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BMJ Open Informal care provision for mental versus somatic disorders in the Netherlands: a cross-sectional investigation of caregiving context and quality of life outcomes

Leonarda GM Bremmers 💿, Leona Hakkaart-van Roijen, Carin A Uyl-de Groot, Isabelle N Fabbricotti

ABSTRACT

Objectives To investigate to what extent informal caregivers of persons with a mental disorder and a somatic disorder compare, in terms of their caregiving context and quality of life measures.

Design Cross-sectional analysis of an existing panel survey dataset.

Setting The Netherlands, 2020.

Participants Informal caregivers that provided long-term care and support to a loved one with either a somatic disorder (n=428) or mental disorder (n=176).

Outcome measures Self-assessed care-related, healthrelated and mental health-related quality of life and the caregiving context, including background and contextual factors of the informal caregiver and care recipient, caregiving strains and coping and support.

Results A significant degree of variation was present among the two caregiving groups, in terms of their caregiving context. Notably, caregivers for individuals with mental disorders had a higher subjective burden (p<0.001), care recipient comorbidity (p<0.001), need for permanent surveillance (p=0.003) and total caregiving intensity (p<0.001). Significantly worse caregiver outcomes were reported for caregivers of individuals with mental disorders for care-related (p<0.001), healthrelated (p=0.011) and mental health-related quality of life (p<0.001). However, the presence of a mental disorder was only found to be significantly associated with worse care-related quality of life scores (B=-4.635, p=0.002). Conclusions Our findings established that informal caregivers of individuals with mental disorders not only provide care and support in more burdensome caregiving contexts, but also suffer from a worse quality of life compared with informal caregivers of individuals with somatic disorders. Particularly, the impact on care-related quality of life was concerning, with the presence of a mental disorder in the care recipient found to be directly associated with a significantly worse outcome.

INTRODUCTION

Informal care is 'the long-term care or support lent on (a) voluntary basis to a family member, friend or acquaintance for physical or mental

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Multiple conceptualisations of quality of life were considered in this study, which allowed a broader impact of caregiving to be captured.
- \Rightarrow The cross-sectional design of the dataset falls short of meeting the criterion of temporal priority of the cause over the effect; hence, this study can establish associations but cannot prove causality.
- \Rightarrow There may be a notable probability of omitted variable bias, as evidenced by the low adjusted R² values for the regression analyses for mental health-related and health-related quality of life; consequently, the impact of mental disorders could have been overestimated or underestimated for these conceptualisations of quality of life.

text and data minii health problems or problems due to ageing' (Hoefman et al, p6).¹ A high proportion of individuals assume caregiving roles for indi-≥ viduals with care needs, with approximately 34.3 % of individuals engaging in informal care provision in Europe. On average, 7.6 % 9 of these informal caregivers are considered intensive caregivers, providing at least 11 hours <u>0</u> of care and support per week.² Informal caregiving is widely recognised as a vital form of $\overline{\mathbf{a}}$ care and support, whereby family members and other loved ones assume responsibility for the day-to-day needs of individuals with **O** chronic conditions. These caregiving tasks $\hat{\mathbf{G}}$ include medication management, emotional **3** assistance, support with activities of daily living and financial support.^{3 4} Empirical evidence has demonstrated that the care and support provided by informal caregivers complement and, in some instances, substitute formal care,^{5–7} with an increase in informal care associated with a decrease in the utilisation of formal home care services.⁵ The escalating prevalence of mental and chronic

Protected by copyright, including for uses related to

Correspondence to

Leonarda GM Bremmers; bremmers@eshpm.eur.nl conditions and an ageing population, coupled with the burgeoning healthcare costs, has led to a discernible shift towards community-centred treatment approaches. Consequently, there has been a notable upsurge in the reliance on informal care.⁸ The dependence on informal care has been compounded by cutbacks in residential and professional home care.⁹¹⁰ These policy reforms have been accompanied by a public narrative that emphasises the importance of patient self-sufficiency and encourages individuals to remain at home for as long as possible. As a result, family members and other loved ones are obligated to enter new care arrangements and shoulder additional caregiving responsibilities.¹⁰

Under these circumstances, the relationship between the care recipient and the informal caregiver has become increasingly imbalanced and dominated by care provision.^{11 12} Thus, informal care is often characterised as distressing and burdensome, with a significant portion of informal caregivers feeling overburdened as a result of their caregiving responsibilities.¹³ This could have widespread implications for the informal caregiver¹⁴ and their care recipient,¹⁶¹⁷ due to the reciprocal nature of the caregiver-care recipient relationship.¹⁷ Remarkably, the provision of informal care has been found to impact various aspects of informal caregivers' quality of life,¹⁸ with informal care affecting their 'general state of physical, mental and social functioning and well-being' (Martin *et al*, p1042).¹⁹ This calls into question how sustainable informal care provision is in the long term.⁸ Furthermore, it is essential to prioritise the well-being and engagement of informal caregivers in order to effectively implement interventions for patients.^{20 21} Therefore, there is a need to better understand how informal care provision impacts informal caregivers' quality of life, particularly in different caregiving situations.

Care recipient disorder may have a significant impact on the caregiving experiences of informal caregivers and their respective outcomes, owing to variations in care needs.²²⁻²⁵ Informal caregivers for individuals with mental disorders are often assumed to be a particularly vulnerable group of caregivers that require additional support and attention.¹³ However, only a limited number of studies have empirically investigated the difference between caring for individuals with somatic disorders compared with those with mental disorders, and the respective impact on informal caregivers. These existing literature bases have demonstrated that informal caregivers for individuals with mental disorders generally have worse caregiving situations and healthrelated outcomes when compared with other caregiving groups.^{22–25} However, these studies have either focused on the comparison of particular disorders^{22 24 25} or primarily investigated the difference in terms of caregiving context (ie, objective and subjective burden).^{23 24} While these studies may provide an initial insight into the comparison of these two caregiving groups, in terms of caregiving context and impact, they lack comprehensive outcomes that consider the multifaceted impact of informal care

provision. Furthermore, additional research facilitates early identification of at-risk caregiver groups, enabling the development of targeted support programmes and policies that are tailored to individual caregiver needs and circumstances.

Hence, it remains unclear whether informal caregivers for individuals with mental disorders truly constitute a more vulnerable caregiving population when considering the caregiving context and impact. It should be noted that informal caregivers for individuals with mental disorders encounter distinct challenges throughout their caregiving trajectory. For example, factors specifically related to mental disorders, such as behavioural problems and difficulties in understanding the care recipient's negative symptoms, have been associated with unfavourable care- 8 giver outcomes.^{26–28} The fragmentation of the mental healthcare system also contributes to worse caregiving experiences,²⁹ due to insufficient ambulatory care, long waiting lists and exclusion of informal caregivers from the care trajectory.^{30–33} Additionally, these informal caregivers face structural discrimination and isolation as a consequence of disorder-related stigma.³⁴⁻³⁶ Furthermore, mental disorders are often chronic and long-lasting in mental disorders are often chronic and long-lasting in nature, leading to multidimensional disability.³⁷ Hence, the aim of this study was to investigate to what extent the caregivers of persons with a mental disorder and a somatic disorder compare, in terms of their caregiving context and quality of life measures. Three quality of life $\overline{\mathbf{a}}$ text measures were included in this assessment, namely carerelated, health-related and mental health-related quality of life. This helped to ensure a comprehensive evaluation of the impact of caregiving that considers the breadth and complexity of informal care provision.^{18 38}

METHODS

Study design and participants

data mining, AI training, A cross-sectional data analysis was conducted using an existing dataset.³⁹ The dataset originated from an online survey administered to a panel of Dutch informal caregivers (n=1006) in June 2020. Respondents were considered eligible for inclusion if they reported that they were adults (≥18 years of age) who provided a minimum of 2 hours of informal care per week to a person (≥ 18 years of age) with a somatic or mental disorder for at least a 3-month period. Informal caregivers who reported that their care recipient had a terminal illness, intellectual disability or dementia were excluded (n=366; refer to g online supplemental file 1 for the flow chart of the exclusion process).

A total of 604 informal caregivers were included in the final analyses, which consisted of informal caregivers for care recipients with somatic disorders (n=428) and mental disorders (n=176). The mental disorder group included persons with psychological (eg, depression or anxiety disorders) and psychosocial problems (eg, loneliness or addiction), while the somatic disorder group included persons with a short-term (eg, as a result of an accident or operation) or long-term physical disability and symptoms related to ageing.

Measurements

The impact of informal care provision is multifaceted and can have lasting effects on the health and well-being of informal caregivers, particularly their quality of life. 40-42To avoid presenting a limited perspective on caregiver quality of life, research should include multiple conceptualisations of quality of life,¹⁸ especially since informal care provision has been associated with worse mental and physical health outcomes.^{11 41 43} Hence, we selected quality of life instruments that assessed care-related, health-related and mental health-related quality of life.

Quality of life measures

Care-related quality of life

The CarerQoL is a validated measurement instrument⁴⁴⁻⁴⁶ that determines the care-related quality of life and combines a subjective burden measure that provides a description of the caregiving situation (CarerQoL-7D) with a valuation of informal caregiver happiness (CarerQoL-Visual Analogue Scale (VAS)). The questionnaire operationalises the impact of informal care into positive dimensions (fulfilment from caregiving and support with lending care) and negative dimensions (relational problems, mental health problems, problems combining daily activities with care, financial problems and physical health problems).⁴⁷ A weighted sum score of the CarerQoL was employed, which was calculated based on the preferences of the Dutch general adult population. Higher scores indicate a better care-related quality of life.48

Health-related quality of life

The European Quality of Life-5 dimension-5 level (EQ-5D-5L) is a validated health-related quality of life measurement⁴⁹ instrument that consists of five dimensions-mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The respondent is asked to indicate his/her health state by selecting the most appropriate statement, with five levels ranging from 'no problems' to 'extreme problems'.⁵⁰ The 5-level version of the questionnaire was selected due to the improved sensitivity and less prevalent ceiling effects.^{51 52} The Dutch tariff for the 5-level version of the EQ-5D-5L was employed to calculate a preference-based utility score. In the EQ-5D-5L utility score '1' represents full health whereas '0' is equivalent to death.53

Mental health-related quality of life

The validated Mental Health Quality of Life Questionnaire (MHQoL)^{54 55} assesses the respondent's mental health-related quality of life and comprises seven questions that assess: self-image, independence, mood, relationships, daily activities, physical health and future. Each dimension has four response levels, including 'very satisfied', 'satisfied', 'dissatisfied' and 'very dissatisfied'.⁵⁵ The Dutch tariff for the MHQoL was employed to calculate

a preference-based utility score. In the MHOoL utility score, '1' represents full mental health, whereas '0' is equivalent to death.⁵⁶

Caregiving context

The caregiving context has been evidenced to influence an informal caregiver's adaptation to their informal care provision and ultimately, caregiver outcomes. Hence, differences in the caregiving context can continue to health and well-being disparities among caregiver groups and should be considered when assessing caregiver ^{12,57,58} However limited empirical research has been conducted to investigate differences in caregiving context between informal caregivers for individuals with mental disorders and informal caregivers for individuals with somatic disorders.²²⁻²⁵

ight The caregiving context can broadly be conceptualised into three main variable groups: background and contextual factors, caregiving strains and coping and support. The background and contextual factors are the sociodemographic characteristics of informal caregivers and care recipients. In the interest of clarity, the background ð and contextual factors have been separated into two categories-informal caregiver and care recipient-for this study. Caregiving strains are defined as the difficult circumstances experienced by informal caregivers while lated caregiving. Coping and support are the social, personal and material resources that help regulate the reported đ tex caregiving strains.⁵⁸ The selection of variables was based on their theoretical and empirical relevance.^{12 22-25 57 58} and

Informal caregiver characteristics included the following a caregiving context variables: informal make ends meet (0 'easy to make ends meet'; 1 'difficult to make ends meet'), informal caregiver child caregiving ≥ responsibilities (0 'does not care for a child under 18 years of age'; 1 'provides care to a child under 18 years of age'), informal caregiver age (years), informal caregiver employment status (0 'unemployed, including retired, student, homemaker'; 1 'employed, including full- time and part-time employment'), informal caregiver gender S (0 'male'; 1 'female'), informal caregiver highest attained education level (0 'lower-intermediate level of education, including primary education (LO), lower vocational education (LBO), general secondary education (MAO), higher general secondary education (HAO) and secondary vocational education (MBO)'; 1 'higher level of education, including higher professional education (HBO) and research university (WO)'), informal caregiver marital status (0 'other'; 1 'currently married/registered partner') and duration of caregiving (months).

Background and contextual factors: care recipient

For the care recipient characteristics, the following variables were assessed: care recipient age (years), care recipient comorbidity (0 'does not have a comorbidity'; 1 'has a comorbidity'), care recipient gender (0 'male'; 1

'female'), care recipient kinship (0 'not a family member, including friend, acquaintance or neighbour'; 1 'a family member, including partner, mother(-in-law), father(in-law), daughter, son, sister, brother or other family member') and care recipient living situation (0 'care recipient does not live with caregiver'; 1 'care recipient lives with caregiver').

Caregiving strains

Caregiving strains were assessed with need for permanent surveillance (0 'can easily stay alone for a couple of hours' 1 'cannot easily stay alone (eg, only for an hour or requires constant supervision)'), subjective burden (score) and total caregiving intensity (hours per week).

Subjective burden was assessed using the self-rated burden scale, which employs a horizontal VAS to judge the burden of caregiving on a scale from 0 ('not straining at all') to 10 ('much too straining').⁵⁹ Intensity of caregiving was measured using an adapted version of the Intensity of Informal Care Ouestionnaire, which assessed the hours of support with household tasks, support with self-care tasks, emotional support and practical support.¹

Coping and support

Coping and support included the following caregiving context variables: ability to cope (0 'less than 2 years' 1 'more than 2 years'), social support (0 'no social support'; 1 'receives social support') and informal caregiver support services (0 'no utilisation of informal caregiver support services in past month'; 1 'utilisation of informal caregiver support services in past month').

Ability to cope was determined using a validated singlequestion instrument that asks informal caregivers to report 'if the informal care situation stays as it is now, how long will you be able to cope with the care?'.⁶⁰ For the purpose of this study, the response categories were dichotomised.⁶¹

Procedures

Respondents were categorised into two caregiving groups-somatic disorders and mental disorders-based on the reported care recipient disorder. Somatic disorders included short-term and long-term physical disorder and age-related complaints, while mental disorders included psychological and psychosocial problems. Forced-choice questions were employed; hence, there were no missing data.

Statistical analyses

Statistical analyses were conducted using IBM SPSS Statistics (V.28.0.1.0), with the level of statistical significance (α) set at 0.05.

Descriptive statistics (mean, SD, percentages) were computed to determine the caregiving context and caregiving outcomes for the respective caregiver groups. These were then compared between informal caregivers for somatic and mental disorders by means of independent t-tests for continuous variables and Pearson's χ^2 for categorical variables. If Levene's test indicated a

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violation of the assumption of equal variances, Welch's t-test was employed to account for heterogeneity of variances.

To determine whether differences in caregiver outcomes were a result of the care recipient's condition, multivariable linear regression analyses were conducted for each dependent variable (health-related, mental health-related and care-related quality of life) that adjusted for the caregiving context. The presence of a mental disorder was entered as an independent variable in each model and coded 0 'somatic disorder' and 1 'mental disorder'. Patient and public involvement Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research. RESULTS Characterising and comparing the caregiving context by care recipient disorder giving context. The presence of a mental disorder was

recipient disorder Table 1 presents the descriptive statistics for the care-giving context by care recipient disorder. The caregiving g rei context was found to differ significantly for informal caregivers of persons with somatic disorders versus mental at ed disorders. Informal caregivers for individuals with mental health problems reported more difficulties to make ends of meet (p<0.001), were younger of age (p<0.001) and had more child caregiving responsibilities (p=0.001). Furthermore, they had a longer duration of caregiving (p=0.008) and were more commonly women (p=0.048). In terms of the background and contextual factors for care recipients, care recipients with a mental disorder were found to be significantly younger (p<0.001), have a comorbidity \mathbf{a} (p<0.001) and be male (p<0.001) compared with care ۷. recipients with a somatic disorder. Informal caregivers for individuals with mental disorders also reported experiencing more caregiving strains compared with informal caregivers for persons with somatic disorders across a variety of outcomes. For example, they had a significantly higher subjective burden (p<0.001) and provided more hours of informal care per week (p<0.001). On aggregation of caregiving intensity, the amount of informal care provided was only found to be significantly higher for emotional support (p<0.001) and support with self-care (p=0.038). Additionally, relatively more care recipients g with mental disorders could also not easily be left alone (p=0.003). However, ability to cope (p=0.107), access to social support (p=0.246) and utilisation of caregiver support services (p=0.384) did not differ by care recipient disorder.

Comparison of quality of life measures

Across all quality of life measures, informal caregivers for individuals with mental disorders were found to have significantly worse outcomes (see table 2).

Table 1 Caregiving context by care recipient disorder			
	Mean/frequency (SD		
	Somatic disorders	Mental disorders	Significance
Background and contextual factors: informal caregiver			
CG's ability to make ends meet			***
Easy to make ends meet	260 (60.7%)	79 (44.9%)	
Difficult to make ends meet	168 (39.3%)	97 (55.1%)	
CG's age (years)	54.84 (15.51)	49.86 (15.55)	***
CG's child caregiving responsibilities			**
Not caring for a child under the age of 18	365 (85.3%)	130 (73.9%)	
Caring for a child under the age of 18	63 (14.7%)	46 (26.1%)	
CG's employment status			
Unemployed	209 (48.8%)	78 (44.3%)	
Employed	219 (51.2%)	98 (55.7%)	
CG's gender			*
Female	221 (51.6%)	107 (60.8%)	
Male	207 (48.4%)	69 (39.2%)	
CG's highest attained education level			
Lower-intermediate level	281 (65.7%)	108 (61.4%)	
Higher level	147 (34.3%)	68 (38.6%)	
CG's marital status			
Currently married/registered partner	256 (59.8%)	97 (55.1%)	
Other	172 (40.2%)	79 (44.9%)	
Duration of caregiving (mean, months)	79.14 (82.62)	99.53 (92.65)	**
Background and contextual factors: care recipient			
CR's age (years)	72.87 (16.05)	54.07 (20.39)	***
CR's comorbidity			***
No comorbidity	307 (71.7%)	71 (40.3%)	
Comorbidity	121 (28.3%)	105 (59.7%)	
CR's gender			***
Female	307 (71.7%)	98 (55.7%)	
Male	121 (28.3%)	78 (44.3%)	
CR's kinship			
Family member	372 (86.9%)	148 (84.1%)	
Not a family member	56 (13.1%)	28 (15.9%)	
CR's living situation			
Lives with CG	148 (34.6%)	57 (32.4%)	
Does not live with CG	280 (65.4%)	119 (67.6%)	
Caregiving strains			
Need for permanent surveillance			**
CR cannot easily be left alone	57 (13.3%)	41 (23.3%)	
CR can easily be left alone for several hours (or more)	371 (86.7%)	135 (76.7%)	
Subjective burden score†	4.48 (2.51)	5.36 (2.48)	***
Total caregiving intensity hours per week	20.82 (22.55)	28.89 (31.11)	***
Emotional support	3.26 (5.77)	8.10 (13.81)	***
Household tasks	7.08 (8.95)	7.69 (10.08)	
Practical support	5.25 (7.55)	6.52 (8.28)	
Support with self-care	5.23 (6.55)	6.59 (8.95)	*

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Continued

Table 1 Continued			
	Mean/frequency (SD/per cent, %)		
	Somatic disorders	Mental disorders	Significance
Coping and support			
Ability to cope			
Less than 2 years	135 (31.5%)	68 (38.6%)	
More than 2 years	293 (68.5%)	108 (61.4%)	
Social support			
No access to social support	95 (22.2%)	47 (26.7%)	
Access to social support	333 (77.8%)	129 (73.3%)	
CG support services			
Utilisation of CG support services in the past month	88 (20.6%)	42 (23.9%)	
No utilisation of CG support services in the past month	340 (79.4%)	134 (76.1%)	

Significance of χ^2 and t values reported.

*p<0.05, **p<0.01, ***p<0.001.

+Scale ranging from 0 ("not straining at all") to 10 ("much too straining").

CG, informal caregiver; CR, care receiver.

Exploration of differences in guality of life measures Care-related quality of life

After controlling for caregiving context, the presence of a mental disorder in the care recipient was significantly (p=0.002) associated with the informal caregivers' care-related quality of life (see table 3). Additionally, several factors within the caregiving context were significantly associated with care-related quality of life. These included the informal caregiver's ability to make ends meet (B=4.963 p<0.001), duration of caregiving (B=-0.017, p=0.014), care recipient gender (B=-3.037, p=0.015), need for permanent surveillance (B=5.672, p<0.001), subjective burden (B=-2.526, p<0.001), ability to cope (B=9.206, p<0.001) and social support (B=5.695, p<0.001). Hence, informal caregiver ability to make ends meet, shorter duration of caregiving, care recipient being male, no need for permanent surveillance, lower subjective burden, longer ability to cope and social support were associated with a higher care-related quality of life score. The overall regression model was statistically significant (adjusted R^2 =0.444, F (20, 583)= 25.095, p<0.001).

Health-related quality of life

After controlling for the caregiving context, the presence of a mental disorder in the care recipient was not

for significantly (p=0.142) associated with the informal uses caregivers' health-related quality of life (see table 4). However, several factors within the caregiving context re were significantly associated with health-related quality ated to text of life. These included informal caregiver's ability to make ends meet (B=0.084, p<0.001), employment status (B=0.049, p=0.004), gender (B=-0.038, p=0.027), and marital status (B=0.048, p=0.008); as well as care recipient age (B=0.001, p=0.019) and comorbidity (B=-0.067, p<0.001). Additionally, duration of caregiving (B=0.000, p<0.001), subjective burden (B=-0.008, p=0.035) and ability to cope (B=0.068, p<0.001) were also significantly associated with health-related quality of life. Hence, informal caregiver ability to make ends meet, informal caregiver employment, informal caregiver being male, ⊳ married informal caregivers, older care recipient age, no care recipient comorbidity, shorter duration of caregiving, lower subjective burden and longer ability to cope , and were associated with a higher health-related quality of life score. The overall regression model was statistically signifsimilar technologies. icant (adjusted $R^2=0.181$, F (20, 583)= 7.654, p<0.001).

Mental health-related quality of life

When controlling for the caregiving context, the presence of a mental disorder in the care recipient was not

Table 2 Comparison of caregiver outcomes for informal caregivers of individuals with somatic disorders and mental disorders			
	Mean (range); SD)		
Caregiver outcomes score	Somatic disorders	Mental disorders	Significance
Care-related quality of life	80.45 (15.90 to 100.00; 16.45)	70.60 (0.00 to 100.00; 20.13)	***
Health-related quality of life	0.83 (-0.29 to 1.00; 0.19)	0.79 (-0.25 to 1.00; 0.23)	*
Mental health-related quality of life	0.82 (-0.26 to 1.00; 0.23)	0.74 (-0.74 to 1.00; 0.32)	***

Significance of t values reported.

*p<0.05, **p<0.01, ***p<0.001.

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	Unstand	lardised c	oefficients
	В	SE	Significance
resence of mental disorder in the CR ref. somatic disorder	-4.635	1.508	**
ackground and contextual factors: informal caregiver			
CG ability to make ends meet ref. 'easy to make ends meet'	4.963	1.202	***
CG age	0.051	0.051	
CG child caregiving responsibilities ref. 'does not care for a child under 18 years of age'	-3.047	1.660	
CG employment status ref. 'unemployed, including retired, student, homemaker'	1.597	1.247	
CG gender ref. male	-1.857	1.242	
CG highest attained education level ref. 'lower-intermediate level of education'	-0.667	1.229	
CG marital status ref. 'other'	0.290	1.310	
Duration of caregiving	-0.017	0.007	*
ackground and contextual factors: care recipient			
CR age	-0.017	0.037	
CR comorbidity ref. 'does not have a comorbidity'	-0.409	1.254	
CR gender ref. male	-3.037	1.249	*
CR kinship ref. 'not a family member, including friend, acquaintance or neighbour'	-0.118	1.722	
CR living situation ref. 'care recipient does not live with caregiver'	2.100	1.485	
aregiving strains			
Need for permanent surveillance ref. 'can easily stay alone for a couple of hours'	-5.672	1.637	***
Subjective burden	-2.526	0.262	***
Total caregiving intensity	-0.040	0.026	
oping and support			
Ability to cope ref. 'less than 2 years'	9.206	1.423	***
Social support ref. 'no social support'	5.695	1.462	***
CG support services ref. "no utilisation of informal caregiver support services in past month	" 0.860	1.422	
odel summary	Adjusted F (20, 58	l R ² =0.444 3)= 25.095	5, p<0.001
><0.05, **p<0.01, ***p<0.001. G. informal caractives: CP. cara recipient.			

significantly (p=0.935) associated with the informal caregivers' mental health-related quality of life (see table 5). However, several factors within the caregiving context were significantly associated with informal caregivers' mental health-related quality of life. These included informal caregiver's ability to make ends meet (B=0.100, p<0.001), marital status (B=0.077, p<0.001), care recipient comorbidity (B=-0.101, p<0.001), duration of caregiving (B=0.000, p<0.001), subjective burden (B=-0.019, p<0.001), ability to cope (B=0.071, p=0.003), and social support (B=0.066, p=0.008). Hence, the ability to make ends meet, married informal caregivers, no care recipient comorbidity, shorter duration of caregiving, lower subjective burden, longer ability to cope, and social support were associated with a higher mental health-related quality of life score. The overall regression model was statistically significant (adjusted $R^2 = 0.224$, F(20, 583) = 9.687, p<0.001).

, and with mental disorders are often regarded as a caregiving population that is more susceptible to adverse outcomes.¹³ However, limited studies have empirically investigated the differences between informal caregivers of individuals with somatic disorders and those with mental disorders, with respect to their caregiving context and quality of life.^{22–25} Additionally, all previous quality of life research has been limited to general health-related quality of life measures.^{22 23} The findings of our study revealed significant variations in the caregiving context based on the disorder of the care recipient. Notably, informal caregivers of individuals with mental disorders reported experiencing more caregiving strains, including higher levels of subjective burden and overall caregiving intensity and the increased need for permanent surveillance of their loved one. Additionally, this particular population of informal caregivers tended to be younger, have longer durations of caregiving and consisted of more women.

 Table 4
 Multivariate regression analysis for health-related quality of life

	Unstandardised coefficients		
	В	SE	P value
Presence of mental disorder in the CR ref. somatic disorder	0.030	0.021	
Background and contextual factors: informal caregiver			
CG ability to make ends meet ref. 'easy to make ends meet'	0.084	0.017	***
CG age	-0.001	0.001	
CG child caregiving responsibilities ref. 'does not care for a child under 18 years of age'	-0.035	0.023	
CG employment status ref. 'unemployed, including retired, student, homemaker'	0.049	0.017	**
CG gender ref. male	-0.038	0.017	*
CG highest attained education level ref. 'lower-intermediate level of education'	0.005	0.017	
CG marital status ref. 'other'	0.048	0.018	**
Duration of caregiving	0.000	0.000	***
Background and contextual factors: care recipient			
CR age	0.001	0.001	*
CR comorbidity ref. 'does not have a comorbidity'	-0.067	0.017	***
CR gender ref. male	-0.001	0.017	
CR kinship ref. 'not a family member, including friend, acquaintance or neighbour'	0.026	0.024	
CR living situation ref. 'care recipient does not live with caregiver'	-0.002	0.020	
Caregiving strains			
Need for permanent surveillance ref. 'can easily stay alone for a couple of hours'	-0.007	0.022	
Subjective burden	-0.008	0.004	*
Total caregiving intensity	0.000	0.000	
Coping and support			
Ability to cope ref. 'less than 2 years'	0.068	0.020	***
Social support ref. 'no social support'	0.017	0.020	
CG support services ref. 'no utilisation of informal caregiver support services in past month'	0.000	0.020	
Model summary	Adjusted R ² =0.181 F(20, 583)= 7.654, p<0.001		

*p<0.05, **p<0.01, ***p<0.001.

CG, informal caregiver; CR, care recipient.

Moreover, informal caregivers for individuals with mental disorders were found to have a significantly worse quality of life compared with informal caregivers for individuals with somatic disorders. Nevertheless, the lower quality of life scores could not be attributed to the care recipient's mental disorder, with the exception of care-related quality of life. In summary, our findings suggest that informal caregivers tending to individuals with mental disorders have a distinct caregiving context and exhibit a comparatively worse state of physical, mental and social functioning, as well as a reduced sense of well-being within the context of their informal care provision, compared with informal caregivers of individuals with somatic disorders.

The findings of this study highlight the overall challenging nature of caregiving; however, caring for individuals with mental disorders is even more taxing, as evidenced by their informal caregivers consistently reporting a worse quality of life. These findings were confirmed when comparing our results with published reference values for our selected quality of life measures.

Protected by copyright, including for uses related to text and data mining, Al training, and In terms of care-related quality of life, informal caregivers of individuals with mental disorders were notably lower compared with a representative sample of adult Dutch informal caregivers (70.6 vs 79.1, respectively).³⁹ While the care-related quality of life of informal caregivers for individuals with somatic disorders was comparable to this general caregiving population (80.5 vs 79.1, respectively).⁶¹ A similar trend was present when comparing the care-related quality of life score of informal caregivers for individuals with mental disorders to other somatic caregiving populations, including breast cancer patients (87.0 vs 70.7, respectively)⁶² and elderly individuals after a hip fracture (83.7 vs 70.7, respectively).⁶³ We also found that the health-related quality of life of informal caregivers for individuals with mental disorders was significantly lower compared with informal caregivers of individuals with somatic disorders. These results have been confirmed by other peer-reviewed literature.^{22 23} Additionally, when compared with Dutch general population reference values, the health-related quality of life for both caregiving

Table 5 Multivariate regression analysis for mental health-related quality of me			
	Unstandardised coefficients		
	В	SE	P value
Presence of mental disorder in the CR ref. somatic disorder	-0.002	0.026	
Background and contextual factors: informal caregiver			
CG ability to make ends meet ref. 'easy to make ends meet'	0.100	0.020	***
CG age	0.001	0.001	
CG child caregiving responsibilities ref. 'does not care for a child under 18 years of age'	0.023	0.028	
CG employment status ref. 'unemployed, including retired, student, homemaker'	0.019	0.021	
CG gender ref. male	-0.015	0.021	
CG highest attained education level ref. 'lower-intermediate level of education'	-0.014	0.021	
CG marital status ref. 'other'	0.077	0.022	***
Duration of caregiving	0.000	0.000	***
Background and contextual factors: care recipient			
CR age	0.000	0.001	
CR comorbidity ref. 'does not have a comorbidity'	-0.101	0.021	***
CR gender ref. male	0.009	0.021	
CR kinship ref. 'not a family member, including friend, acquaintance or neighbour'	0.009	0.029	
CR living situation ref. 'care recipient does not live with caregiver'	0.000	0.025	
Caregiving strains			
Need for permanent surveillance ref. 'can easily stay alone for a couple of hours'	-0.034	0.028	
Subjective burden	-0.019	0.004	***
Total caregiving intensity	0.000	0.000	
Coping and support			
Ability to cope ref. 'less than 2 years'	0.071	0.024	**
Social support ref. 'no social support'	0.066	0.025	**
CG support services ref. 'no utilisation of informal caregiver support services in past month'	0.035	0.024	
Model summary	Adjusted F(20, 583	R ² =0.224)= 9.687, p	0<0.001
A 0.05 H 0.04 H 0.004			

*p<0.05, **p<0.01, ***p<0.001,

CG, informal caregiver; CR, care recipient.

populations was markedly lower (0.87 vs 0.83 for somatic)disorders and 0.87 vs 0.78 for mental disorders, respectively).⁵³ At the moment of study completion, no reference values were available for the MHQoL. Nevertheless, our study demonstrated that informal caregivers for individuals with mental disorders are more susceptible to poor quality of life outcomes compared with informal caregivers for individuals with somatic disorders.

However, the presence of a mental disorder was only directly related to a worse care-related quality of life score, despite informal caregivers for individuals with mental disorders having a significantly lower healthrelated and mental health-related quality of life. This may be explained by two reasons. First, the instrument that we implemented to assess care-related quality of life, the CarerOoL, was specifically developed to assess caregiver quality of life within the context of informal care provision. In contrast, the EQ-5D-5L⁵⁰ and MHQoL⁵⁵ are developed to assess the quality of life of patients. Patientreported outcome measures, such as the EQ-5D-5L⁵⁰ and

Protected by copyright, including for uses related to text and data mining, AI training, and MHOoL,⁵⁵ do not account for the intricacies of informal care provision and hence, may not be sensitive enough to detect differences between caregiving populations. Second, the CarerQoL instrument is a broad valuation sim measure that encompasses 'all the different effects of informal care, such as health effects, financial problems or fulfilment from caregiving [...] taken into account through their impact on general well-being' (Hoefman et al, p1109).⁶⁴ This allows us to assess caregiver quality of life in a valid manner for both types of informal caregivers and quantifies the main concerns that have been $\overline{\mathbf{g}}$ reported by informal caregivers.44 45 49

However, the impact of caregiving goes beyond the dimensions captured by the quality of life measures that we employed, suggesting that even more perspectives should be considered.³⁸ For example, when considering the impact that caregiving can have on the mental health of the informal caregiver, a wide spectrum of concepts related to the informal caregiver's mental health should be considered. These concepts include but are not

limited to anxiety symptomology,65 memory errors,66 unresolved grief⁶⁷ and worry.⁶⁸ Similarly, a diverse set of dimensions has been identified for the overall impact on caregiving (eg, safety fears,⁶⁹ self-efficacy⁷⁰ and interaction guilt)⁷¹ and health (eg, disability status⁷² and general medical symptoms).⁷³³⁸ This suggests that when assessing caregiver quality of life, a broader perspective should be adopted.

Societal and scientific implications of findings

The findings of our study establish that informal caregivers of individuals with mental disorders differ significantly from informal caregivers of individuals with somatic disorders. Some of these factors, such as the increased caregiving strains and low care-related quality of life, may impede informal caregivers' willingness and ability to continue providing informal care^{14 16} and also have negative consequences for care recipients.^{16 17} Moreover, caregivers of individuals with mental disorders provide care to younger care recipients for a longer duration of time compared with caregivers of individuals with somatic disorders, which may be explained by the early onset of mental disorders.⁷⁴ In light of the chronic and long-lasting nature of mental disorders,³⁷ it is expected that these caregivers will have to continue giving support and care to their loved ones for an extended amount of time. This is concerning due to their comparatively lower quality of life scores, especially related to the informal care provision. To ensure that this caregiving group is able to continue with their tasks and responsibilities in a productive manner, more targeted support and recognition is required. A generic approach may be inadequate in light of the varying caregiving contexts.

Moreover, we found that the impact of caregiving should be investigated from a variety of perspectives, as the consequences of caregiving extend beyond health. Similar results have been found in empirical research with informal caregivers of children with an autism spectrum disorder.¹⁸ Systematic literature reviews have been conducted to assess which concepts are used to assess the impact of caregiving 38 75 76 ; however, there is no gold standard.³⁸ Hence, more research is needed to establish a battery of measurement instruments and concepts that should be employed when assessing the impact of caregiving. Preferably, these concepts should reflect the lived experiences of informal caregivers and quantify their impact and be employed across a variety of caregiving populations.

Study limitations

There are some limitations that should be acknowledged in this study. First, while this study can establish associations, it cannot prove causality. The cross-sectional design of the dataset falls short of meeting the criterion of temporal priority of the cause over the effect. Second, there is a notable probability of omitted variable bias, as evidenced by the low adjusted R^2 values for the regression analyses for mental health-related and health-related quality of life. Consequently, the impact of mental disorders could have been overestimated or underestimated for these conceptualisations of quality of life. Third, some deviations from normality were observed in the distribution of quality of life scores, particularly in the form of skewness and kurtosis (see online supplemental file 2). However, parametric tests such as the Welch t-test and regression analysis are generally robust to violations of normality, especially with sufficiently large sample sizes.⁷⁷ The central limit theorem ensures that the sampling distribution of the mean approximates normality when sample sizes exceed 30 per group, supporting the validity

of our findings.⁷⁸ Additionally, minor deviations from normality are common in quality of life data, particu-larly in relatively healthy populations, where scores often cluster toward the higher end of the scale.⁷⁹ Given these considerations, our analyses align with established statistical practices in health-related quality of life research, and slight deviations from the normality assumption are not a concern. Lastly, study findings can only be generalised to the care recipient conditions included in the study population. No conclusions can be drawn about 5 specific mental and somatic disorders, due to the collective study of these groups of disorders. However, that was not the goal of this study; rather, we were interested in exploring whether there were differences between somatic and mental disorders in terms of caregiving.

Conclusions

Our findings established that informal caregivers of individuals with mental disorders not only provide care and support in more burdensome caregiving contexts, but also suffer from a worse quality of life compared with informal caregivers of individuals with somatic disorders. Particularly, the care-related quality of life was concerning, with **a** the presence of a mental disorder in the care recipient \triangleright directly associated with a significantly worse outcome. More research is needed to confirm our findings in other study populations. Furthermore, additional research is needed to investigate how to best support this highly and similar technologies burdened caregiving population and assess how the impact of caregiving may differ across specific diagnoses and may change over time with longitudinal research.

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