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# Does willingness to care fluctuate over time? A weekly diary study among informal caregivers

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## ABSTRACT

**Objective:** Informal caregivers are expected to be willing to care for relatives with care needs. Little is known about whether and how willingness to care changes over time. Using a weekly diary study, we examined changes in the willingness of 955 caregivers from nine countries. Caregivers provided information on their caregiving context, relationship type, and relationship satisfaction with the care recipient.

**Methods and measures:** For 24 consecutive weeks, caregivers evaluated willingness to care as it was 'right now'.

**Results:** Willingness differs from one caregiver to another (68% between-level variability) but also fluctuates in the same caregiver from week to week (32% within-level variability), with a decrease over 6 months (intercept = 8.55; slope = -0.93;  $p < .001$ ). Regardless of individual differences in average willingness to care based on caregiving context and relationship satisfaction, caregivers reported decreases in willingness. Caregivers who presented one or more health conditions themselves reported higher weekly fluctuations in willingness than caregivers with no health conditions.

**Conclusion:** Willingness is not a stable attitude because it decreases and caregivers experience fluctuations from week to week. A clearer understanding of weekly processes is optimal for monitoring the caregivers' well-being and tailoring interventions in line with weekly individual variations.

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## KEYWORDS

Informal caregiver; willingness to care; intensive longitudinal design; weekly diary study; within-processes; between-differences

## Introduction

Over a third of the European population provides care to a relative or friend with a chronic illness, disability, or other care need (i.e. care recipients), and they are typically referred to as informal caregivers (hereafter referred to as caregivers) (Verbakel et al.,

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2017). Willingness to provide care has previously been defined as a caregiver's 'attitude toward providing emotional, instrumental and nursing support' (Abell, 2001). Noticeably, existing definitions (Abell, 2001; Wilk & Petriner, 2021) describe the notion of willingness to care as a stable trait to perform diverse caregiving tasks, while they do not consider whether and how willingness evolves over time. Since caregiving tasks develop over time, different skills and types of knowledge are needed, the intensity of care varies, and the burden of caregiving changes, as a consequence, willingness to care could be expected to fluctuate over time (Zarzycki & Morrison, 2021). However, existing research does not provide insights into potential fluctuations in willingness to care over time. The current weekly diary study investigated whether the willingness to care might be considered a *stable trait* or a *fluctuating state* that varies from week to week in the caregiving experience.

Most research on caregivers' willingness to care has been cross-sectional, providing a snapshot of willingness and motivation to care at one time-point only (Dykstra & Fokkema, 2012; Trujillo et al., 2016; Wells & Kendig, 1996). Longitudinal quantitative research on temporal aspects of willingness to care is scarce (Zarzycki & Morrison, 2021). For instance, in a systematic review of motivation and willingness to care in dementia care, which included a limited number of longitudinal studies, changes over time were not investigated as it appeared to be that caregivers are willing or they become willing to care and remain so over time (Greenwood & Smith, 2019). In an earlier systematic review, only a few studies explored willingness over time, suggesting that variations in willingness are often associated with demographic (e.g. gender, age), physical (e.g. caregiver health status and care recipient characteristics of the illness), psychological (e.g. motivation/choice and family dynamics), and social (e.g. expectations of health professionals, preparedness of caregiving) indicators (Burrige et al., 2007). A recent qualitative meta-synthesis on caregiver motivations and willingness to care included 16 longitudinal studies and evidenced the presence of temporal shifts in motivations and willingness to provide care (Zarzycki et al., 2023).

Overall, two different foci of investigation can be derived from the literature on willingness to care over time, there are those which consider the *caregiving context*, including the caregiver, the care recipient, and contextual characteristics, and those which consider *relationship elements* such as relationship types (i.e. spouses, adult children, parents, siblings, and friends) and satisfaction. According to the first focus on the caregiving context, caregivers' willingness to care was found to decrease with caregivers' own deteriorating health status (Wells & Kendig, 1996), perceptions of no choice in taking up the caregiving role (Pertl et al., 2019; Schulz et al., 2012) and lower preparation for caregiving, that is caregivers' perceptions of having inadequate information on future care demands (Brereton & Nolan, 2000). Moreover, changes in willingness over time were found to be associated with care recipients' illness progression and severity of symptoms (Azoulay et al., 2003; McDonnell et al., 1991; Morrison & Williams, 2020). With regard to the second focus of the investigation, variations in willingness to care are known to exist between spouses, adult children, and other types of caregivers (Lyonette & Yardley, 2003; Pinquart & Sorensen, 2011). For example, spouses were found to be more willing and committed to providing care over time, despite a higher care load, whereas adult children varied largely, reporting inconsistent findings in their level of care intensity and motivational factors (Broese van Groenou

et al., 2013; Ng et al., 2016). Moreover, the quality of the caregiving relationship was found to be an important influence on a caregiver's willingness to provide care (e.g. pre-existing and current relationships characterized by high satisfaction, love, affection, and intimacy) (Camden et al., 2011; Wells & Kendig, 1996; Zarzycki et al., 2023) or on the contrary to give up the caregiving role (e.g. conflicts, feelings of frustration, poor relationship quality) (Feeney & Collins, 2003; Knussen et al., 2005).

As such, the above-mentioned studies tell us which groups of caregivers are more or less willing to care over time (i.e. associations between willingness and individual differences) and collected data with long intervals between waves (e.g. 1 year), referring to development and changes in caregiving from a long-term perspective. However, knowledge about fluctuations in willingness to care over time (e.g. from week to week) within caregivers, and individual differences (i.e. based on different caregiving contexts and relationship elements) associated with the degree of fluctuations within caregivers, is limited. As suggested by the aforementioned longitudinal research, some caregivers may be more likely than others to experience changes in their willingness to care. Of special interest in this study is whether such willingness also fluctuates across time and differs systematically as a function of individual differences based on caregiving context (e.g. duration of caregiving, intensity of care, co-residency with the care recipient, care recipient, and caregiver health conditions, presence of other informal caregivers and previous caregiving experience) and relationship elements (e.g. spousal vs. non-spousal caregivers and relationship satisfaction).

Investigating willingness to care as a dynamic process, using repeated assessments over time, is important for several additional reasons. First, exploring if and how caregivers vary around their own mean in terms of willingness to care (i.e. weekly fluctuations) is of great importance to gain better insights into processes that unfold in individual caregivers' daily lives. Such a temporal approach might help to identify when caregiving might become troublesome for some individuals (Pihet et al., 2017) which can also inform psychosocial programs seeking to provide timely support for caregivers. Such support, for example, could include monitoring and offering caregivers to speak with caregiving consultants or coaches on a weekly basis, especially for some caring roles which may last over a decade, such as in dementia care (Koerner & Kenyon, 2007). Moreover, a greater understanding of fluctuations in willingness to care and how much they are attributable to individual differences at a contextual and relational level is essential to guide research and tailored interventions to maintain the willingness to care amongst diverse groups of caregivers. Finally, on a societal level, capturing fluctuations of willingness to care is of high importance given that almost all long-term care systems rely heavily on informal caregivers' support and, thus, rely indirectly on people's willingness to provide care to their care recipients (de Jong et al., 2023).

Therefore, the aims of the current weekly diary study are: (1) to explore to what extent variability in willingness to care can be explained by between-level differences, that is measuring the % of willingness that can be explained by average differences between caregivers (willingness as stable trait and differing from one caregiver to another). And to what extent variability in willingness can be explained by within-level differences, that is the remaining % of willingness to care that could be explained by individual fluctuations in the same caregiver (willingness as a fluctuating state

differing within the same caregiver over time). (2) To explore rates of changes and weekly fluctuations in caregivers' willingness to care over time. (3) To explore whether individual differences in contextual and relationship elements explain within and between level differences in willingness to care.

## Methods

### Participants

Diary data used in this study are part of the ENTWINE iCohort, a multinational, trans-disciplinary, longitudinal study of caregiving (Elayan et al., 2022; Morrison et al., 2022), conducted in nine countries: Germany, Greece, Ireland, Israel, Italy, the Netherlands, Poland, Sweden, and the United Kingdom, between August 2020 and August 2021. This weekly diary study obtained intensive longitudinal data (i.e. 24 weekly repeated assessments over 6 months) from caregivers. Caregivers were recruited online *via* multi-language advertisements, flyers, and informative videos with the survey link placed on different social media. Eligible caregivers were 18 years or older and currently providing care for a family member or a friend with a chronic health condition, disability, or any other care need. Exclusion criteria were not having access to the Internet and not having the self-declared cognitive capacity to complete the questionnaire online.

### Procedure

The study received ethical approvals in all participating countries (Morrison et al., 2022), and eligible participants signed an electronic informed consent form before participation. Measures included in the ENTWINE iCohort survey are reported in the protocol (Morrison et al., 2022), and measures used in the current analyses are described below. Before being invited to the weekly diary study, participants were asked to complete a web-based baseline survey (Elayan et al., 2022; Morrison et al., 2022). Regardless of whether they completed all parts of the baseline survey, they were invited to participate in the weekly diary study. Of the 1872 caregivers enrolled in the iCohort study, 955 (51%) agreed to participate also in the weekly diary study. The weekly diary study was delivered online once per week (on Tuesdays) at the same time, in the afternoon, for 24 consecutive weeks. Participating caregivers were provided with instructions (i.e. an infographic) for the diary procedure the first time they opened the first weekly questionnaire. Given the intensity of our study, participants received reminders during the week (on Wednesdays and Fridays) and emails on the 3rd, 6th, 12th, and 18th week either to sustain their motivation in completing the weekly diaries over time, while remaining clear that they could leave the study at any time, or to thank them for their participation (e.g. motivational cards and thankful video messages recorded by members of the research team).

Moreover, after missing four consecutive weekly diary assessments, participants were automatically removed from the diary study after being notified by email. Access to the weekly diary assessments was provided *via* Questback Enterprise Feedback Suite®, a specialized survey platform for online data collection. Weekly assessments

were accessible *via* a computer, laptop, or any other smart device (e.g. smartphones and tablets). A potential total of 22,920 diary assessments (955 caregivers × 24 weeks) was expected. However, data was obtained from 459 (48%) caregivers who completed a total of 11,016 diary assessments (5 or fewer weeks), 138 (14%) caregivers who completed 3312 diary assessments (between 6 and 12 weeks), and 358 (38%) caregivers who completed 8592 diary assessments (more than 12 weeks). The highest drop-out rates were registered after the first diary entry (22%) and drop-out slowly declined during the diary period.

## **Baseline measures**

### **Demographics**

Self-reported caregiver age, gender, level of education, relationship status, country of residence, employment status, care recipient's age, gender, type, and duration of health conditions were assessed by self-report in the baseline questionnaire or during the first diary week (if they did not complete the baseline questionnaire). Caregivers were asked to complete measures concerning their main care recipients (referred to as *loved ones*) (e.g. care recipient's health, age).

### **Caregiving context**

Caregiving context variables included: (1) the health condition(s) of the care recipient, which were re-categorized into physical impairments (including cardiovascular diseases, cancer, diabetes, kidney diseases, and lung diseases), neurological/mental impairment (including stroke, cognitive or memory impairment, mental health conditions) and other impairments/comorbidities; (2) whether the caregiver presented one or more health conditions or not; (3) intensity of care (total number of hours per week spent on caregiving tasks); (4) the duration of the caregiving period; (5) whether the caregiver has support from other informal caregivers or not; (6) co-residency status of the caregiver and the care recipient (i.e. whether they are living in the same household or not).

### **Caregiving relationship**

Relationship type was dichotomized into spousal (including spouses and partners) vs. non-spousal caregivers (including adult children, parents, siblings, and friends). Relationship satisfaction was assessed with one item (*How satisfied are you with your relationship with your loved one?*) from the Relationship Assessment Scale-Generic (RAS-G; Renshaw et al., 2011). Item responses range from 1 (*not satisfied*) to 5 (*very satisfied*), and higher scores represent higher levels of relationship satisfaction.

### **Weekly willingness to care**

Caregivers' weekly willingness to provide care was assessed using one item with a 10-point Likert scale from 1 (*not all*) to 10 (*extremely*) based on the Willingness to care Scale (Abell, 2001). The item was adapted to measure caregivers' willingness to

care at that specific moment of that week (*How willing are you to look after your loved one's needs right now?*). Higher scores indicated a greater willingness to care.

### Statistical analysis

Growth models were estimated using multilevel modeling with IBM SPSS statistics 28 to estimate caregivers' trajectories of willingness to care over time. Multilevel modeling is appropriate to the analysis of nested data, that is, weekly diary assessments (level 1: time) nested within caregivers (level 2: individuals) (Bolger & Laurenceau, 2013). Multilevel models allow for the disaggregation of within- and between-person effects and for the study of individuals over time *via* growth curve modeling, including modeling within-subject associations over time (Papp, 2004).

To check whether drop-out related to participant characteristics (Ji et al., 2018; Vachon et al., 2019), missing data patterns were tested by examining whether caregivers who completed only one diary assessment ( $n=215$ ; the point of highest drop-out) differed systematically from caregivers who completed more than one diary assessment ( $n=740$ ). This was achieved using t-tests (for continuous variables) and Chi-square tests (for categorical variables). No significant differences were found for caregivers' gender,  $X^2_{(1, 954)}=0.83$ ,  $p=.360$ ; caregiver's health condition(s),  $X^2_{(1, 954)}=0.65$ ,  $p=.421$ ; intensity of care,  $t_{(9095)}=-1.22$ ,  $p=.220$ ; or willingness to care,  $t_{(9831)}=0.93$ ,  $p=.353$ . Significant differences were found in relation to caregivers' age, education, and relationship status; however, the effect sizes of these relationships were trivial ( $d_{\text{age}}=0.03$ ;  $\Phi_{\text{education}}=0.02$ ;  $\Phi_{\text{relationship}}=0.05$ ). Given that multilevel modeling using restricted maximum likelihood estimation is robust to missing data, we included all participants who completed one or more weeks of diary study (Singer & Willett, 2003). Moreover, sensitivity analyses were run, including 1) caregivers who completed 5 or fewer weekly diary assessments, (2) caregivers who completed between 6 and 12 weekly diary assessments, and (3) caregivers who completed more than 12 weekly diary assessments. The sensitivity analyses with the different groups did not show differences in the pattern of results.

Descriptive analyses were conducted (i.e. means and standard deviations for continuous variables and frequencies and percentages for categorical variables). To answer the first research question, that is, exploring the degree of variability in willingness to care attributable to the between- and within-person levels, an intercept-only model (i.e. no predictor variables were included) was estimated. From this model, we were able to estimate the average level of willingness and the variability of willingness for the 'typical' caregiver. Next, we were able to calculate the intraclass correlation coefficient (ICC) to decompose the proportion of variance associated with the within-person (level 1) and between-person (level 2) levels. The within-person level specifies that each caregiver's individual willingness score is composed of the person-specific mean of willingness to care plus the time-specific deviation of willingness from their own mean. The between-person level specifies that a caregiver's mean willingness score is composed of the overall mean score across all caregivers and that person-specific deviation from the overall mean.

For the second research question, addressing rates of change and fluctuations in willingness to care over time, an unconditional growth model was constructed. In this, time was added as a predictor variable, centered in a way that zero represents



the first diary week and one the change over the 24-week diary period, and willingness to care was entered as the dependent variable. Fixed effects parameters of the unconditional growth model for willingness to care estimate the typical caregiver with an average level of willingness to care when time is zero (i.e. intercept) and their rates of change in willingness to care (i.e. slope) over time. Random effects estimate the size of the weekly fluctuations, which are random deviations of subjects above or below their own (within-level random effects) and their group (between-level random effects) average in terms of variances of intercepts, slopes, and covariances of intercepts and slopes.

For the third research question, a final conditional growth model was constructed which included several between-level predictors to test individual differences in willingness to care over time. Following previous research, caregiving contexts (e.g. caregivers' and care recipients' health condition(s), intensity of care, caregiving period, other caregivers, previous caregiving experience, and co-residency) and relationship elements (e.g. caregiving relationship type and satisfaction) were added as between-level predictor variables. Moreover, we controlled for caregivers' age ( $r=0.05$ ,  $p < .001$ ), gender [ $t_{(9740,1)}=-9.16$ ,  $p < .001$ ], and education [ $F_{(9740,1)}=30.33$ ,  $p < .001$ ] because the variables of interest have been found to be associated with willingness to care. Finally, to explore individual differences (i.e. based on caregiving contexts and relationship elements) in within-level variability of willingness to care, an individual score of deviation was calculated for each caregiver around the slope of willingness to care over time. The individuals' residuals for each assessment point were then extracted, and the standard deviation of the residuals was computed. Next, we compared the individual standard deviations of willingness to care over time in the different caregivers using t-tests/ANOVAs and correlations. All statistical analyses were performed at a significance level of 0.05.

## Results

### *Descriptive statistics*

Table 1 shows the sample descriptive information. The 995 caregivers had an average age of 56.7 years (range 18–88) and were mostly female (89.4%). More than two-thirds had a partner (69.4%), and 43.6% had post-secondary academic education. Caregivers were mainly non-spousal (62.8%;  $n=600$ ) and the largest group provided care for a parent (42.2%;  $n=403$ ). About half of the care recipients were male (50.4%), with an average age of 68.69 (range 18–103). In total, 40.4% of the caregivers reported providing care to a person with a physical impairment only, 27.1% to a person with neurological/mental impairments, and 32.5% to people with comorbidity of physical and neurological conditions. On average, caregivers provided 43.1 h of care per week. Regarding the duration of caregiving, our sample comprised 'new' caregivers who have been providing care for less than a year ( $n=136$ ), 'medium-long caregivers' between 1 and 5 years; ( $n=389$ ), 'long caregivers' (5–10 years;  $n=247$ ), and 'very long caregivers' (over 10 years;  $n=174$ ). Given that not-significant differences were found between the above-mentioned four categories of caregiving duration and willingness to care [ $F(3,951)=0.92$ ,  $p=0.429$ ], we recategorized years spent providing care as

**Table 1.** Sample characteristics and descriptive of caregivers ( $N = 955$ ).

Caregivers $N = 955$	$N$ (%)	$M$ (SD)
Age (range 18–88)		56.72 (11.27)
Gender		
Female	854 (89.4%)	
Male	96 (10.1%)	
Other	5 (0.6%)	
Education		
Primary	10 (1.0%)	
Secondary	138 (14.5%)	
Post-secondary vocational	376 (39.4%)	
Post-secondary academic	416 (43.6%)	
Other	15 (1.6%)	
Relationship status		
Single	137 (14.3%)	
Married/domestic partnership	663 (69.4%)	
Divorced	95 (9.9%)	
Widowed	30 (3.1%)	
Other	30 (3.1%)	
Country of residence		
Germany	15 (1.6%)	
Greece	97 (10.2%)	
Ireland	52 (5.4%)	
Israel	73 (7.6%)	
Italy	184 (19.3%)	
The Netherlands	221 (23.1%)	
Poland	68 (7.1%)	
Sweden	94 (9.8%)	
The UK	151 (15.8%)	
CG health conditions (yes)	440 (46.1%)	
Currently employed (yes)	463 (48.5%)	
Caregiving duration		
<1 year	136 (14.2%)	
1–5 years	389 (40.7%)	
5–10 years	247 (25.9%)	
>11 years	174 (18.2%)	
Other informal caregivers (yes)	328 (34.3%)	
Previous caregiving experience (yes)	373 (39.1%)	
Sharing the same household with the CR		
Yes	614 (64.3%)	
No	341 (35.7%)	
In their own home	284 (29.7%)	
In someone's else home	14 (1.4%)	
Assisted living facility	26 (2.7%)	
Nursing care	18 (1.9%)	
Intensity of care (hours of care per week)		43.14 (36.80)
Relationship satisfaction		2.30 (6.23)
<b>Care recipients' information given by the CG</b>		
CR Age (range 18–103)		68.69 (19.86)
CR gender		
Female	465 (48.7%)	
Male	481 (50.4%)	
Other	9 (0.9%)	
Relation of the CR to the CG		
Spouse/partner	355 (37.2%)	
Parent/parent-in-law	403 (42.2%)	
Daughter/son	106 (11.1%)	
Another family member	52 (5.4%)	
Non-relative member	39 (4.1%)	
CR health conditions		
Stroke or cerebral vascular disease	155 (16.2%)	
Alzheimer's, dementia, or any other memory impairment	314 (32.9%)	
Parkinson disease	88 (9.2%)	
Multiple sclerosis	24 (2.5%)	

(Continued)

**Table 1.** Continued.

Caregivers <i>N</i> =955	<i>N</i> (%)	<i>M</i> ( <i>SD</i> )
Traumatic brain injury	28 (2.9%)	
Cancer	120 (12.6%)	
Chronic kidney disease	47 (4.9%)	
Cardiovascular disease	348 (36.4%)	
Chronic lung disease	93 (9.7%)	
Diabetes	152 (15.9%)	
Fractures	85 (8.9%)	
Arthritis	121 (13.7%)	
Mental health condition	73 (7.6%)	
Other condition(s)	384 (40.2%)	
Not been diagnosed with any conditions	41 (4.3%)	
CR health conditions (3 categories)		
CR physical impairment	386 (40.4%)	
CR neurological impairment	259 (27.1%)	
CR other/comorbidities	310 (32.5%)	

CG: caregiver; CR: care recipient.

<1 year and more than 1 year (84.8%). Lastly, more than one-third of the caregivers (34.3%) had other caregivers providing care to the same care recipient, and 39.1% reported having previous caregiving experiences.

### Research question one

#### *Between and within level variability in willingness to care*

On average, caregivers had relatively high levels of willingness to care ( $M=8.37$ ). More than half (68%) of the variability in willingness to care was attributable to between-person differences (i.e. an ICC of 0.68), and therefore the remaining 32% of the variability in willingness to care was explained by weekly fluctuations and errors (within-level variability).

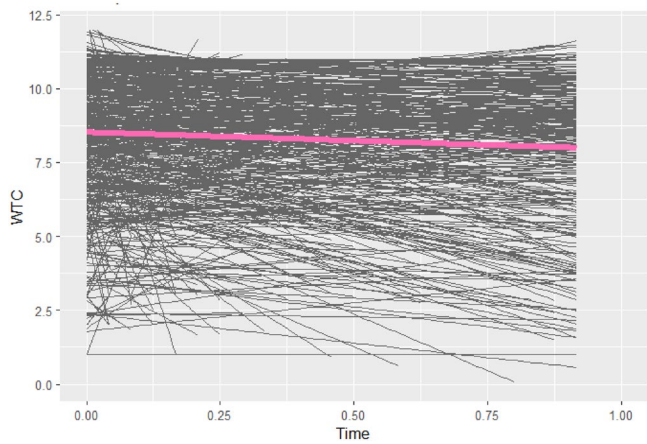
### Research question two

#### *Rates of change and fluctuations in willingness to care*

The results of the unconditional growth model are presented in Table 2 and Figures 1 and 2. Fixed effects (i.e. rates of change) are results of willingness to care for a typical caregiver (intercept  $b=8.55$ ,  $p<.001$ ), and a significant linear decrease over time in willingness to care is shown (slope  $b=-0.93$ ,  $p<.001$ ). These fixed effects are represented by the heavy color line in Figure 1. Random effects (i.e. fluctuations) describe willingness variances at two levels of analysis. At the between-level, intercept variance ( $b=4.23$ ;  $p<.001$ ) was significant, and it corresponded to an *SD* of 2.05, which indicates that 95% of the population varies between  $\pm 2.10$  units of the typical intercept of the typical caregiver (range = 6–10). Slope variance was significant ( $b=2.93$ ;  $p<.001$ ), and it corresponded to an *SD* of 1.71, which indicates that 95% of the population vary between  $\pm 3.42$  units of the typical slope of the typical caregiver (range =  $-2.5$ – $4.3$ ). The between-level random effects are represented in Figure 1 by the individual regression grey lines. Covariance between intercept and slope was not significant ( $p=.118$ ), meaning that there is no tendency for caregivers with

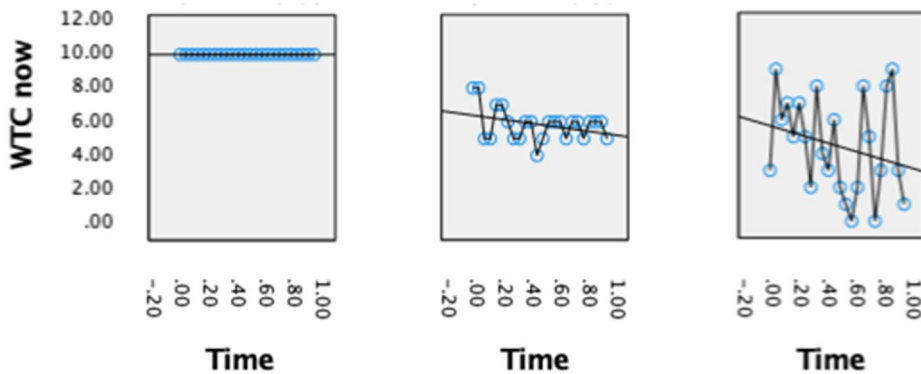
**Table 2.** Unconditional growth model.

Fixed effects (intercept, slopes)	<i>b</i> ( <i>SE</i> )	<i>t</i> <sub>(954)</sub>	<i>p</i>	CI <sub>95%</sub> for <i>b</i>	
				Lower	Upper
Intercept (willingness to care at week 1)	8.55 (.07)	117.20	.000	8.41	8.70
Time	−0.93 (.10)	−8.69	<.001	−1.14	−0.72
Random effects ([co] variances)	<i>b</i> ( <i>SE</i> )	<i>z</i>	<i>p</i>	CI <sub>95%</sub> for <i>b</i>	
				Lower	Upper
Between-level					
Intercept	4.23 (.23)	18.01	<.001	3.80	4.72
Time	2.93 (.36)	7.98	<.001	2.29	3.74
Intercept and time	0.24 (.25)	0.98	.325	−0.24	0.73
Within-level					
Residual	1.96 (.03)	56.75	.000	1.90	2.03
Autocorrelation	0.21 (.01)	15.88	<.001	0.18	0.23



**Figure 1.** Spaghetti plot of willingness to care over 24 weeks for 955 caregivers. *Note.* Fixed effects and between-level random effects are represented by average (coloured thick) and subject-specific (thin) time course of willingness to care for the whole sample of caregivers over 24 weeks. This graph was computed on the ggplot2 package on R software.

larger or smaller intercepts (i.e. willingness to care) to have larger or smaller slopes (i.e. increases or decreases in time). Within-level residuals, the extent to which a caregiver’s willingness to care on a given week deviates above or below the value predicted by their specific regression line, (i.e. weekly fluctuations), were significant ( $b = 1.96$ ;  $p < .001$ ) and corresponded to an SD of 1.40 implying that 95% of observed residuals lie between  $\pm 2.80$  units of their fitted values. The within-level random effects are represented in [Figure 2](#) by raw data and fitted lines for a selection of three caregivers with different variances in willingness to care. There is evidence of small but significant autocorrelation in the within-level residuals ( $r = 0.21$ ;  $p < .001$ ), meaning that caregivers with a higher-than-average intercept also tend to have a higher-than-average slope. That is, some caregivers might have larger vs. smaller intercepts (or initial levels of willingness) and might change more rapidly vs. less rapidly over time.



**Figure 2.** Panel plot of weekly fluctuations of willingness to care from a subsample of caregivers. Note. Within-level random effects of willingness to care in a caregiver with minimum range (right graph— $SD = .00$ ), medium range (left graph— $SD = 1.47$ ), and maximum range (central graph— $SD = 2.77$ ) of standard deviations of the residuals. The figure serves to visualize possible patterns of three different caregivers' weekly fluctuation of willingness to care.

An unstructured variance-covariance matrix was used to accommodate the nested nature of the data. This type of variance-covariance matrix applies no restrictions to the variance components and thus can better fit the data than methods with restrictions (e.g. autocorrelation, compound symmetry; Singer & Willett, 2003). Alternative variance-covariance structures were explored; however, none provided a significantly better fit than the unstructured.

### Research question three

#### Individual differences in willingness to care

Parameter estimates for the model are displayed in Table 3. Results showed that willingness scores still decreased linearly over time ( $b = -2.00$ ;  $p = .021$ ), and rates of change (slopes) did not differ between different caregivers over the 24 weeks (i.e. not significant time-by-group interactions). However, individual differences were detected in mean levels of willingness to care. In terms of contextual elements and willingness to care, caregivers of care recipients with physical impairments reported a higher willingness to care than the ones taking care of care recipients with neurological conditions ( $b = 0.35$ ;  $p < .005$ ). Caregivers with one or more health conditions had a lower willingness to care ( $b = -0.31$ ,  $p = .043$ ) than caregivers with no health conditions. Higher intensity of care was associated with a slightly higher willingness to care ( $b = 0.01$ ,  $p < .001$ ). Caregivers who shared caregiving with other informal caregivers were less willing to care ( $b = -0.42$ ,  $p < .001$ ), and those who had a previous caregiving experience were more willing to care ( $b = 0.25$ ,  $p = .034$ ). In terms of relationship elements and willingness to care, there was no significant effect of relationship type ( $b = 0.19$ ,  $p = .409$ ), however, caregivers who reported on average higher relationship satisfaction with their care recipients reported higher willingness to care ( $b = 0.11$ ,  $p < .001$ ). With regard to random effects, since predictors were between-level variables, they

**Table 3.** Conditional growth model.

Fixed effects (intercept, slopes)	<i>b</i> (SE)	<i>t</i> <sub>(954)</sub>	<i>p</i>	CI <sub>95%</sub> for <i>b</i>	
				Lower	Upper
Intercept (willingness to care at week 1)	7.85 (.93)	8.40	<.001	6.01	9.68
Time	−2.00 (.86)	−2.31	.021	−3.70	−0.30
Duration of caregiving (1 year ≥ 1 year)	−0.25(.25)	−0.96	.333	−0.75	0.25
Time*Duration of caregiving	0.44 (.36)	1.21	.224	−0.27	1.17
Intensity of care (hours of care per week)	0.01 (.00)	4.42	<.001	0.00	0.01
Time*Intensity of care	−0.00 (.00)	−1.46	.143	−0.00	0.00
Co-residency (yes or not)	0.15 (.19)	0.79	.429	−0.22	0.53
Time*Co-residency	0.14 (.28)	0.52	.601	−0.40	0.70
CR neurological conditions (vs. physical)	0.35 (.18)	1.92	.005	−0.00	0.71
Time*CR neurological conditions	0.38 (.25)	1.49	.136	−0.12	0.89
CR neurological conditions (vs. comorbidities)	−0.10 (.19)	−0.54	.588	−0.49	0.28
Time*CR comorbidities	0.30 (.28)	1.06	.287	−0.26	0.87
CG health conditions (yes or not)	−0.31 (.15)	−2.03	.043	−0.61	−0.01
Time*CG health conditions	0.01 (.22)	0.04	.962	−0.42	0.44
Other informal caregivers (yes or not)	−0.42 (.12)	−3.48	<.001	−0.66	−0.18
Time*Other informal caregivers	−0.17 (.17)	−1.01	.313	−0.52	0.16
Caregiving experience (yes or not)	0.25 (.12)	2.12	.034	0.01	0.49
Time*Caregiving experience	0.18 (.17)	1.09	.274	−0.15	0.52
Relationship type (spousal vs. not spousal)	0.19 (.24)	0.82	.409	−0.27	0.67
Time*Relationship type	−0.13 (.27)	−.48	.628	−0.66	0.40
Relationship satisfaction (lower to higher)	0.11 (.02)	4.65	<.001	0.06	0.16
Time*Relationship satisfaction	0.00 (.04)	0.04	.965	−0.07	0.08
Covariates					
CG age	0.00 (.00)	1.14	.254	−0.00	0.02
CG gender	0.74 (.27)	2.65	.008	0.19	1.28
Relationship status single	−0.27 (.29)	−0.95	.342	−0.85	0.29
Relationship status partnership	−0.29 (.23)	−1.26	.207	−0.74	0.16
Education vocational	0.21 (.22)	−0.93	.349	−0.65	0.23
Education academic	−0.47 (.21)	−2.18	.029	−0.91	−0.04

CG: caregiver; CR: care recipient.

were not expected to account for momentary fluctuations in willingness to care levels and hence between and within-person variance components are essentially unchanged with respect to the unconditional growth model (Table 2).

While exploring individual differences in within-level variability of willingness to care, no significant differences were detected, except for caregivers' health condition,  $t_{(954)} = -2.42$ ,  $p < .008$ . That is, caregivers who presented one or more health conditions reported slightly more within-level variability in willingness to care over time (mean difference = 0.07). Results are in the [Supplementary Material](#).

## Discussion

This weekly diary study provided evidence for caregivers' willingness to care as a dynamic process that not only differs from one caregiver to another (between-level) but also fluctuates in the same caregiver from week to week (within-level). Decreases in willingness to care were reported by caregivers regardless of individual differences based on caregiving contexts and relationship elements. On a weekly level, only caregivers who presented one or more physical health conditions reported higher weekly fluctuations in willingness to care with respect to caregivers without any physical health condition.

To the best of our knowledge, this is the first study describing the unfolding of the temporal process of willingness to care among caregivers. In line with Pearlin's temporal orientation (Pearlin et al., 1990) and with longitudinal evidence (Burridge et al., 2007; Morrison & Williams, 2020), our findings extend knowledge by documenting the existence of weekly fluctuations in caregivers' willingness to care, along with substantial variability between caregivers. With 24 potential repeated measurements over time, for the same caregiver, the observed variance was decomposed into a between-person stable component (trait) and a within-person fluctuating component (state) (Kenny & Zautra, 2001). Our results stress the importance of charting daily or weekly ups and downs in the caregiver experiences to reduce the risk of missing important variations in willingness or episodes of distress (Koerner & Kenyon, 2007). Willingness to care can hardly be considered a stable caregiver's attitude or trait to provide care as it presents a non-negligible (i.e. 32%) portion of individual variability that develops from the accumulation of repeated experiences over time (Abell, 2001; McDonnell et al., 1991).

In line with previous research, our results support that caregivers might have different average levels of willingness to care. For example, caregivers of care recipients with neurological impairments reported lower levels of willingness (Hurt et al., 2017; Quinn et al., 2019), caregivers who shared caregiving with other informal caregivers were less willing to care and caregivers with lower levels of relationship satisfaction with care recipients were also less willing to care (Revenson et al., 2016). Although such individual differences, based on the aforementioned caregiving context and relationship elements, can lead to different levels of willingness to care on average, passage of time seems to flatten such differences, as seen in our data. Indeed, willingness significantly decreased over time regardless of caregivers' individual differences, as suggested by the absence of significant interaction terms. Perhaps, as the *wear and tear hypothesis* suggests, the long-term strain of providing care might lead to a lower willingness to care (Townsend et al., 1989). A considerable number of caregivers in our sample (84.8%) had already been providing care for a long period (i.e. >1 year), however the decline in willingness does not seem to happen only in those who have been caring for a longer time. Interestingly, such a decline does not seem to change as a function of any contextual and relational between-level variable of our interest. Perhaps, on a methodological level, repeatedly assessing willingness over time might make caregivers aware of the burden potentially linked to decreases in willingness, an effect often called *reactivity* in diary studies (Bolger & Laurenceau, 2013).

Similarly, while exploring within-level fluctuations, again, individual differences in caregiving context and relationship elements did not contribute to explaining different variability in week-to-week willingness fluctuations. Only caregivers who had to deal with their own compromised health status were found to experience greater week-to-week variations in willingness to care. This finding is of particular importance since we know, from previous studies, that caregivers are often at risk of poorer physical health over time (Shaffer et al., 2016). Perhaps higher willingness variability might be a reflection of higher risks for variability in caregivers' own physical well-being. Further research might explore whether the willingness to care and physical well-being are associated on a daily/weekly level.

### ***Future research and implications***

The current study informs future research to make use of diary studies to detect patterns of within-person processes rather than only focusing on overall time trends for the whole sample. Indeed, intensive longitudinal methods allow us to observe whether and how certain processes occur in everyday life (Nezlek, 2020). From this perspective, further studies should prioritize exploring whether and which everyday events or interactions between caregivers and care recipients might determine different levels of caregivers' willingness to care or, more in general, their well-being (i.e. within-person associations). Moreover, by using diary studies, we will be able to answer between-person differences questions, which are questions we can address in more traditional correlational studies (e.g. are caregivers who are less satisfied with their relationship with care recipients less willing to care?), whilst also determining whether such processes are mirrored in within-person associations (e.g. on days/weeks when caregivers experience less relationship satisfaction, they are less willing to care) (Bolger & Laurenceau, 2013). Thus, diary studies appear to be an ideal framework for investigating both within and between levels of analysis. A further step in this direction might be to measure both caregiving context and relationship elements on a weekly basis and, if possible, to include both dyad members' perspectives, to tap more into dynamic aspects of relationship experiences in the caregiving context. Finally, the presence of variability at both the between and within levels suggests that future studies should address the interplay between momentary state fluctuations (i.e. in cognitions, emotions, and behaviours) and more dispositional traits (i.e. gender and personality) that may coexist in willingness to care.

From a clinical perspective, our findings highlight the importance of assessing and monitoring caregivers' willingness to provide care, given the presented evidence of a decrease over time and of weekly fluctuations, these potentially could impact the quality of care and the dyad members' long-term wellbeing (Connell et al., 2001). In line with traditional cross-sectional or longitudinal research that focused on how caregivers differed from one another, our findings suggest that interventions could usefully target subgroups of caregivers more at risk of lower willingness to provide care (Connell et al., 2001). Based on our findings, such subgroups might comprise caregivers of care recipients with neurological impairments, caregivers living in the same household as care recipients, caregivers with no previous caring experience, and caregivers less satisfied with their relationship with the care recipient. Given



research suggests that most people with a chronic physical and/or mental condition also have other comorbidities, as emerged from our findings, and that caring for older adults with multimorbidity impacts caregivers (Amer Nordin et al., 2019), further research should investigate whether caregivers' outcomes, including willingness to care, may be amplified when a care recipient has multiple conditions. There is not a 'one size fits all' categorization of care recipients' health conditions (e.g. Amer Nordin et al., 2019). Future research should encompass the different ways in which care recipient's health conditions can be operationalised and categorized, going beyond simple yes/no item categorizations by including, for example, the severity of health conditions and more fully recognising the strengths and limitations of various types of categorizations used.

Also, a relatively unexplored area in addressing the impact of the care recipient's health condition is the perceived progressive nature of the health condition which might differently impact fluctuations in willingness to care. Lastly, although relationship type (spousal vs. non-spousal) was not significant in our findings, future research is needed to explore potential differences not only among spousal and non-spousal caregivers but also among spousal, adult child, and 'other' caregivers (Broese van Groenou et al., 2013).

On a daily/weekly level, by zooming into caregivers' daily life, our results suggest that willingness to care should be targeted in psychosocial programs offering support in the face of daily caregiving experiences. The presence of weekly fluctuations in willingness to provide care to a loved one calls for more dynamic and more regular assessments and tailored interventions (Teri et al., 2005). In doing so, special attention should be reserved for older or disabled caregivers with health or care needs, who might be particularly susceptible to variations in willingness, as suggested by our findings. Moreover, results showed the importance of educating health and social care practitioners, but also caregivers, on the fluctuating nature of willingness to care, that is, normalizing the fact that there might be days or weeks when caregivers feel more/less willing to give care than others (Koerner & Kenyon, 2007).

### ***Strengths and limitations***

One of the major strengths of this study is its large and multinational sample of caregivers. Moreover, having more time points per person (i.e. up to 24 consecutive weekly assessments) increased the power of the study and allowed us to explore willingness to care over time in ways that would not be possible with other designs. On a statistical level, the use of multilevel modeling facilitated the differentiation of within- and between-person variability (Stadler et al., 2013). Finally, results obtained by asking caregivers' willingness to care as it was 'right now', for 24 weeks, provided a more accurate reflection of participants' willingness to care with a reduction in recall bias, than through asking them to recall how they generally were willing to care in the past weeks (Bolger & Laurenceau, 2013).

In addition to these strengths, the contributions of the present study might be viewed in light of some limitations. The first limitation pertains to missing data. Although some attrition is expected in intensive longitudinal studies, the most important question is to what extent instances of drop-out are related to participant

characteristics (Ji et al., 2018). In our case, we tested and confirmed that dropouts did not differ in meaningful ways from participants who completed more weekly assessments. Although sensitivity analyses indicated that the number of completed weeks did not predict missingness in our sample, the relatively high dropout rate after the first week (22%) may somewhat limit the generalisability of our findings. Another limitation is the use of only one item to measure the willingness to care. This did not allow us to properly test the reliability of the adapted scale as well as the potential differences when assessing generic vs. task-specific willingness to care patterns. As care tasks varied (e.g. instrumental, nursing, and emotional), also willingness fluctuations may differ depending on care and the tasks required (Abell, 2001). Our large and multinational sample might also be considered as a limitation, as it was not possible to add country of residence as a third-level component in our multilevel model, due to complexity and limited sample size in some of the included countries. Also, the generalisability of the current findings is limited by the caregivers' characteristics as the sample comprised predominantly female, highly educated caregivers. Although the overrepresentation of female caregivers is consistently observed in studies on informal care and women are still overrepresented in caregiving roles, gender, and education may introduce bias into our findings. Other potential limitations to consider is that the duration of caregiver was categorised very broadly (less/more than 1 year) as was the care recipient's health conditions (physical/neurological/comorbidities). These categorisations were implemented with the specific and pragmatic goal of simplifying the interpretation of the complex results obtained from the study. However, it is crucial to acknowledge that this may have inadvertently led to certain subtle differences within the data being missed. These limitations should be taken into account when interpreting the findings of the study and considering its broader implications.

## Conclusion

This is the first study descriptively showing the unfolding of caregivers' willingness to care. Overall, our findings illustrate that willingness to care can hardly be considered stable because it decreases over time and presents a non-negligible portion of individual fluctuations from week to week. Moreover, individual differences in caregiving context and relationship elements should be considered as potential reasons why some caregivers are more or less willing to care than others. However, healthcare practitioners should also be aware that caregivers' willingness to care might indistinctly decrease over time. Finally, individualized interventions should be reserved for caregivers dealing with their own compromised health status, who might be at risk for higher variations in willingness. Weekly experiences are therefore optimal for understanding *whether* caregivers remain more or less willing to care. Further within-processes research is needed to shed light on *why* they remain (or not) willing to care for their care recipients.

## Disclosure statement

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## Data availability statement

The data that support the findings of this study are available from the corresponding author GF, upon reasonable request.

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