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Caregiver activation of relatives of patients with advanced cancer

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Abstract

Objective: Relatives of patients with advanced cancer often have many caring responsibilities. Not everyone may have sufficient knowledge, skills, and confidence—also known as caregiver activation—to provide such care. We assessed caregiver activation in relatives and its association with their personal characteristics and their own well-being.

Methods: A cross-sectional study among relatives of patients with advanced cancer. Measures included caregiver activation (C-PAM), resilience, personal self-care, caregiver burden, depressive symptoms, quality of life, and social well-being. The C-PAM distinguishes four levels of activation, ranging from poor (level 1) to adequate (level 4). Bivariate and multivariable regression analyses were performed.

Results: Two hundred fifty-four relatives were included; 32% had level 1 activation, 30% level 2, 27% level 3 and 11% level 4. Higher levels of caregiver activation were found among partners, those who provided more hours of informal care, were more resilient, and scored higher on personal self-care. Higher caregiver activation was associated with lower caregiver burden, less depressive symptoms, and better social well-being.

Conclusion: In our study, the majority of relatives seem insufficiently prepared to provide care for their loved one. Supporting them in gaining knowledge, skills, and confidence to provide such care may improve their own well-being.

KEYWORDS
advanced cancer, caregiver activation, informal caregivers, palliative care, relatives, self-management

1 | INTRODUCTION

A diagnosis of advanced cancer has immense physical, emotional, social, and practical impact on the lives of both patients and their relatives (Ellis, 2012; Lung et al., 2022; Stenberg et al., 2010). Relatives often

have important and extensive caregiving responsibilities (Lung et al., 2022; van Ryn et al., 2011). In 2015, the majority of informal caregivers of patients with cancer in England indicated to provide up to nineteen hours per week of care for their loved one (Buckner & Yeandle, 2015). Their responsibilities can include medical care

provision, emotional support, financial assistance, and care coordination (Carstairs, 2010; Stenberg et al., 2010). However, relatives are often poorly prepared or have insufficient capabilities for this caregiver role (Bishop et al., 2007; Lung et al., 2022). Many feel overwhelmed and suffer from high levels of caregiver burden and numerous health-related problems, such as sleep disturbances (Lung et al., 2022; Stenberg et al., 2010). They suffer more frequently from psychological morbidities, such as depressive symptoms, compared with the general population (Grande et al., 2018; Trevino et al., 2018). Moreover, many face marital tension, impaired social relationships, financial problems, and problems at work (Lung et al., 2022; Stenberg et al., 2010).

Stressing the importance of relatives in the day-to-day care of patients, the concept of 'caregiver activation' has been put forward (Hibbard et al., 2004). It builds on the concept of patient activation, which is defined as patients' 'knowledge, skills, and confidence for self-management of one's health or chronic condition'. Patient activation has been associated with improved health-related behaviours, better health outcomes such as health-related quality of life, higher treatment adherence, and reduction of symptoms and hospital admissions (Druss et al., 2010; Hibbard et al., 2009; Lorig et al., 2009). Caregiver activation is defined as 'the knowledge, skills, and confidence of the informal caregiver to provide care for the patient' (Hibbard et al., 2004). It entails coordinating medical care and treatment, preventing and solving the patient's health problems, and collaborating with healthcare professionals (Hibbard et al., 2004).

There are four levels of caregiver activation, ranging from poor (level 1) to adequate (level 4) (Box 1). Up till now, little research has been conducted on caregiver activation. In a population of relatives of patients with Alzheimer's disease, 50% had relatively low levels of caregiver activation (level 1 and 2) (Parker, 2015). Among relatives of colorectal cancer survivors, this percentage was 23% (Mazanec et al., 2016). In relatives of patients with Alzheimer's disease, higher levels of caregiver activation were related to lower levels of relatives' physical and psychological distress and better general health and vitality (Parker, 2015). In relatives of colorectal cancer survivors, higher levels of caregiver activation were associated with female gender and younger age, but not with relatives' quality of life and health status (Mazanec et al., 2016).

Caregiver activation seems a potentially promising, intermediate, and modifiable construct in efforts to improve caregivers' well-being. However, little is known about caregiver activation of relatives of patients with advanced cancer while this group is faced with increasingly complex caregiving responsibilities. Therefore, this study aimed to assess the level of caregiver activation in relatives of patients with advanced cancer and its association with sociodemographic and personal characteristics, and their own well-being.

2 | METHODS

2.1 | Study design and population

This study is nested in the eQuiPe study, a prospective longitudinal observational cohort study on experienced quality of care and quality

> **BOX 1   The four levels of the Caregiver Patient Activation Measure (C-PAM) (Hibbard et al., 2004; Parker, 2015)**
>
> **Level 1 (C-PAM scores ≤47.0):** Caregivers may not yet believe that they play a role in managing the patients health – they may not believe that their role is important.
>
> **Level 2 (C-PAM scores between ≥47.1 and ≤55.1):** Caregivers lack knowledge and confidence to take action on behalf of the patient.
>
> **Level 3 (C-PAM scores between ≥55.2 and ≤72.4):** Caregivers are beginning to take action and feel confident that they are gaining control.
>
> **Level 4 (C-PAM scores ≥72.5):** Caregivers are confident, but they may struggle with maintaining their level of involvement over time.

of life of patients with advanced cancer and their relatives (van Roij et al., 2020). Patients with a solid metastasized tumour (stage IV) were eligible for inclusion. Additional inclusion criteria for patients with breast and prostate cancer were metastases in multiple organ systems and castration-resistant disease, respectively. Patients were asked to recommend a relative for participation in the study. For patients and relatives to be eligible for inclusion, criteria were ≥18 years, able to complete a Dutch self-report questionnaire, able to understand the objective of the study, having no history of severe psychiatric illness, and having signed the informed consent form. Relatives could be for example partners, children, other family members, or friends. Participants could take part regardless of the enrolment of the other. Patients could indicate more than one relative. Detailed information on the study can be found elsewhere (van Roij et al., 2020). In the present study, we used the first follow-up moment of the relatives who had completed the C-PAM measure.

2.2 | Study procedure

From November 2017 until March 2020, patients and relatives were enrolled in 40 hospitals participating in the eQuiPe study. Contact details of potential patient participants were provided by health care professionals. The research team contacted patients by telephone. They asked whether the patient wanted to participate and whether they had a relative who potentially wanted to participate. The research team then contacted the relative and asked whether he/she wanted to participate in the study. Participation in the study was also possible via self-referral. After giving informed consent, participants received questionnaires on paper or online via the Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship (PROFILES) registry (van de Poll-Franse et al., 2011).

2.3 | Measures

Caregiver activation was measured with the validated caregiver version of the 13-statement Patient Activation Measure® (C-PAM®) (Hibbard et al., 2004). The four answer categories range from *disagree strongly* to *agree strongly*, with *not applicable* (NA) as a fifth response option. A conversion table provided by the developers was used to calculate a standardised score ranging from 0 to 100 (the C-PAM score). Higher scores suggest higher activation. C-PAM scores can be used to segment individuals into one of the four increasing levels of activation (see Box 1).

Resilience was measured with the two-item Connor-Davidson Resilience Scale (CD-RISC) (Vaishnavi et al., 2007). Each item can be scored from 0 to 4, yielding a total sum score range of 0–8. Higher scores indicate better resilience.

Personal self-care was measured with the nine-item short version of the Self-Care Practices Scale (SCPS) (Lee et al., 2016). Each item can be scored from 0 to 4, yielding a total sum score range of 0–36. Higher scores indicate more frequent engagement in personal self-care practices.

Caregiver burden was assessed with the Zarit Burden Interview 12 (ZBI-12) (Bédard et al., 2001; Higginson et al., 2010). The ZBI-12 consists of 12 Likert scale questions with two factorial subscales for personal strain and role strain. Scores range from 0 to 48. A score of ≥17 suggests that the informal caregiver experiences a high burden.

Depressive symptoms were assessed with the seven-item subscale of the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). Items are scored from 0 to 3. Scores range from 0 to 21 and higher scores indicate greater levels of depressive symptoms. A score of ≥11 indicates severe depressive symptoms.

Quality of life was measured with two subscales of the validated European Organisation for Research and Treatment of Cancer quality of life questionnaire (EORTC-QLQ-30): emotional functioning and global health (Aaronson et al., 1993). Scores on the four-item emotional functioning subscale range from 1 to 4 and those on the two-item global health status subscale from 1 to 7. Raw scores were transformed into a range of 0–100 for each scale. Higher scores indicate better quality of life.

Social well-being was assessed with a subscale of the Caregiver FACT-G, consisting of 6 items (Cella et al., 1993). Response options range from 0 to 4, yielding a total sum score range of 0–24. Higher scores indicate better social well-being.

Relatives' sociodemographic and personal characteristics were assessed in the baseline questionnaire, including their relation to the patient, marital status, gender, age, ethnicity, education, religious affiliation, (the number of) children (living at home), informal care provision in the last 3 months (yes/no), and the number of hours of care provision per week.

2.4 | Statistical analysis

According to the algorithm of the developers, participants who had C-PAM surveys with missing values were excluded from the analysis.

When a participant completed the C-PAM survey but answered ≥4 times with NA, the conversion table automatically designated this person with level 2 activation ('lacks knowledge and confidence to take action on behalf of the patient'). This designation was primarily intended for healthcare providers in guiding their support of relatives, especially when a baseline score had not previously been established. For research purposes, in consultation with the developers, we used in our analyses a more refined approach. When relatives scored ≥7 times NA on C-PAM items, they were excluded from further analyses. When relatives scored 4, 5, or 6 items as NA, we used multiple imputation for the NAs. Complete case analyses concerning NAs yielded virtually comparable results as analyses based on multiple imputation; the latter are reported. To normalise the C-PAM scores, logarithmic transformation was performed.

Descriptive statistics were performed to examine relatives' sociodemographic and personal characteristics, levels of caregiver activation, and well-being. Scatter plots between the predictors and caregiver activation were used to visualise whether the continuous variables were linearly related to the C-PAM score. For each included variable, residual plots were made. Crude bivariate linear regression analyses were performed to investigate associations between the C-PAM scores and relatives' sociodemographic and personal characteristics and health-related measures. Multivariable linear regression analysis was performed to examine which background characteristics were associated with C-PAM scores. Variables were only included if they were (borderline) significantly associated with caregiver activation in bivariate analyses ($p < 0.1$). Associations between C-PAM scores and health-related measures were adjusted for (borderline) significant background characteristics in separate analyses. For continuous predictor variables, standardised values were used. Analyses were performed with SPSS statistics V.25.

3 | RESULTS

Figure 1 shows the inclusion process of the participants. In total, 1,171 relatives were enrolled in the eQuiPe study; of these, 831 completed the baseline survey, and of these, 301 received the follow-up questionnaire including the C-PAM measure. Two hundred fifty-four of these participants were included in the analysis. Reasons for exclusion were: C-PAM not completed ($n = 29$), answering ≥7 C-PAM items with NA ($n = 17$), and one duplicate participant ($n = 1$). For 14 patients, more than one relative participated.

3.1 | Sociodemographic characteristics of relatives

The mean age of the relatives was 61 years (SD = 13), 65% were woman, and 78% were the partner of the patient (Table 1). Of these partners, all but one lived together with the patient and 74% had children living at home (not shown in table). The vast majority of participants were Dutch (99%). 22% had lower secondary education or less, 47% had upper secondary education, and 30% had higher education.
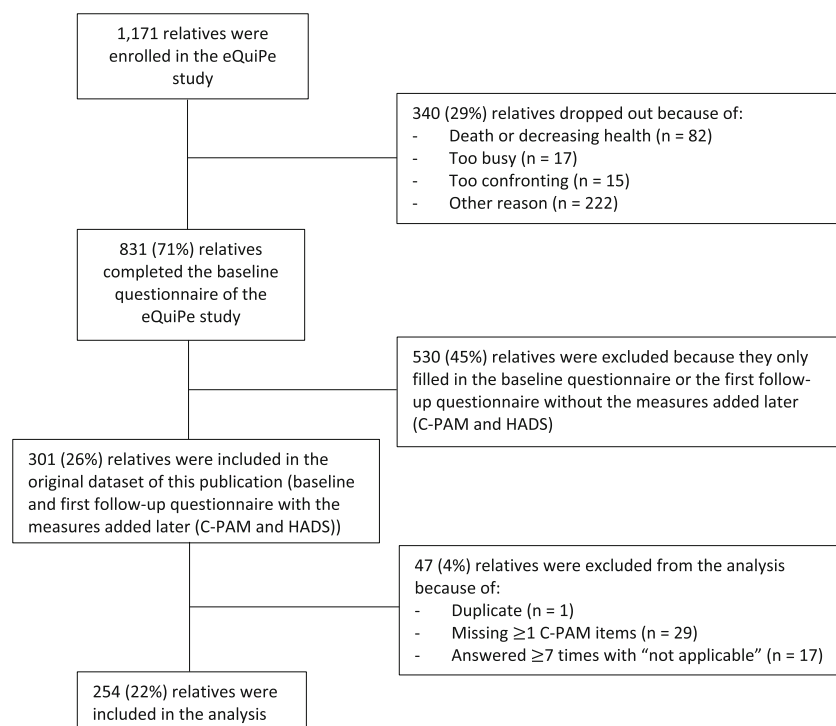
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┌─────────────────────────┐
│ 1,171 relatives were    │
│ enrolled in the eQuiPe  │
│ study                   │
└─────────────────────────┘
            │
            │      ┌──────────────────────────────────────────────┐
            │      │ 340 (29%) relatives dropped out because of:  │
            ├──────│ -   Death or decreasing health (n = 82)      │
            │      │ -   Too busy (n = 17)                        │
            │      │ -   Too confronting (n = 15)                 │
            │      │ -   Other reason (n = 222)                   │
            │      └──────────────────────────────────────────────┘
┌─────────────────────────┐
│ 831 (71%) relatives     │
│ completed the baseline  │
│ questionnaire of the    │
│ eQuiPe study            │
└─────────────────────────┘
            │
            │      ┌──────────────────────────────────────────────┐
            │      │ 530 (45%) relatives were excluded because they│
            ├──────│ only filled in the baseline questionnaire or │
            │      │ the first follow-up questionnaire without the│
            │      │ measures added later (C-PAM and HADS)        │
            │      └──────────────────────────────────────────────┘
┌─────────────────────────────────────┐
│ 301 (26%) relatives were included in │
│ the original dataset of this         │
│ publication (baseline and first      │
│ follow-up questionnaire with the     │
│ measures added later (C-PAM and HADS))│
└─────────────────────────────────────┘
            │
            │      ┌──────────────────────────────────────────────┐
            │      │ 47 (4%) relatives were excluded from the     │
            │      │ analysis because of:                         │
            ├──────│ -   Duplicate (n = 1)                        │
            │      │ -   Missing ≥1 C-PAM items (n = 29)          │
            │      │ -   Answered ≥7 times with "not applicable"  │
            │      │     (n = 17)                                 │
            │      └──────────────────────────────────────────────┘
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│ 254 (22%) relatives were│
│ included in the analysis│
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Many reported having provided informal care in the last 3 months (63%), with a median of 14 h per week (IQR = 24). Relatives had a mean resilience score of 6 (SD = 2) and a mean personal self-care score of 20 (SD = 5).

3.2 | Caregiver activation and health-related measurements

The median caregiver activation score was 51 (IQR = 13, range 0–100) (Table 2). In total, 32% were classified as level 1 (defined as 'did not believe their role is important'); 30% as level 2 ('lacked knowledge and confidence to take action on behalf of the patient'); 27% as level 3 ('began to take action and felt confident at gaining control'); and 11% as level 4 ('was confident but could struggle to maintain their level of involvement'). An overview of respondents' C-PAM scores per item can be found in the Appendix (Table A1). The median caregiver burden score was 9 (IQR = 12, range 0–48); 21% perceived high burden. The median HADS score was 3 (IQR = 5, range 0–21); 12% reported severe depressive symptoms. Relatives' mean emotional function score was 72 (SD = 22), their mean global quality of life score was 76 (SD = 19), and their mean social well-being score was 17 (SD = 3).

3.3 | Associated personal factors with caregiver activation

Bivariate regression analyses showed that relatives with higher activation scores were more often the partner of the patient (compared with other relatives; exp [beta]: 1.12, CI: 1.04–1.18, $p < 0.01$), were more often male (exp [beta]: 1.07, CI: 1.01–1.13, $p = 0.02$), provided more hours of care (exp [beta]: 1.04, CI: 1.01–1.07, $p = 0.01$), were more resilient (exp [beta]: 1.04, CI: 1.01–1.07, $p < 0.01$), and were more frequently engaged in personal self-care practices (exp [beta]: 1.03, CI: 1.00–1.06, $p = 0.02$) (Table 3). Multivariable regression analysis confirmed these findings for the relation of the caregiver to the patient (partners compared with others; exp [beta]: 1.09, CI: 1.03–1.17, $p = 0.01$), hours spent caregiving (exp [beta]: 1.04, CI: 1.01–1.07, $p = 0.01$), resilience (exp [beta]: 1.03, CI: 1.00–1.06, $p = 0.04$), and personal self-care (exp [beta]: 1.04, CI: 1.01–1.07, $p = 0.01$), explaining 10.7% of the total variance (Table 4).

Crude bivariate regression analyses showed that relatives with higher activation scores had significantly lower caregiver burden (exp [beta]: 0.97, CI: 0.94–1.00, $p = 0.03$) and better social well-being (exp [beta]: 1.04, CI: 1.01–1.07, $p < 0.01$) (Table 5, model 1). After adjusting the individual associations for sociodemographic variables, those with higher activation scores had significantly lower caregiver burden (exp [beta]: 0.96, CI: 0.94–0.99, $p = 0.01$), less depressive symptoms (exp [beta]: 0.97, CI: 0.94–1.00, $p = 0.03$), and better social well-being (exp [beta]: 1.04, CI: 1.02–1.07, $p < 0.01$) (Table 5, model 2). After adjusting the individual associations for sociodemographic variables, resilience, and personal self-care, none of the measurements were significantly associated with caregiver activation (Table 5, model 3).

4 | DISCUSSION

4.1 | Main findings

The majority of the relatives of patients with advanced cancer in this study had low levels of caregiver activation. Higher levels of caregiver

TABLE 1 Sociodemographic and personal characteristics of caregivers

Sample characteristic (n = 254)	Sample description
Relation of caregiver to the patient, n (%)	
Partner	196 (77.5)
Son or daughter	40 (15.8)
Other family member	10 (4.0)
Friend	4 (1.6)
Other	3 (1.2)
Gender, n (%)	
Male	89 (35.0)
Female	165 (65.0)
Age (years), mean (SD)	61.2 (12.5)
Ethnicity, n (%)	
Dutch	250 (99.2)
Western immigrant	2 (0.8)
Education, n (%)	
Lower secondary education or less	56 (22.2)
Upper secondary education	120 (47.4)
Higher vocational or academic education	77 (30.4)
Religious affiliation, n (%)	
Protestant Christian, active	29 (11.6)
Protestant Christian, not active	25 (10.0)
Roman Catholic, active	12 (4.8)
Roman Catholic, not active	58 (23.1)
Humanistic	11 (4.4)
None	107 (42.6)
Other	9 (3.6)
Children, n (%)	
No	46 (18.2)
Yes, not living at home	161 (63.6)
Yes, and living at home	46 (18.2)
Number of children, n (%)	
0	46 (18.9)
1	37 (14.6)
2	102 (40.2)
≥ (3)	67 (26.4)
Has provided informal care in the last 3 months, n (%)	
No	92 (36.8)
Yes	158 (63.2)
If yes: Number of hours per week, median (IQR)	14.0 (24.0)
Resilience, mean (SD)[a]	6.0 (1.5)
Personal self-care practices scale (SCPS), mean (SD)[b]	19.7 (5.0)

Note: Because of rounding, not all percentages total 100.
Abbreviations: SD, standard deviation; IQR, interquartile range.
[a]Range for Resilience is 0–8 (higher scores indicate being more resilient).
[b]Range for Personal Self-Care Practices Scale is 0–36 (higher scores indicate more frequent engagement in personal self-care practices).
Missings range: Relation of caregiver to patient (n = 1), Age (n = 5), Ethnicity (n = 2), Education (n = 1), Religious affiliation (n = 3), Children (n = 1), Number of children (n = 2), Informal care provided in the last 3 months (n = 4), Number of hours per week (n = 5), Resilience (n = 1), SCPS (n = 3–6).

TABLE 2 Caregiver activation and health-related measurements

	Sample description (n = 254)
Caregiver activation	
Caregiver patient activation measure (C-PAM), median (IQR)[a]	51.0 (12.9)
Activation levels based on C-PAM score, n (%)	
Level 1: May not believe their role is important (≤47.0)	82 (32.3)
Level 2: Lacking knowledge and confidence to take action (≥47.1 and ≤55.1)	75 (29.5)
Level 3: Taking action and feeling confident in gaining control (≥55.2 and ≤72.4)	69 (27.2)
Level 4: Confident, but may struggle with maintaining behaviours over time (≥72.5)	28 (11.0)
Health related measurements	
Caregiver burden (ZBI-12), median (IQR)[b]	9.0 (12.0)
Depressive symptoms (HADS), median (IQR)[c]	3.0 (5.0)
Quality of life (EORTC-QLQ-30)	
Emotional function, mean (SD)[d]	72.0 (22.1)
Global quality of life (QOL), mean (SD)[e]	75.6 (18.5)
Social well-being (FACT-G), mean (SD)[f]	17.1 (3.4)

Note: Missings range: C-PAM (n = 21–24), ZBI-12 (n = 1–3), HADS (n = 3–4), Emotional function (n = 3–4), Global QOL (n = 2–3), FACT-G (n = 2–3).
SD, standard deviation; IQR, interquartile range.
[a]Range for Caregiver Patient Activation Measure is 0–100 (higher scores indicate greater use of self-management skills).
[b]Range for Caregiver Burden is 0–48 (higher scores indicate greater care load).
[c]Range for Depressive symptoms is 0–21 (higher scores indicate higher prevalence of depressive symptoms).
[d]Range for Emotional Function is 0–100 (higher scores indicate less tense, irritable, depressed or worried feelings).
[e]Range for Global Quality of Life is 0–100 (higher scores indicate greater overall physical condition and quality of life).
[f]Range for Social Well-being is 0–24 (higher scores indicate better social well-being).

activation were in particular present among partners, those who provided more hours of informal care, those who were more resilient, and those who engaged more frequently in personal self-care practices. Relatives with higher levels of caregiver activation had less caregiver burden, less depressive symptoms, and better social well-being.

TABLE 3 Bivariate linear regression of sociodemographic and personal characteristics of caregivers and caregiver activation

	Caregiver patient activation measure, log transformed(C-PAM), n = 254	
	Exp (beta) (95% CI)	p-value
Relation of caregiver to the patient		
Partner	1.12 (1.04–1.18)	<0.01
Other	Ref	
Gender		
Female	Ref	
Male	1.07 (1.01–1.13)	0.02
Age (per year)	1.03 (1.00–1.05)	0.05
Education[a]		
Low	Ref	
High	1.00 (0.94–1.06)	0.88
Religious affiliation		
Active	Ref	
Other	1.03 (0.96–3.01)	0.46
Children		
No	Ref	
Yes, but not living at home	1.04 (0.97–1.01)	0.27
Yes, and living at home	0.99 (0.90–1.08)	0.81
Number of hours of care provision per week (per 10 h)[b]	1.04 (1.01–1.07)	0.01
Resilience	1.04 (1.01–1.07)	<0.01
Personal self-care (SCPS)	1.03 (1.00–1.06)	0.02

Abbreviations: exp, exponent; CI, confidence interval.
[a]Low = upper secondary education or less; High = higher vocational or academic education.
[b]If the participant did not provide informal care in the last 3 months, number of hours per week = 0.

4.2 | Comparison with caregiver activation in other populations

About two-third of relatives were categorised as having rather low caregiver activation levels, indicating that they may not believe their role is important (yet), or may lack knowledge and confidence to take up the caregiver role. The median caregiver activation score of 51 found in our population is lower compared with C-PAM scores in relatives of persons with Alzheimer's disease (mean C-PAM score: 59), where relatives spent on average 79 h of caregiving per week (Parker, 2015). It is also lower compared with a study about caregiver activation among relatives of colorectal cancer survivors, who had a mean C-PAM score of 66 post-surgical hospitalisation, which decreased to 62 after 4 months (Mazanec et al., 2016).

TABLE 4 Multivariable linear regression of sociodemographic and personal characteristics of caregivers and caregiver activation

	Caregiver patient activation measure, log transformed(C-PAM), n = 254	
	Exp (beta) (95% CI)	p-value
Relation of caregiver to the patient		
Partner	1.09 (1.03–1.17)	0.01
Other	Ref	
Number of hours of care provision per week (per 10 h)[a]	1.04 (1.01–1.07)	0.01
Resilience	1.03 (1.00–1.06)	0.04
Personal self-care (SCPS)	1.04 (1.01–1.07)	0.01

Note: Adjusted R^2 = 0.107. Variables entered into the regression analysis were (borderline) significantly associated with caregiver activation in bivariate analyses (p < 0.1) and included relation of caregiver to the patient, gender, age, number of hours per week of informal care provision, resilience, and personal self-care.
Abbreviations: exp, exponent; CI, confidence interval.
[a]If the participant did not provide informal care in the last 3 months; number of hours per week = 0.

Lower activation scores in our study population were in particular present among relatives who were not the partner and provided fewer hours of informal care, and among those who reported lower resilience and less frequent engagement in personal self-care practices. Lau and colleagues found that caregivers of home hospice patients acknowledged self-confidence as a factor that facilitated medication management of their loved ones (Lau et al., 2010). The lower level of caregiver activation in our population may on the one hand be explained by fewer caregiver responsibilities resulting in a lower 'necessity' of caregivers to take up this role. This is supported by the finding that partners had a somewhat higher median C-PAM score than relatives who were not a partner (53 versus 49). In cancer patients, health-related problems are common during treatment. However, they have a rather high level of independent functioning until late in the disease trajectory (Lunney et al., 2002). Serious functional decline is mostly seen in the last few months of life (Cohen-Mansfield et al., 2017). This may indicate that during longer periods only close relatives, often partners, are involved in the support of patients with advanced cancer. Our patient population concerns patients with advanced cancer who even in stable periods may consistently need the support of their relatives to deal with their illness. The relatively low levels of caregiver activation may therefore mean that close relatives do not interpret their support as caregiving responsibilities (Deshields et al., 2012). However, it could also mean that a subgroup of family caregivers of patients with advanced cancer may not be prepared to take on caregiver responsibilities.

TABLE 5   Associations between caregiver activation and health-related measurements[a]

Caregiver patient activation measure, log transformed (C-PAM), n = 254	Caregiver burden (ZBI-12)		Depressive symptoms (HADS)		Emotional function (EORTC-QLQ-30)		Global quality of life(EORTC-QLQ-30)		Social well-being (FACT-G)	
	Exp (beta) (95% CI)	p-value	Exp (beta) (95% CI)	p-value	Exp (beta) (95% CI)	p-value	Exp (beta) (95% CI)	p-value	Exp (beta) (95% CI)	p-value
Model 1[b]	0.97 (0.94–1.00)	0.03	0.99 (0.96–1.01)	0.33	1.02 (0.99–1.04)	0.27	1.01 (0.98–1.04)	0.56	1.04 (1.01–1.07)	<0.01
Model 2[c]	0.96 (0.94–0.99)	0.01	0.97 (0.94–1.00)	0.03	1.03 (1.00–1.06)	0.05	1.02 (1.00–1.05)	0.09	1.04 (1.02–1.07)	<0.01
Model 3[d]	0.98 (0.95–1.01)	0.16	1.00 (0.97–1.04)	0.83	1.01 (0.98–1.04)	0.64	1.01 (0.98–1.03)	0.72	1.02 (0.99–1.05)	0.22

Abbreviations: exp, exponent; CI, confidence interval.

[a]C-PAM is dependent variable.

[b]Bivariate linear regression.

[c]The association is adjusted for relation of the caregiver to the patient, gender, age, and number of hours per week of informal care provision.

[d]The association is adjusted for relation of the caregiver to the patient, gender, age, number of hours per week of informal care provision, resilience, and personal self-care.

4.3 | Associations of caregiver activation with relatives' well-being

In our study, higher caregiver activation scores were associated with lower caregiver burden, less depressive symptoms, and greater social well-being of the relative. Relatives who are proactively involved in care, and who have more knowledge about the disease and trajectory, and therefore know what to expect, might experience problems as less urgent and, as a result, experience less stress. This, in turn, could have positively influenced the different dimensions of caregiver burden. Furthermore, activated relatives may be better able to leverage their social network. Also, relatives with a strong social network might be better able to share caregiver tasks and feel able to handle the patient's needs. In other research, the associations between the caregiver role of relatives and their symptoms of depression, anxiety, and stress have been described too. Often, these are described as complex and possibly cyclic because negative emotions may act as a blockade to activation (Elliott et al., 2010; Hibbard et al., 2007; Lau et al., 2010; O'Rourke, 2009; Wang et al., 2021). Relatives who feel prepared and are competent to meet the patient's demands, have been described to report emotional satisfaction and good well-being as a result of being able to help their loved one through a challenging situation (Otis-Green & Juarez, 2012). Other research also indicates that a considerable amount of variance in caregiver well-being is influenced by social support (Deshields et al., 2012). Relatives underline that good relationships, support networks, and shared caregiver responsibilities give a sense of security, connectedness, and manageability (Milberg & Strang, 2004; Stajduhar et al., 2008; Stoltz et al., 2006). This means that more activated relatives might be better able to maintain low burden levels. After adjusting the associations between caregiver activation and caregiver burden, depressive symptoms, and social well-being for both resilience and personal self-care, the associations were not significant anymore. This could imply that resilience and/or self-care are on the causal pathway, with adjustment for these variables resulting in overadjustment bias.

4.4 | Caregiver activation as a possible intervention target?

Evidence suggests that patient activation is an important precursor of patient self-management (Hibbard et al., 2007). Patient activation is associated with healthy behaviours and it is suggested to be a potential modifiable intermediate construct of patients' outcomes and care (Hibbard et al., 2007; Mosen et al., 2007). The same is hypothesized to be true for caregiver activation, which might be a modifiable precursor of health-related outcomes for relatives, given its association with caregiver burden, depressive symptoms, and social well-being. Future longitudinal and intervention studies are needed to confirm this hypothesis. Other research suggests that strengthening the role of the relative can positively affect the well-being of both relatives and patients, and acceptance of illness has been found to play a mediating role (Wang et al., 2021). Programs aimed at supporting relatives to

take up an active role in the care and enhance caregiver skills, improved relatives' knowledge and ability to cope, decreased caregiver burden, and had a positive impact on quality of life of relatives as well as patients (Belgacem et al., 2013; Honea et al., 2008; McMillan et al., 2006; Sörensen et al., 2002). Examples of caregiver-focused programs are caregiver skill training interventions, problem-solving therapy, and dyadic communication programs (Bell & D'Zurilla, 2009; Berry et al., 2012; Li & Loke, 2014; McMillan et al., 2006). Although not all these studies did assess caregiver activation, they suggest that activating relatives could positively affect themselves, the patients, and their mutual relationships (Bell & D'Zurilla, 2009; Berry et al., 2012; Li & Loke, 2014; McMillan et al., 2006).

4.5 | Strengths and limitations

This study has several strengths. To our knowledge, this is one of the first studies that addressed caregiver activation in a population of relatives of patients with advanced cancer. Second, the eQuiPe study, from which the data originate, was based on a large multicentre observational cohort with relatively high response rates for both patients and relatives (van Roij et al., 2021). Some limitations should be considered when interpreting these findings. First, given the cross-sectional nature of the study design, we cannot make inferences about causality. Future longitudinal and intervention research based on these exploratory results is needed to examine the effect of covariates on key outcomes. Second, selection bias could have influenced the results to some extent. There was almost no variety in ethnic backgrounds, the majority of participants completed upper secondary education or higher, and relatives with a history of severe psychiatric illness were excluded from participation in the eQuiPe study. Third, we did not assess how many informal caregivers or health care providers were involved in the care for the patient, although this might have affected relatives' activation levels. Fourth, it can be argued that the scope of the C-PAM is somewhat limited, as the items do not include psychosocial support, they only focus on the patient and not on taking care of caregivers' own well-being, and do not take into account the possible dyadic, reciprocal nature of patient and caregiver support (McCauley et al., 2021). Focus on only improvement of caregiver's knowledge and skills might be no guarantee for successful performance of caregiving tasks if the ability for caregiving is disrupted by other factors such as caregiver's negative emotional state (Lau et al., 2010). Moreover, the C-PAM focuses on the individual, but the care system and social network must also be taken into account. When the care system offers too little support, the burden that relatives and patients experience will not be relieved by simply enhancing the caregiver's role.

4.6 | Clinical implications and future research

Of the participants, 21% perceived high burden and 12% reported to have severe depressive symptoms. This is almost twice as much

compared with the normative population, in which only 7% suffer from severe depressive symptoms (Breeman et al., 2015). From intervention studies targeting patient activation, it is known that activation levels are modifiable and that patient outcomes can be improved. Future research into caregiver activation needs to be conducted to understand whether this is also the case for caregiver activation. If true, the C-PAM could be used to identify relatives who are at greater risk for caregiver burden and depressive symptoms (Green et al., 2010; Hibbard et al., 2007; Parker, 2015). What might be needed to improve activation of relatives, will depend on their current activation level. Relatives with a lower level could benefit from support aimed to increase knowledge about the disease and treatment (Larsen et al., 2021). Those with a higher activation level could benefit from interventions aimed to increase and maintain their confidence and skills for different caregiving tasks (Hibbard et al., 2004). Such support can be provided by the general practitioner or by the patient's attending physician. Clinicians should keep the role and well-being of relatives in mind during the whole disease trajectory (van Roij et al., 2022). They should be aware that relatives may not yet be activated to take up a role as informal caregivers. This requires timely involvement of relatives, by informing them about the disease and prognosis, taking stock of their preparedness, and involving them in decision making (Larsen et al., 2021).

5 | CONCLUSION

There is quite some variation in levels of caregiver activation among relatives of patients with advanced cancer. The majority of relatives seem insufficiently prepared to provide care for their loved one. Higher levels of caregiver activation were found among partners and those who provided more hours of informal care, were more resilient, and scored higher on personal self-care. Higher levels of caregiver activation are associated with better well-being of relatives. Relatives who do not sufficiently take care of themselves could be at risk for suboptimal performance of their caregiver role. Empowering relatives of patients with advanced cancer in managing the care for their loved one may improve their own well-being.

CONFLICT OF INTEREST
None declared.

DATA AVAILABILITY STATEMENT
Since 2011, PROFILES registry data is freely available according to the FAIR (Findable, Accessible, Interoperable, Reusable) data principles for non-commercial (international) scientific research, subject only to privacy and confidentiality restrictions. The datasets analysed during the current study are available through Questacy (DDI 3.x XML) and can be accessed by our website (www.profilesregistry.nl). In

order to arrange optimal long-term data warehousing and dissemination, we follow the quality guidelines that are formulated in the 'Data Seal of Approval' (www.datasealofapproval.org) document, developed by Data Archiving and Networked Services (DANS). The data reported in this manuscript will be made available when the eQuiPe study is completed.

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APPENDIX A

Table A1 Overview caregiver activation

Statements	Disagree strongly, n (%)	Disagree, n (%)	Agree, n (%)	Agree strongly, n (%)	NA, n (%)
Statement 1 (n = 254) *I am responsible for seeing that this persons health is managed properly.*	9 (3.5)	41.4 (16.3)	124 (48.8)	69.4 (27.3)	10.2 (4.0)
Statement 2 (n = 254) *Taking an active role in this persons healthcare is one of the most important factors in determining her/his health and ability to function.*	4.4 (1.7)	64 (25.2)	129.2 (50.9)	41.4 (16.3)	15 (5.9)
Statement 3 (n = 254) *I am confident that I can take actions that will help prevent or minimise some symptoms or problems associated with this persons health.*	11.4 (4.5)	39.6 (15.6)	153.8 (60.6)	42.2 (16.6)	7 (2.8)
Statement 4 (n = 254) *I know what each of this persons prescribed medications does.*	12.2 (4.8)	56.6 (22.3)	120.8 (47.6)	60 (23.6)	4.4 (1.7)
Statement 5 (n = 254) *I am confident that I can tell when this person needs to get medical care and when I can handle the problem myself.*	5 (2.0)	62.2 (24.5)	135.2 (53.2)	48.6 (19.1)	3 (1.2)
Statement 6 (n = 254) *I am confident I can tell a doctor or nurse the concerns that I have about this persons health even when he or she does not ask.*	1 (0.4)	15 (5.9)	142.4 (56.1)	91.4 (36.0)	4.2 (1.7)
Statement 7 (n = 254) *I am confident that I can carry out medical treatments I need to do for this person at home.*	5 (2.0)	34 (13.4)	145.8 (57.4)	46.2 (18.2)	23 (9.1)
Statement 8 (n = 254) *I understand the nature and causes of this persons health.*	3 (1.2)	23 (9.1)	163 (64.2)	60 (23.6)	5 (2.0)
Statement 9 (n = 254) *I know the different medical treatment options available for this persons health.*	6 (2.4)	28 (11.0)	162 (63.8)	52.8 (20.8)	5.2 (2.0)
Statement 10 (n = 254) *I am able to help this person maintain lifestyle changes, like healthy eating or exercising, for her/his condition.*	7 (2.8)	36.2 (14.3)	152.2 (59.9)	53.2 (20.9)	5.4 (2.1)
Statement 11 (n = 254) *I know how to prevent problems with this persons health.*	15.4 (6.1)	105.4 (41.5)	106.2 (41.8)	20 (7.9)	7 (2.8)
Statement 12 (n = 254) *I am confident I can work out solutions when new situations or problems arise with this persons health.*	20.6 (8.1)	122.8 (48.3)	88.2 (34.7)	16.4 (6.5)	6 (2.4)
Statement 13 (n = 254) *I am confident I can help this person with lifestyle changes, like healthy eating and exercise, even during times of stress.*	10.2 (4.0)	68 (26.8)	138.2 (54.4)	29.4 (11.6)	8.2 (3.2)