



## research article

# Informal care trajectories over the lifecourse in the Netherlands

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This study sets out to identify and describe informal care trajectories over the lifecourse in the Netherlands, and evaluate theoretical ideas on informal care trajectories. We conduct latent profile analysis on a sample of 949 respondents who retrospectively reported on all informal care episodes they had ever experienced, based on the number of episodes, age at first caring episode, duration and overlap. We identified four informal care trajectories – the one-time partner, mid-aged parental, serial and lifelong care trajectories – and assessed their differences in felt obligation, intensity and task complexity. The theoretical ideas of Keating and colleagues find support in our empirical evidence.

**Key words** informal care • lifecourse • trajectories • latent profile analysis

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## Introduction

This study starts from the premise that in order to fully understand the consequences of informal care provision for carers, for instance, for their well-being or labour market careers, it is not sufficient to consider ‘snapshot’ informal care situations (Moen and DePasquale, 2017; Keating et al, 2019; Fast et al, 2021). Instead, full care histories are needed, which incorporate the timing, duration, frequency and overlap of care episodes over the informal carer’s lifespan. After all, it is easier to understand why two apparently similar 60-year-old women experience different consequences of providing informal care to their frail father for eight hours a week if one knows that one of them has also provided intensive and complex care to her mentally disabled son for over 30 years and lives with a partner with increasing health problems, whereas the other is just providing informal care for the first time. A lifecourse perspective (Elder et al, 2004) acknowledges that it is the accumulation of care episodes over the lifespan rather than an isolated care episode that likely shapes carers’ outcomes in life. In addition, it acknowledges that timing matters, that is, in which life stage informal care is provided, and that experiences earlier in life can have long-term effects.

In this study, we apply the lifecourse approach to informal care in the Netherlands. We define informal care as help or care provided to a partner, family members, friends, neighbours, acquaintances or colleagues because of physical, psychological or mental disabilities, or problems related to old age. Types of help may include household tasks, personal care, medical care, administrative tasks, transport and emotional support. Hence, we take a broad view of informal care but explicitly exclude help or care as a volunteer or as part of one's job. Our first aim is to identify and comprehensively describe informal care trajectories in the Netherlands. An informal care trajectory is a sequence of informal care experiences defined by transitions or changes in one's carer role (based on Elder et al, 2004; Alwin, 2012). An informal care trajectory starts at the age of the first transition into care and is formed by care episodes (that is, a period of care provision to an individual care receiver), which can be sequential or partly overlapping (Keating et al, 2019). A lifecourse perspective on informal care becomes increasingly relevant in the Dutch context. As in other Western countries, the demand for care in the Netherlands is rising due to population ageing and the increasing prevalence of chronic illnesses (Colombo et al, 2011). In response to the increasing demand for care, the Dutch government relies more heavily on informal care (Verbeek-Oudijk et al, 2014). One of the expected consequences is that informal care will increasingly become an integral part of life: more citizens will experience more, and sometimes overlapping, informal care situations over their lifespan, in more various life stages, and for longer periods of time. Consequences of informal care provision will therefore increasingly be the cumulative result of combined experiences over the lifecourse rather than of a single care experience.

With our assessment of informal care trajectories, we add to a recent line of research. An important theoretical contribution on informal care trajectories comes from Keating and colleagues (2019). They proposed three theoretical care trajectories, each with distinct characterisations, labelled as 'generational', 'career' and 'serial' care trajectories (more elaborate explanation follows). Fast and colleagues (2021) have empirically examined informal care trajectories in a Canadian sample, providing evidence for distinct patterns of informal care over the lifespan. They applied latent profile analysis (LPA), using the following information as input: age at onset of the first care episode; number of care episodes; total duration of care provision; and amount of overlap of episodes. They largely confirmed the theoretical care trajectories proposed by Keating and colleagues (2019) but also added more nuanced differentiations through their final typology of five trajectories. The second aim of this study is to contribute to this line of research. In particular, we want to evaluate Keating et al's theoretical ideas on informal care trajectories, following a twofold strategy. First, we will offer another empirical examination of informal care trajectories, though in a new context (the Netherlands), and compare the Dutch patterns with the Canadian ones found by Fast and colleagues (2021). If the Canadian results regarding the identification and description of informal care trajectories were to be replicated in the Dutch context, the empirical evidence for the theoretical ideas of Keating and colleagues (2019) is broadened. The second strategy is to empirically assess, more elaborately than before, the foundations of Keating et al's theoretical differentiation between trajectories, particularly with respect to felt obligation, intensity (that is, hours spent on care) and task complexity. We do so by analysing unique and rich retrospective information on informal care histories in a Dutch sample.

## *Theoretical background and empirical evidence*

In their theoretical contribution, Keating and colleagues (2019) proposed three informal care trajectories. First, they used the label ‘generational care trajectory’ for the ‘classic family care trajectory’ (Keating et al, 2019: 153). This trajectory consists of care episodes to close kin, typically a parent or partner. Parental and partner care carries high levels of expectation and obligation. Typically, people first care for their (older) parents(-in-law), which may then be followed by care for their partner. Fast and colleagues (2021) empirically differentiated three typologies that all fall under the umbrella of the generational care trajectory. The three – labelled the ‘compressed generational’, ‘broad generational’ and ‘intensive parent care’ trajectories – differed predominantly with respect to the duration of the first episode, age at onset of the first episode and the number of episodes. The second trajectory proposed by Keating et al is the ‘career care trajectory’, which refers to a trajectory consisting of a single episode of care of long duration to close kin. These caring episodes are argued to involve high caring obligations and highly complex tasks. A typical example would be care for a child, parent or partner with a lifelong disability. Third, they define the ‘serial care trajectory’ as a trajectory with multiple, sequential care episodes to less close care receivers. Such caring episodes are expected to be less strongly characterised by normative pressure and are often less intense. These types of trajectories emphasise the type of informal care that takes place outside the family.

The theoretical differentiation into three trajectories as put forward by Keating and colleagues (2019) was based on several characteristics of care episodes. Besides patterns in care episodes over the lifespan (reflected by duration, timing, frequency and sequencing), they considered the relationship between caregiver and care receiver (close kin; non-kin), the obligatory nature of the care relationship (partly linked to whether or not care is provided to close kin) and the intensity or complexity of care (indicating how heavy the care task is in ‘objective’ terms). Implicitly, the assumption seems to be that felt obligation and intensive or complex care also lead to heavier care episodes in a ‘subjective’ sense, with, in turn, more severe negative consequences for the informal carer. In characterising the empirically found trajectories, Fast and colleagues (2021) confirmed that the generational care trajectory and career care trajectory indeed predominantly involved care to close kin, whereas the serial care trajectory involved care to a variety of care receivers, including less close kin and non-kin. Thanks to the richness of our data, we are able to extend the characterisation of the informal care trajectories by also assessing whether the empirically found trajectories differ in terms of obligation felt by the carer, intensity and the complexity of care tasks as expected by the theoretical ideas of Keating and colleagues (2019).

## **Method**

### *Data*

We collected data on informal care histories from the Longitudinal Internet studies for the Social Sciences (LISS) (see: [www.lissdata.nl](http://www.lissdata.nl)) in March 2020 (Verbakel and Centerdata, 2021). The LISS panel has run since 2007 and is based on a random sample of Dutch households. Households are equipped with computer and Internet access should they lack such resources. The panel consists of more than 4,500 households, comprising approximately 6,500 individuals aged 16 and older. The participants in the

panel receive online questionnaires every month, receiving financial compensation for each completed questionnaire. LISS has core modules that are repeated yearly, as well as various other modules. Response rates in the panel are high (79 per cent on average). In January 2020, we fielded a screening questionnaire to identify all respondents who provided informal care at least once during their lives (the response rate was 83 per cent of the total LISS sample). In March 2020, we approached this group (with an age range of 16 to 78 years) with retrospective questions on the start and end date (if applicable), as well as the relationship with the care receiver (for example, partner or parent) for a maximum of seven care episodes. To reduce the survey load for respondents, extensive retrospective information on the care situation (such as intensity, the complexity of tasks, health status and living situation of the care receiver at the start and end of the care episode) and their personal experiences (such as positive or negative consequences) was only asked for a maximum of three (randomly selected) care episodes. The total sample consisted of 3,061 respondents, implying a response rate of 87.5 per cent, and 7,487 care episodes.<sup>1</sup>

### *Sample selection*

Several selections were needed to prepare the data for the LPA (more information on the analytical strategy follows). We first restricted our sample to respondents without missing values on the start date of their care episodes, as this information was crucial to constructing the input variables for the LPA (38 carers and 38 care episodes were excluded). Second, care episodes were removed if the relationship to the care receiver was identified as non-informal care (35 carers and 86 care episodes were excluded). Third, similar to Fast and colleagues (2021), we selected carers aged 65 and older at the moment of interview (1,966 carers and 4,594 episodes were excluded). This age restriction ensured that we assessed carers with approximately equally long lifecourses and informal care trajectories that are as complete as possible, though some respondents still care at age 65 or will care again in the future. Fourth, we removed carers who indicated they had more than seven care episodes (66 carers and 446 episodes were excluded<sup>2</sup>), as we only knew the start and end dates for up to seven episodes, which made it impossible to correctly determine the timing of the first care episode, the total duration of all care episodes and the extent to which care episodes overlapped when there were eight or more care episodes. Finally, because of unrealistic values, carers were excluded if their first care episode started before age five<sup>3</sup> (seven carers and 12 episodes were excluded). The final sample consisted of 949 carers and 2,311 care episodes.

### *Measurements*

In line with Fast et al (2021) and Keating et al (2019), four variables were used to identify informal care trajectories. The *number of care episodes* was the sum of all episodes on which we had information (with a maximum of seven). On average, carers experienced 2.4 episodes. We also took into account the *age at which the respondent first started to provide care*. The youngest starting age was five years old; the oldest was 78 years old. The mean age at which respondents reported starting their first episode of informal care was 50.5 years old. Total *duration* of care represented the number of years<sup>4</sup> during the lifespan in which care was provided (either in one episode or in

multiple episodes simultaneously), ranging from 0.1 to 68.8 years, with an average of 12.4 years. *Overlap* was expressed in years with multiple care episodes going on at the same time. The minimum number of years of overlap was 0 and the maximum was 43.9, with an average of 2.8 years of at least two overlapping care episodes.

To further describe the profiles of care trajectories, we used several additional variables at both the carer and episode level. At the carer level, we examined *sex* (53.4 per cent were female and 46.6 per cent were male). At the episode level, we examined the *age at the start and end of each episode*. Average start age in the sample was 55.3 and average end age was 61.8. We also looked at the *relationship to the care receiver*, distinguishing the following categories: partner (13.5 per cent), (step-)parent(-in-law) (34.5 per cent), (step)child (8.5 per cent), sibling (7.5 per cent), other kin (8.9 per cent) and non-kin (27.2 per cent).

In line with our aim to empirically assess, more elaborately than before, the foundations of Keating et al's theoretical differentiation between trajectories, we used substantive information on the episode level to characterise the nature of the profiles. It should be noted that this information was only available for a maximum of three episodes per carer, implying that these variables were available in a subsample of episodes only. Feelings of *obligation* were assessed on a five-point Likert scale, ranging from completely disagree to completely agree, by rating the statement: 'I experience/experienced the care for [name of care receiver] as a duty.' High scores meant higher levels of felt obligation. Valid scores were recorded for 1,882 episodes. Care *intensity* was measured as the average hours of care at the start and end of the care episode. In the case of ongoing care episodes, the 'end situation' was represented by the situation at the moment of interview. Intensity was available for 1,910 episodes. The *complexity of tasks* was first assessed by the total number of tasks the carer provided in a particular episode. This number was the sum of three separate dummy variables, which we also assessed separately: emotional support, practical help and personal or nursing care. The dummy variables were coded 1 if either at the start or at the end of the episode (or at the moment of interview if the episode was still ongoing) one or multiple tasks belonging to that category were provided, and 0 otherwise. Emotional support included companionship or emotional support. Practical help included transportation, assistance when visiting a doctor, administrative help, housekeeping and/or arranging or coordinating care. Personal or nursing care covered personal care (for example, showering or visiting the toilet) and/or nursing care (for example, administering medicine or tending to wounds). Valid information on task complexity was available for 2,311 episodes. Descriptive information on the constructed variables can be found in Table A1 in Appendix 1.

## LPA

LPA was applied to identify different types of care trajectories. LPA is a clustering technique that is appropriate when the set of input variables is continuous. It groups cases into meaningful subgroups that show more homogeneity in the patterns of means and (co)variances of the input variables (Collins and Lanza, 2010). The input variables were the number of care episodes, age at entering the first care episode, duration of care and months of overlap. The optimal number of profiles was determined by inspecting multiple fit indices, the means on the variables that informed the profile formation, theoretical interpretation as well as face validity of the profile solutions, and

classification diagnostics. Fit indices considered here included the Bayesian information criterion (BIC), sample-adjusted BIC (SABIC), Akaike information criterion (AIC),  $-2$  loglikelihood ( $-2LL$ ) and the bootstrap likelihood ratio test (BLRT); lower values represent better-fitting models (Nylund et al, 2007). We considered entropy as a classification diagnostic, which indicates how accurately the model defines the profiles; higher values reflect higher accuracy, with values over 0.80 being acceptable (Weller et al, 2020). We used the package ‘mclust’ in R Version 4.1.1 to perform the LPA (Scrucca et al, 2016). This package applies the expectation maximisation (EM) algorithm. Starting values were generated using hierarchical clustering to avoid model-convergence issues and to optimise the profile solution (Biernacki et al, 2003). We ran consecutive models with an increasing number of profiles to compare different model variants and compared the best-fitting ones based on the fit indices. The final solution was estimated with the model variant ‘VVV’ (varying volume, varying shape and varying orientation), which means that the (co)variances were allowed to vary both within and between profiles. Each respondent was assigned to one of the identified profiles based on the highest estimated probability of the respondent’s membership to the profiles. We subsequently characterised the profiles by mean scores of their group members on the input variables and the additional substantive variables, and tested differences between the profiles with  $t$ -tests or post hoc analysis or variance (ANOVA) tests.

## Results

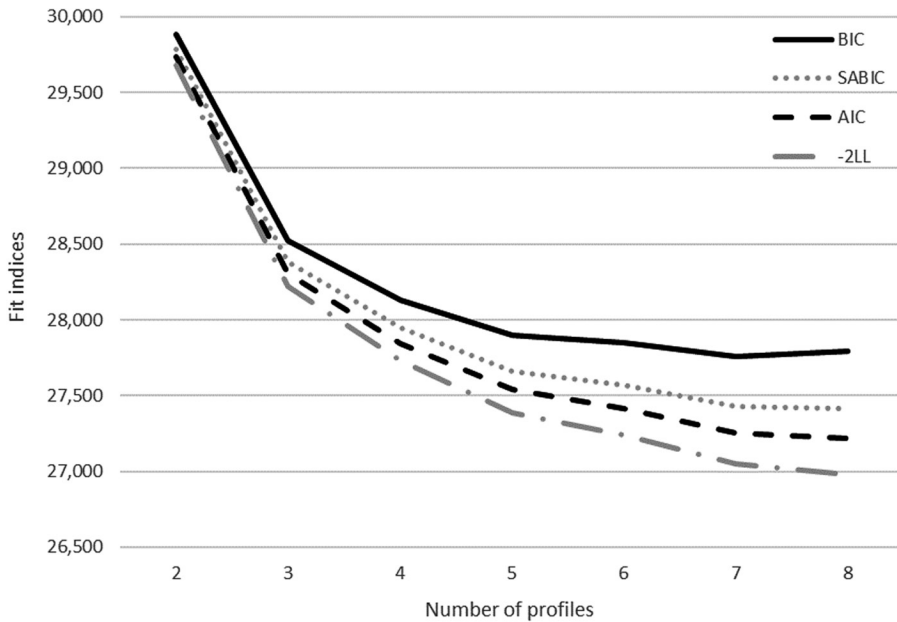
### Identifying informal care trajectory profiles

As mentioned, the optimal number of profiles was determined by: (1) inspection of the fit indices; (2) differentiation between profiles in the means on the input variables that informed the profile formation; and (3) theoretical interpretation and face validity. Based on the fit indices, we first decided to continue with the three-, four- and five-profile solutions. As can be seen in both Table 1 and Figure 1, there was a substantial gain in model fit up to the five-profile model, yet going from five to six profiles added relatively little. In particular, the slope of the BIC flattened between the five- and six-profile models. Solutions with more than five profiles also made less sense substantively. Second, compared to the three- and five-profile solutions, the four-profile solution was better able to distinguish meaningfully different profiles in terms of their mean values on the input variables, as indicated by statistically

**Table 1: Fit indices for latent profile models**

| Model      | df  | -2LL     | AIC      | BIC      | SABIC    | BLRT ( $p$ ) | Entropy |
|------------|-----|----------|----------|----------|----------|--------------|---------|
| 2 profiles | 29  | 29681.48 | 29739.47 | 29880.28 | 29788.18 | 0.000        | 0.915   |
| 3 profiles | 44  | 28220.40 | 28308.40 | 28522.03 | 28382.29 | 0.000        | 0.924   |
| 4 profiles | 59  | 27727.16 | 27845.16 | 28131.63 | 27944.25 | 0.000        | 0.876   |
| 5 profiles | 74  | 27389.26 | 27537.25 | 27896.55 | 27661.53 | 0.000        | 0.889   |
| 6 profiles | 89  | 27238.00 | 27416.01 | 27848.14 | 27565.48 | 0.000        | 0.875   |
| 7 profiles | 104 | 27048.14 | 27256.15 | 27761.11 | 27430.81 | 0.000        | 0.865   |
| 8 profiles | 119 | 26976.52 | 27214.52 | 27792.31 | 27414.37 | 0.000        | 0.874   |

Note:  $N = 949$ .

**Figure 1: Results of the LPA**

significant differences in these values for all pairwise comparisons between profiles (see Table A2 in Appendix 1). Third, the theoretical interpretation also favoured four profiles over three or five profiles. Finally, the four-profile solution resulted in a decent distribution of cases over the four profiles and the entropy was high (0.88). These considerations altogether strongly supported the four-profile model.

### *Describing informal care trajectories*

We will describe each of the four identified trajectories in terms of their mean values on the input variables (see Table 2), as well as their gender distribution (see Table 3), the most common relationships between carer and care receiver (see Table 4) and the average start and end age of each episode (see Table 5).

#### *One-time partner care*

The first profile, which we labelled the ‘one-time partner care’ trajectory, comprised 32 per cent ( $N = 303$ ) of the carers in our sample. This trajectory started in later life (at age 61.6 on average) and always consisted of only one episode, relatively often to the partner. It should be noted that this does not mean that other types of care relations were non-existent, but in comparison to the other profiles, partner care stood out. This trajectory had by far the shortest duration (3.7 years on average) of all trajectories we identified. Moreover, it was unique in the sense that men were over-represented in this trajectory (54 per cent), which corresponded to the fact that the proportion of spousal care was highest in this trajectory. In sum, the one-time partner care trajectory is characterised by a short, one-time episode of care in late life, relatively often to a partner and with many male carers.

**Table 2: Mean values on input variables by informal care trajectory**

|                            | One-time partner care | Mid-aged parental care | Serial care        | Lifelong care |
|----------------------------|-----------------------|------------------------|--------------------|---------------|
| Number of episodes         | 1.00                  | 2.29                   | 3.66               | 4.02          |
| Age at start first episode | 61.58                 | 46.01                  | 49.34              | 35.96         |
| Total duration in years    | 3.74                  | 12.74 <sup>b</sup>     | 12.48 <sup>b</sup> | 32.94         |
| Overlap in years           | 0.00 <sup>a</sup>     | 0.10 <sup>a</sup>      | 3.74               | 14.63         |
| <i>N</i>                   | 303                   | 293                    | 232                | 121           |

Notes: <sup>a, b</sup> No significant ( $p < 0.05$ ) difference between trajectories marked with the same letter. All other differences between trajectories were significant ( $p < 0.05$ ).  $N = 949$ .

**Table 3: Sex distribution by informal care trajectory (%)**

|          | One-time partner care | Mid-aged parental care | Serial care       | Lifelong care |
|----------|-----------------------|------------------------|-------------------|---------------|
| Male     | 54.1 <sup>a</sup>     | 47.1                   | 36.6 <sup>a</sup> | 45.5          |
| Female   | 45.9                  | 52.9                   | 63.4              | 54.6          |
| <i>N</i> | 303                   | 293                    | 232               | 121           |

Notes: <sup>a</sup> Significant ( $p < 0.05$ ) difference between trajectories marked with the same letter. All other differences between trajectories were not significant.

### *Mid-aged parental care*

The ‘mid-aged parental care’ trajectory comprised about another third of the informal carers in our sample (31 per cent;  $N = 293$ ). It started in mid-life (average age of onset was 46 years), typically starting with a relatively long episode of care (8.6 years on average) to a parent. Over the lifespan, additional episodes followed (on average, 2.3 in total) over a period of about 20 years, though with hardly any overlap. In total, carers in this trajectory spent on average about 13 years of their life in care. These carers were slightly more likely to be female than male (53 per cent versus 47 per cent). Together with the one-time partner care trajectory, the mid-aged parental care trajectory can be considered a ‘classic family care’ trajectory, as labelled by Keating and colleagues (2019). In sum, the mid-aged parental care trajectory is characterised by a long first episode of care to a parent starting in mid-life, followed by one or two shorter episodes of care without overlap.

### *Serial care*

The third most common trajectory can be labelled as the ‘serial care’ trajectory (24 per cent;  $N = 232$ ). Similar to the mid-aged parental care trajectory, its onset was in mid-life (at age 49 on average), continued into carers’ 50s and often 60s, and the first episode frequently comprised care for a parent, which spanned 6.8 years on average. The serial care trajectory was distinct, however, with respect to its relatively high number of episodes (3.7 on average). All carers in this trajectory experienced at least a second episode and 71 per cent also a third one, almost half (46 per cent) experienced a fourth one, and 5 per cent experienced even seven episodes. Furthermore, the serial care trajectory stood out because it had the relatively highest occurrence of care to non-kin and the strongest gender divide (63 per cent females versus 37 per cent males).



**Table 4: Relationship between carer and care receiver by informal care trajectory, averaged over all episodes and for each episode separately (%)**

|                  | One-time partner care | Mid-aged parental care | Serial care | Lifelong care |
|------------------|-----------------------|------------------------|-------------|---------------|
| <b>Total</b>     |                       |                        |             |               |
| Partner          | 27.9                  | 13.1                   | 10.6        | 10.3          |
| Children         | 5.0                   | 7.9                    | 7.5         | 13.0          |
| Parents          | 26.9                  | 40.7                   | 32.4        | 34.2          |
| Sibling          | 4.7                   | 8.1                    | 8.1         | 7.4           |
| Other kin        | 9.6                   | 7.6                    | 10.3        | 7.8           |
| Non-kin          | 25.9                  | 22.7                   | 31.1        | 27.4          |
| <i>N</i>         | 301                   | 671                    | 849         | 486           |
| <b>Episode 1</b> |                       |                        |             |               |
| Partner          | 27.9                  | 13.0                   | 10.3        | 14.1          |
| Children         | 5.0                   | 7.2                    | 3.9         | 15.7          |
| Parents          | 26.9                  | 51.5                   | 50.0        | 42.2          |
| Sibling          | 4.7                   | 6.1                    | 6.0         | 5.8           |
| Other kin        | 9.6                   | 6.5                    | 8.6         | 6.6           |
| Non-kin          | 25.9                  | 15.7                   | 21.1        | 15.7          |
| <i>N</i>         | 301                   | 293                    | 232         | 121           |
| <b>Episode 2</b> |                       |                        |             |               |
| Partner          |                       | 14.1                   | 10.8        | 8.3           |
| Children         |                       | 8.4                    | 7.3         | 12.4          |
| Parents          |                       | 38.6                   | 37.1        | 43.0          |
| Sibling          |                       | 8.4                    | 6.5         | 9.1           |
| Other kin        |                       | 7.2                    | 11.6        | 9.1           |
| Non-kin          |                       | 23.3                   | 26.7        | 18.2          |
| <i>N</i>         |                       | 249                    | 232         | 121           |
| <b>Episode 3</b> |                       |                        |             |               |
| Partner          |                       | 12.6                   | 12.8        | 6.0           |
| Children         |                       | 8.7                    | 7.9         | 17.0          |
| Parents          |                       | 23.3                   | 23.8        | 34.0          |
| Sibling          |                       | 10.7                   | 10.4        | 6.0           |
| Other kin        |                       | 11.7                   | 12.8        | 8.0           |
| Non-kin          |                       | 33.0                   | 32.3        | 29.0          |
| <i>N</i>         |                       | 103                    | 164         | 100           |
| <b>Episode 4</b> |                       |                        |             |               |
| Partner          |                       | 7.7                    | 10.2        | 4.1           |
| Children         |                       | 7.7                    | 9.3         | 13.5          |
| Parents          |                       | 7.7                    | 21.3        | 25.7          |
| Sibling          |                       | 15.4                   | 9.3         | 8.1           |
| Other kin        |                       | 7.7                    | 10.2        | 9.5           |
| Non-kin          |                       | 53.9                   | 39.8        | 39.2          |

(Continued)

Table 4: Continued

|                  | One-time partner care | Mid-aged parental care | Serial care | Lifelong care |
|------------------|-----------------------|------------------------|-------------|---------------|
| <i>N</i>         |                       | 26                     | 108         | 74            |
| <b>Episode 5</b> |                       |                        |             |               |
| Partner          |                       |                        | 10.3        | 14.3          |
| Children         |                       |                        | 16.2        | 4.8           |
| Parents          |                       |                        | 11.8        | 14.3          |
| Sibling          |                       |                        | 10.3        | 11.9          |
| Other kin        |                       |                        | 4.4         | 2.4           |
| Non-kin          |                       |                        | 47.1        | 52.4          |
| <i>N</i>         |                       |                        | 68          | 42            |
| <b>Episode 6</b> |                       |                        |             |               |
| Partner          |                       |                        | 3.1         | 40.0          |
| Children         |                       |                        | 6.3         |               |
| Parents          |                       |                        | 9.4         | 10.0          |
| Sibling          |                       |                        | 15.6        |               |
| Other kin        |                       |                        | 12.5        | 10.0          |
| Non-kin          |                       |                        | 53.1        | 40.0          |
| <i>N</i>         |                       |                        | 32          | 20            |
| <b>Episode 7</b> |                       |                        |             |               |
| Partner          |                       |                        | 7.7         |               |
| Children         |                       |                        | 15.4        |               |
| Parents          |                       |                        |             | 25.0          |
| Sibling          |                       |                        | 7.7         | 12.5          |
| Other kin        |                       |                        | 7.7         | 12.5          |
| Non-kin          |                       |                        | 61.5        | 50.0          |
| <i>N</i>         |                       |                        | 13          | 8             |

Note: For significance tests of differences between trajectories, see Table A2 in Appendix 1.

In sum, the serial care trajectory is characterised as a female-dominated trajectory, stretching over a 15- to 20-year period in mid-life and consisting of multiple care episodes, including many non-kin relations.

### *Lifelong care*

The least common trajectory was observed among 13 per cent ( $N = 121$ ) of the carers in our sample. The 'lifelong care' trajectory had the most extreme averages on all input variables. It was characterised by the youngest age at onset (36), the highest number of episodes (4.0), the longest duration (33 years) and most overlap (15 years). The first episode of care took, on average, almost 23 years. All of the carers in this trajectory also experienced a second episode, which lasted a long time too (15.7 years on average). The third and following episodes were still common and relatively long. Compared to the other trajectories, care for a child (with lifelong or acquired health conditions) was typical, next to care for a parent. A total of 55 per cent of the carers

**Table 5: Age at start and end of the episode by informal care trajectory, for each episode separately and averaged over all episodes**

|           | One-time partner care |       |      | Mid-aged parental care |       |      | Serial care |       |      | Lifelong care |       |      |
|-----------|-----------------------|-------|------|------------------------|-------|------|-------------|-------|------|---------------|-------|------|
|           | N                     | Start | End  | N                      | Start | End  | N           | Start | End  | N             | Start | End  |
| Episode 1 | 303                   | 61.6  | 65.2 | 293                    | 46.0  | 54.6 | 232         | 49.3  | 56.1 | 121           | 36.0  | 58.8 |
| Episode 2 |                       |       |      | 250                    | 59.5  | 63.1 | 232         | 55.8  | 60.5 | 121           | 46.6  | 62.0 |
| Episode 3 |                       |       |      | 103                    | 64.2  | 66.3 | 165         | 59.6  | 62.7 | 100           | 53.4  | 63.1 |
| Episode 4 |                       |       |      | 26                     | 66.1  | 67.4 | 108         | 62.1  | 65.7 | 74            | 58.4  | 64.8 |
| Episode 5 |                       |       |      |                        |       |      | 68          | 64.4  | 66.8 | 42            | 61.7  | 67.0 |
| Episode 6 |                       |       |      |                        |       |      | 32          | 64.8  | 67.5 | 20            | 65.8  | 69.2 |
| Episode 7 |                       |       |      |                        |       |      | 13          | 67.5  | 68.9 | 8             | 67.8  | 70.5 |
| Total     | 303                   | 61.6  | 65.2 | 672                    | 54.6  | 60.1 | 850         | 56.8  | 61.3 | 486           | 49.6  | 62.7 |

Note: For significance tests of differences between trajectories, see Table A2 in Appendix 1.

in this trajectory were female. In sum, the lifelong care trajectory is characterised by a lifelong path, with many, often overlapping, care episodes, typically to children or parents.

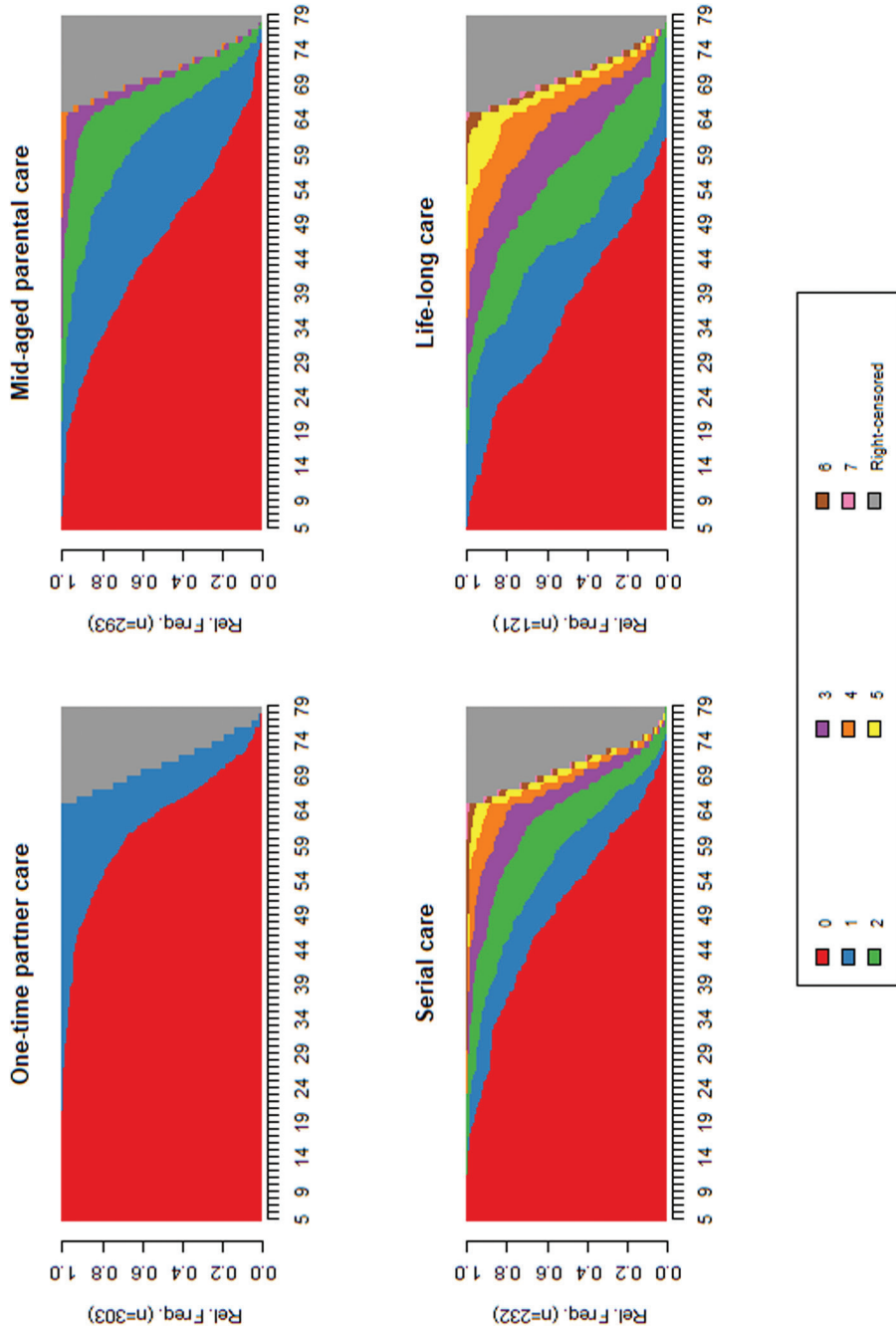
Figure 2 shows a graphical representation of the informal care trajectories. It shows, for each trajectory and at each age, the number of care episodes in proportions of carers. The one-time partner care trajectory stands out, with many zero episodes (that is, not having started care provision yet) at relatively late ages, and with at most one episode over the lifespan. The high occurrence of experiencing many episodes during one's life becomes clear in the serial care trajectory and even more so in the lifelong care trajectory. Also, the relatively young starting age can be distilled from the lifelong care trajectory plot: over 60 per cent of carers in this trajectory started their first episode of care before the age of 40.

### *Characterising informal care trajectories*

We continue with further characterisation of the care trajectories to contribute to their theoretical foundations. Such characterisation aids in understanding how the trajectories differ in nature and, subsequently, in theorising how their consequences for carers, for instance, for their well-being or labour market outcomes, may differ. We characterised the trajectories in terms of felt obligation by the carer, care intensity (that is, average hours per week spent on care) and the complexity of tasks. We will particularly focus on the first episode and all episodes together (see Table 6). Significance tests of the mean differences between the trajectories can be found in Table A2 in Appendix 1.

Obligation was felt most strongly by carers in the lifelong care trajectory (2.89 in first episode; 2.61 over all episodes) and significantly more strongly, at least at a 10 per cent significance level, compared to the other trajectories' first episodes. This corroborates the initial theoretical idea that people who are confronted with a care situation early in life, often involving their disabled child or their parent, feel a strong sense of obligation to take up care. Put differently, they largely do so because they do not feel they have a choice. Felt obligation was on average lower in the one-time partner care trajectory (2.50 in first episode; 2.50 in total), the serial care trajectory

Figure 2: Sequence distribution plot of care episodes by age in each of the four informal care trajectories



(2.47 in first episode; 2.42 in total) and the mid-aged parental care trajectory (2.42 in first episode; 2.29 in total), all of which did not differ significantly from each other. In sum, only the lifelong care trajectory stood out from the others with a high(er) level of felt obligation.

**Table 6: Characterisation of informal care trajectories in terms of felt obligation, intensity and task complexity for first episode and averaged over all episodes**

|                                         | One-time partner care |       | Mid-aged parental care |       | Serial care |       | Lifelong care |      |
|-----------------------------------------|-----------------------|-------|------------------------|-------|-------------|-------|---------------|------|
|                                         | N                     | Mean  | N                      | Mean  | N           | Mean  | N             | Mean |
| <i>Obligation (1–5)</i>                 |                       |       |                        |       |             |       |               |      |
| Episode 1                               | 292                   | 2.50  | 276                    | 2.42  | 189         | 2.47  | 89            | 2.89 |
| Total                                   | 292                   | 2.50  | 633                    | 2.29  | 619         | 2.42  | 338           | 2.61 |
| <i>Intensity (1–168)</i>                |                       |       |                        |       |             |       |               |      |
| Episode 1                               | 301                   | 12.47 | 280                    | 14.43 | 191         | 9.48  | 90            | 9.61 |
| Total                                   | 301                   | 12.47 | 642                    | 13.68 | 625         | 10.33 | 342           | 7.82 |
| <i>Task complexity: sum score (0–3)</i> |                       |       |                        |       |             |       |               |      |
| Episode 1                               | 303                   | 1.83  | 293                    | 1.86  | 232         | 1.53  | 121           | 1.42 |
| Total                                   | 303                   | 1.83  | 672                    | 1.76  | 850         | 1.31  | 486           | 1.26 |
| <i>Emotional support (0–1)</i>          |                       |       |                        |       |             |       |               |      |
| Episode 1                               | 303                   | 0.76  | 293                    | 0.77  | 232         | 0.70  | 121           | 0.60 |
| Total                                   | 303                   | 0.76  | 672                    | 0.76  | 850         | 0.61  | 486           | 0.58 |
| <i>Practical help (0–1)</i>             |                       |       |                        |       |             |       |               |      |
| Episode 1                               | 303                   | 0.81  | 293                    | 0.81  | 232         | 0.66  | 121           | 0.64 |
| Total                                   | 303                   | 0.81  | 672                    | 0.77  | 850         | 0.56  | 486           | 0.56 |
| <i>Personal or nursing care (0–1)</i>   |                       |       |                        |       |             |       |               |      |
| Episode 1                               | 303                   | 0.26  | 293                    | 0.27  | 232         | 0.17  | 121           | 0.19 |
| Total                                   | 303                   | 0.26  | 672                    | 0.23  | 850         | 0.14  | 486           | 0.13 |

Note: For significance tests of differences between trajectories, see Table A2 in Appendix 1.

The overall pattern regarding intensity and task complexity showed a divide between the mid-aged parental care and one-time partner care trajectories, on the one hand, and the lifelong care and serial care trajectories, on the other, with the former being characterised by more intense and complex care than the latter. In the mid-aged parental care trajectory, carers spent on average 14.43 hours per week on care in the first episode (on average, 13.86 hours in all episodes), and in the one-time partner care trajectory, intensity amounted to 12.47 hours per week. This was substantially more compared to the first episode of the lifelong care and serial care trajectories, with on average 9.61 and 9.48 hours, respectively. When averaged across all episodes (7.82 for the lifelong care trajectory; 10.33 for the serial care trajectory), the absolute differences are somewhat smaller, though they now reach the level of significance ( $p < 0.05$ ). A similar pattern was found regarding task complexity. The total number of different types of tasks (with a maximum of three) performed by the carer was significantly higher in the mid-aged parental care trajectory (1.86 in first episode; 1.76 in total) and the one-time partner care trajectory (1.83 in first episode; 1.83 in total) than in the serial care trajectory (1.53 in first episode; 1.31 in total) and the lifelong care trajectory (1.42 in first episode; 1.26 in total). When we dig deeper into the types of tasks, that is, distinguishing between personal/nursing care, practical help and emotional support, we find that the patterns are comparable. In sum, the two ‘classic family care trajectories’, which

are dominated by care to a partner and parent, are most intense in terms of time investment and task complexity.

## Conclusion and discussion

This study set out to identify and describe informal care trajectories over the lifecourse in the Netherlands. Based on the retrospective care careers of 949 respondents who cared at least once during their life, selected from a random sample of the Dutch population, we identified four types of trajectory based on the number of care episodes, age when the first episode began, total duration and overlap between episodes. Interpreting the identified trajectories in terms of these four lifecourse elements, as well the relationship to the care receiver, we labelled them as the ‘one-time partner care’, ‘mid-aged parental care’, ‘serial care’ and ‘lifelong care’ trajectories.

With this study, we aimed to evaluate the theoretical foundations of informal care trajectories as presented by Keating and colleagues (2019). To that end, we will now first compare our findings on the Netherlands to findings from Canada (Fast et al, 2021), which is – to the best of our knowledge – the only other study that empirically identifies informal care trajectories. Subsequently, we will evaluate Keating et al’s theoretical ideas against our results, including the empirical assessment of how the trajectories differ with regard to felt obligation, intensity and the complexity of care.

Comparing the empirical results from the study on Canada (Fast et al, 2021) and our study on the Netherlands, we see clear similarities, which strengthens the empirical evidence for the theoretical informal care trajectories as proposed by Keating et al (2019). The Canadian study (Fast et al, 2021) identified five trajectories. Our one time-partner care trajectory showed a strong resemblance to Fast et al’s compressed generational trajectory, having about one episode of care, the shortest duration and overlap, and starting in carers’ early 60s. Both comprised spousal care relatively often, and both had the highest proportion of men among all trajectories. The mid-aged parental care trajectory that we identified in the Dutch data was most similar to Fast’s broad generational trajectory. Both started in mid-age, though onset was about five years earlier in the Netherlands than in Canada and spanned about 13 years, with hardly any overlap between the few episodes of care. Whereas parental care was dominant in the mid-aged parental care trajectory, the broad generational trajectory was characterised by both parental and spousal care. In the Canadian study, parental care was especially present in the intensive parent care trajectory, which was identified as a separate trajectory but for which we did not find an equivalent in the Dutch data. The less common intensive parent care trajectory was a bit more outspoken than the broad generational trajectory, in the sense that parental care was even more dominant and that it included more, partly simultaneous, episodes in a shorter time span. The Dutch mid-aged parental care trajectory could be interpreted as a mix of the Canadian intensive parent care and broad generational trajectories. Our serial care trajectory resembled Fast et al’s equally labelled trajectory, in the sense that they comprised multiple care episodes over a longer period, with quite some overlap. Additionally, they often started with parental care, after which several, also notably non-kin, care relations occurred, and both were most strongly dominated by women, as compared to the other profiles. There were some notable differences as well. The serial care trajectory in the Netherlands started later (on average, 49 versus 36) and, correspondingly, had a shorter total duration. Moreover, the non-kin character of the

care relationships seemed more pronounced in the Dutch serial care trajectory than in the Canadian one. Finally, our lifelong care trajectory was most akin to Fast et al's career care trajectory. In both, care provision started at a young age and spanned over 30 years, with a very long first episode. In both countries, care to children with long-term health conditions was most pronounced in this profile. An interesting and large difference between the Dutch and Canadian trajectories was the number of episodes. In the Netherlands, this trajectory had by far the highest number of episodes, longest duration and most overlap of all profiles. In Canada, the first long episode was only followed by a second one in about half of the cases. Therefore, this trajectory signified an even stronger care-dominated lifecourse in the Netherlands than it did in Canada.

The similarity in informal care trajectories in the Netherlands and Canada emerged despite striking differences between the Dutch and Canadian samples. At the same time, these sample differences help to better understand the few dissimilarities between the trajectories that were identified in the two studies. First, the average number of care episodes was higher in the Dutch sample (2.44) than in the Canadian sample (1.52). Second, carers in the Dutch sample reported more diversity in care relationships than those in the Canadian sample, with relatively more non-kin relations (27.2 per cent versus 18.6 per cent) and fewer care episodes to parents and partners (48.0 per cent versus 66.7 per cent).<sup>5</sup> Third and finally, the gender distribution in the Dutch sample (53 per cent female) was more equal than in the Canadian sample (62 per cent female). To some extent, these differences may reflect contextual or cultural differences between the Netherlands and Canada, suggesting that informal care provision is a more common thing to do in the Netherlands (among men too), that care provision should extend to non-kin or that care to non-kin is more commonly recognised as informal care. However, the reported differences may also partly stem from differences between the two samples and data collections. For instance, the question wordings<sup>6</sup> were different, with the Dutch questionnaire possibly prompting more memories on care episodes, especially to non-kin. In addition, the Dutch data were collected eight years later than the Canadian data (2020 versus 2012). Over recent years, the demand for care has increased and governments have been retrenching formal care provision while emphasising the role of informal care. The Dutch data may therefore represent a later stage in the trend towards increasing informal care and increasing awareness of, and hence identification with, the role of informal carer. Another difference was that age was maximised at 78 in the Dutch sample, whereas the Canadian sample did not have an upper age limit. Partner care often particularly takes place later in life, which may thus partly explain why the Dutch data picked up fewer spousal care relations (but not parental care relations) than the Canadian data. The fact that the maximum number of care episodes was capped at seven in the Dutch questionnaire and at six in the Canadian questionnaire hardly affected the difference in the average number of episodes per carer. If the Dutch data were capped at six episodes, its average would still have been 2.33 (versus 2.44 now).

What conclusions can we draw about the evidence for the theoretical ideas by Keating et al (2019)? The empirical study on Canada (Fast et al, 2021) largely confirmed these theoretical ideas. They identified the career care trajectory and serial care trajectory. The generational care trajectory was decomposed into three distinguishable sub-profiles: the compressed generational, broad generational and intensive parent care trajectories. The findings from our Dutch study largely coincided with the theoretical description of informal care trajectories by Keating

et al (2019) as well. Our two largest profiles – the one-time partner care and mid-aged parental care trajectories – could be placed under the heading of the generational care trajectory. Together, they represented the ‘classic family care trajectories’ (Keating et al, 2019: 153), that is, the types most typically thought of when picturing informal carers. They involved caring for close kin in the same (partner) or higher (parent) generation at ‘age-appropriate’ moments in life. According to Keating et al (2019), these trajectories follow normative expectations and would therefore entail high levels of obligation. Our study could not empirically confirm this expectation. The two ‘classic family care trajectories’ (one-time partner care and mid-aged parental care) did not differ from the serial care trajectory in terms of experienced obligation.

As theorised by Keating et al (2019), we found evidence for a serial care trajectory, characterised by diverse care episodes, relatively often to non-kin. We can add that it was predominantly women who followed this care trajectory. Carers fitting this profile might be characterised by a general tendency to care and a willingness to be a good neighbour and community member. Obligation and care intensity were expected to be low, which we could empirically corroborate. Together with the one-time partner care and mid-aged parental care trajectories, the serial care trajectory scored lowest on felt obligation. Moreover, together with the lifelong care trajectory, it scored lowest on all our measures of intensity and task complexity. Although the differences with the other profiles were not always as large or as significant as expected, the overall pattern that emerged was that the serial care trajectory was the ‘easiest’ of all in terms of obligation and care provided.

Finally, our lifelong care trajectory resembled the theoretically proposed career care trajectory, sharing the essential element that carers started providing care to close kin (among which were children with long-term health conditions) early in life and provided such care for a long time. In contrast to the career care trajectory proposed by Keating et al (2019), our lifelong care trajectory did not consist of a single care episode over the lifespan. Instead, carers in this profile tended to take up care for several other persons during their life. The bottom line, however, is that caring was an ever-present element in the lives of these carers. Our results demonstrate that this trajectory is characterised by the highest level of felt obligation, which supports the ideas of Keating and colleagues. This strongly felt duty may explain why people started caring at an age at which providing care is not so normatively expected. They likely did not feel that they had a choice in becoming a carer in the situation they encountered. Surprisingly, our results show that the lifelong care trajectory is characterised by relatively low intensity and task complexity.

Our overall evaluation of the theoretical ideas on informal care trajectories presented by Keating and colleagues (2019) is that it finds much support in the existing empirical evidence. We identified a few inconsistencies that are worth considering in future studies. The first unexpected result we want to highlight is the absence of relatively strong feelings of obligation in trajectories in which normative pressure to care was expected to be high, either because of the embeddedness of the relation in a marital contract (in the one-time partner care trajectory) or because of norms regarding intergenerational solidarity and reciprocity (in the mid-aged parental care trajectory). The second finding that contrasts with Keating et al’s theoretical ideas is the relatively low intensity and task complexity observed in the lifelong care trajectory. Given the presumable seriousness of the care situations, which forced carers into a care situation



at an early age, high intensity and complexity were expected. Possibly, carers fitting this trajectory were relatively likely to share their caring tasks with other informal or formal helpers, precisely because they anticipated a lifelong care career at the onset of their first care episode.

A few characteristics of our data and sample selection are important to mention, as they may have influenced our results. First, we did not observe complete lifecourses, though we tried to come closest to entire lifecourses by only selecting respondents aged 65 and older at the time of interview. A substantial group of carers in our 65+ sample will experience other care episodes in later life. As spousal care is most likely to have its onset in later life, we likely under-reported the total number of partner care episodes in carers' lifecourses. Moreover, our data did not include people aged 65 years or older who had not started their first care episode at the time of interview. As our results show that starting a care career at a later age with care to a partner is a common trajectory in the Netherlands, this aspect of our data structure may imply that the relative prevalence of the one-time partner care trajectory is even higher than we observed.

Second, our data were retrospective, meaning that we asked carers to recall all care episodes in their lives. Retrospective data might be biased. It is likely that we missed 'insignificant' or 'short' care episodes, especially those longer ago (Kjellsson et al, 2014). We have no convincing arguments why that would have affected the identification of our four trajectories. In terms of impact on carers' lives, it seems safe to assume that the unreported care episodes played a minimal role.

In closing, we believe that the LPA offered an insightful way to describe distinct care trajectories, but of course, much variation exists within each of the four identified trajectories. Yet, we argue that acknowledging the existence of variation in not only current care situations ('snapshots') but also carers' lifecourses is an important step forward. With increasing reliance on informal care due to increasing demands of care and governments that are retrenching formal care, we can expect that care careers will increasingly be characterised by more, longer and overlapping care episodes. Existing literature has already shown that providing informal care harms well-being (Pinquart and Sörensen, 2003; Verbakel et al, 2017), competes with employment and lowers wages (Heitmueller and Inglis, 2007; Van Houtven et al, 2013; Schmitz and Westphal, 2017; Moussa, 2019). More, longer and/or overlapping care episodes may strengthen the negative impact, leading to cumulative disadvantages over carers' lifecourses (DiPrete and Eirich, 2006; Crystal et al, 2017). With this study, we hope to have further fuelled interest in care trajectories rather than snapshot care situations and to have provided a new route to understanding variation among carers in terms of their well-being and labour market outcomes.

## Notes

<sup>1</sup> In response to the COVID-19 pandemic, the Dutch government imposed a partial lockdown from 15 March to 1 June 2020. Since the partial lockdown may have affected informal care provision, it was checked whether the response patterns of respondents who participated in the survey in the second half of March significantly differed from those who participated in the first half of March. No relevant differences were found (for more details, see Raiber et al, 2021).

<sup>2</sup> Dropping carers with eight or more care episodes reduced the average number of episodes per carer from 2.72 to 2.44 in the current sample.

<sup>3</sup> From age five, we assume children to start realising they are living in a family with a care demand and to be capable of doing (small) household tasks to help the family.

<sup>4</sup> Information was available at the level of months but was recoded to years to facilitate interpretation.

<sup>5</sup> Calculations of the distribution of care relationships in the Canadian sample were approximate, as numbers too low to be reliable were not published in the article and set to zero in our calculation.

<sup>6</sup> The question wording in the Dutch questionnaire was:

First we would like to know to whom you provided this informal care. Below we will ask you to indicate all the people known to you to whom you have ever provided informal care on account of their health issues. These people could be your partner, a family member, a friend, neighbour, acquaintance or colleague who needs or needed help *because of physical, psychological or mental limitations or because of old age*. Examples of informal care are doing household chores, helping with washing and dressing, keeping company, providing transport or performing odd jobs. You may have done so for a short period or for a long period. It could involve people known to you to whom you provided care *in the past*, but could also involve people known to you to whom you are providing care *at present*. Care provided as part of your occupation or as a volunteer does *not* count. Please take a moment to think about the people known to you to whom you have provided or are providing informal care because of health issues (see: [https://www.dataarchive.lisdata.nl/study\\_units/view/1067](https://www.dataarchive.lisdata.nl/study_units/view/1067)).

The question wording in the Canadian questionnaire was: 'Have you *ever* provided care to someone with a long-term health condition, disability or problems related to aging? Exclude paid assistance to clients or patients and volunteering on behalf of an organization' (see: [https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=getInstrumentList&Item\\_Id=122399&UL=1V&](https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=getInstrumentList&Item_Id=122399&UL=1V&)).

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## Conflict of interest

The authors declare that there is no conflict of interest.

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