# ORIGINAL RESEARCH: EMPIRICAL RESEARCH – QUANTITATIVE

# Symptom trajectory and symptom burden in older people with multimorbidity, secondary outcome from the RCT AGe-FIT study

Jeanette Eckerblad, Kersti Theander, Anne W. Ekdahl & Tiny Jaarsma

Accepted for publication 30 April 2016

Correspondence to J. Eckerblad: e-mail: jeanette.eckerblad@liu.se

Jeanette Eckerblad PhD RN Junior Lecturer Department of Social and Welfare Studies, Faculty of Medicine and Health Sciences, Linkoping University, Sweden

Kersti Theander PhD RN Associate Professor Faculty of Health, Science and Technology, Department of Health Sciences, Nursing, Karlstad University, Sweden

Anne W. Ekdahl MD PhD Senior consultant in Geriatric Medicine Department of Research and Education, Helsingborg Hospital, Sweden and Division of Clinical Geriatrics, Department of Neurobiology, Caring Sciences and Society, Karolinska Institutet, Stockholm, Sweden

Tiny Jaarsma PhD RN Professor in caring sciences Department of Social and Welfare Studies, Faculty of Medicine and Health Sciences, Linkoping University, Sweden ECKERBLAD J., THEANDER K., EKDAHL A.W. & JAARSMA T. (2016) Symptom trajectory and symptom burden in older people with multimorbidity, secondary outcome from the RCT AGe-FIT study. *Journal of Advanced Nursing* 72 (11), 2773–2783. doi: 10.1111/jan.13032

#### Abstract

Aim. The aim of this study was to follow the symptom trajectory of community-dwelling older people with multimorbidity and to explore the effect on symptom burden from an ambulatory geriatric care unit, based on comprehensive geriatric assessment.

**Background.** Older community-dwelling people with multimorbidity suffer from a high symptom burden with a wide range of co-occurring symptoms often resulting to decreased health-related quality of life. There is a need to move from a single-disease model and address the complexity of older people living with multimorbidity.

**Design.** Secondary outcome data from the randomized controlled Ambulatory Geriatric Assessment Frailty Intervention Trial (AGe-FIT).

Methods. Symptom trajectory of 31 symptoms was assessed with the Memorial Symptom Assessment Scale. Data from 247 participants were assessments at baseline, 12 and 24 months, 2011–2013. Participants in the intervention group received care from an ambulatory geriatric care unit based on comprehensive geriatric assessment in addition to usual care.

Results. Symptom prevalence and symptom burden were high and stayed high over time. Pain was the symptom with the highest prevalence and burden. Over the 2-year period 68–81% of the participants reported pain. Other highly prevalent and persistent symptoms were dry mouth, lack of energy and numbness/tingling in the hands/feet, affecting 38–59% of participants. No differences were found between the intervention and control group regarding prevalence, burden or trajectory of symptoms.

Conclusions. Older community-dwelling people with multimorbidity had a persistent high burden of symptoms. Receiving advanced interdisciplinary care at an ambulatory geriatric unit did not significantly reduce the prevalence or the burden of symptoms.

**Keywords:** community care, nurses, nursing, older people, quality of care, symptom management

© 2016 John Wiley & Sons Ltd 2773

### Why is this research or review needed?

- With An ageing population living with long-standing chronic conditions there is a need for research to move from a single-disease model and address the complexity of older people with multimorbidity
- There is a lack of research including older people with multimorbidity, especially longitudinal studies and randomized control trials.
- There is a lack of research reporting on the co-occurring multidimensional symptoms and changes of symptoms over time, especially regarding older people with multimorbidity.

#### What are the key findings?

- Older people with multimorbidity suffer a high and persistent symptom burden.
- Pain was the symptom with highest prevalence and symptom burden score at all three assessments, baseline 12 and 24 months.
- The symptom prevalence and symptom burden did not significantly change as result of being enrolled in an ambulatory geriatric unit.

# How should the findings be used to influence policy/practice/research/education?

- Older people with multimorbidity needs special attentions since a high symptom burden is common and a high symptom burden often leads to a decreased health-related quality of life.
- Symptoms in older people with multimorbidity need to be communicated and assessed properly to get managed and evaluated.
- Intervention studies with Comprehensive Geriatric Assessment need to include a validated symptom instrument in day to day care, to evaluate possible effect on symptom burden.

# Introduction

Older community-dwelling people with multimorbidity suffer from a high symptom burden with a wide range of cooccurring symptoms (Eckerblad *et al.* 2015b). A high symptom burden might lead to an increased need of health care such as hospitalization, visits to the Emergency Department (Salanitro *et al.* 2012), or admission to a nursing home (Sheppard *et al.* 2013), generating higher healthcare costs (Wolff *et al.* 2002, Condelius *et al.* 2007). For the individual, a high symptom burden can lead to a feeling of being dependent, dejected, inadequate and limited (Eckerblad

et al. 2015a) and it often results in a high caregiver burden (Kuzuya et al. 2011). Approximately, 70% of all people above 80 years have been reported to suffer from multimorbidity (Boeckxstaens & De Graaf 2011). With an ageing population living with long-standing chronic conditions (WHO 2002), there is a need for care and research to move from a single-disease model and address the complexity of older people with multimorbidity (Zulman et al. 2011). Older people with distressing symptoms have a need for comprehensive assessment and management of symptoms (Clini et al. 2014) but there is still a lack of longitudinal studies of the trajectory of co-occurring symptoms in this group. Although symptom research in older people with multimorbidity is scarce, we have learnt from other research areas that symptoms of deterioration such as, pain, fatigue and lack of appetite might not just be a sign of a disease in progress, but also a predictor of impending death (Sutradhar et al. 2014). This indicates the importance of following the course of symptoms over time.

# Background

A symptom is defined as a 'subjective experience reflecting the bio-psycho-social functioning, sensations or cognition of an individual' (Dodd et al. 2001, p. 669). Symptoms have been conceptualized as multidimensional and includes the dimensions intensity, timing, distress and quality (Lenz et al. 1997). The symptom management theory states that the goal of symptom management is to prevent or delay a negative outcome through biomedical, professional and management strategies to reduce the frequency, minimize the severity and relive the distress associated with co-occurring symptoms. The theory also proposes that all troublesome symptoms should be managed (Humphreys et al. 2014). A multidimensional measurement provides a detailed assessment of symptoms that could be used both in clinic and research, especially for guiding interventions and as an outcome measurement (Lenz et al. 1997).

A high proportion of older people stay at home during the last years of life, which is challenging for healthcare organizations (Boeckxstaens & De Graaf 2011). In a previous paper based on baseline data from this study, we found that close to 70% of older people living at home reported pain and approximately 50% of community-dwelling older people suffered from the symptoms of dry mouth and lack of energy (Eckerblad *et al.* 2015b). With a healthcare organization based on a single-disease model, older people with multimorbidity tend to receive care that is fragmented, ineffective and unsafe and that leads to higher healthcare costs

than necessary (Bergman et al. 1997). A key method to turn this around could be Comprehensive Geriatric Assessment (CGA). CGA is defined as a 'multidimensional interdisciplinary diagnostic process focused on determining a frail older person's medical, psychological and functional capability to develop a coordinated and integrated plan for treatment and long-term follow-up' (Rubenstein et al. 1991 p 8s). Older people cared for in a CGA context in hospital have a decreased risk of deterioration, improved cognitive functioning and are more likely to survive the hospitalization and return to their own home compared with usual care (Ellis et al. 2011). The hallmarks of CGA are the interdisciplinary teams (Sletvold et al. 1996). One factor that have proven to be successful in CGA is use of protocols, when implemented and acted on with a high degree of consistency (Ellis et al. 2011). This study present secondary data from the Ambulatory Geriatric Assessment - a Frailty Intervention (AGe-FIT) study. To examine the costs and effects of care based on CGA provided by an ambulatory geriatric care unit, in addition to usual care, a single-centre randomized controlled trial was performed (Ekdahl et al. 2015). The study hypothesis of the AGe-FIT was that the care based on CGA provided by an ambulatory geriatric outpatient clinic would reduce hospitalization (primary outcome) compared with usual care. The main results of the AGe-FIT showed that an ambulatory outpatient clinic based on CGA increased the older person's sense of security and reduced the days of inpatient care in hospital compared with usual care; this without increasing the healthcare costs (Ekdahl et al. 2015). Long-term evaluation (36 months) of the AGe-FIT also showed a higher survival rate for the intervention group (Ekdahl et al. 2016). To gain further insight into the effects of the AGe-FIT intervention we now present data from the secondary outcome related to symptom burden. Given the lack of randomized clinical trials that assess both the complexity of older people with multimorbidity and the effectiveness of comprehensive interventions (Clini et al. 2014) this study might contribute valuable knowledge on the symptom trajectory of older people with multimorbidity and on whether attending an ambulatory outpatient clinic based on CGA can reduce the symptom burden.

# The study

#### Aim

The aim of this study was to follow the symptom trajectory of community-dwelling older people with multimorbidity and to explore the effect on symptom burden from an ambulatory geriatric care unit, based on comprehensive geriatric assessment.

#### Design

The Ambulatory Geriatric Assessment Frailty Intervention Trial (AGe-FIT) (Mazya et al. 2013) was a randomized, controlled, single-centre trial with 382 participants in two parallel groups that aimed to include community-dwelling older people with multimorbidity with a high need of health care. The study protocol has been described in detail (Mazya et al. 2013) and the outcome of the main study has been reported (Ekdahl et al. 2015, 2016). The current paper reports the symptoms experienced by the participants, as a secondary outcome of the AGe-FIT. The study registration in clinicaltrials gov identifier is: NCT01446757.

# Participants and procedures

Participants for this study were identified using the Care Data Warehouse of Ostergotland, a population-based administrative database maintained by the county council. In this study, only the participants that participated in all three assessments, baseline, 12 and 24 months were included. Of the 247 participants included in this study 143 were assigned to the intervention group (IG) and 104 to the control group (CG). Inclusion criteria were ≥75 years, having three or more concomitant medical diagnoses and three or more hospitalizations during the preceding year. One exclusion criteria were used in this study, people who lived in a nursing home at the time of inclusion were excluded since this was one outcome of the main study. Participants were randomly assigned to one out of two groups based on a randomization master list using SPSS software (version 18.0). The intervention group received interdisciplinary care at an Ambulatory Geriatric Unit (AGU), based on a comprehensive geriatric assessment (CGA), in addition to their usual care, while the control group received care as usual. The 135 participants from the main study, not reported here, were people that died (64%), declined follow-up measurement (31%) or could not be reached or had moved from the city (5%) after baseline or at the first year followup.

#### Intervention

After baseline assessment, participants in the IG were invited to receive care at the AGU, provided by several different healthcare professionals. Each participant had the opportunity to meet a nurse, a geriatrician, a municipal care manager, an occupational therapist, a physiotherapist, a dietician, and a pharmacist. The CGA aimed to systematically identify, quantify, manage and evaluate the medical, psychological, and functional capabilities of the participant (Ellis et al. 2011). Initially, the CGA was based on a standardized procedure but was later personalized according to the patient's situation and needs. The frequency of the contacts between the participant and the clinic was dependent on the patient's needs and wishes and ranged from a few contacts per year for some patients to daily or weekly contacts for others. Symptoms were treated and documented according to clinical practice and no standardized symptom instrument was used to assess or evaluate symptoms in day to day care. If participants were admitted to the hospital, the AGU team members visited them to provide further information to patients and staff with the goal of facilitating care, discharge and/or transfer to other types of care. Participants in the IG had, beside the AGU, the same access to standard care participants in the CG, which was usual health and social care, i.e., healthcare provided by the primary care, in- and outpatient hospital care and social care.

#### Data collection

Data were collected between February 2011–December 2013 in a municipality in the rural and urban areas in Sweden that contains approximately 130,000 inhabitants, 8·3% of which were aged >75 years. Data were collected by protocol guided interviews performed by specially trained RNs or a registered occupational therapist in the participants' homes at baseline, 12 and 24 months.

#### Measures

Symptom prevalence and symptom burden were assessed with the Memorial Symptom Assessment Scale (MSAS) (Portenoy et al. 1994). MSAS covers the prevalence of 32 commonly occurring symptoms. It considers three dimensions, frequency, severity and distress for 24 symptoms and two dimensions, severity and distress for eight symptoms. The prevalence is answered with a yes/no answer, the frequency is scored 1-4, severity 1-4 and distress 0-4, with higher scores indicating higher frequency, severity and more distress. To avoid making the participant feel uncomfortable one symptom from the original instrument was removed after the initial assessments in the pilot (sexual problems), leaving the instrument with 31 symptoms. The MSAS produces four subscales, the MSAS Physical (MSAS-PHYS) MSAS Psychological (MSAS-PSYCH), MSAS Global Distress Index (MSAS-GDI) and the MSAS total symptom burden score, (TMSAS) (Portenoy *et al.* 1994). MSAS also produces a symptom burden score for each symptom, which is the average of the frequency, severity and distress (Portenoy *et al.* 1994, Zambroski *et al.* 2005).

Background data such as age, sex, educational level, cohabitation, hearing and vision were assessed by interview. The Mini-Mental State Examination, (MMSE) were used to screen for cognitive impairment. In this 30-point brief test, ≥24 points are considered normal cognitive function and 18-23 is considered as mild–moderate cognitive dysfunction. Scores below 18 indicates severe cognitive dysfunction (Mitchell 2009). The likelihood of depression was assessed using the Geriatric Depression Scale (GDS-15). GDS is a self-report measure of depression in older adults and uses 'yes/no' answers.

### Validity and reliability

The instruments in this study are all valid and reliable and have previously been used in an older population. MSAS was originally developed to measure symptoms in people treated for cancer (Portenoy et al. 1994, Pettersson et al. 2014) but has lately been used with chronic diseases (Eckerblad et al. 2014, 2015b) (Zambroski et al. 2005). The Cronbach's alpha coefficient for TMSAS in this study at baseline was 0-82. The short form of GDS 15 is recommended to be used in a non-specialist setting to evaluate the likelihood of depression in late life (Sheik & Yesavage 1986). MMSE is one of the most widely used cognitive tests in community or primary care and are one of the best tests for ruling-out a diagnosis of dementia in a non-specialist care setting (Mitchell 2009).

#### Ethical considerations

Research that involves human beings must protect the participant rights, this requires a careful consideration from all researchers, data collectors or personnel involved in every step of a research study (Polit & Beck 2013). An invitation letter explaining the purpose of the study was sent to the identified participants. Those willing to participate were offered an appointment in their home for a protocol-directed interview where written consent was obtained. The study was approved by the regional ethical review board in Linkoping (Dnr. 2011/41-31).

#### Data analysis

Categorical data are presented by frequencies and percentages, continuous data by means and standard deviations

(SD) or median (min/max). The MSAS symptom burden scores are presented as mean (SD) for comparison with previous research, although most of the data are skewed. A Student's t-test was used to compare continuous data between the groups for normally distributed data and a non-parametric Mann-Whitney U-test for data that was skewed. A Chi-square test was used to compare categorical data. Comparison of symptom experience between the IC and CG regarding prevalence was carried out by Chi-square or Fisher's exact test as appropriate, while a Mann-Whitney U-test was used to establish differences regarding the MSAS symptom burden score and subscales. Symptom trajectory was tested with Cochran's O test followed by McNemar's test for categorical data, or by non-parametric Friedman's ANOVA followed by Wilcoxon related samples signed-rank test for continuous data. P values were twosided and the significance level was set at  $P \le 0.01$  to correct for multiple testing and avoid type one errors. The data were analysed using PASW Statistical (SPSS) version 22.

### Result

#### Background characteristics

The mean age of the participants was 82 years at baseline and 52% were women (Table 1). The 247 participants included in the analysis did not differ in age, gender or number of symptoms per person from the 135 participants in the main study. The participants in this study had many co-occurring chronic diseases, on average the participants had diseases from more than seven ICD chapters per person (mean (SD) 7.4 (2.0)). No statistically significant differences were found in the background characteristics between the IG and CG.

# The trajectory of symptom prevalence and symptom burden

Both prevalence and the burden of symptoms were high and stayed high over the 2-year period. Highly prevalent symptoms in this group of older people were pain, dry mouth, numbness/tingling in hands/feet and lack of energy, with approximately half of the study population reporting these symptoms during the previous week. Pain was the symptom with the highest prevalence of all; almost 70% of the participants reported experiencing pain and the prevalence of pain increased slightly (not significantly) in both follow-up measurements (Table 2).

The pain trajectory (Figures 1 and 2) shows that for some individuals the presence or absence of pain changed over time and they did not report pain in every assessment, while others reported a more constant presence of pain. Of the total 170 participants who reported pain at baseline, 128 (75%) also reported pain at the second year follow-up. Twenty participants out of 247 did not report pain at all (not reported in figure). The MSAS subscale scores with the total symptom burden TMSAS, the physical MSAS-PHYS, psychological MSAS-PSYCH and global index score GDS did not change significantly over time (Table 3).

# Differences in symptom prevalence and symptom burden

The prevalence of the symptom 'itching' was higher in the CG than the IC during all measurements and reached statistical significance during the second follow-up. No other statistically significant differences in the prevalence of symptoms were found between the two groups (Table 2). None of the MSAS subscale scores or total symptom per person differed between the groups (Table 3) and neither did the symptom burden score (Table 4).

# Discussion

There is a lack of studies reporting on the symptom burden in older people with multimorbidity. In a previous paper from the AGe-FIT, we have reported that older people with multimorbidity suffer a high symptom burden (Eckerblad et al. 2015b) and in this study we elaborate that this high symptom burden is persistent and remains high over time. Symptoms reported on in this study were as highly prevalent at the beginning as at the end of the 2-year study period. The intervention with interdisciplinary care at an Ambulatory Geriatric Unit, based on CGA, did not reduce the total symptom burden or the single symptom burden. However, our study does not confirm previous studies that showed that symptoms often increase over time both in community-dwelling older people (Walke et al. 2007) and for older people in nursing homes (Estabrooks et al. 2015). This might partly be explained by excluding the people who died during the study from this analysis. Among older people with multimorbidity restricting and burdensome symptoms with an impact of daily life such as fatigue, pain, weakness in arm or leg have shown to increase the last 5 month of life (Chaudhry et al. 2013). To organize the care with CGA have proven to be beneficial to older people with multimorbidity in several studies (Ellis et al. 2011, ref, Clini et al. 2014). The multiple overlapping problems in this group demands both assessments and actions across medical, psychiatric, functional and social domains (Ellis

Table 1 Background characteristics of older people with multimorbidity.

	All	IG	CG	
	N = 247	n = 143	n = 104	P value
Age (years), mean (SD)	82 (4.5)	82 (4.4)	82 (4.7)	0.51
Women, n (%)	128 (52)	73 (51)	55 (53)	0.79
Lived alone, n (%)	124 (50)	65 (46)	59 (57)	0.07
Educational level				
Elementary school, n (%)	149 (61)	87 (61)	62 (60)	0.24
Secondary school, n (%)	59 (24)	31 (22)	28 (27)	
University, n (%)	36 (15)	23 (16)	13 (12)	
Poor hearing with and without hearing device, $n$ (%)	76 (31)	45 (32)	31 (30)	0.88
Poor vision with and without glasses, n (%)	65 (26)	31 (22)	34 (33)	0.06
Smoking, <i>n</i> (%)	18 (7)	11 (8)	7 (7)	0.81
Alcohol on daily basis, $n$ (%)	16 (6)	9 (6)	7 (7)	1.00
MMSE, mean (SD)	26.7 (2.7)	26.4 (3.0)	27.2 (2.2)	0.05
MMSE ≤24, <i>n</i> (%)	42 (19)	30 (23)	12 (14)	0.11
GDS mean (SD)	3.5 (3.0)	3.5 (3.2)	3.5 (2.7)	0.72
GDS $\geq$ 5, $n$ (%)	74 (30)	43 (30)	31 (30)	1.00
Diagnosis according to ICD 10 Chapter				
01. Certain infectious and parasitic diseases (A00-B99), n (%)	108 (44)	68 (48)	40 (38)	0.19
02. Neoplasma (C00-D48), n (%)	100 (40)	56 (39)	44 (42)	0.69
03. Diseases of the blood and blood-forming organs and certain	65 (26)	37 (26)	28 (27)	0.88
disorders involving the immune mechanism (D50-D89), n (%)				
04. Endocrine, nutritional and metabolic diseases (E00-E90), n (%)	116 (47)	67 (47)	49 (47)	1.00
05. Mental and behavioural disorders (F00-F99), n (%)	77 (31)	47 (33)	30 (29)	0.57
06. Diseases of the nervous system (G00-G99), n (%)	83 (34)	51 (38)	32 (31)	0.49
07. Diseases of the eye and adnexa (H00-H59), n (%)	147 (60)	84 (59)	63 (61)	0.79
08. Diseases of the ear and mastoid process (H60-H95), n (%)	88 (36)	52 (36)	36 (35)	0.79
09. Diseases of the circulatory system (I00-I99), n (%)	234 (95)	134 (94)	100 (96)	0.56
10. Diseases of the respiratory system (J00-J99), n (%)	125 (51)	73 (51)	52 (50)	0.89
11. Diseases of the digestive system (K00-K93), n (%)	131 (53)	79 (55)	52 (50)	0.44
12. Diseases of the skin and subcutaneous tissue (L00-L99), n (%)	104 (42)	58 (41)	46 (44)	0.60
13. Diseases of the musculoskeletal system and connective tissue (M00-M99), <i>n</i> (%)	194 (78)	114 (80)	80 (77)	0.63

MMSE, mini-mental state examination; GDS-15, geriatric depression scale; ICD, international classification of diseases.

2011). Previously, we reported that the intervention of AGe-FIT was successful in reducing the number of days in hospital care and it raised the participant's sense of security (Ekdahl et al. 2015) and a 36 month follow-up showed that the intervention group lived longer (Ekdahl et al. 2016). However from the current analysis we learnt that the intervention did not reduce the prevalence and burden of symptoms significantly. The participants suffered from persistent pain and pain was the symptom reported with the highest prevalence (70-80%), at all three assessment points. This is high compared with previous studies where the prevalence of pain among older people living in the community was found to vary between 25-75% of people over the age of 65 (Abdulla et al. 2013, Molton & Terrill 2014), whereas in older people living in nursing homes it ranged between 83-93% (Abdulla et al. 2013). The location of pain was not registered in this study but the most common sites of pain in older people are the back, leg/knee or hip and other joints (Abdulla *et al.* 2013). Persistent pain has a high impact on the psychological health of older adults, with a higher anxiety level and lower quality of life as a result (Tse *et al.* 2013). Pain is also known to lead to limitation of physical activity and to a cycle of restriction, decreased participation and greater disabilities and it often overlaps with symptoms of depression (Molton & Terrill 2014). To describe the trajectory and the persistence of symptoms, systematic and repeated assessments are crucial.

Among the 247 participants included in this study, pain, lack of energy, feeling sad, difficulty sleeping and numbness/tingling in hands/feet were all highly prevalent symptoms. There is a lack of research addressing the prevalence and management of co-occurring symptoms and symptom burden in older people with multimorbidity and even less is known about possible interactions between these symptoms

Table 2 Difference in symptom prevalence between IG (n = 143) and CG (n = 104) older people with multimorbidity at baseline after 1 year and 2 years.

Symptoms	Baseline, n (%)		First year, n (%)		Second year, n (%)	
	IG	CG	IG	CG	IG	CG
Pain	100 (70)	70 (68)	106 (74)	71 (68)	115 (81)	74 (71)
Dry mouth	68 (48)	49 (47)	82 (57)	51 (49)	84 (59)	56 (54)
Lack of energy	64 (45)	48 (47)	74 (52)	55 (53)	65 (46)	46 (45)
Numbness/tingling in hands/feet	64 (45)	52 (51)	65 (45)	51 (49)	73 (51)	39 (38)
Difficulty sleeping	64 (45)	39 (38)	60 (42)	33 (32)	54 (38)	40 (38)
Feeling drowsy	62 (44)	31 (31)	48 (34)	35 (34)	51 (36)	38 (36)
Dizziness	63 (44)	42 (41)	55 (38)	41 (39)	52 (36)	41 (40)
Swelling of arms or legs	54 (38)	35 (34)	65 (45)	37 (36)	57 (40)	38 (36)
Feeling sad	51 (36)	35 (34)	51 (36)	34 (33)	50 (35)	32 (31)
Cough	49 (34)	36 (35)	44 (31)	26 (25)	41 (29)	29 (28)
Worrying	49 (34)	29 (28)	53 (37)	34 (33)	52 (36)	30 (29)
Problems with urination	47 (33)	29 (29)	44 (31)	33 (31)	44 (31)	40 (40)
Shortness of breath	47 (33)	41 (40)	52 (36)	45 (43)	56 (39)	43 (41)
Feeling nervous	39 (28)	26 (25)	37 (26)	24 (23)	36 (25)	20 (19)
Itching	35 (24)	38 (36)	43 (30)	35 (34)	29 (20)	38 (37)*
Feeling bloated	33 (23)	23 (23)	32 (26)	28 (27)	31 (22)	27 (26)
Constipation	33 (23)	20 (19)	32 (22)	25 (24)	28 (20)	28 (27)
Feeling irritable	33 (23)	22 (21)	45 (31)	22 (21)	32 (22)	20 (19)
Changes in skin	30 (21)	27 (26)	38 (26)	18 (17)	34 (24)	23 (22)
Sweating	24 (17)	20 (19)	22 (15)	13 (12)	24 (17)	15 (14)
Difficulty concentrating	24 (17)	21 (20)	27 (19)	14 (13)	28 (20)	20 (19)
Lack of appetite	21 (15)	11 (11)	31 (21)	13 (12)	17 (12)	15 (14)
Nausea	18 (13)	13 (13)	19 (13)	10 (10)	26 (18)	12 (11)
Diarrhoea	19 (13)	13 (13)	23 (16)	13 (12)	25 (18)	15 (14)
Mouth sores	18 (13)	9 (9)	18 (12)	14 (13)	16 (11)	13 (12)
Difficulty swallowing	15 (10)	25 (24)	19 (13)	16 (15)	12 (8)	18 (17)
Change in the way food tastes	15 (10)	10 (10)	15 (10)	10 (10)	16 (11)	11 (11)
Hair loss	10 (7)	6 (6)	7 (5)	7 (7)	7 (5)	8 (8)
"I don't look like myself"	9 (6)	5 (5)	10 (7)	3 (3)	17 (12)	9 (9)
Weight loss	6 (4)	5 (5)	10 (7)	9 (9)	11 (8)	10 (10)
Vomiting	4 (3)	2 (2)	9 (6)	3 (3)	6 (4)	2 (2)

Prevalence of 31 symptoms using the MSAS. Comparison of symptom prevalence between the IC and CG was carried out by Chi-square or Fisher's exact test. Difference between the IG and the CG are marked with \* and the exact P = 0.006. Symptom trajectory was tested with Cochran's Q test followed by Mc Nemar's test, statistically significant level were set at  $P \le 0.01$  but no differences were found.

or the symptom clusters. Meanwhile, this is a frequent and well-known problem, but clinical practice guidelines on symptom management for this population are lacking for almost all other symptoms except for pain (Combs *et al.* 2013). With a growing number of older people living at home there is a need for clinical practice guidelines to support symptom management (Boeckxstaens & De Graaf 2011).

There might be several explanations for why we did not see an effect of the intervention on symptom burden. First, symptoms were not the main outcome of this study and the AGU healthcare providers did not target specific symptoms in day to day care at the clinic. Second, the lack of effect of the intervention on symptom burden might be related to underreporting of symptoms by older people. Some symptoms assessed by the MSAS might not have been brought up in discussion by older people themselves since they often assume that old age and symptoms are supposed to go hand in hand (Eckerblad *et al.* 2015a). It has been suggested that old age might cause an age-related response shift in symptoms that cause older people to respond and report symptoms differently than younger people (Riegel *et al.* 2010, Ritchie *et al.* 2014). However, when directly asked, participants in this study did report a high symptom burden. Previous studies have shown that a high symptom burden and symptom distress are associated with negative outcomes

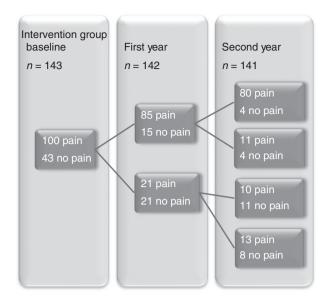


Figure 1 The pain trajectory in the Intervention Group. Participants who had or did not have pain over the period of 2 years.

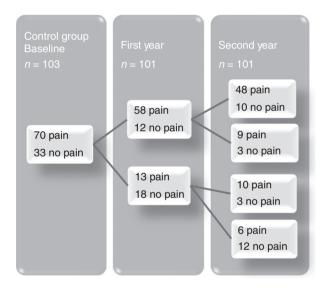


Figure 2 The pain trajectory in the Control Group. Participants that had or did not have pain over the period of 2 years.

such as a lower health-related quality of life (Zambroski et al. 2005, Blinderman et al. 2008, 2009).

Implementation of systematic CGA in health care is time consuming and it could be difficult for the healthcare providers to maintain close contact with all community-dwelling older people relying on this care. A self-administered questionnaire with follow-ups by telephone could be one way to go about it (Ornstein *et al.* 2013). The use of a self-administered questionnaire has been studied with older cognitively healthy adults and with persons with mild cognitive

impairment and has been found to be promising (Beauchet et al. 2014). The systematic use of repeated symptom assessments combined with symptom management has been shown to reduce symptom burden for community-dwelling people receiving palliative care (Ornstein et al. 2013). A symptom scale used in clinical practice, either assessed by the healthcare providers or self-reported, might have revealed symptoms that were unknown to and therefore never addressed or managed by the AGU staff. An explanation of the lack of effects from the intervention might be the 2-year time limit of the AGU clinic. To launch a new unit, recruit healthcare personnel and make this run smooth and with consistency takes time. Nevertheless, this result provides valuable information that might draw attention to the high symptom burden in community-dwelling older people.

The MSAS instrument was first develop to assess symptoms in patient treated for cancer and some symptom included in the instrument might not be as relevant to older people with multimorbidity, e.g. hair loss (Portenoy et al. 1994). Nevertheless, MSAS gives a good description of the multidimensional symptom profile and an insight of the total symptom burden. In clinical practice, healthcare providers are challenged to choose an instrument that on the one hand includes all the relevant symptoms but at the same time still is brief enough to avoid a high response burden. A multidimensional symptom instrument that includes more than 30 items provides a detailed description of the symptom profile but may be overwhelming to a seriously ill older person. But at the same time, there is a danger to use an instrument that is too limited. It has been suggested that an instrument with 10 symptom or less are likely to exclude symptoms that burden seriously ill older people (Walke et al. 2006). However, healthcare providers have the responsibility to give each person optimal support and symptom relief (Dodd et al. 2001) and the use of a standardized multidimensional symptom instrument in clinical care might help to address that issue.

# Strength and limitations

A strength of this study is the representativeness of our sample, since we used a minimum of exclusion criteria. There is a large gap in multimorbidity evidence relates to the regular exclusion of older adults and especially in clinical trials (Zulman *et al.* 2011). The knowledge provided by this study might help us to fully understand the magnitude of the symptom experience in this group and give insights when new interventions are designed. A limitation of this study is the lack of data on the medical diagnoses for the second year follow-up.

Table 3 MSAS subscale scores.

	Baseline Median (min/max)		First year follow Median (min/ma	1	Second year follow-up Median (min/max)		
	IG	CG	IG	CG	IG	CG	
TMSAS	0.54 (0/2.57)	0.48 (0/2.08)	0.56 (0/1.78)	0.51 (0/2.06)	0.54 (0.0/1.95)	0.48 (0/2.27)	
MSAS-PSYCH	0.57 (0/3.83)	0.47 (0/3.74)	0.51 (0/3.01)	0.41 (0/3.32)	0.47 (0.0/2.78)	0.36 (0/3.23)	
MSAS-PHYS	0.60 (0/2.26)	0.52 (0/1.95)	0.56 (0/2.25)	0.54 (0/2.06)	0.62 (0.0/2.75)	0.51 (0/3.23)	
MSAS-GDI	0.78 (0/3.42)	0.68 (0/2.75)	0.75 (0/2.73)	0.74 (0/2.96)	0.73 (0.0/2.52)	0.66 (0/3.06)	
Sympt/pers	7.00 (0/24)	7.00 (0/21)	8.00 (0/29)	7.00 (0/22)	8.00 (0/23)	7.00 (0/24)	

The trajectory was tested with Friedman's anova followed by Wilcoxon related samples signed-rank test. Comparison of subscale scores between the IC and CG was carried out by Mann–Whitney U-test. Statistically significant level was set at  $P \le 0.01$ , no differences were found. MSAS-PHYS, the overall physical symptom score; MSAS-PSYCH, Psychological Symptom score; MSAS-GDI, the Global distress index; TMSAS, Total MSAS index score.

Table 4 MSAS symptom burden score based on the ten symptoms with the highest prevalence at baseline, and differences between IG and CG

	Baseline Mean (sd)		First year follow-up Mean (SD)		Second year follow-up Mean (SD)	
	IG	CG	IG	CG	IG	CG
Pain	2.72 (0.70)	2.66 (0.71)	2.76 (0.70)	2.86 (0.59)	2.70 (0.61)	2.55 (0.56)
Lack of energy	2.59 (0.64)	2.50 (0.62)	2.52 (0.68)	2.41 (0.63)	2.64 (0.68)	2.48 (0.75)
Feeling sad	2.59 (0.68)	2.22 (0.67)	2.41 (0.69)	2.40 (0.79)	2.23 (0.58)	2.43 (0.58)
Difficulty sleeping	2.58 (0.70)	2.61 (0.69)	2.70 (0.71)	2.69 (0.64)	2.39 (0.64)	2.46 (0.63)
Numbness/tingling in hands/feet	2.43 (0.70)	2.43 (0.80)	2.41 (0.80)	2.51 (0.80)	2.29 (0.65)	2.53 (0.73)
Dizziness	2.27 (0.81)	2.40 (0.86)	2.47 (0.81)	2.28 (0.66)	2.29 (0.88)	2.36 (0.76)
Swelling of arms or legs	2.18(0.75)	1.87 (0.92)	2.03(0.73)	2.21 (0.72)	2.02 (0.85)	1.98 (0.72)
Dry mouth	2.18 (0.60)	2.28 (0.85)	2.28 (0.65)	2.38(0.67)	2.15 (0.60)	2.26 (0.65)
Feeling drowsy	2.12 (0.66)	1.99 (0.71)	2.18 (0.68)	2.12 (0.55)	2.10 (0.62)	2.15 (0.57)
Cough	2.01 (0.59)	2.09 (0.70)	2.12 (0.63)	2.26 (0.53)	2.12 (0.61)	2.16 (0.71)

The MSAS symptom burden score is the mean score of the three dimensions: frequency, severity and distress. The trajectory was tested with Friedman's ANOVA followed by Wilcoxon related samples signed-rank test. Comparison of symptom burden scores between the IC and CG was carried out by Mann–Whitney U-test. Statistically significant level was set at  $P \le 0.01$ , no differences were found.

#### Conclusion

Older community-dwelling people with multimorbidity had a high burden of symptoms. The prevalence and burden of symptoms did not increase or decrease over time and many symptoms were as highly prevalent and burdensome at the beginning as at the end of the 2 year study period. Despite receiving advanced interdisciplinary care at an ambulatory geriatric unit, based on comprehensive geriatric assessment, neither the symptom prevalence nor the symptom burden was reduced compared with the group that received care as usual.

# Acknowledgements

The authors would like to thank the AGe-FIT research group, clinic employees and the participants in this study.

# **Funding**

Original funding's was provided by the Faculty of Health sciences, Linkoping University; the county council of Ostergotland and the Signe and Olof Wallenius trust fund. The funding sources were independent and had no influence on the study whatsoever.

# Conflict of interest

We hereby confirm that no conflict of interest has been declared by the authors.

#### Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/recommendations/)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

# References

- Abdulla A., Adams N., Bone M., Elliott A.M., Gaffin J., Jones D., Knaggs R., Martin D., Sampson L., Schofield P. & British Geriatric S. (2013) Guidance on the management of pain in older people. *Age and Ageing* 42(Suppl 1), i1–i57.
- Beauchet O., Launay C.P., Merjagnan C., Kabeshova A. & Annweiler C. (2014) Quantified Self and Comprehensive Geriatric Assessment: Older Adults Are Able to Evaluate Their Own Health and Functional Status. PLoS ONE 9(6), 1–5.
- Bergman H., Beland F., Lebel P., Contandriopoulos A.P.,
  Tousignant P., Brunelle Y., Kaufman T., Leibovich E., Rodriguez
  R. & Clarfield M. (1997) Care for Canada's frail elderly
  population: fragmentation or integration? *Canadian Medical Association Journal* 157(8), 1116–1121.
- Blinderman C.D., Homel P., Billings J.A., Portenoy R.K. & Tennstedt S.L. (2008) Symptom distress and quality of life in patients with advanced congestive heart failure. *Journal of Pain and Symptom Management* 35(6), 594–603.
- Blinderman C.D., Homel P., Billings J.A., Tennstedt S. & Portenoy R.K. (2009) Symptom distress and quality of life in patients with advanced chronic obstructive pulmonary disease. *Journal of Pain and Symptom Management* 38(1), 115–123.
- Boeckxstaens P. & De Graaf P. (2011) Primary care and care for older persons: Position Paper of the European Forum for Primary Care. *Quality in Primary Care* 19(6), 369–389.
- Chaudhry S.I., Murphy T.E., Gahbauer E., Sussman L.S., Allore H.G. & Gill T.M. (2013) Restricting symptoms in the last year of life: a prospective cohort study. *JAMA Internal Medicine* 173 (16), 1534–1540 7p.
- Clini E., Beghe B. & Fabbri L.M. (2014) Symptomatic, frail, elderly patients: the urgent need for comprehensive assessment and management. The European Respiratory Journal 44(6), 1397–1400.
- Combs S., Kluger B.M. & Kutner J.S. (2013) Research priorities in geriatric palliative care: nonpain symptoms. *Journal of Palliative Medicine* 16(9), 1001–1007.
- Condelius A., Edberg A.-K., Jakobsson U. & Hallberg I.R. (2007) Hospital admissions among people 65 + related to multimorbidity, municipal and outpatient care. *Archives of Gerontology and Geriatrics* 46(1), 41–55.
- Dodd M., Janson S., Facione N., Faucett J., Froelicher E.S., Humphreys J., Lee K., Miaskowski C., Puntillo K., Rankin S. & Taylor D. (2001) Advancing the science of symptom management. *Journal of Advanced Nursing* 33(5), 668–676.
- Eckerblad J., Todt K., Jakobsson P., Unosson M., Skargren E., Kentsson M. & Theander K. (2014) Symptom burden in stable COPD patients with moderate or severe airflow limitation. *Heart & Lung: The Journal of Critical Care* 43(4), 351–357.
- Eckerblad J., Theander K., Ekdahl A., Jaarsma T. & Hellstrom I. (2015a) To adjust and endure: a qualitative study of symptom

- burden in older people with multimorbidity. *Applied Nursing Research* 28(4), 322–327.
- Eckerblad J., Theander K., Ekdahl A., Unosson M., Wirehn A., Milberg A., Krevers B. & Jaarsma T. (2015b) Symptom burden in community-dwelling older people with multimorbidity: a cross-sectional study. *BMC Geriatrics* **15**(1), 1.
- Ekdahl A.W., Wirehn A.B., Alwin J., Jaarsma T., Unosson M., Husberg M., Eckerblad J., Milberg A., Krevers B. & Carlsson P. (2015) Costs and effects of an ambulatory geriatric unit (the AGe-FIT study): a randomized controlled trial. *Journal of the American Medical Directors Association* 16(6), 497–503.
- Ekdahl A.W., Alwin J., Eckerblad J., Husberg M., Jaarsma T., Mazya A.L., Milberg A., Krevers B., Unosson M., Wiklund R. & Carlsson P. (2016) Original Study: Long-Term Evaluation of the Ambulatory Geriatric Assessment: A Frailty Intervention Trial (AGe-FIT): Clinical outcomes and total costs after 36 months. *Journal of the American Medical Directors Association* 17(3), 263–268.
- Ellis G., Whitehead M.A., Robinson D., O'Neill D. & Langhorne P. (2011) Comprehensive geriatric assessment for older adults admitted to hospital: meta-analysis of randomised controlled trials. British Medical Journal Publishing Group 343(7832), d6553.
- Estabrooks C.A., Hoben M., Poss J.W., Chamberlain S.A., Thompson G.N., Silvius J.L. & Norton P.G. (2015) Dying in a nursing home: treatable symptom burden and its link to modifiable features of work context. *Journal of the American Medical Directors Association* 16(6), 515–520.
- Humphreys J., Janson S., Donesky D.A., Dracup K., Lee K.A., Puntillo K., Faucett J.A., Aouizerat B., Miaskowski C., Baggot C., Carrieri-Kohlman V., Barger M., Franck L. & Kennedy C.; the University of California, San Francisco (UCSF) School of Nursing Symptom Management Faculty Group (2014) Chapter 7, Theory of symptom management. In Middle Range Theory for Nursing, 3rd edn (Smith M.J.L. & Patricia R., eds), Springer Publishing Co, New York, pp. 141–165.
- Kuzuya M., Enoki H., Hasegawa J., Izawa S., Hirakawa Y., Shimokata H. & Akihisa I. (2011) Regular research article: impact of caregiver burden on adverse health outcomes in community-dwelling dependent older care recipients. *The American Journal of Geriatric Psychiatry* 19, 382–391.
- Lenz E.R., Pugh L.C., Milligan R.A., Gift A. & Suppe F. (1997) The middle-range theory of unpleasant symptoms: an update. *Advances in Nursing Science* 19(3), 14–27.
- Mazya A.L., Eckerblad J., Jaarsma T., Hellström I., Krevers B., Milberg A., Unosson M., Westöö A. & Ekdahl A. (2013) The Ambulatory Geriatric Assessment a Frailty Intervention Trial (AGe-FIT) A randomised controlled trial aimed to prevent hospital readmissions and functional deterioration in high risk older adults: a study protocol. *European Geriatric Medicine* 4(4), 242–247.
- Mitchell A.J. (2009) A meta-analysis of the accuracy of the minimental state examination in the detection of dementia and mild cognitive impairment. *Journal of Psychiatric Research* **43**(4), 411–431.
- Molton I.R. & Terrill A.L. (2014) Overview of persistent pain in older adults. *American Psychological Association* **69**(2), 197–207.
- Ornstein K., Wajnberg A., Kaye-Kauderer H., Winkel G., DeCherrie L., Zhang M. & Soriano T. (2013) Reduction in symptoms for homebound patients receiving home-based primary and palliative care. *Journal of Palliative Medicine* 16(9), 1048–1054.

- Pettersson G., Berterö C., Unosson M. & Börjeson S. (2014) Symptom prevalence, frequency, severity and distress during chemotherapy for patients with colorectal cancer. Supportive Care in Cancer 22(5), 1171-1179.
- Polit D.F. & Beck C.T. (2013) Essentials of Nursing Research: Appraising Evidence for Nursing Practice, 8th edn. Wolters Kluwer Health/Lippincott Williams & Wilkins, Philadelphia, PA, cop. 2014.
- Portenov R.K., Thaler H.T., Kornblith A.B., Lepore J.M., Friedlander-Klar H., Kiyasu E., Sobel K., Coyle N., Kemeny N., Norton L. & Scher H. (1994) The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. European Journal of Cancer 30A(9), 1326-1336.
- Riegel B., Dickson V.V., Cameron J., Johnson J.C., Bunker S., Page K. & Worrall-Carter L. (2010) Symptom recognition in elders with heart failure. Journal of Nursing Scholarship 42(1), 92-100.
- Ritchie C., Dunn L.B., Paul S.M., Cooper B.A., Skerman H., Merriman J.D., Aouizerat B., Alexander K., Yates P., Cataldo J. & Miaskowski C. (2014) Differences in the symptom experience of older oncology outpatients. Journal of Pain and Symptom Management 47(4), 697-709.
- Rubenstein L.Z., Stuck A.E., Siu A.L. & Wieland D. (1991) Impacts of geriatric evaluation and management programs on defined outcomes: overview of the evidence. Journal of The American Geriatrics Society 39(9 Pt 2), 8S.
- Salanitro A.H., Hovater M., Hearld K.R., Roth D.L., Sawyer P., Locher J.L., Bodner E., Brown C.J., Allman R.M. & Ritchie C.S. (2012) Symptom burden predicts hospitalization independent of comorbidity in community-dwelling older adults. Journal of The American Geriatrics Society 60(9), 1632-1637.
- Sheik J. & Yesavage J. (1986) Geriatric Depression Scale (GDS): recent evidence and development of a shorter version. Clinical Gerontologist 5(165-172).
- Sheppard K.D., Brown C.J., Hearld K.R., Roth D.L., Sawyer P., Locher J.L., Allman R.M. & Ritchie C.S. (2013) Symptom burden predicts nursing home admissions among older adults. Journal of Pain and Symptom Management 46(4), 591-597.

- Sletvold O., Tilvis R., Jonsson A., Schroll M., Snaedal J., Engedal K., Schultz-Larsen K. & Gustafson Y. (1996) Geriatric work-up in the Nordic countries. The Nordic approach to comprehensive geriatric assessment. Danish Medical Bulletin 43 (4), 350-359.
- Sutradhar R., Atzema C., Seow H., Earle C., Porter J. & Barbera L. (2014) Repeated assessments of symptom severity improve predictions for risk of death among patients with cancer. Journal of Pain and Symptom Management 48(6), 1041-1049.
- Tse M., Wan V.T. & Wong A.M. (2013) Pain and pain-related situations surrounding community-dwelling older persons. Journal of Clinical Nursing 22(13-14), 1870-1879.
- Walke L.M., Byers A.L., McCorkle R. & Fried T.R. (2006) Symptom assessment in community-dwelling older adults with advanced chronic disease. Journal of Pain and Symptom Management 31(1), 31-37.
- Walke L.M., Byers A.L., Tinetti M.E., Dubin J.A., McCorkle R. & Fried T.R. (2007) Range and severity of symptoms over time among older adults with chronic obstructive pulmonary disease and heart failure. Archives of Internal Medicine 167(22), 2503-2508.
- WHO (2002). Retrieved from http://whqlibdoc.who.int/hq/2002/ WHO\_NMC\_CCH\_02.01.pdf on 11 May 2015.
- Wolff J.L., Starfield B. & Anderson G. (2002) Prevalence, expenditures and complications of multiple chronic conditions in the elderly. Archives of Internal Medicine 162(20), 2269-2276.
- Zambroski C.H., Moser D.K., Bhat G. & Ziegler C. (2005) Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. European Journal of Cardiovascular Nursing 4(3), 198-206.
- Zulman D.M., Sussman J.B., Chen X., Cigolle C.T., Blaum C.S. & Hayward R.A. (2011) Examining the evidence: a systematic review of the inclusion and analysis of older adults in randomized controlled trials. Journal of General Internal Medicine 26(7), 783-790.

The Journal of Advanced Nursing (JAN) is an international, peer-reviewed, scientific journal. JAN contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. JAN publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit JAN on the Wiley Online Library website: www.wileyonlinelibrary.com/journal/jan

#### Reasons to publish your work in JAN:

- High-impact forum: the world's most cited nursing journal, with an Impact Factor of 1.917 ranked 8/114 in the 2015 ISI Journal Citation Reports © (Nursing (Social Science)).
- Most read nursing journal in the world: over 3 million articles downloaded online per year and accessible in over 10,000 libraries worldwide (including over 3,500 in developing countries with free or low cost access).
- Fast and easy online submission: online submission at http://mc.manuscriptcentral.com/jan.
- · Positive publishing experience: rapid double-blind peer review with constructive feedback.
- Rapid online publication in five weeks: average time from final manuscript arriving in production to online publication.
- · Online Open: the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).