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Linkages between informal and formal care-givers in home-care networks of frail older adults

MARIANNE JACOBS*, THEO VAN TILBURG*,
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ABSTRACT

In ageing societies, policy makers aim for more contact between informal and formal care-givers as it may enhance the quality of care. So far, the linkage between formal and informal care-givers is generally studied from a one-sided or a single dyadic perspective, without taking into account that care networks of community-dwelling older adults often exist of multiple informal and formal care-givers. The current study examines discussion of care between all potential informal–formal care-giver dyads in a care network, and relates this to characteristics of the older care recipient, the care network and the care-givers. Seventy-four Dutch older care recipients provided information on all care-givers who helped with five different types of tasks; 410 care-givers reported on the contact between all care-givers identified. Multi-level logistic regression was conducted in 2,150 informal–formal care-giver dyads and revealed that in 26 per cent of all these dyads discussion on care occurred. This was more likely when both care-givers performed multiple types of tasks, the informal care-giver was residing with the care recipient, and contact within the formal and the informal sub-network was higher. To enhance discussion of care between informal and formal care-givers in care networks where no discussion occurs at all, home-care organisations may need to allocate formal care-givers who form a bridge with an extra-residential care-giver of care recipients living alone.

KEY WORDS – care network, frail older adults, informal care-givers, formal care-givers.

Introduction

By 2030, 24 per cent of the population will be over 65 years of age in the European Union, with 30 per cent of them being older than 80 (Eurostat

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2015). Many of them will be community-dwelling older adults who suffer from long-term and complex health problems, for which both informal (*e.g.* spouses, children, friends) and formal care-givers (*e.g.* publicly or privately paid home-care professionals) need to be deployed. This will contribute to an increase in the prevalence of mixed-care networks in which multiple informal and formal care-givers will have to collaborate in providing care in the home environment. Policy makers aim for more contact and co-operation between informal and formal care-givers as it may enhance the quality of care (Huber and Hennessy 2005). Research shows as well that timely and satisfactory co-operation between these different types of care-givers is a prerequisite for good quality of care (Gittell 2002). Co-operation enables care-givers to know how their tasks fit to tasks of other care-givers, which allows them to adjust their tasks for the overall care delivery. Moreover, discussion of care activities can help to understand the needs of the elderly. Although good co-operation is proven to be indispensable, few studies are conducted on the level of contact and communication between informal and formal care-givers in the home-care context (Sims-Gould and Martin-Matthews 2010). Discussing the care provision among care-givers may serve as a first step to co-operation and is the focus of our study. Our main goal is to examine under which conditions informal and formal care-givers in a care network do discuss the care.

There is an extensive body of literature on the relationship between formal and informal care-givers, but most studies are limited in focus. These studies are performed from a one-sided perspective, like the viewpoint of either the formal or the informal care-giver, are based in nursing home contexts or used qualitative methods to study the subjective experiences and attitudes of the care-giver (Åstedt-Kurki *et al.* 2001; Bauer and Nay 2011; Guberman *et al.* 2006; Haesler, Bauer and Nay 2007). Also, when looking at informal–formal care-giver relationships, studies generally focus on one central informal–formal care-giver dyad and disregard the presence of multiple informal and formal care-givers (Bell and Rutherford 2013; Kruijswijk, Da Roit and Hoogenboom 2014; Piercy and Dunkley 2004; Wiles 2003). We extend this literature by focusing on the informal–formal dyad in the care network in three innovative ways. First, we acknowledge that the formal–informal care-giver interaction may be dependent on the condition of the care recipient. We argue that a care recipient's needs, wishes and capacities to control the care provision can affect the 'necessity' for informal and formal care-givers to discuss the care. Second, we consider the dyad to be part of a larger care network in which linkages may exist between multiple care-givers (Carpentier and Ducharme 2003; Ryan, Puri and Liu 2013). As the linkages to others may be stronger *within* the formal and *within* the informal sub-networks than

between the two sub-networks, specific formal–informal dyads may serve as bridges between sub-networks, decreasing the need for other formal–informal dyads to discuss the care. Third, we use data from a quantitative study on mixed-care networks of community-dwelling older adults and we are, to our knowledge, among the first to present multivariate analyses on all formal–informal dyads within such networks.

The new perspective thus involves that both care network characteristics as well as the characteristics of the care recipient at stake provide the 'meeting opportunities' to discuss the care. Characteristics of individual care-givers may also be relevant for formal–informal care discussion, *e.g.* the types of tasks they perform or the extent to which they are providing care. Therefore, taking care recipient, care context and the individual care-givers into account, the research question reads: To what extent is discussion of the care between an informal and a formal care-giver in a mixed-care network related to characteristics of the care recipient, the care network at large and the dyads between the three actors involved?

Theoretical framework and hypotheses

Care recipient characteristics

The care recipient is generally viewed as being a 'user' of care, which has a rather passive connotation to it. However, many care recipients decide how much care is used, from whom it is received and how the care process is organised. Several studies corroborate that care recipients prefer either formal or informal care (Pinquart and Sorensen 2002) and are inclined to maintain a certain level of control over the care received (Bastiaens *et al.* 2007). In such cases, the care recipient can posit himself or herself between, for example, an informal and formal care-giver and take care of all communication with both care-givers, decreasing the necessity for both care-givers to discuss the care with each other. However, being in control may require social and organisational skills and care recipients may find it more difficult to do so when their health problems limit their capabilities and energy level. In addition, complex health problems make it more difficult to remain in control of the care process, and increase the necessity for informal and formal care-givers to discuss the care. Prior research shows that with increasing health problems of the care recipient, families and professional care-givers interact more often (Kemp *et al.* 2009). The effect of the care recipients' health on the discussion of care within the formal–informal dyad may thus be either direct (necessitating communication) or indirect (via lower perceived control). We hypothesise that an informal and a formal care-giver are more likely to discuss the care when the care recipient

has more impaired health (Hypothesis 1a) and perceives little control over the care provision (Hypothesis 1b).

Care network characteristics

In mixed-care networks consisting of more than two different care-givers, dyadic interaction may also depend on the interaction with and between other care-givers. Both the number and the type of care-givers may be important. When the total number of care-givers is small, it is easier for all care-givers to get in touch with each other than when the number of both informal and formal care-givers is larger. So, we first postulate that discussion of care between an informal and a formal care-giver is less likely when the number of informal and formal care-givers is higher (Hypothesis 2a). Next, both the informal and formal care-giver are embedded to some degree in their own informal and formal sub-network. The contact within the informal and formal sub-networks may affect the likelihood that either one of the care-givers in this sub-network connects with a care-giver from the other type of sub-network. A study by Tucker and Edmondson (2003) showed that nurses in a hospital were not likely to negotiate aspects of care provision with others besides their fellow formal care-givers providing the same type of care. Informal care-givers, being all socially related to the care receiver, are likely to communicate in particular amongst each other. In both sub-networks a particular care-giver may be appointed as being the one to discuss the care with the other sub-network, serving as the bridge to the other (in)formal care-givers. In this case, the necessity of other informal and formal care-givers to discuss the care is largely decreased. We presume that when there is more contact *within* the informal and *within* the formal sub-network, discussion of care *between* an informal and a formal care-giver is less likely to occur (Hypothesis 2b).

The care-giver–care recipient dyad

Meeting opportunities for two care-givers are larger when they are both frequently in the same social context or within close geographical distance (Argyle 1989; Mollenhorst, Völker and Flap 2011). These meeting opportunities may vary for informal care-givers by the social relationship they have with the care recipient. Partners provide more care than children who, in turn, provide more care than other relatives or non-kin (*e.g.* Keating and Dosman 2009). In particular, the co-residency of the informal care-giver increases the opportunity to meet other care-givers. For non-residential care-givers (both formal and informal), the frequency of care provision is more decisive for meeting other care-givers, as this reflects how often

they are present in the home of the care recipient. For both informal and formal care-givers, the frequency, variety in type of care and duration of care provided increase the time spent in the home and may thus increase the opportunity to meet other care-givers. We expect that when the informal care-giver is residing with the care recipient (Hypothesis 3a) and when the care-giving intensity (as indicated by number of hours of care provision, number of different types of tasks and duration of care in years) for both the informal and formal care-giver is higher (Hypothesis 3b), it is more likely that an informal and a formal care-giver discuss the care.

The informal–formal care-giver dyad

Finally, we take the formal–informal care-giver dyad into account. Feld posits with his 'focus theory' that individuals organise their social relations around foci, which are 'social, psychological, legal or physical entities around which joint activities are organized' (1981: 1016). Feld assumes that 'two individuals who share a focus are more likely to share joint activities with each other than two individuals who do not have that focus in common' (Feld 1981: 1016). We translate this to care tasks, theorising that the greater the overlap in type of care tasks the informal and formal care-giver perform, the more compatible the focus is. This is in line with Nembhard and Edmondson (2006), who state that the higher the degree of task interdependency, the more opportunities people have to communicate with each other. Likewise, when individuals perform the same tasks, tuning is more necessary (Sims-Gould and Martin-Matthews 2010), implying a need for discussion to organise the care. We hypothesise that the greater the overlap in types of tasks between the formal and informal care-giver, the greater the likelihood that they will discuss the care (Hypothesis 4).

Methods

Sample

Data have been collected in the context of the 'Care Networks of Frail Older Adults' study in the Netherlands. Care recipients living at home were identified via eight home-care organisations and three voluntary care organisations in Amsterdam and surroundings in 2012. Team and case managers together with professional care-givers from the home-care organisations and the co-ordinating staff of the volunteering organisations approached care recipients who were in their opinion cognitively able to participate in a face-to-face interview, were aged 65 or older, and received care from at least two types of the

following care-givers: informal care-givers, formal care-givers or care volunteers. Of the 119 care recipients approached, 75 participated in the study (62%). Respondents who did not participate were physically not able to participate or found it too burdensome or stressful (N = 22), did not match the inclusion criteria according to the research co-ordinator (N = 21) or died before they were contacted by the research co-ordinator (N = 1). In one network we could not interview any care-giver, therefore the response of 74 older adults is analysed in the current study.

During the interview, the care recipients were asked to identify all the persons by name that helped them with instrumental activities of daily living (IADL), activities of daily living (ADL), nursing, transport and administrative tasks. Receiving *help with IADL tasks* was described as household work, such as preparing food or drinks, cleaning the house, washing, ironing, sewing clothes, doing the groceries or small jobs in the house or in the garden. *Help with ADL tasks* was explained as (un)dressing, putting stockings on/off, washing, combing, shaving, helping with going to the toilet, moving indoors, giving food or drinks. *Nursing tasks* were described as help with wound care, stoma care, insertion of a probe or catheter, giving injections, and distributing or giving medication. *Transport* was determined as helping moving outdoors, making excursions and visits to family or friends, and facilitating contact with health services (such as the general practitioner or hospital). *Administrative tasks* were specified as arranging assistance, assistive devices or home modifications, and regulating financial and administrative matters.

The 74 care recipients identified 220 informal care-givers and 190 formal care-givers (*see* Figure 1); 75 formal care-givers were representative of a team, *i.e.* a collection of formal care-givers who performed the same type of task regularly and in alternation. As team representative, the care-giver was chosen who visited the older adults most, or when such a person could not be identified, who had visited the older adult last. We asked the care recipients to identify the most important care-givers of which at least two different types (informal, formal) were approached for an interview. We interviewed 94 informal care-givers (including 11 volunteers) and 102 formal care-givers. In 32 networks two care-givers were interviewed, and in 42 networks more than two care-givers were interviewed, *e.g.* because several types of care were performed by different care-givers.

Measurement of discussion on care

Each of the interviewed care-givers was asked about his or her contact with each of the other care-givers identified: 'How often do you discuss the care provision with…?' We defined 'discussing the care' as involving every
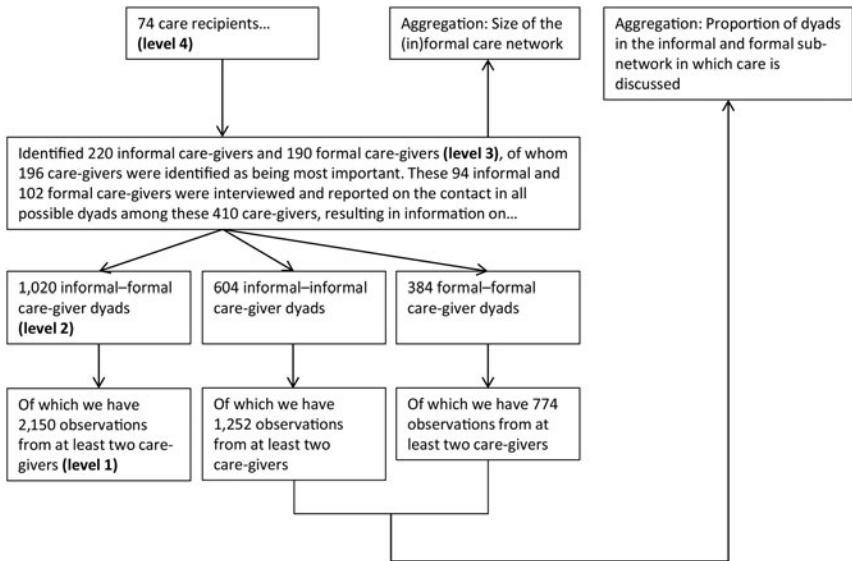
Figure 1. Overview of the four levels in the multi-level analysis.

exchange of information between two care-givers concerning the care situation of the care recipient. This can be communication in case of an emergency, or consulting one another on how to deal with specific issues concerning the older adult, *e.g.* on technical, medical or social procedures. A seven-point answering scale varying from 'never' (1) to 'daily' (7) was offered and we dichotomised the frequency of discussion into 'no discussion' (1) and 'discussion' (2–7) due to the skewed distribution. In addition, because we could not interview every care-giver who was identified, we asked the interviewed care-givers to serve as a proxy and indicate in a matrix whether each of the other identified care-givers discussed the care between another or not (0, 1, do not know). As investigating the discussion of every single formal care-giver who was part of a team with all other care-givers would become too extensive, we included only the representatives of the teams and the single care-givers who were not part of a team in our study. Hence, the team members were not identified in the network on the dyadic level, but were only used for calculating network size.

Independent variables

Care recipient characteristics. In addition to *age* (in years) and *sex* (0 = male, 1 = female), the care recipient was asked who in the care network was in *control of the care decisions.* Their answers were rearranged into 0 = care-giver

only or do not know, 1 = care recipient only or care recipient with care-giver. Further, we assessed the *educational level* (1 = low, elementary school; 2 = middle, vocational education; 3 = high, higher vocational or university level). As a measure of disability, we included the Instrumental Activities of Daily Living Scale (Lawton and Brody 1969) and the Index of Independence in Activities of Daily Living Health (Katz *et al.* 1963) in the interview. We asked the care recipients to indicate on a five-point scale to what extent they could independently perform seven IADL and eight ADL activities (ranging from 1 = without any difficulty to 5 = not at all). The scores of these 15 items were summed (range 15–75) to calculate *functional limitations* ($\alpha = 0.83$). A higher score implied more functional limitations. Finally, we asked the older adults whether they experienced *memory problems*, resulting in 0 = no memory problems and 1 = some memory problems.

Informal and formal care-giver characteristics. Relationship to the care recipient was categorised in six categories for the informal and formal care-givers (resident partner/child, child not living with care recipient, extended family, other informal care-giver, household worker, personal care-giver, nurse or other professional).[1] For each care-giver, information on care load (hours per week per task) and duration of the care (in years) was asked. We summed the total number of *hours of care* provided in each of the five tasks by each care-giver, and calculated the maximum *duration* of the care in number of years. Further, we included the *number of different types of tasks* of the informal and the formal care-givers (0 = one task, 1 = two or more tasks). *Task overlap* (0 = no task overlap, 1 = task overlap) was established by identifying whether the two care-givers provided at least one same type of task.

Care network characteristics. The *number of informal and formal care-givers* identified was counted. For the formal care-givers we included the number of formal care-givers in a team, resulting in a total of 499 formal care-givers. We calculated for both the informal and the formal sub-network whether there was little (less than 50%) or much (50% or more) *discussion*, or whether there was only one person in the sub-network, in which case no discussion could be determined.

Procedure

Descriptive statistics were provided for the 74 care recipients and network characteristics. We further computed per care network the proportion for type of relationship and the mean for duration, hours and different types

of tasks to show the distribution of all variables under study. Next, multi-level logistic analysis was applied using the MLwiN program, with iterative generalised least squares (IGLS), and a second-order predictive quasi-likelihood (PQL) procedure (Rasbash *et al.* 2009), to take the multi-level structure (the dependency of observations on different levels) into account. We transformed the hours provided by taking the natural log, because the distribution was skewed to the right.

The dyads between the 220 informal care-givers and 190 formal care-givers inform us on the discussion of care; 1,020 informal–formal care-giving relationships are included in the analyses. Information on these relationships was provided by the interviewed care-givers (on average 2.1 observations per dyad), who could be the care-giver in the dyad as well as another care-giver who served as a proxy reporter. Figure 1 illustrates that the 2,150 observations of the dyads (level 1 data in the multi-level analysis) are nested in 1,020 dyads (level 2), which are nested within 410 care-givers (level 3), who at their turn are nested within the 74 care recipients (level 4). Missing values (when the interviewed care-giver did not know whether two others discussed the care) were left out of the analysis. Information on the 410 care-givers were used to assess the size of the informal and the formal network. Next, the data on the 604 informal–informal care-giving relationships and 384 formal–formal care-giving relationships were used to assess discussion within the informal sub-network and the formal sub-network, by aggregating the dyadic information to a network level to establish whether there was little (in less than 50% of the dyads discussion occurred) or much (50% or more) discussion (Figure 1). Figure 2 gives an example of a care network in which two care-givers are interviewed.

All independent variables were first added separately to perform bivariate analyses, and second added at the same time in the model. Collinearity statistics were calculated for the set of explanatory variables and were within an acceptable range (highest variance inflation factor = 1.73). As living alone or living with a care-giver largely impacts meeting opportunities, we describe the care networks of two groups: care recipients living alone (N = 56) and care recipients living with a residing care-giver (N = 18), of which 13 were partners and five were children.

Results

Description of the different characteristics

The care recipients were on average 82.8 years old (standard deviation = 7.6) and 51 were female (Table 1). The sample was physically frail, on average scoring 35.7 on functional limitations (range 17–74) and 30 per cent
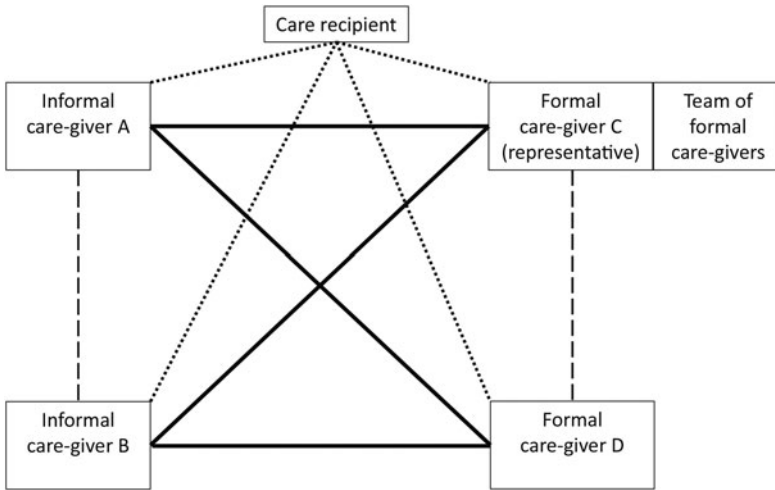
Figure 2. Example of a care network with two informal (informal care-giver A and informal care-giver B) and two formal (formal care-giver C, representative of a team and formal care-giver D) care-givers. Care-giver A and C are interviewed. The dotted lines reflect the characteristics of the ties between the care recipient and the care-givers (*e.g.* type of relationship, type of care provided). The dashed lines represent information on discussion in the informal–informal and formal–formal dyad. The straight lines provide data on the dependent variable: discussion of care between each informal and formal care-giver. Each line represents four observations, resulting from two care-givers reporting on two dyads. For example, consider the tie between care-giver B and D. The four observations are: [B–D]A, [B–D]C, [D–B]A, [D–B]C, in which [B-D]A is the dyad between care-givers B and D as nested in dyad B, as observed by care-giver A. Note that [B–D]A and [D–B]A are identical but included twice in the analysis as they are nested within different care-givers. In most cases there are two observations per dyad, but in cases where more than two care-givers are interviewed, more observations per dyad are present. Within the whole sample there were on average 2.1 care-givers reporting per dyad. Regarding the level structure of the data (*see also* Figure 1), the case in Figure 2 represents one care recipient on the fourth level, four care-givers on the third level, eight dyads on the second level and 16 observations on the first level.

reported memory problems. The majority of the care recipients (N = 49) indicated that a care-giver (either informal or formal) was in control of their care or they did not know who was in control. A minority (N = 25) indicated that they were controlling the provision of care, either themselves or together with a care-giver. On average, almost ten care-givers were involved in the care network, of whom three informal and seven formal care-givers. Most of the informal care-givers were children not living with the care recipient (on average 1.3), and most of the formal care-givers provided help with personal care. In the care networks, the informal care-givers performed 7.1 hours per week care on average, as compared to 3.6 hours of the formal care-givers. Further, most care-givers performed only one type of task. In 55 per cent of the care networks much discussion occurred between informal care-givers. For the formal–formal care networks, the proportion was

TABLE 1. *Descriptives of care recipient and network characteristics*

	Total	Living alone without care-givers	Living with care-giver(s)
N	74	56	18
		Mean (SD) range or proportion	
Older adult:			
Age	82.8 (7.6) 66–99	82.8 (7.4) 66–99	83.0 (8.5) 71–97
Sex (1 = female)	0.69	0.77	0.44
Educational level:			
Low (0)	0.35	0.36	0.33
Middle (1)	0.45	0.43	0.50
High (2)	0.20	0.21	0.17
Perceived control (1 = care recipient only or with care-giver)	0.34	0.36	0.28
Functional limitations	35.7 (11.2) 17–74	33.3 (8.4) 18–54	42.9 (15.4) 17–74
Memory problems (1 = yes)	0.30	0.29	0.33
Informal network:			
Residing care-giver (0–1)	0.22	0.00	0.89
Number of non-residing children	1.3 (1.5) 0–7	1.4 (1.6) 0–7	1.1 (1.2) 0–4
Number of other family	0.6 (0.9) 0–5	0.7 (1.0) 0–5	0.1 (0.3) 0–1
Number of other informal care-givers	1.0 (1.2) 0–6	1.2 (1.3) 0–6	0.2 (0.5) 0–2
Total number of informal care-givers	3.0 (2.0) 1–9	3.3 (2.1) 1–9	2.1 (1.5) 1–5
Informal care-giver hours per week	7.1 (15.6) 0–81	2.5 (3.1) 0–16	21.4 (27.0) 1–81
Informal care-giving duration (years)	5.9 (5.6) 1–32	5.1 (4.0) 1–20	8.6 (8.5) 1–32
Informal care-giver providing more than two types of tasks	0.34	0.26	0.51
Discussion in informal network:			
Only one person	0.28	0.21	0.50
Little discussion	0.16	0.20	0.06
Much discussion	0.55	0.59	0.44

Formal network:			
Number of domestic care-givers	1.0 (0.7) 0–3	1.1 (0.6) 0–3	0.7 (0.8) 0–3
Number of personal care-givers	3.2 (3.4) 0–10	3.2 (3.4) 0–10	3.4 (3.5) 0–10
Number of nurses	2.2 (3.4) 0–14	2.1 (3.6) 0–14	2.4 (2.7) 0–9
Other formal care-givers	0.4 (0.6) 0–2	0.4 (0.6) 0–2	0.2 (0.5) 0–2
Total number of formal care-givers	6.7 (3.8) 1–18	6.7 (3.8) 1–15	6.8 (4.0) 1–18
Formal care-giver hours per week	3.6 (2.5) 1–14	3.6 (2.6) 1–14	3.5 (2.2) 1–9
Formal care-giving duration (years)	4.1 (3.3) 0–16	4.4 (3.5) 1–16	3.0 (2.3) 0–9
Formal care-giver providing more than two types of tasks	0.17	0.18	0.15
Discussion in formal network:			
Only one person	0.15	0.11	0.28
Little discussion	0.57	0.61	0.44
Much discussion	0.28	0.29	0.28
Total network:			
Total number of care-givers	9.7 (4.6) 2–22	10.0 (4.7) 2–22	8.8 (4.3) 2–20
Task overlap in mixed network:			
Little task overlap	0.69	0.71	0.61
Much task overlap	0.31	0.29	0.39
Discussion in mixed network:			
Little discussion	0.72	0.82	0.39
Much discussion	0.28	0.18	0.61

Note: SD: standard deviation.

28 per cent. In 22 per cent of the care networks, no discussion occurred at all between the informal and formal care-givers, in 7 per cent there was one 'bridge', one dyad in which discussion occurred, and in 72 per cent two or more bridges were present (results not shown).

Discussion of care between the formal and informal care-giver

The empty model of the multi-level analysis revealed that the probability for an informal and a formal care-giver to discuss the care was 0.26. Many of the explanatory variables were statistically significant for discussion of care, but their shared level of variance reduced their impact in the multivariate analyses (Table 2). The results of the multivariate model, including all explanatory variables, revealed that control of care decisions by the care recipient and care need did not significantly impact discussion between an informal and formal care-giver, which is in contrast to Hypotheses 1a and 1b. Next, when the educational level of the care recipient was high, the probability that an informal care-giver discussed care with a formal care-giver was low (0.11) compared to care recipients with a low educational level (0.36). Considering network characteristics, the finding is in contrast with Hypothesis 2a: the greater the number of formal care-givers, the higher the likelihood of discussion between an informal and formal care-giver. Especially the contact within the informal and formal sub-networks mattered in two conditions: the more discussion occurred in the sub-network or when an informal care-giver was providing the care by him- or herself without help from others, the higher the likelihood that an informal and formal care-giver discussed the care, in contrast to Hypothesis 2b.

When focusing on the informal and formal care-giver characteristics (considering Hypotheses 3a and 3b), the results show that type of relationship mattered. When the informal care-giver was residing with the care recipient, the likelihood of discussing the care between a formal and an informal care-giver was higher (probability = 0.46) than for other informal care-givers (0.17). Also non-residing children and personal care-givers discussed the care more than other informal care-givers. In addition to co-residence and type of relationship, the results showed that when a care-giver performed more types of tasks instead of one, the likelihood that the informal and formal care-giver discussed the care was greater (probability = 0.38 *versus* 0.22). Although support was found for Hypothesis 4 in the bivariate analysis, the results of the multivariate analysis showed that task overlap did not contribute significantly to more discussion.

The analyses showed that residing care-givers are most likely to discuss the care with professional care-givers. In order to get more insight in the care networks of respondents with and without a residing care-giver, we

TABLE 2. *Multi-level logistic regression of discussion between informal and formal care-givers*

	Odds ratios	
	Bivariate	Multivariate
Age of care recipient in years (66–99)	1.007	1.044
Female care recipient (Ref. Male)	0.390	0.470
Educational level of care recipient (Ref. Low):		
Middle	1.013	0.602
High	0.200*	0.221**
Functional limitations of care recipient (17–47)	1.079**	1.035
Memory problems of care recipient (Ref. None)	1.420	0.971
Level of control: care recipient only or with care-giver (Ref. Others or do not know)	0.355	1.093
Total number of informal care-givers (1–9)	0.660***	0.867
Discussion in informal network (Ref. Little discussion):		
Only one person	25.636***	6.246*
Much discussion	5.830*	3.251*
Total number of formal care-givers (1–18)	1.160*	1.150*
Discussion in formal network (Ref. Little discussion):		
Only one person	0.691	1.392
Much discussion	3.819*	3.258**
Relationship to care-giver (Ref. Other informal care-giver):		
Resident partner/child	16.281***	4.208**
Child not living with care recipient	2.588**	1.865*
Extended family	1.328	1.204
Household worker	1.964	1.408
Personal care-giver	2.968**	2.217*
Nurse	2.633**	1.855
Other professional	2.104	1.649
Log number of hours for care-giver (−2.00 to 2.05)	1.481***	1.165
Care-giving duration in years (0–34)	1.048*	1.026
Two or more tasks for care-giver (Ref. One task)	3.850***	2.179**
Task overlap (Ref. No overlap)	1.706**	1.452

Notes: N = 2,150. Ref.: reference category.
Significance levels: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

compared the care recipients and their networks on all variables under study. Table 1 shows that in the care networks with a residing care-giver (N = 18), the care recipient was more often male (56% *versus* 23%), had more functional limitations (42.9 *versus* 33.3) and experienced less control of the care (28% *versus* 36%). These care networks held on average two informal care-givers (2.1), consisting of a spouse and a non-residing child, who provided many hours of care (21.4), and for a long period of time (8.6 years). When there was more than one informal care-giver, they were likely to discuss the care with each other. As for the care recipients living without a care-giver, the care networks were larger

(3.3 persons), consisting of several types of informal care-givers, providing on average only a few hours (2.5) of care per week. The characteristics of the formal care-givers did not seem to differ that much between the two groups, they did however more often have task overlap with the informal care-giver in networks with a residing care-giver (39% *versus* 29%). In the case of care networks with a residing care-giver, the small, highly interconnected informal care network was strongly connected to the formal sub-network, as the proportion of the informal–formal dyads discussing the care was much higher than in the care networks of care recipients living alone (61% *versus* 18%). Without a residential care-giver being present, the linkage between informal and formal sub-networks appears to be less established. Further analyses (not shown) showed that in 27 per cent of the care networks without a residing care-giver no discussion occurred, in 7 per cent there was one bridge and in 66 per cent more than one dyad in which discussion occurred was present. As opposed to the care networks with a residing care-giver, in which 6 per cent (one network) had no discussion, in 6 per cent one bridge was present and 89 per cent had several bridges.

Discussion

In this study, we explored whether and under which conditions an informal and a formal care-giver discuss the care they provide to a frail older adult. Using a network perspective, we added to the current knowledge on informal–formal dyads by taking into account additional information about the care recipient, the informal and formal sub-network, as well as the dyadic characteristics. These different characteristics were shown to be important.

First, regarding characteristics of the older adult and the necessity to discuss the care, it is neither the perceived degree of control of the care recipient that determines discussion nor the need for care as indicated by physical frailty as well as memory problems. Instead, a high educational level appeared more important in this respect, and seemed a better indicator of the older adults' capabilities to control the care compared to the other two characteristics. A higher education was associated with less discussion, so possibly the higher-educated care receiver serves as a bridge between formal and informal care-givers. As a concept, perceived control does not seem to be a well-known concept to the older adults themselves. As one respondent replied to the question who was in charge of her care: 'I guess that must be the CEO of [name of care organisation]'.

Second, size of and connection within the sub-networks were shown to matter in two ways. First, when more formal care-givers were involved,

more discussion occurred with informal care-givers. Possibly the type of care tasks or the more complex care which is related to the presence of more formal care-givers, ask for more discussion, as it was also the care-giver providing personal care who discussed the care most. Second, adding information about the informal and formal sub-network showed that the more discussion occurred among informal care-givers themselves and formal care-givers themselves, the more discussion occurred within a particular informal–formal dyad. This is in contrast with our hypothesis. Possibly discussing the care within the sub-networks leads to more questions being generated, leading in turn to more discussion between the informal and formal care-givers. Another explanation could be, following Carpentier and Grenier (2012), that receiving advice and emotional support from their informal support network leads to linkage with professional care-givers. Either way, in most care networks, more than one bridge was present, which suggests that there is not one care-giver reporting to his or her sub-network.

Our study showed that the linkage with formal care-givers is merely maintained by a residential care-giver, who serves an important bridging function doing so. These results also point at the importance of meeting opportunities for informal and formal care-givers to discuss the care, as in particular those who provide multiple types of care for many hours per week discuss the care with each other. This was shown to be specifically important when no residing care-giver was present. As the different types of tasks influenced whether or not an informal and a formal care-giver discussed the care, tuning of the different care tasks seems to matter for discussion. This indicates that a shared focus on care (Feld 1981) is determining the need for discussion of care as well.

This research provides a first picture of the functioning of different care-givers in the care networks of older adults, but several limitations of this study have to be identified. As this is a cross-sectional study, it provides a snapshot of the features associated with the discussion of care in mixed-care networks. Our findings suggest that a larger involvement of informal and formal care-givers may increase the discussion of care amongst them. A larger involvement may be due to changes in health or the availability of informal care-givers over time. Earlier qualitative research showed that established relationships with staff could be challenged when the needs of care recipients changed (Bauer and Nay 2011; Kemp *et al.* 2009) and that boundaries between nurses and family care-givers constantly shift (Ward-Griffin and McKeever 2000). Longitudinal investigation of care networks would give insight into how care networks change over time, for example in case of temporary hospitalisation, health deterioration of the older adult or the loss of an important care-giver.

Furthermore, we limited the study to task characteristics of the two types of care-givers, but their personal features, such as years of training, motivation for care provision or role expectations, may also be important in this respect. For example, previous studies show that informal care-givers are more likely to collaborate with formal care-givers when they have confidence in the abilities and communication skills of the staff (Bauer and Nay 2011; Haesler, Bauer and Nay 2007; Hertzberg and Ekman 2000) and are less uncertain about what formal care-givers expect them to do (Hertzberg, Ekman and Axelsson 2001). As developing a trusting relationship usually takes time, stability of the staff enhances linkages between informal and formal care-givers (Carpentier and Grenier 2012). A barrier to communication for formal care-givers may be that informal care-givers may be 'worn out', giving the formal care-givers the impression that they do not want to be burdened with discussing the care. Another obstacle arises when formal care-givers prefer to ignore 'annoying' informal care-givers, experiencing them as a burden when they are highly demanding (Benzein, Johansson and Saveman 2004; Hertzberg and Ekman 2000; Hertzberg, Ekman and Axelsson 2003). A suggestion for future studies in the domain of communication should thus include individual preferences, motives and experiences of both informal and formal care-givers.

A third limitation is that we could not differentiate between co-resident partners and co-resident children, given the small number of residing children. Communication could, however, be different between these two types of care-givers, as child care-givers might need to combine multiple roles, such as work and caring, for both their own children and their parents (Hansen and Slagsvold 2014; Keating and Dosman 2009). Further research could possibly distinguish between those two groups.

Finally, characteristics of the professional's organisation might affect informal–formal discussion of care as well, *e.g.* whether or not the organisation stimulates active co-operation with informal care-givers or not. Friedemann *et al.* (1997) showed that informal care-giver-oriented practices can promote informal care-givers' connectedness to the professional care-givers in nursing homes. Such practices might enhance the formation of informal–formal care-giver relationships and discussion for community-dwelling care recipients as well.

Several recommendations can be done based on this study as the increased understanding about conditions of discussion of care can inform policy makers and health-care professionals about how to deal with mixed-care networks where co-operation is lacking but needed. Overall, we see that in a quarter of all dyads discussion occurred. We propose that not every care-giver needs to discuss the care with each of the others in a care network, but it is important that discussion of the

care does occur in at least one dyad between the informal and formal care-giver (*i.e.* a 'bridge'), for tuning the care, in cases of emergency situations or when one needs to consult the other in the care network. Our study shows that such a bridge is often available in care networks in which a care-giver is residing. This implies that particular networks, without residing care-givers, are at risk of lacking communication between the informal and formal care-givers, especially when non-residing children are missing. Our findings reveal that such a bridge is missing in 20 per cent of the current networks. That being said, care situations differ in how much discussion is needed. In the current study, 30 per cent of the older adults had some memory problems, but were still capable of participating in an interview. For care recipients with dementia, more discussion among care-givers might be needed. Moreover, a care recipient might wish to retain his or her independence, sometimes even leading to care avoidance. Hence, in every care situation it is important to assess how much discussion is needed for a good quality of care, and who will be the care-givers taking the lead in this.

Stimulating discussing in at least one informal–formal care-giver dyad could be provided for in several ways. A first suggestion could be that formal care-givers should be given the opportunity to perform more types of tasks, instead of several formal care-givers only performing one type of task (*i.e.* less task differentiation), as care-givers who provide more types of tasks discuss the care more often. Secondly, as the mixed-care networks of community-dwelling older care recipients can be relatively large, one can, next to a central informal care-giver, stimulate the appointment of a central formal care-giver who provides care to the care recipient and who is responsible for communicating with the informal care-givers. Both persons would have to feel the responsibility for signalling transitions in the care situation or in the care need, as well as actively meeting each other. In this way all care-givers in the network can be activated and knowledge can be transferred. Thirdly, to enhance discussion, both care-givers would also need a clear image of what kinds of issues they can approach the other party for. As for the care networks where there are no informal care-givers residing with the care recipient, a co-ordinator of the care for both the informal and formal side seems even more in order.

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NOTE

1 The formal care-givers were mostly publicly paid home-care professionals, although in some cases the household help was privately arranged and paid. In the Netherlands, the use of professional home care and residential care is based on the degree of functional disabilities, the availability of informal care and the level of income. The need for care is assessed by professionals. If a need for care (*e.g.* household care, personal care, guidance) is assessed, the care recipient can choose between cash-for-care benefits to pay for privately arranged care, on the one hand, or care provided by home-care professionals, on the other hand. Only a very small proportion of the older Dutch care recipients use cash-for-care benefits. Dependent on one's income, one has to pay for a part of the care oneself, but the threshold is rather low. Over the past years the allocation of professionally paid care has become less universal and generous as it was in the 1990s and early 2000s (Da Roit 2012).

References

Argyle, M. 1989. *The Social Psychology of Work*. Penguin, Baltimore, Maryland.

Åstedt-Kurki, P., Paavilainen, E., Tammentie, T. and Paunonen-Ilmonen, M. 2001. Interaction between adult patients' family members and nursing staff on a hospital ward. *Scandinavian Journal of Caring Sciences*, **15**, 2, 142–50.

Bastiaens, H., Van Royen, P., Pavlic, D. R., Raposo, V. and Baker, R. 2007. Older people's preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries. *Patient Education and Counseling*, **68**, 1, 33–42.

Bauer, M. and Nay, R. 2011. Improving family–staff relationships in assisted living facilities: the views of family. *Journal of Advanced Nursing*, **67**, 6, 1232–41.

Bell, D. and Rutherford, A. 2013. Individual and geographic factors in the formation of care networks in the UK. *Population, Space and Place*, **19**, 6, 727–37.

Benzein, E., Johansson, B. and Saveman, B. I. 2004. Families in home care: a resource or a burden? District nurses' beliefs. *Journal of Clinical Nursing*, **13**, 7, 867–75.

Carpentier, N. and Ducharme, F. 2003. Care-giver network transformations: the need for an integrated perspective. *Ageing & Society*, **23**, 4, 507–25.

Carpentier, N. and Grenier, A. 2012. Successful linkage between formal and informal care systems: the mobilization of outside help by caregivers of persons with Alzheimer's disease. *Qualitative Health Research*, **22**, 10, 1330–44.

Da Roit, B. 2012. The Netherlands: the struggle between universalism and cost containment. *Health & Social Care in the Community*, **20**, 3, 228–37.

Eurostat 2015. *Main scenario–Population on 1st January by sex and single year age*. Available online at http://ec.europa.eu/eurostat/data/database. [Accessed 1 June 2015].

Feld, S. L. 1981. The focused organization of social ties. *American Journal of Sociology*, **86**, 5, 1015–35.

Friedemann, M. L., Montgomery, R. J., Maiberger, B. and Smith, A. A. 1997. Family involvement in the nursing home: family-oriented practices and staff–family relationships. *Research in Nursing & Health*, **20**, 6, 527–37.

Gittell, J. H. 2002. Coordinating mechanisms in care provider groups: relational coordination as a mediator and input uncertainty as a moderator of performance effects. *Management Science*, **48**, 11, 1408–26.

Guberman, N., Lavoie, J. P., Pepin, J., Lauzon, S. and Montejo, M. E. 2006. Formal service practitioners' views of family caregivers' responsibilities and difficulties. *Canadian Journal on Aging/Revue canadienne du vieillissement*, **25**, 1, 43–53.

Haesler, E., Bauer, M. and Nay, R. 2007. Staff–family relationships in the care of older people: a report on a systematic review. *Research in Nursing & Health*, **30**, 4, 385–98.

Hansen, T. and Slagsvold, B. 2014. Feeling the squeeze? The effects of combining work and informal caregiving on psychological well-being. *European Journal of Ageing*, **12**, 1, 51–60. doi:10.1007/s10433–014–0315-y.

Hertzberg, A. and Ekman, S. L. 2000. 'We, not them and us?' Views on the relationships and interactions between staff and relatives of older people permanently living in nursing homes. *Journal of Advanced Nursing*, **31**, 3, 614–22.

Hertzberg, A., Ekman, S. L. and Axelsson, K. 2001. Staff activities and behaviour are the source of many feelings: relatives' interactions and relationships with staff in nursing homes. *Journal of Clinical Nursing*, **10**, 3, 380–8.

Hertzberg, A., Ekman, S. L. and Axelsson, K. 2003. 'Relatives are a resource, but…': Registered Nurses' views and experiences of relatives of residents in nursing homes. *Journal of Clinical Nursing*, **12**, 3, 431–41.

Huber, M. and Hennessy, P. 2005. *Long-term Care for Older People*. Organisation for Economic Cooperation and Development, Paris.

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A. and Jaffe, M. W. 1963. Studies of illness in the aged: the index of ADL: a standardized measure of biological and psychosocial function. *Journal of the American Medical Association*, **185**, 12, 914–9.

Keating, N. and Dosman, D. 2009. Social capital and the care networks of frail seniors. *Canadian Review of Sociology/Revue canadienne de sociologie*, **46**, 4, 301–18.

Kemp, C. L., Ball, M. M., Perkins, M. M., Hollingsworth, C. and Lepore, M. J. 2009. 'I get along with most of them': Direct care workers' relationships with residents' families in assisted living. *The Gerontologist*, **49**, 2, 224–35.

Kruijswijk, W., Da Roit, B. and Hoogenboom, W. 2014. Elasticity of care networks and the gendered division of care. *Ageing & Society*, **35**, 4, 675–703. doi:10.1017/S0144686X13000822.

Lawton, M. P. and Brody, E. M. 1969. Assessment of older people: self-maintaining and instrumental activities of daily living. *The Gerontologist*, **9**, 3, 179–86.

Mollenhorst, G., Völker, B. and Flap, H. 2011. Shared contexts and triadic closure in core discussion networks. *Social Networks*, **33**, 4, 292–302.

Nembhard, I. M. and Edmondson, A. C. 2006. Making it safe: the effects of leader inclusiveness and professional status on psychological safety and improvement efforts in health care teams. *Journal of Organizational Behavior*, **27**, 7, 941–66.

Piercy, K. W. and Dunkley, G. J. 2004. What quality paid home care means to family caregivers. *Journal of Applied Gerontology*, **23**, 3, 175–92.

Pinquart, M. and Sorensen, S. 2002. Older adults' preferences for informal, formal, and mixed support for future care needs: a comparison of Germany and the United States. *International Journal of Aging & Human Development*, **54**, 4, 291–314.

Rasbash, J., Charlton, C., Browne, W. J., Healy, M. A. and Cameron, B. 2009. *MLwiN Version 2.1*. Centre for Multilevel Modelling, University of Bristol, Bristol, UK.

Ryan, D. P., Puri, M. and Liu, B. A. 2013. Comparing patient and provider perceptions of home- and community-based services: social network analysis as a service integration metric. *Home Health Care Services Quarterly*, **32**, 2, 92–105.

Sims-Gould, J. and Martin-Matthews, A. 2010. We share the care: family caregivers' experiences of their older relative receiving home support services. *Health & Social Care in the Community*, **18**, 4, 415–23.

Tucker, A. L. and Edmondson, A. C. 2003. Why hospitals don't learn from failures: organisational and psychological dynamics that inhibit system change. *California Management Review,* **45**, 2, 55–72.

Ward-Griffin, C. and McKeever, P. 2000. Relationships between nurses and family caregivers: partners in care? *Advances in Nursing Science,* **22**, 3, 89–103.

Wiles, J. 2003. Informal caregivers' experiences of formal support in a changing context. *Health & Social Care in the Community,* **11**, 3, 189–207.

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