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Assessment of activity limitations and participation restrictions with persons with chronic fatigue syndrome: a systematic review

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ABSTRACT

Purpose

To summarize measurement instruments used to evaluate activity limitations and participation restrictions in patients with chronic fatigue syndrome (CFS) and review the psychometric properties of these instruments.

Method

General information of all included measurement instruments was extracted. The methodological quality was evaluated using the COSMIN checklist. Results of the measurement properties were rated based on the quality criteria of Terwee et al. (2007). Finally, overall quality was defined per psychometric property and measurement instrument by use of the quality criteria by Schellingerhout et al. (2011).

Results

A total of 68 articles were identified of which eight evaluated the psychometric properties of a measurement instrument assessing activity limitations and participation restrictions. One disease-specific and 37 generic measurement instruments were found. Limited evidence was found of the psychometric properties and clinical usability of these instruments.

Conclusion

The psychometric properties of the reviewed measurement instruments are not sufficiently evaluated, except of the CFS-APQ. It is disease-specific, has acceptable content validity and construct validity. Therefore it is recommended to use the CFS-APQ in scientific research and clinical practice. Future research is needed to evaluate the psychometric properties of the measurement instruments, including the other properties of the CFS-APQ.

INTRODUCTION

Chronic fatigue syndrome (CFS) is a complex, clinically defined illness characterized by severe fatigue that cannot be explained by another medical or psychiatric condition and is not sufficiently reduced by resting. Patients also have to experience substantial reductions in previous levels of occupational, educational, social or personal activities, leading to limitations in one or more areas of life [1]. These limitations may result in financial problems, because some patients are unable to stay at work [2-3].

Another characteristic of CFS is the exacerbations of symptoms after performing too much physical or mental activities [1,4]. Patients perform less activities to avoid an increase of their symptoms and develop an activity-related strategy of complete rest expecting that this strategy will cause improvement. However, this strategy results in social isolation, depression, increased limitations and restrictions or even leading to a situation of being homebound. Re-activation and reduction of social isolation is therefore one of the most important therapeutic goals in CFS [3,5].

One of the core concepts of rehabilitation is to support patients in performing their daily life activities in a client centered way that promotes or maintains their health, well-being, participation and autonomy [6-11]. It is therefore important to be capable of identifying possible restrictions in activities and participation by means of standardized, reliable and valid measurement instruments and registration documents [3,7,9-10].

The number of assessment tools measuring activity limitations and participation restrictions has strongly increased during the last years. As a result, it has become more difficult to choose the most appropriate measurement instrument that covers the desired construct [7,13]. Different aspects, such as the target group and psychometric properties within the desired population, are

important to consider in order to organize a good health service and to support the patient's rehabilitation [7,10].

Given the relevance of a correct identification of restrictions in activities and participation in a disabled and generally inactive group like the CFS population, insight in the characteristics and psychometric properties of the different measurement instruments within this specific population is required. Up to now, different (generic) measurement instruments are used. However, consensus on the psychometric characteristics of these measurement instruments in patients with CFS is lacking.

The present systematic literature review will try to summarize answers to the following research questions:

1) Which measurement instruments are currently used to evaluate activity limitations and participation restrictions in patients with CFS?

2) What is known about the psychometric properties of these measurement instruments in patients with CFS?

3) Which of these measurement instruments are appropriate to use in patients with CFS?

METHOD

This systematic review is reported following the PRISMA-guidelines (Preferred Reporting Items for Systematic reviews and Meta-Analyses), which is an updated statement addressing the conceptual and methodological issues of the original QUOROM Statement [14].

Eligibility criteria

To be included in the present systematic review, studies had to report the use of measurement instruments evaluating activity limitations and participation restrictions in patients with CFS. The definitions for activity, participation, limitations and restrictions from the International Classification of Functioning, Disability and Health (ICF) were used to identify relevant measurement instruments [12]. Quality of life (QOL) measurements assessing a person's satisfaction or limitations with performing daily activities or participation restrictions were also included.

Information sources and search strategy

The literature search was executed by use of the electronic databases PubMed and Web of Science from 1 July 2012 until 31 October 2012. A sensitive search filter, developed by Terwee et al. in 2009 was used [15]. This search filter consists of a combination of search terms and is designed to find studies on psychometric properties of measurement instruments in the electronic database PubMed. Because the sensitivity of this filter is 97.4% [15], other searches were also used to make sure no relevant studies were missed. Reference lists of included articles were screened as well. No limits were set for the date of publication.

The search strategy was built by combining "chronic fatigue syndrome" both as free text word and MeSh-term with different key words related to the assessment (assessment, "outcome

measure”, survey, questionnaire) or activities and participation ("activities of daily living", disability, "daily functioning", limitations, participation).

Study selection

The study selection was performed in two different screening phases.

Following inclusion criteria were applied:

1. The study had to be executed on adult humans;
2. Studies were written in English or Dutch;
3. Studies included at least one measurement instrument that identifies limitations in activities of daily living or participation restrictions.

Following exclusion criteria were applied:

1. Studies about medication, genetics, epidemiologic research, immunology, prevalence, endocrinology, alternative therapy, diagnostics by use of medical imaging;
2. Systematic reviews and meta-analyses.

The first selection was based on title and abstract. Articles that met the first two inclusion criteria were included for full text reading. The third inclusion criterion was only applied during full text reading, because not all articles mention the measurement instrument in their abstract. All articles identified during the literature search are included in the first part.

Studies evaluating the psychometric properties of relevant articles are included in the second part.

Data-extraction and rating

1. Part 1: Overview of measurement instruments used in scientific research

All data concerning measurement instruments evaluating activity limitations and participation restrictions in individuals with CFS were extracted with the help of a form based on 'Worksheet 12: Test critique form' by Fawcett (2009) and compiled in one table (see online supplement).

2. Part 2: Evaluation of psychometric properties of measurement instruments

All articles evaluating the psychometric properties of measurement instruments used with CFS were included in the further analysis of the systematic review. General information (Table 4) was retrieved with the help of the 'Generalizability' box of the COSMIN checklist [17]. The research methodology used to evaluate the psychometric property was rated with the help of the COSMIN checklist. The COSMIN checklist was developed in 2010 according to a Delphi study by international experts in health related measurement instruments [18]. The COSMIN checklist evaluates 10 psychometric properties and consists of four possible answers: 'excellent', 'good', 'fair' and 'poor'. A general score for the methodological quality was provided for every individual psychometric property for every measurement instrument by taking the lowest score from every box (Table 5) [17]. The 'Interpretability' box was filled in for every article and scored based on the number of questions that could be answered with 'yes' (1 or 2 = poor; 3 or 4 = fair; 5 or 6 = good; 7 = excellent). The results of the psychometric properties rated based on the quality criteria of Terwee et al. (2007) [19] (Table 2) .

Synthesis of best evidence

The level of evidence for every psychometric property was defined by combining the rating of the methodological quality from the COSMIN checklist and rating of the research results according to the quality criteria of Terwee et al. (2007). A general score was given to each measurement instrument and was either ‘strong’, ‘moderate’, ‘limited’, ‘conflicting’ or ‘unknown’. The levels of evidence for the overall quality, similarly as proposed by the Cochrane Collaboration Back Review Group and modified by Schellingerhout et al. (2011) were used to determine the score [19,20].

Results

From 249 unique hits, 99 articles were identified based on their title and abstract. Full text reading resulted in the exclusion of another 31 articles. A total of 68 relevant articles were included. Only five articles evaluated the psychometric properties of a measurement instrument (Figure 1).

All information regarding the measurement instruments was compiled in a table (see online supplement). The references of all included articles, except the five evaluating the psychometric properties of a measurement instrument, were checked. Based on this additional search, three more articles that evaluated the psychometric properties of a measurement instrument in CFS were identified. A total of eight articles were included for further analysis and five measurement instruments were evaluated. The methodological quality of these eight studies is presented by measurement instrument and psychometric property in Table 5. The rating of the results are presented by psychometric property in Table 6.

Insert figure 1 about here

Part 1: Overview of measurement instruments used in scientific research

A total of 38 different measurement instruments were used to evaluate activity limitations and participation restrictions in scientific research with a patient population with CFS. All measurement instruments and their psychometric properties are compiled in Table 1 (more information see online supplement).

Content	Measurement instrument	Goal	Psychometric properties	Ref.
Activity	Activity and symptom diary	To monitor activities	None mentioned	57
	Activity Restriction Index (ARI)	To measure a person's current ability to engage in activities	Intraclass Correlation Coefficient (ICC) = 0.84	23
	General questions (Vercoulen et al., 1994)	To measure the interference of complaints with daily activities	None mentioned	67
	Interview (Solomon et al., 2003)	To measure hours spend on meaningful activities	None mentioned	76
	Baecke Physical Activity Questionnaire (BPAQ)	To assess habitual leisure and occupational physical activities	Reliability coefficients of the BPAQ and associations with other measurements were mentioned	23,56
	The Barthel index measures	To measure the degree of independence in ADL	None mentioned	92
	The Canadian Occupational Performance Measure (COPM)	To measure the performance of and satisfaction with ADL	None mentioned	44
	Subsidiary measures of functioning (Sharpe et al., 1996)	To measure ADL and employment status	None mentioned	62
	The Frenchay Activities Index	To measure the degree of involvement in domestic tasks, social events, hobbies, and employment	None mentioned	92
	One-Time Measure (Andersen et al., 2004)	To rate symptoms and measure functional changes	None mentioned	58
	Human Activity Profile (HAP)	To measure daily activities and relate them to a known amount of average energy expenditure (MET)	None mentioned	60

	Patient-Reported Outcomes Measurement Information System, Health Assessment Questionnaire (PROMIS HAQ)	To assess a person's ability to carry out ADL	None mentioned	65
	PAQ	To measure functional patterns	None mentioned	53
	Interview (Assefi et al., 2003)	To measure a person's financial, occupational and social status	None mentioned	2
	Questionnaire (Nijs et al., 2008)	To assess work participation and social activity	None mentioned	81
	Stanford Health Assessment Questionnaire (HAQ)	To assess a person's functional capacity to perform ADL	None mentioned	45
	Work and Social Adjustment Scale	**To measure a person's ability to work, engage in household management and participate in social and private leisure activities and relationships**	**Part 2**	**59,89**
General health	19- Item Medical Outcome Study Short-Form General Health Survey (MOS-19)	To measure general health on the basis of multiple subscales	Reliability coefficients were mentioned	21-22
	20-Item Medical Outcome Study Short-Form General Health Survey (MOS-20)	To measure general health on the basis of multiple subscales	Pearson product-moment correlation coefficient that measured the correlation between the scores of the MOS-20 and the Wood Mental Fatigue Inventory was described	23
	Euroqol 5 dimensions (EQ-5D)	**To measure general health and subdivide patients in 243 different health states**	**Part 2**	**87**
Disability / limitations	Brief Disability Questionnaire (BDQ)	To measure functional impairment	None mentioned	57

	Functional Status Questionnaire (FSQ)	To measure functional disability over the previous month	None mentioned	61
	Karnofsky Performance scale	To assess a person's degree of disability	Good agreement (Cohen's K greater than 0.8 at every time point) Valid and reliable in several patient population, but no exact values were mentioned	23,62-64
	PROMIS HAQ	To measure a person's degree of functional impairment	None mentioned	65
	Two variables (Gadalla 2008, 2008a)	To asses short-term disability	None mentioned	77-78
	Questionnaire (Perrucio et al., 2007)	To measure limitations in activities due to a disease or illness	None mentioned	79
	The Sickness Impact Profile (SIP)	To measure disability/functional limitations associated with health problems	Reliable and valid for a variety of patient groups, but no exact values were mentioned	64,69-71
	SIP 8	To measure disability/functional limitations associated with health problems	Cronbach's alpha (Dutch version) = 0.91	29,52,66-68
	SIP short version	To measure disability/functional limitations associated with health problems	Reliable and valid for a variety of patient groups, but no exact values were mentioned	72
Participation	**Chronic Fatigue Syndrome Activities and Participation Questionnaire (CFS-APQ)**	**To measure both activity limitations and participation restrictions**	**Part 2**	**39,41-44,56, 73-75, 82-83**
Quality of Life (QOL)	Manchester Short Assessment of Quality of Life (MANSA)	To measure satisfaction with life as a whole and in specific life situations	High concordance with the Lancashire Quality of Life Profile, but no exact values were mentioned	49
	Danish CFS Questionnaire Repeated Measure	To measure a person's coping with ADL	None mentioned	58

	Medical Outcome Study Short-Form General Health Survey (SF-36)	**To measure functional status and QOL**	**Part 2**	**24-55, 83,85-87,90**
	Quality of Life Scale	To measure the satisfaction with different life activities with persons with chronic illnesses	High test-retest reliability, convergent and discriminate construct validity, but no exact values were mentioned	31
	Quality of Life Questionnaire	To assess QOL	Good internal consistency (Cronbach's alpha = 0.851)	51
	WHOQOL-100	**To measure different facets of QOL**	**Part 2**	**88**
Impact of fatigue / other symptoms	Activity and symptom diary	To measure the influence of fatigue and other symptoms on activities	None mentioned	57
	General questions (Vercoulen et al., 1994)	To measure the interference of complaints with ADL	None mentioned	67
	Multidimensional Assessment of Fatigue (MAF)	To evaluate the influence of fatigue on ADL	Good internal consistency (Cronbach's alpha = 0.92)	50,60
	Questionnaire (Butler et al., 1991)	To assess the impact of a person's symptoms on occupational, household and leisure activities	None mentioned	80
	SIP	To measure the impact of an illness on ADL	Reliable and valid for a variety of patient groups, but no exact values were mentioned	29,52, 64, 66-72

Part 2: Discussion of psychometric properties of measurement instruments

Psychometric studies of the CFS-APQ, SF-36, EQ-5D, WHOQOL-100 and WSAS were found and therefore included for further analysis. They were rated by use of the COSMIN checklist and quality criteria of Terwee et al. (2007).

Table 2: Results COSMIN checklist

Measurement instrument	Internal consistency	Reproducibility Reliability	Reproducibility Agreement	Content validity	Criterion validity	Construct validity	Responsiveness	Interpretability
CFS-APQ								
Nijs et al. (2003)	poor	poor		good		poor		poor
Nijs et al. (2004c)	poor					good		poor
SF-36								
Myers et al. (1999)								poor
Buchwald et al. (1996)	poor					poor		poor
Ware et al. (1992)				poor				
EQ-5D								
Myers et al. (1999)						poor		good
WHOQOL-100								
De Vries et al. (1997)	poor			good		fair		poor
WSAS								
Cella et al. (2011a)	excellent					poor	poor	poor

Table 3: Results quality psychometric properties of measurement instruments: synthesis of best evidence

Measurement instrument	Internal consistency	Reproducibility Reliability	Reproducibility Agreement	Content validity	Criterion validity	Construct validity	Responsiveness	Floor and ceiling effects	Interpretability
CFS-APQ	unknown	unknown		moderate		moderate			unknown
SF-36	unknown			unknown		unknown			unknown
EQ-5D						unknown		limited	moderate
WHOQOL-100	unknown			moderate		limited			unknown
WSAS	strong					unknown	unknown		unknown

Levels of evidence for the overall quality of the psychometric property (based on Schellingerhout et al. 2011) defined by combining the rating of the methodological quality from the COSMIN checklist with the Quality criteria for psychometric properties (based on Terwee et al. 2007) [17,19-20].

strong = consistent findings in multiple studies of good methodological quality OR in one study of excellent methodological quality; moderate = consistent findings in multiple studies of fair methodological quality OR in one study of good methodological quality; limited = one study of fair methodological quality; conflicting = conflicting findings; unknown = only studies of poor methodological quality

Chronic Fatigue Syndrome-Activities and Participation Questionnaire (CFS-APQ)

The CFS-APQ evaluates a person's health status over the past seven days [82]. It is based on the 'International Classification of Functioning, Disability and Health' (ICF) [82-83] and was constructed based on self-reported activity limitations and participation restrictions of 141 patients with CFS. It consists of 26 items that are scored on a four point Likert-type scale (range 1-4; range total score 1: 1-16; range total score 2: 1-4) [84]. The average application time is eight minutes [73].

The literature search identified nine studies that used the CFS-APQ in their study to measure activity limitations and participation restrictions with persons with CFS. Four of these studies mentioned information about its internal consistency, test-retest reliability, content validity, convergent validity and criterion validity and mentioned the exact values that were evaluated by two other studies [43,56,73,75].

Although two studies evaluated its psychometric properties [82-83], no studies of good methodological quality were found that evaluated the internal consistency, reliability, agreement, criterion validity or responsiveness.

The *content validity* was evaluated according to a good methodological quality and found to be good [83].

Two studies evaluated the *internal consistency* (Cronbach's $\alpha > 0.80$ for total score 1 and 2; variation from 0.87 to 0.94), but did not evaluate the factor structure [82-83].

Test-retest reliability was measured in different test conditions and was 0.80 for all items en total scores except for items 6 and 18 [83].

One study of good methodological quality evaluated the *convergent validity* with the MOS SF-36. Correlations of the CFS-APQ total scores varied from 0.53 to 0.78 for the subscales 'physical functioning', 'social functioning' and 'bodily pain', the other correlations were lower

than 0.50 [82]. No information is available about the ability of the CFS-APQ to discriminate between patients with CFS and other conditions where fatigue causes limitations [83].

Medical Outcomes Study Short-Form 36 (SF-36)

The SF-36 is a generic, self-reporting measurement instrument that evaluates functional status and well-being or quality of life [85]. It contains 36 items and eight subscales. The application time of the English version is 10 minutes or less [86]. A higher score on the scale indicates a better health and less bodily pain [85-86].

Thirty-two articles were found that used the SF-36 in their study. One mentioned the internal consistency of the SF-36 in persons with CFS (Cronbach's $\alpha = 0.86$) that was evaluated in another study [34]. There was little information mentioned in the articles on the (other) psychometric properties of the SF-36.

Three studies evaluated the psychometric properties of the SF-36, but no studies of good methodological quality were found that evaluated the internal consistency, reliability, agreement, content validity, construct validity, criterion validity and responsiveness.

Correlation between the own subscales of the SF-36 varied from 0.26 to 0.84, except for the subscale 'role limitations due to physical problems' which did not correlate with any other subscale [87]. *Internal consistency* was calculated for each subscale (Cronbach's α 0.74 to 0.90), but a factor analysis was not performed [86].

The SF-36 is capable of *discriminating* between patients with CFS (and chronic fatigue (CF)) and major depression (MD) based on intensity of impairment and heterogeneous patterns of disability [86]. According to research the SF-36 is too sensitive in the subscales 'role limitations due to physical problems' and 'role limitations due to emotional problems', mostly because a limited range of scores. This causes a floor effect [86-87] and makes the measurement instrument unable to adequately discriminate between persons with mild, moderate and severe

limitations [87]. One study used the Receiver Operating Characteristics (ROC) to identify the subscales that discriminate best between persons with CFS and healthy persons in two study samples, a community sample and one from tertiary care. Three subscales ('vitality', 'role limitations due to physical problems' and 'general health') had an area under the curve of 0.91($p < 0.05$) in the study sample from tertiary care and three subscales had a moderate sensitivity: 'vitality', 'role limitations due to physical problems' and 'social functioning' in both study samples [85].

Euroqol Questionnaire (EQ-5D)

The EQ-5D is a short questionnaire that can be completed in a short time span**.** The first part consists of five items each divided in three levels which can subdivide patients in 243 different health states. The questionnaire also uses a VAS on which patients can score their own health between 0 and 100 [87].

No studies of good methodological quality evaluated the reliability, agreement, content validity, criterion validity, construct validity and responsiveness. One study compared the EQ-5D with the SF-36 [87]. The EQ-5D appears less sensitive when there are lower levels of perceived ill-health, mainly in the first two elements of the questionnaire 'mobility' and 'self-care'. A ceiling effect occurs which reduces the EQ-5D to a two-point scale for these two elements [87]. There were also ceiling effects for all other items of the EQ-5D (> 15% of the respondents scored 1 on all five items). A floor effect occurred on the 'Pain' item of the EQ-5D (17.64% of the respondents scored 3) [87].

Table 4: General information per study

Study	Population and pathology		Measurement instrument	Psychometric qualities and evaluation	
Buchwald et al. (1996)	N = 431 **CFS (n = 185)** 39 years ♀: n = 162 (88%) *Disease duration* 4.7 years **CF (n = 246)** 41 years ♀: n = 164 (67%) *Disease duration:* 5.6 years	**AIM (n = 111)** 21 years ♀*:* n = 57 (51%) *Disease duration:* 0.05 years **MD (n = 25)** 36 years ♀: n = 18 (72%) *Disease duration:* 8.7 years **HC *(n = 99)*** 44 years ♀: n = 61 (62%)	SF-36	Discrimination Internal consistency Construct validity	 ? ?
Cella et al. (2011a)	**Cohort 1 CFS (n = 640)** 38.3 years SD 11.8 years ♂: 22%	**Cohort 2 CFS (n = 384)** 39.1 years SD 10.1 years ♂: 37%	WSAS	Internal consistency Construct validity Responsiveness	+++ ? ?
De Vries et al. (1997)	N = 436 **CFS (n = 73)** 39.3 years SD 9.55 years 21-62 years ♀: n = 64 (87.7%)	**Healthy controls (n = 147)** 39.4 years SD 11.13 years 21-74 years ♀: n = 130 (88.4%)	WHOQOL-100	Internal consistency Content validity Construct validity	? ++ -
Jason et al. (2011)	**Community sample of Chicago CFS (n = 32)** 40.8 years ♀: 71.9% **Healthy controls (n = 47)** 41.5 years *Sex* ♀: 48.8%	**Tertiary care sample CFS (n = 114)** 8 years ± 11.6 years ♀: 83.3%	SF-36	Sensitivity Specificity Discrimination	

Table 4: General information per study (continued)

Myers et al. (1999)	N = 127 ***CFS (n= 85)*** 39.2 years SD 12.7 years 14.6-73.6 years ♀: n = 57 *Disease duration* 3 months		EQ-5D SF-36	*EQ-5D* Construct validity Sensitivity Floor-and ceiling effects *SF-36* Sensitivity Discrimination	? -
Nijs et al. (2003)	CFS (N = 111) **Validity** **(n = 47)** 36.5 years SD 11.1 years 18-60 years ♀: n = 39 (83.0%) *Disease duration* 4.8 years	**Reliability** **(n = 34)** 38.9 years SD 9.2 years 20-59 years ♀: n = 30 (88.2%) *Disease duration* 5.6 years	CFS-APQ	Internal consistency Test-retest reliability Content validity Construct validity	? ? ++ ?
Nijs et al. (2004c)	CFS (N = 149) **Responders (n = 88)** 40.3 years SD 9.5 years ♂: n = 13 (14.8%) *Disease duration* 8.1 years	**Non-responders (n = 61)** 41.3 years SD 9.5 years ♂: n = 17 (27.9%) *Disease duration* 8.6 years	CFS-APQ	Internal consistency Construct validity	? ++
Ware et al. (1992)	No population included		SF-36	Content validity	?

CF = chronic fatigue; AIM = acute infectious mononucleosis; MD = major depression; HC = healthy controls

Psychometric properties and evaluation: +++/--- = strong; ++/-- = moderate; +/- = limited; ± = conflicting; ? = unkown

The World Health Organization Quality Of Life Assessment Instrument (WHOQOL-100)

The WHOQOL-100 encompasses 100 items and evaluates 24 facets of QOL within six domains and also has a general component: 'Global quality of life and general health'. Each facet comprises of four items answered on a five point Likert-type scale [88]. No studies of good methodological quality were found that evaluated the internal consistency, reliability, agreement, criterion validity and responsiveness.

The development of the measurement instrument started with the development of a definition of QOL. Subsequently, discussion groups evaluated the definition and searched for facets that they thought that belonged to it. Then, focus groups consisting of health professionals, lay persons and persons suffering from a chronic illness evaluated and developed the facets further and finally suggested items for the facets. The pilot instrument was completed by healthy and unhealthy persons. The method of development and evaluation suggests that, according to the COSMIN checklist, the measurement instruments has a good *content validity* [88].

The study has moderate methodological quality for the evaluation of the *convergent validity* between the WHOQOL-100 and the Sickness Impact Profile (SIP), Fatigue Impact Scale (FIS) and social support scales 'Practical support', 'Emotional support' en 'Understanding'. The correlations between de WHOQOL-100 and the SIP varied from 0.00 to 0.71, but only three subscales correlated higher than 0.50. Three domains of the WHOQOL-100 correlated significant with the dimension 'Psychosocial functioning' of the SIP (-0.53, -0.60 en -0.55). Some social support scales were significantly correlated with Domain IV 'social relations', the facet 'social support', 'personal relations' and 'sexual activity' of the WHOQOL-100 with correlations from 0.50 to 0.84. The WHOQOL-100 was capable to distinguish patients with CFS from healthy persons, which supports its discrimination capability [88].

Work and Social Adjustment Scale (WSAS)

The WSAS is a five-item scale that evaluates a person's ability to perform ADL [59,89]. Each item is scored on a nine-point scale (range 0-8; range total score 0-40). A higher score indicates more limitations [89].

One study used the WSAS, but mentioned its psychometric properties merely vaguely [89].

One study evaluated its psychometric properties, but did not evaluate the reliability, agreement, construct validity, criterion validity and responsiveness according to a good methodological quality.

It does have an excellent methodological quality for the evaluation of the *internal consistency* of the WSAS. The principal component analysis supports the unidimensionality of the WSAS (range of the explained variance in the solutions: 59.1% to 67.6%). Cronbach's alpha was 0.79 for cohort 1 and 0.89 for cohort 2 at initial administration and 0.93 for cohort 2 after treatment and 0.94 after both six and 12 months. Analysis of Variance (ANOVA) that classified groups per WSAS quartile indicated that persons who have a high disability rate according to the WSAS also had a high disability score on other measurement instruments [89].

Discussion

The literature search identified 38 different measurement instruments used in scientific research to evaluate activity limitations and participation restrictions in persons with CFS.

The most frequently used measurement instruments are: SF-36 (n = 32), SIP (n = 11), CFS-APQ (n = 9) and Karnofsky Performance Scale (n = 4). Based on the lack of information about the psychometric properties of most measurement instruments, more research is needed to determine whether these instruments have acceptable psychometric properties to be used in future studies.

Most measurement instruments that were evaluated in this study are generic, except for the CFS-APQ, which is disease-specific [42,56,82]. Most generic measurement instruments are incapable of measuring all activity limitations and participation restrictions in patients with CFS, have limited content validity for this population, are difficult to interpret and time-consuming [83,91]. All this restricts their clinical usability [83]. Disease-specific measurements focus on the domains of quality of life that are related to a specific disease or a group of similar disorders. These measurement instruments are therefore more sensitive to detect significant clinical changes such as the increase or decrease of symptoms and/or functional status [91].

The literature search revealed eight psychometric studies of measurement instruments evaluating activity limitations and participation restrictions in a population with CFS [82-83,85-90]. The Dutch version of the CFS-APQ and WHOQOL-100 and the English version of the SF-36, EQ-5D and WSAS were studied [82-83,85-90]. The CFS-APQ en SF-36 were the only instruments that were evaluated by at least two studies [82-83,86,90].

Due to the lack of evidence and the limited information about the psychometric properties, the results of this literature research should be treated with caution. The different studies showed the same methodological shortcomings.

None of the studies performed or referred to a factor analysis to evaluate the internal consistency, except for the study of the WSAS [82-83,86,88]. The confirmation of the dimensionality of the measurement instruments is therefore unknown. Secondly, most studies did not mention the hypothesis about the expected correlations to evaluate the psychometric property 'construct validity' [82,87-89]. Finally, the content and psychometric properties of the comparison measurement instrument to evaluate the convergent validity were not always mentioned sufficiently [82,87-89].

Additionally, there are other aspects that need to be considered when choosing a measurement instrument. First of all, the application method is a point of interest. The CFS-APQ, SF-36, EQ-5D, WHOQOL-100 and WSAS are self-report measurement instruments [82-83,88-89]. According to Myers et al. self-report instruments have limited value for patients with CFS, because they are prone to hypochondria and often score their performance worse than it actually is [87]. On the other hand, the application of objective measurement instruments is often expensive, time consuming and constitutes a greater burden for the participants than self-report instruments [32]. Therefore Myers et al. suggest that the use of self-report measurement instruments, which evaluate the health status of a patient, may be a useful addition to detailed assessment and observations of a health care worker during intake.

This systematic review shows that the psychometric properties of measurement instruments used in scientific research with patients with CFS are insufficiently evaluated within this population. This leads to scientific and clinical limitations. The measurement instruments are

mostly used in scientific research for discriminative and evaluative purposes, for example to measure the effect of a treatment. The results of these measurement instruments cannot be judged objectively, because there is a chance that these results are not reliable or valid. This also has a large influence on clinical practice. First of all, professional caregivers consult scientific literature to ascertain their approach is evidence-based [84]. Professional caregivers therefore need reliable and valid measurement instruments. This systematic review shows that it is still unclear which measurement instruments are suitable to use in clinical practice with patients with CFS. The reliability and validity of the instruments cannot be guaranteed as long as the psychometric properties are not sufficiently evaluated according to an appropriate methodology.

If professional caregivers or researchers should be in need of a measurement instrument to evaluate activity limitations and participation restrictions, the CFS-APQ currently seems the most appropriate measurement instrument. Although it is a self-report instrument, it is easy to administer, disease-specific and has moderate content and construct validity. However, the results obtained with the CFS-APQ still need to be used with caution because of its limited psychometric information.

The SF-36 is the most used measurement instrument in scientific research, but the quality of its psychometric properties is unknown due to the use of inadequate research methodologies. It is recommended to evaluate its psychometric properties in a population with CFS, because it could be a valuable measurement instrument for research and clinical practice given its broad content. Future research should be focused on evaluating the remaining unknown psychometric properties. The studies of poor methodological quality should be repeated with sound methodology to provide strong evidence of the quality of a psychometric property. It seems appropriate to wait with the development of new measurement instruments until studies of high

methodological quality indicate that there are significant shortcomings in the current ones, and new measurement instruments are warranted.

Conclusion

The psychometric properties of measurement instruments that evaluate activity limitations and participation restrictions are currently insufficiently evaluated in patients with CFS. At the moment, it is recommended to use the CFS-APQ. While it is a self-report instrument, it is disease-specific and has moderate content and construct validity. But a lot of information is still missing about its psychometric properties, so further research is necessary.

These findings do not suggest that the current measurement instruments are not good, but indicate that there is still a lot of research of high quality to be done to evaluate the psychometric properties correctly. It is recommended to use the COSMIN checklist while performing the research.

On the other hand, this systematic research indicates that there are enough measurement instruments available to evaluate activity limitations and participation restrictions.

One can conclude that the development of new measurement instruments is unnecessary, but adequate evaluation of the current measurements constitutes a priority.

Declaration of Interest

The authors report no conflicts of interest.

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