

ORIGINAL ARTICLE

WILEY

Health and
Social Care in the community

You never walk alone: An exploratory study of the needs and burden of an informal care group

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Abstract

Little is known about the dynamics of a group of people giving informal care together. The aim of this study was to investigate the characteristics of an informal care group, the obstacles the informal care group experiences, the needs and desires they have and how the informal care group can be supported by general practitioners (GPs) and other professionals. Nine informal care groups were interviewed based on a questionnaire that was preapproved by the six Flemish official informal caregiver organisations. The results were analysed using open coding. A survey was conducted among 137 caregivers who were part of a group. Univariate analysis was performed. Informal care group usually consist of close relatives of the patient, with often the partner of the patient as the main caregiver. The size of the informal care group depends on the size of the family. If there are more caregivers in a group, the perceived burden of the individual caregiver decreases. The support of the other caregivers in the group increases capacity. The cooperation and agreements are often spontaneously organised and few problems are reported. There is a large variation in the expectations of support from the general practitioner, ranging from availability in emergencies to information about the possibilities of formal home care. This study depicts a positive image of the informal care group. Being part of a caregiver group both decreases burden and increases capacity. Informal care groups usually function well without a need for formal agreements within the group, and they rarely need a third party to coordinate with them or intervene.

KEYWORDS

caregiver burden, carers, psychological well-being, support

1 | INTRODUCTION

Although there are numerous studies about informal caregiving the informal care group is relatively unknown in literature. Informal care groups represent a new dimension in caregiving, in which the burden of care is shared with several informal caregivers. The “informal care group” can be defined as follows: “a group of two or more persons who together provide informal care to a dependent person, beyond the scope of professional care or organised

volunteering, but as members of the immediate vicinity of the dependent.” Sharing care is a social trend that becomes inevitable due to ageing population and limited places in nursing homes. It has become a possibility thanks to policy initiatives to encourage and professionalise family caregiving sharing informal caregiving has important advantages. Since caring puts a high psychosocial, physical and economic burden on the involved caregiver, sharing caregiving task might deliver benefits or relief pressure. Individuals sharing care in an informal care group need less time to fulfil specific caregiver tasks and have more time to cope with external stressors and to participate in social and professional life (occupation,

Abbreviations: GP, general practitioner; QUAGOL, Qualitative Analysis Guide of Leuven.

household, family and social life, personal health issues). It is important that informal caregivers invest in their own social network, thus increasing personal strength and resilience. In addition, caregivers in group receive support from each other, which strengthens their self-efficacy (De Koker & Jacobs, 2008). Research on the determinants of care load in Flemish informal caregivers showed that the presence of other informal caregivers is inversely associated with caregiver burden. Assistance of professionals or volunteers has little or no impact on experienced burden (De Koker & Jacobs, 2008). This also indicates a higher psychosocial well-being of the older care recipient. However, caregiving implements decision-making and different personal values and beliefs within an informal care group can cause emotional friction (Deltour, 1999). Moreover, the involvement of more caregivers (formal or informal) may also be a source of conflict. The adherence of each caregiver to caring responsibilities varies and dissatisfaction about the allocation of caregiver tasks may occur. Finally, interests and values may also substantially differ among caregivers. Good functioning and communication in the informal care group is needed to take on the all the aspects and responsibilities of informal care, to conduct the informal care tasks adequately and to maximise the members' psychosocial well-being. Generally, it can be assumed that individual informal caregivers of informal care groups reporting high levels of cohesion, expressiveness, communication and problem solving skills, will report lower levels of psychosocial problems. The aim of this study was to analyse the characteristics of an informal care group, the obstacles the caring group experiences, the needs and desires the group has and the ways informal caregivers can be supported by general practitioners (GPs) and other professionals.

2 | MATERIALS AND METHODS

2.1 | Design and outcome measures

This field study consisted of a quantitative and a qualitative component. In the qualitative part of this study, in-depth interviews were conducted in the presence of all members of the informal care group. A questionnaire, validated by the six officially recognised Flemish informal care organisations, was used as guide for these in-depth interviews.

The descriptive quantitative research involved a short survey with four short questions identifying the informal care group, a question about the expectations of the GP and seven statements with answer possibilities on a Likert scale. The questions and statements of the survey can be found in Table 1. To achieve a high response rate, the questionnaire was deliberately kept brief and distributed online through the newsletters of informal care organisations and through social media. Paper surveys were distributed to GP practices, local service centres, home nursing organisations and social workers.

The outcome measures for both components of this field study were: (a) identity of the informal care group; (b) insights in the organisation of the informal care group and the cooperation with professionals;

What is known about this topic

- The informal care group is relatively unknown in literature.
- Informal care groups represent a new dimension in caregiving, in which the burden of care is shared with several informal caregivers.
- Sharing care is a social trend that becomes inevitable due to ageing population and limited places in nursing homes.

What this paper adds

- The results of this exploratory study provide a very positive picture of informal care groups.
- Informal caregiving as a group not only reduces the burden by sharing the care, but also creates opportunities through sharing expertise, supporting each other and shared decision-making.

TABLE 1 Questions and statements of the short informal care in Group Survey

Identification of the informal care group
<ul style="list-style-type: none">• What is the condition or illness of the person you care for?• What is the relationship between you and the person you care for?• What is the number of informal caregivers of your informal care group?• What type of tasks do you carry out within your informal care group?
Expectations of the general practitioner (GP)
What are your expectations of the GP?
Statements of informal care in group (5-point Likert scale: absolutely agree, agree, disagree, absolutely disagree)
<ul style="list-style-type: none">• The whole informal care group is well aware of the recent changes in the health status and/or treatment of the patient.• There are clear agreements on the division of caregiving tasks within the informal care group.• The division of caregiving tasks is fair.• Informal caregiving in group creates more stress.• We find support in each other.• Our informal care group grew closer together by the caregiving tasks.• Informal caregiving in group primarily provides discussion on financial matters.

(c) benefits and disadvantages of informal care groups; and (d) expectations of the informal care group regarding their GP.

2.2 | Population

Because of the explorative character of this study, the broadest possible study population was chosen. This means that there were

a limited number of inclusion criteria and the groups were mainly recruited on the basis of the definition of informal care group in the Introduction section. The sample consisted of Dutch-speaking Flemish informal care groups. Informal caregivers who operated solely or in a professional or voluntary context, were excluded. The informal care groups were approached and recruited by local caregiver organisations, local service centres, social workers and home nurses to reach a representative sample.

2.3 | Analysis

The interviews were recorded with informed consent of each participant. After verbatim transcription of the interviews, the analysis was performed according to the QUAGOL method (Qualitative Analysis Guide of Leuven, Dierckx De Casterlé, Gastmans, Bryon, & Denier, 2011). Each interview was read several times and described in a narrative report. From these narrative reports, a conceptual scheme was constructed, which was re-examined in the interviews. Next, the interviews were coded and a code tree was developed of the conceptual scheme, which was again re-examined.

The online surveys (quantitative component) were exported to a spreadsheet and the paper surveys were manually imported into the same spreadsheet. The data were standardised to perform univariate analysis using Excel.

2.4 | Ethical board

The Ethics Committee of the K.U. Leuven and U.Z. Leuven granted formal permission for this study on 30 November 2015. Each caregiver signed a written informed consent and the Ethics Committee acknowledged that the study is carried out according to the prevailing ethical standards.

3 | RESULTS

The following report is a description of the data resulting from the interviews, supplemented with quantitative data from the surveys. Population characteristics are presented in Tables 2 and 3.

3.1 | Population

A total of 137 survey respondents were reached (see Table 2), of whom 72 (52.55%) responded online, and 65 (47.45%) through paper surveys. The largest group of these respondents of the survey were informal caregivers for an older patient with multimorbidity (31.40%) or for a patient with dementia (27.74%). Other groups provided help for a patient with Parkinson's disease, cancer, a history of stroke or a birth defect. Almost half of the participating caregivers were children of the care recipient (47.45%) and nearly 30% of respondents were partners. Most informal care groups consisted of only two caregivers (45.26%), 41.61% of the groups consisted of three or four caregivers and 13.14% of caregivers were a group of five or more

TABLE 2 Characteristics of the interviewed informal care groups

(Co)morbidities of the patient	Composition of the informal care group
<ul style="list-style-type: none"> Terminal cancer, stoma or intestinal problems Stroke with hemiplegia (2x) Ageing with multimorbidity (2x) Terminal dementia, bedridden and not-responsive Parkinson with multimorbidity Older couple with multimorbidity and dementia Mental and functional disabilities 	<ul style="list-style-type: none"> Two children Partner and patient's sister Partner as main informal caregiver and patient's two sisters in law Five children and their partners Partner as main informal caregiver, daughter and granddaughter, to a lesser extent patient's son in law and neighbours Partner as main informal caregiver and three children Parents of the patient Four children Seven children

TABLE 3 Characteristics of the respondents of the survey

A. (Co)morbidities of the patient		
Ageing and multimorbidity	31.39%	N = 137
Dementia	27.74%	
Stroke	8.03%	
Cancer	8.03%	
Child with birth defects	5.11%	
Parkinson	4.38%	
Others	15.33%	
B. Relationship with the patient		
Child	47.45%	N = 137
Partner	29.20%	
Other family member	9.49%	
Parent	6.57%	
Brother or sister	4.38%	
Not family (friends, neighbours)	2.92%	
C. Age of the informal caregiver		
20–29 years	3.03%	N = 132
30–39 years	8.33%	
40–49 years	9.85%	
50–59 years	34.85%	
60–69 years	21.97%	
70–79 years	9.85%	
80 years and older	12.12%	
D. Size of the informal care group		
2	45.26%	N = 137
3	29.93%	
4	11.68%	
5	6.57%	
6	2.92%	
>6	3.65%	

persons. In 84.67% of cases, one of the caregivers was a spouse or a first degree relative of the patient.

3.2 | Identity of the informal care group

To identify the characteristics of the informal care group, nine in-depth interviews were conducted within a wide variety of informal care groups. Most care recipients were older persons with disorders such as a previous stroke, Alzheimer's disease and Parkinson's disease. In some cases, there was an increased need of care due to multimorbidity. Two interviews involved a terminally ill patient. In one interview, the patient was a son with multiple disabilities.

The members of the informal care group were mainly close relatives. If the care recipient had a partner, this person was the main caregiver, responsible for most of the tasks. The informal care groups ranged in size from two to seven people. The burden experienced by the various caregivers was inversely correlated with the size of the group, unless a main caregiver was present. The absence of a partner as main caregiver was experienced as a serious disadvantage by the informal care group.

Most of the interviewed caregivers considered themselves in good physical and mental health condition. Caregivers with a poorer health condition experienced more burden. In these care-burdened situations, other caregivers were involved in caregiving tasks. Nearly all participants reported emotional burden. Reversal of the parent-child relationship was experienced as a stressful situation in two informal care groups. Other caregivers experienced difficulties in combining caregiving tasks with their own household and family life. "Yes, when I come home my child is crying, because I wasn't there during the evening. Combining care with my private life is very hard."—"I think I react quite drastically in that respect. Maybe too drastically. My mother is ill, and all the rest comes second, actually."—Caregiving daughter of an older patient with cancer.

Because of feelings of guilt, caregivers find it difficult to distance themselves from the tasks. The patient's character also plays a role in caregiver burden. Informal care was perceived as more burdensome when the patient needed more attention or showed less gratitude.

3.3 | Organisation

If the patient had a cohabiting partner, most caregiving tasks were provided by this caregiver. The social-emotional support of the patient was almost exclusively borne by the partner and was only occasionally shared by the children. In situations where all caregivers were children of the patient, more formal agreements on care were made. The following quote confirms the importance of a partner as the main caregiver: "It is difficult that she has no partner. You can see that in other couples, when one partner is becoming frail, there is still the partner who can take care of them."—Caregiving daughter of an older patient with cancer.

The allocation of tasks among the caregivers often developed organically with increasing patient care needs. In most cases, there were no formal agreements. Although caregivers all had their own tasks, all of them reported a high degree of flexibility, overlap in

tasks and frequent changes in task distribution. In one informal care group, the tasks were documented: "And A. makes a schedule of where he is going to eat and when he goes to a club. We all get a monthly update of this schedule."—Caregiving daughter of an older patient with multimorbidity.

Sharing caregiving tasks depended on the physical distance between the patient and caregiver residency. Household chores were usually taken on by one caregiver while personal care and socioemotional support were more likely to be shared. In two informal care groups, one of the members was a nurse, which had a positive impact on the group's caring ability, as confirmed by the following quote: "In the afternoon, I had to wash him and if I wondered how to treat the wounds, I just called my granddaughter and she explained what to do. Because of this support, I don't feel alone. It's very convenient that my granddaughter is a nurse."—Caregiving partner of a demented patient in a terminal phase.

Communication about sharing of caregiving tasks often occurred in direct conversations, and spontaneously at family gatherings. Almost 90% of respondents indicated that everyone was well-informed about changes in the health status and well-being of the patient. Barriers to call each other were low. With increasing care needs, the need for more formal agreements arises. Some informal care groups organised meetings to agree on important decisions regarding the care provision. Some examples that were mentioned in the context of these specific meetings were DNR (do not resuscitate) policy, transfer to a nursing home and renovations in the patient's house.

3.4 | Collaboration with professionals

Family help and cleaning services substantially reduced the burden of work of the main caregiver. Day and night respite centres were also mentioned as a valuable alternative of support of the informal care group. Long waiting lists were a main issue. The advisory role and expertise of home care nurses and palliative support teams were highly appreciated.

Frequent staff changes contributed to a negative attitude towards home services. In addition, many informal caregivers reported loss of freedom and control over care once professionals were involved. Professionals, such as home care nurses, sometimes showed up at "an inappropriate moment" or adhered to a tight timetable. Informal caregivers attached great value to the flexibility of support services: "At six o'clock in the morning, they are there to take care of my wife. I don't see Mom getting up at six! I know those people need to do their job. They should adapt... but it is better when you have kids, then you get some help from them."—Caregiving partner of a patient with Parkinson.

Other informal caregivers found professional services unreliable and insufficiently available because there was no replacement in case of absence. Finally, some informal caregivers experienced the intervention of professional help as a personal failure: "For older people this is a little bit... It's the pride, because you have always done it on your own."—Caregiving partner of a demented patient in a terminal phase.

3.5 | Collaboration with the GP

Many informal caregivers indicated that GPs play only a limited role in coordinating care. According to some informal caregivers, GPs should organise meetings with other professionals. Informal caregivers felt that GPs are well positioned to encourage patients to expand professional home care. Some informal care groups expected GPs to explore and prepare the care pathway. However, other groups indicated that this was not a GP's task. Furthermore, informal caregivers stated that flexibility, responsiveness and availability are important characteristics of a GP. Finally, the interviewed informal caregivers appreciated the clear communication with the GPs. GPs were expected to involve the informal care group in decision-making.

Also in the surveys, the majority of informal caregivers (81.75%) indicated that the GP mainly had a coordinating role. Three-quarters (75.91%) would like the GP to give them information about home-care services. One-fifth of all informal caregivers (20.44%) indicated they had no expectations of the GP.

3.6 | Benefits and challenges

The practical benefits of caregiving in a group are evident: sharing the workload and relieving the main caregiver's burden: "The great value of care in a group is that the workload is shared more."—Caregiving father of a disabled patient.

The combination of the caring task with the carer's own family and social life remained feasible. In most situations, there is a high level of flexibility among informal caregivers: "Yes, you ask more directly for help; I wouldn't doubt to call them out of bed, with friends I wouldn't dare."—Caregiving partner of demented patient in a terminal phase.

Each member of the informal care group also brought along own expertise: financial and administrative affairs, medical knowledge or skills in caring. Informal caregivers appreciated the mutual psychosocial support of each other. They could discuss with each other, share the emotional burden and responsibility. Informal caregivers also encouraged each other to self-care. "She comes here, she goes to sleep at home and she comes back here. But then I say no, do not struggle, go out and have some fun."—Caregiving daughter of a patient with cancer.

In some informal care groups conflicts arose: "But in the beginning it gave some problems. Because she actually expected me to do the same as what she did."—Caregiving daughter of a patient with cancer.

With this statement, the informal caregiver reported that a fellow caregiver provided care very intensively at the expense of herself. There appeared to be more conflicts in situations with higher care burden. Different personal characters or viewpoints on the caregiving context between informal caregivers can indeed cause conflicts. Sometimes caregivers reported resentment about an imbalance in the distribution of tasks. Occasionally there was a larger conflict but in most situations, collaboration was constructive: "There are four of us and three want to take care of them and we want to leave

everything as it is now: cleaning help, family help, someone to cook, and so on. But our eldest brother sees things differently; it is a difficult situation for us."—Caregiving daughter of an older patient with multimorbidity.

In informal care groups who had formed a close network before caregiving began, collaboration was better. Other informal caregivers indicated that they became closer by the caregiving tasks. Based on this study, larger informal groups were not experiencing more problems, comparing to small informal care groups. A larger number of members of the informal care group was not correlated with more problems in this study. On the contrary, a larger informal care group reduced the burden when collaboration was good: "Whether you are ten or two, it is both just as bad if you don't agree."—Caregiving granddaughter of a demented patient.

Almost all caregivers reported that disagreement or conflicts were usually resolved quickly. Each care group had its own system to deal with conflict issues. In some care groups, the final decision or input was left to the patient or the main caregiver. Other groups left the final decision to the caregiver with the most expertise in a certain domain or context. Communication in most groups was good, with most groups providing opportunities for discussion and mutual deliberation. In one group, there was disagreement on sharing the care responsibilities and on the use of the care benefit.

3.7 | Additional responses

Based on the responses on the statements in the survey, the participants of this study clearly agreed that the whole group was well-informed about the health status and treatment of the patient: 89.70% of the respondents answered with "I absolutely agree" or "I agree" (Table 4). Clear agreements on task sharing were reported in 81.34% of the participants. More than three-quarters (76.12%) believed the sharing of tasks was fair. Only 6.72% totally disagreed with this statement. Caregiving as a group did not cause more stress in 68.66% of the informal caregivers. Moreover, 87.40% of the members of the informal care group found mutual support with each other. The informal care group was reported to have become closer by the caregiving situation by 72.18% of the caregivers. Only a minority (10.45%) indicated that caregiving as a group led to discussions about financial matters.

4 | DISCUSSION

Our results showed that the informal care group often consists of the immediate family of the patient. Most informal care groups consist of two to four persons. Family and informal caregiving groups have the advantage that the members know each other well and can thus interact more easily. They often come together on informal occasions, such as family parties. This improves communication about the care situation.

The literature shows that the support of family members in particular and, to a lesser extent, the support of friends positively

TABLE 4 Responses to the statements of the survey

How is informal caregiving in group experienced?	Number of respondents (Percentage %)				
Statements	Absolutely agree	Agree	Disagree	Absolutely disagree	Total
1. The whole informal care group is well aware of the recent changes in the health status and/or treatment of the patient	82 (60.29)	40 (29.41)	13 (9.56)	1 (0.74)	136 (100.00)
2. There are clear agreements on the division of caregiving tasks within the informal care group	61 (45.52)	48 (35.82)	18 (13.43)	7 (5.22)	134 (100.00)
3. The division of caregiving tasks is fair.	49 (36.57)	53 (39.55)	23 (17.15)	9 (6.72)	134 (100.00)
4. Informal caregiving in group creates more stress	16 (11.94)	26 (19.40)	51 (38.06)	41 (30.60)	134 (100.00)
5. We find support in each other	60 (44.44)	58 (42.96)	10 (7.41)	7 (5.19)	135 (100.00)
6. Our informal care group grew closer together by the caregiving tasks	44 (33.08)	52 (39.10)	25 (18.80)	12 (9.02)	133 (100.00)
7. Informal caregiving in group primarily provides discussion on financial matters	6 (4.48)	8 (5.97)	44 (32.84)	76 (56.72)	134 (100.00)

contribute to the experienced self-efficacy of informal caregivers. Family members often share the same values and background as the other informal caregivers and are more aware of the prevailing relations. Consequently, their support is more meaningful for informal caregivers (Shirai, Silverberg Koerner, & Baete Kenyon, 2009).

Informal caregivers who are part of a group mentally support each other, slow each other down if needed and encourage self-care where appropriate. The motivation to take up the caregiver role is different for each informal caregiver and in each situation. A sense of duty sometimes constitutes a significant motive for informal care. Children who care for their parents when they become dependent usually experience two ambivalent principles. First, there is the deferred reciprocity whereby the informal caregiver sees his care as a moral duty. The intensity of care is therefore often in proportion to the quality of the relationship. The quality of the parent–child relationship additionally affects the perceived burden of children who take care of their parents (Daire, 2002). Second, there is the principle of solidarity between generations. Taking care of close family members is then taken for granted, without any consideration expected (Jacobs & Lodewijckx, 2004).

Partners of dependent relatives experience a greater burden in care (Broese van Groenou, de Boer, & Iedema, 2013). In informal care groups where no spouse is available as main caregiver, their absence is perceived as a great loss. The spouse in the informal care group usually takes on the major part of care tasks.

Caregiving brought most informal care groups closer together. Because care is provided on a regular basis, there is a regular contact between caregiver and patient, but also amongst the informal caregivers themselves, which enhances friendships and family bonds.

The collaboration in informal caregiving is usually very good: communication occurs spontaneously and the threshold to contact each other is low. An informal care group sometimes meets particularly to discuss specific problems. Task sharing usually develops spontaneously, depending on individual informal caregivers' expertise. Most informal caregivers have their regular job responsibilities, but there is great flexibility in the groups. Appointments are generally not formalised or recorded in written form because this does not add to proper group functioning. Formal ways of sharing of tasks and workload are probably more useful when problems arise in task allocation or when more intensive care is needed, such as permanent patient supervision.

If one of the members of the informal care group is (professionally) specialised in care provision, this is experienced as an important advantage for the group's self-efficacy. These group members have expertise and skills for which other informal care groups need to rely on professionals.

Disagreements occur but are usually resolved through open and direct communication. One explanation for this may be that families who had already been close before caring started, more easily proceed to shared caregiving. Another hypothesis is that informal caregivers are restrained in their statements about conflicts or friction due to the presence of other group members. In the survey, up to a quarter of respondents indicated that task sharing in their caregiving situation was not fair and that the group had not been strengthened by the caregiving situation.

In this study, no clear hierarchy in informal care groups could be demonstrated. Decisions are usually made after group consultation, and the final decision addressing issues or problems is most of the time made by other persons such as the GP.

Sometimes the caregiver with the most expertise of a certain situation takes a decision and sometimes it is the patient or main informal caregiver.

Difficulties informal care groups experienced in collaboration with professionals are similar to those experienced by individual informal caregivers. The lack of flexibility of professionals and handing over control complicate the situation for both patient and informal caregivers.

Informal caregivers vary widely with regard to their expectations towards GPs. Some feel that the GP, besides being accessible in case of emergency and providing good patient care, has no other role in the care situation. Others want the GP to guide them through the care pathway, including all financial and psychosocial support systems. Almost all informal caregivers believe it is important that GPs answer their concerns and that GPs keep them informed of the patient's health status. If the patient is reluctant to accept professional help, informal caregivers believe that the GP has a role in convincing the patient to accept (more or other) home care. Moreover, GPs are expected anticipate the increasing care need and prepare patient and informal caregivers for the need for professional home care in the long term.

Increasing elderly population, shortage of residential availability and shortened length of hospital stays put more stress on home care. It is therefore necessary that informal caregivers, where possible, are adequately supported. GPs are often well positioned to play a role in organising informal and formal care. However, the question remains if informing caregivers about home care is a task that can and should be taken up by GPs.

4.1 | Strengths and weaknesses

The interviews were conducted in-depth, but on a small scale. Nine interviews were conducted with very diverse informal care groups. However, with this small sample, it is likely that some information was missed and that the sample was not representative enough.

We tried to interview all caregivers of one particular informal care group together, so it is plausible that there was some reluctance to mention conflicts or problems in the group. To focus on the disadvantages of informal care groups, individual in-depth interviews could be more useful because they are perceived as less threatening. This seems to be confirmed by the surveys that have been conducted individually and anonymously, some negative points on care collaboration were revealed.

The surveys included open questions of which the answers needed to be labelled and reduced into categories by interpretation of the researchers. Although this process was elaborated following a standardised model and procedure, there will always be a certain loss of information. For example, an open question was: "What do you expect from the GP regarding care?" The answers to this question seemed to be driven by what informal caregivers were missing in collaboration with their own GP, so expectations and needs that were already met, were not explicitly mentioned. This explains the high number of respondents who did not have any particular expectations of their GP.

The survey statement "care in group creates more stress" did not explicitly compare group caring to caring as an individual. Therefore, this statement could be interpreted as "Informal care creates stress" with the emphasis on care and not on care conditions (group or alone).

5 | CONCLUSION

In a scientific area where specific research about informal care in group is lacking and more extensive research is needed, the results of this exploratory study provide a very positive picture of informal care groups. Informal caregiving as a group not only reduces the burden by sharing the care but also creates opportunities through sharing expertise, supporting each other and shared decision-making. Sharing care in a small informal group can significantly lower the care burden of patient's partner. Informal care groups generally function well and seem to survive without external coordination or support. Although further and more extensive research is recommended to gain more insight in the well-being of informal care groups with an analysis of both positive and negative aspects, this study shows that caregiving in group for a dependent relative greatly reduces the burden of care in the current healthcare context.

ACKNOWLEDGEMENTS

All authors contributed in a proportionate way to the research and the written report. We are grateful to the caregivers to participate in this study.

DECLARATIONS

Ethics approval and consent to participate: The Ethics Committee of the K.U. Leuven and U.Z. Leuven granted formal permission for this study on 30 November 2015. Each caregiver signed a written informed consent and the Ethics Committee acknowledged that the study is carried out according to the prevailing ethical standards.

Consent for publication: All participants were informed about the use of data for analyses, further research and publication. All data were anonymously processed and analysed.

Availability of data and material: available on request, delivered by www.wetransfer.com

AUTHORS' CONTRIBUTIONS

LE and AV developed the study design, carried out the in-depth interviews, distributed the surveys, analysed and interpreted the results and wrote the original paper with support of LJ and BS. The paper was rewritten into an article by LJ and finally revised by BS. All authors read and approved the final manuscript.

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How to cite this article: Jansen L, Eecloo L, Vanwing A, Schoenmakers B. You never walk alone: An exploratory study of the needs and burden of an informal care group. *Health Soc Care Community*. 2018;00:1–8. <https://doi.org/10.1111/hsc.12655>