Hand; Lymph-ICF: Lymphoedema Functioning, Disability, and Health Questionnaire; PIPP: Perceived Impact of Problem Profile; PROMIS: Patient-Reported Outcome Measurement Information System; WHODAS: World Health Organization Disability Assessment Schedule; PASE: Physical Activity Scale for the Elderly; RNL: Reintegration to Normal Living Index; WSAS: Work and Social Adjustment Scale; CIQ: Community Integration Questionnaire

Figures

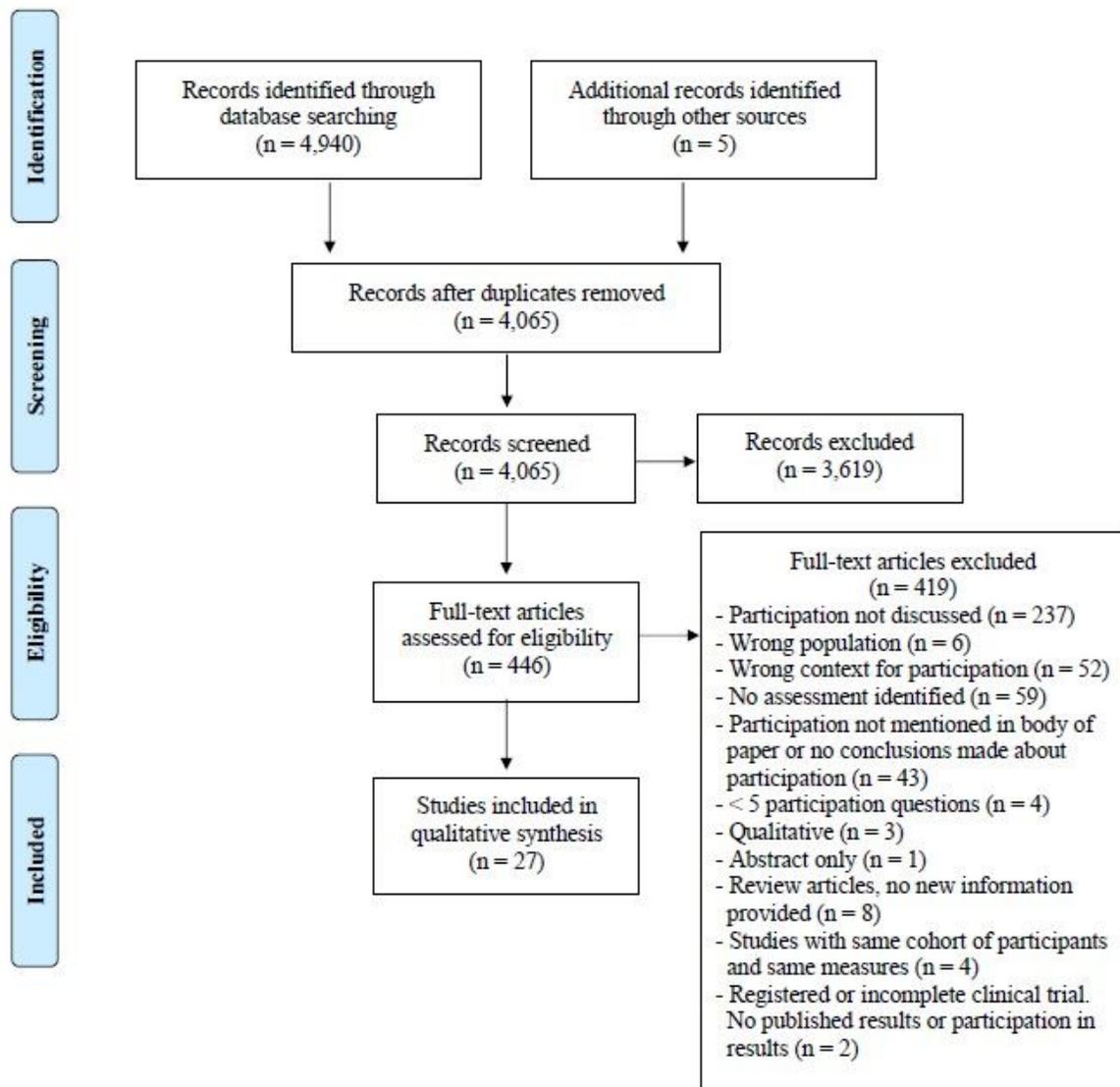


Figure 1

Selection of Sources of Evidence

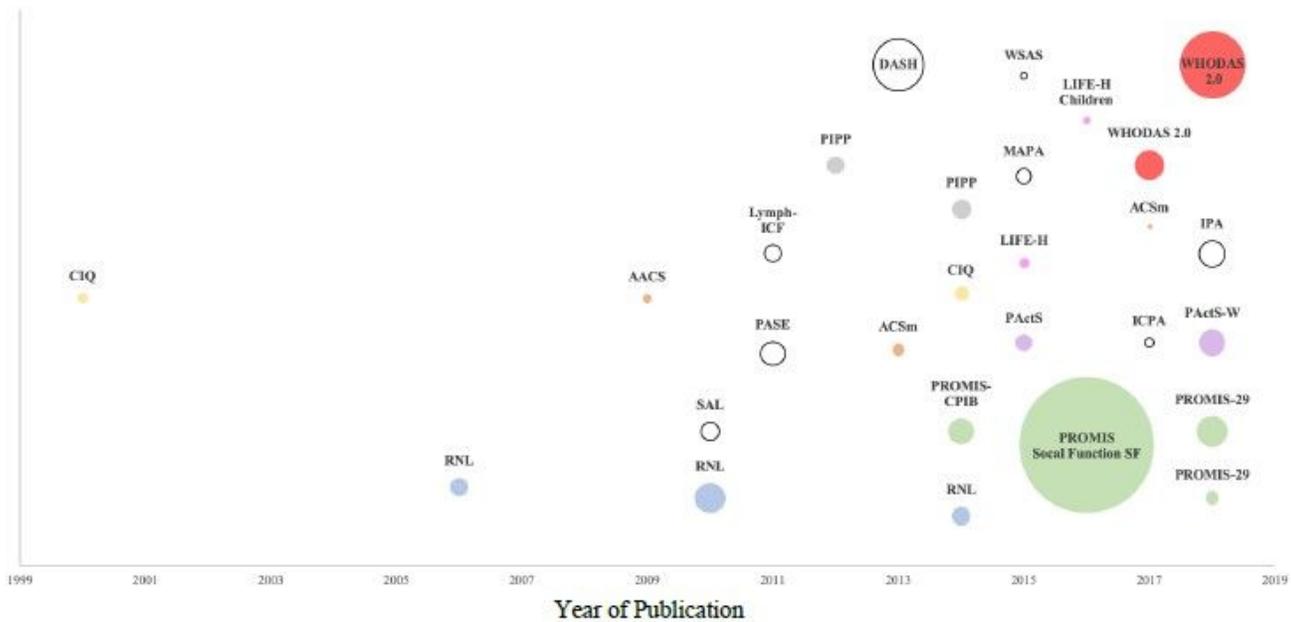


Figure 2

Articles Published with Each Assessment by Year and Sample Size Note: Bubble size corresponds to the study sample size. Matching colors indicate the same assessment, or assessments in the same family (i.e. LIFE-H for adults and children). White bubbles denote assessments used in only one study. CPIB= communicative participation item bank and SF= short form; all other abbreviations are listed with Table 2.

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