

# Zelfmanagementondersteuning - Rapportage uitgangsvraag 1

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## **Vraagstelling**

Welke meerwaarde van zelfmanagementondersteuning ervaren mensen met een verstandelijke beperking en ouderen met een chronische aandoening die gebruik maken van langdurige zorg?

#### Methoden

Selectie van relevante onderzoeken

Geïncludeerd werden kwalitatieve onderzoeken waarin de ervaringen of percepties van mensen met een verstandelijke beperking of ouderen met een chronische aandoening die gebruik maken van langdurige zorg, met zelfmanagementondersteuning. Zelfmanagementondersteuning werd daarbij gedefinieerd als: ondersteuning voor cliënten bij het omgaan met de gevolgen van hun aandoening(en) (mentaal, fysiek en sociaal). Zelfmanagementondersteuning omvat ten minste één van de volgende componenten: informatie en leefstijladviezen, klinische actieplannen, klinische beoordeling en monitoring, praktische ondersteuning, uitrusting en advies/ondersteuning, opleiding, sociale ondersteuning. Het belangrijkste kenmerk van zelfmanagementondersteuning is dat de ondersteuning gericht is op een actieve rol van de cliënt. Onder langdurige zorg werd verstaan: intensieve en permanente zorg die niet gericht is op (volledig) herstel, maar als doel heeft kwaliteit van leven te behouden en verbeteren. Deze zorg wordt op (ten minste) dagelijkse basis verleend door formele en/of informele zorgverleners. Er waren geen beperkingen m.b.t. locatie, wet- en regelgeving en financiën. In relevante onderzoeken over ouderen was de gemiddelde of mediane leeftijd ≥65 jaar of was ten minste de helft van de deelnemers ≥ 65 jaar. Publicaties in een taal anders dan het Nederlands, Engels, Duits of Frans werden niet meegenomen.

Aan de hand van bovengenoemde criteria selecteerde één onderzoeker de relevante onderzoeken. Ten minste 10% van alle referenties werd gecontroleerd door een tweede onderzoeker, waaronder in ieder geval alle onderzoeken waarvan de eerste onderzoeker twijfelde aan de relevantie.

#### Data-extractie en kwaliteitsbeoordeling

Eén onderzoeker verzamelde van iedere publicatie relevante gegevens, te weten de kenmerken van de populatie en de interventie, en de resultaten van de ervaren meerwaarde van zelfmanagementondersteuning. Interventies werden ingedeeld aan de hand van de PRISMS-taxonomie (Pearce 2015). Resultaten werden geëxtraheerd aan de hand van het framework van Boger (Boger 2015). Dit framework deelt zelfmanagementuitkomsten in naar de volgende thema's: toepasbare kennis (applicable knowledge), onafhankelijkheid (independence), mezelf zijn (being me), zelfmanagementvaardigheden (self-management skills), optimale emotionele/fysiek/sociale gezondheid (optimal emotional/physical/social health). Eén onderzoeker beoordeelde tevens van ieder onderzoek de methodologische kwaliteit en gebruikte daartoe AMSTAR-2 (Shea 2017) die op details werd aangepast aan reviews van kwalitatief onderzoek (zie Supplement S2), en de CASP-tool voor de beoordeling van primair kwalitatief onderzoek (Critical Appraisal Skills Program, 2018). Bij twijfel over de te extraheren data of de methodologische kwaliteit volgde overleg met een tweede onderzoeker.

#### **Analyses**

Resultaten werden kwalitatief samengevat aan de hand van het eerder genoemde framework van Boger. Aan elk van de thema's uit dit framework kende één onderzoeker aan de hand van de GRADE-CERQual-methodiek een *level of confidence in the evidence* toe en besprak deze met een tweede onderzoeker (Lewin 2018a; Lewin 2018b). GRADE-CERQual bestaat uit vier componenten waarvoor de mate van vertrouwen in de evidence beoordeeld wordt:



methodologische beperkingen, coherentie (overeenstemming tussen de data uit de primaire onderzoeken en de uiteindelijke, overkoepelende reviewbevinding), adequaatheid van de data (hoeveelheid en rijkdom van de data die de reviewbevinding ondersteunen) en relevantie (mate waarin data uit primaire onderzoeken van toepassing zijn op de context van de uitgangsvraag; denk aan perspectief of populatie, het onderzochte fenomeen en de setting). De beoordeling voor deze vier componenten leidt tot een overall beoordeling, die vier niveaus kent:

*High confidence*: de reviewbevinding is zeer waarschijnlijk een redelijke weergave van het onderzochte fenomeen.

*Moderate confidence*: de reviewbevinding is waarschijnlijk een redelijke weergave van het onderzochte fenomeen.

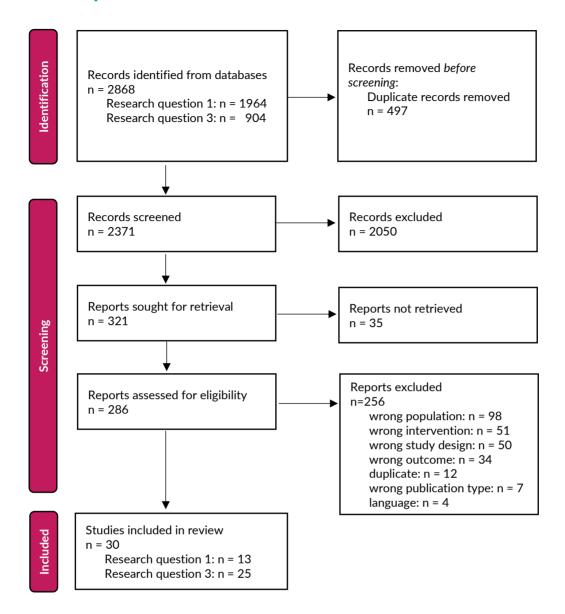
Low confidence: de reviewbevinding is mogelijk een redelijke weergave van het onderzochte fenomeen.

**Very low confidence:** het is onduidelijk of de reviewbevinding een redelijke weergave van het onderzochte fenomeen is.

Ten slotte werden conclusies geformuleerd (inclusief de mate van vertrouwen in de evidence) t.a.v. de meerwaarde van zelfmanagementondersteuning voor zowel mensen met een verstandelijk beperking als ouderen met een chronische aandoening die gebruik maken van langdurige zorg.



## **Selectieproces**



Figuur 1 Flow-chart van selectieproces voor uitgangsvraag 1 (gecombineerd met selectie voor uitgangsvraag 3)



# Kenmerken van geïncludeerde onderzoeken

Tabel 1 Kenmerken van geïncludeerde onderzoeken over de ervaren meerwaarde van zelfmanagementondersteuning door mensen met een verstandelijke beperking (n=5) en ouderen met een chronische aandoening die langdurige zorg krijgen (n=8)

Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
People with inte	ellectual disabilities (n=	5 studies)*								
MacRae 2015	Design: systematic review of 5 qualitative studies, published in English, of which n=3 addressed the views of people with intellectual disabilities and n=3 the views of caregivers  Country: Europe, North America, New Zealand, Australia, China and Hong Kong	Description and main diagnosis: people with intellectual disabilities and diabetes type 1 and type 2, either living in community housing or residential accommodation  No. clients: 35 in total (in 3 studies addressing views of participants)  Characteristics:  Age: mean ages were 52, 35 and 50.9 years, range from 23 to 70 years	Short description: all participants in included studies received a form of diabetes management support, which varied per person.  Delivery mode: variable  Intensity, frequency, and duration: variable  Personnel delivering support: family members or professional care staff	x	×	×	NA	NA	x	NA



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
	Method of data collection: literature search up to November 2013	<ul> <li>% female: 52% to 75%; unknown in one study</li> <li>Comorbidities: not reported</li> <li>Other participants: Parents, guardians, professional caregivers and health care staff (n=3 studies)</li> </ul>								
Maine 2017	Design: qualitative study  Country: United Kingdom  Method of data collection: semi structured, face-to-face interviews (with or without a carer)	Description and main diagnosis: people with mild (n=8) to moderate (n=2) intellectual disabilities and (type 2) diabetes, living at home (n=9) or in residential care (n=1)  No. clients: 10  Characteristics:  Age: mean 49 years, range 25-67 years  Million of the main of	Short description: no specific (self-management) intervention was provided, but participants have received some form of support (education programs, equipment for insulin injections and other tools).  Delivery mode: variable  Intensity, frequency, and duration: variable	x	NA	x	x	x	x	NA



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
		Comorbidities: not reported  Other participants: two of the participants were accompanied by carers for the interview	Personnel delivering support: (this varied through experiences) support workers, caregivers, support networks, doctors, spouses, day service personnel, nurses							
Maine 2020	Design: literature review using a meta-aggregative synthesis and an appraisal of rigor, including 8 qualitative studies published in English in peer-reviewed journals  Country: Netherlands (n=2), United Kingdom (n=2), New Zealand (n=3) and Australia (n=1)  Method of data collection: literature	Description and main diagnosis: people with intellectual disabilities and (type 1 or type 2) diabetes  No. clients: 65 in total (range from n=4 to n=67 participants per study)  Characteristics:  Age: mean ages from 35 to 52 years (7 studies); age range 20 to 54 years (1 study)  Member 1 study  Member 2 study  Member 3 study  Member 3 study  Member 3 study  Member 4 study  Member 4 study  Member 4 study	Short description: not specifically reported by most included studies, however, according to review authors 2 studies described the selfmanagement approaches of individual participants as "diet alone", "medication", and "insulin".  Delivery mode: not specified  Intensity, frequency, and duration: not specified  Personnel delivering support: not specified	x	x	NA	×	NA	NA	NA



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
	search (search date	Comorbidities: not								
	not reported)	reported  Other participants: some studies included (in)formal caregivers alone (2 studies) or additionally (3 studies)								
Sandjojo 2019	Design: qualitative study  Country: Netherlands  Method of data collection: focus groups with people with intellectual disabilities, focus groups with legal representatives and focus groups with support staff	Description and main diagnosis: people with borderline or mild intellectual disabilities, living in a group home or semi-independently in their own apartment with ambulatory support (no specific other diagnoses)  No. clients: 7  Characteristics:  • Mean age (sd) in 2 focus groups 40.4 (16.9) and 29.1 (1.1)  • % female: 14%	Short description: no specific self-management intervention, but authors mention that the level of independence of clients was highly variable: some need help with basic Activities of Daily Living (ADL), whereas others can live independently with only some ambulatory support. All needed at least some support.  Delivery mode: variable  Intensity, frequency, and duration: variable	x	x	NA	NA	NA	×	NA



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
		Comorbidities: not reported  Other participants: legal representatives (n=13) and support staff (n=17)	Personnel delivering support: variable: support workers or legal representatives (often family)							
Wilson 2011	Design: mixed method approach, case study design  Country: United Kingdom  Method of data collection: diaries of and focus groups with people with intellectual disabilities; interviews with lay tutors and other key stakeholders	Description and main diagnosis: people with (mainly moderate) intellectual disabilities and one or more long-term conditions, living in a residential home (76%), with family (10%), with partner (7%) or alone (7%)  No. clients: 35  Characteristics:  Age: <30y: 25%; 30-39y: 28%, 40-49y: 17%, 50-59y: 10%, 60-69y: 21%  Member of male	Short description: Expert Patients Programme (EPP), based on the Chronic Disease Self-Management Program: 8-week small-group intervention attended and facilitated by people with different chronic conditions; grounded in principles of empowerment and inclusion, with peer instructors (lay tutors) facilitating the programme. Central to the course is the setting of weekly goals and action planning.  Delivery mode: face-to-face group intervention	x	x	NA	NA	x	x	x



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
		and female participants."  Comorbidities: Epilepsy (24%) Cerebral palsy (15%) Arthritis (11%) Diabetes (7%) Hypertension (6%) Mental health (4%) Asthma (4%) Muscular dystrophy (4%) Other conditions (25%)  Other participants: lay tutors and stakeholders (n=29)	Intensity, frequency, and duration: not specified  Personnel delivering support: lay tutors from the EPP, who lived with a chronic condition but did not have intellectual disabilities, and were experienced at delivering the generic EPP.							



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
Andersen 2017	Design: qualitative, longitudinal study  Country: Denmark  Method of data collection: repeated participant observations, informal interviews, and in-depth interviews with clients	Description and main diagnosis: Patients with COPD, hospitalized due to an acute exacerbation of COPD.  No. clients: 15  Characteristics:  Age range: 55-86 years  Kemale: 67%  Charlson Index of comorbidity score: 1: n=8, 2: n=4, 4: n=1, 5: n=2  Other participants: Not applicable	Short description: Integrated health system in accordance with the "Chronic Care Model" that incorporates a self- management approach  Delivery mode: Unclear Intensity, frequency, and duration: Unclear  Personnel delivering support: Unclear	x	NA	x	NA	NA	x	NA



Author, year	Author, year Study characteristics	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
Bove 2017	Design: nested post- trial qualitative study  Country: Denmark  Method of data collection: face-to- face interviews with clients	Description and main diagnosis: patients with advanced COPD and anxiety  No. clients: 20  Characteristics:  Age mean (range): 69 years (54-88)  % female: 70%  55% had one or more comorbidities  Other participants: 6 spouses were present at the interviews. Their experiences were not explored.	Short description: Home-based psychoeducation on COPD related to dyspnea and anxiety  Delivery mode: face-to-face and telephone calls  Intensity, frequency, and duration: single, 1-hour psychoeducation session and a 20-minute telephone booster session two weeks after.  Personnel delivering support: Nurses	x	x	NA	NA	NA	x	NA



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
Goransson 2018	Design: qualitative  Country: Sweden  Method of data collection: Individual semi-structured interviews with clients and nurses	Description and main diagnosis: older people that received home care  No. clients: 17  Characteristics:  Age mean (SD): 86 years (6.5)  Keep female: 65%  Sample: 65%  Sample: 65%  Insuliness; 18% Insuliness	Short description: Interaktor app, with health concerns assessments and access to self-care advice and alerts to health care professionals  Delivery mode: App on smartphone or on tablet  Intensity, frequency, and duration: 3 months using the app, clients could fill out the assessments twice a week.  Personnel delivering support: app was introduced by researcher, follow-up of assessments is done by nurses	x	NA	x	NA	x	NA	NA
Markle-Reidz 2016	Design: mixed methods  Country: Canada	Description and main diagnosis: older adults with multiple chronic conditions and type 2 diabetes	Short description: the Aging, Community and Health (ACHRU)— Community Partnership Program, an interprofessional, nurse-	x	х	х	NA	NA	х	x



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
	Method of data collection: semi-structured interviews with clients, focus groups with providers, focus groups with peer support volunteers	No. clients: 36  Characteristics: Age: 65-69: 33.3%, 70-74: 41.7%, 75-79: 11.1%, 80+: 13.9% Members female: 56% Hypertension: 86.1% Dyslipidemia: 77.8% Arthritis: 75.0 % Hearing loss: 47.2% Depression or anxiety: 33.3% Cataracts: 30.6% Acid reflux/hiatal hernia: 27.8% History of heart attack: 25.0%; Peripheral neuropathy/poor circulation: 30.6%  Other participants: 3 staff members and 3	led flexible program for community-living older adults with type two diabetes and multiple chronic conditions tailored to the individual needs. Intervention also includes monthly nurseled case conferences for team members, and nurse-led care coordination.  Delivery mode: face-to-face, alone and in a group  Intensity, frequency, and duration: 4 in-home visits, 6 monthly group sessions (3h per session) and assessment by kinesiologist  Personnel delivering support: a specialized diabetes clinic in partnership with a program coordinator,							



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
		peer support volunteers	physical activity leader from a seniors' association, peer support volunteers, a registered kinesiologist							
Sheridan 2019	Design: qualitative  Country: New Zealand and Canada  Method of data collection: face-to- face interviews with clients	Description and main diagnosis: older adults with multiple long-term care conditions  No. clients: 40  Characteristics: Age: 50-64: 17,.5%, 65-74: 22.5%, >75: 60% Kemale: 63% Comorbidities not reported  Other participants: Not applicable	Short description: patients had received general self-management support as part of their care, not further specified  Delivery mode: Unclear  Intensity, frequency, and duration: Unclear  Personnel delivering support: Unclear	x	x	x	x	x	x	x



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
Lind 2014	Design: qualitative  Country: Sweden  Method of data collection: face-to- face interviews with clients and informal caregivers	Description and main diagnosis: people with heart failure  No. clients: 7  Characteristics:  Age: mean age: 84 years  Kemale: 21%  Comorbidities not reported  Other participants: Not applicable	Short description: a Health Diary system with a digital pen with system generated alarms for daily monitoring.  Delivery mode: Telehealth Intensity, frequency, and duration: clients performed daily assessments and measurements  Personnel delivering support: A nurse instructed the patients on how to handle the equipment. The system was monitored by health professionals.	NA	NA	x	x	x	NA	NA
Schumacher 2021	Design: nested post- trial qualitative study  Country: Canada  Method of data collection: semi-	Description and main diagnosis: home care clients, often with cardiorespiratory symptoms, coronary heart disease, heart failure COPD or recent	Short description: A client-centred and integrated health systems approach to improve selfmanagement consisting of a scheduled 15-week nurse-led selfmanagement support,	x	x	x	x	х	x	NA



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
	structured interviews with clients and informal caregivers	ED visit or hospitalization  No. clients: 20  Characteristics:  • Mean age: 78 years, range from 51 to 98 years  • % female: 79%  • Comorbidities not reported  Other participants: 9 informal caregivers participated	access to a staff helpline, education on vaccines, advance care and goal planning, medication reconciliation with a pharmacist and documented recommendations to support continuity-of-care in the community. Intervention also includes interprofessional team case rounds and use of the situation-background-assessment-recommendation (SBAR) technique by the professionals involved.  Delivery mode: face-to-face and telephone  Intensity, frequency, and duration: 15-week support, 4 home visits and 4 telephone assessments. Clients could choose in which							



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
			they would like to be involved in.  Personnel delivering support: a nurse, a nursestaffed helpline, a pharmacist, care coordinators, an interprofessional team and a social worker, or psychosocial support counsellor was consulted in advance care planning in complex patients							
Vanderboom 2013	Design: mixed methods  Country: USA  Method of data collection: questionnaires and interviews with both clients, informal caregivers, and nurses	Description and main diagnosis: older adults living at home with multiple chronic conditions  No. clients: 3  Characteristics:  • Mean age (SD): 77 (4.5) years  • % female: 66%  • Comorbidities not reported	Short description: the Community Connections Program (CCP), as a short-term, intensive, team-based intervention that provided a plan of care at initial team meeting with professionals, client and informal caregiver and weekly review of goals. In a final review after 3 months, plan of care was updated, and client	x	x	x	NA	x	х	х



Author, year	Study	Population	Intervention	PRISMS						
	characteristics			Information and lifestyle advice (PRISMS 1, 2, 14)	Clinical action plans (PRISMS 3)	Clinical review and monitoring (PRISMS 4, 5)	Practical support (PRISMS 6)	Provision of equipment and advice/ support (PRISMS 7, 8)	Training in self- management skills (PRISMS 9, 10, 11, 12)	Social support (PRISMS 13)
		Other participants: 5 team members (nurses) and 3 support persons (informal caregivers) participated.	transitioned to usual home care.  Delivery mode: face-to-face team meetings and telephone calls  Intensity, frequency, and duration: at least 1 initial and 1 final team meeting 3 months after, and more meetings if necessary. Unclear how many or how regular phone calls were scheduled.  Personnel delivering support: Two nurse care coordinators, two community service providers and a public health nurse							

<sup>\*</sup>Included studies in the review of MacRae et al. 2015 were also included in the review by Maine et al. 2020. The other included studies were not included in one of the included systematic reviews.



# Kwaliteitsbeoordeling

## Systematische reviews

Tabel 2 Methodologische kwaliteit van de geïncludeerde systematische reviews (aangepaste AMSTAR 2 [Shea 2017], zie ook Supplement S2)

	1. Focused question	2. A priori study design	3. Study design explanation	4. Comprehensive search strategy	5. Duplicate study selection	6. Duplicate data extraction	7. List of excluded studies	8. Details of included studies	9. Critical appraisal	10. Funding sources of included studies	11. Appropriate methods to combine findings	12. Potential impact of methodological	13. Conflict of interest statement
People with intel	lectual disa	abilities											
MacRae 2015	Y	N	N	Y	?	Υ	N	Υ	Y	N	Y	Y	Y
Maine 2020	Y	N	N	PY	?	Υ	N	PY	Υ	N	Y	Y	Y

Y=yes, N=no, PY=partial yes, NA=not applicable



### Primaire onderzoeken

Tabel 3 Methodologische kwaliteit van de geïncludeerde kwalitatieve studies (Critical Appraisal Skills Programme (CASP) tool for qualitative studies)

Author, year	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	Overall judgement of methodological concerns
People with intell	ectual disabilit	ties								
Maine 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No concerns
Sandjojo 2019	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Minor concerns
Wilson 2011	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Unclear	No	Moderate concerns
Elderly living at	home, receiv	ing long term	care							
Andersen 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Minor concerns
Bove 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No concerns
Goransson 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Minor concerns
Markle-Reids 2016	Yes	Yes	Unclear	Yes	Yes	No	Yes	No	No	Moderate concerns
Sheridan 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No concerns
Lind 2014	Yes	Yes	Unclear	Unclear	Unclear	No	Yes	No	Yes	Moderate concerns
Schumacher 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Minor concerns
Vanderboom 2013	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Moderate concerns



## Samenvatting van de resultaten (inclusief GRADE-CERQual)

Tabel 3: Samenvatting van de kwalitatieve bevindingen betreffende de ervaren meerwaarde van zelfmanagementondersteuning door mensen met een verstandelijke beperking en ouderen met een chronische aandoening die langdurige zorg krijgen. De onderbouwing voor de GRADE-CERQual beoordeling staat in Supplement S3.

#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE- CERQual Assessment	References
1. PEOI	PLE WITH INTELLECTUAL DISABILITIES			
1	Applicable knowledge People with intellectual disabilities experience increased condition knowledge as an outcome/ (added) value of self-management support. It was also described that education tools and strategies need to be tailored to overcome barriers to self-management such as visual and memory impairments.	Moderate confidence	No/Very minor concerns regarding methodological limitations, minor concerns regarding coherence and adequacy, and moderate concerns regarding relevance, because the majority of participants had diabetes and very few other conditions were represented among the participants in the included studies.	MacRae et al. 2015; Maine et al. 2017; Maine et al. 2020; Wilson & Goodman 2011; Sandjojo et al. 2019;
2	Independence People with intellectual disabilities report the feeling of being in control of the condition and having the confidence to manage it as an outcome / (added) value of self-management support, potentially leading to independency from health professionals as well as physical independency. Participants mentioned family members and professional care staff as their main source of advice and support and a positive relationship with caregivers and involvement of family members was described to be highly important and (positive) feedback from caregivers could be a facilitator to self-management. When one of the participants was asked what he enjoyed about hillwalking, it appeared that the positive feedback from one of his caregivers was a motivational factor: "I like walkin' up the hillsSheona says I'm good at walkin'" Another participant also highlighted his good relationship with nurses "Aye, aye they make you happy some of the times and that, because they're cheerful. and they're all right with me and I'm alright with them. And I think they're happy with me cos I, I turn up for my appointments and that eh?".	Moderate confidence	No/Very minor concerns regarding methodological limitations and adequacy, minor concerns regarding coherence, and moderate concerns regarding relevance, because the majority of participants had diabetes and very few other conditions were represented among the participants in the included studies.	MacRae et al. 2015; Maine et al. 2017; Maine et al. 2020; Wilson & Goodman 2011; Sandjojo et al. 2019;
3	Being Me People with intellectual disabilities report managing their condition within the context of their life and having choices and options over management	Moderate confidence	No/Very minor concerns regarding methodological limitations, Minor concerns regarding coherence and	MacRae et al. 2015; Maine et al. 2017; Maine et al. 2020;



#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE- CERQual Assessment	References
	strategies as outcomes / (added) value of self-management support. Consistency within the team and collaboration with health care professionals and family members were identified as additional important contextual support factors. Care givers can be a role model, but people with intellectual disabilities self-managing the same condition were also mentioned to positively influence each other: "I met a girl when I was at [training location], and she said I can't try anything like that, try and change my dietthen I said, I've got a sample with me, if you [want to] try it." Participants appeared to find it relatively easy to describe what they had done differently because of the self-management programme and were able to make positive exercise and dietary choices. In addition, one study (7 participants) identified 'feeling normal' as a theme, describing that people with intellectual disabilities "just want to lead a "normal" life, in which they can live, work, and travel independently, just as people of their age without intellectual disabilities".		adequacy, and Moderate concerns regarding relevance, because the majority of participants had diabetes and very few other conditions were represented among the participants in the included studies.	Wilson & Goodman 2011; Sandjojo et al. 2019;
4	Self-Management Skills People with intellectual disabilities report managing consequences of treatment and emotions, motivation to self-management and feeling empowered as outcomes / (added) value of self-management support. Participants in included studies expressed awareness and confidence regarding diet, medication and monitoring (e.g. blood sugar levels), and condition knowledge as a result of self-management support. They also experienced accompanying emotions, mainly related to lifestyle adjustments (e.g. following a diabetes diagnosis), including frustration and a sense of loss in regard what they could do and where they could go. Empowerment to access health care, communicating with health professionals more confidently, and becoming more independent contribute to being motivated to self-management. One of the studies provided an example of a participant providing herself positive feedback despite the difficulty of the circumstances, having the intention to carry out the goal: "And I'm gonna have it framed and I'm gonna sit and look at it, and focus my mind onto losing the weight again."	Moderate confidence	No/Very minor concerns regarding methodological limitations, minor concerns regarding coherence and adequacy, and moderate concerns regarding relevance, as the majority of participants in the included studies had diabetes and very few other conditions were represented.	MacRae et al. 2015; Maine et al. 2017; Maine et al. 2020; Wilson & Goodman 2011; Sandjojo et al. 2019;
5	Optimal Health - Emotional People with intellectual disabilities experience improved self-confidence and feeling good and well as outcomes / (added) value of self- management support. Reflecting on areas in which they were successful with regard to disease management may enhance the self-confidence of people with intellectual disabilities. Besides that it may also lead to	Moderate confidence	No/Very minor concerns regarding methodological limitations and coherence, minor concerns regarding adequacy, and moderate concerns regarding relevance, because the majority of participants had diabetes	Maine et al. 2017; Maine et al. 2020; Wilson & Goodman 2011; Sandjojo et al. 2019;



#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE- CERQual Assessment	References
	increased self-worth and a sense of pride, additional to having a better mood, as was reported by participants in de study of Sandjojo et al.  Another study (Wilson et al.) reported on benefits with regard to communication as a result of being more self-confident: "the programme also appeared to increase confidence when communicating with doctors and pharmacists about their medication."		and very few other conditions were represented among the participants in the included studies.	
6	Optimal Health - Physical  None of the included studies identified outcomes within this domain.			
7	Optimal Health – Social  None of the included studies identified outcomes within this domain.  Two of the three subdomains focus on caregivers relationships with people with intellectual disabilities, and do not so much reflect experiences from people with intellectual disabilities themselves (as was the focus of this qualitative evidence synthesis).			
2. ELDE	RLY WITH LONG-TERM CONDITIONS WHO RECEIVE LONG-TERM CARE			
8	Applicable Knowledge Elderly with long-term conditions who receive long-term care experience changes in condition knowledge and report to have trustworthy and accessible information and resources as outcomes/ (added) value of self-management support. This knowledge was gained through contact with professionals (Andersen, Bove, Markle-Reid, Sheridan, Schumacher, Vanderboom) or through applications in which the elderly could search for information themselves (Goransson). The study of Sheridan reported that time and repetition facilitated successful learning. The study of Schumacher one participant who previous exposure to self-management intervention, found it useful to participate and refresh on self-management principles. Information resources, decision aids and handouts helped elderly in understanding and refreshing their knowledge. For example in the study of Bove, elderly with COPD were given laminated cards that they could use when they had anxiety.	Moderate confidence	Minor concerns regarding methodological limitations (lack of reporting in studies regarding data collection and analysis), Minor concerns regarding coherence (not all outcomes are expressed as added value), No/Very minor concerns regarding adequacy, and Minor concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in self-management support interventions).	Andersen et al. 2017; Bove et al. 2017; Goransson et al. 2018; Schumacher et al. 2021; Lind & Karlsson 2014; Vanderboom et al. 2013; Sheridan et al. 2019;
9	Independence In all studies elderly with long-term conditions who receive long-term care report to have positive relationships with professionals as an outcome /(added) value of self-management support. Which could also be seen as a prerequisite for successful self-management support, as some clients mention this as a need rather than a consequence. The feeling of being in control of the condition and having the confidence to manage was also frequently reported by the elderly. The sense of confidence was described	Moderate confidence	Minor concerns regarding methodological limitations (lack of reporting in studies regarding data collection and analysis), Minor concerns regarding coherence (not all outcomes are expressed as added value), No/Very minor concerns regarding adequacy, and Minor	Andersen et al. 2017; Bove et al. 2017; Markle-Reid et al. 2016; Goransson et al. 2018; Schumacher et al. 2021; Lind & Karlsson 2014;



#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE- CERQual Assessment	References
	as an increased sense of security that was mostly related to monitoring of health or monitoring of symptoms. Other subdomains less frequently reported as an outcome / (added) value of self-management support were; feeling holistically supported by health services, involvement of family members in self-management, equity of power with professionals, independence from professionals, 'not being a burden to family' and physical independence.		concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in self-management support interventions)	Vanderboom et al. 2013; Sheridan et al. 2019;
10	Being Me In some studies, elderly with long-term conditions who receive long-term care report to manage their condition within the context of their life as an outcome /(added) value of self-management support. An example of this from the study of Sheridan is that the elderly refer to the importance of affordability of services and that it helped them when professionals knew that and could take that into account in self-management support. Elderly also reported to feel 'normal'. In the study of Bove clients with COPD expressed relief of knowing that certain feelings, thoughts behaviors and sensations are part of having advanced COPD. Having choices and options over management strategies was also reported as an outcome /(added) value of self-management support, as in the study of Vanderboom one client refers: 'I liked that they were my decisions.'	Low confidence	Minor concerns regarding methodological limitations (lack of reporting in studies regarding data collection and analysis), Moderate concerns regarding coherence (not all outcomes are expressed as added value), Moderate concerns regarding adequacy (not many studies support each outcome), and Moderate concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in self-management support interventions).	Bove et al. 2017; Markle-Reid et al. 2016; Schumacher et al. 2021; Sheridan et al. 2019;
11	Self-Management Skills Elderly with long-term conditions who receive long-term care report motivation to self-management and feeling empowered as an outcome /(added) value of self-management support. Motivation could be a potential issue if there is lack of support in the study of Andersen. The feeling of empowerment came from either knowing what to do to manage themselves, or who to contact, or through monitoring. Elderly also reported to be able to manage their emotions, stress and consequences of treatment as an outcome /(added) value of self-management support.	Moderate confidence	Minor concerns regarding methodological limitations (lack of reporting in studies regarding data collection and analysis), Minor concerns regarding coherence not all outcomes are expressed as added value), Minor concerns regarding adequacy (not all outcomes are strongly represented throughout the studies), and Minor concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in selfmanagement support interventions).	Andersen et al. 2017; Bove et al. 2017; Markle-Reid et al. 2016; Goransson et al. 2018; Schumacher et al. 2021; Lind & Karlsson 2014; Vanderboom et al. 2013;
12	Optimal Health - Physical Elderly with long-term conditions who receive long-term care report preventing deterioration and an improved health in general as outcomes	Moderate confidence	Minor concerns regarding methodological limitations (lack of reporting in studies regarding data	Schumacher et al. 2021; Lind & Karlsson 2014;



#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE- CERQual Assessment	References
	/(added) value of self-management support. In the study of Lind, a few elderly with heart failure expressed a sense of less unstable heart, despite their multimorbid state, while they used digital monitoring.		collection and analysis), Minor concerns regarding coherence (not all outcomes are expressed as added value), Minor concerns regarding adequacy, and Minor concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in selfmanagement support interventions)	Vanderboom et al. 2013;
13	Optimal Health - Emotional Elderly with long-term conditions who receive long-term care report to have an improved confidence/self-efficacy and to feel good and well as outcomes /(added) value of self-management support. Several studies report that elderly felt more confident when (more) time was spent on reviewing information and verifying understanding. Sheridan: "She said written information about a healthy diet had not had an impact, but having the dietician visit the supermarket with her and show her how to read the labels on different food items gave her the confidence to make healthier choices."	Moderate confidence	Minor concerns regarding methodological limitations (lack of reporting in studies regarding data collection and analysis), Minor concerns regarding coherence (not all outcomes are expressed as added value), Minor concerns regarding adequacy (improved confidence was stronger represented than other outcomes), and Minor concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in selfmanagement support interventions).	Andersen et al. 2017; Bove et al. 2017; Goransson et al. 2018; Schumacher et al. 2021; Lind & Karlsson 2014; Vanderboom et al. 2013; Sheridan et al. 2019;
14	Optimal Health - Social  None of the included studies identified outcomes within this domain. Two of the three subdomains focus on caregivers relationships with elderly, and do not so much reflect experiences from elderly themselves (as was the focus of this qualitative evidence synthesis).			



#### **Conclusies**

#### Mensen met een verstandelijke beperking

Mensen met een verstandelijke beperking ervaren waarschijnlijk meerwaarde van
zelfmanagementondersteuning op het gebied van toegepaste kennis, onafhankelijkheid,
"zichzelf zijn", zelfmanagementvaardigheden en emotionele gezondheid (GRADECERQual: moderate level of confidence). Op basis van de geïdentificeerde onderzoeken kon
geen onderscheid gemaakt worden tussen mensen met verstandelijke beperking die thuis
wonen of die in een instelling wonen.

#### Ouderen met een chronische aandoening

- Ouderen met een chronische aandoening die gebruik maken van langdurige zorg in een thuissituatie ervaren waarschijnlijk meerwaarde van zelfmanagementondersteuning op het gebied van toegepaste kennis, onafhankelijkheid, zelfmanagementvaardigheden en fysieke en emotionele gezondheid (GRADE-CERQual: moderate level of confidence). Zij ervaren mogelijk ook meerwaarde op het gebied van 'zichzelf zijn' (GRADE-CERQual: low level of confidence).
- Er werden geen studies geïdentificeerd die de ervaren meerwaarde van zelfmanagementondersteuning onderzochten onder ouderen met een chronische aandoening die langdurige zorg krijgen in een instelling.



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# **Supplement**

## S1. Uitgesloten onderzoeken

Tabel Overzicht van uitgesloten onderzoeken (n=291)

Reports not retrieved (n=35)		
Reports not retrieved (n=35) AHRQ 2009		
Alakeson 2010		
Anonymous 2003		
Archer 2018		
Backman 2003		
Badger 2002		
Baird 2003		
Beltz 2001		
Bendixen 2006		
Benjamin 2007		
Borda 2018		
Burgiss 2003		
Cahill 2017		
Carter 2010		
Chan 2013		
Chen 2016		
Cintra 2005		
Cohen-Mansfield 2007		
Coker 2009		
Da Silva 2003		
de Klerk 1996		
Gaidys 2013		
González Marcos 2005		
Jones 2020		
Kajander 2017		
King 2006		
King-Sears 2005		
Metzger 2012		
Mitchell 1997		
Muller-Mundt 2011		
Nebeker 2008		
Rees 2010		
Unknown 2006		
Vandenberg 2019		
Williams 2011		
Reports excluded (n=255)	Reason for exclusion	
Aarts 2015	wrong intervention	



Abramsohn 2019 Algilani 2017	wrong population
Algilani 2017	
· ·	wrong population - no long-term care
Allen 2018	wrong population
Aman 2007	wrong study design
Andersen 2017	duplicate
Andersen 2017	duplicate
Andersen 2017	wrong intervention
Andersen 2018	duplicate
Andersen 2018	wrong intervention
Andersson 2019	wrong study design
Angwenyi 2019	wrong population
Anuruang 2014	wrong study design
Athilingam 2018	wrong outcome
Aw 2019	wrong study design
Aweko 2018	wrong population - no long-term care
Bach 2013	wrong study design
Backman 1999	wrong intervention
Backman 2006	wrong intervention
Baird 2003	wrong intervention
Ball 2004	wrong outcome
Banbury 2014	wrong outcome
Barker 2016	wrong study design
Barry Hultquist 2015	wrong study design
Bartels 2018	wrong intervention
Beentjes 2020	wrong outcome
Bendixen 2018	wrong intervention
Beristain Iraola 2021	wrong population type
Bernardes 2019	wrong intervention
Bernhard 2017	wrong population - no long-term care
Beverly 2008	wrong population - no long-term care
Beverly 2011	wrong intervention
Bhattarai 2019	wrong study design
Bhattarai 2020	wrong population type
Black 2013	wrong outcome
Black 2015	wrong outcome
Blancafort Alias 2021	wrong study design
Blickem 2013	duplicate
Blickem 2013	wrong population
Boer 2019	wrong study design



Bolscher-Niehuis 2021 wrong population - no long-term care  Bond 2006 wrong outcome  Booker 2021 wrong intervention  Boots 2018 wrong study design  Boult 2010 wrong study design  Br 2013 wrong intervention  Brazil 2020 wrong study design  Brenan 2010 wrong outcome  Broadbent 2012 wrong intervention  Browder 2000 wrong outcome  Brown 2007 duplicate  Brown 2007 wrong population  Brunec 1997 language  Brunk 2017 wrong population - no long-term care  Buck 2019 wrong intervention  Bustamante 2018 wrong intervention  Cadzow 2013 wrong population - no long-term care  Bustamante 2018 wrong population - age  Carbone 2007 wrong population - age  Carbone 2007 wrong population - age  Castro 2002 wrong intervention  Cardol 2012 wrong intervention  Cardol 2012 wrong intervention  Cardol 2018 wrong population - age  Castro 2002 wrong intervention  Cardol 2019 wrong intervention  Cardol 2010 wrong population - age  Castro 2002 wrong intervention  Cardol 2014 wrong population - age  Castro 2002 wrong study design  Chang 2016 wrong study design  Chang 2010 wrong population - no long-term care  Clark 2004 wrong population - no long-term care  Caleland 2021 wrong population - no long-term care  Coco 2019 wrong population - no long-term care  Codling 2011 wrong population - no long-term care		
Bond 2006 wrong outcome  Booker 2021 wrong intervention  Boots 2018 wrong study design  Boult 2010 wrong study design  Br 2013 wrong intervention  Brazil 2020 wrong study design  Brenana 2010 wrong outcome  Broadbent 2012 wrong intervention  Browder 2000 wrong outcome  Brown 2007 duplicate  Brown 2007 wrong population  Brunec 1997 language  Brunk 2019 wrong population - no long-term care  Buck 2019 wrong intervention  Burkow 2013 wrong population  Burkow 2013 wrong population - age  Carbone 2007 wrong intervention  Cadzow 2013 wrong population - age  Carbone 2007 wrong intervention  Cardol 2012 wrong intervention  Chapla 2015 wrong population - no long-term care  Casida 2018 wrong population - no long-term care  Casida 2018 wrong population - age  Castro 2000 wrong intervention  Cardol 2012 wrong intervention  Chapla 2015 wrong population - no long-term care  Chapla 2016 wrong study design  Chang 2010 wrong study design  Chang 2006 wrong study design  Chang 2010 wrong study design  Chapman 2014 wrong outcome  Chang 2010 wrong study design  Chapman 2014 wrong population - no long-term care  Clark 2004 wrong intervention  Clark 2014 wrong population - no long-term care  Clark 2004 wrong intervention  Clark 2014 wrong population - no long-term care  Clark 2004 wrong intervention  Clark 2015 wrong population - no long-term care  Clark 2004 wrong intervention  Clark 2005 wrong population - no long-term care  Clark 2004 wrong population - no long-term care  Clark 2005 wrong population - no long-term care  Clark 2004 wrong intervention  Coco 2019 wrong population - no long-term care  Codling 2011 wrong population - no long-term care	Bolenius 2017	wrong study design
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Boots 2018 wrong study design  Boult 2010 wrong study design  Br 2013 wrong intervention  Brazil 2020 wrong study design  Brennan 2010 wrong outcome  Broadbent 2012 wrong outcome  Browder 2000 wrong outcome  Brown 2007 duplicate  Brown 2007 wrong population - no long-term care  Buck 2019 wrong intervention  Burkow 2013 wrong population - age  Bustamante 2018 wrong intervention  Carlon 2001 wrong intervention  Carlol 2012 wrong intervention  Carlol 2012 wrong population - age  Carlol 2012 wrong intervention  Carlol 2012 wrong intervention  Carlol 2012 wrong intervention  Carlol 2010 wrong intervention  Carlol 2011 wrong population - age  Carlol 2012 wrong intervention  Carlol 2010 wrong intervention  Carlol 2011 wrong population - no long-term care  Carlol 2010 wrong intervention  Carlol 2011 wrong intervention  Carlol 2012 wrong intervention  Carlol 2014 wrong population - no long-term care  Casida 2018 wrong population - age  Castro 2002 wrong intervention  Chang 2006 wrong study design  Chang 2010 wrong study design  Chang 2010 wrong study design  Chapman 2014 wrong outcome  Chapman 2014 wrong outcome  Chapman 2014 wrong population - no long-term care  Clark 2004 wrong population - no long-term care  Clark 2015 wrong population - no long-term care  Clark 2014 wrong population - no long-term care  Clark 2015 wrong population - no long-term care  Clark 2015 wrong population - no long-term care  Clark 2015 wrong population - no long-term care  Cleland 2021 wrong population - no long-term care  Cleland 2021 wrong population - no long-term care  Cleland 2021 wrong population - no long-term care  Codling 2011 wrong population - no long-term care	Bond 2006	wrong outcome
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Coco 2019 wrong population - no long-term care  Codling 2011 wrong outcome  Codling 2015 wrong intervention	Clark 2015	wrong population - age
Codling 2011 wrong outcome  Codling 2015 wrong intervention	Cleland 2021	wrong population
Codling 2015 wrong intervention	Coco 2019	wrong population - no long-term care
	Codling 2011	wrong outcome
Cohen 2010	Codling 2015	wrong intervention
Collen 2019 wrong study design	Cohen 2019	wrong study design



Cohen-Mansfield 2006	wrong study design
Cohen-Mansfield 2007	wrong outcome
Cohen-Mansfield 2007	wrong study design
Cohen-Mansfield 2007	wrong study design
Cole 2016	duplicate
Cole 2016	wrong study design
Coleman 2004	wrong study design
Coleman 2014	duplicate
Coleman 2014	wrong study design
Colungo 2018	wrong population - no long-term care
Convery 2019	wrong population - no long-term care
Cooper 2010	wrong population - no long-term care
Cooper 2017	wrong population - no long-term care
Cooper 2020	wrong population - no long-term care
Corbett 2020	wrong population
Cornelison 2019	wrong study design
Coughlan 2012	wrong population - no long-term care
Cramm 2017	wrong study design
Cross 2016	wrong study design
Culjis 2013	wrong population
da Costa 2014	language
da Silva Jacobi 2016	wrong population - no long-term care
Dadosky 2018	wrong population
Dannenberg 2016	wrong study design
Davis 2008	wrong population - no long-term care
Davis 2016	wrong intervention
Davisson 2018	wrong population type
de la Luz Martinez-Maldonado 2007	wrong study design
de Oliva Menezes 2012	language
De San Miguel 2013	wrong study design
Dessureault 2021	wrong population - no long-term care
Dhillon 2016	duplicate
Dhillon 2016	wrong study design
Dickerson 2011	wrong study design
Doekhie 2019	wrong study design
Donald 2019	duplicate
Donald 2019	wrong population - no long-term care
Duggan 2015	wrong population - no long-term care
Dutzi 2019	wrong population



Early 2009	wrong population - no long-term care
Fazio 2020	wrong intervention
Fera 2008	wrong study design
Fex 2009	wrong population - age
Fischer 2012	wrong population - no long-term care
Foster 2018	wrong population - no long-term care
Francis 2020	wrong population - age
Gallagher-Thompson 2012	wrong outcome (not about collaboration)
Gallant 2010	wrong population type
Gilmartin 2010	wrong intervention
Gong 2019	wrong outcome
Gramstad 2014	wrong intervention
Hage 2005	wrong study design
Hammerschmidt 2010	language
Hardiman 2018	wrong intervention
Harkes 2014	wrong intervention
Harry 2017	wrong intervention
Haslbeck 2015	wrong population - no long-term care
Heisler 2009	wrong population - no long-term care
Heller 2012	wrong study design
Hole 2013	wrong outcome
Holm 2014	wrong outcome
Holm 2014	wrong outcome
Hsu 2010	wrong study design
Huijbregts 2009	wrong population - no long-term care
Hwang 2009	wrong study design
Islam 2013	wrong population - age
Jacelon 2018	wrong outcome
Jager 2018	wrong population - no long-term care
Jamieson 2021	wrong population
Jiang 2020	wrong population - no long-term care
Jiang 2021	wrong population - no long-term care
Jillings 2005	wrong outcome
Jones 2016	wrong population - no long-term care
Jones 2017	wrong population - age
Kaufman 2003	wrong study design
Keller 2019	wrong population - age
Kellett 2007	wrong intervention
Kennedy 2016	wrong population - no long-term care



Kerr 2010 wrong population - no long-term care Kim 2018 wrong population Kim 2021 duplicate Kim 2021 wrong population Kristense 2018 wrong population Kristense 2018 wrong population Kristense 2018 wrong population Kristense 2018 wrong population Laraggy 2020 wrong intervention Laraggy 2020 wrong intervention Laraggy 2020 wrong intervention Letter 2018 wrong intervention Letter 2018 wrong intervention Letter 2018 wrong intervention Letter 2010 wrong study design Levine 2006 wrong intervention Li 2018 wrong study design Lind 2013 wrong population type Lind 2013 wrong population Liu 2020 wrong population Liu 2020 wrong population - no long-term care Liu 2021 wrong population - no long-term care Loeb 2003 wrong population - no long-term care Long 2016 wrong population - no long-term care Long 2016 wrong population - no long-term care Lorg 2017 wrong population - no long-term care Lu 2014 wrong population - no long-term care Lu 2012 wrong study design Machado 2015 wrong population - no long-term care MacKichan 2011 wrong study design Mansson 2020 wrong population - no long-term care MacKichan 2011 wrong study design McCulloch 2012 wrong study design McCulloch 2012 wrong study design McCulloch 2012 wrong study design McCulloch 2015 wrong population - no long-term care McCulloch 2010 wrong study design McCulloch 2010 wrong intervention McNally 2015 wrong intervention McNally 2006 wrong intervention McNally 2006 wrong intervention Milne 2000 wrong population - no long-term care Minstodani 2013 wrong population - no long-term care Minstodani 2013 wrong population - no long-term care Minstodani 2013 wrong population - no long-term care		
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Möller-Mundt 2011         wrong study design           Nabors 2021         wrong outcome           Naccashian 2015         wrong population - no long-term care           Nonnemacher 2008         wrong intervention           Nonnemacher 2011         wrong population - no long-term care           O'Neill 2020         wrong intervention           Or 2011         wrong outcome           Orellano-Colon 2020         wrong population - no long-term care           Pallisera 2018         wrong intervention           Park 2017         wrong intervention           Park 2017         wrong population - no long-term care           Pettersson 2019         wrong population - no long-term care           Pettersson 2021         wrong population - no long-term care           Pettersson 2021         wrong study design           Phelan 2002         wrong study design           Phelan 2006         wrong study design           Piamjariyakul 2012         wrong population - age           Picard 2014         wrong population           Pratt 2017         wrong population           Radhakrishnan 2016         wrong population - no long-term care           Reindl 2016         wrong intervention           Robben 2013         wrong intervention           Robinson 2		
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Schumacher 2018 wrong intervention	Schoberer 2016	wrong outcome
	Schrank 2012	wrong population
Schwarz 2020 wrong population	Schumacher 2018	wrong intervention
	Schwarz 2020	wrong population
Scott 2019 wrong population	Scott 2019	wrong population
Sefcik 2018 wrong population - no long-term care	Sefcik 2018	wrong population - no long-term care



Shao 2016	wrong population - no long-term care
Shen 2013	wrong population - no long-term care
Shepherd-Banigan 2014	wrong population - no long-term care
Smallfield 2021	wrong outcome
Son 2020	wrong intervention
Song 2010	wrong outcome
Stalker 1997	wrong intervention
Stiles-Shields 2019	wrong outcome
Swenson 2019	wrong outcome
Tilley 2020	wrong intervention
Vargiu 2019	wrong population type
Vaughan Dickson 2015	wrong population - no long-term care
Walters 2012	wrong population - no long-term care
Watchman 2019	wrong outcome
Weiss 2019	wrong population
White 2013	wrong population - no long-term care
Whitehead 2016	duplicate
Wilde 2015	wrong population
Wolfe 1996	wrong intervention
Yang 2021	wrong population type
Yates 2019	wrong outcome

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## S2. Template (aangepaste) AMSTAR-2 tool

Domain	Instructions (Check all that apply)	Judgement	Comments (optional)
Focused question	1. Did the review address a clearly focused question?	□Yes	
		□No	
Protocol	2. Did the report of the review contain an explicit statement that the review	□Yes	
	methods were established prior to the conduct of the review and did the report	□Partial Yes	
	justify any significant deviations from the protocol?	□No	
	For Partial Yes:		
	The authors state that they had a written protocol or guide that included ALL the		
	following:		
	☐ review question(s)		
	☐ a search strategy		
	☐ inclusion/exclusion criteria		
	☐ a risk of bias assessment		
	For Yes:		
	As for partial yes, plus the protocol should be registered and should also have		
	specified:		
	☐ a meta-analysis/synthesis plan, if appropriate, <i>and</i>		
	☐ a plan for investigating causes of heterogeneity		
	☐ justification for any deviations from the protocol		
Study design	3. Did the review authors explain their selection of the study designs for inclusion	□Yes	
explanation	in the review?	⊠No	
Comprehensive	4. Did the review authors use a comprehensive literature search strategy?	□Yes	
search strategy		□Partial Yes	
	For Partial Yes (all the following):	□No	
	☐ searched at least 2 databases (relevant to research question)		
	provided key words and/or search strategy		
	☐ justified publication restrictions (e.g. language)		
	For Yes, should also have (all the following):		
	☐ searched the reference lists / bibliographies of included studies		
	☐ searched trial/study registries		
	☐ included/consulted content experts in the field		
	☐ where relevant, searched for grey literature		



	□ conducted search within 24 months of completion of the review		
Duplicate study	5. Did the review authors perform study selection in duplicate?	□Yes	
selection		□No	
	For Yes, either ONE of the following:		
	$\square$ at least two reviewers independently agreed on selection of eligible studies and		
	achieved consensus on which studies to include		
	$\square$ OR two reviewers selected a sample of eligible studies <u>and</u> achieved good		
	agreement (at least 80 percent), with the remainder selected by one reviewer.		
Duplicate data	6. Did the review authors perform data extraction in duplicate?	□Yes	
extraction		□No	
	For Yes, either ONE of the following:		
	□at least two reviewers achieved consensus on which data to extract from		
	included studies		
	$\square$ OR two reviewers extracted data from a sample of eligible studies <u>and</u>		
	achieved good agreement (at least 80 percent), with the remainder		
	extracted by one reviewer.		
Details of excluded	7. Did the review authors provide a list of excluded studies and justify the	□Yes	
studies	exclusions?	□Partial Yes	
		□No	
	For Partial Yes:		
	☐ provided a list of all potentially relevant studies that were read in full-text form		
	but excluded from the review		
	For Yes, must also have:		
	☐ Justified the exclusion from the review of each potentially relevant study		
Description of	8. Did the review authors describe the included studies in adequate detail?	□Yes	
included studies		□Partial Yes	
	For Partial Yes (ALL the following):	□No	
	☐ described populations		
	□ described interventions (N/A)		
	□ described comparators (N/A)		
	☐ described outcomes		
	☐ described research designs		
	For Yes, should also have ALL the following:		
	☐ described population in detail		
	☐ described intervention in detail (including doses where relevant)		
	described intervention in detail (including doses where relevant)		
	described comparator in detail (including doses where relevant)		
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	☐ timeframe for follow-up		
Critical appraisal	9. Did the review authors use a satisfactory technique for assessing potential methodological limitations in individual studies that were included in the review?	□Yes □Partial Yes □No	
Funding sources	10. Did the review authors report on the sources of funding for the studies included in the review?	□Yes □No	
	For Yes  Must have reported on the sources of funding for individual studies included in the review. Note: Reporting that the reviewers looked for this information but it was not reported by study authors also qualifies		
Evidence synthesis	11. Does the method of evidence synthesis matches the research aim (i.e. to assemble and pool data [Integration/Aggregation/Summation] or to develop concepts and theories that integrate the themes described in the primary qualitative studies [Interpretation and theory development])  For Yes:  ☐ The authors justified combining the data in a meta-analysis ☐ AND they used an appropriate method to combine study results.	□Yes □No	
Risk of bias and interpretation results	12. Did the review authors discuss the potential impact of methodological limitations in individual studies on the results of the evidence synthesis?	□Yes □No	
Conflicts of interest	13. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?  For Yes:	□Yes □No	
	☐ The authors reported no competing interests OR ☐ The authors described their funding sources and how they managed potential conflicts of interest		



## S3. Evidence profiel

#	Finding	Methodologica limitations	Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
	OPLE WITH INTELLECTUAL DISABILITIES						
1	Applicable knowledge People with intellectual disabilities experience increased condition knowledge as an outcome/ (added) value of self-management	No/Very minor concerns	Minor concerns	Minor concerns	Moderate concerns	Minor concerns	MacRae et al. 2015; Maine et al.
	support. It was also described that education tools and strategies	Explanation: 2	Explanation:	Explanation:	Explanation:	Explanation:	2017; Maine
	need to be tailored to overcome barriers to self-management such	reviews with no	Minor concerns	Minor concerns	Moderate	No/Very minor	et al. 2020;
	as visual and memory impairments.	major	regarding	regarding	concerns	concerns	Sandjojo et
		U	coherence	adequacy. All 5		regarding	al. 2019;
		concerns and 3	because	included studies		methodological	Wilson &
		studies, of which 1 with no			because the	limitations,	Goodman
			we assessed	theme, although in two of them		minor concerns	2011;
		-	framework)	the data were	participants had	regarding	
		minor	were not always		diabetes. Three		
		methodological		addressing the			
		concerns, 1 with	'added value' by		studies (2	concerns	
		moderate	the participants	, indirectly	reviews and 1	regarding	
		methodological	but were	(Sanjojo et al.;	. , , , , , , , , , , , , , , , , , , ,	relevance,	
		, ,	sometimes	Wilson et al.)	specifically	because the	
		due to missing	stated as a need	i	focused on	majority of	
		information)	or prerequisite for (more)		participants with intellectual	participants had	
			effective self-		disabilities	very few other	
			management.			conditions were	
					Of the other	represented	
					two (primary)	among the	
					studies one	participants in	
						the included	
					participants) did	studies.	
					not address a		
					certain		
					condition outside having		



#	Finding	Methodologica limitations	l Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
					an intellectual disability and the other addressed having any chronic comorbidity.		
2	Independence People with intellectual disabilities report the feeling of being in control of the condition and having the confidence to manage it as an outcome / (added) value of self-management support, potentially leading to independency from health professionals as well as physical independency. Participants mentioned family members and professional care staff as their main source of advice and support and a positive relationship with caregivers and involvement of family members was described to be highly important and (positive) feedback from caregivers could be a facilitator to self-management. When one of the participants was asked what he enjoyed about hillwalking, it appeared that the positive feedback from one of his caregivers was a motivational factor: "I like walkin' up the hillsSheona says I'm good at walkin'" Another participant also highlighted his good relationship with nurses "Aye, aye they make you happy some of the times and that, because they're cheerful. and they're all right with me and I'm alright with them. And I think they're happy with me cos I, I turn up for my appointments and that eh?".	major methodological concerns and 3 studies, of which 1 with no methodological concerns, 1 with minor methodological concerns, 1 with moderate methodological concerns (mainly due to missing information)	regarding coherence because	findings with regard to independance. Especially on the subthemes sfeeling in control of the condition and having confidence to manage it as well a positive relationship with caregivers and involvement of family members the data were rich.	concerns regarding relevance because the majority of studies participants had diabetes. Three of the included studies (2 reviews and 1 primary study) specifically focused on participants with intellectual disabilities having diabetes. Of the other two (primary) studies one	coherence, and moderate concerns regarding relevance, because the majority of participants had diabetes and very few other conditions were represented among the participants in the included	MacRae et al. 2015; Maine et al. 2017; Maine et al. 2020; Sandjojo et al. 2019; Wilson & Goodman 2011;



#	Finding	Methodologica limitations	Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
					not address a certain condition outside having an intellectual disability and the other addressed having any chronic comorbidity.		
3	Being Me People with intellectual disabilities report managing their condition within the context of their life and having choices and options over management strategies as outcomes / (added) value of self-management support. Consistency within the team and collaboration with health care professionals and family members were identified as additional important contextual support factors. Care givers can be a role model, but people with intellectual disabilities self-managing the same condition were also mentioned to positively influence each other: "I met a girl when I was at [training location], and she said I can't try anything like that, try and change my dietthen I said, I've got a sample with me, if you [want to] try it." Participants appeared to find it relatively easy to describe what they had done differently because of the self-management programme and were able to make positive exercise and dietary choices. In addition, one study (7 participants) identified 'feeling normal' as a theme, describing that people with intellectual disabilities "just want to lead a "normal" life, in which they can live, work, and travel independently, just as people of their age without intellectual disabilities".	minor methodological concerns, 1 with moderate methodological concerns (mainly due to missing information)	regarding coherence because outcomes that we assessed (from the Boger framework) were not always identified as an 'added value' by the participants but were sometimes	the context of one's life and having choices sand options over management strategies were described by 2 reviews and 2 distudies (n=110 participants) with adequate richness of data	Moderate concerns  Explanation: Moderate concerns regarding relevance because the majority of studies participants had diabetes. Three of the included studies (2 reviews and 1 primary study) specifically focused on participants with intellectual disabilities having diabetes.	adequacy, and Moderate concerns regarding relevance, because the majority of participants had	MacRae et al. 2015; Maine et al. 2017; Maine et al. 2020; Sandjojo et al. 2019; Wilson & Goodman 2011;



#	Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
				by a single studie (n=7 participants).	two (primary) studies one (n=7 participants) did not address a certain condition outside having an intellectual disability and the other addressed having any chronic comorbidity.	among the participants in the included studies.	
4	Self-Management Skills People with intellectual disabilities report managing consequences of treatment and emotions, motivation to self-management and feeling empowered as outcomes / (added) value of self-management support. Participants in included studies expressed awareness and confidence regarding diet, medication and monitoring (e.g. blood sugar levels), and condition knowledge as a result of self-management support. They also experienced accompanying emotions, mainly related to lifestyle adjustments (e.g. following a diabetes diagnosis), including frustration and a sense of loss in regard what they could do and where they could go. Empowerment to access health care, communicating with health professionals more confidently, and becoming more independent contribute to being motivated to self-management. One of the studies provided an example of a participant providing herself positive feedback despite the difficulty of the circumstances, having the intention to carry out the goal: "And I'm gonna have it framed and I'm gonna sit and look at it, and focus my mind onto losing the weight again."	reviews with no major methodological concerns and 3 studies, of which 1 with no methodological concerns, 1 with minor methodological concerns, 1 with moderate methodological concerns (mainly due to missing	regarding coherence because outcomes that we assessed (from the Boger framework) were not always identified as an 'added value' by the participants but were sometimes stated as a need	sand one of the primary studies	Moderate concerns  Explanation: Moderate concerns regarding relevance because the majority of distudies aparticipants had diabetes. Three of the included studies (2 reviews and 1 primary study) specifically focused on	adequacy, and	MacRae et al. 2015; Maine et al. 2017; Maine et al. 2020; Sandjojo et al. 2019; Wilson & Goodman 2011;



#	Finding	Methodologica limitations	l Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
			for (more) effective self- management.	were less extensively described by two studies each.	having diabetes. Of the other	diabetes and very few other conditions were represented.	
5	Optimal Health - Emotional People with intellectual disabilities experience improved self-confidence and feeling good and well as outcomes / (added) value of self-management support. Reflecting on areas in which they were successful with regard to disease management may enhance the self-confidence of people with intellectual disabilities. Besides that it may also lead to increased self-worth and a sense of pride, additional to having a better mood, as was reported by participants in de study of Sandjojo et al. Another study (Wilson et al.) reported on benefits with regard to communication as a result of being more self-confident: "the programme also appeared to increase confidence when communicating with doctors and pharmacists about their medication."	studies, of which 1	contradictory of unclear results and results of al included studies	adequacy Ilbecause self- s confidence was mentioned in 4 studies (117 participants in total), of which two (n=42 participants)	Moderate concerns regarding relevance because the majority of studies participants had diabetes. Two of the included studies (1	adequacy, and	Maine et al. 2017; Maine et al. 2020; Sandjojo et al. 2019; Wilson & Goodman 2011;



#	Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
		concerns (mainly due to missing information)	identify the outcomes (themes within the Boger framework) as an 'added value'.	described by a	with intellectual disabilities having diabetes Of the other	very few other.conditions were represented among the participants in the included	
6	Optimal Health - Physical  None of the included studies identified outcomes within this domain.				,		
7 2 FLDI	Optimal Health - Social  None of the included studies identified outcomes within this domain. Two of the three subdomains focus on caregivers relationships with people with intellectual disabilities, and do not so much reflect experiences from people with intellectual disabilities themselves (as was the focus of this qualitative evidence synthesis).  ERLY WITH LONG-TERM CONDITIONS WHO RECEIVE LONG-TER	PM CAPE					



#	Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
8	Applicable Knowledge Elderly with long-term conditions who receive long-term care experience changes in condition knowledge and report to have trustworthy and accessible information and resources as outcomes/ (added) value of self-management support. This knowledge was gained through contact with professionals (Andersen, Bove, Markle-Reid, Sheridan, Schumacher, Vanderboom) or through applications in which the elderly could search for information themselves (Goransson). The study of Sheridan reported that time and repetition facilitated successful learning. The study of Schumacher one participant who previous exposure to self-management intervention, found it useful to participate and refresh on self-management principles. Information resources, decision aids and handouts helped elderly in understanding and refreshing their knowledge. For example in the study of Bove, elderly with COPD were given laminated cards that they could use when they had anxiety.	limitations because some studies did not report adequate information about data collection and data analysis (of which one was mixed methods). Most studies did not report on reflexivity of the researcher(s).	Explanation: Minor concerns regarding coherence because outcomes that we assessed (from the Boger framework) were not always identified as an 'added value' by the participants but were sometimes stated as a need	Most studies had adequate richness of data two studies (Lind and Vanderboom) were less rich due to low number of rincluded elderly (Vanderboom) or information presented was anot as in-depth as it focused on using a new technology rather than the outcomes or added values of selfmanagement support (Lind).	regarding relevance , because from most studies it is not clear whether the elderly receive daily care, though it is likely. There is also a wide variety in self- management support, some describe interventions aimed at a specific chronic disease such as	studies regarding data collection and analysis), Minor concerns regarding coherence (not all outcomes are expressed as added value), No/Very minor concerns regarding adequacy, and Minor concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in	Andersen et al. 2017; Bove et al. 2017; Goransson et al. 2018; Lind & Karlsson 2014; Schumacher et al. 2021; Sheridan et al. 2019; Vanderboom et al. 2013;



#	Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
9	to monitoring of health or monitoring of symptoms. Other subdomains less frequently reported as an outcome / (added) value	limitations because some studies did not report adequate information about data collection and data analysis (two mixed methods studies). Most studies did not report on reflexivity of the researcher(s).	Explanation: Minor concerns regarding coherence because outcomes that we assessed (from the Boger framework) were not always identified as an 'added value' by the participants but were sometimes stated as a need	Subdomains of Independece were mentioned in 9 studies. Most studies had adequate richness of data sthree studies (Lind, Markle-Reid, Vanderboom) were less rich due to low Inumber of included elderly (Vanderboom); information presented was	regarding relevance dbecause from most studies it is not clear whether the ,elderly receive daily care, though it is likely. There is also a wide variety in self- management support, some describe interventions aimed at a specific chronic disease such as	studies regarding data collection and analysis), Minor concerns regarding coherence (not all outcomes are expressed as added value), No/Very minor concerns regarding adequacy, and Minor concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in	Andersen et al. 2017; Bove et al. 2017; Goransson et al. 2018; Lind & Karlsson 2014; Markle-Reid et al. 2016; Schumacher et al. 2021; Sheridan et al. 2019; Vanderboom et al. 2013;



#	Finding	Methodologica limitations	l Coherence		Relevance	GRADE- CERQual assessment of confidence	References
10	Being Me In some studies, elderly with long-term conditions who receive long-term care report to manage their condition within the context of their life as an outcome /(added) value of self-management support. An example of this from the study of Sheridan is that the elderly refer to the importance of affordability of services and that it helped them when professionals knew that and could take that into account in self-management support. Elderly also reported to feel 'normal'. In the study of Bove clients with COPD expressed relief of knowing that certain feelings, thoughts behaviors and sensations are part of having advanced COPD. Having choices and options over management strategies was also reported as an outcome /(added) value of self-management support, as in the study of Vanderboom one client refers: 'I liked that they were my decisions.'	Explanation: Minor concerns regarding methodological limitations because one mixed methods study did not adequately justify methods for qualitative data collection and analysis.	Explanation: Moderate concerns regarding coherence because outcomes in the domain 'Being me' were more interpretive,	outcomes in the domain 'Being me' were reported in few studies (1 to 4) and with	the elderly receive daily care, though it is likely. There is also a wide variety in self-	studies regarding data collection and analysis), Moderate sconcerns regarding coherence (not all outcomes are expressed as added value), Moderate concerns regarding adequacy (not many studies support each outcome), and Moderate	et al. 2021; Sheridan et al. 2019;



#	Finding	Methodologica limitations	l Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
						wide variety in self- management support interventions).	
11	Self-Management Skills Elderly with long-term conditions who receive long-term care report motivation to self-management and feeling empowered as an outcome /(added) value of self-management support.  Motivation could be a potential issue if there is lack of support in the study of Andersen. The feeling of empowerment came from either knowing what to do to manage themselves, or who to contact, or through monitoring. Elderly also reported to be able to manage their emotions, stress and consequences of treatment as an outcome /(added) value of self-management support.	Explanation: Minor concerns regarding methodological limitations because some studies did not report adequate information about data collection and data analysis (of which one was mixed methods). Most studies did not report on reflexivity of the researcher(s).	Explanation: Minor concerns regarding coherence because outcomes that we assessed	regarding adequacy because motivation to self- management is clearly sdescribed in 5 studies. Other outcomes are not as strongly reflected in the results.	regarding relevance because from most studies it is not clear whether the elderly receive daily care, though it is likely. There is also a wide variety in self- management support, some describe interventions aimed at a	studies regarding data collection and analysis), Minor concerns regarding coherence not all outcomes are expressed as added value), Minor concerns regarding adequacy (not all outcomes are strongly represented throughout the studies), and Minor concerns regarding	



#	Finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
					symptom of COPD (anxiety).	(unclear, but likely, that elderly received daily care and a wide variety in self- management support interventions).	
	Elderly with long-term conditions who receive long-term care report preventing deterioration and an improved health in general as outcomes /(added) value of self-management support. In the study of Lind, a few elderly with heart failure expressed a sense of less unstable heart, despite their multimorbid state, while they used digital monitoring.	limitations because some studies did not report adequate information about data collection and data analysis (of which one was mixed methods). Most studies did	Explanation: Minor concerns regarding coherence because outcomes that we assessed (from the Boger framework) were not always identified as an 'added value' by	regarding adequacy because outcomes do not strongly reflect in studies s(improved health in 2 studies, printing	regarding relevance because from most studies it is not clear whether the elderly receive daily care, though it is likely. There is	studies regarding data collection and analysis), Minor concerns regarding	Karlsson 2014; Schumacher et al. 2021; Vanderboom et al. 2013;
		reflexivity of the researcher(s).	but were sometimes stated as a need or prerequisite for (more) effective self-management.	1	variety in self- management support, one	coherence (not all outcomes are expressed as added value), Minor concerns regarding adequacy, and Minor concerns regarding relevance (unclear, but	



#	Finding	Methodologica limitations	Coherence	Adequacy	Relevance	GRADE- CERQual assessment of confidence	References
					approach and one with home cardiac	likely, that elderly received daily care and a wide variety in self- management support interventions)	
13	Optimal Health: Emotional Elderly with long-term conditions who receive long-term care report to have an improved confidence/self-efficacy and to feel good and well as outcomes /(added) value of self-management support. Several studies report that elderly felt more confident when (more) time was spent on reviewing information and verifying understanding. Sheridan: "She said written information about a healthy diet had not had an impact, but having the dietician visit the supermarket with her and show her how to read the labels on different food items gave her the confidence to make healthier choices."	not report adequate information about data collection and data analysis (of which one was mixed methods). Most studies did not report on reflexivity of the	Explanation: Minor concerns regarding coherence because outcomes that we assessed (from the Boger framework) were not always identified as an 'added value' by the participants but were sometimes stated as a need or prerequisite for (more)	regarding adequacy because improved confidence/self efficacy is strongly sreflected in the results of 6 studies. Feeling good and well and an improved liquality of life is	regarding relevance because from most studies it is not clear whether the elderly receive daily care, though it is likely. There is also a wide variety in self- management support, some describe interventions aimed at a specific chronic	Minor concerns  Explanation: Minor concerns regarding methodological limitations (lack of reporting in studies regarding data collection and analysis), Minor concerns regarding coherence (not all outcomes are expressed as added value), Minor concerns regarding adequacy (improved confidence was stronger represented	Andersen et al. 2017; Bove et al. 2017; Goransson et al. 2018; Lind & Karlsson 2014; Schumacher et al. 2021; Sheridan et al. 2019; Vanderboom et al. 2013;



#	Finding	Methodological limitations	Coherence	Adequacy	Relevance	of confidence	References
			outcome (quality of life).			outcomes), and dinor concerns regarding relevance (unclear, but likely, that elderly received daily care and a wide variety in selfmanagement support interventions).	
14	Optimal Health - Social  None of the included studies identified outcomes within this domain. Two of the three subdomains focus on caregivers relationships with elderly, and do not so much reflect experiences from elderly themselves (as was the focus of this qualitative evidence synthesis).						