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Linkages between informal and formal caregivers

“Madam herself is in between. And, I provide care to madam.
And I think you should not pass someone if someone does not
want that.”

Nurse, 04921

“There is no cooperation and this is also not necessary.”

Older adult, 05300

“If something does go wrong, then you should be able to find
each other.”

Cousin, 07511

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Abstract

In ageing societies, policymakers aim for more contact between informal and formal caregivers as it may enhance the quality of care. So far, the linkage between formal and informal caregivers 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 caregivers. The current study examines discussion of care between all potential informal-formal caregiver dyads in a care network, and relates this to characteristics of the older care recipient, the care network, and the caregivers.⁷⁴ Dutch older care recipients provided information on all caregivers who helped with five different types of tasks.⁴¹⁰ caregivers reported on the contact between all caregivers identified. Multilevel logistic regression was conducted in 2150 informal-formal caregiver dyads and revealed that in 26 per cent of all these dyads discussion on care occurred. This was more likely when both caregivers performed multiple types of tasks, the informal caregiver 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 caregivers in care networks where no discussion occurs at all, home care organizations may need to allocate formal caregivers who form a bridge with an extra-residential caregiver of care recipients living alone.

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 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 caregivers (e.g. publicly- or privately-paid homecare professionals) need to be deployed. This will contribute to an increase in the prevalence of mixed care networks in which multiple informal and formal caregivers will have to collaborate in providing care in the home environment. Policymakers aim for more contact and cooperation between informal and formal caregivers as it may enhance the quality of care (Huber & Hennessy, 2005). Research shows as well that timely and satisfactory cooperation between these different types of caregivers is a prerequisite for good quality of care (Gittell, 2002). Cooperation enables caregivers to know how their tasks fit to tasks of other caregivers, 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 cooperation is proven to be indispensable, few studies are conducted on the level of contact and communication between informal and formal caregivers in the home care context (Sims-Gould & Martin-Matthews, 2010). Discussing the care provision among caregivers may serve as a first step to cooperation and is the focus of our study. Our main goal is to examine under which conditions informal and formal caregivers in a care network do discuss the care.

There is an extensive body of literature on the relationship between formal and informal caregivers, 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 caregiver, are based in nursing home contexts or used qualitative methods to study the subjective experiences and attitudes of the caregiver (Åstedt-Kurki, Paavilainen, Tammentie, & Paunonen-Ilmonen, 2001; Bauer & Nay, 2011; Guberman et al., 2006; Haesler, Bauer, & Nay, 2007). Also, when looking at informal-formal caregiver relationships, studies generally focus on one central informal-formal caregiver dyad and disregard the presence of multiple informal and formal caregivers (Bell & Rutherford, 2013; Kruijswijk et al., 2014; Piercy & 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 caregiver 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 caregivers to discuss the care. Second, we consider the dyad to be part of a larger care network in which linkages may exist between multiple caregivers (Carpentier & Ducharme, 2003; Ryan et al., 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 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 caregivers may also be relevant for formal-informal care discussion, for example the type of tasks they perform or the extent to which they are providing care. Therefore, taking care recipient, care context and the individual caregivers into account, the research question reads: To what extent is discussion of the care between an informal and a formal caregiver 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 organized. Several studies corroborate that care recipients prefer either formal or informal care (Pinqart & Sörensen, 2002) and are inclined to maintain a certain level of control over the care received (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007). In such cases the care recipient can posit himself between, for example, an informal and formal caregiver and take care of all communication with both caregivers,

decreasing the necessity for both caregivers to discuss the care with each other. However, being in control may require social and organizational 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 caregivers to discuss the care. Prior research shows that with increasing health problems of the care recipient, families and professional caregivers interact more often (Kemp, Ball, Perkins, Hollingsworth, & Lepore, 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 hypothesize that an informal and a formal caregiver 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 caregivers, dyadic interaction may also depend on the interaction with and between other caregivers. Both the number and the type of caregivers may be important. When the total number of caregivers is small, it is easier for all caregivers to get in touch with each other than when the number of both informal and formal caregivers is larger. So, we first postulate that discussion of care between an informal and a formal caregiver is less likely when the number of informal and formal caregivers is higher (Hypothesis 2a). Next, both the informal and formal caregiver 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 caregivers in this sub-network connects with a caregiver 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 caregivers providing the same type of care. Informal caregivers, being all socially related to the care receiver, are likely to communicate in particular amongst each other. In both sub-networks a particular caregiver 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 caregivers. In this case, the necessity

of other informal and formal caregivers 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 caregiver is less likely to occur (Hypothesis 2b).

The caregiver-care recipient dyad

Meeting opportunities for two caregivers are larger when they are both frequently in the same social context or within close geographical distance (Argyle, 1989; Mollenhorst et al., 2011). These meeting opportunities may vary for informal caregivers 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 & Dosman, 2009). In particular, the co-residency of the informal caregiver increases the opportunity to meet other caregivers. For non-residential caregivers (both formal and informal), the frequency of care provision is more decisive for meeting other caregivers, as this reflects how often they are present in the home of the care recipient. For both informal and formal caregivers, the frequency, variety in type of care and duration of care provided increase the time spend in the home and may thus increase the opportunity to meet other caregivers. We expect that when the informal caregiver is residing with the care recipient (Hypothesis 3a) and when the caregiving 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 caregiver is higher (Hypothesis 3b), it is more likely that an informal and a formal caregiver discuss the care.

The informal-formal caregiver dyad

Finally, we take the formal-informal caregiver dyad into account. Feld posits with his ‘focus theory’ that individuals organize their social relations around foci, which are “social, psychological, legal or physical entities around which joint activities are organized” (1981: pp. 1016). He further 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”. We translate this to care tasks theorizing that the greater the overlap in type of care tasks the informal and formal caregiver 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 & Martin-Matthews, 2010), implying a need for discussion to organize the care. We hypothesize that the greater the overlap in type of tasks between the formal and informal caregiver, 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 homecare organizations and three voluntary care organizations in Amsterdam and surroundings in 2012. Team and case managers together with professional caregivers from the homecare organizations and the coordinating staff of the volunteering organizations 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 caregivers: informal caregivers, formal caregivers 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 coordinator (N = 21), or died before they were contacted by the research coordinator (N = 1). In one network we could not interview any caregiver, 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 caregivers and 190 formal caregivers (see Figure 5.1); 75 formal caregivers were representative of a team, i.e. a collection of formal caregivers who performed the same type of task regularly and in alternation. As team representative the caregiver 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 caregivers of which at least two different types (informal, formal) were approached for an interview. We interviewed 94 informal caregivers (including 11 volunteers) and 102 formal caregivers. In 32 networks two caregivers were interviewed, and in 42 networks more than two caregivers were interviewed, for example because several types of care were performed by different caregivers.

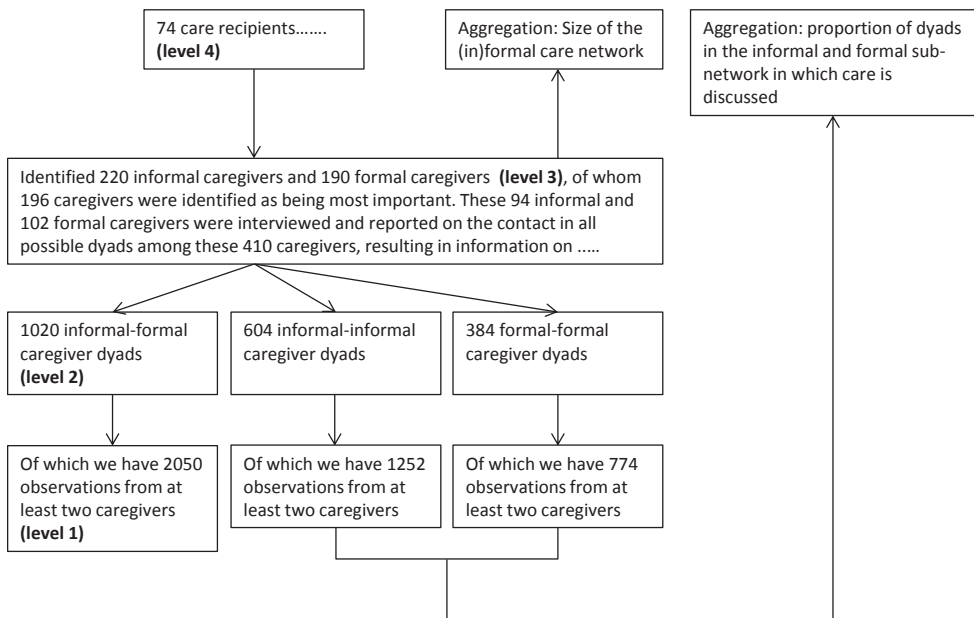


Figure 5.1 Overview of the four levels in the multilevel analysis

Measurement of discussion on care

Each of the interviewed caregivers was asked about his or her contact with each of the other caregivers identified: “How often do you discuss the care provision with...?” We defined ‘discussing the care’ as involving every exchange of information between two caregivers 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, for example on technical, medical or social procedures. A seven-point answering scale varying from ‘never’ (1) to ‘daily’ (7) was offered and we dichotomized 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 caregiver who was identified, we asked the interviewed caregivers to serve as a proxy and indicate in a matrix whether each of the other identified caregivers discussed the care between another or not (0, 1, do not know). As investigating the discussion of every single formal caregiver who was part of a team with all other caregivers would become too extensive, we included only the representatives of the teams and the single caregivers 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 in 0=caregiver only or do not know, 1= care recipient only or care recipient with caregiver. 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 5-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 caregiver characteristics

Relationship to the care recipient was categorized in six categories for the informal and formal caregivers (resident partner/child, child not living with care recipient, extended family, other informal caregiver, household worker, personal caregiver, nurse or other professional). For each caregiver, 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 caregiver, 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 caregivers (0 = one task, 1 = two or more tasks). Task overlap (0 = no task overlap, 1 = task overlap) was established by identifying whether the two caregivers provided at least one same type of task.

Care network characteristics

The number of informal and formal caregivers identified was counted. For the formal caregivers we included the number of formal caregivers in a team, resulting in a total of 499 formal caregivers. 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, multilevel logistic analysis was applied using the MLwiN program, with iterative generalized least squares (IGLS), and a second order predictive quasi-likelihood (PQL) procedure (Rasbash, Charlton, Browne, Healy, & Cameron, 2009), to take the multilevel 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 caregivers and 190 formal caregivers inform us on the discussion of care; 1020 informal-formal caregiving relationships are included in the analyses. Information on these relationships was provided by the interviewed caregivers (on average 2.1 observations per dyad), who could

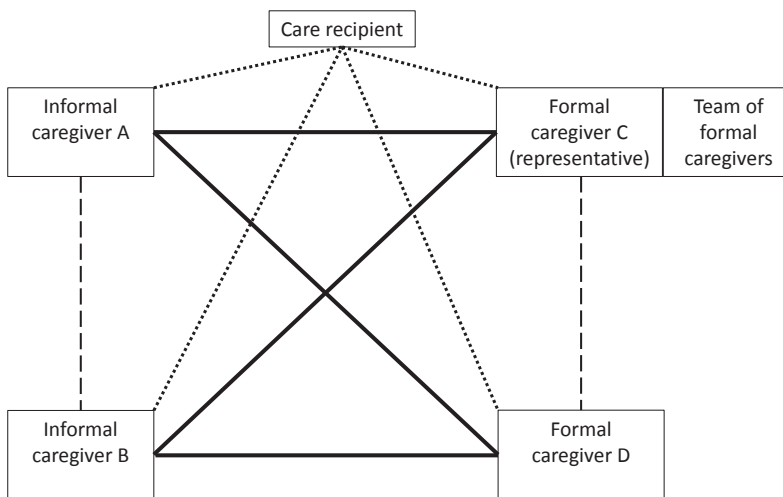


Figure 5.2. Example of a care network with two informal (Informal Caregiver-A and Informal Caregiver-B) and two formal (Formal Caregiver-C, representative of a team and Formal Caregiver-D) caregivers. Caregiver A and C are interviewed. The dotted lines reflect the characteristics of the ties between the care recipient and the caregivers (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 caregiver. Each line represents four observations, resulting from two caregivers reporting on two dyads. For example, consider the tie between caregiver 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 caregivers B and D as nested in dyad B, as observed by caregiver A. Note that [B-D]A and [D-B]A are identical but included twice in the analysis as they are nested within different caregivers. In most cases there are 2 observations per dyad, but in cases where more than two caregivers are interviewed, more observations per dyad are present. Within the whole sample there were on average 2.1 caregivers reporting per dyad. Regarding the level structure of the data (see also Figure 5.1), the case in Figure 5.2 represents 1 care recipient on the fourth level, 4 caregivers on the third level, 8 dyads on the second level and 16 observations on the first level.

be the caregiver in the dyad as well as another caregiver who served as a proxy reporter. Figure 5.1 illustrates that the 2150 observations of the dyads (level 1 data in the multilevel analysis) are nested in 1020 dyads (level 2), which are nested within 410 caregivers (level 3), who at their turn are nested within the 74 care recipients (level 4). Missing values (when the interviewed caregiver did not know whether two others discussed the care) were left out of the analysis. Information on the 410 caregivers were used to assess the size of the informal and the formal network. Next, the data on the 604 informal-informal caregiving relationships and 384 formal-formal caregiving 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 5.1). Figure 5.2 gives an example of a care network in which two caregivers 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 caregiver 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 caregiver ($N = 18$), of which 13 were partners and 5 were children.

Results

Description of the different characteristics

The care recipients were on average 83.3 years old ($SD = 7.7$) and 51 were female (table 5.1). The sample was physically frail, on average scoring 35.7 on functional limitations (range 17-74), and 30 per cent reported memory problems. The majority of the care recipients ($N = 49$) indicated that a caregiver (either informal or formal) was in control of the 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 caregiver. On average almost ten caregivers were involved in the care network, of which three informal and seven formal caregivers. Most of the informal caregivers were children not living with the care recipient

Table 5.1 Descriptives of care recipient and network characteristics (N = 74)

	Total (N = 74)	Living alone without caregivers (N = 56)	Living with caregiver(s) (N = 18)
Older adult			
Age	83.3 (7.7) 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 caregiver)	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 caregiver (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 caregivers	1.0 (1.2) 0-6	1.2 (1.3) 0-6	0.2 (0.5) 0-2
Total number of informal caregivers	3.0 (2.0) 1-9	3.3 (2.1) 1-9	2.1 (1.5) 1-5
Hours informal caregiver	7.1 (15.6) 0-81	2.5 (3.1) 0-16	21.4 (27.0) 1-81
Duration informal caregiver	5.9 (5.6) 1-32	5.1 (4.0) 1-20	8.6 (8.5) 1-32
Informal caregiver providing more than two types of tasks	0.34	0.26	0.51
Discussion 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 caregivers	1.0 (0.7) 0-3	1.1 (0.6) 0-3	0.7 (0.8) 0-3
Number of personal caregivers	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
Number of other professionals	0.4 (0.6) 0-2	0.4 (0.6) 0-2	0.2 (0.5) 0-2
Total number of formal caregivers	6.7 (3.8) 1-18	6.7 (3.8) 1-15	6.8 (4.0) 1-18
Hours formal caregiver	3.6 (2.5) 1-14	3.6 (2.6) 1-14	3.5 (2.2) 1-9
Duration formal caregiving	4.1 (3.3) 0-16	4.4 (3.5) 1-16	3.0 (2.3) 0-9
Formal caregiver providing more than two types of tasks	0.17	0.18	0.15

(on average 1.3), and most of the formal caregivers provided help with personal care. In the care networks the informal caregivers performed 7.1 hours per week care on average, as compared to 3.6 hours of the formal caregivers. Further, most caregivers performed only one type of task. In 55 per cent of the care networks much discussion occurred between informal caregivers. For the formal-formal care networks, the proportion was 28 per cent. In 22 per cent of the care networks, no discussion occurred at all between the informal and formal caregivers, 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 in table).

Discussion of care between the formal and informal caregiver

The empty model of the multilevel analysis revealed that the probability for an informal and a formal caregiver to discuss the care was .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 5.2). 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 caregiver, which is in contrast to Hypothesis 1a and 1b. Next, when the educational level of the care recipient was high, the probability that an informal caregiver discussed care with a formal caregiver was low (.11) compared to care recipients with a low educational level (.36). Considering network characteristics, the finding is in contrast with Hypothesis 2a: the greater the number of formal caregivers, the higher the likelihood of discussion between an informal and formal caregiver. 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 caregiver was providing the care by him- or herself without help from others, the higher the likelihood that an informal and formal caregiver discussed the care, in contrast to Hypothesis 2b.

When focusing on the informal and formal caregiver characteristics (considering Hypotheses 3a and 3b), the results show that type of relationship mattered. When the informal caregiver was residing with the care recipient, the likelihood of discussing the care between a formal and an informal caregiver was higher (probability = .46) than for other informal caregivers (.17). Also non-residing children and personal caregivers discussed the care more than other informal

Table 5.2 Multilevel logistic regression of discussion between informal and formal caregivers. (N = 2150) (Odds Ratios)

	Bivariate OR	Multivariate OR
Age care recipient in years (66-99)	1.007	1.044
Female care recipient (ref = male)	0.390	0.470
Educational level care recipient (ref = low)		
Middle	1.013	0.602
High	0.200*	0.221**
Functional limitations care recipient (17-47)	1.079**	1.035
Memory problems care recipient (ref = none)	1.420	0.971
Level of control: care recipient only or with caregiver (ref = others or do not know)	0.355	1.093
Total number of informal caregivers (1-9)	0.660***	0.867
Discussion informal network (ref = little discussion)		
Only one person	25.636***	6.246*
Much discussion	5.830*	3.251*
Total number of formal caregivers (1-18)	1.160*	1.150*
Discussion formal network (ref = little discussion)		
Only one person	0.691	1.392
Much discussion	3.819*	3.258**
Relationship caregiver (ref = other informal caregiver)		
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 caregiver	2.968**	2.217*
Nurse	2.633**	1.855
Other professional	2.104	1.649
Log number of hours caregiver (-2.00-2.05)	1.481***	1.165
Duration caregiver in years (0-34)	1.048*	1.026
Two or more tasks caregiver (ref = one task)	3.850***	2.179**
Task overlap (ref = no overlap)	1.706**	1.452

* $p < .05$; ** $p < .01$; *** $p < .001$

caregivers. In addition to co-residence and type of relationship, the results showed that when a caregiver performed more types of tasks instead of one, the likelihood that the informal and formal caregiver discussed the care was greater (probability = .38 vs. .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 caregivers are most likely to discuss the care with professional caregivers. In order to get more insight in the care networks of respondents with and without a residing caregiver, we compared the care recipients and their networks on all variables under study. Table 5.1 shows that in the care networks with a residing caregiver (N = 18) the care recipient was more often male (56% vs 23%), had more functional limitations (42.9 vs 33.3) and experienced less control of the care (28% vs 36%).

These care networks held on average two informal caregivers (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 caregiver, they were likely to discuss the care with each other. As for the care recipients living without a caregiver, the care networks were larger (3.3 persons), consisting of several types of informal caregivers, providing on average only a few hours (2.5) of care per week. The characteristics of the formal caregivers did not seem to differ that much between the two groups, they did however more often have task overlap with the informal caregiver in networks with a residing caregiver (39% vs 29%). In the case of care networks with a residing caregiver, 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% vs 18%). Without a residential caregiver being present, the linkage between informal and formal sub-networks appears to be less established. Further analyses (not shown in table) showed that in 27 per cent of the care networks without a residing caregiver 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 caregiver, 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 caregiver 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 additional information about the care recipient, the informal- and formal sub-network, as well as the dyadic characteristics into account. These different characteristics showed 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 caregivers. 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 care organization]".

Second, size of and connection within the sub-networks showed to matter in two ways: when more formal caregivers were involved, more discussion occurred with informal caregivers. Possibly the type of care tasks or the more complex care which is related to the presence of more formal caregivers, ask for more discussion, as it was also the caregiver 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 caregivers themselves and formal caregivers 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 caregivers. 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 caregivers. Either way, in most care networks, more than one bridge was present, which suggests that there is not one caregiver reporting to his or her sub-network.

Our study showed that the linkage with formal caregivers is merely maintained by a residential caregiver, who serves an important bridging function doing so. These results also point at the importance of meeting opportunities for informal and formal caregivers 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 showed to be specifically important when no residing caregiver was present. As the different types of tasks were of influence of whether or not an informal and a formal caregiver 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 caregivers 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 caregivers may increase the discussion of care amongst them. A larger involvement may be due to changes in health or the availability of informal caregivers over time. Earlier qualitative research showed that established relationships with staff could be challenged when the needs of care recipients changed (Bauer & Nay, 2011; Kemp et al., 2009) and that boundaries between nurses and family caregivers constantly shift (Ward-Griffin & McKeever, 2000). Longitudinal investigation of care networks would give insight in how care networks change over time, for example in case of temporary hospitalization, health deterioration of the older adult or the loss of an important caregiver.

Furthermore, we limited the study to task characteristics of the two types of caregivers, but their personal features, 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 caregivers are more likely to collaborate with formal caregivers when they have confidence in the abilities and communication skills of the staff (Bauer & Nay, 2011; Haesler et al., 2007; Hertzberg & Ekman, 2000) and are less uncertain what formal caregivers expect them to do (Hertzberg et al., 2001). As developing a trusting relationship usually takes time, stability of the staff enhances linkages between informal and formal caregivers (Carpentier & Grenier, 2012). A barrier to communication for formal caregivers may be that

informal caregivers may be ‘worn out,’ giving the formal caregivers the impression that they do not want to be burdened with discussing the care. Another obstacle arises when formal caregivers prefer to ignore ‘annoying’ informal caregivers, experiencing them as a burden when they are highly demanding (Benzein et al., 2004; Hertzberg & Ekman, 2000; Hertzberg et al., 2003). A suggestion for future studies in the domain of communication should thus include individual preferences, motives, and experiences of both informal and formal caregivers.

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 caregivers, as child caregivers might need to combine multiple roles, such as work and caring for both their own children and their parents (Hansen & Slagsvold, 2014; Keating & Dosman, 2009). Further research could possibly distinguish between those two groups.

Finally, characteristics of the professional’s organization might affect informal-formal discussion of care as well, for example whether or not the organization stimulates active cooperation with informal caregivers or not. Friedeman et al. (1997) showed that informal caregiver-oriented practices can promote informal caregivers’ connectedness to the professional caregivers in nursing homes. Such practices might enhance the formation of informal-formal caregiver relationships and discussion for community-dwelling care recipients as well.

Several recommendations can be done based on this study as the increased understanding on conditions of discussion of care can inform policy makers and health care professionals how to deal with mixed care networks where cooperation is lacking but needed. Overall, we see that in a quarter of all dyads discussion occurred. We propose that not every caregiver 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 caregiver (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 caregiver is residing. This implies that in particular networks without residing caregivers are at risk of lacking communication between the informal and formal caregivers, 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 still capable to participate in an interview. For care recipients with dementia more discussion among caregivers 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 caregivers taking the lead in this.

Stimulating discussing in at least one informal-formal caregiver dyad could be provided for in several ways. A first suggestion could be that formal caregivers should be given the opportunity to perform more types of tasks, instead of several formal caregivers only performing one type of task (i.e. less task differentiation), as caregivers 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 caregiver, stimulate the appointment of a central formal caregiver who provides care to the care recipient and who is responsible for communicating with the informal caregivers. 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 caregivers in the network can be activated and knowledge can be transferred. Thirdly, to enhance discussion, both caregivers would also need a clear imagine on what kind of issues they can approach the other party for. As for the care networks where there are no informal caregivers residing with the care recipient, a coordinator of the care for both the informal and formal side seems even more in order.