

Subjective Cognitive Decline in Older Adults: An Overview of Self-Report Measures Used Across 19 International Research Studies

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Abstract. Research increasingly suggests that subjective cognitive decline (SCD) in older adults, in the absence of objective cognitive dysfunction or depression, may be a harbinger of non-normative cognitive decline and eventual progression to dementia. Little is known, however, about the key features of self-report measures currently used to assess SCD. The Subjective Cognitive Decline Initiative (SCD-I) Working Group is an international consortium established to develop a conceptual framework and research criteria for SCD (Jessen et al., 2014, *Alzheimers Dement* 10, 844–852). In the current study we systematically compared cognitive self-report items used by 19 SCD-I Working Group studies, representing 8 countries and 5 languages. We identified 34 self-report measures comprising 640 cognitive self-report items. There was little overlap among measures—approximately 75% of measures were used by only one study. Wide variation existed in response options and item content. Items pertaining to the memory domain predominated, accounting for about 60% of items surveyed, followed by executive function and attention, with 16% and 11% of the items, respectively. Items relating to memory for the names of people and the placement of common objects were represented on the greatest percentage of measures (56% each). Working group members reported that instrument selection decisions were often based on practical considerations beyond the study of SCD specifically, such as availability and brevity of measures. Results document the heterogeneity of approaches across studies to the emerging construct of SCD. We offer preliminary recommendations for instrument selection and future research directions including identifying items and measure formats associated with important clinical outcomes.

Keywords: Cognition, cognitive complaints, dementia, early detection, memory complaints, subjective cognition, mild cognitive impairment, preclinical Alzheimer's disease, questionnaire, subjective cognitive impairment, subjective memory complaints

INTRODUCTION

Subjective cognitive decline (SCD) in older adults is increasingly recognized as a potential indicator of

non-normative cognitive decline and eventual progression to dementia [1–5]. Moreover, there is emerging evidence of associations of SCD with Alzheimer's disease (AD) biomarkers and neuroimaging markers

[6–16], such as gray matter volume loss [6–8], cerebral hypometabolism [10], and amyloid deposition [12–14], in the absence of objective cognitive dysfunction or depression. Given research supporting SCD as a risk factor for AD in some individuals, the National Institute on Aging–Alzheimer’s Association preclinical AD working group has included SCD as a feature, highlighting its importance in disease detection and prevention [17]. In addition to preclinical AD, SCD is relevant to other conditions affecting older adults, for example: depression and anxiety [18–19], physical health problems and common chronic diseases [18, 20], and non-AD dementias [1, 21].

By definition, SCD is contingent on self-report of cognition, and this assessment approach is associated with certain practical advantages such as brevity, ease of administration, and low cost [22]. However, the field currently lacks a single accepted approach to the assessment of SCD, including the fundamental nature of the questions (present status versus decline), cognitive domains of greatest interest, and optimal items for each domain [22, 23]. Also, since the prevalence of cognitive complaints in the general adult population is relatively high [24] and can be affected by factors such as mood and personality [25], it becomes difficult to ascertain which complaints indicate underlying AD versus other neurodegenerative pathologies or psychological conditions. This underscores the need for a high degree of rigor in deriving self-report items with concurrent validity for the construct of SCD and predictive validity for future cognitive and clinical outcomes. The definition of the external validators for SCD is itself the subject of discussion [22, 23].

In contrast to extensive efforts to refine and standardize AD biomarkers [26–28] and criteria for conditions such as mild cognitive impairment (MCI) [29–33], research on the standardization and quantification of SCD is relatively limited. Many approaches are used to define and quantify SCD and related constructs, such as cognitive complaints, memory complaints, subjective memory impairment, and subjective cognitive impairment, with no agreed-upon standards [22, 23]. The variability in definition and large number of operational procedures for assessing SCD makes it difficult to compare findings and refine the construct for use in clinical and research settings.

A review of both the SCD and broader cognitive aging literature suggests heterogeneity in important aspects of cognitive self-report measures including mode of administration [34–41], number of items [42–53], and response option types [38, 54–59]. Other dimensions on which self-report measures vary are

item content and complexity including whether items relate to memory exclusively [57, 60–62] or include additional cognitive domains [50, 63, 64] or non-cognitive items [51, 55, 65], whether items tap current cognitive ability or disability/impairment [65–67] versus intraindividual change [57, 68], and whether items inquire about general versus specific aspects of cognition. In terms of the origin of instruments, while some studies use complete published questionnaires [54–60, 65], others use groups of items from existing measures [69–71] or develop new items for a specific study [12, 72–77]. Finally, while selecting appropriate measures stands among the most critical decisions made in clinical research contexts, the SCD literature in many cases does not thoroughly discuss selection decisions.

An international consortium known as the Subjective Cognitive Decline Initiative (SCD-I) Working Group recently was established to develop common terminology and basic criteria for SCD to enable joint research efforts across studies and settings [23]. The current study describes the characteristics of self-report measures employed by studies represented by SCD-I investigators. Specifically, we focus on key structural and content validity issues and investigate content overlap among the questionnaire items as well as questionnaire selection decisions. Our goals are to identify areas of variability and consistency, raise issues related to the adequacy of assessment approaches, and ultimately develop improved tools for diverse research and clinical settings.

MATERIALS AND METHODS

The SCD-I

The SCD-I was launched in October 2012 and formed a working group that included AD researchers with a specific interest in SCD. Members were identified by a systematic literature search in addition to targeted inclusion of leading researchers in the field of preclinical AD assessment. The working group’s first project established a conceptual framework and research criteria for SCD [23]. Members of the SCD-I were subsequently invited to participate in the current item analysis project.

Questionnaire characteristics and coding procedures

Based on our review of the SCD literature, considerations of relevance to the field, and feasibility, we

investigate the following ten issues through descriptive and content analysis of SCD-I Working Group measures: (1) number of self-report measures used by participating working group studies; (2) origin of instruments and mode of administration; (3) format and range of response options; (4) timeframe referenced by the items; (5) prevalence of items related to specific cognitive domains; (6) prevalence of items tapping cognitive ability/disability-impairment (and referents of frequency, severity, and impact) versus change or decline (and referents of temporal and atemporal); (7) item specificity and complexity; (8) overlap in measures used by working groups; (9) most commonly occurring items; and (10) considerations driving measure selection and the grouping of questionnaires within a given study. Coding of cognitive self-report items occurred prior to data analysis for research issues 1, 5, 6, 7, 9, and 10. For all coding procedures, working group member LAR carried out the initial coding. Two additional expert raters (working group members CMS and SAMS) subsequently identified items that they considered to be miscoded. Items in dispute were then reviewed and discussed until consensus was reached, occasionally after discussing disputed items with working group member PKC.

Selection of cognitive items

SCD-I Working Group members sent electronic copies of their subjective self-report measures to author LAR. For studies conducted in a language other than English, working group members sent a translated version of their measures. The raters then reviewed all measures to determine whether they merited inclusion in the current study by virtue of containing items that assess the self-perception of memory and other cognitive abilities. Notably, while the raters recognized that mood, anxiety, health complaints, and other variables are relevant to SCD and often included in cognitive self-report measures, they are not the focus of the current study.

Categorization by cognitive domain

The raters next classified items by cognitive domain. They first developed a list of cognitive domain categories under which to subsume all items. The list was revised following feedback from additional working group members and included the following categories: (1) *memory* (short-term/long-term/episodic/semantic/prospective memory and learning

new information); (2) *attention/working memory/processing speed* (also includes basic attention, sustained attention, focused attention, concentration, divided attention, and alertness); (3) *language* (expressive and receptive language, word finding, reading, and spelling); (4) *executive function* (organizing, planning, switching, initiating, multi-tasking, reasoning, judgment, problem solving, decision-making, handling emergencies, impulsivity and self-regulation, clarity of mind, motor programming, handling money, and self-awareness of problems); (5) *basic calculation and arithmetic* tasks; (6) *orientation* to person, time, place, or situation; (7) *general cognitive ability* (memory and other thinking abilities grouped together in a single item); and (8) *visuospatial skills* (visuoperception, route finding, and directional orientation). The raters assigned each item to a single category using the widely-recognized neuropsychological framework suggested by Lezak and colleagues [78]. Though many items arguably could be categorized into more than one cognitive domain, the raters assigned a primary category for each item.

Categorization by ability/disability and change

The raters considered each cognitive item (both stem and response options) to determine whether the item inquired about a participant's ability to perform a given cognitive task or whether the item inquired about change (improvement or decline). For items that assess ability versus disability/impairment, items could portray the intensity or severity of problems, their frequency, or impact on everyday life. The raters therefore coded for referents of severity (degree of seriousness), frequency (rate of occurrence), and impact (effect on real-world outcomes). For items that assess change, items could portray temporal change (relative to a general or specific timeframe) or atemporal change (relative to peers, a previous state, or rate of change). The raters therefore coded for both temporal and atemporal referents.

Categorization by item specificity and complexity

To address issues of item specificity and complexity, the raters coded memory items according to generality versus specificity and whether they were double-barreled (i.e., involved multiple sub-questions within the one item). A general memory item was defined as a cognitive self-report item that inquires about memory functioning without specifying a particular memory activity, problem, or task. The raters did

not extend the coding of general versus specific items to cognitive domains other than memory because of the complexity of establishing coding criteria for non-memory domains. A double-barreled cognitive item was defined as an item that asks respondents to rate or respond to two or more different issues while allowing for only one response.

Most commonly occurring items

After close review of all items across the 34 questionnaires, the raters identified items with overlapping content (e.g., memory for recent events, memory for names, losing one's train of thought) despite non-identical item wording (as there were no items with verbatim wording for both item stems and response options). Subsequently, the raters generated a list of the 10 most common item themes.

Selection decisions

To understand the decision-making behind each research group's choice of measures or development of new measures, the raters distributed a brief survey to working group members. The survey asked the following:

(1) for working groups utilizing existing cognitive self-report measures, respondents were asked to identify the "primary" self-report measure and state why the measure was initially selected for use, endorsing all responses that applied from among various options; (2) for working groups that developed their own cognitive self-report measures, respondents were asked to state why they chose to develop a new measure (free response); and (3) for working group studies that administered more than one cognitive self-report measure, respondents were asked to describe the rationale for including the specific number of measures in the study (free response).

RESULTS

Table 1 lists the names, institutional affiliations, and other key features of the 19 working group studies including country, research environment, approximate number of study participants, and number of SCD measures utilized. The United States houses the greatest number of working group studies ($n = 7$), followed by Germany ($n = 3$), Australia ($n = 2$), France ($n = 2$), and Spain ($n = 2$). Canada and the Netherlands house one study each, and the Alzheimer's Disease Neuroimaging Initiative (ADNI) has multi-

ple international locations including the United States, Canada, Australia, Germany, and the United Kingdom. There was substantial variability in terms of research environment, with representation of memory clinics ($n = 4$), volunteer samples ($n = 3$), community-based samples ($n = 3$), population-based samples ($n = 2$), a general practice registry ($n = 1$), and mixed sampling approaches ($n = 6$).

Below we present results related to the 10 instrument dimensions outlined in the Methods section.

(1) Number of self-report measures and items used.

Table 2 presents the names and key structural and administrative features of the 34 self-report measures used by the 19 studies. The number of measures used per study ranged from 1 to 8 with a mean of 2.4 ($SD = 2.1$) and a mode of 1. While some measures included cognitive items exclusively, other measures primarily focused on mood or activities of daily living but included one or more cognitive items highly relevant to the current analysis. There were a total of 922 items across all measures. Of the 34 measures, 61.8% ($n = 21$) contained items that did not involve specific cognitive complaints. This included items related to the use of memory/other cognitive strategies, emotional and psychological functioning, reactions to cognitive changes, personality and interpersonal functioning, physical and motor functioning, vocational and social tasks, general health, fatigue or sleep behaviors, apraxia, basic activities of daily living, general health, general beliefs about memory and aging, and items that were not self-report. These non-SCD items were identified with <4% discrepancies between raters, eliminated for the purposes of the current study, and not considered further. All subsequent results relate to the subset of 640 cognitive items that tap the subjective perception of memory and other cognitive abilities, representing 69.4% of the total items across the 34 questionnaires. The number of cognitive items per questionnaire ranged from 1 to 56 with a mean of 18.8 ($SD = 15.5$). Table 2 shows the percentage of cognitive self-report items within each questionnaire.

(2) Origin of instruments and mode of administration.

With respect to the origin of their instruments, working group studies utilized existing published questionnaires and instruments developed specifically for their research studies with equal frequency (15 each, accounting for 88% of all measures). The remaining 12% of measures ($n = 4$) comprised subsets of items from lengthier published measures. The vast majority of measures (82.4%, $n = 28$) were self-

Table 1
Participating Subjective Cognitive Decline Initiative (SCD-I) working group studies

Study name	Institutional affiliation	Country	Research environment	Approximate number of participants	Number of measures
AgeCoDe Study	University of Bonn and 5 other German universities	Germany	General practice registry-based	3,327	2
Alzheimer's Disease Center Clinical Core and Center for Brain Health	New York University School of Medicine	United States	Volunteer	525	1
Alzheimer's Disease Neuroimaging Initiative (ADNI)	Over 100 international affiliates: ads.org/Research/ClinicalSite.aspx	United States, Canada, Australia, Germany, United Kingdom	Volunteer and memory clinic	1,204	1
Amsterdam Dementia Cohort	VU University Medical Center	Netherlands	Memory clinic	1,244	2
Australian Imaging Biomarkers and Lifestyle Flagship Study of Ageing (AIBL)	University of Melbourne	Australia	Volunteer and physician referred	851	2
Barcelona Group	IDIBAPS, Hospital Clinic, Barcelona	Spain	Volunteer and memory clinic	400	1
Bonn Memory Clinic	University of Bonn and the German Center for Neurodegenerative Diseases, Bonn	Germany	Memory clinic	120	1
Dartmouth-Indiana Longitudinal Cohort	Dartmouth Medical School, Indiana University School of Medicine	United States	Volunteer and physician referred	269	8*
Einstein Aging Study	Albert Einstein College of Medicine	United States	Community-based	2,500	7**
Harvard Aging Brain Study	Harvard Medical School, Brigham and Women's Hospital and Massachusetts General Hospital	United States	Volunteer	280	3
IMAP Caen Group	Inserm, University and Hospital of Caen	France	Memory clinic	86	1
Leipzig Longitudinal Study of the Aged (LEILA 75+)	University of Leipzig	Germany	Population-based	1,265	1
Mayo Clinic Study of Aging (MCSA)	Mayo Clinic	United States	Population-based	4,500	2
Memory Clinic - Fundació ACE	Fundació ACE, Barcelona Alzheimer Treatment and Research Center	Spain	Community-based	660	1
PreAl Study	Hôpital de la Salpêtrière, AP-HP	France	Memory clinic	180	1
Sydney Memory and Ageing Study	University of New South Wales	Australia	Community-based	873	3
University of Pittsburgh Study/Monongahela-Youghiogheny Health Aging Team (MYHAT)	University of Pittsburgh	United States	Clinic-community volunteer sample and population-based	2,100	3
Vanderbilt Memory and Alzheimer's Center (VMAC)	Vanderbilt University School of Medicine	United States	Memory clinic, physician referred, and community-based	158	1
Victoria Subjective Cognitive Decline Study (SCDS)	University of Victoria	Canada	Volunteer	42	5

*A subset of participants received all 8 questionnaires. The remaining participants received 5 questionnaires. **A subset of participants received all 7 questionnaires. The remaining participants received 3 questionnaires.

Table 2
Key structural and administrative features of self-report measures used by Subjective Cognitive Decline Initiative (SCD-I) Working Group studies

Questionnaire/ item subset abbreviation	Language	Administration mode	Total number of items	Number (percentage) of items relevant to analysis*	Response type and options	Timeframe
ADL	English	5Self-administered paper questionnaire	63	33 (52.4%)	7 pts. "Above average ability" to "Severe disability", plus "Not applicable"	Current
ADL Abbrev	English	5Self-administered paper questionnaire	50	45 (90.0%)	7 pts. "Much better" to "Much worse"	Compared to 5 years ago
AgeCoDe MQ	German	5Examiner- administered in person	2	2 (100%)	Yes/No/Don't know; 3 pts. "No" to plus "Don't know" and "Not applicable"	Unspecified and current
AIBL Screen Blessed	English English	5Examiner- administered by telephone 5Self-administered paper questionnaire	1 6	1 (100%) 5 (83.3%)	Yes/No Yes/No/Don't know; 4 pts. "Better than when I was younger" to "Definitely worse than when I was younger"	Current Compared to when "younger"
BRIEF-A CAPM-C	English English	5Self-administered paper questionnaire 5Self-administered paper questionnaire	75 15	36 (48.0%) 13 (86.7%)	3 pts. "Never" to "Often" 4 pts. "Strongly disagree" to "Strongly agree"	Past month Current
CCI	English	5Self-administered paper questionnaire	20	20 (100%)	5 pts. "No change" to "Much worse"	Compared to 5 years ago
CDS-Q CERAD-Self	French English	5Self-administered paper questionnaire 5Self-administered paper questionnaire	39 36	33 (84.6%) 22 (61.1%)	5 pts. "Never" to "Very often" Yes/No/Don't know; 4 pts. "Less than six months ago" to "More than two years ago"; 3 pts. "Very gradually" to "Suddenly", plus "Other"; 3 pts. "Steadily worsened" to "Got worse then leveled off", plus "Other" and "Don't know"	Current Current
CFQ ECog Self	English English, German, French	5Self-administered paper questionnaire 5Self-administered paper questionnaire	25 40	17 (68.0%) 40 (100%)	5 pts. "Never" to "Very often" Yes/No; 4 pts. "Better or no change" to "Consistently much worse", plus "Don't know"	Past 6 months Compared to 10 years ago
Einstein HSA	English	5Self-administered paper questionnaire	20	6 (30.0%)	Yes/No/Don't know; 4 pts. "Frequently" to "Never"; 3 pts. "More often" to "About the same"; Free response (percent)	Unspecified; Past year; Compared to 1 and 10 years ago
GDS Long GDS Short	English English, Dutch	5Self-administered paper questionnaire 5Self-administered paper questionnaire	30 15	4 (13.3%) 1 (6.7%)	Yes/No Yes/No	Past week Past week

(Continued)

Table 2
(Continued)

Questionnaire/ item subset abbreviation	Language	Administration mode	Total number of items	Number (percentage) of items relevant to analysis*	Response type and options	Timeframe
IQCODE Short	English	5Self-administered paper questionnaire	16	15 (93.8%)	5 pts. "Much improved" to "Much worse"	Compared to 10 years ago Current
LEILA 75+ Questions	German	5Examiner- administered in person	4	4 (100%)	4 pts. "No problems" to "Always", plus "Don't know"; 4 pts. "Not at all" to "Highly", plus "Don't know" and "Not applicable"; Free response (age), plus "Not applicable"	Current
MAC-Q (a)	English	5Self-administered paper questionnaire	6**	6 (100%)	5 pts. "Much better now" to "Much poorer now"	Compared to high school or college
MAC-Q (b)	English	5Self-administered paper questionnaire	6	6 (100%)	5 pts. "Much better now" to "Much poorer now"	Compared to 5 years ago Current
MATS	English	5Examiner- administered by telephone	13	13 (100%)	Yes/No/Don't know; The Same/Worse/Don't know; Free response (age of onset)	Current
MFE-30	Spanish	5Self-administered paper questionnaire	30	29 (96.7%)	5 pts. "Never or almost never" to "Always or almost always"	Current
MFQ***	English	5Self-administered paper questionnaire	63 or 64	49 (77.8%) or 50 (78.1%)	7 pts. "Major Problems" to "No problems"; 7 pts. "Always" to "Never"; 7 pts. "Very poor" to "Very well"; 7 pts. "Very serious" to "Not serious"; 7 pts. "Much worse" to "Much better"	Current; Compared to 1, 5, 10, and 20 years ago; Compared to age 18
MIA	English	5Self-administered paper questionnaire	108	35 (32.4%)	5 pts. "Strongly disagree" to "Strongly agree"	Current
MMQ	German	5Self-administered paper questionnaire	57	32 (56.1%)	5 pts. "Strongly agree" to "Strongly disagree"; 5 pts. "Always" to "Never"	Past 2 weeks
SCCS	English	5Self-administered paper questionnaire	30	27 (90.0%)	Yes/No; 4 pts. "Excellent" to "poor"; 2 pts. "Suddenly/Gradually" and "Other"; 3 pts. "Better" to "The Same", plus "Never performed this activity"; Free response (age)	Multiple [†] Current Current and compared to 2 years ago Past year
SCD-SID	English	5Examiner- administered by telephone	1	1 (100%)	Yes/No	Current
SCD-Q: Part 1 MyCog	Spanish	5Self-administered paper questionnaire	27	26 (96.3%)	Yes/No	Current and compared to 2 years ago Past year
SCF	Dutch	5Self-administered paper questionnaire	4	2 (50.0%)	7 pts. "Very strong improvement" to "Very sharp decline"	Past year

Table 2
(Continued)

Questionnaire/ item subset abbreviation	Language	5 Administration mode	Total number of items	Number (percentage) of items relevant to analysis*	Response type and options	Timeframe
SCQ	French	5Self-administered paper questionnaire	14	14 (100%)	4 pts. "The same" to "Much worse"; 4 pts. "No" to "Most of the time"; 4 pts. "No" to "Definitely"; 4 pts. "No" to "Very much"	Past year
SMDS	German	5Examiner- administered in person	4	4 (100%)	3 pts. "No" to "Yes, a lot worse"	Compared to 10 years ago
Squire Memory Self-Rating	English	5Self-administered paper questionnaire	18	18 (100%)	9 pts. "Worse than ever before" to "Better than ever before"	Compared to "ever before"
STDA	English	5Self-administered paper questionnaire	7	7 (100%)	Yes/No	Current
Sydney-SCQ Wave 1	English	5Self-administered paper questionnaire	18	16 (88.9%)	Yes/No/Don't know; 4 pts. "No, less difficulty" to "Yes, a lot more difficulty"; plus "Not applicable"	Unspecified and compared to 5 years ago
VMAC Cognitive Complaint Question- naire	English	5Self-administered paper questionnaire	57	56 (98.2%)	Yes/No/Prefer not to answer; 3 pts. "Never" to "Always"; 3 pts. "No problems" to "Major problems"	Multiple†

*Items relevant for the current analysis relate to the subjective perception of one's cognition (see text for details about eliminated items). **The NYU version of the MAC-Q contains a different item stem for item 4 (bringing the total number of overall items to one more than the totals displayed in columns 3 and 4). Also, the MAC-Q was separated into versions a and b because of the different timeframe references. ***The University of Pittsburgh's version of the questionnaire contains one additional item. †Timeframe includes current, compared to 1 year ago, and compared to how "you used to be", and some items have unspecified time frames. ‡Timeframe includes current, compared to 1 year ago, compared to 2 years ago, compared to 5 years ago, compared to 10 years ago, and compared to 20 years ago, and some items have unspecified time frames.

AIBL Screen, Melbourne Australian Imaging Biomarkers and Lifestyle Flagship Study of Ageing (AIBL) Memory Screen Question [99]; ADL, Activities of Daily Living Rating Scale Self-Version [100]; ADL Abbrev. Activities of Daily Living Rating Scale Self-Version, Abbreviated (Saykin, unpublished); AgeCoDe MQ, AgeCoDe Study Memory Questions [101]; Blessed, Blessed Memory Test [102]; BRIEF-A, Behavioral Rating Inventory of Executive Function-Adult Version [103]; CAPM-C, Comprehensive Assessment of Prospective Memory-Section C [66]; CCI, Cognitive Change Index [7]; CDS-Q, Cognitive Difficulties Scale [58]; CERAD-Self, Consortium to Establish a Registry for Alzheimer's Disease-Self Version [104]; CFQ, Cognitive Failures Questionnaire [55]; ECog Self, Everyday Cognition-Subject/Self-Report [68]; GDS Long, Geriatric Depression Scale-Long Version [105]; GDS Short, Geriatric Depression Scale-Short Version [106]; HSA, Albert Einstein Health Self-Assessment [107]; IQCODE Short, Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly [108]; LEILA 75 + Questions, Leipzig Longitudinal Study of the Aged Questionnaire [109-110]; MAC-Q(a), Memory Complaint Questionnaire [57]; MAC-Q(b), Memory Complaint Questionnaire [65]; MATS, Memory and Aging Telephone Screen [67]; MFE-30, Memory Failures Everyday [111]; MFQ, Memory Functioning Questionnaire [60]; MIA, Metamemory in Adulthood Questionnaire [65]; MMQ, Multifactorial Memory Questionnaire [54]; SCCS, Subjective Cognitive Complaint Scale-(also referred to as the Subjective Memory Scale) [74,112]; SCD-SID, Subjective Cognitive Decline Self-Identification Item [47]; SCD-Q: Part 1 MyCog, Subjective Cognitive Decline Questionnaire: Part 1 My Cognition [50]; SCF, Subjective Cognitive Functioning [113]; SCQ, Self-Evaluation of Cognition Questionnaire [114]; SMDS, Subjective Memory Decline Scale [115]; Squire Memory Self-Rating Questionnaire [116]; STDA, Adapted from Structured Telephone Dementia Assessment [13, 38]; Sydney-SCQ, Sydney Subjective Complaint Questions, Wave 1 [92]; VMAC Cognitive Complaint Questionnaire, Vanderbilt Memory and Alzheimer's Center Cognitive Complaint Questionnaire [40].

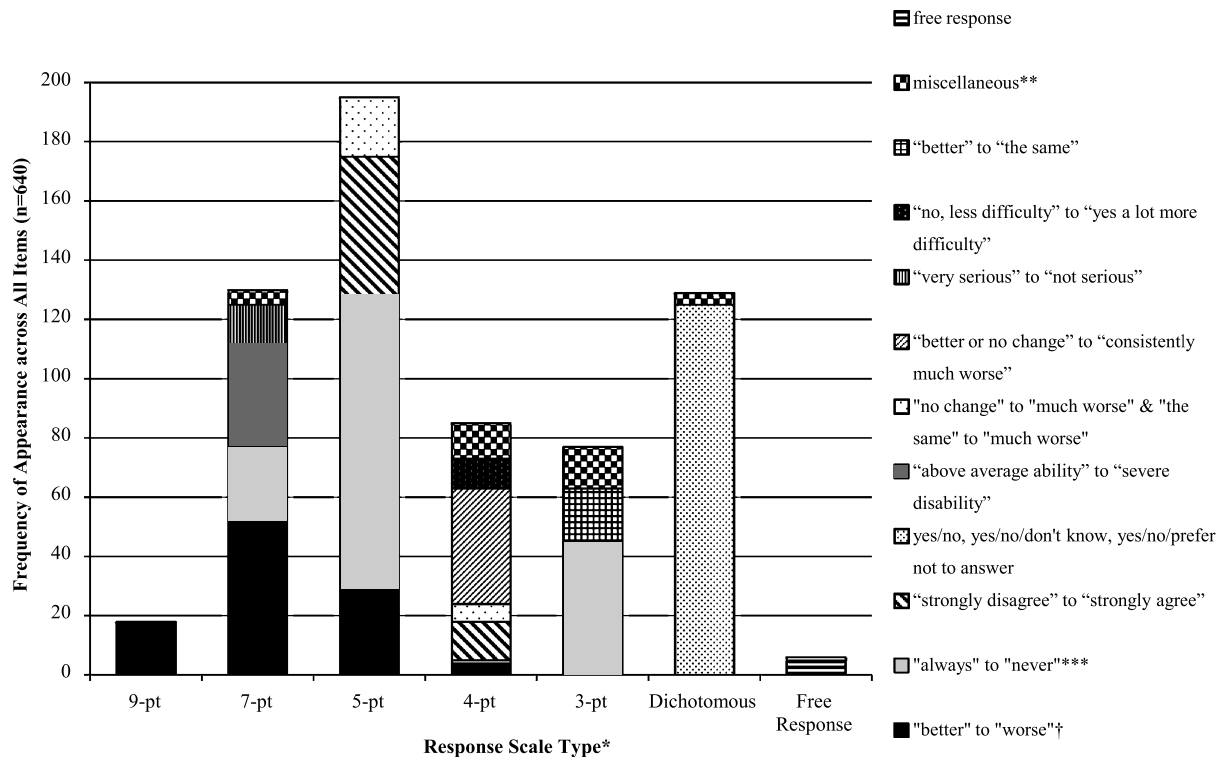


Fig. 1. Summary of response types and options.

Notes: *14 out of 34 questionnaires include multiple response types. **Includes: <10 each of “very poor” to “very well”; “major problems” to “no problems”; “no” to “most of the time”; “no” to “definitely”; “no” to “yes, a lot worse”; “no problems” to “always”; and “more often” to “about the same”. Includes one each of “no” to “yes, that worries me seriously”; “less than 6 months ago” to “more than two years ago”; “very gradually” to “suddenly”; “steadily worsened” to “got worse and then leveled off”; “not at all” to “highly”; “excellent” to “poor”; “no” to “very much”; agree/disagree; good/poor; same/worse; and suddenly/gradually. ***Includes: “always” to “never”; “frequently” to “never”; “always or almost always” to “never or almost never”; “very often” to “never”, and “often” to “never”. †Includes: “better than ever before” to “worse than ever before”; “much better” to “much worse”; “very strong improvement” to “very sharp decline”; “much improved” to “much worse”; “much better now” to “much poorer now”; and “better than when I was younger” to “definitely worse than when I was younger”.

administered via paper questionnaire. The remaining measures were examiner-administered by telephone (8.8%, $n = 3$) or in person (8.8%, $n = 3$); in both cases, examiners read the questions aloud to participants and recorded responses.

(3) Format and range of response options.

There was considerable variability in response options with 21 measures (61.8%) having a single type of response option and the remaining 13 having between 2 to 5 different option types within a single measure (see Table 2). Traditional Likert and rank-ordered/categorical item scales were the most common, appearing on 27 (79.4%) measures. Dichotomous (yes/no) response options were also common, with 8 (23.5%) measures employing this format. An additional 7 (20.6%) measures used response options with yes/no/don’t know or yes/no/prefer not to answer formats. Four measures (11.8%) used free response

options, which were primarily for reporting the age of onset of cognitive symptoms.

Figure 1 presents information related to response options in terms of the scaling methods and item response content. Five- and 7-point scales were used most often, accounting for 30.5% ($n = 195$) and 20.3% ($n = 130$) of items, respectively. We categorized response options into 12 types. Scales from “always” to “never” (or similar) were used most often, comprising 26.6% ($n = 170$) of all items in the form of 7-point, 5-point, 4-point, and 3-point scales. Other commonly used response options were yes/no, yes/no/don’t know, and yes/no/prefer not to answer (19.5%, $n = 125$); “better” to “worse” (or similar) in the form of 9-point, 7-point, 5-point, and 4-point scales (15.6%, $n = 100$); and “strongly disagree” to “strongly agree” in the form of 5-point and 4-point scales (9.4%, $n = 60$). All content categories are represented in Fig. 1.

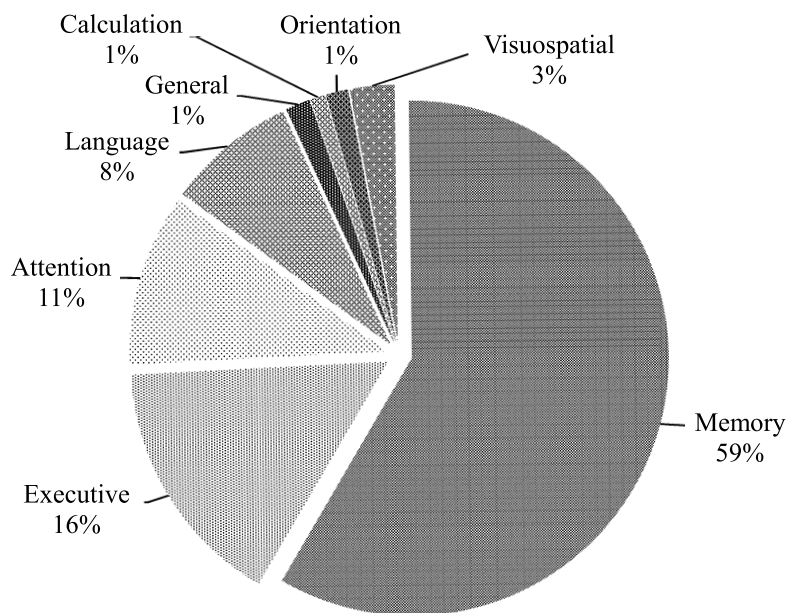


Fig. 2. Percentage of items by cognitive domain.

Notes: Memory includes short-term, long-term, episodic, semantic, and prospective memory and learning new information; Attention includes basic, sustained, focused, and divided attention, working memory, concentration, processing speed, and alertness; Language includes expressive and receptive language, word finding, reading, and spelling; Executive includes executive functions such as organizing, planning, initiating, switching, multi-tasking, reasoning, problem solving, decision-making, impulsivity, and self-regulation; Calculation includes basic calculation and arithmetic; Orientation includes orientation to person, time, place, and situation; General refers to memory and other cognitive abilities grouped together in a single item; and Visuospatial includes visuoception, route finding, and directional orientation.

(4) Timeframe.

As shown in Table 2, the most common response timeframe referred to by the cognitive items was the recent past with 47.1% ($n=16$) of measures asking participants to reflect about current functioning or functioning over the past week, 2 weeks, or 6 months. An additional 5.9% ($n=2$) of measures referenced the past year. Other measures required comparisons to 5 years ago ($n=3$), 10 years ago ($n=3$), and lengthier timeframes including “younger,” “ever before,” and “high school or college” ($n=3$). The remaining measures ($n=7$) referenced more than one timeframe within a single questionnaire.

(5) Prevalence of items related to specific cognitive domains.

The raters categorized each item according to one of eight neuropsychological domains, with rater discrepancies arising in <4% of cases. As shown in Fig. 2, memory items represented the majority (58.6%, $n=375$) of items, followed by executive function (15.8%, $n=101$), attention/working memory/processing speed (10.8%, $n=69$), and language (8.1%, $n=52$). The remaining four domains of visuospatial skills, general cognitive ability, orientation,

and basic calculation/arithmetic tasks together accounted for 6.7% of items ($n=43$).

(6) Prevalence of items tapping ability/disability-impairment versus change.

We further investigated item content by categorizing items as ability/disability-impairment versus change; coding discrepancies between raters arose in <4% of cases. Of the 640 cognitive items, 58.4% ($n=374$) tapped ability/disability-impairment and 41.6% ($n=266$) assessed intraindividual change or decline. Of the 374 items tapping ability/disability-impairment, 49.5% ($n=185$) assessed ability in terms of frequency, 44.7% ($n=167$) assessed ability in terms of severity, and the remaining 5.9% ($n=22$) of items assessed ability in terms of its impact on functioning. Of the 266 items assessing intraindividual change or decline, 97.7% ($n=260$) assessed change in diachronic (or temporal) terms while 6 items (2.3%) assessed change in synchronic (or atemporal) terms. Table 3 presents example items within these various content designations.

(7) Item specificity and complexity.

We next considered item stem specificity, which refers to whether an item is general or specific, and

Table 3
Sample items categorized by ability or change

Domain	Referent	Sample items
Ability (n = 374)	<i>Severity</i>	Please rate your current level of ability or functioning, or the severity of any problems: Ability to reason through a complicated problem 1 = above average ability; 2 = normal ability; 3 = mild disability; 4 = mild to moderate disability; 5 = moderate disability; 6 = moderate to severe disability; 7 = severe disability; not applicable How would you rate your memory in terms of the kinds of problems you have? 1, 2 = major problems; 3, 4, 5 = some minor problems; 6, 7 = no problems
	<i>Frequency</i>	How often does remembering or doing the following things present a problem for you? Losing the thread of thought in conversation 1, 2 = always; 3, 4, 5 = sometimes; 6, 7 = never I forget details of what I did or what happened the day before. 0 = never or almost never; 1 = rarely; 2 = sometimes; 3 = often; 4 = always or most always
	<i>Impact</i>	Do you feel that your everyday life is difficult now due to your memory decline? 0 = no; 1 = yes; 2 = prefer not to answer How is your everyday life affected by the memory problems? 0 = not at all; 1 = a little; 2 = somewhat; 3 = highly
Change (n = 266)	<i>Temporal</i>	Compared to 10 years ago, has there been any change in verbally giving instructions to others? 1 = better or no change; 2 = questionable/occasionally worse; 3 = consistently a little worse; 4 = consistently much worse; don't know My ability to pay attention to what goes on around me is: -4 = worse than ever before; -3, -2, -1, 0 = no change; 1, 2, 3, 4 = better than ever before
	<i>Atemporal</i>	Are you worried or concerned about a decline in your thinking abilities, more than normal aging? 0 = no; 1 = yes Do you feel your memory got worse suddenly or gradually? 1 = suddenly; 2 = gradually; 3 = other, specify

Table 4
Sample memory items categorized by item stem specificity

Variable	Sample item stems
General memory items (n = 110)	How would you rate your memory in terms of the kinds of problems you have? Do you have problems with your memory compared to the way it was 5 years ago? Do you feel that you have more problems with memory than most? Any other problems with your memory? How long ago did your memory problems start?
Specific memory items (n = 265)	How often do you leave something behind when you meant to bring it with you? Do you have trouble recalling conversations a few days later? I am good at remembering birthdates. Compared to your peers, do you think you have more difficulty learning new information? I forget details about myself (age, telephone number).

complexity, which refers to whether items are double-barreled. As noted above, we limited our coding of general and specific items to memory items and did not extend this coding to other cognitive domains. There were discrepancies in <3% of cases for specificity and <2% for complexity. The vast majority of the 375 memory items were specific (70.7%, n = 265) as opposed to general (29.3%, n = 110). In addition, 98 of the 640 (15.3%) cognitive items were double-barreled. Tables 4 and 5 present examples of general and specific items and double-barreled items, respectively.

(8) *Overlap in measures used by working groups.*

Table 6 shows the overlap in use of self-report measures by the working group studies. The 34 measures were used 46 times by the 19 working group studies; each study incorporated from 1 to 8 measures. Of the 34 measures, 25 (73.5%) were used only in a single study, 7 (20.6%) were used in 2 studies, the MAC-Q was used in 3 studies, and the ECog was used in 4 studies. Note that scales called that MAC-Q were actually used in 4 studies, but one study used a different timeframe so the raters

Table 5
Sample cognitive items with double-barreled item stems

Sample item stems
Are you concerned that you have a memory or other thinking problem?
Do you have any difficulty in understanding or following spoken instructions?
Do you talk less because of memory or word-finding difficulties?
Compared to 10 years ago, I am much worse at remembering titles of books, films or plays.
I find it harder to remember street and city names.
Forgets appointments, dates, or where things are stored.
Organizing daily activities and keeping a schedule.
I have trouble finding things in my room, closet, or desk.
Following a story in a book, movie, or TV.
Recalling telephone numbers or zip codes that you use on a daily or weekly basis.
Have you sought evaluation or treatment for your memory problems?
My ability to search through my mind and recall names or memories I know are there is.
Do you find you forget whether you've turned off a light or a fire or locked the door?
Remembering what day/date/month it is?
I get lost or I follow the wrong directions on trips, strolls, or buildings that I have previously been in.

designated the versions as MAC-Qa and MAC-Qb (see Tables 2 and 6).

(9) Most commonly occurring items.

We next coded the most commonly occurring items (i.e., items grouped together because they inquire about the same cognitive issue), with <4% discrepancies between raters. Table 7 presents the items that appear most frequently across the 34 questionnaires and their item counts. Note that in some cases a particular item is administered more than once within a measure. Items related to memory change and memory for the names of people were most common, followed by general memory problems and remembering where the participant had put common objects. We also determined item commonality by identifying items that appear on the most measures. For this analysis we only counted each item once per questionnaire. As shown in Table 7, items relating to memory for the names of people and remembering where the individual had put common objects appeared on the greatest number of self-report measures, followed by general memory problems, word finding, and remembering appointments.

(10) Considerations driving questionnaire selection and the grouping of measures within a given study.

For working groups that reported using an existing SCD measure as their "primary" cognitive self-report measure ($n = 10$), the most commonly endorsed reasons were the measure's availability to the researchers, the measure's brevity and convenience of administration, and the routine use of the measure in studies of cognitive impairment in aging (see Table 8). For working groups that reported developing their own cognitive self-report measure ($n = 9$), reasons cited related to one of three general themes: (1) categorization of participants into SCD versus non-SCD groups; (2) addressing

concerns specific to SCD individuals not captured by other measures; and (3) enabling the researchers to tap cognitive domains of interest. For working groups that reported using more than one self-report measure within a specific study ($n = 7$), reasons cited related to one of four general themes: (1) use of one measure to classify SCD and additional measure(s) to quantify specific aspects of cognitive functioning; (2) for complete coverage of domains of interest; (3) to permit more variability in the distribution of responses; and (4) to replicate what is used by other studies with similar participant demographics.

DISCUSSION

Overview of findings

The current study is the first to provide a systematic descriptive summary of the cognitive self-report measures used in 19 international cognitive aging studies affiliated with the Subjective Cognitive Decline Initiative (SCD-I) Working Group. Participating studies were diverse with respect to research environment, number of participants, number of self-report measures utilized, and language in which measures were administered. Results indicated that participating studies adopted a wide range of methods to assess SCD—specifically, 34 different self-report measures—the vast majority of which used only within a single study. Measures most commonly used across studies were the MAC-Q [57] and ECog [68], each used at four sites, though two different timeframes were used for the MAC-Q. Almost all self-report measures were self-administered in paper-and-pencil format. The cognitive domain most often targeted was memory, followed by executive

Table 6
Overlap in use of cognitive self-report measures by Subjective Cognitive Decline Initiative (SCD-I) Working Group studies

Questionnaire abbreviation	SCD-I research study																		
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
ADL								X											
ADL Abbrev									X*										
AgeCoDe MQ	X																		
AIBL Screen					X														
Blessed												X							
BRIEF-A								X	X*										
CAPM-C									X*										
CCI								X*											
CDS-Q										X									
CERAD-Self									X										
CFQ																	X		
ECog Self			X					X*		X			X						
Einstein HSA									X										
GDS Long								X*											X
GDS Short				X					X										
IQCODE Short								X								X			
LEILA 75+ Questions												X							
MAC-Q (a)		X			X														X
MAC-Q (b)																X			
MATS								X											X
MFE-30													X						
MFQ										X							X		
MIA									X*										X
MMQ							X												
SCCS																	X		
SCD-SID																			X
SCD-Q: Part I MyCog						X													
SCF				X															
SCQ														X					
SMDS	X																		
Squire Memory Self-Rating								X											
STDA										X									
Sydney - SCQ Wave 1																X			
VMAC Cognitive Complaint Questionnaire																		X	

*Questionnaire administered to a subset of participants. Columns with gray shading indicate measures administered in a language other than English, as specified below. Columns with line shading indicate measures administered in English plus one or more additional languages, as specified below. Working group study numbers: (1) AgeCoDe Study (German); (2) Alzheimer’s Disease Center Clinical Core and Center for Brain Health; (3) Alzheimer’s Disease Neuroimaging Initiative (ADNI; English, German, French); (4) Amsterdam Dementia Cohort (Dutch); (5) Australian Imaging Biomarkers and Lifestyle Flagship Study of Ageing (AIBL); (6) Barcelona Group (Spanish); (7) Bonn Memory Clinic (German); (8) Dartmouth-Indiana Longitudinal Cohort; (9) Einstein Aging Study; (10) Harvard Aging Brain Study; (11) IMAP Caen Group (French); (12) Leipzig Longitudinal Study of the Aged (LEILA 75+) (German); (13) Mayo Clinic Study of Aging (MCSA); (14) Memory Clinic -Fundació ACE (Spanish); (15) PreAl Study (French); (16) Sydney Memory and Ageing Study; (17) University of Pittsburgh Study/ Monongahela-Youghiogheny Health Aging Team (MYHAT); (18) Vanderbilt Memory and Alzheimer’s Center (VMAC); (19) Victoria Subjective Cognitive Decline Study (SCDS).

function. Items related to memory for the names of people, remembering placement of common objects, and general memory problems occurred on the greatest percentage of measures. The vast majority of memory items tapped specific, rather than general, aspects of memory functioning.

Results highlight wide variation across studies ostensibly interested in the same construct and suggest that many factors may affect instrument choice beyond simple measurement of SCD. Most respondents indicated that measure selection decisions were based on accessibility and convenience of administration, as

Table 7
Ten most frequently occurring cognitive self-report items

Item theme and sample item stems	<i>n</i> (%) of total items	<i>n</i> (%) of measures that contain item
1. Memory change <i>How is your memory compared to the way it was 10 years ago?</i> <i>Do you feel you remember things less well than you did a year ago?</i>	36 (5.6%)	14 (41.2%)
2. Memory for names of people (longstanding and recently acquired names) <i>Do you find you forget people's names?</i> <i>How is your ability to remember the names of close friends and relatives?</i>	32 (5.0%)	19 (55.9%)
3. General memory problems <i>Have you noticed difficulty with your memory?</i> <i>Do you feel like your memory has become worse?</i>	30 (4.7%)	16 (47.1%)
4. Remembering where you put common objects/finding familiar objects <i>Do you feel you are forgetting where things were placed?</i> <i>Finding everyday objects? (e.g. keys, wallet)</i>	29 (4.5%)	19 (55.9%)
5. Word finding <i>I'm worse at finding the word I want to use in a conversation.</i> <i>Do you have more difficulty finding the right words (e.g. feeling like the word is on the tip of your tongue)?</i>	19 (3.0%)	15 (44.1%)
6. Remembering appointments <i>How is your ability to remember appointments correctly?</i> <i>When you actually forget in the following situations, how serious of a problem do you consider the memory problem to be?: appointments</i>	17 (2.7%)	15 (44.1%)
7. Remembering recent events <i>Do you have more trouble remembering things that have happened recently?</i> <i>I forget details of what I did or what happened the day before.</i>	16 (2.5%)	13 (38.2%)
8. Remembering recent conversations/things told to you <i>Do you have difficulty remembering a conversation from a few days ago?</i> <i>I forget things that I was told yesterday or a few days ago.</i>	15 (2.3%)	14 (41.2%)
9. Memory for intentions <i>Beginning to do something and forgetting what you were doing</i> <i>Remembering what you entered a room to do</i>	15 (2.3%)	12 (35.3%)
10. Remembering phone numbers (frequently used or just checked) <i>Trouble recalling frequently used phone numbers</i> <i>Having trouble remembering a telephone number you just looked up</i>	14 (2.2%)	8 (23.5%)

Table 8
Factors driving questionnaire selection decisions for existing measures (*n* = 10 SCD-I Working Group studies)

Reason	Number (%) of responses
Readily available	8 (19.5%)
Brief/convenient for administration (low participant or researcher burden)	8 (19.5%)
Routinely used in studies of cognitive impairment in aging	7 (17.1%)
Cost-effective (e.g., free/public domain)	5 (12.2%)
Already being used in existing on-site studies	4 (9.8%)
Useful in terms of tapping specific cognitive domains of interest relevant to SCD	4 (9.8%)
Robust in terms of psychometric properties (i.e., reliability and validity)	3 (7.3%)
Good for discriminating differing levels of cognitive impairment	1 (2.4%)
Other considerations	1 (2.4%)

well as the frequency of use in the cognitive aging literature. Given that several sites reported very large sample sizes (i.e., >3,000 individuals), these decisions are understandable. Being mindful of participant and researcher burdens, this suggests that extensive batteries that fully characterize SCD may not be tractable for many sites to administer.

Our examination of currently used instruments demonstrated wide variation in the format, range,

timeframe, and response options both within and across different measures. Items also varied as to whether they tapped ability/disability versus change or decline, with time referents for intraindividual change items ranging from the past 1, 2, 5, 10, or 20+ years to various other periods of life. Given that the subjective, first-person experience of SCD has been relatively understudied, such a broad swath of response options might increase the odds of successfully extracting the

unique ways that various subgroups of individuals with SCD conceptualize their concerns.

There are limitations to quantifying an inherently subjective phenomenon such as a complaint. First, asking about complaints in such a large number of ways, largely atheoretical with regards to SCD, raises concern that group differences may emerge from type I error (i.e., statistical bias) incidence rather than actual distinction. In addition, large variability in reference periods has been shown to result in differing question interpretation and subsequent reporting by respondents [79, 80]. With shorter reference periods (e.g., over the past 6 months), respondents tend to report specific minor issues like forgetting names, whereas longer reference periods (e.g., over the past 5 years) tend to tap global, non-specific problems such as general age-related cognitive decline. In general, attentiveness to reference periods seems advisable [81]. Moreover, Likert (and related) formats used by many measures assume an experience of SCD continuous with that of healthy older adults, distinguished only by degree of frequency or severity of complaint, which has not been established as factually evident. Indeed the perception of severity may well vary by demographic factors, such as education [82, 83] at the very least, so endorsement of the same items may mean different things to people of different experiential backgrounds. It is also noteworthy that a significant proportion of items (15%) were double-barreled, where participants could respond to either or both semantic referents, with no systematic way to address resultant ambiguity. This is particularly problematic when directly comparing self- and informant-responses to the same subjective report items, where double-barreled items make it impossible to determine which element(s) of an item stem a given respondent has addressed [84, 85].

A previous review of the SCD literature indicated that SCD has primarily been examined in longitudinal clinical research that follows individuals who decline to MCI and dementia over the course of the studies [86]. Retrospective examination of these cases determined that individuals often complained about declines in cognition many years before decline was detected on standardized clinical assessment—as long as 15 years before manifest cognitive impairment [86, 87]. Given that episodic memory is the cognitive domain most often impaired in MCI patients who subsequently progress to AD [30, 88], one would expect cognitive self-report measures to focus heavily on memory. This was borne out by our data, where well over half of all items and the most frequently occurring items

pertained to memory. However, these memory items are not necessarily the best items to include in SCD assessments. In fact, several population-based studies suggest that a large percentage of older adults will endorse some complaint about memory [24, 82], and it is questionable whether the most commonly occurring memory items have the requisite sensitivity and specificity to reliably identify individuals progressing toward MCI and dementia. A report from the Nurses' Health Study indicated that trouble following a group conversation or finding one's way around familiar streets were more highly associated with the risk of cognitive impairment than memory complaints such as forgetting things from one moment to the next [89]. Finding one's way in a familiar place might be classified as orientation or as spatial memory, a specific type of memory, and following a conversation might not be considered memory at all, but rather attention or executive function. Reisberg and colleagues specifically recommended use of the term *cognitive* rather than *memory* impairment precisely because the unique phenomenology of SCD is not fully understood and may not be limited to memory [86]. Thus, memory as typically conceived might not be the primary complaint of individuals with SCD due to preclinical AD, and items from other domains may prove to have better discriminant validity at this early stage of non-normative cognitive decline.

Considerations

The current study was intended to serve as a selective overview of the cognitive self-report measures used in studies performed by SCD-I Working Group members, whose primary focus is on preclinical AD. Thus, we were unable to include every extant self-report measure, and this may have biased results to some extent. However, we feel confident that we have captured many of the instruments used to assess cognitive complaints in large aging cohort studies around the globe. In light of our findings, we provide several considerations for the measurement of SCD going forward:

First, the heterogeneity of measures used suggests the exercise of great caution in comparing findings across studies. This does not mean that every site investigating SCD should or could use exactly the same self-assessment battery. Research environment, for example, is an important consideration in selecting measures, as complaints likely mean something different in a population/volunteer sample as compared to a clinical sample. One might assume that individuals

recruited from a clinic have specific concern or worry about their cognitive function, which is different from the report of complaints *per se*. While the literature tends to conflate complaints and concern, recent studies suggest that specific concern or worry about cognitive function has predictive value over and above complaints [21, 47].

Second, researchers might consider approaches from measurement science to inform proper selection of instruments to characterize SCD. Such approaches could be used to investigate the psychometric properties of existing measures, refine or shorten scales (by eliminating less informative items), or optimize measures for specific subgroups of the population of interest (e.g., a brief screen for SCD in a volunteer sample of highly educated older adults). Another application is computer adaptive testing, whereby participants are administered a set of self-report items tailored to their unique cognitive complaint profile estimated from previous item responses, resulting in use of the least number of items to estimate a person's underlying subjective cognitive ability [90]. To our knowledge, computer algorithms to identify specific items to administer are not currently used. At a basic level it is necessary to investigate psychometric properties such as internal consistency, test-retest reliability, and content validity, as many of the instruments we reviewed were recently developed or not formally validated.

Third, more sophisticated and nuanced analytic approaches should be applied to the datasets on older adults available worldwide. At a minimum, this might include specificity and sensitivity analyses to derive items, for example, which discriminate SCD due to preclinical AD from healthy controls. Identifying items not only with sensitivity but also specificity for SCD is particularly salient in light of discussions about overdiagnosis and the potential to trigger a health crisis in the worried well if researchers over-screen for cognitive complaints [91].

Fourth, future research on SCD should include items related to mood, personality, and health. While the current study focused exclusively on cognitive self-report items, there is likely to be unique variance in perceived cognitive function explained by factors such as mood, personality, and health [69, 92–95]. Therefore, research on the predictive validity of self-report items should include non-cognitive measures to explain as much variance in the experience of SCD as possible. Additionally, we chose not to examine informant-report or clinician rating scales such as the Brief Cognitive Rating Scale, which incorporates

various sources of information including self report of memory, objective observation of cognitive deficit on clinical interview, and assessment of functional ability [41]. These methods warrant investigation alongside self-report measures. Informant report, for example, may prove vital, not only in its own right, but also with respect to how it converges or diverges with self-report at different points along the spectrum of pathologic cognitive decline [96].

Fifth, the meaning of complaints tends to vary as a function of demographic characteristics such as level of education and age. Two previous studies [82, 83], for example, found that cognitive complaints in highly educated participants were associated with increased risk of decline to AD. In fact, self-report measures may provide the optimal approach for measuring and monitoring high-functioning individuals in the earliest stages of neurodegenerative cognitive decline, since these individuals may perform at ceiling level on neuropsychological tests [93]. Age of participants also may impact the meaning of complaints, with research suggesting that memory concerns in the young-old associate with anxiety, depression, or personality variables, while memory complaints expressed by older individuals may reflect actual impairment or decline [82]. Cross-site collaboration may be fruitful to the extent that sites share a common setting and common participant demographics. However, any sensitivity and specificity analyses may need to be conducted within the context of local norms for response frequency.

Finally, as noted by Reisberg and colleagues [86], the first-person experience of SCD remains largely unknown. While one might assume that SCD varies from MCI and AD only by degree, it may manifest as a phenomenologically distinct entity. This is likely to be true at least to the extent that individuals with SCD are assumed to have preserved awareness of their difficulties when compared to individuals further along the spectrum of pathologic cognitive decline. Likewise, the first-person experience of SCD due to mood or health complaints may differ from the preclinical AD form of SCD. Aside from the psychometric strategies already discussed, another approach to characterizing SCD could involve gathering qualitative data from persons classified as SCD to reveal their first-person experience, including the frequency and types of complaints most salient to them. This approach would be sensitive to possible cultural differences in the expression of SCD and allow researchers to develop measures specific to their sample demographic characteristics.

Conclusions and recommendations

SCD is rapidly becoming a topic of major interest in cognitive aging and dementia. The current study is the first of its kind, involving an in-depth review of self-report measures currently employed by 19 international sites focused on the study of SCD. Overall, our findings serve as a call for international collaboration to promote harmonization and pooling of cognitive self-report data and greater consistency in the measurement of SCD. The majority of instruments we reviewed were developed within the past 10 years, in some cases within the context of a specific research study, and have limited psychometric evidence. However, validation is an ongoing process, and psychometric data are hopefully forthcoming. With these caveats in mind, we offer the following recommendations:

A. Select measures with appropriate demographic characterization:

- Ensure that your target population corresponds to the population for which the questionnaire was developed, understanding that response patterns may vary as a function of demography (e.g., general population versus clinic-based, young-old versus old-old participants). A good selection criterion is involvement of the target population in the questionnaire development process.

B. Select measures with adequate content coverage for the target population:

- Ensure that item stems are simple and easy to understand. Questionnaires should not contain double-barreled items, which are known to confuse respondents and undermine the accuracy of responses [84, 97].
- Combining multiple constructs within a single measure (e.g., items related to cognition in addition to aspects of mood, personality, or health status) may pose problems for calculating and interpreting scores and is generally not recommended.
- Inquire about cognitive issues that older adults encounter frequently in their daily lives. For example, while older adults routinely face the task of recalling a loved one's name, some have never attempted to handle financial affairs and may rely on ideas about related skills they do possess, such as basic mathematics [117]. An optimal approach may involve tailoring questions to individuals based on knowledge about their particular experiences or medical history [117].

- Sample cognitive domains beyond episodic memory because items that tap into other aspects of memory, or other domains, might be more pathognomonic of non-normative decline at the early AD stages.
- Utilize measures that contain a greater number of specific rather than general cognitive items. Specific items prompt older adults to search for explicit instances in which they experience memory problems in their daily lives, which leads to more accurate reporting. Broadly worded items, by contrast, may cause older adults to fall back upon global beliefs about their abilities and the cognitive aging process more generally [84, 117].
- Ensure that response options correspond to the measurement purpose. When the primary purpose is to distinguish between groups, a dichotomous scale might be sufficient. For the measurement of change over time, a Likert scale might represent a better choice. Notably, to the extent that SCD implies a perceived decline, measures should include some items targeting cognitive change. Another consideration is whether response options should target the frequency of problems (*how often*) versus quality of performance (*how well*). To address frequency, it is essential to utilize manageable timeframes (e.g., number of times the individual misplaced car keys over the past week as opposed to the past year). To assess quality of performance, one should keep in mind that individuals will provide responses based on aggregated experience rather than specific problematic instances [117].
- Ensure that the reference period is specific, appropriate, and narrow. Inquiring about experiences over the past month, week, or even several days is preferable to longer timeframes because these windows enable older adults to focus on concrete recent events rather than rely on beliefs about "typical" performance or the cognitive aging process as a whole [117, 118]. Commonly used longer timeframes (e.g., >1 year, 5 years) may seem face valid but could pose difficulties for older adults trying to recall specific recent events. Vague reference periods should never be used.

C. Consider issues of psychometric adequacy:

- Select questionnaires that have been published, and for which there is at least some evidence for adequate reliability, construct validity, test-retest reliability, and differences between subgroups of interest.

- Validate measures in the population of interest. For example, some instruments might have self and informant versions but have only been validated for one or the other population. One cannot assume that validity will generalize across populations, particularly as individuals and their informants contribute unique sources of variance to estimates of current cognitive function.
- Consider whether items appropriately measure the cognitive domains of interest. This is especially important in cross-cultural collaborative research, where cognitive complaints might not mean the same thing in Western versus non-Western settings. Western conceptualizations of executive function, for example, often include time pressure/cognitive efficiency, which may not generalize. For questionnaires adapted for use in a different culture, language, or country, two types of validation must occur: linguistic validation (established equivalence of language) and cultural validation (item revision based on cultural appropriateness of wording and potential misinterpretation due to differences in ways of thinking about cognition) [98].

D. Develop new measures:

- There is a need to derive a small number of well-constructed, easy-to-administer items with adequate reliability across diverse samples of older adults. Ideally, these items should discriminate subgroups of SCD, for example those with SCD due to preclinical AD from healthy older adults (concurrent validity), as well as indicate who of the SCD group is likely to decline to MCI and AD (predictive validity). A multi-method approach to assessment incorporating objective cognitive and biomarker measures might help establish the validity of self-report items.

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