

Supporting an informal care group – Social contacts and communication as important aspects in the psychosocial well-being of informal caregivers of older patients in Belgium

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Abstract

Background: Increasingly, informal caregivers in Belgium care in group for an older patient. This study aimed to decrease the caregiver burden and to increase the well-being of caregivers and patients by supporting the needs of informal care groups of older patients (≥ 70 years).

Method: Through an online self-management tool, the groups were supported to make informed choices concerning the care for the older patient, taking into account the standards, values, concerns and needs of every caregiver and patient. A pre-post study was performed.

Results: Although patients and caregivers considered the self-management tool as useful and supportive, no clear evidence for decreased caregiver burden was found. There was a positive trend in group characteristics such as the distribution of tasks, communication and prevalence of conflicts. Caregivers also stated that they took more time for themselves, had less feelings of guilt and experienced less barriers to ask help.

Conclusion: Tailor-made support of informal care groups starts with facilitating and guiding a process to achieve consent within the group to optimise the care for the patient and also for the caregivers. With a shared vision and supported decisions, caregivers can enter into conversations with the professional caregiver to coordinate adjusted support regarding the care needs.

KEYWORDS

aged, caregivers, informal care, online intervention, primary care, psychosocial factors, support

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1 | BACKGROUND

The ageing of the Belgian population is resulting in a higher number of chronic diseases and multimorbidity. Current healthcare is going through a transition due to both an ageing population with an accompanied higher number of chronic diseases and multimorbidity, and important socio-demographic changes like a decreased intergenerational cohabitation, an increased geographical distance between adult children and their older parents, an increased number of professionally working women and a higher retirement age (Spillman & Pezzin, 2000; Vanderleyden & Moons, 2015a, 2015b). This transition requires an adjusted healthcare approach and paradigms. Increased involvement of the patient and more responsibility of the informal caregiver are required. Increasingly, informal caregivers are taking care of a patient in collaboration with other informal caregivers. Although little research has been done on informal care in groups, Broese van Groenou et al. already in 2009 found that only one-third of the informal caregivers received no help from other informal caregivers (Broese van Groenou, 2009). This was confirmed in a Flemish study (Vanderleyden & Moons, 2012), where 70% of the patients received help from more than one caregiver.

We defined an 'informal care group' as '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' (Jansen et al., 2018). The different members, like family members, friends or neighbours, contribute to the care process in an equitable but non-proportional manner. The dynamics in an informal care group are different from those in a family where one central informal caregiver is responsible for the care of the dependent relative: each individual of the informal care group has their own values and standards and behind every caregiver, there is also a partner and/or children who influence the care motivations and accountability. In other words, it is not only important to what extent and in which way individual members of the informal care group contribute to the care of the patient, but also the concerns and needs of everyone should be considered in the follow-up of the patient's care.

Sharing informal caregiving has important advantages. Individuals of the 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, household, family and social life, personal health issues). Also, caregivers in group receive support from each other, which strengthens their self-efficacy (De Koker & Jacobs, 2008; Jacobs & Lodewijckx, 2004; Jansen et al., 2018). Research on the determinants of care load in Flemish informal caregivers showed that the presence of other (in)formal caregivers is inversely associated with caregiver burden (Jacobs & Lodewijckx, 2004). However, the involvement of more caregivers (formal or informal) might 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.

What is known about this topic

- Increasingly more caregivers care in group for an older patient
- In informal care groups, caregivers contribute to the care process in an equitable but non-proportional manner
- These groups have specific support needs, like communication skills and tailor-made interventions in order to provide good care

What this paper adds

- The well-being of caregivers is highly individualised, depending on the well-being of both caregiver and patient and the functioning of the informal care group
- Caregivers do not need new support but more visibility, accessibility and guidance to the available support systems
- Tailor-made support starts with facilitating and guiding a process to achieve consent within the group to optimise the care

Caregivers caring in group have other support needs than the individual caregiver, like communication skills and tailor-made interventions in order to provide good care for the older patient. This study aimed to support the needs of informal care groups of older patients (≥ 70 years). We focused on their needs, aimed to decrease the caregiver burden and increase the well-being of both older patient and caregivers. Therefore, we developed and implemented a tool to support decision making, adjusted to the needs, norms and values of informal care groups.

2 | OBJECTIVES

2.1 | Primary objective

- To determine the effect of tailor-made support for informal care groups of older patients (≥ 70 years) on the psychosocial well-being of patient and caregivers.

2.2 | Secondary objectives

- To determine the met and unmet needs of informal care groups.
- To determine characteristics of informal care groups and to evaluate the impact of these characteristics on the psycho-social well-being of both older patient and caregivers.
- To determine prognostic factors of the caregiver burden and depression in informal care groups.

2.3 | Measurement outcomes

The primary outcome in this study was the psychosocial well-being of the informal caregivers, measured by the caregiver burden and experienced depressive complaints.

Secondary outcomes were the met and unmet needs and the characteristics of informal care groups. Anxiety, feelings of guilt, self-care and asking for support were additional outcomes on the psychosocial well-being of informal caregiver. The characteristics of the informal care group comprised:

- Socio-demographic characteristics: e.g. age, living conditions, education and ethnicity
- Physical well-being: e.g. visits to the general practitioner (GP) and use of (prescribed and over-the-counter medicine or nonprescription medicine [OTC]) medication
- Caregiving information: composition and functioning of the informal care group, division of tasks, communication, group cohesion and dynamics
- Psychosocial and physical well-being of the patient: e.g. feelings of anxiety, depressive complaints, loneliness, daily functioning, subjective health evaluation, visits to the GP and use of (prescribed and OTC) medication

3 | METHODS & DESIGN

3.1 | Study design

The study had a before-and-after design and the tailored support was available for every informal care group. The study was considered as a practice improvement project and implemented in the existing care context. Therefore, no control group was included in this study. The intervention started from the available support, strengthened by means of a self-management tool, the 'Keuzewijzer'.

The study took place between September 2018 and May 2019, individuals from the participating informal care groups and the older patients were questioned within 1 month after inclusion (baseline) and after 6 months. The intervention took place after finishing the baseline questionnaire by the informal caregivers and older patient.

3.2 | Study population

3.2.1 | Study population definition

In this study, older patients were included together with their informal care groups. These patients were 70 years or older and lived independently at home, and not in a residential care centre, in the Leuven region in the Flemish part of Belgium. The informal care groups consisted of two or more relatives, friends or neighbours

caring for the older patient, beyond the scope of professional care or organised volunteering. There was no age restriction for the informal caregivers.

3.2.2 | Inclusion and exclusion criteria

Both the older patient and the informal caregiver gave their written consent after being informed. Only patients aged 70 years or older and their informal caregivers who have a thorough command of Dutch were included. Older patients with a formal diagnosis of dementia, too ill to participate or in a palliative phase were excluded, because of the inability to fill in a questionnaire and to participate in the intervention.

3.2.3 | Recruitment

The older patients and their informal caregivers were recruited in cooperation with an independent home care organisation in the region of Leuven. The informal care groups were contacted by the regional manager of the home care organisation, who was also their contact person. After permission of the patient, the researchers contacted the informal care group to ask for participation and to plan an introduction conversation with the informal care group including the older patient.

3.3 | Intervention

The intervention started from the available support, strengthened by means of a self-management tool, the 'Keuzewijzer'. This online tool supports informal care group members to make informed choices concerning the care for the older patient, taking into account the standards, values, concerns and needs of every informal caregiver and older patient (Deltour, 1999). The 'Keuzewijzer' consisted of a questionnaire based on ten life domains of the patient (living environment, physical well-being, nutrition, mobility, personal hygiene, medication, psychosocial well-being, social life, administration and finances, intimacy), asking what the individual value, importance, needs and objectives are for these domains. The intervention primarily aims to develop a care planning focused on the older patients with a clear distribution of tasks. The second purpose is to stimulate the communication between the informal caregivers and the older patient, allowing timely adjustments in the care planning and preventing for caregiver burden.

During an introduction conversation, the dual purpose of the study was explained to the informal care group. On the one hand, the psychosocial well-being of the informal caregivers and the older patient was mapped by means of the personal interviews. On the other hand, tailored support was offered through the intervention. Afterwards, both the individual members of the informal care group and the older patient completed the online self-management

tool individually. The tool consisted of questions about their needs, values and standards on ten important life domains (e.g. personal hygiene, mobility, food, mental well-being, intimacy) of the older patient. After completing the 'Keuzewijzer, the participants got an overview of advice and referrals. Hereby, the informal care group gained insight into the available support in response to their needs, concerns, values and standards. Direct contact could be made with the organisations involved and the tailored support could be started. After the intervention, the informal care group was offered a final conversation (6 months), in which the effect of the intervention was discussed and the intervention itself was evaluated.

3.4 | Data collection

3.4.1 | Baseline data collection

After signing the informed consent, the informal care groups and the older patients were questioned individually through a web survey. When a caregiver or older patient was unable to complete the questionnaire online, a paper version was offered.

Both informal caregivers and older patients were asked about socio-demographic characteristics, like age, living conditions, educational level and ethnicity. The physical well-being of the informal caregivers comprised of their subjective health evaluation, visits to the GP and use of (prescribed and OTC) medication. The older patients were additionally asked about current diagnoses, healthcare use, activities of daily living (ADL, Katz index; Katz & Chimm, 1959; Katz et al., 1970) and instrumental activities of daily living (IADL, Lawton scale; Lawton & Brody, 1969). The informal caregivers were asked about type of caregiving tasks, time investment, social and financial consequences of caregiving. They were also asked about the group functioning, like division of tasks, communication, group cohesion and dynamics (Jansen et al., 2018). The met and unmet needs were reported as current and preferred professional support and knowledge about available support and information channels. Psychosocial well-being was measured by the Zarit Burden Interview (Bachner & O'Rourke, 2007; Schoenmakers et al., 2009; Zarit et al., 1986). The Geriatric Depression Scale was used to measure depressive complaints in both informal caregivers and patients (Mitchell et al., 2009). To examine the informal caregiver's and patient's feelings of anxiety, the State Anxiety subscale of the State Trait Anxiety Inventory was used (Van der Ploeg, 1982). Loneliness of older patients was measured by the loneliness scale (De Jong-Gierveld & Kamphuis, 1985).

3.4.2 | Data collection during follow-up

The data collection during follow-up took place online through a web survey. The Zarit Burden Inventory (ZBI-12 items) and the Geriatric Depression Scale (GDS-15 items) were included in the

follow-up interview of the informal caregiver, to examine changes in their psychosocial well-being over time. Besides, the follow-up interviews also included questions about their physical well-being, support, functioning of the informal care group and socio-demographics. The follow-up interview of the older patient included the Geriatric Depression Scale (GDS-15 items), Activities of Daily Living (ADL, Barthel index) and the Instrumental Activities of Daily Living (IADL, Lawton IADL scale), besides socio-demographic questions.

3.4.3 | Qualitative data

The intervention included both an introductory and final conversation with the informal care groups. During the idem conversation, the psychosocial well-being and needs of both the individual caregivers of the informal care group and the older patient were mapped by means of a group interview. The final conversation gave the informal care group the opportunity to discuss their experiences regarding the intervention. In addition, the current care situation, including needs, was mapped out. The interviewer, (LJ), an experienced clinical psychologist and family psychotherapist, used to combine taking notes and conducting an interview or therapeutic session with more than one participant, took notes of both group interviews and noted the quotes given by both the informal caregivers and the older patient. Both the notes and the quotes were checked by the participants, by presenting them before the interviews were completed.

3.5 | Analysis

Descriptive statistical analyses were used for describing the characteristics of the older patients, the individual informal caregivers and informal care group at baseline and during follow-up. Bivariate analyses were used to indicate the associations between caregiver burden and depressive complaints and the characteristics of both the patients and the caregivers. For the analysis process of the group interviews related to the intervention, we based ourselves on the QUAGOL guide which includes comprehensive guidelines to structure and deepen the analysis process (Dierckx De Casterlé et al., 2011). The written notes and quotes from the group interviews were discussed within the research team and rewritten into a narrative report. From these narrative reports, a conceptual scheme was constructed, which was re-examined in the notes and quotes of the interviews. These group interviews were used to supplement and clarify the data from the questionnaires.

3.5.1 | Sample size calculation

Using the Wilcoxon–Mann–Whitney test (t-test on paired data), based on the main outcome measurement (the psychosocial

well-being of the caregiver) with a type I error of 0.05, a power of 0.9, a effect size d (σ/μ) of 0.73 and a lost of follow-up of 25%, the minimum sample size is 62 older patients and their informal care groups. We used the standard deviation (σ : 6.92) and mean (μ : 9.48) of caregiver burden, obtained from the baseline data of our ongoing observational study with informal caregivers of older patients with cancer (KLIMOP study), derived from the Zarit Burden Interview (ZBI 12 item). With regard to the determination of the design effect ($DE = 1 + ICC(M - 1)$), we used a ICC of 0.07³⁰⁻³⁴ and an average number of informal caregivers per group of 3, determined from our pilot study (Adams et al., 2004; Bell & McKenzie, 2003; Campbell et al., 2000; Elley et al., 2005; Jansen et al., 2018; Ukoumunne et al., 1999). The calculation was performed with G*power 3.1.9.2.

3.5.2 | Ethics

This study was approved by the ethical review board of KU- and UZ Leuven (S61218).

4 | RESULTS

4.1 | Study population

A total of 44 informal care groups were included in this study (Table 1), consisting of 110 informal caregivers and 44 older patients. The informal caregivers were on average 65 years old and 60 (54%) of them were female (Table 1). Eighty-four informal caregivers (76%) were caregiving children (in law) and fourteen (13%) caregiving partners. The other informal caregivers were grandchildren. Sixty informal caregivers (54%) combined the caregiving with a paid job. The informal caregivers spent on average 19 hr per week (SD 32.3) caring for their older relative since on average 7 years (SD 9.1). Twenty-two informal caregivers (20%) lived together with the older patient. For 19 informal caregivers (17%) there was also another dependent relative to care for. Forty-six informal caregivers (41%) already cared in the past for a dependent relative.

The patients had a mean age of 85 years and 27 (66%) of them were female (Table 1). Twenty-four older patients (56%) were living alone and also 24 older patients (56%) were widowed. Thirty-nine patients (98%) used prescribed medication on daily basis with on average eight different medications (SD 4.9). The older patients had on average four formal diagnoses (SD 1.7) and 36 patients (88%) had two or more diagnoses. The most frequent diagnoses were osteoarthritis, arthrosis, heart disease, diabetes, cancer, back problems or other forms of rheumatism. Six patients (15%) were under treatment in the hospital and the patients described on average seven GP visits in the last 6 months (SD 4.3). Thirty-seven patients (95%) scored dependent on the Katz and Lawton scale. Three patients were unable to complete the questionnaire because of their suddenly deteriorated physical condition.

4.2 | Characteristics of the informal care groups

On average, three caregivers per informal care group participated (SD 1.3) (Table 2). Twenty-seven informal care groups (61%) consisted of three or more informal caregivers. The actual reported mean group size was four caregivers (SD 1.7). All groups consisted of caregiving relatives and in 13 informal care groups (30%), there was a spousal caregiver besides caregiving children (in law). In more than 3/4 of the informal care groups, central informal caregivers were present. In most cases, the central caregiver was a caregiving child or partner.

More than 85% of the informal caregivers agreed with the statement that the informal care group was well informed about the well-being of the patient or about the care context. For 76% of the informal caregivers, there were clear agreements about the division of the caregiving tasks. Two-third of the informal caregivers (absolutely) agreed about clear agreements on and a fair division of caregiving tasks. More than 80% of the informal caregivers felt supported by the other caregivers. Five informal caregivers (4.5%) indicated that there were further discussions on financial issues. Only 13.7% indicated that caregiving in group created more stress than caring individually for a dependent relative.

The main caregiving tasks consisted of emotional care, domestic tasks and care planning, followed by medical or physical care and financial support (Table 1). Pre-existing professional care consisted of domestic help, home care and transport. Caregiver needs included financial and emotional support. More than 60% of the informal caregivers indicated that no additional professional support was requested at baseline. The most important sources of information were the general practitioner, health insurances, social services, followed by family and friends.

4.3 | Follow-up

After 6 months, 31 informal caregivers and 12 patients representing 15 informal care groups were still included in the study (Table 1). Eight informal care groups stopped participating in the study due to the decease of the patient. Five patients moved to a residential care centre and in seven patients, health deteriorated to such an extent that the informal care group no longer wished to participate in the study. In total, nine informal care groups stopped participating in the study because of a loss of interest.

In general, there were minimal differences between the informal caregivers included at 6 months in the study and the informal caregivers who were loss to follow-up (Table 1). However, looking at the psychosocial well-being, the experienced caregiver burden at baseline was significantly higher in the caregivers who were loss to follow-up. There were also significantly more hospitalisations and multimorbidity among the patients at baseline in the groups that were loss to follow-up.

Among informal caregivers who participated at both measurement moments, a significant increase was found in the number of

TABLE 1 Baseline and follow-up characteristics of both individual caregivers and patients

	Baseline		Follow-up at 6 months ^{c,d}	
Study population				
Informal care groups	44		23	
Informal caregivers	110		44	
Older patients	41		17	
Socio-demographics	Caregiver	Patient	Caregiver	Patient
Age ^a	64.8 (17.3)	84.9 (6.9)	–	–
Sex (female) ^b	60 (54.1)	27 (65.9)	–	–
Country of birth (Belgium) ^b	105 (94.6)	41 (100)	–	–
Married or legally cohabiting ^b	85 (76.6)	19 (44.2)	25 (96.2)	7 (41.2)
Living together with partner, children and/or parents ^b	100 (90.9)	17 (41.5)	42 (95.5)	12 (70.6)
Paid job ^b	60 (54.1)	–	14 (43.8)	–
<i>Informal care</i>				
Years ^a	7.4 (9.1)	–	–	–
Hours/week ^a	19.1 (32.3)	–	26.6 (35.5)	–
Living together with the patient ^b	22 (19.8)	–	–	–
Relationship with the patient ^b				
Partner	14 (12.6)	–	–	–
Other family (Son (in-law), daughter (in-law), grandchildren)	96 (85.6)	–	–	–
Current informal care for another patient ^b	19 (17.1)	–	10 (31.3)**	–
Type of informal care ^b				
Emotional support	79 (71.2)	–	24 (75.0)	–
Domestic tasks	98 (88.3)	–	24 (75.0)	–
Physical or medical care	34 (30.6)	–	14 (43.8)**	–
Organisation of care	64 (57.7)	–	22 (68.8)**	–
Financial support	29 (26.1)	–	8 (25.0)	–
Present professional support ^b				
Psychosocial support	4 (3.6)	–	3 (9.4)	–
Domestic help	76 (68.5)	–	21 (65.6)	–
Home care	79 (71.2)	–	23 (71.9)	–
Transport	16 (14.4)	–	6 (18.8)**	–
Financial support	8 (7.2)	–	4 (12.5)	–
Not necessary at the moment	15 (13.5)	–	10 (31.3)**	–
Other (daycare)	7 (6.3)	–	1 (3.1)	–
Preferred professional support ^b				
Psychosocial support	21 (18.9)	–	5 (15.6)	–
Domestic help	11 (9.9)	–	6 (18.8)	–
Home care	7 (6.3)	–	3 (9.4)	–
Transport	5 (4.5)	–	2 (6.3)	–
Financial support	10 (9.0)	–	4 (12.5)	–
Not necessary at the moment	69 (62.2)	–	18 (56.3)	–
Other (daycare)	4 (3.6)	–	0 (0.0)	–

(Continues)

TABLE 1 (Continued)

Socio-demographics	Caregiver	Patient	Caregiver	Patient
<i>Information channels^b</i>				
General practitioner	63 (56.8)	—	21 (65.6)**	—
Health insurance	62 (55.9)	—	20 (62.5)**	—
Social services	51 (45.9)	—	13 (40.6)	—
Family or friends	52 (46.8)	—	11 (34.4)	—
Not necessary at the moment	7 (6.3)	—	4 (12.5)	—
Other (home care)	8 (7.2)	—	3 (9.4)	—
<i>Psychosocial well-being</i>				
<i>Depressive complaints</i>				
Total score ^a	2.5 (3.0)	7.6 (3.6)	2.0 (2.2)	7.1 (4.0)**
Cut-off ^b	19 (17.6)	28 (68.3)	5 (15.6)	10 (71.4)
<i>Caregiver burden</i>				
Total score ^a	9.1 (7.3)	—	8.3 (7.2)	—
Cut-off ^b	17 (15.7)	—	4 (12.5)	—
<i>Feelings of guilt regarding the caregiving^b</i>				
Never/rarely	59 (54.1)	—	29 (90.7)	—
Sometimes/ often/almost always	50 (45.9)	—	3 (9.4)	—
<i>Taking time for myself^b</i>				
Never/rarely	48 (44.1)	—	13 (40.6)	—
Sometimes/often/almost always	61 (55.9)	—	8 (25.0)	—
<i>Difficulty to ask help from others^b</i>				
Never/rarely	62 (56.8)	—	28 (87.5)	—
Sometimes/ often/ almost always	47 (43.2)	—	4 (12.5)	—
<i>Anxiety</i>				
Total score ^a	45.2 (4.2)	47.6 (5.6)	36.2 (9.1)**	41.4 (13.9)
Cut-off ^b	5 (4.6)	6 (14.0)	1 (3.1)	3 (21.4)
<i>Social loneliness</i>				
Total score ^a	—	1.3 (1.5)	—	1.0 (1.1)
Cut-off ^b	—	13 (31.7)	—	4 (28.6)
<i>Emotional loneliness</i>				
Total score ^a	—	3.2 (2.2)	—	3.4 (1.4)
Cut-off ^b	—	27 (65.9)	—	11 (78.6)
<i>Physical health</i>				
<i>Daily use of medication^b</i>				
Medication/day ^a	22 (68.8)	39 (97.5)	22 (68.8)	13 (92.9)
Medication/day ^a	2.0 (2.4)	8.0 (4.9)	2.1 (2.1)	6.8 (3.1)
<i>Multi-morbidity</i>				
Total ^a	—	3.5 (1.7)	—	3.0 (1.7)
(≥2 diagnoses) ^b	—	36 (87.8)	—	12 (85.7)**
Currently treated in the hospital ^b	—	6 (15.0)	—	2 (14.3)**
<i>In the last 6 months^b</i>				
Visit to the GP	2.6 (3.1)	7.4 (4.3)	3.2 (4.5)	7.9 (6.1)**
Visit to the specialist	—	2.9 (3.5)	—	1.2 (1.9)
Emergency unit	—	0.7 (0.9)	—	0.3 (0.5)
Day hospitalisation	—	0.1 (0.5)	—	0 (0.0)
Overnight stays in the hospital	—	10.9 (20.8)	—	2.0 (3.4)

TABLE 1 (Continued)

Socio-demographics	Caregiver	Patient	Caregiver	Patient
Days in residential home care or revalidation centre	—	4.7 (11.3)	—	2.9 (10.7)**
Overnight stays in residential home care or revalidation centre	—	1.4 (5.7)	—	0 (0.0)
Katz scale				
Total score ^a	—	2.9 (1.9)	—	3.4 (1.7)
Cut-off ^b	—	37 (90.2)	—	13 (92.9)
Lawton scale				
Total score ^a	—	3.7 (1.6)	—	4.6 (0.9)**
Cut-off ^b	—	37 (94.9)	—	14 (100.0)

^aMean score (SD).

^bAmount (percentage in %).

^cCaregivers and patients who participated at both baseline and after 6 months (follow-up).

^dReasons for loss to follow-up were: decease of the patient ($n = 3$), move of the patient to residential home care ($n = 1$), deterioration of the patient ($n = 8$), loss of interest ($n = 9$).

*Significant difference (independent samples' t-test, $p \leq 0.05$) in comparison with the informal caregivers who participated on both measurement moments); **Significant difference (independent samples' t-test, $p \leq 0.05$) in comparison with baseline).

hours caregiving per week and caregivers taking also care for another dependent relative (Table 1).

4.4 | Psychosocial well-being of the informal caregivers

Overall, more than 15% of the informal caregivers experienced high to severe burden at baseline (Table 3). The mean score of caregiver burden at baseline was 9.1 (SD 7.3). Looking at the selection of informal caregivers participated both at baseline and 6 months, the percentage of informal caregivers with high-to-severe burden at baseline was only 6.5 percent, but increased to 12.5% after 6 months. The mean score remained stable after 6 months.

More than 17% of the informal caregivers experienced depressive complaints with a mean score of 2.5 (SD 3.0). This percentage decreased to 16.1% after 6 months for the informal caregivers who participated at both measurement moments, like the mean score.

Looking at the individual trends of the caregivers regarding burden and depressive complaints at both measurement moments, there are both decreasing and increasing trends with no clear general direction. Non-adjusted associations of caregiver burden or depressive complaints were seen with poorer psychosocial well-being of the caregiver and poorer informal care group functioning (Table 3). After 6 months, the non-adjusted associations were more or less the same.

Anxiety was experienced in five informal caregivers (4.6%) with a mean score of 45.2 (SD 4.2). Fifty informal caregivers (45.9%) reported that they experienced sometimes to almost always feelings of guilt regarding the caregiving. Sixty-one informal caregivers (55.9%)

experienced sometimes to almost always difficulties in taking time for themselves and 47 informal caregivers (43.2%) experienced difficulties in asking for help from others.

At group level, one-third of the informal care groups had at least one informal caregiver who experienced high to severe caregiver burden and/or depressive complaints (Table 2). Less than 10% of the informal care groups had at least one informal caregiver with anxiety. Looking at the inter-group trends, no clear increase or decrease can be seen after the intervention, except for the mean score of anxiety of the informal care groups.

Indicating the influence of the intervention on the well-being of the informal care groups, trend plots were made (Figures 1 and 2). Looking at the mean scores of the informal care groups on the seven statements on informal care in group, a positive trend was seen for statement 2 'There are clear agreements on the division of caregiving tasks within the informal care group' and statement 5 'We find support in each other'. A negative trend was seen for statement 7 'Informal caregiving in group primarily provides discussion on financial matters'. For the other statement, no clear trends were identified.

The number of hours caregiving per week per informal care group increased slightly with differences between the groups. This was also seen in the inter-group trends, whereby some informal groups decreased and other increased in the numbers of hours caregiving per week. The same can be told about the GP visits of the informal care groups.

Regarding spiritual resources and needs (Table 4), the most common resources of joy, pleasure, happiness and satisfaction were family (69%), friends (26%), religion or existential thoughts (24%) and hobbies (25%). Reported resources of consolation were religion or existential thoughts (42%), family (50%) and friends (17%). Spiritual needs were formulated as difficulties in daily living, which challenges the psychosocial well-being of the informal

TABLE 2 Characteristics of the informal care groups

	Baseline		Follow-up							
Number of older patients per informal care group ^a	0.9 (0.4)		0.3 (0.5)							
Number of informal caregivers per informal care group (included in the study) ^a	2.5 (1.2)		0.7 (1.1)							
Actual size of the informal care group (including non-participating caregivers mentioned by the informal caregivers) ^a	3.6 (1.7)		—							
Central informal caregiver present in the informal care group ^b	35 (79.5)		—							
Number of informal care groups with informal caregivers with caregiver burden (cut-off score ≥ 17 on the ZBI-12 items) ^b	15 (34.0)		2 (14.2)							
Number of informal care groups with informal caregivers with depressive complaints (cut-off score ≥ 5 on the GDS-15 items) ^b	15 (34.0)		4 (28.6)							
Number of informal care groups with informal caregivers with anxiety (cut-off score ≥ 51 (10th decile) on the 20-item State subscale of the STAI-DY) ^b	4 (9.1)		1 (7.1)							
Informal care groups with the older patient living alone ^b	21 (47.7)		—							
Hours of caregiving/week per informal care group ^a	24.6 (35.6)		27.9 (24.4)							
Statements on informal care in group ^b	Baseline (N = 109 informal caregivers)					Follow-up (N = 31 informal caregivers)				
	Absolutely agree	Agree	Not agree/not disagree	Disagree	Absolutely disagree	Absolutely agree	Agree	Not agree/not disagree	Disagree	Absolutely disagree
Well informed about the patient's status	49 (44.5)	46 (41.8)	10 (9.1)	4 (3.6)	1 (0.9)	16 (50.0)	12 (37.5)	4 (12.5)	0 (0.0)	0 (0.0)
Clear agreements on the division of tasks	27 (24.5)	57 (51.8)	18 (16.4)	7 (6.4)	1 (0.9)	13 (40.6)	11 (34.4)	5 (12.6)	3 (9.4)	0 (0.0)
Fair division of caregiving tasks	27 (24.5)	47 (42.7)	23 (20.9)	12 (10.9)	1 (0.9)	11 (34.4)	9 (28.1)	8 (25.0)	2 (6.3)	2 (6.3)
Caregiving in group creates more stress	7 (6.4)	8 (7.3)	31 (28.2)	42 (38.2)	22 (20.0)	1 (3.1)	7 (21.9)	8 (25.0)	9 (28.1)	7 (21.9)
Finding support in each other	31 (28.2)	60 (54.5)	15 (13.6)	3 (2.7)	1 (0.9)	17 (53.1)	10 (31.3)	3 (9.4)	1 (3.1)	1 (3.1)
Group grew closer together	15 (13.6)	46 (41.8)	39 (35.5)	10 (9.1)	0 (0.0)	11 (34.4)	9 (28.1)	9 (28.1)	2 (6.3)	1 (3.1)
Provides discussion on financial matters	0 (0.0)	5 (4.5)	17 (15.5)	41 (37.3)	47 (42.7)	2 (6.3)	1 (3.1)	3 (9.4)	7 (21.9)	19 (59.4)

^aMean score (SD).^bAmount (percentage in %).

caregiver, like the informal care (14%), physical complaints (14%) and stress (12%). Thirty-eight informal caregivers (35%) indicated that they had no current difficulties, which challenged their daily living.

4.5 | Qualitative analysis of the intervention – Reflections of the informal care groups

A total of 36 informal care groups completed the 'Keuzewijzer' on average between the 2 and 3 months after baseline, including 74 informal caregivers and 26 patients. After completing the

instrument, the participants received both the individual and group report of the answers on the 'Keuzewijzer'. Almost all groups (96%) discussed the results of the 'Keuzewijzer', although it was not always possible to bring all informal caregivers of the group together.

In 34 informal care groups (94%), the priority was to keep the patient at home. Unmet needs and related objectives were related to this priority, resulting in contacting home care organisations, cleaning services or *traiteurs* to arrange extra support or a (partly) redistribution of caregiving tasks within the informal care group. The 'Keuzewijzer' also helped the informal care groups to think and discuss about the future, especially about the limits of the patient living

TABLE 3 Prevalence and non-adjusted associations of caregiver burden and depressive complaints with patient and caregiver characteristics at baseline and follow-up

Prevalence of caregiver burden and depressive complaints	Caregiver burden				Depressive complaints			
	Baseline		Follow-up		Baseline		Follow-up	
	All	Selection ^b	Selection ^b	Drop-outs	All	Selection ^b	Selection ^b	Drop-outs
Total score	9.1 (7.3)	6.8 (5.6)	8.3 (7.2)	10.1 (7.2)	2.5 (3.1)	2.1 (2.1)	2.0 (2.2)	2.6 (3.4)
Cut-off score ^a								
No	91 (84.3)	29 (93.5)	28 (87.5)	62 (80.5)	89 (82.4)	26 (83.9)	27 (84.4)	63 (81.8)
Yes	17 (15.7)	2 (6.5)	4 (12.5)	15 (19.5)	19 (17.6)	5 (16.1)	5 (15.6)	14 (18.2)
Non-adjusted associations of caregiver burden and depressive complaints ^c	Baseline Caregiver burden		Follow-up Caregiver burden		Baseline Depressive complaints		Follow-up Depressive complaints	
	All caregivers	OR (CI 95%) ^e	Selection ^b	OR (CI 95%) ^e	All caregivers	OR (CI 95%) ^e	Selection ^b	OR (CI 95%) ^e
Informal caregiver characteristics								
Socio-demographics								
Age (≥70 years)	5 (29.4)	<u>1.2–15.2</u>	2 (40.0)	0.4–23.7	6 (31.6)	<u>1.4–15.7</u>	5 (62.5)	<u>2.7–110.4</u>
Sex (female)	11 (64.7)	0.2–1.8	4 (80.0)	<u>1.1–117.4</u>	6 (31.6)	0.2–1.5	4 (50.0)	0.4–10.0
Living situation (living together)	15 (88.2)	0.1–3.8	0 (0.0)	<u>0.8–0.9</u>	17 (89.5)	0.2–4.3	7 (87.5)	0.0–3.8
Paid job (yes)					10 (52.6)	0.6–4.3	6 (85.7)	0.9–81.7
Caregiving characteristics								
Relationship with the patient (Son [in law] or daughter [in law])	9 (52.9)	<u>0.1–0.9</u>	3 (60.0)	0.1–4.9	14 (73.7)	0.2–2.2	4 (50.0)	0.0–1.1
Living together with the patient (yes)	8 (47.1)	<u>0.1–0.5</u>	2 (40.0)	<u>0.0–0.9</u>	12 (63.3)	<u>0.1–0.9</u>	4 (50.0)	<u>0.0–0.8</u>
Currently caring for another patient (yes)	3 (17.6)	0.3–3.9	5 (100.0)	<u>1.0–1.4</u>	16 (84.2)	0.3–4.5	8 (100.0)	<u>1.1–1.6</u>
Informal care tasks (≥2)	16 (94.1)	0.4–24.4	4 (80.0)	0.1–6.0	14 (73.7)	0.1–1.2	5 (62.5)	0.0–0.8
Number of informal caregiver per group (>2 informal caregivers)	8 (47.1)	0.2–1.8	3 (60.0)	0.1–6.0	7 (36.8)	0.1–1.1	3 (37.5)	0.1–1.6
Presence of central caregiver (yes)	16 (94.1)	0.9–60.2	5 (100.0)	<u>1.0–1.5</u>	15 (78.9)	0.5–5.1	5 (62.5)	0.2–5.1
Statements^d								
1. Well informed about the patient's status	12 (70.6)	0.1–1.0	4 (80.0)	0.0–3.4	14 (73.7)	0.1–1.2	8 (100.0)	<u>1.1–1.5</u>
2. Clear agreements on the division of tasks	9 (52.9)	<u>0.1–0.8</u>	2 (40.0)	0.0–1.1	9 (11.0)	<u>0.1–0.6</u>	5 (62.5)	0.1–2.0
3. Fair division of caregiving tasks	8 (47.1)	0.1–1.1	2 (40.0)	0.0–1.7	12 (63.2)	0.3–2.3	6 (75.0)	0.2–7.6
4. Caregiving in group creates more stress	11 (64.7)	<u>0.1–0.6</u>	3 (60.0)	0.0–1.6	13 (68.4)	<u>0.1–0.7</u>	7 (87.5)	0.1–12.5
5. Finding support in each other	11 (64.7)	<u>0.1–0.9</u>	4 (80.0)	0.1–6.0	15 (78.9)	0.2–2.6	7 (87.5)	0.1–10.0
6. Group grew closer together	9 (52.9)	0.3–2.7	3 (60.0)	0.2–8.0	9 (47.4)	0.3–1.9	4 (50.0)	0.2–3.9
7. Provides discussion on financial matters	16 (94.1)	0.1–5.6	5 (100.0)	–	18 (94.7)	0.1–6.4	8 (100.0)	–
Psychosocial well-being								
High-to-severe caregiver burden (yes)	–	–	2 (40.0)	<u>1.5–319.5</u>	10 (52.6)	<u>4.0–42.6</u>	1 (12.5)	0.2–28.0
Depressive complaints (yes)	10 (58.8)	<u>3.9–42.1</u>	2 (40.0)	0.6–39.7	–	–	4 (50.0)	<u>2.1–113.5</u>
Anxiety (yes)	1 (5.9)	0.1–12.8	0 (0.0)	<u>0.8–0.9</u>	0 (0.0)	<u>0.7–0.9</u>	0 (0.0)	<u>0.7–0.9</u>
Feelings of guilt regarding caregiving ^d	5 (29.4)	<u>1.5–22.1</u>	0 (0.0)	–	6 (31.6)	<u>2.0–28.8</u>	0 (0.0)	–
Taking time for myself ^d	10 (58.8)	<u>3.6–36.8</u>	2 (40.0)	0.6–38.4	9 (47.4)	<u>2.1–18.9</u>	3 (37.5)	0.9–37.3
Difficulty to ask help from others ^d	10 (58.8)	<u>6.5–91.1</u>	2 (40.0)	<u>1.5–310.0</u>	7 (36.8)	<u>1.8–19.0</u>	2 (25.0)	0.6–42.8
Physical well-being								
Polypharmacy (≥5 medications)	5 (45.5)	<u>1.1–18.1</u>	1 (20.0)	0.2–36.3	7 (36.8)	0.4–2.9	5 (62.5)	<u>2.8–392.6</u>
GP visits (≥7 visits to the GP)	3 (21.4)	<u>1.5–65.5</u>	0 (0.0)	0.8–1.0	3 (17.6)	<u>1.2–49.1</u>	0 (0.0)	<u>0.7–0.9</u>
Patient characteristics								

(Continues)

TABLE 3 (Continued)

Non-adjusted associations of caregiver burden and depressive complaints ^c	Baseline Caregiver burden		Follow-up Caregiver burden		Baseline Depressive complaints		Follow-up Depressive complaints	
	All caregivers	OR (CI 95%) ^e	Selection ^b	OR (CI 95%) ^e	All caregivers	OR (CI 95%) ^e	Selection ^b	OR (CI 95%) ^e
<i>Informal caregiver characteristics</i>								
Socio-demographics								
Age (≥70 years)	108 (100)	—	5 (100.0)	—	108 (100)	—	8 (100.0)	—
Sex (female)	13 (76.5)	0.1–1.4	4 (80.0)	0.0–3.7	8 (42.1)	0.4–3.1	1 (12.5)	0.0–1.9
Psychosocial well-being								
Depressive complaints (yes)	15 (88.2)	<u>1.1–23.8</u>	5 (100.0)	<u>1.0–1.5</u>	16 (84.2)	<u>1.0–13.3</u>	3 (37.5)	0.1–1.6
Anxiety (yes)	3 (17.6)	0.3–3.9	0 (0.0)	<u>0.8–0.9</u>	4 (21.1)	0.4–4.5	1 (12.5)	0.2–28.7
Social loneliness (yes)	4 (23.5)	0.9–14.4	1 (20.0)	0.3–56.4	9 (47.4)	<u>1.0–7.6</u>	1 (12.5)	0.1–5.3
Emotional loneliness ^b (yes)	8 (47.1)	0.9–7.6	1 (20.0)	0.1–10.4	15 (78.9)	0.6–6.9	5 (62.5)	0.3–6.4
Physical well-being								
Polypharmacy (≥5 medications)	14 (82.4)	0.7–9.9	1 (20.0)	0.0–1.5	17 (89.5)	—	6 (75.0)	—
GP visits (≥7 visits to the GP)	16 (94.1)	—	4 (80.0)	—	6 (31.6)	0.3–2.4	2 (25.0)	0.1–4.7
Multimorbidity (≥2 diagnoses)	16 (94.1)	0.2–11.6	5 (100.0)	<u>1.0–1.3</u>	16 (84.2)	0.2–2.5	6 (75.0)	0.1–3.3
Functional impairment (≥1 on ADL or IADL)	15 (88.2)	0.2–4.7	4 (80.0)	0.1–8.8	17 (89.5)	0.1–3.3	7 (87.5)	0.1–9.7

^aCut-off score (≥17) on the ZBI-12 items for caregiver burden and Cut-off score (≥5) on the GDS-15 items for depressive complaints

^bInformal caregivers who participated at both measurement moments (N = 31).

^cCut-off scores.

^d(Absolutely) agree.

^eUnderlined OR>1 means an association with higher odds of outcome. Underlined OR<1 means an association with lower odds of outcome. A small CI indicates a higher precision of the OR.

at home: how much longer will it be realistic for the patient to live at home?

Both the informal caregivers and patients indicated that the 'Keuzewijzer' was helpful. Most of the informal caregivers stated that there were not that much new aspects but it gave them an overview of the care context. This overview helped them to fulfil the wishes and needs of the patient, to discuss some smaller conflicting aspects between patient and caregiver and gave them the opportunity to stimulate other informal caregivers or even the patient to help. Otherwise, the informal caregivers indicated that the 'Keuzewijzer' could be used as an evaluation instrument by every change in the care context due to the status of the patient but also due to the well-being and possibilities of the caregivers. Although most of the informal care groups concluded that there were not much differences within the group regarding their concerns and needs, they concluded that the rapport of the 'Keuzewijzer' strengthened them to go on together, it gave them reassurance that they were doing well together. When objectives were created through the 'Keuzewijzer', these were solved by the informal care group, or it was realised that this was specific to the current situation and could not be adjusted immediately. However, it was then discussed what was experienced as helping.

Not only the objectives resulting from the 'Keuzewijzer' were important for both the patients and the informal caregivers, but even

more the encouragement to consider the current situation together as well as individually. Especially the caregiving children emphasised that taking a moment for themselves to think about the current care situation helped them to both reconsider choices they made and even their own psycho-social well-being.

5 | DISCUSSION

A better cohesion between informal caregivers with open communication about the support of the patient, the individual needs and the division of caregiving tasks, resulted in a better psychosocial well-being of both the individual informal caregivers of the group and patient. This is also confirmed by Broese van Groenou et al. (2013), Nissen et al. (2016), Rodakowski et al. (2012), and Siminoff et al. (2010). Our findings also indicated that informal care in group mostly originates from a good cooperation within families with mutual support, respect and consultation. This was also confirmed by Kissane et al. (1994) and Schuler et al. (2014) and is in line with the need for social support in individual informal caregivers and appears to be a key success factor in the development and sustainability of informal care groups. Having and maintaining social contacts is essential in the psychosocial well-being of informal caregivers. It is not always the frequency of the contacts or the practical support that counts, but especially the connectedness with family, with the

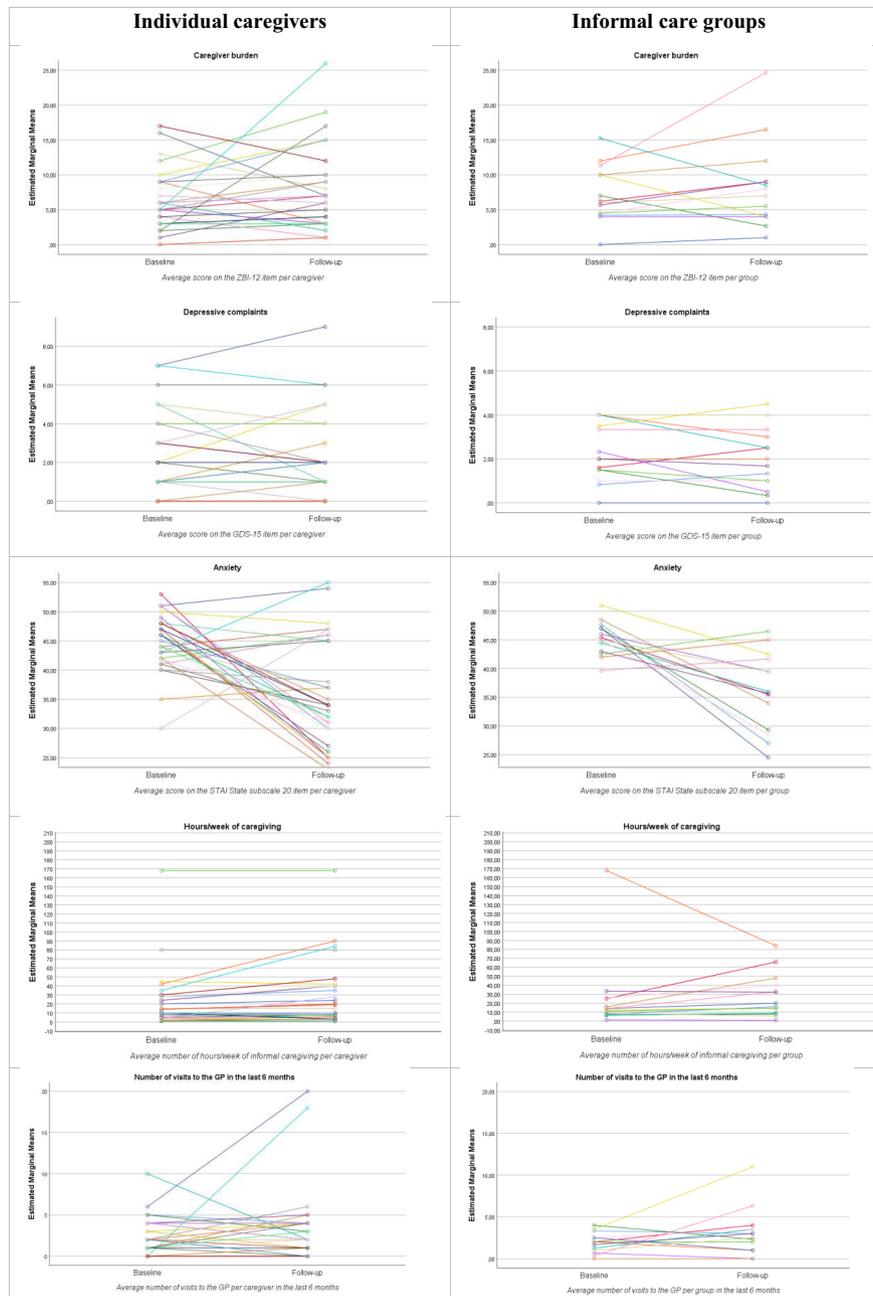


FIGURE 1 Trends in individual informal caregivers and informal care groups

immediate environment or even with the community. Knowing that there is someone around to fall back on when challenges arose, was experienced as essential by the informal caregivers in our research. The same observation was made in a Japanese study of Shiba et al. (2016) and is an important aspect on which our self-management tool the 'Keuzewijzer' is based. Bringing together all involved but also less involved informal caregivers and the patient, ensures that a shared vision on the patient's care situation is created, and that all caregivers are aware of this situation and can respond easily to each other, taking into account everyone's needs.

The support tested in our research (the 'Keuzewijzer') aimed at allowing timely adjustments in the care planning and preventing caregiver burden. Although, patients and informal caregivers considered

the 'Keuzewijzer' as useful and supportive, no clear evidence about decreased caregiver burden was found. However, there was a positive trend in the group characteristics such as the distribution of tasks, communication and the prevalence of conflicts. Besides, informal caregivers stated that they took more time for themselves, had less feelings of guilt and experienced less barriers to ask for help. This is in line with the research by Feld & Dunkle (2006), who found that the more other informal caregivers are involved in the care context, the lower the barrier to ask for help. Freedman & Spillman (2014) stated in an American study on disabled elderly, that almost every older patient has a group of three to four potential informal caregivers. They concluded that in reality often only one or two informal caregivers are effectively involved in the care for the patient. This seems to confirm that facilitating

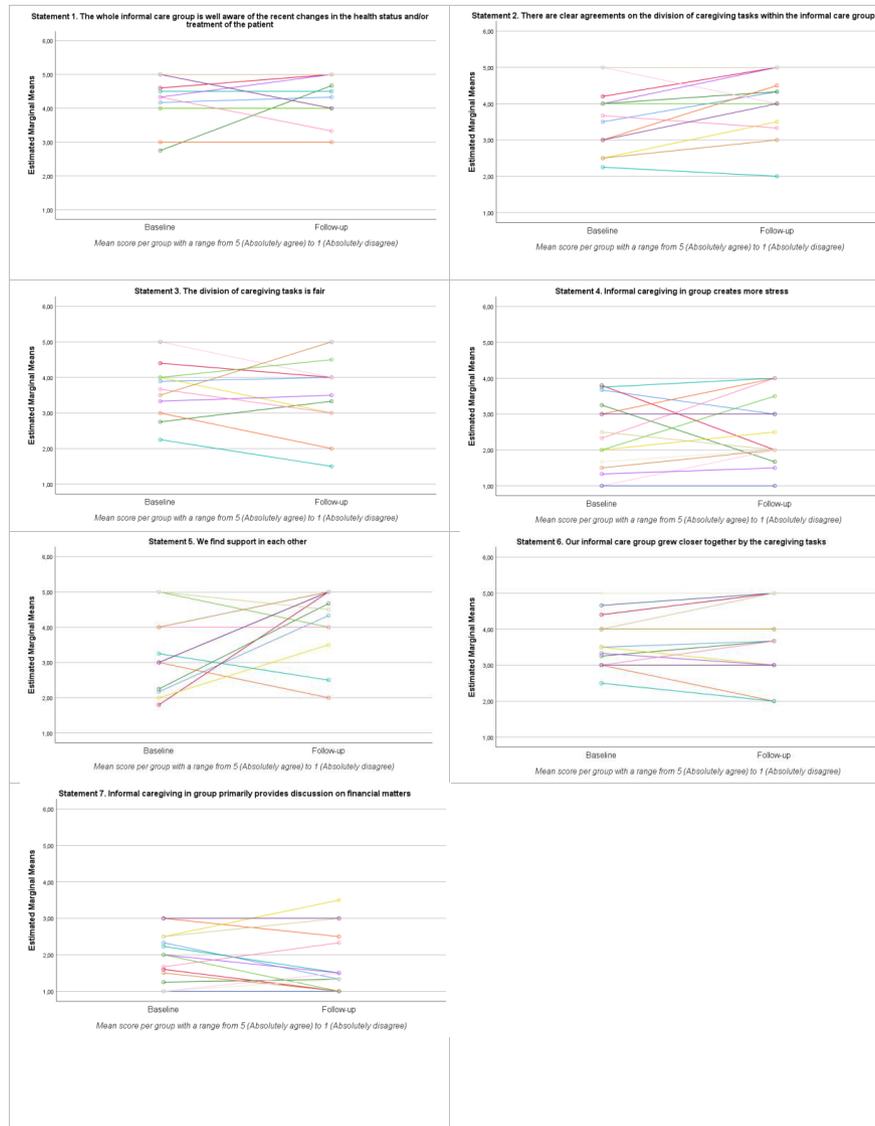


FIGURE 2 Within group trends about informal care in group

communication within the informal care group by means of tailor-made support could lead to more involvement of the other group members, to a better division of care tasks, to mutual support and to lower caregiver burden. This observation strengthened the purpose of our tested intervention. However, further research regarding the psychosocial well-being and support of informal care groups is needed. Literature about caregiving families is very limited and mainly based upon Asian or African studies (Kita & Ito, 2013; Kusaba et al., 2016; Or & Kartal, 2019). This might refer to the more individualistic perspective of informal caregiving in Western countries.

5.1 | Strengths & limitations

To our knowledge, our study is the first study to support the psychosocial well-being of informal care groups, taking specific account of both the individual and group characteristics of informal

care. However, the intended recruitment target was not reached, in which the definition of caregiver, among others, played an important role. We started this study from the assumption that the concept of informal caregivers is well known within the Belgian society. However, informal care groups, mainly families, took up the caring role as an evident action and often had not realised that they were an informal caregiver, or even a member of an informal care group. In addition, the term 'informal care group' is a new term that was introduced in our research, which, to our knowledge has not been studied extensively before. We realised that this term was not always helpful in finding participants for our studies. Often, additional explanation was needed about who was meant by the term informal caregiver and we probably also missed a significant part of the intended population. If someone does not identify with the definition of informal caregiver, he or she will not feel addressed to participate in the study. It is therefore conceivable that the study population is biased and the study mainly contains informal care groups that had

TABLE 4 Spiritual resources and difficulties in daily living reported by informal caregivers of older patients (N = 109)

	Resources of joy, pleasure, happiness, satisfaction	Resource of consolation	Difficulties in daily living ^b
Religion or existential thoughts	26 (23.9) ^a	46 (42.2)	
Friends	28 (25.7)	19 (17.4)	
Hobbies	27 (24.8)	12 (11.0)	
Sport	19 (17.4)	3 (2.8)	
Traveling	8 (7.3)	1 (0.9)	
Job or education	17 (15.6)	3 (2.8)	9 (8.3)
Family	75 (68.8)	54 (49.5)	10 (9.2)
Informal care	16 (14.7)	3 (2.8)	15 (13.8)
None	6 (5.5)	9 (8.3)	38 (34.9)
Physical complaints (fatigue)			15 (13.8)
Stress or agitation			13 (11.9)
Depressive complaints or worrying			9 (8.3)
Uncertainty			9 (8.3)
Other external factors			7 (6.4)
Grief			4 (3.7)
Feeling unappreciated			3 (2.8)
Loneliness			1 (0.9)

^aNumber (%) of informal caregivers who mentioned this resource or difficulty in daily living.

^bSpiritual needs were reported as in difficulties in daily living.

already found their way to professional care. Not identifying oneself as an informal caregiver implies not claiming any form of support like respite care or financial support. As a result, governments are unable to tailor professional support insufficiently to the needs of informal caregivers, which indirectly affects the psychosocial well-being of informal caregivers.

In recruiting study participants, a selection bias may have occurred; we have mainly included informal caregivers who are actually doing well and have already found their way to professional care. We were less able to recruit more vulnerable informal caregivers or informal care groups with internal conflicts. This could also be a reason why no clear evidence of decreased caregiver burden was found. Otherwise, the study was confronted with a high drop-out rate, mainly due to decease or deteriorating of the patients. This is characteristic of the population studied, but can of course also aggravate caregiver burden. The term vulnerability was an additional challenge, due to the resistance that caregivers and patients experienced. Both patients and (potential) informal caregivers preferred to identify through their strengths instead of their vulnerabilities. Maybe, caregiver burden is not be the best outcome measure to study the well-being of the informal caregiver. For future studies, we would rather recommend positively related outcome measures such as resilience, controllability of one's own life and connectedness or mutual support. However, the size of the study population had a major impact on the results of this study. Therefore, efforts should be made to achieve greater inclusion of informal care groups, taking into account the strengths rather than the vulnerabilities of informal care.

5.2 | Clinical implications

Although this study does not provide clear evidence about a resulting decrease in caregiver burden, the support tested seemed to stimulate underlying processes which seem to indirectly increase the psychosocial well-being of informal care groups: communication and mutual support between and the self-care of caregivers and patients. However, the size of the study population had a major impact on the results of this study. Therefore, efforts should be made to achieve greater inclusion of informal care groups, taking into account the strengths rather than the vulnerabilities of informal care.

The psychosocial well-being of informal caregivers of informal care groups, caring for an older patient is highly individualised and depends on the well-being of both caregiver and patient and the functioning of the informal care group. The support of the individual caregiver must fit in the broader context of the informal care group. Within this context, a formal framework with good communication is essential to support informal caregivers in order to provide good care for the older patients. Moreover, within this framework, tailor-made support for these informal caregivers is essential to improve and maintain their psychosocial well-being.

Caregivers do not need new support or interventions but more visibility, accessibility and guidance to the available support systems. Tailor-made support of informal care groups starts with facilitating and guiding a process to achieve consent within the group to optimise the care for the patient and indirectly also for the informal caregivers. With a shared vision and supported decisions, the caregivers can enter into conversations with the professional caregiver

to coordinate adjusted but currently available support regarding the care needs.

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CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

AUTHOR CONTRIBUTION

LJ and BS designed and directed the study. LJ performed the interviews and analysed the data. TdB supported data acquisition and analysis. LJ prepared the first draft of the manuscript. All authors were involved in data interpretation and revising the manuscript. FB and MA supervised the project. All authors approved the final version of the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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