Supplementary Table 1

Symptoms and functional status impacted by Sjögren's syndrome.

Symptoms	Measures	Number of measures	References
Symptom burden			
	Glandular		
Sicca symptoms	Sicca Symptoms Inventory (SSI)	4	1–12
	Liverpool Sicca Inventory		1
	EULAR Sicca Scale (ESS)		13–18
	Sicca symptoms Visual Analog Scale (VAS)		19–23
General dryness	Global dryness VAS	7	5,24–31
	Oral dryness VAS		23,24,28,32–46
	Ocular dryness VAS		23,24,28,33–44,46–51
	Tracheal dryness VAS		28,35,46
	Skin dryness VAS		24,28,35,46,52
	Vaginal dryness VAS		24,28,35,46
	Numeric Analog Scale		53
Oral symptoms	Oral dryness VAS	24	23,24,28,32–46
	Mouth discomfort VAS		37,45
	Salivary gland swelling VAS		42
	Difficulty swallowing VAS		54
	Oral Health Impact Profile (OHIP-49)		2,55–57
	Oral Health Impact Profile (OHIP-14)		1,58–61
	Oral symptoms questionnaire		62
	General Oral Health Assessment Index (GOHAI)		44,63
	Xerostomia Inventory (XI)		1,2,36,44,63–66
	Xerostomia Numeric Rating Scale (NRS-11)		67
	Xerostomia VAS		54,68,69
	Smell/taste threshold test		70

Symptoms	Measures	Number of measures	References
Oral symptoms (cont.)	7-item VAS questionnaire with questions about dry mouth, and effect on chewing, swallowing, taste, speech, burning sensation, and denture retention		71
	Questionnaire about patient's perception of dry mouth and swallowing ability		72
	Oral dryness VAS including desire to sip water when eating a meal, difficulty speaking, difficulty chewing, tasting, and swallowing food		73
	Degree of xerostomia VAS including subjective complaints of dry mouth, burning tongue, painful oral mucosa, diminished taste, difficulty in mastication/swallowing, need to sip liquids to aid swallowing, difficulty in speaking, dryness at night or awakening, frequent need to moisten oral mucosa		73,74
	Dry mouth VAS including domains of mouth dryness, discomfort of the mouth, ability to sleep, ability to speak without drinking liquids, ability to chew and swallow food, ability to wear dentures		45
	Symptom questions relating to nocturnal dryness, sinus and ocular discomfort, cough, and throat-clearing frequency		64
	VAS measuring degree of xerostomia and associated subjective complaints of dry mouth, burning oral mucosa, difficulty in mastication, need to sip liquids to aid swallowing and frequent need to moisten oral mucosa		34
	Voice Handicap Index		75
	Voice-Related Quality of Life (V-RQOL)		12
	Dysphonia VAS		75
	Speech clarity VAS		75
	Reflux Symptom Index (RSI)		76
Ocular symptoms	Ocular dryness VAS	11	23,24,28,33,35–44,46–51
	Ocular discomfort VAS		77
	Feeling of sand/gravel in eyes VAS		50
	Ocular symptoms		78
	Ocular Surface Disease Index (OSDI)		1,2,44,55,63,66,77,79,80, 81–83

Symptoms	Measures	Number of measures	References
Ocular symptoms (cont.)	Dry eye questionnaire		62
	Dry eyes Numeric Rating Scale (NRS-11)		67
	Xerophthalmia VAS		54,69
	Xerophthalmia Severity Score		66
	Ocular discomfort severity and frequency questionnaire		82
	National Eye Institute Visual Function Questionnaire (NEI VFQ-25)		1,2,82
	Extraglandular		
Fatigue	Fatigue VAS	14	2,5,17,19–21,24–31,33,35,36,38,43,46,51,54,84–94
	Multidimensional Fatigue Inventory (MFI)		22,39,50,85,89,95–100
	Profile of Fatigue (ProF)		14,15,17,91–93,95,101–110
	Profile of Fatigue and Discomfort (PROFAD)		1,2,4,7–11,19,33,53,84,89,106–110
	Fatigue Severity Scale (FSS)		1,2,38,40,41,87,89–91,94,105,111
	Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)		1,2,18,38,78,84,89,108,109,112–115
	SF-36 vitality		38
	ESSPRI fatigue domain		65,66
	Multidimensional Assessment of Fatigue (MAF)		46
	Fatigue Impact Scale (FSI)		2,16,89
	Chalder Fatigue Scale (CFS)		1
	Piper Fatigue Scale (PFS)		1,89
	Fatigue Assessment Instrument (FAI)		1
	Numeric Analog Scale		53

Symptoms	Measures	Number of measures	References
Pain	Pain VAS	14	3,5,20,26–30,37,39,50, 85,86,88,91,102,116
	Arthralgia VAS		36,51,54,117
	Myalgia VAS		36,54
	Limb pain VAS		24
	Musculoskeletal pain VAS		25,41
	Eyeball pain VAS		40
	Parotid pain VAS		23
	Neuropathic Pain Questionnaire (NPQ)		41
	Pain catastrophizing scale (PCS)		111
	Pain Anxiety Symptoms Scale (PASS)		111
	Short-Form McGill Pain Questionnaire		105
	Brief Pain Inventory (BPI)		108,111
	Fibromyalgia Impact Questionnaire (FIQ)		41,88
	Numeric Analog Scale		53
Depression	Depression VAS	8	36
	Hospital Anxiety and Depression Scale (HADS)		14,15,17,18,29,41,53,78, 93,98,102,104,111,118, 119,120
	Center for Epidemiological Studies Depression Scale (CES-D)		91,105,108,109,121
	Zung Self-rating Depression Score (ZSDS)		39,50,88,96,115
	Beck Depression Inventory (BDI)		40,87,90,94,106,122
	Hamilton Rating Scale for Depression (HRSD)		120
	Patient Health Questionnaire (PHQ-9)		110
	Self-rating Depression Scale (SDS)		117
Anxiety	Anxiety VAS	5	36,40
	Hospital Anxiety and Depression Scale (HADS)		15,17,18,29,41,53,78,93, 98,102,111, 118–120

	Zung Self-rating Anxiety Scale (ZSAS)		88
	Hamilton Anxiety Scale (HAMA)		120
	State-Trait Anxiety Inventory		115
Sleep	Epworth Sleepiness Scale (ESS)	7	14,15,64,102
	Pittsburg Sleep Quality Index (PSQI)		40,41
	Insomnia Severity Index (ISI)		40]
	Athens Insomnia Score		115]
	Sleep VAS		45,86]
	Lund University Sleep Questionnaire		17]
	Restless legs syndrome (RLS) diagnostic criteria		17]
Sexual function	Female Sexual Function Index (FSFI)	4	98,119,122]
	Female Sexual Distress Scale (FSDS)		98]
	Physical Disability Sexual and Body Esteem scale (PDSBE)		78]
	Modified Hill questionnaire		[78]
Emotional function	Stress VAS	6	[41]
	Berkeley Expressivity Questionnaire (BEQ)		[123]
	Toronto Alexithymia Scale-20 (TAS-20)		[123]
	Emotion Regulation Questionnaire (ERQ)		[123]
	Defense Style Questionnaire (DSQ)		[124]
	Hostility and Direction Hostility Questionnaire (HDHQ)		[124]
Cognitive performance	Digit – Symbol Substitution Test (DSST) (attention, perceptual speed, motor speed, visual scanning, and memory)	5	[121]
	Cambridge Neuropsychological Test Automated Battery (CANTAB) (attention, vigilance, executive function and memory)		[121]
	North American Adult Reading Test (NAART) (verbal IQ)		[121]
	Cognitive Emotion Regulation Questionnaire-short (CERQ-short)		[123]
	Thinking scale		[108]
Discomfort	Profile of Discomfort (ProD)	1	[101]
Impact of symptoms	Symptom Distress Checklist (SCL-90-R)	1	[35,124]

Learned helplessness	Rheumatology Attitude Index (RAI)	1	[91]
Physical activity	International Physical Activity Questionnaire-short form (IPAQ-short)	2	[100,112]
	Tampa scale of kinesiophobia (TSK)		[100,123]
Personality	NEO Personality Inventory-Revised (NEO-PI-R)	2	[125]
	Eysenck Personality Questionnaire Scale		[115]
Relationship status	Maudsley Marital Questionnaire (MMQ)	1	[98]
Autonomic function	Orthostatic Grading Scale (OGS)	3	[14,102]
	Composite Autonomic Symptom Scale (COMPASS)		[15,112]
	Autonomic Symptom Profile (ASP)		[104,126]
Headaches	International Classification of Headache Disorders (ICHD-II)	3	[94,127]
	Headache Impact Test-6 (HIT-6)		[127]
	Migraine Disability Assessment (MIDAS)		[127]
Gastrointestinal (GI) disease	Rome III diagnostic questionnaire for the adult functional GI disorders and Scoring Algorithm	1	[128]
Lung involvement	High-resolution CT (HRCT) and/or pulmonary function tests (PFTs)	1	[129]
Functional status			
Quality of life	Short Form 36 (SF-36)	11	[2,5,10,12,22,24,26–28,31–33,35,36,38,39,43,46,47,51,53,57,58,60,61,63,78,84,89,92,93,96,97,99,106–109,113,114,119,121,129–133]
	RAND-36		[98,99]
	SF-12		[70]
	SF-12v2		[41]
	EQ-5D		[2,13–16,33,40,65,66,102]

	World Health Organization Quality of Life Assessment - Abbreviated Version (WHOQOL-BREF)		[2,107,114,124,131]
	Health Assessment Questionnaire (HAQ)		[3,51,78,88]
	Xerostomia-related quality of life scale		[1]
	Illness Perceptions Questionnaire - revised (IPQ-R)		[111]
	General health VAS		[84]
	Global health VAS		[30,33,37,85,86,116]
Functional status	Hannover Functional Questionnaire (HFQ)	3	[110]
	Global Assessment of Functioning (GAF) Scale		[121]
	Health Assessment Questionnaire (HAQ)		[86,102,116]
Employment	Gainful employment	4	[110]
	Employment rate		[114]
	Disability compensation		[133]
	Employment and disability questionnaire		[133]
Utility	EQ-5D	1	[2,13–16,33,40,65,66,102]

EULAR = European League Against Rheumatism.

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