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2019

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van Wieringen, M. (2019). “Care is not just about care anymore”: Micro-level responses to institutional complexity and change in the Dutch home-care sector.

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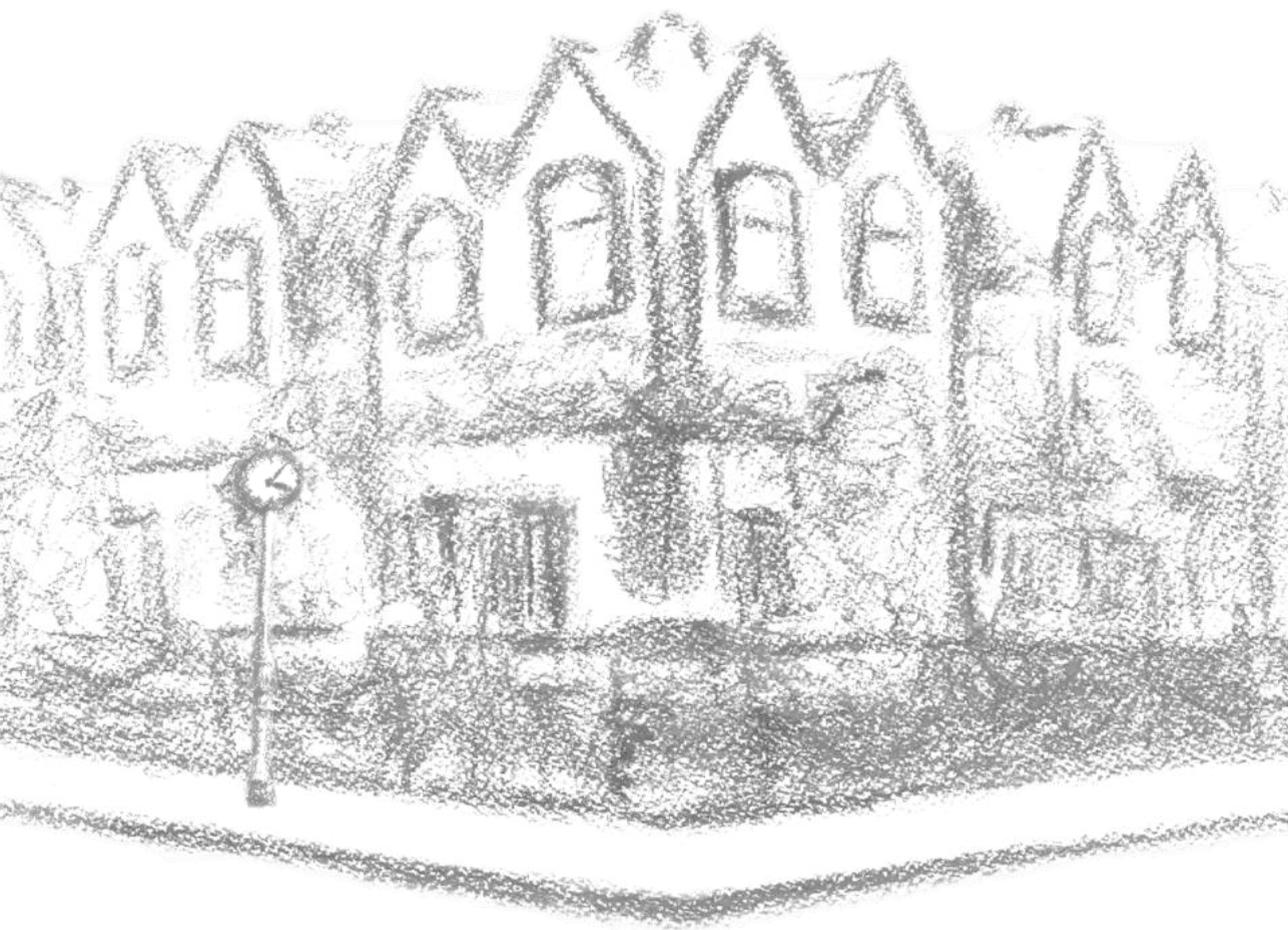
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Chapter two

Impact of home-care management on the involvement of informal caregivers by formal caregivers*

Abstract

This study explores the link between management characteristics of home-care agencies and the involvement of informal caregivers in caregiving. Based on a study of policy documents of two agencies and semi-structured interviews with five team managers and 31 formal caregivers, we conclude that, although the importance of involving informal caregivers is emphasized in official documentation, actual contact with informal caregivers is often lacking. Comparison of the work processes of the two agencies shows that contact with informal caregivers and their potential involvement are enhanced by smaller teams, less task division, and clarity about the responsibilities of formal caregivers. We discuss that a lack of policy implementation is conducive to the lack of alignment between formal policy and the organizational of work practices with regard to informal caregiver involvement.

*This chapter is based on: Van Wieringen, M., Broese van Groenou, M. I., & Groenewegen, P. (2015). Impact of home care management on the involvement of informal caregivers by formal caregivers. *Home health care services quarterly*, 34(2), 67-84.

2.1 Introduction

In The Netherlands, informal caregivers (partners, family, neighbors, or friends) provide a large part of the long-term care given to community-dwelling frail older adults. In 2013, their combined input equalled a monetary value of \$8 billion, while \$25 billion is spent annually on publicly funded professional long-term care – which includes youth care, care for the disabled, and care for the elderly (De Boer, Woittiez, & Van Zonneveld, 2013). Recently, the Dutch national government introduced a policy aimed at containing costs of publicly funded care, by advocating an even higher involvement of informal caregivers and promoting “aging in place” for older people (Da Roit, 2013). This means that older people have to turn to informal caregivers for services such as home-making or collecting medication, which were formerly provided by formal caregivers. Only when the care need grows, or becomes too complicated, formal care can be requested, and a situation evolves in which both formal and informal caregivers offer parts of the necessary care. This is when formal caregivers are expected to support informal caregivers, in order to prevent informal caregivers from becoming overburdened, and to “connect with” informal caregivers to establish partnerships and enhance the quality of care (VWS, 2013).

Because of the renewed focus on caregiver involvement, and continuous budget cuts (Da Roit, 2013), home-care agencies have to reconsider how they can best organize caregiving. Research is needed, for instance, to identify what style of organizing the caregiving process enhances caregiver involvement and support (Coyne, O’Neill, Murphy, Costello, & O’Shea, 2011; Nies et al., 2013). By conducting two case studies, we will render insight into whether and how caregiver involvement is enhanced by the policies of agencies and their organization of work processes.

It is well-known that agencies’ roles and procedures guide day-to-day practices of formal caregivers (Sims-Gould & Martin-Matthews, 2010). Thus far, however, little research has been done on the actual embedding of informal caregivers in policy and the organization of work processes of home-care agencies (Black & Fauske, 2007; Byrne, Sims-Gould, Frazee, & Martin- Matthews, 2011; Kemp, Ball, & Perkins, 2013), even though an understanding of how such features are associated to actual caregiver involvement is crucial. The aims of our study are to explore: (a) how agencies view the involvement of informal caregivers; (b) how

this view is reflected in the organization of work processes; and (c) how this results in contact between formal and informal caregivers in the actual care setting (“work floor level”).

2.2 Literature review

Over two decades ago, Twigg (1989) identified that social care agencies can take three broad views of caregivers: “carer as resource,” “carer as co-worker,” or “carer as co-client.” These views show a gradation in the degree of interaction between professionals and caregivers, and the level of support that caregivers ought to receive. Using this framework, Pickard and Glendinning (2002) state that professionals generally regard caregivers “coworkers” (partners in care), because both parties perform comparable tasks, such as home-making or rendering personal care. Informal caregivers often do not feel treated as “co-worker,” though, because they are hardly involved in the decision-making about care (Pickard & Glendinning, 2002). Moreover, caregivers can experience a lack of sympathy and support from professionals (Ward-Griffin & Marshall, 2003; Ward-Griffin & McKeever, 2000). This usually results from the limited knowledge that professionals have of caregivers’ needs or attitudes toward care. Overall, it can be said that professionals do not always interact with caregivers (Forbes et al., 2008; Phillipson & Jones, 2011).

Research in institutional settings has shown how characteristics of the organization of work processes – such as a high caseload, time constraints, and discontinuity of staff, as well as policy that undermines the time spend with caregivers – can impede the development of a relationship with this group (Coyne et al., 2011; Haesler, Bauer, & Nay, 2010). Similar factors can play a role in home-care settings, exerting a negative influence on professional-client relationships (Gjevjon, Eika, Romøren, & Landmark, 2014; Hall & McWilliam, 2006; Martin-Matthews & Sims-Gould, 2008); we suggest the same could apply also to the professional-caregiver relationship. As stated before, however, a fruitful relationship is important in home-care settings, because professionals enter the private domain of both the client and caregivers (Aronson, 2004). In addition, caregivers often assume a more central caring role here (Ryan, Puri, & Liu, 2013), requiring a different form of interaction than in institutional settings.

Yet, despite the fact that agency-level factors – such as policy and procedures – are often said to guide formal caregivers (Martin-Matthews & Sims-Gould, 2008; Sims-Gould & Martin-Matthews, 2010), the actual view that agencies have on informal care remains largely unexplored (Kemp et al., 2013). Research evidence is also lacking on how such a view should be translated into work processes and (care) practices of formal caregivers in the home.

2.2.1 Home-care agencies in the Netherlands

In the Netherlands, home-care is provided by private nonprofit agencies. Regulated by government laws, agencies are expected to offer good, affordable, and accessible care (Oldenhof et al., 2014). Similar to other professional health care organizations (Shortell & Kaluzny, 2006), over the past few decades many Dutch agencies have merged in an attempt to counter the effect of budget cuts (Postma, Oldenhof, & Putters, 2015). This process has resulted in large, hierarchically managed agencies. As agencies have increased in size, so has the tendency to introduce “Tayloristic notions” in care (Da Roit, 2013; Nies et al., 2013; Postma et al., 2015): caregiving is characterized by a focus on efficiency and productivity, standardization of work processes and differentiation of tasks (Mintzberg, 1979; Tønnessen, Nortvedt, & Førde, 2011; Van der Boom, 2008), with tasks being assigned to “different care workers, depending on required professional capabilities” (Postma et al., 2015, p. 67).

In the early 2000s, the Taylorist way of organizing care sparked off criticism in society and from professionals about care being impersonal, resulting in calls for smaller scale and more personalized care. This movement has gained political support, and has led to the certification of smaller agencies without supposedly redundant management layers. In these smaller agencies, nurses work in self-managed teams, and have discretionary room to organize the caregiving process as they see fit (Nies et al., 2013). Because the hierarchical agencies continue to exist, there are now different types of agencies with different ways of managing care.

2.3 Methods

Our research forms part of a larger Dutch mixed-methods study aimed at investigating the functioning of mixed care networks of home-dwelling frail older adults from the perspective

of older adults, informal caregivers, and agency employees. Based on their size and the neighborhood they served, eight agencies in one urbanized area were purposively sampled for the overarching study. For this study, we examine a representative agency of either of the two “ideal types” described above. Their names are withheld for reasons of confidentiality.

Agency A is a large, hierarchical agency, with four organizational layers from the management to the work floor level (Figure 2.1). Communication is top-down and decision-making is centralized. Tasks are clearly demarcated and standardized at the caretaking level. Team managers are indirectly responsible for the functioning of teams providing either home-making services, personal care, and/or nursing care. Home-making – i.e., cleaning – is delivered by home helps. Personal care includes showering, dressing, and other uncomplicated tasks (Postma et al., 2015), such as putting on compression stockings. Personal care is provided by a subteam of auxiliary nurses, under the direct supervision of registered nurses. Besides supervising lower level nurses, registered nurses also provide more complex care – such as giving injections, dressing wounds, and specialized care (e.g., to diabetics). Finally, in every team one registered nurse additionally has care-coordinating tasks – which include care need assessment, developing a care plan, coordinating tasks of other registered and auxiliary nurses, and involving informal caregivers.¹⁰

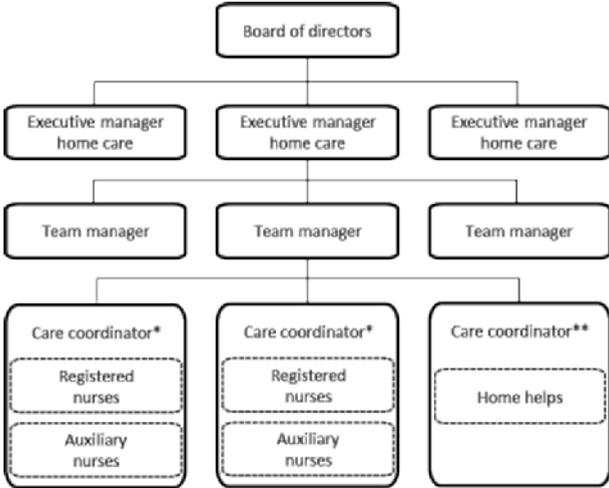


Figure 2.1. Schematic representation of agency A.
*Is a registered nurse, part of registered nurses team, **Non-nursing background.

¹⁰ In this chapter, these nurses are referred to as care coordinators.

Agency B has a flat organizational structure (Figure 2.2): directly “below” the executive manager there are autonomous, self-steering teams of registered nurses and auxiliary nurses who provide nursing and/or personal care. The tasks of the team members, such as care coordination or planning, are loosely defined; the teams decide for themselves the actual division of tasks.

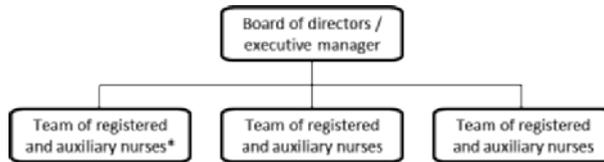


Figure 2.2. Schematic representation of agency B

*Both registered and auxiliary nurses can be a care coordinator.

2.3.1 Data

In order to acquire an in-depth understanding of the agencies’ views on informal caregivers and their organization of work processes, we adopted a qualitative descriptive approach in this part of the study. We drew on qualitative data from topic list interviews in which respondents were asked whether their agency had policy on involving informal caregivers, and what role they usually assigned to informal caregivers. Respondents were also asked to describe when and why they had contact with informal caregivers, which served as an indication of actual work practices. Information about the organization of work processes was obtained by letting respondents describe the caregiving process in terms of the people involved and the division of tasks and responsibilities at both the coordinating and the practice level.

The first author conducted interviews with five team managers and six care coordinators from Agency A, and eight care-coordinating nurses from Agency B (referred to below as “care coordinators”). The interviews were held between December 2012 and June 2013 in the participants’ offices. Interviews ranged in length from 45 to 90 minutes. All interviews were recorded and transcribed verbatim. In addition, from each agency written documentation was collected on the agencies’ mission statement, their policy on informal care, job descriptions, and/or work processes.

To further our understanding of the work floor level, we collected information on the intensity of contact between formal and informal caregivers, and the types of care given to

six older adult clients of each agency with comparable care needs. We drew on data from semi-structured interviews with 11 (non-care-coordinating) auxiliary nurses from Agency A, and six auxiliary nurses from Agency B. These nurses were identified in the following manner. Care coordinators were given a flyer explaining the purposes of the study. These were distributed among clients of at least 65 years old, who were cognitively capable of being interviewed, and had at least one informal caregiver. Clients who agreed to participate in the study were contacted by telephone for confirmation, after which a face-to-face interview was scheduled.¹¹ During a semi-structured interview clients were asked, among other things, to identify their care network by answering questions on who, in an average week, provided help with home-making, personal care, nursing care, guidance, and administrative arrangements. With the clients' consent, the primary formal caregiver(s) were subsequently contacted. The purpose of the study was explained and, if they agreed to participate, an interview was scheduled. In the interview, nurses were asked, among other things, which task(s) they performed for the client in question. They were also asked to give an indication of the frequency of contact with each identified informal caregiver about the care given to the client (1 = daily to 7 = never), and whether they had asked caregivers if they needed any support (no/yes). The interviews were held between December 2011 and December 2012, and were conducted in the agencies' offices.

The topic lists for the interviews with care coordinators and team managers, and the semi-structured questionnaire for the interviews with other nurses were developed with guidance from an external advisory group. This group consisted of scientists, government policy-makers (national and local level), policy-makers from two agencies that participated in the larger project, and formal and informal caregivers. Members were either known to the researchers personally, or via mutual relatives; they were all purposefully chosen based on their expertise in the field.

2.3.2 Analyses

The interview transcripts and written documentation were systematically analyzed using MAXQDA, a software package to manage and analyze qualitative data.¹² After several

¹¹ The interviews are not included in the body of data on which this dissertation builds.

¹² See: <http://www.maxqda.com>; VERBI GmbH, Berlin, Germany.

readings of the transcripts and documentation, the data were systematically coded according to two themes: “view on informal caregivers,” “characteristics of work processes.” Within these overarching themes, subthemes were coded and compared, such as different roles for informal caregivers, or the division of tasks. Finally, views and practices were compared. Regarding the quantitative data, we used SPSS (SPSS Inc., Chicago, IL, USA) for descriptive analyses (frequencies).

2.4 Findings

2.4.1 View on informal caregivers

Agency A had a formal policy on informal caregivers, published on the agency’s website. The policy document stated that employees are expected to be accessible to informal caregivers, have to consult informal caregivers on a regular basis, and must check if support is needed to secure informal caregivers’ caregiving role and preserve their well-being. It was not specified, however, who should be responsible for these tasks.

Interestingly, respondents from Agency A did not know that this policy document existed. Nonetheless, most team managers stated that the caregiving process was fine-tuned with informal caregivers, and that formal caregivers ought to offer support. Most care coordinators also emphasized how important informal caregivers are:

“They can do a lot for us, our right-hand man, so to say. We fine-tune a lot. We inform them about what they have to do; medicine they can collect. Together we can accomplish a lot, and that is very important to us.” (Care coordinator, Agency A)

“Sometimes we have to say to daughters and sons, ‘You really have to do this for your mother, because she can’t do it herself.’ [...] Things like home-making, buying clothes, or, for example, when there’s no shampoo left, then informal caregivers really have to go out and get some.” (Care coordinator, Agency A)

As both quotes illustrate, cooperation and “fine-tuning” with informal caregivers in practice often consisted of assigning tasks to informal caregivers that formal caregivers were not allowed to provide anymore.

Agency B had a publicly available printed document specifying the agency's founding principles. The document also described that cooperation with informal caregivers is considered necessary, and that informal caregivers are involved in the caregiving process as much as possible. Lastly, it stated that informal caregivers must be given attention and support, and, if needed, have to receive care themselves.

This "official view" was largely underscored by descriptions given by care coordinators. One care coordinator stated that formal and informal caregivers complement each other. Some expected informal caregivers to perform certain tasks, while others indicated that the involvement of informal caregivers depended on their willingness and capabilities, and tasks should be divided accordingly. Attention was also paid to (potential) overburdening:

"We are very much alert to overburdened [informal] caregivers. [. . .] Because some [informal] caregivers just go on and on. We do not expect caregivers to be always there whatever it takes." (Care coordinator, Agency B)

Regarding our first aim, we can conclude that the written documentation from both agencies stressed the importance of involving and supporting informal caregivers. This view was largely underscored by respondents in both agencies. Although nuances were found: whereas care coordinators in Agency A tend to focus on what tasks informal caregivers should perform for them, care coordinators in Agency B think in terms of how they can share caregiving with informal caregivers, and the potential need for support of informal caregivers.

2.4.2 Organization of caregiving processes and contact with informal caregivers

In both agencies, the caregiving process started with a so-called "intake." With the aid of a questionnaire, the intake served to get acquainted with the older adult, and an assessment was made of their care needs and of what tasks were carried out by informal caregivers. Also, contact details were noted down of a (noncaregiving) family member or friend, who could be contacted in case of an emergency. In their turn, care coordinators, left a phone number, which in Agency A was a call-center number, and in Agency B a 24/7 reachable cell phone number.

Despite what the written documentation and care coordinators said about the importance of caregivers, in both agencies it is not the custom at the intake stage to get to know informal caregivers personally. Informal caregivers, or noncaregiving family members, were not directly invited to attend the intake, although they were welcome to do so if the client agreed to this; some respondents from Agency B said they stimulated family members to be present. In practice, this meant that informal caregivers were not always involved in care plan development.

Although the intake questionnaires of both agencies were similar in content, the procedure differed with respect to who did the intake, and the subsequent organization of work processes. As these differences contribute to the type and intensity of contact between formal and informal caregivers, we will describe the agencies separately in what follows.

Agency A: differentiated tasks, ambiguous responsibilities

In Agency A, the intake was always carried out by the care coordinator of the personal care and nursing team. Besides coordinating the caregiving process of an average of 75 clients, the care coordinator also provided care to some of these clients, but not all of them. This meant that most clients would not receive direct care from or regularly see their care coordinator. As an additional consequence, the care coordinator was unlikely to meet informal caregivers, although informal caregivers were invited to read and note down any questions in the case record that was kept at the client's home.

The job description of care coordinators stated that they should proactively keep in contact with informal caregivers, yet most care coordinators indicated that they hardly ever did so. The same applied to the care coordinators of the home-making teams. Moreover, when asked about the role of informal caregivers in giving care to certain clients – the clients they had suggested for the larger study – care coordinators often did not know what exactly this role entailed. Interestingly, our questions seemed to raise awareness that contact with informal caregivers needed initiation or intensification:

“I think we do not involve them enough. [. . .] It is not always the case that, if an informal caregiver has called me to request care, I immediately call them back saying, ‘This is what we will do, and what tasks will you perform for us?’ That does not happen often enough

yet. For me personally, there is not enough initiative for consultation or cooperation with informal caregivers, if this is not initiated by them.” (Care coordinator, Agency A)

Care coordinators themselves differed as to whom they considered responsible for the contact with informal caregivers. For clients receiving both home-making and personal care or nursing services, a care coordinator of a home-making team indicated that the right contact person was the care coordinator of the personal care and nursing team, and vice versa. In addition, some care coordinators assigned a “first person responsible” role to other registered or auxiliary nurses who regularly provided care to the client, which role was said to include keeping in contact with informal caregivers. Some team managers even increased ambiguity by assigning the responsibility to maintain contact with informal caregivers to all nurses or home-helpers, assuming that this would indeed be done.

In practice, there was hardly contact between the interviewed (non-care-coordinating) formal and informal caregivers. As can be seen in Table 2.1, in three of the six networks, there was no contact at all. In Network A-6, weekly consultation took place between a formal caregiver and one informal caregiver (spouse). Moreover, all except one of the formal caregivers indicated that they had never asked informal caregivers whether they needed any support for their own well-being. Some had failed to do so because they assumed such support was not needed. Another reason mentioned was that formal caregivers never encountered informal caregivers.

Our data indicate that the lack of contact between formal and informal caregivers was largely due to the number of formal caregivers involved in the caring process. In Table 2.1, it can be seen that the different teams generally provided just one type of care. The exception is one team in Network A-5, which provided three types of care; in all other networks, a relatively large number of different formal caregivers visited the client to provide either home-making, personal care, or nursing services. Such a differentiation of tasks decreased the opportunity for individual formal and informal caregivers to meet each other.

To conclude, in Agency A both a lack of regular contact with informal caregivers, and the failure to ask informal caregivers if they needed support seemed to result from the way in which work processes were organized. Multiple subteams, a differentiation of tasks within and between teams, and an unclear distinction between the tasks of care coordinators and

those of other formal caregivers resulted in ambiguity about the responsibilities toward informal caregivers.

Agency B: combined tasks, opportunities for contact

In Agency B, the intake was done by the nurse who was expected to act as primary caregiver and who would visit the client most frequently. Depending on a client's dominant care need (either personal or nursing care), this could be either a registered nurse or auxiliary nurse. The primary caregiver was designated beforehand and carried overall responsibility for the caregiving process, which included maintaining contact with informal caregivers. Formal caregivers were care coordinators for 6-10 clients.

Table 2.1. Frequency formal-informal contact & types of formal care provided

Agency & network	Informal/formal caregivers involved	Contact*				Types of formal care delivered**
		Never	Less than once a month	Once or twice a month	Weekly	
A						
1	2/10	100%	-	-	-	h***; pc; g
2	9/11	100%	-	-	-	h; pc
3	2/9	100%	-	-	-	h; pc
4	2/10	75%	25%	-	-	pc; nc
5	3/11	50%	25%	25%	-	h; h+pc+nc
6	2/3	50%	-	-	50%	pc
B						
1	1/1	100%	-	-	-	pc+nc
2	6/9	86%	14%	-	-	pc
3	7/6	83%	17%	-	-	pc+nc
4	3/5	75%	25%	-	-	pc+nc; pc+nc+a
5	2/5	-	100%	-	-	pc
6	4/1	-	-	-	100%	pc

* Contact with 'any of the informal caregivers' in the network of the older adult

** The '+' indicates that a team combines tasks, the ';' indicates another team provides this type of help.

*** h = home-making, pc = personal care, nc = nursing care, g = guidance, a = arrangements

The lower part of Table 2.1 shows that teams of Agency B usually combined different types of care. For example, registered nurses would provide both nursing and personal care when they visited a client, which saved having to send over an auxiliary nurse for personal

care services. In other words, there was a lower level of task differentiation than in Agency A, and fewer formal caregivers. These formal caregivers had a somewhat higher level of contact with identified informal caregivers than formal caregivers in Agency A (Table 2.1). In Network B-6, there was weekly consultation with a spouse, the only informal caregiver. In Networks B-5 and B-6 all informal caregivers were consulted, although in Network B-5 such contact took place less than once a month. It was only in one Network (B-1) that informal caregivers were never consulted. Even so, care coordinators were able to provide detailed information about clients, their informal caregivers, and the care provided by informal caregivers. In response to the question whether support was offered to informal caregivers, the majority of nurses said they had done so. Some nurses also indicated that they considered contact and cooperation with informal caregivers unnecessary if the client still coordinated the caregiving process.

To conclude, in Agency B the tasks and responsibilities with regard to informal caregivers were clearly defined. By combining tasks and assigning these to one accessible care coordinator, contact with informal caregivers was enhanced, or at least established relatively easily.

2.5 Discussion and conclusion

The aim of this article was to explore whether and how the policies on informal care and the organization of work processes of home-care agencies either enhanced or hampered contact between formal and informal caregivers. Although the agencies studied had comparable views on informal caregiver involvement, our results showed slightly different levels of contact between formal and informal caregivers. We assert that these differences resulted from differences in the organization of work processes, that is, the degree of task differentiation, and the division of tasks and responsibilities held by formal caregivers.

In Agency A, we found that both ambiguity about the different responsibilities of care coordinators and other formal caregivers, and the differentiation of tasks within and between teams, hampered contact with informal caregivers. In comparison, nurses from Agency B tended to combine different tasks, which resulted in more frequent visits to a client's home, and increased the opportunity to meet and establish contact with informal caregivers.

Moreover, the responsibilities with regard to informal caregivers were more clearly defined in Agency B.

To further our understanding of these findings, and maybe offer alternative explanations, insights from organizational theory can prove useful. First, we assert that when tasks are demarcated and differentiated over different functional levels, as is generally the case in hierarchical organizations such as Agency A (Mintzberg, 1979; Shortell & Kaluzny, 2006), the need increases to specify and clearly align these tasks. Alignment refers to a state in which the organization of work processes supports the guiding principles (policy) of an agency to secure their enactment by employees (Bart & Tabone, 1998). A lack of alignment, on the contrary, thwarts the enactment of policy. This is what may have occurred in Agency A, and marked its main difference with Agency B, where work processes seemed to be better aligned with the expressed need for informal caregiver involvement.

Another cause of a policy view not being reflected in day-to-day practices is decoupling (Meyer & Rowan, 1977). Decoupling refers to a situation in which work practices are detached from organizational policy. Symbolic adoption of policy in response to external pressure and to enhance organizational legitimacy is one reason for decoupling (Meyer & Rowan, 1977; Yang et al., 2007). Another and related reason, is a lack of policy implementation by (team) managers, resulting in policy-practice decoupling (Bromley & Powell, 2012). The finding that members of Agency A were unaware that there was a policy document on informal care may be an indication of symbolic policy adoption. The ambiguous, overlapping, and often loose manner in which nurses' responsibilities were defined and divided testifies a lack of policy implementation by managers.

In some instances, care coordinators were assigned the responsibility to contact informal caregivers to a "first person responsible." This strategy was probably well-intentioned, and aimed at ensuring that there was a contact person closer to the client and informal caregivers. However, care coordinators and team managers from Agency A failed to assess the actual level of contact with informal caregivers, and mistakenly assumed that they were involved.

Previous research has shown that the presence of multiple, successive formal caregivers hinders the development of a constructive relationship with clients (Byrne et al., 2011; Forbes et al., 2008; Gjevjon, Eika, et al., 2014; Gjevjon, Romøren, Kjøs, & Hellesø, 2013). Our findings suggest that the same applies to informal caregivers: in Agency A the high level

of task differentiation resulted in a “succession of strangers” (Aronson, 2004) and decreased the chance of formal and informal caregivers meeting each other. In contrast, formal caregivers from Agency B had a lower caseload, which made them more accessible to informal caregivers who could contact them (Black & Fauske, 2007; Dalby & Hirdes, 2008).

Although contact at the beginning of the caregiving process seems to be important, our respondents noted that the need for contact was less if the demand for care was relatively stable, or if clients coordinated caregiving themselves. Guidelines could specify in which situation contact between formal and informal caregivers is indispensable, for instance, at the beginning of the caregiving process, if changes occur in the caregiving situation, or when clients lose the ability to make arrangements themselves. Accessibility to and clarity about who serves as the contact person in the agency is essential at all times though (Jorgensen, Arksey, Parsons, & Jacobs, 2009).

In line with earlier research, our results show that nurses acknowledge the importance of caregiver involvement, but that agencies’ policy and work processes may center around caregiving to clients (Coyne et al., 2011) – for which there is little time as it is due to budget cuts, while no extra time is available for involving and supporting informal caregivers. Another noteworthy point is that nurses sometimes fear de-professionalization of their work, because tasks appear to be rather easily assigned to nonprofessional caregivers. In addition, nurses tend to worry about the quality of care given by caregivers (Da Roit, 2013), and may have doubts about who is responsible and accountable for the quality of informal care.

The two agencies we studied are representative for the types of agencies that are currently prevalent in The Netherlands. Being based on multiple perspectives within each agency, our findings are well-founded in the case studies. Nonetheless, our small sample size implicates that the results should be interpreted with some caution. Future research could include more agencies to see whether the differences found in this exploratory study hold. Also, we interviewed our respondents at only one moment in time, while caregiving networks are dynamic, because of changing care needs, and the presence of informal caregivers (Kietzman, Benjamin, & Matthias, 2008; Ryan et al., 2013). During our interviews, some care coordinators realized they had had little or no contact with informal caregivers. Longitudinal research would reveal whether this awareness resulted in more frequent contact with informal caregivers.

Our findings result in the following recommendations. At the (Dutch) national government level, a greater degree of formalization of roles and responsibilities in policy on informal caregivers could form a guideline for agencies to integrate informal caregiver involvement in their policy and work processes. Formalization also allows for the inclusion of “informal caregiver involvement and support” as a dimension of quality of care assessments. The latter are currently being reassessed in light of government policy development in many Western (European) countries (Leichsenring & Nies, 2012). Besides, time could be allocated to agencies for involvement of informal caregivers.

To enhance informal caregiver involvement, and in line with insights from other (long-term) care settings (Johnson, 2000; Reinhard, Given, Petlick, & Bemis, 2008), we recommend agencies to concentrate on developing a shared view on the involvement and support of informal caregivers that clearly specifies different roles and responsibilities for formal and informal caregivers. One responsibility would be for care coordinators, informal caregivers, and the client to develop a care plan together which describes, among others, the division of tasks between formal and informal caregivers, and mutual expectations regarding communication and support. Regular reassessment of the care plan will stimulate keeping in contact with informal caregivers, as well as providing an opportunity to assess the functioning of informal caregivers and their potential need for support. Managers should implement this view by organizing time and space accordingly.

To conclude, the present study has contributed to the understanding of the different characteristics of agencies that either enhance or hamper contact between formal and informal caregivers in home-care settings. In view of current policy developments in many Western countries, our insights are relevant for agencies in those countries where formal and informal caregivers provide home-care together, and where agencies have to respond to the needs of informal caregivers as well.