

Supplementary data

DT Eton et al.

A Systematic Review of Patient-Related Measures of Burden of Treatment in Three Chronic Diseases

Literature search strategies

Supplementary table 1. Scale characteristics

Supplementary table 2. Scale reliability and analyses

Supplementary table 3. Scale validity and sensitivity to change

Literature search strategies

(Note: Searches were re-run and results updated in November, 2011)

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1950 to Present

Searches Results

- 1 exp *diabetes mellitus/bl, di, px, dh, dt, th, pc, ec, co or *blood glucose self-monitoring/ or exp *hypoglycemic agents/ad, ae, tu 96126
- 2 exp *heart failure/px, di, dt, dh, th, rh, pc, ec, co 24727
- 3 exp *kidney failure, chronic/bl, ci, co, dt, di, ec, dh, eh, px, th, rh 28173
- 4 exp *renal replacement therapy/ae, co, ec, px 19169
- 5 or/1-4 164287
- 6 (questionnaire* or tool*1 or scale* or instrument* or measur* or survey* or assess* or estimat* or evaluat* or rate or rating).mp. and 5 [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 67837
- 7 5 and ((observation* or (cross adj section*) or cohort*).mp. or randomized controlled trial.pt.) [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 22155
- 8 5 and exp cohort studies/ 14836
- 9 6 or 7 or 8 76519
- 10 (complex* adj2 (regimen* or intervention*)).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 1330
- 11 9 and 10 78
- 12 drug administration schedule/ or medication adherence/ 71074
- 13 9 and (*guideline adherence/ or 12) 1881
- 14 *lifestyle/ or *activities of daily living/ or *absenteeism/ or *quality of life/ or *patient compliance/ or *treatment refusal/ or *self care/ or *self administration/ 84114
- 15 *patient participation/ or patient education as topic/ or disrupt*.mp. or barrier*.mp. or nonadher*.mp. or noncompliant*.mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 311845
- 16 ((treat* or therap* or patient*) adj (time* or burden* or workload*)).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 7317
- 17 9 and 16 122
- 18 9 and (14 or 15) 5949
- 19 18 and (burden* or workload*).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 223
- 20 9 and (patient* adj2 perception*).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 188
- 21 office visits/ or "appointments and scheduling"/ or empower*.mp. or "out of pocket".mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 13684
- 22 9 and 21 253
- 23 9 and (*transportation/ or driving.mp. or distance*.mp. or *educational status/ or health literacy/) [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 536
- 24 9 and (rural and urban).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 150
- 25 9 and (social support/ or life change events/ or demands.mp.) [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 736
- 26 9 and (*income/ or *costs of illness/ or *fear/ or *pain/ or *poverty/ or skipped.mp. or *exercise/ or *health care costs/) [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 1065
- 27 exp *Prescriptions/ 11260
- 28 9 and 27 79
- 29 17 or 19 or 20 or 22 or 23 or 24 or 25 or 26 or 28 3179
- 30 9 and (*drug administration schedule/ or *medication adherence/ or *guideline adherence/) 228
- 31 29 or 30 3393
- 32 limit 31 to (english language and humans) 3072

33 (questionnaire* or tool*1 or scale* or instrument* or measur* or survey* or assess* or estimat* or evaluat*).mp. and 5 [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier] 60125

34 (33 or 7 or 8) and 32 2981

35 34 not (letter or news or editorial).pt. 2943

EMBASE 1988 to 2010 Week 06

Searches Results

1 exp *diabetes mellitus/ 134884

2 *chronic kidney disease/ 5265

3 *blood glucose monitoring/ 1402

4 exp *antidiabetic agent/ae, ad, do, it, dt, to [Adverse Drug Reaction, Drug Administration, Drug Dose, Drug Interaction, Drug Therapy, Drug Toxicity] 25649

5 exp *heart failure/ 55150

6 *hemodialysis/ 19518

7 *hemodialysis patient/ 1808

8 or/1-7 223669

9 *patient satisfaction/ or exp *quality of life/ 21734

10 exp patient compliance/ or exp patient attitude/ 110057

11 ((patient* or treatment* or therap*) adj2 (time or burden* or workload*)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] 32744

12 8 and (9 or 10 or 11) 6761

13 limit 12 to (human and english language) 5865

14 (questionnaire* or survey* or instrument* or scale* or tool* or measur* or assess* or evaluat* or interview*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] 3572368

15 13 and 14 3926

16 11 and 15 723

17 9 and 10 and 15 153

18 16 or 17 872

19 ((complicat* or complex*) adj2 regimen*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] 646

20 15 and 19 16

21 (qualitative analysis/ or semi-structured interview/) and 15 73

22 18 or 20 or 21 950

23 22 not case report/ 936

24 ((low or poor) adj2 adheren*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] 1394

25 15 and 24 53

26 23 or 25 984

27 ((complex* or complicat*) adj2 (regimen* or treatment* or therap*)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] 15263

28 15 and 27 34

29 15 and (attitude* or instrus* or disrupt*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] 705

30 26 or 28 or 29 1594

31 ((questionnaire* or survey* or instrument* or scale* or tool* or measur* or assess* or evaluat* or interview*).mp. or rating scale/) and 30 [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] 1594

32 ../ 31 lg=en and hu=y 1594

33 32 not case report/ 1588

34 clinical study/ or exp case control study/ or exp case study/ or exp intervention study/ or exp major clinical study/ or exp prospective study/ or exp retrospective study/ 1270242

35 33 and 34 878

36 33 and (cross-section* or observation* or cohort* or survey*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] 460
37 35 or 36 1027

PsyclINFO 1967 to February Week 3 2010

Searches Results

1 Diabetes/ or exp Diabetes Mellitus/ 6609

2 exp Kidney Diseases/ or exp Hemodialysis/ or exp Dialysis/ 1683

3 exp Heart Disorders/ 7156

4 *Diabetes/ or exp *Diabetes Mellitus/ or (exp *Kidney Diseases/ or exp *Hemodialysis/ or exp *Dialysis/) or exp *Heart Disorders/ 13237

5 exp Client Attitudes/ or exp Treatment Compliance/ or exp Compliance/ or exp Self Management/ or exp Psychosocial Factors/ 47495

6 exp Client Satisfaction/ 2953

7 5 or 6 47495

8 4 and 7 1970

9 ((patient* or therap* or treatment* or management*) adj2 (burden* or workload*)).mp. [mp=title, abstract, heading word, table of contents, key concepts] 481

10 4 and 9 11

11 limit 8 to ("0400 empirical study" or "0451 prospective study" or "0452 retrospective study" or "0800 literature review" or "0830 systematic review" or 1200 meta analysis or 1600 qualitative study or 1800 quantitative study or "2000 treatment outcome/randomized clinical trial") 1564

12 limit 11 to (all journals and human and english language) 1134

13 quality of life/ or cost*.mp. or travel*.mp. or distance*.mp. or skipped.mp. or nonadher*.mp. [mp=title, abstract, heading word, table of contents, key concepts] 92760

14 12 and 13 150

15 10 or 12 or 14 1143

16 (questionnaire* or survey* or instrument* or interview* or assess* or tool*1 or examin* or rating* or evaluat*).mp. [mp=title, abstract, heading word, table of contents, key concepts] 1169427

17 15 and 16 902

18 14 and psychometr*.mp. [mp=title, abstract, heading word, table of contents, key concepts] 2

19 17 or 18 902

CINAHL

Select / deselect all Search ID# Search Terms Search Options Actions

S18 S13 or S17 Search modes - Boolean/Phrase View Results (85)

S17 S5 and S12 and S16 Search modes - Boolean/Phrase View Results (77)

S16 (MH "Attitude to Health+") Search modes - Boolean/Phrase View Results (47163)

S15 MM "heart failure, congestive Psychosocial" Search modes - Boolean/Phrase View

S14 MM "Heart Failure, Congestive Economics" Search modes - Boolean/Phrase View Results (58)

S13 S11 and S12 Search modes - Boolean/Phrase View Results (50)

S12 (MH "Research Measurement+") Limiters - English Language; Peer Reviewed; Research Article; Exclude MEDLINE records

S11 S5 and S9 Limiters - English Language; Peer Reviewed; Research Article; Exclude MEDLINE records

Search modes - Boolean/Phrase View Results (112)

S10 S5 and S9 Search modes - Boolean/Phrase View Results (1443)

S9 S6 or S7 or S8 Search modes - Boolean/Phrase View Results (31033)

S8 "burden*" Search modes - Boolean/Phrase View Results (14045)

S7 (MH "Treatment Refusal") Search modes - Boolean/Phrase View Results (2520)

S6 (MH "Patient Compliance+") or (MH "Medication Compliance") Search modes - Boolean/Phrase View Results (14920)

S5 S1 or S2 or S3 or S4 Search modes - Boolean/Phrase View Results (28981)

S4 (MM "Heart Failure, Congestive+") Search modes - Boolean/Phrase View Results (9066)

S3 (MM "Dialysis Patients") Search modes - Boolean/Phrase View Results (1325)

S2 (MH "Kidney Failure, Chronic") Search modes - Boolean/Phrase View Results (6303)
Database - CINAHL

S1 (MM "Diabetic Patients") or (MM "Diabetes Mellitus") Search modes - Boolean/Phrase View
Results (13124)

Supplementary table 1. Scale characteristics

Diabetes Measures							
Instrument	Relevant subscales (no. of items)	Study	Baseline N	Mean age	Gender (female)	Disease focus	Patient input in item generation?
Barriers to Adherence Questionnaire	Diet (4) Insulin injection (3) Exercise (3) Glucose testing (5) Total score (15)	Glasgow, 1986 ¹	65	32	58%	T1 & T2 Diabetes	Yes
		Khattab, 2010 ²	917	57.4	50%		
Barriers to Diabetes Adherence: BDA	Stress and burnout (4) Time pressure and planning (5) Stigma (6)	Mulvaney, 2011 ³	123	15.0	48%	T1 Diabetes	Yes
Barriers in Diabetes Questionnaire: BDQ	Self-control & advice from providers (subscale I) (9) Injecting, monitoring, & overall self-regulation (subscale II) (10) Self-regulation in specific situations (subscale III) (9) Total score (28)	Mollem, 1996 ⁴	240	47	53%	T1 & T2 Diabetes (insulin treated)	Unclear
Blood glucose monitoring system rating questionnaire: BGMSRQ Insulin delivery system rating questionnaire: IDSRQ	Convenience (NR) Interference (NR) BG Burden (NR) Convenience (NR) Interference (NR) BG Burden (NR) ^a	Peyrot, 2005 ⁵	197	46.4	53%	T1 & T2 Diabetes	BGMSRQ: Unclear IDSRQ: Yes
		Peyrot, 2009 ⁶	28	47.2	54%		
		Rubin, 2009 ⁷	311	43 (median)	63%		
Continuous Glucose Monitoring	Hassles (20)	DirecNet Study Group, 2005 ⁸	66	12.3	45%	T1 Diabetes with CGM	No

Satisfaction Scale: CGM-SAT		JDRF CGM Study Group, 2010 ⁹	447	NR	NR		
Glucose Monitoring Survey: GMS	Glucose control (7) Social complications (6) Total score (22) (note, 9 items do not load on either subscale)	Tansey, 2011 ¹⁰	432	NR	55%		
Diabetes-39	Diabetes control (12)	Boyer, 1997 (study 1) ¹¹	516	52.4	55%	T1 & T2 Diabetes	Yes
		Boyer, 1997 (study 2) ¹¹	Sample 1 165 Sample 2 262	Sample 1 61.7 Sample 2 55.3	Sample 1 55% Sample 2 65%		
		Khader, 2008 ¹²	368	56.6	56%		
Diabetes Distress Scale: DDS	Emotional burden (5) Regimen related distress (5)	Polonsky, 2005 ¹³	683	56.3	48%	T1 & T2 Diabetes	Yes
		Trief, 2007 ¹⁴	1356	NR	NR		
		Halford, 2010 ¹⁵	54	44.8	52%		
		Peyrot, 2010 ¹⁶	112	54.5	37%		
DDS-2, DDS-3, & DDS-4	Total scores for entire scales (2-, 3-, and 4- items, respectively)	Fisher, 2008 ¹⁷	496	57.8	57%	T2 Diabetes	Yes
Diabetes Family Adherence Measure: D-FAM	Coercion (7)	Lewin, 2010 ¹⁸	165	13.5	59%	T1 Diabetes	No
Diabetes Family Behavior Checklist: DFBC	Non-supportive behaviors (7)	Schafer, 1986 ¹⁹	Adults 54 Youths 18	Adults 35.6 Youths 14.3	Adults 57% Youths 56%	T1 Diabetes	Yes

		Ott, 2000 ²⁰	143	14	56%		
Diabetes Family Conflict Scale-revised: DFCS	Direct management (9) Indirect management (10) Total score (19)	Hood, 2007 ²¹	202	13.3	54%	T1 Diabetes	Yes
		de Wit, 2008 ²²	91	14.8	47%		
		Anderson, 2009 ²³	121	NR	50%		
		Muller-Godeffoy, 2009 ²⁴	117	10.5	45%		
		de Wit, 2010 ²⁵	81	15.8	49%		
		Sander, 2010 ²⁶	276	15.6	48%		
Diabetes Family Support & Conflict Scale: DFSC	Family conflict (4)	Paddison, 2010 ²⁷	629	63	47%	T2 Diabetes	Yes
Diabetes Fear of Injecting and Self-testing Questionnaire: D-FISQ	Fear of self-injecting (15) Fear of self-testing (15) Total score (30) ^b	Snoek, 1997 ²⁸	266	54.3	50%	T1 & T2 Diabetes	No
		Mollema, 2000 ²⁹	Sample 1 252 Sample 2 24	Sample 1 47.9 Sample 2 44.5	Sample 1 51% Sample 2 71%		
		Simmons, 2007 ³⁰	113	12.9	57%		
Diabetes Health Profile: DHP	Barriers to activity (NR)	Meadows, 1996 (study 1) ³¹	25	NR	NR	T1 & T2 Diabetes	Yes
		Meadows, 1996 (study 2) ³¹	239	40.9	NR		
		Meadows, 1996 (study 3) ³¹	2239	40.0	49%		
		Meadows, 1996 (study 4) ³¹	233	51.5	48%		

		George, 2008 ³²	114	41	55%		
		Cleveringa, 2010 ³³	1060	64.5	49%		
		Gorter, 2011 ³⁴	994	65.1	46%		
Diabetes Medication Satisfaction Measure: DiabMedSat	Burden (11) Symptoms (5)	Brod, 2006 ³⁵	409	56.0	50%	T1 & T2 Diabetes	Yes
		Brod, 2009 ³⁶	18,817	57.6	44%		
		Brod, 2010 ³⁷	17,488	57.2	43%		
		Williams, 2011 ³⁸	2074	60.1	NR		
Diabetes Medication Treatment Satisfaction Tool: DMSAT	Lifestyle (5) Convenience (3) Well-being (3)	Anderson, 2009 ³⁹	149	63	NR	Diabetes (type un-specified)	Yes
Diabetes-specific Quality of Life Scale: DSQOLS	Diet restrictions (9) Daily hassles (6)	Bott, 1998 ⁴⁰	657	36	42%	T1 Diabetes	Yes
		Bott, 2003 ⁴¹	424	36.9 (median)	46%		
		Nicolucci, 2008 ⁴²	1341	35	50%		
Diabetes Responsibility and Conflict Scale: DRCS	Conflict (NR)	Harris, 1999 ⁴³	119	14.3	57%	T1 Diabetes	Unclear
Diabetes Self-Care Barriers Assessment for Older Adults: DSCB-OA	Blood glucose monitoring barriers (4) Diet regimen barriers (4) Exercise barriers (4) Total score (12)	Tu, 1993 ⁴⁴	82	68	67%	T2 Diabetes	Yes
		Schoenberg, 2001 ⁴⁵	51	74	100%		
Diabetic Foot Ulcer	Treatment (ulcer care) (4)	Abetz, 2002	173	59	30%	T1 & T2	Yes

Scale: DFS	Financial (2)	(study 1) ⁴⁶ Abetz, 2002 (study 2) ⁴⁶ Bann, 2003 (study 1) ⁴⁷ Bann, 2003 (study 2) ⁴⁷	288 288 347	NR 27-87 (range) 29-88 (range)	NR 26% 29%	Diabetes	
DISABKIDS Diabetes module	Impact / acceptance (6) Treatment (4)	Baars, 2005 ⁴⁸ Chaplin, 2009 ⁴⁹	Pilot 59 Field Test 207 361	NR 13.3	NR 50%	T1 Diabetes	Yes
General Barriers to Diabetes Self- Management Dietary Barriers	Diet (7) Exercise (7) Glucose testing (7) Medication taking (7) General barriers (4) Total score (31) At home (7) Food purchasing (8) Away from home (5) Total score (27)	Glasgow, 1997 ⁵⁰ Wen, 2004 ⁵¹	2056 138	59 64.1	62% 67%	T1 & T2 Diabetes	Yes
Insulin Pen Questionnaire	Convenience (7) Facilitation of self-care (6) Cost (1)	Peyrot, 2011 ⁵²	549	59.1	NR	T2 Diabetes (insulin pen treated)	Yes
Insulin Treatment Appraisal Scale: ITAS	Negative appraisal (16)	Snoek, 2007 ⁵³	282	59	54%	T2 Diabetes	Yes
Insulin Treatment Questionnaire: ITQ	Perceptions of Insulin Therapy (12)	Peyrot, 2010 ⁵⁴	119	54.9	33%	T2 Diabetes (insulin)	No

						treated)	
Insulin Treatment Satisfaction Questionnaire: ITSQ	Inconvenience of regimen (5) Lifestyle flexibility (3) Delivery device satisfaction (6) ^c	Anderson, 2004 ⁵⁵ Bode, 2004 ⁵⁶ Brod, 2007(a) ⁵⁷ Brod, 2007(b) ⁵⁸ Farmer, 2011 ⁵⁹	Sample 1 170 Sample 2 402 125 298 197 554	Sample 1 48.7 Sample 2 55.6 41.2 40.5 52.2 61.5	Sample 1 63% Sample 2 43% 58% 45% 47% 35%	T1 & T2 Diabetes	Yes
Measure of Invasiveness as a Reason for Skipping Self-Monitoring of Glucose: MISS	Total score (7)	Wagner, 2005 ⁶⁰	339	54	66%	T1 & T2 Diabetes	Unclear
Multidimensional Diabetes Questionnaire: MDQ	Misguided support behaviors (4)	Talbot, 1997 ⁶¹	249	54.9	45%	T2 Diabetes	Yes
Multidimensional Diabetes Self-Management Checklist: MDSC	Burden of dietary self-management (3) Burden of injecting insulin (3) Burden of blood glucose monitoring (3) Burden of adjusting insulin dose (3)	Weijman, 2005 ⁶²	292	44.6	33%	T1 & T2 Diabetes	Unclear
Patient Satisfaction with Insulin Therapy: PSIT	Convenience/ease of use (10) Social comfort (5) Global satisfaction total (15)	Cappelleri, 2000 ⁶³ Cappelleri, 2002 ⁶⁴	69 51	37.4 52.3	46% 39%	T1 & T2 Diabetes	Yes

Pediatric Quality of Life Inventory (PedsQL) 3.0 Diabetes module	Treatment barriers (4) Treatment adherence (7)	Varni, 2003 ⁶⁵ Allan, 2008 ⁶⁶ McCarty, 2010 ⁶⁷	237 28 467	13.1 15.0 13.0	57% 68% 52%	T1 & T2 Diabetes	Yes
Perceived Burden of Diabetes Treatment	Single item on perceived burden of treatment	van der Does, 1998 ⁶⁸	174	63.6	55%	T2 Diabetes	No
Perceived Difficulties in Diabetes Self-Care	Individually scored items assessing difficulties in: insulin treatment (2), blood glucose monitoring (1), diet (3), exercise (1), smoking (1), daily self-care (1), and self-care during certain occasions (4)	Toljamo, 2001 ⁶⁹	213	40	42%	Insulin-treated Diabetes	Yes
Perceptions About Medications for Diabetes: PAM-D	Scheduling flexibility (3) Portability convenience (2) Regimen inconvenience (5) Difficulty remembering medications (2) Gastrointestinal side effects (3) Weight/edema side effects (3) Emotional side effects (10)	Monahan, 2009 ⁷⁰	343	59.4	72%	T2 Diabetes	Yes
Perceptions of Insulin Shots & Fingersticks	Four individually scored items: pain with injections (1), fear with injections (1), pain with fingersticks (1), and fear with fingersticks (1)	Howe, 2011 ⁷¹	23	9.9	48%	T1 Diabetes	No

Personal Diabetes Questionnaire: PDQ	Diet barriers (7) Medication barriers(8) Monitoring barriers (8) Exercise barriers (7)	Stetson, 2011 ⁷²	783	T1 patients 39.7 T2 patients 55.4	54%	T1 & T2 Diabetes	Yes
Practicality/comfort of treatment	Single item on practicality & comfort of treatment	Lerman, 2009 ⁷³	29	59	62%	T2 Diabetes	No
Problem Areas in Diabetes: PAID	Treatment-related problems (3) Food-related problems (3)	Snoek, 2000 ⁷⁴	1472	51	49%	T1 & T2 Diabetes	Yes
		Keers, 2005 ⁷⁵	61	44	51%		
		Kokoszka, 2009 ⁷⁶	101	63.2	50%		
		McGuire, 2010 ⁷⁷	1153	53.8	52%		
Survey of Treatment Burdens in Diabetes	Individually scored items assessing perceived burden of: oral agents (1), insulin (4), oral + insulin therapy (1), self-monitoring of blood glucose (3), diet (2), pain (1), and interference with activities (1)	Vijan, 2005(a) ⁷⁸	1653	64	2%	T2 Diabetes	No
		Vijan, 2005(b) ⁷⁹	197	62.1	33%		
Treatment-related Impact Measure – Diabetes: TRIM-D TRIM-Diabetes Device	Treatment burden (6) Daily life (5) Psychological health (8) Device function (5) Device bother (3) Total Device (8)	Brod, 2009 ⁸⁰	507	51.4	53%	T1 & T2 Diabetes	Yes
Treatment Satisfaction Measure for People with Insulin-	Perceived compatibility with lifestyle (PCL) (3)	Lewis, 1988 ⁸¹	128	16-59 (range)	51%	T1 Diabetes	Yes

dependent Diabetes							
Kidney Disease Measures							
Instrument	Relevant subscales (no. of items)	Study	Baseline N	Mean age	Gender (female)	Disease focus	Patient input in item generation?
Health Beliefs About Fluid Adherence	Barriers to fluid adherence (7)	Welch, 2003 ⁸²	147	54.4	43%	Kidney Disease (dialysis treated)	No
Hemodialysis Stressor Scale: HSS	Physiological Psychosocial Total score ^d	Baldree, 1982 ⁸³	35	42.2	54%	Kidney Disease (dialysis treated)	No
Continuous Ambulatory Peritoneal Dialysis (CAPD) Stressor Scale		Murphy, 1985 ⁸⁴	174	47.6	NR		
		Bihl, 1988 ⁸⁵	36	50	35%		
		Tsay, 2005 ⁸⁶	57	50.7	52%		
Renal Adherence Attitudes Questionnaire: RAAQ	Attitude towards social restrictions (8) Acceptance/lifestyle impact (11)	Rushe, 1998 ⁸⁷	35	54	31%	Kidney Disease (dialysis treated)	Yes
Satisfaction with Care Questionnaire: SCQ	Financial/transportation (7)	Ferrans, 1987 ⁸⁸	416	56.6	47%	Kidney Disease (dialysis treated)	Yes
Treatment Effects Questionnaire: TEQ	Total score (20)	Griva, 2009 ⁸⁹	262	50.2	37%	Kidney Disease (transplant and dialysis treated)	Unclear
		Griva, 2010 ⁹⁰	145	50.1	50%		
		Jansen, 2010 ⁹¹	109	64.3	36%		

Heart Failure Measures							
Instrument	Relevant subscales (no. of items)	Study	Baseline N	Mean age	Gender (female)	Disease focus	Patient input in item generation?
Beliefs about Medication Compliance Scale: BMCS	Medication barriers (6)	Bennett, 1997 ⁹²	101	64	16%	Heart failure	Yes
		Bennett, 2001 ⁹³	234	64	53%		
Beliefs about Dietary Compliance Scale: BDCS	Diet barriers (5)	Nieuwenhuis, 2011 ⁹⁴	84	70	32%		
Dietary Sodium Restriction Questionnaire: DSRQ	Perceived behavioral control (7) ^e	Lennie, 2008 ⁹⁵	246	65	45%	Heart failure	Yes
		Bentley, 2009 ⁹⁶	174	62.4	44%		
Perceived difficulty affording health care	Single item on economic burden of medical costs	Spertus, 2005 ⁹⁷	480	64.5	32%	Heart failure (treated with surgery or percutaneous coronary intervention)	No
		Conard, 2006 ⁹⁸	539	60.9	23%		

Abbreviations. T1: Type 1. T2: Type 2. NR: not reported. DirecNet: Diabetes Research in Children Network. JDRF: Juvenile Diabetes Research Foundation. **Notes.** ^aModified from original scoring⁵ which scored two subscales: treatment satisfaction (15 items) & treatment interference with activities (11 items). ^bMollema et al. (2000)²⁹ added 4 items to fear of injecting and 4 items to fear of testing subscales. ^cBode et al.⁵⁶ used a modified scoring procedure for all subscales. ^dNumber of items in the subscales and the overall scale fluctuate across studies. A third subscale (“dependency/ restriction”) was identified in Murphy (1985).⁸⁴ ^eOriginal scoring⁹⁵ recorded only response frequencies of individual items.

Supplementary table 2. Scale reliability and analyses

Diabetes Measures				
	Reliability		Scale analyses	
Instrument	Cronbach's alpha	Test-retest (interval)	Item-total correlation	Factor analysis
Barriers to Adherence Questionnaire	NR	$r = 0.36 - 0.71$ (6 month) ¹	NR	NR
Barriers to Diabetes Adherence: BDA	$0.75 - 0.85^3$	NR	$r = 0.39 - 0.70^3$	Principal components analysis (PCA) supported a 5-factor solution (63% of total variance) including the 3 domains relevant to burden of treatment (stress, time pressure, and stigma). ³
Barriers in Diabetes Questionnaire: BDQ	$0.65 - 0.85^4$	NR	NR	Mollem (1996) report that a prior factor analysis confirmed the 3 domains represented in the subscales (details unreported). ⁴
Blood glucose monitoring system rating questionnaire: BGMSRQ	$0.84 - 0.94^{6,7}$	NR	NR	NR
Insulin delivery system rating questionnaire: IDSRQ	$0.67 - 0.95^6$			
Continuous Glucose Monitoring Satisfaction Scale: CGM-SAT	0.93^9	NR	NR	PCA supported the Hassles domain of the CGM-SAT (9% of total variance). ⁹
Glucose Monitoring Survey: GMS	$0.77 - 0.90^9$	$r = 0.63 - 0.76$ (6 month) ⁹	NR	PCA supported the Glucose control (28% of variance) and Social complications (9% of variance) domains of the GMS. ⁹
Diabetes-39	$0.85 - 0.91^{11,12}$	NR	$r = 0.45 - 0.84^{11,12}$	Exploratory factor analysis (EFA) and confirmatory

				factor analysis (CFA: principal factor method) supported a 5-factor solution (90% of total variance), including the one domain relevant to burden of treatment (Diabetes control). ¹¹
Diabetes Distress Scale: DDS	0.88 – 0.90 ¹³	NR	NR	PCA supported a 4-factor solution, including the 2 domains relevant to burden of treatment (emotional burden, regimen distress). Percent variance explained is unreported. ¹³
DDS-2, DDS-3, & DDS-4	0.73 (DDS-2); 0.83 (DDS-3); 0.86 (DDS-4) ¹⁷	NR	NR	NR
Diabetes Family Adherence Measure: D-FAM	0.82 ¹⁸	r = 0.85 (2 week) ¹⁸	NR	EFA supported a 4-factor solution (63% of total variance), including the one domain relevant to burden of treatment (coercion). ¹⁸
Diabetes Family Behavior Checklist: DFBC	0.43: adults 0.60: youths ¹⁹	r = 0.69: adults (2 month) r = 0.60: youths (6 month) ¹⁹	NR	NR
Diabetes Family Conflict Scale-revised: DFCS	0.69 – 0.95 ^{21,23,24}	NR	NR	EFA supported a 2-factor solution (24% of total variance), including direct and indirect management. ²¹
Diabetes Family Support & Conflict Scale: DFSC	0.75 ²⁷	NR	r's ≥ 0.50 ²⁷	PCA supported a 2-factor solution (55% of total variance), including family conflict (23% of variance). ²⁷
Diabetes Fear of Injecting and Self-testing Questionnaire: D-FISQ	0.89 – 0.97 ²⁸⁻³⁰	r = 0.50 – 0.58 (3 month) ²⁹	r = 0.36 – 0.85 ²⁸	EFA supported a 2-factor solution (54% of total variance), including fear of injecting (40% of variance) and fear of testing (14% of variance). ²⁹
Diabetes Health Profile: DHP	0.82 – 0.85 ³¹	NR	r = 0.47 – 0.75 ³¹	EFA supported a 3-factor solution (33% of total variance), including barriers to activity (8% of variance) relevant to burden of treatment. Meadows (1996) replicated this factor structure in multiple sub-

				studies and samples. ³¹
Diabetes Medication Satisfaction Measure: DiabMedSat	0.87 – 0.89 ³⁵	NR	NR	PCA supported a 3-factor solution, including the 2 domains relevant to burden of treatment (burden and symptoms). Percent variance explained is unreported. ³⁵
Diabetes Medication Treatment Satisfaction Tool: DMSAT	0.89 – 0.95 ³⁹	NR	NR	EFA supported a 4-factor solution (75% of total variance), including the domains relevant to burden of treatment (lifestyle, convenience, and well-being). ³⁹
Diabetes-specific Quality of Life Scale: DSQOLS	0.70 – 0.88 ^{40,42}	NR	$r's \geq 0.40$ ⁴²	CFA supported a 6-factor solution, including the 2 domains relevant to burden of treatment (diet restrictions and daily hassles). Goodness of fit index = 0.81 ⁴⁰
Diabetes Responsibility and Conflict Scale: DRCS	NR	NR	NR	NR
Diabetes Self-Care Barriers Assessment for Older Adults: DSCB-OA	0.60 – 0.86 ^{44,45}	NR	NR	PCA supported a 3-factor solution (47% of total variance), including blood glucose monitoring barriers (19% of variance), diet barriers (18% of variance), and exercise barriers (10% of variance). ⁴⁴
Diabetic Foot Ulcer Scale: DFS	0.74 – 0.88 ^{46,47}	ICC = 0.47 – 0.59 (4 week) ⁴⁷	mean of $r's = 0.52 - 0.68$ ⁴⁶	EFA supported a 6-factor solution for short-form version, including ulcer care relevant to burden of treatment. Percent variance explained is unreported. ⁴⁷ CFA supported 11 factors on the long-form version, including ulcer care and financial domains relevant to burden of treatment; however, some item re-scaling suggested. No goodness of fit measures provided. ⁴⁶
DISABKIDS Diabetes module	0.83 – 0.84 ⁴⁸	NR	NR	PCA supported 2 domains (impact and treatment). Percent variance explained is unreported. ⁴⁸

General Barriers to Diabetes Self-Management	0.76 – 0.92 ⁵⁰	NR	NR	NR
Dietary Barriers	0.70 – 0.92 ⁵⁰			
Insulin Pen Questionnaire	0.84 – 0.87 ⁵²	NR	NR	NR
Insulin Treatment Appraisal Scale: ITAS	0.90 ⁵³	NR	$r = 0.46 – 0.74^{a53}$	EFA supported a 2-factor solution (45% of total variance), including the domain relevant to burden of treatment (negative appraisal). ⁵³
Insulin Treatment Questionnaire: ITQ	0.86 – 0.89 ⁵⁴	NR	NR	Factor analysis (type un-specified) supported 2 factors for the Perceptions of Insulin Therapy domain (positive items and negative items). Factors combined into a single composite “Perceptions” score due to lack of substantive meaning for the separate factors. ⁵⁴
Insulin Treatment Satisfaction Questionnaire: ITSQ	0.78 – 0.90 ^{55,57}	$r = 0.75 – 0.94$ (2 week) ⁵⁵	$r = 0.68 – 0.93^{57}$	EFA supported a 5-factor solution, including the domains relevant to burden of treatment (inconvenience, lifestyle, and device satis.). CFA supported this solution (comparative fit index = 0.96). ⁵⁵
Measure of Invasiveness as a Reason for Skipping Self-Monitoring of Glucose: MISS	0.89 ⁶⁰	NR	NR	NR
Multidimensional Diabetes Questionnaire: MDQ	0.70 ⁶¹	NR	NR	CFA supported 7 factors, including misguided support behaviors relevant to burden of treatment (goodness of fit index = 0.93; comparative fit index = 0.96) ⁶¹
Multidimensional Diabetes Self-Management Checklist: MDSC	0.75 – 0.90 ⁶²	NR	NR	NR

Patient Satisfaction with Insulin Therapy: PSIT	0.82 – 0.89 ⁶³	$r = 0.50 - 0.64$ (12 week) ⁶³	$r = 0.27 - 0.80$ ⁶³	EFA supported a 2-factor solution including convenience/ease of use (66% of variance) and social comfort (20% of variance). ⁶³
Pediatric Quality of Life Inventory (PedsQL) 3.0 Diabetes module	0.27 – 0.66 ^{65,66}	NR	NR	NR
Perceived Burden of Diabetes Treatment	NA	NR	NA	NA
Perceived Difficulties in Diabetes Self-Care	NR	NR	NR	NR
Perceptions About Medications for Diabetes: PAM-D	0.71 – 0.93 ⁷⁰	ICC = 0.54 – 0.83 (1 to 3 month) ⁷⁰	$r = 0.40 - 0.83$ ⁷⁰	PCA supported a 9-factor solution (60% of total variance), including the 7 domains relevant to burden of treatment. ⁷⁰
Perceptions of Insulin Shots & Fingersticks	NR	NR	NR	NR
Personal Diabetes Questionnaire: PDQ	0.65 – 0.83 ⁷²	NR	NR	NR
Practicality/comfort of treatment	NA	NR	NA	NA
Problem Areas in Diabetes: PAID	0.46 – 0.78 ^{74,76,77}	$r = 0.64 - 0.74$ (2 month) ⁷⁴	NR	EFA supported a 4-factor solution, including treatment- and food-related problems. Follow-up CFA's provided further support for the same 4-factor model (comparative fit indices = 0.94 – 0.95). ⁷⁴
Survey of Treatment Burdens in Diabetes	NR	NR	NR	NR
Treatment-related	0.86 – 0.91 ⁸⁰	ICC = 0.75 – 0.83	NR	EFA supported a 5-factor solution for the TRIM-D,

Impact Measure – Diabetes: TRIM-D		(2 week) ⁸⁰		including the 3 domains relevant to burden of treatment (treatment burden, daily life, and psychological health).
TRIM-Diabetes Device	0.80 – 0.83 ⁸⁰	ICC = 0.78 – 0.89 (2 week) ⁸⁰	NR	EFA also supported the function and bother domains of the TRIM-Diabetes Device. ⁸⁰
Treatment Satisfaction Measure for People with Insulin-dependent Diabetes	NR	NR	NR	Three separate factor analyses (method unspecified) supported a 3-factor solution, including the perceived compatibility domain (variance accounted for ranged from 18% to 35%). ⁸¹
Kidney Disease Measures				
	Reliability		Scale analyses	
Instrument	Cronbach's alpha	Test-retest (interval)	Item-total correlation	Factor analysis
Health Beliefs About Fluid Adherence	0.78 ⁸²	NR	NR	NR
Hemodialysis Stressor Scale: HSS	0.79 – 0.89 ⁸⁴⁻⁸⁶	r = 0.71: HSS total score only (2 week) ⁸³	r = 0.33 – 0.66 ^{b 84}	EFA supported a 3-factor solution, including physiological (24% of variance), psychosocial (4% of variance), and dependency/restriction (4% of variance). ⁸⁴
Continuous Ambulatory Peritoneal Dialysis (CAPD) Stressor Scale	0.93: CAPD total score only ⁸⁵	NR		
Renal Adherence Attitudes Questionnaire: RAAQ	0.86 – 0.88 ⁸⁷	r = 0.84 – 0.88 (2-3 day) ⁸⁷	NR	PCA supported a 4-factor solution, including the 2 domains relevant to burden of treatment: attitude toward social restrictions (28% of variance) and acceptance/lifestyle impact (7% of variance). Subject-to-variable ratio was somewhat small (N = 35). ⁸⁷
Satisfaction with Care Questionnaire: SCQ	0.73 ⁸⁸	NR	NR	NR

Treatment Effects Questionnaire: TEQ	0.88 – 0.94 ^{89,91}	NR	NR	NR
Heart Failure Measures				
	Reliability		Scale analyses	
Instrument	Cronbach's alpha	Test-retest (interval)	Item-total correlation	Factor analysis
Beliefs about Medication Compliance Scale: BMCS	0.65 – 0.91 ^{92,93}	ICC = 0.41 (8 week) ICC = 0.47 (52 week) ⁹²	No $r < 0.30$ ^{c,92,93}	Two separate PCA's supported 2-factor solutions for both the BMCS and BDCS, with each including the domains relevant to burden of treatment: medication barriers (19% - 21% of variance) and diet barriers (19% - 20% of variance), respectively. ^{92,93}
Beliefs about Dietary Compliance Scale: BDCS	0.66 – 0.77 ^{92,93}	ICC = 0.46 (8 week) ICC = 0.42 (52 week) ⁹²	No $r < 0.30$ ^{c,92,93}	
Dietary Sodium Restriction Questionnaire: DSRQ	0.76 ⁹⁶	NR	$r = 0.41 - 0.61$ ⁹⁶	PCA supported a 3-factor solution, including the perceived behavioral control domain relevant to burden of treatment (18% of variance). ⁹⁶
Perceived difficulty affording health care	NA	NR	NA	NA

Abbreviations. NR: not reported. NA: not applicable. ICC: Intraclass correlation coefficient. PCA: Principal Components Analysis. EFA: Exploratory Factor Analysis. CFA: Confirmatory Factor Analysis. **Notes.** ^aOne item outside of the reported range ("insulin causes weight gain": $r=0.10$). ^bEach item with HSS total score; no item-subscale correlations reported. ^cSpecific correlation magnitudes were not reported.

Supplementary table 3. Scale validity and sensitivity to change

Diabetes Measures				
Instrument	Convergent / discriminant validity	Known-group validity	Related variables	Sensitivity to change
Barriers to Adherence Questionnaire	NR	- Patients with poor glycemic control > total barriers than patients with good glycemic control ($p=.002$) ² - Females > overall barriers than males ($p<.05$) ¹	Correlated with lower self-reported adherence to diabetes care in short term ($r=-0.11$ to -0.28) and long term (6 months: $r=-0.21$ to -0.52) ¹	NR
Barriers to Diabetes Adherence: BDA	NR	Females > stigma barriers than males ($p=.01$). No differences on other subscales ³	Stress & time pressure barriers correlated with lower adherence to diabetes self-care ($r's=-0.21$) ³	NR
Barriers in Diabetes Questionnaire: BDQ	NR	NR	More self-regulation barriers associated with higher median HbA1c ($p's<.05$). Total barriers associated with poorer self-reported health ($r=-0.40$) ⁴	NR
Blood glucose monitoring system rating questionnaire: BGMSRQ	NR	BGMSRQ: CBGM + CSII > interference than SMBG + CSII ($p<.001$). No differences on other subscales. ⁷	NR	BGMSRQ: No differences in change scores between patients treated with CBGM + CSII and those treated with SMBG + multiple daily injections ⁷
Insulin delivery system rating questionnaire: IDSRQ		IDSRQ: CBGM + CSII > convenience than SMBG + CSII ($p<.001$). No differences on other subscales. ⁷		IDSRQ: More improved convenience ($p<.001$) and burden scores ($p<.05$) in CBGM + CSII-treated patients than SMBG + multiple daily injection-treated patients. ⁷

Continuous Glucose Monitoring Satisfaction Scale: CGM-SAT	CGM-SAT: NR	CGM-SAT: More frequent CGM users report fewer hassles than less frequent users ($p's < .001$) ¹⁰	CGM-SAT: Adults report fewer hassles than youths ($p < .001$) ¹⁰	NR
Glucose Monitoring Survey: GMS	GMS: Lower total "current problems" associated with more frequent daily blood glucose measurement ($r = -0.22$) in adults. ⁹	GMS: CGM users (both adult and youth) report more favorable "change" scores than non-CGM users ($p's < .001$) ⁹	GMS: NR	
Diabetes-39	Lower diabetes control associated ($r's \geq 0.30$) with worse SF-36 domain scores (social, role-emotional, mental health, vitality, pain, physical, role-physical, and general health) ¹¹	NR	Lower diabetes control associated with worse perceived disease severity ($r's > 0.40$) and worse perceived QOL ($r's > 0.20$) ¹¹	NR
Diabetes Distress Scale: DDS	Emotional burden ($r = 0.55$) and regimen-related distress ($r = 0.42$) associated with CES-D (depression) ¹³	Users that stop CGM report > regimen distress than continuous users of CGM ($p < .05$). No difference on emotional burden ¹⁵	More emotional burden and regimen distress associated with younger age ($r's > 0.29$), poorer adherence to meal planning ($r's > 0.21$), and higher total cholesterol ($r's > 0.17$) ¹³	Declines in regimen distress with pramlintide or insulin analog treatment ($p < .05$). No changes in emotional burden ¹⁶
DDS-2, DDS-3, & DDS-4	DDS-2, DDS-3, and DDS-4 all associated with total DDS ($r's = 0.69, 0.69, \text{ and } 0.71$, respectively) ¹⁷	NR	High distress (all measures) associated with higher HbA1c ($p's < .01$), higher cholesterol ($p's \leq .05$), and higher caloric intake ($p's < .01$) ¹⁷	NR
Diabetes Family Adherence Measure: D-FAM	Coercion highly associated with non-supportive behavior scale of DFBC ($r = 0.65$); less associated with warmth/caring ($r = 0.22$)	NR	Coercion associated with higher HbA1c ($r = 0.39$) and frequency of diabetic ketoacidosis ($r = 0.30$) ¹⁸	NR

	and guidance/control (r=0.14) scales of DFBS ¹⁸			
Diabetes Family Behavior Checklist: DFBC	Non-supportive behavior scores of adult patients associated with non-supportive behavior scores of family members (r's between 0.27 and 0.68); associations between youth patients and family members were non-significant (r's<0.28) ¹⁹	Youths report occurrence of more non-supportive behaviors from family members than do their parents (p's<.05) ^{19,20}	- Fewer non-supportive behaviors associated with greater care responsibilities in youths (r=-0.23) ²⁰ - Fewer non-supportive behaviors associated with better adherence to glucose testing (r=-0.39), diet (r=-0.42), and on-time insulin injections (r=-0.62) in adults ¹⁹	Increasing non-supportive behaviors associated with poorer adherence to glucose testing (r=-0.37), diet (r=-0.42), and on-time insulin injections (r=-0.32) ¹⁹
Diabetes Family Conflict Scale-revised: DFCS	- More family conflict over direct and indirect management associated with more negative affect re. glucose monitoring (r's≥0.24) ²¹ - More total family conflict associated with poorer overall QOL (r=-0.36) ²¹	NR	- More family conflict (subscales and total score) associated with higher HbA1c (r's≥0.22) ²¹ - More total family conflict predicts lower self-esteem in youths (beta=-0.89, p=.03) ²⁵ - More total family conflict associated with lower diabetes self-efficacy in youths (r=-0.34) ²⁶	DFCS total scores improved from before to after an office-based QOL intervention for youths with T1 diabetes (p<.05) ²⁵
Diabetes Family Support & Conflict Scale: DFSC	NR	NR	- More family conflict associated with more family support (r=0.21) ²⁷	NR
Diabetes Fear of Injecting and Self-testing Questionnaire: D-FISQ	Fear of injecting, fear of testing, & D-FISQ total associated with more hypoglycemia worry (r's≥0.27) and more trait anxiety (r's≥0.35) ²⁸	Pts who avoid self-testing > fear of testing than pts who are able to self-test (p=.01) ²⁹	- Fear of injecting and testing associated with age; younger age > fear (p's<.001) ²⁸ - Fear of injecting and testing associated with self-reported pain of each (r's≥0.30) ²⁸	NR
Diabetes Health	More barriers to activity	No gender or age group	Fewer barriers associated	Declines in barriers to

Profile: DHP	associated with more HADS anxiety ($r=0.51$), more HADS depression ($r=0.50$), lower SF-36 social ($r=-0.50$) and general health ($r=-0.51$) scores ³¹	differences ³¹	with taking personal responsibility for diabetes self-care ($OR=3.68$, $p<.05$) ³⁴	activity after a psycho-educational intervention vs. usual care ($p's <.05$) ³²
Diabetes Medication Satisfaction Measure: DiabMedSat	- Higher satisfaction (low burden, low symptoms) associated with greater life and work productivity ($r's \geq 0.38$) ³⁵ - Higher satisfaction (low burden, low symptoms) associated with higher ITAS satisfaction scores and higher satisfaction with medication ($r's \geq 0.27$) ³⁵	Hypoglycemic pts > burden and symptoms than non-hypoglycemic pts ($p's <.0001$) ³⁸	- Less burden associated with longer diabetes duration in regression model ($p<.01$) ³⁷ - Lower symptoms associated with prior insulin treatment in regression model ($p<.001$) ³⁷	Improvements in burden and symptom scores with biphasic insulin aspart treatment ($p's <.001$, $ES's \geq 0.55$) ³⁷
Diabetes Medication Treatment Satisfaction Tool: DMSAT	NR	Pts with low HbA1c > well-being scores than pts with high HbA1c ($p<.05$) ³⁹	Higher lifestyle and convenience scores associated with lower treatment complexity, better glucose control, and fewer health worries ($p's <.05$) ³⁹	NR
Diabetes-specific Quality of Life Scale: DSQOLS	Fewer diet restrictions and daily hassles associated with better overall positive well-being ($r's \geq 0.35$) ⁴⁰	Fewer diet restrictions and daily hassles for CSII-treated pts than multiple daily insulin injection-treated pts ($p's \leq .01$) ⁴²	Fewer diet restrictions associated with higher socio-economic status ($r=0.19$) ⁴⁰	Improvements in diet restrictions and daily hassles with insulin treatment ($p's <.05$) ⁴¹
Diabetes Responsibility and Conflict Scale: DRCS	NR	No differences in conflict across type of household: 2-parent vs. single-parent; intact vs. blended vs. single-parent ⁴³	NR	NR
Diabetes Self-Care Barriers Assessment for	NR	Total barriers higher in African Americans than whites and those with less	NR	NR

Older Adults: DSCB-OA		than 8 th grade education ($p's < .001$) ⁴⁵		
Diabetic Foot Ulcer Scale: DFS	Less bother due to ulcer care and financial problems associated with better SF-36 domain scores: physical, vitality, role-emotional, and mental health ($r's > 0.30$) ^{46,47}	Less bother due to financial problems in pts with healed vs. un-healed ulcers ($p < .05$) ⁴⁶	NR	No changes in ulcer care or financial domains with platelet growth factor- treatment of foot ulcers. ⁴⁶
DISABKIDS Diabetes module	NR	- Less impact and greater treatment acceptance in boys than girls ($p's < .05$) ⁴⁹ - Less impact of diabetes among children in West Sweden vs. children in the rest of Europe ($p < .05$) ⁴⁹	Less impact and greater treatment acceptance in younger children than older children ($p's < .05$) ⁴⁹	NR
General Barriers to Diabetes Self- Management Dietary Barriers	NR	Higher total barriers associated with being female, younger, more highly educated, Caucasian, having T1 diabetes, and having managed care or no insurance (vs private or government) ($p's < 0.01$) ⁵⁰	Fewer diet barriers associated with greater family support ($\beta = -0.09$, $p = .01$) ⁵¹	NR
Insulin Pen Questionnaire	NR	Current pen users rated pens as more convenient, facilitative of self-care, and lower cost than former pen users ($p's < .05$) ⁵²	Lower pen convenience ($OR = 0.12$, $p = .007$) and higher pen cost ($OR = 0.16$, $p < .001$) associated with likelihood of terminating pen use. ⁵²	NR
Insulin Treatment Appraisal Scale: ITAS	More negative appraisal associated with diabetes distress (PAID total: $r = 0.33$) and poorer overall well- being (WHO-5: $r = -0.12$) ⁵³	More negative appraisal in insulin-naïve than insulin- treated pts ($p < .001$) ⁵³	NR	NR

Insulin Treatment Questionnaire: ITQ	No significant associations of Perceptions of Insulin Therapy with SF-36 PCS and MCS scores (correlations NR) ⁵⁴	No study arm differences on Perceptions of Insulin Therapy (inhaled insulin vs. inhaled placebo: $p=.128$) ⁵⁴	NR	Perceptions of Insulin Therapy score improved from before to 12 weeks after use of inhaled insulin ($p=.002$, $ES=0.56$) ⁵⁴
Insulin Treatment Satisfaction Questionnaire: ITSQ	- Less regimen convenience, less lifestyle flexibility, and less device satisfaction associated with more diabetes distress (PAID total: $r's=-0.45$ to -0.69), less treatment satisfaction (WHO-Diabetes Treatment Satisfaction: $r's=-0.42$ to -0.74), and lower mental well-being (SF-12 MCS: $r's=0.33$ to 0.54) ⁵⁵ - No significant associations with physical well-being (SF-12 PCS: $r's=0.03$ to 0.16) (discriminant validity) ⁵⁵	Less regimen convenience, less lifestyle flexibility, and less device satisfaction in pts treated with insulin 3x daily vs. 2x or once daily ($p's\leq.0001$) ⁵⁹	-Less regimen convenience, less lifestyle flexibility, and less device satisfaction associated with presence of neuropathy ($p's<.05$) ⁵⁸ - More regimen convenience and more device satisfaction associated with improved HbA1c ($r's=-0.15$ to -0.17) ⁵⁸	Insufficient evidence (data on only 4 pts) ⁵⁷
Measure of Invasiveness as a Reason for Skipping Self-Monitoring of Glucose: MISS	- Greater invasiveness associated with greater fear of insulin injection and self-testing (D-FISQ total: $r=0.50$) ⁶⁰ - Greater invasiveness associated with greater perc. burden of SMBG ($r's=0.38$ to 0.45) ⁶⁰	Greater invasiveness for pts without knowledge of importance of glycemic control ($p<.05$) ⁶⁰	Greater invasiveness associated with lower objective adherence to SMBG ($r=-0.47$) ⁶⁰	NR
Multidimensional Diabetes Questionnaire: MDQ	NR	Lower report of misguided support behaviors by women than men ($p<.01$) ⁶¹	No significant associations of misguided support behaviors and age, education, income, depression, internal locus of control, self-care adherence, HbA1c, diabetes duration, or	NR

			complications ⁶¹	
Multidimensional Diabetes Self-Management Checklist: MDSC	NR	NR	- Higher burden of diet self-manage., inj. insulin, glucose monitor., and adj. insulin assoc. with lack of self-efficacy (OR's=1.89 to 5.30, p's<.05) ⁶² - Higher burden of inj. insulin assoc. with higher job workload (OR's=2.15 to 2.29, p's<.05) ⁶² - Higher burden of glucose monitor. assoc. with more avoidant coping (OR's=1.88 to 2.90, p's<.01) ⁶²	NR
Patient Satisfaction with Insulin Therapy: PSIT	NR	Pts treated with inhaled insulin reported greater improvement in global satisf. than pts treated with subcut. insulin (p<.05) ⁶⁴	- Higher convenience/ease and higher global satisf. assoc. with lower HbA1c (r's=-0.24 to -0.25) ⁶³ - Higher social comfort assoc. with lower age (r=-0.32) and shorter diabetes duration (r=-0.25) ⁶³	Improved glycemic control (baseline to 12 weeks) assoc. with positive changes in global satisf, controlling for trt regimen (r=0.30, p<.05) ⁶⁴
Pediatric Quality of Life Inventory (PedsQL) 3.0 Diabetes module	Lower treatment barriers & greater adherence assoc. with higher PedsQL General QL score (r's between 0.35 and 0.66) ⁶⁵	Youths using complementary/ alternative med reported more trt. barriers than non-users (p=.03). No sign. diffs in trt. adherence ⁶⁷	- Fewer trt. barriers assoc. with lower HbA1c (r=-0.27) ⁶⁵ - Greater trt. adherence assoc. with lower HbA1c (r=-0.20) ⁶⁵	NR
Perceived Burden of Diabetes Treatment	NR	Less strict glycemic control assoc. with lower perc. burden than more strict glycemic control (p<.05) ⁶⁸	NR	NR
Perceived Difficulties in	NR	NR	Self-care adherence assoc. with evaluation of nutrient	NR

Diabetes Self-Care			content ($r=0.37$), and difficulties in daily self-care ($r=0.30$), self-care at parties ($r=0.27$), and self-care while traveling ($r=0.25$) ⁶⁹	
Perceptions About Medications for Diabetes: PAM-D	NR	Sign. worse PAM-D scores for people taking oral meds + insulin than oral meds alone: schedule flexibility ($p<.01$), portability convenience ($p<.001$), regimen inconvenience ($p<.01$), gastro-intestinal side-effects ($p<.01$), and emotional side-effects ($p<.001$) ⁷⁰	NR	NR
Perceptions of Insulin Shots & Fingersticks	NR	Younger children (<9 yrs) reported sign. more fear of injections and pain with fingersticks than older children (≥ 9) (p 's<.05) ⁷¹	No sign. assoc's of fear or pain with HbA1c ⁷¹	Pain and fear (both injections & fingersticks) decreased from diagnosis to 6-9 mo f.u. (descriptive statistics only) ⁷¹
Personal Diabetes Questionnaire: PDQ	NR	<ul style="list-style-type: none"> - More diet barriers reported by T2 pts not on insulin than T1 pts ($p<.001$)⁷² - More medication barriers reported by T2 pts on insulin than T1 pts ($p=.03$)⁷² - No diffs. in monitoring or exercise barriers by diabetes type/treatment⁷² 	<ul style="list-style-type: none"> - More diet barriers sign. assoc. with higher HbA1c in T1 & T2 pts not on insulin (r's=0.14 to 0.19) & with higher BMI in T2 pts not on insulin ($r=0.29$)⁷² - More medication barriers sign. assoc. with higher HbA1c in T1 & T2 pts not on insulin (r's=0.15 to 0.25)⁷² - More monitoring barriers sign. assoc. with higher HbA1c in T1 & T2 pts on insulin (r's=0.19 to 0.77) & with higher BMI in T2 pts not on insulin ($r=0.19$)⁷² 	NR

			- More exercise barriers sign. assoc. with higher BMI in T1 & T2 pts (r's=0.18 to 0.61) ⁷²	
Practicality/comfort of treatment	NR	NR	NR	NR
Problem Areas in Diabetes: PAID	- More trt-related problems assoc. with WBQ-12, negative well-being (r=0.33), HFS-worry (r=0.33), & STAI-trait (r=0.42). Lower assoc. with HbA1c & SMBG (r's=0.12) (discriminant validity) ⁷⁴ - More food-related problems assoc. with WBQ-12, negative well-being (r=0.33), HFS-worry (r=0.33), & STAI-trait (r=0.41). Lower assoc. with HbA1c & SMBG (r's≤0.05) (discriminant validity) ⁷⁴	- No diffs in trt-related problems by depression status (p=0.12) ⁷⁶ - Pts with depression or sub-clinical depression had more food-related problems than patients without depression (p=0.003) ⁷⁶	More trt- & food-related problems reported by U.S. Type 1 pts than Dutch Type 1 pts (p's<.001) ⁷⁴	Trt- & food-related problems declined after 1 year of intensive diabetes education (p's<0.01) ⁷⁵
Survey of Treatment Burdens in Diabetes	NR	Pts without experience of treatment reported sign. more burden than pts with trt. experience on all but one survey item (oral agents) (p's<.001) ⁷⁸	- Higher perc. burden assoc. with worse self-care adherence for multiple survey items, including: oral agents (p=.006), SMBG (p's≤.02), diet (p<.001), and insulin (p<.05) ⁷⁸ - Higher perc. burden of moderate diet assoc. with more frequent visits to dietician (p=.029) ⁷⁹	NR
Treatment-related Impact Measure – Diabetes: TRIM-D	- Trt burden assoc. with burden scale of DiabMedSat (r=0.45)	- Trt burden greater in pts using insulin vs. oral meds (p<.001)	- Greater trt burden, more daily life limitations, and worse psychol. health	NR

TRIM-Diabetes Device	<ul style="list-style-type: none"> - Daily life limitations assoc. with worse Activity Impairment Index scores ($r=-0.67$) - Worse psychol. health assoc. with PAID total distress ($r=-0.75$)⁸⁰ - Higher device fx assoc. with convenience scale of Trt Satisfaction Q. for Medication ($r=0.60$) & device satisfaction scale of ITSQ ($r=0.46$) - Greater device bother assoc. with burden scale of DiabMedSat ($r=0.63$) - Total device score assoc. with overall satisfaction with diabetes med. device ($r=0.55$)⁸⁰ 	<ul style="list-style-type: none"> - Fewer daily life limitations in pts missing fewer work days due to diabetes ($p<.001$) - Worse psychol. health in pts with more severe depression, CES-D screened ($p<.001$)⁸⁰ - Higher device fx & less device bother for patients with low fear of injections ($p's<.001$)⁸⁰ 	<ul style="list-style-type: none"> assoc. with higher HbA1c ($p's<.001$)⁸⁰ - Worse TRIM-Diabetes Device scores (fx, bother, total) assoc. with higher HbA1c ($p's<.02$) - Better TRIM-Diabetes Device scores (fx, bother, total) assoc. with older age ($p's<.05$)⁸⁰ 	NR
Treatment Satisfaction Measure for People with Insulin-dependent Diabetes	NR	Higher perc. compatibility with lifestyle (PCL) in pts treated with CSII than pts treated with conventional insulin and monitoring ($p<.01$) ⁸¹	<ul style="list-style-type: none"> - PCL assoc. with more frequent blood testing ($r=-0.30$)⁸¹ - PCL assoc. with perc. blood glucose control ($r=0.32$)⁸¹ 	NR
Kidney Disease Measures				
Instrument	Convergent / discriminant validity	Known-group validity	Related variables	Sensitivity to change
Health Beliefs About Fluid Adherence	NR	NR	Pts in precontemplation stage of change readiness (fluid reduction) perceived fewer barriers than pts in the preparation stage ($p=.004$) ⁸²	NR

Hemodialysis Stressor Scale: HSS Continuous Ambulatory Peritoneal Dialysis (CAPD) Stressor Scale	NR NR	No diffs in subscale or total score found between hemodialysis and CAPD pts. ⁸⁵	No sign. assoc. in subscales or total scores with age, sex, marital status, education, or coping ⁸³	- Pts in a coping skills training intervention had greater decline in HSS total stressor score than pts in usual care control (p=.005, ES=0.78) ⁸⁶ - Coping skills training group showed declines in physiological (p=.007) & psychosocial subscale scores (p=.002) from before to after intervention. No sign. declines in usual care group. ⁸⁶
Renal Adherence Attitudes Questionnaire: RAAQ	NR	NR	NR	NR
Satisfaction with Care Questionnaire: SCQ	- Financial/transportation subscale items assoc. with overall satisfaction with care (r's=0.36 to 0.62) ⁸⁸ - Financial/transportation subscale assoc. with Quality of Life Index (r=0.37) ⁸⁸	NR	NR	NR
Treatment Effects Questionnaire: TEQ	- Treatment disruptiveness (TEQ total) assoc. with illness disruptiveness (IEQ total: r=0.83), and negative illness perceptions: IPQ-identity (r=0.54), IPQ-timeline (r=0.20), & IPQ-consequences (r=0.51) ⁸⁹ - Higher treatment disruptiveness (TEQ total) assoc. with less perceived control (IPQ-control: r=-	- More trt. disruptiveness in dialysis pts than transplant pts (p<.0001) ⁸⁹ - More trt. disruptiveness in automated peritoneal dialysis pts than CAPD pts (p=.01) ⁹⁰	More trt. disruptiveness assoc. with lower global autonomy (r=-0.42) & lower self-esteem (r=-0.48) ⁹¹	NR

	0.39), and worse SF-36 PCS (r=-0.59) and MCS scores (r=-0.41) (discriminant validity) ⁸⁹			
Heart Failure Measures				
Instrument	Convergent / discriminant validity	Known-group validity	Related variables	Sensitivity to change
Beliefs about Medication Compliance Scale: BMCS	NR	NR	NR	NR
Beliefs about Dietary Compliance Scale: BDCS	NR	- No sign. diff in diet barriers between objectively compliant and non-compliant pts. ⁹⁴	NR	NR
Dietary Sodium Restriction Questionnaire: DSRQ	NR	NR	NR	NR
Perceived difficulty affording health care	NR	- More perc. economic burden in households with lower income (< \$40,000), unemployed, history of heart failure or cerebrovascular disease (p's<.05) ⁹⁷ - More perc. economic burden in non-whites vs. whites (p=.02) ⁹⁷	- KCCQ overall health scores worse in pts. reporting any economic burden vs. no burden (p=.001) ⁹⁸ - SF-12 PCS & MCS scores worse in pts. reporting any economic burden vs. no burden (p's=.001) ⁹⁸	NR

Abbreviations. NR: not reported. HbA1c: Hemoglobin A1c. CBGM: continuous blood glucose monitoring. SMBG: self-monitoring of blood glucose. CSII: continuous subcutaneous insulin infusion. T1: Type 1. T2: Type 2. BMI: Body mass index. QOL: quality of life. ES: Effect size. OR: Odds ratio. **Instruments.** SF-36: Short-Form-36. SF-12: Short-Form-12. HADS: Hospital Anxiety and Depression Scale. CES-D: Center for Epidemiologic Studies-Depression scale. DFBC: Diabetes Family Behavior Checklist. DFBS: Diabetes Family Behavior Scale. ITAS: Insulin Treatment Appraisal Scale. PAID: Problem Areas in Diabetes Scale. WHO-5: World Health Organization 5-item Well-Being index. PCS: Physical component summary. MCS: Mental component summary. WBQ-12: Well-Being Questionnaire. HFS: Hypoglycemia Fear Survey. STAI: State-Trait Anxiety Inventory. IEQ: Illness Effects Questionnaire. IPQ: Illness Perceptions Questionnaire. KCCQ: Kansas City Cardiomyopathy Questionnaire.

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