5.

Self-perceived met and unmet care needs of frail older adults in primary care

PART 2/2

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ABSTRACT

BACKGROUND — In order to provide adequate care for frail older adults in primary care it is essential to have insight into their care needs. Our aim was to describe the met and unmet care needs as perceived by frail older adults using a multi-dimensional needs assessment, and to explore their associations with socio-demographic and health-related characteristics.

METHODS — Cross-sectional baseline data were used from the Frail older Adults: Care in Transition (ACT) study in the Netherlands, consisting of 1137 community dwelling frail older adults aged 65 and above. Patients were recruited through 35 primary care practices. Self-perceived care needs were assessed using the Camberwell Assessment of Need for the Elderly (CANE). Socio-demographic characteristics included age, sex, partner status and educational level. Health-related characteristics included functional capacity, hospital admissions, chronic diseases and the degree of frailty.

RESULTS — Frail older adults reported on average 4.2 care needs out of 13 CANE topics, of which 0.5 were unmet. The physical and environmental domain constituted the highest number of needs, but these were mostly met. Unmet needs were mainly found in the psychosocial domain. Regression analyses revealed that ADL limitations and a higher frailty score were the most important determinants of both met and unmet care needs. A younger age and a higher educational level were associated with the presence of unmet care needs.

CONCLUSION — Most frail older adults in primary care report to receive sufficient help for their physical needs. More attention should be paid to their psychosocial needs.

INTRODUCTION

In aging societies, managing frailty is a major challenge for healthcare professionals in primary care. Frail older adults comprise one of the fastest growing segments of the primary care population [1-3]. In older adults, frailty is defined as a state of increased vulnerability toward adverse health outcomes [4-7]. This increased vulnerability is the result of a loss of resources in one or

more domains of functioning (physical, psychological, social) [8;9]. Frailty causes older adults to experience problems in daily life, and may increase their need for care [10]. Adequately addressing these care needs with targeted interventions may delay or prevent the onset of adverse health outcomes in frail populations [11]. Therefore, it is essential for the general practitioner (GP) to have insight into the care needs of frail older adults. Especially unmet care needs (i.e. lack of care or help to reduce a problem) require attention [12].

One approach to identify care needs is to perform a comprehensive geriatric assessment. In such an assessment the capacities and problems of older adults are evaluated in multiple domains, such as the medical, psychological and environmental domain [13]. Another approach is more patient-centered, and focuses on self-perceived care needs of frail older adults [12;14]. Both approaches may be helpful to identify care needs that were previously not known to the GP [15].

So far, self-perceived care needs and the extent to which needs are met have not been studied among frail older adults in primary care. Furthermore, little is known about the determinants of care needs. There are several patient characteristics associated with frailty that may have an effect on a person's needs, such as the absence of a partner and comorbidity [4;16]. A recent study among frail older adults showed that both socio-demographic and health-related characteristics are associated with the use of formal care [17]. To what extent these factors shape the self-perceived care needs of frail older adults has yet to be established. The aim of this study was to give an overview of the met and unmet care needs as perceived by frail older adults in primary care using a structured multi-dimensional needs assessment. In addition, we explored to what extent socio-demographic and health-related characteristics were associated with care needs.

METHODS

Design and study sample

Cross-sectional baseline data of community-dwelling frail older adults were used from the Frail older Adults: Care in Transition (ACT) study in the Netherlands [18]. The ACT study is a randomized controlled trial designed to evaluate the effectiveness of a Geriatric Care Model based on the chronic

care model [19]. Patients will be followed for 2 years. During that period the intervention will start and every 6 months follow-up measurements will be collected. All data used in the current study were from the baseline measurement, which was collected before any intervention started.

In the ACT study, frail older adults were identified based on a multidimensional definition of frailty (i.e., a loss of resources in the physical domain, psychosocial domain, or a combination of both) [8;9]. Older adults aged 65 and above, who were living at home and who had a PRISMA-7 score of 3 or more were eligible for participation. PRISMA-7 is a brief 7-item questionnaire containing risk factors for functional decline [20;21]. It includes 7 simple items to assess whether someone is more than 85 years old, is male, has activity limitations due to health problems, needs help on a regular basis (autonomy), is homebound (mobility), can count on someone in case of need (availability of social support) and has problems with walking. Answering categories were 'yes' or 'no' for each item. PRISMA-7 has previously been used to select frail older adults for integrated care services [22]. Furthermore, in a pilot study conducted before the ACT study it was shown that PRISMA-7 is an accurate instrument to determine frailty in primary care. It has good agreement with both physical and multidimensional frailty measures [23].

Frail older adults were recruited through 35 primary care practices in two regions (Amsterdam and West-Friesland) in the northwest of the Netherlands. Amsterdam is an urban area, whereas West-Friesland is an area of urbanized rural nature. The recruitment procedure has been described in more detail elsewhere [18]. In brief, the GPs provided the names and addresses of 3111 older patients to be assessed for eligibility. These patients received information by mail and were approached by telephone to be screened for frailty. A total of 1147 patients were eligible for participation and agreed to participate (see flow chart in Figure 1 for all inclusion and exclusion criteria). Analyses showed that excluded patients and non-responders were older compared to patients who were screened for frailty (M = 80.3, SD = 8.2 vs. M = 78.6, SD = 7.3). There were no sex differences. All participants were visited at home by trained interviewers, who collected the data by means of computer assisted personal interviewing between May 2010 and February 2011. Since for some participants data on care needs and socio-demographic characteristics were missing, our final data set consisted of 1137 respondents. Signed informed consent was obtained from all study participants. The study received approval by the medical ethics committee of the VU University Medical Center.

Measurements

Self-perceived care needs were assessed using the Dutch version of the Camberwell Assessment of Need for the Elderly (CANE) [24]. The CANE is a structured, multi-dimensional needs assessment that covers the environmental, physical and psychosocial domain, and identifies both met and unmet care needs. The instrument has good reliability and validity [25;26]. The CANE consists of 24 topics, and was originally developed for use in old-age psychiatry. Since some topics are less appropriate for a more general older population and show very low prevalences in primary care (e.g., psychotic symptoms, self-harm) [15], we included 13 of 24 CANE topics in the current study. Removing items does not have major effects on the validity and reliability of the instrument, because individual CANE topics were separately validated on content and reliability [25;26]. Detailed and hierarchical questions are asked to identify problems, the nature and the severity of the problem, and the extent to which help is received [25]. For each topic, the older adult stated if there was a need, and if the need was met or unmet. An unmet need was defined as the lack of help or insufficient help to reduce the problem.

Socio-demographic characteristics included age, sex, partner status and educational level. Partner status indicated whether a respondent had a spouse or partner. Three categories of educational level were distinguished: low level (elementary school or less), middle level (lower vocational, general intermediate, intermediate vocational or general secondary school) and high level (higher vocational education, college or university).

Health-related characteristics included functional capacity, hospital admissions, chronic diseases and the degree of frailty. Functional capacity was measured using the Katz-15 index of Independence in Activities of Daily Living (ADL) [27]. Respondents were asked whether they had difficulties performing one of the 15 activities (yes or no). A sum score of ADL limitations was calculated. Hospital admissions were assessed by asking 'Have you been hospitalized during the past 12 months?' Five major chronic diseases were assessed by self-report [28]. Respondents were asked whether they currently or in the past 12 months had one of the following chronic diseases: diabetes mellitus, cancer, chronic non-specific lung disease (asthma, chronic obstructive pulmonary disease), arthritis (rheumatoid arthritis or osteoarthritis) and stroke. The PRISMA-7 score was used to measure the degree of frailty of the respondents [21;23]. The PRISMA-7 score ranges from 3 to 7, where a higher score indicates that more risk factors for functional decline are present.

Statistical analysis

Descriptive statistics were calculated to describe the study sample and the number of care needs. To study the determinants of care needs, multivariable regression analyses were performed. Analyses were done separately for total number of care needs, the number of needs in each domain and the total number of unmet needs. Linear regression analyses were applied for total number of care needs, environmental needs and physical needs. Since the number of psychosocial needs and unmet needs were not normally distributed, logistic regression analyses were performed for these two dependent variables. Two binary variables were created, to distinguish respondents with one or more needs from those without needs. Univariate associations of socio-demographic and health-related characteristics with the five dependent variables were tested (not reported). Variables with p <0.20 on one of the dependent variables were entered in the multivariable analyses. All models were adjusted for geographical region to account for possible differences between the two regions. Furthermore, all models were checked for multicollinearity of the included variables by examining correlation coefficients and the variance inflation factors. There were no signs of multicollinearity. Data were analyzed using SPSS version 20.

RESULTS

Study sample

Table 1 shows the characteristics of the 1137 frail older adults participating in this study. The mean age of the participants was 80.5 years (SD = 7.5), and the majority of the sample was female (66.8 %).

Table 1 (right)
Characteristics of the study population (n = 1137)

CANE= Camberwell Assessment of Need for the Elderly; SD=Standard Deviation

	n	(%) or M (SD)
Age, 65-99, mean (SD)	1137	80.5 (7.5)
Sex, % women	759	(66.8)
Region Amsterdam, % West-Friesland, %	537 600	(47.2) (52.8)
Partner status, % no partner	711	(62.5)
Educational level Low, % Middle, % High, %	382 545 210	(33.6) (47.9) (18.5)
Functional capacity (Katz-15) ADL limitations, 0-15, mean (SD)	1137	3.9 (2.8)
Hospital admissions One or more in the past year, %	297	(26.1)

Chronic diseases

	n	(%) or M (SD)
Diabetes mellitus, %	322	(28.3)
Cancer, %	120	(10.6)
Lung disease, %	311	(27.4)
Arthritis, %	657	(57.8)
Stroke, %	76	(6.7)
Number of chronic diseases, 0-5, mean (SD)	1137	1.3 (0.9)
Frailty score (PRISMA-7) 3 4 ≥5	474 403 260	(41.7) (35.4) (22.9)

Care needs (CANE)

	n	(%) or M (SD)
Total needs, 0-13, mean (SD)	1137	4.2 (2.0)
Environmental needs, 0-4, mean (SD)	1137	1.2 (0.8)
Physical needs, 0-5, mean (SD)	1137	2.5 (1.1)
Psychosocial needs, 0-4, mean (SD)	1137	0.5 (0.8)
One or more psychosocial needs, %	369	(32.5)
Unmet needs, 0-13, mean (SD)	1137	0.5 (1.0)
One or more unmet needs, %	330	(29.0)

Met and unmet care needs

Table 1 also shows the average number of care needs. Frail older adults in primary care reported on average 4.2 care needs out of 13, of which 0.5 needs were unmet. The frequencies of specific needs identified are reported in Table 2. The physical and environmental domain constituted the highest number of needs. The most frequently identified needs were 'physical health' (87.6 %), 'household activities' (82.1 %), 'mobility/falls' (76.1 %), 'visual/hearing impairment' (36.7 %), and 'food' (30.4 %). Between 88.5 % and 97.3 % of these needs were met. Although the highest proportions of unmet care needs were found in the psychosocial domain, the total number of needs in this domain was lower than in the physical and environmental domain. The most frequently identified unmet needs were 'company' (67.7 %), 'daytime activities' (48.4 %), 'information' (41.5%), 'caring for another' (36.4 %), and 'accommodation' (34.3 %).

Table 2 (right)
Frequencies of care needs identified using CANE (n = 1137)

Determinants of care needs

The results of the multivariable regression analyses for total number of care needs, environmental needs and physical needs are presented in Table 3. A higher educational level, ADL limitations, previous hospital admissions, a higher number of chronic diseases and a higher frailty score were associated with a higher total number of care needs. The determinants of care needs were slightly different across domains. Age, educational level, ADL limitations and frailty score were associated with the number of environmental needs. All health-related characteristics were associated with the number of physical needs. Table 3 also shows the results of the multivariable logistic regression analyses for psychosocial needs and unmet needs. Age, ADL limitations and frailty score were associated with having one or more psychosocial needs. Age, educational level, ADL limitations and frailty score were associated with the presence of one or more unmet needs. In sensitivity analyses, multilevel linear and logistic regression models were tested using MLwiN [29] to account for clustering within primary care practices. These analyses did not change the results as presented above.

Topic	Description	Needs	Met needs	Unmet needs
		n (%)	n (%)[a]	n (%)[a]

ENVIRONMENTAL NEEDS

Topic	Description	Needs	Met needs	Unmet needs
Accommodation	Inappropriately or inadequately housed, e.g. adaptation needed	99 (8.7)	65 (65.7)	34 (34.3)
Household activities	In need of domestic assistance	934 (82.1)	862 (92.3)	72 (7.7)
Food	Unable to buy or prepare meals, restricted diet or dysphagia	346 (30.4)	325 (93.9)	21 (6.1)
Caring for another	Difficulty with caring for another person	33 (2.9)	21 (63.6)	12 (36.4)

PHYSICAL NEEDS

Topic	Description	Needs	Met needs	Unmet needs
Physical health	Has a physical illness that should be treated appropriately	996 (87.6)	969 (97.3)	27 (2.7)
Medication use	Problems with compliance, side effects, drug abuse or dependency, or medication not recently reviewed by a medical doctor	236 (20.8)	222 (94.1)	14 (5.9)
Visual/hearing impairment	Difficulty with hearing what someone says in a quiet room, difficulty in seeing newsprint or watching television	417 (36.7)	369 (88.5)	48 (11.5)
Mobility/falls	Restricted mobility, falls or problems using public transport	865 (76.1)	787 (91.0)	78 (9.0)
Self-care	Difficulty with dressing, washing	307 (26.9)	294 (95.8)	13 (4.2)

PSYCHOSOCIAL NEEDS

Topic	Description	Needs	Met needs	Unmet needs
Memory	Problems with remembering things that happened recently, often forgets where he/she put things	93 (8.2)	74 (79.6)	19 (20.4)
Company	Few social contacts, loneliness, social isolation	167 (14.7)	54 (32.3)	113 (67.7)
Daytime activities	Difficulty with regular, appropriate daytime activities	128 (11.3)	66 (51.6)	62 (48.4)
Information	Verbal or written information on condition, medication or treatment	135 (11.9)	79 (58.5)	56 (41.5)

[a] Percentages are based on the total number of needs in that specific topic.

DISCUSSION

This study was conducted to gain insight into the self-perceived care needs of frail older adults in primary care. Using a shortened version of the CANE, we observed that frail older adults reported on average 4.2 care needs out of 13 topics, of which 0.5 needs were unmet. They reported the highest number of care needs in the physical and environmental domain, but most of these needs were met. The highest proportions of unmet needs were found in the psychosocial domain. We also explored the associations of care needs with several patient characteristics. The regression analyses showed that ADL limitations and a higher frailty score were the most important factors associated with met and unmet care needs.

Some of our findings corroborate results from previous studies. In a small sample of older adults in primary care, the highest number of unmet needs was also found in the psychosocial domain [15]. The same was observed in studies among older patients in mental health settings [25;30;31]. However, in our sample of frail older adults, physical and environmental needs were much more frequently identified compared to previous studies.

Insight into the care needs of frail older adults should finally lead to improved care for this population in primary care. Analyzing the nature of self-perceived unmet needs may be a starting point for better care. An unmet need may point to either inadequate recognition by healthcare professionals, failure to address the need by the older person, or indicates that the need is recognized but there is no sufficient intervention available [32]. The most common unmet needs in this study were 'company' and 'daytime activities', which indicate loneliness, social isolation and inappropriate daytime activities. In order to respond to these needs GPs may refer a patient to social services or work together with other professionals in interdisciplinary teams to provide customized care [33;34]. However, GPs themselves often have no means to change the social situation of frail older adults. Other common unmet needs have more potential for improvement. Similar to a previous study among a general older population in primary care, we found that 'information' was a frequent unmet need [12]. Healthcare professionals in primary care may improve the provision of information on medical conditions and treatment to frail older adults [35].

In this study, we also explored the associations of several socio-demographic and health-related characteristics with self-perceived care needs. Studying these associations enables us to identify subgroups that need special attention in primary care. Our main findings seem straightforward. Frail older

Table 3
Multivariable linear regression and logistic regression analyses of care needs on socio-demographic and health-related characteristics
(n = 1137)

	Total needs	Environmental needs	Physical needs	Psychosocial needs	Unmet needs
	Beta	Beta	Beta	OR (95% CI)	OR (95% CI)
SOCIO-DEMOGRAPHIC CHARACTERISTICS					
Age (years)	-0.02	0.06*	-0.02	0.98 (0.96-1.00)*	0.96 (0.94-0.98)***
Sex (female)	-0.00	-0.02	0.03	0.99 (0.73-1.35)	1.14 (0.81-1.60)
Partner status (no partner)	0.05	0.05	0.03	0.95 (0.70-1.28)	1.04 (0.75-1.45)
Educational level Low (Ref.) Middle High	– 0.02 0.06*	– 0.01 0.07*	– -0.03 0.02	1.00 1.29 (0.95-1.74) 1.22 (0.82-1.82)	1.00 1.25 (0.90-1.75) 1.75 (1.15-2.67)**
HEALTH-RELATED CHARACTERISTICS					
ADL limitations (0-15)	0.57***	0.51***	0.49***	1.15 (1.09-1.21)***	1.23 (1.16-1.30)***
Hospital admissions (one or more in the past year)	0.06*	0.04	0.08**	0.88 (0.66-1.19)	0.90 (0.65-1.24)
Chronic diseases (0-5)	0.06*	-0.01	0.07**	1.06 (0.91-1.23)	1.10 (0.93-1.29)
Frailty score (PRISMA-7) 3 (ref.) 4 ≥5	– 0.08** 0.13***	– 0.08** 0.07*	– 0.05 0.14***	1.00 1.40 (1.03-1.91)* 1.58 (1.08-2.31)*	1.00 1.47 (1.05-2.06)* 2.00 (1.34-3.01)**
R^2	44 %	35 %	35 %	8 % [a]	20 % [a]

All models were adjusted for geographical region.
Beta = Standardized regression coefficients, OR = Odds Ratio, 95% CI = 95% Confidence Interval.
*p < 0.05, **p <0.01, ***p <0.001
[a]Nagelkerke R^2

adults in primary care with more ADL limitations and a higher frailty score were more likely to report met and unmet care needs across all domains. Furthermore, we found that chronic diseases and previous hospital admissions were associated with physical needs. These results are consistent with those of previous studies among general populations [36;37]. Surprisingly, we found that a younger age and a higher educational level were associated with the presence of unmet needs. One would expect that higher educated older adults are better capable of finding help to meet their needs [38]. On the other hand, it is possible that these findings represent a cohort effect. Recent cohorts of older adults are higher educated, and may have higher expectations regarding healthcare services [39;40].

The included variables in the multivariable analyses explained between 8 % and 44 % of the variance in met and unmet care needs. However, there are other characteristics not included in this study that may be associated with care needs as well. First, the norms and expectations people have regarding healthcare may be important [41]. Second, the mental health status of frail older adults could play a role with regard to their care needs [30]. Finally, it would also be interesting to look at multilevel factors, such as differences between care organizations or countries. The relatively low number of unmet needs in our study, especially in the physical domain, may indicate that frail older adults have access to good healthcare facilities in the Netherlands. To study the effect of healthcare systems, a cross-national comparison would be an interesting direction for future research.

This study has some strengths and limitations. This was the first study to investigate self-perceived care needs of frail older adults. Another major strength of this study is the use of data from a large cohort of frail older adults in primary care. A limitation of this study is that the cross-sectional design limits the interpretation of the associations between the patient characteristics and care needs. Longitudinal data is needed to observe whether patient characteristics predict care needs over time. Furthermore, it is possible that the frailest people were underrepresented in our study, since our non-response analyses revealed that the oldest old were less likely to participate. Finally, this study did not consider objective information on medical conditions. All measures were based on self-report by the patients. Since data from medical records will become available in a later stage of the ACT study, we were not able to include these data in the current study.

The results of this study show that assessing self-perceived care needs can provide important new information on the care needs of frail older adults in primary care. However, the question remains whether it is possible to

implement a comprehensive research instrument such as the CANE in clinical practice. We used a shortened version of the CANE, but performing the assessment was still time-consuming. For clinical practice, a short instrument focusing on the most prevalent self-perceived unmet needs in specific populations may be more appropriate [42]. Another possibility is to incorporate the assessment of self-perceived needs into existing comprehensive geriatric assessment instruments used in clinical practice. An advantage of the latter is that it combines a patient-centered approach with the perspective of the healthcare professional [43].

CONCLUSION

This study shows that assessing self-perceived care needs can provide important information on care needs of frail older adults in primary care. Frail older adults report high numbers of physical and environmental needs, but most of them indicate to receive sufficient help for these needs. Since the highest proportions of unmet needs were found in the psychosocial domain, more attention should be paid to psychosocial needs of frail older adults.

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