

Roles of informal caregivers in communication with healthcare professionals to gain patient-tailored care for patients with heart failure or COPD: a qualitative study

Jannemieke Mulder^{1,2} and Madeleen Uitdehaag³

1 Master student Clinical Health Sciences Utrecht University; Utrecht, the Netherlands;

2 Community Nurse Icare; 't Harde, the Netherlands;

3 Associate professor Palliative Care Saxion University of Applied Sciences; Deventer/ Enschede, the Netherlands.

Student	J. (Jannemieke) Mulder
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Utrecht University, Master Clinical Health Sciences, Nursing Science,
University Medical Centre, Utrecht

ABSTRACT

Background: In patient-tailored care (PTC) awareness is increased for wishes and demands of patients. Informal caregivers (IC) play a fundamental role in PTC, particularly when patients have chronic illnesses such as heart failure (HF) and chronic obstructive pulmonary disease (COPD). Existing research is limited to general communication research or research on communication regarding specific illnesses. As roles of IC in communication differ for each type of illness, insight is needed in roles of IC of HF/ COPD-patients to adjust PTC and communication accordingly.

Aim: To gain insight in which roles IC see for themselves in communication with healthcare professionals (HCPs) to reach PTC for their loved ones with HF or COPD.

Methods: A generic, qualitative study is conducted. Maximum variation sampling was conducted to recruit IC of loved ones with HF or COPD in the north-eastern part of the Netherlands. A topic list was used to structure interviews. Data collection and thematic analysis took place iteratively using software program Atlas.ti.

Results: Semi-structured interviews were held with twelve participants. Main themes which emerged from the interviews are taking control in communication, decision-making, asking questions, practical support and intervening in the process of care. These themes can be divided into sixteen different roles.

Conclusion: IC see different current roles for themselves in communication with HCPs to gain PTC for their loved ones, which vary from highly active roles to minimal or no interference in communication.

Implications of key findings: IC are of great importance in current society. Further exploration of their needs is necessary to tailor care for both patients and IC. A quantitative follow-up study is required, and further research is recommended on use of technology in triadic communication and on involvement of multiple IC in care.

Keywords: COPD (MeSH), heart failure (MeSH), informal caregiver, communication (MeSH), healthcare professional

SAMENVATTING

Achtergrond: In passende zorg (PZ) is steeds meer aandacht voor wensen en behoeftes van de patiënt. Mantelzorgers spelen een cruciale rol in PZ, juist wanneer de patiënt chronisch ziek is, zoals bij hartfalen en chronische obstructieve longziekte (COPD). Bestaand onderzoek beperkt zich tot generiek communicatie-onderzoek of communicatie-onderzoek met betrekking tot specifieke ziektebeelden. Omdat de rollen van mantelzorgers in communicatie per ziekte verschillen, is meer inzicht nodig in rollen van mantelzorgers van hartfalen- en COPD-patiënten. Zo kan zorg en communicatie op maat worden gegeven.

Doelstelling: Inzicht krijgen in welke rollen mantelzorgers voor zichzelf zien in communicatie met zorgverleners om PZ voor hun naasten met HF en COPD te bewerkstelligen.

Methode: Een generiek, kwalitatief onderzoek werd uitgevoerd. Middels maximale variatie werden participanten gerekruteerd in het noordoosten van Nederland om een zo rijk mogelijke beschrijving te verkrijgen. Een topic-lijst werd gebruikt om de interviews te structureren. Dataverzameling en thematische analyse vonden plaats als iteratief proces met gebruik van softwareprogramma Atlas.ti.

Resultaten: Semigestructureerde interviews werden gehouden met twaalf participanten. Dit resulteerde in zestien rollen, verdeeld in vijf thema's. De thema's die uit de data ontstonden zijn regie nemen in communicatie, besluiten nemen, vragen stellen, praktische ondersteuning en interveniëren in het zorgproces.

Conclusie: Mantelzorgers zien diverse huidige rollen voor zichzelf in communicatie met zorgverleners om passende zorg te bereiken voor hun naasten met hartfalen of COPD, variërend van een hoge mate van betrokkenheid in communicatie tot geen of minimale betrokkenheid bij communicatie.

Aanbevelingen: Mantelzorgers zijn van groot belang in de huidige maatschappij. Daarom is het in kaart brengen van hun behoeftes nodig om passende zorg voor zowel patiënt als mantelzorger te bereiken. Een kwantitatieve vervolgstudie wordt geadviseerd, alsook vervolgonderzoek naar technologie in zorgverlener-patiënt-mantelzorger communicatie. Ook wordt onderzoek naar betrokkenheid van meerdere mantelzorgers bij zorgverlening geadviseerd.

Trefwoorden: COPD, hartfalen, mantelzorger, communicatie, zorgverlener

INTRODUCTION

High-quality communication in healthcare is closely linked to patient-centered care (PCC) (appendix 1, abbreviations) or patient-tailored care (PTC).¹⁻³ In PTC, instead of care determined by healthcare professionals (HCPs), awareness is increased in all stakeholders that starting points for care are wishes and demands of the patient.^{2,4-6} Results of PTC are better health outcomes, greater patient satisfaction and reduced health costs.⁷⁻¹⁰ PCC and PTC are closely linked in their definitions, in this study the term PTC will be used.

Next to HCPs and patients, informal caregivers (IC) play a fundamental role in PTC,¹¹ particularly when the patient has chronic and proceeding illnesses.¹²⁻¹⁴ One aspect of informal caregiving is to support their loved one in communication with HCPs.^{12,14,15} In consultations, IC often accompany patients to provide emotional, informational, or practical support and to participate in decision-making.¹⁴⁻¹⁶ Involvement of IC is beneficial to gain PTC and becomes more important for patients when illnesses proceed.¹⁷⁻¹⁹ Involvement leads to higher patient satisfaction and more extensive information exchange.^{13,14,20}

Two chronic illnesses in which PTC is required are heart failure (HF) and chronic obstructive pulmonary disease (COPD).^{8,21-23} HF is defined as a complex clinical syndrome characterized by a reduced ability of the heart to pump and/or fill with blood.²⁴ COPD is a lung disease characterized by chronic obstruction of lung airflow that interferes with normal breathing.²⁵ Both illnesses have increasing death rates and a slow decline with severe episodes which impact quality of life.^{24,26}

Several studies have shown roles of IC involved in patient-HCP communication to gain PTC. IC attend in consultation to a) facilitate patients' and HCPs' understanding;^{16,27} b) give emotional support;¹⁴ c) ask the patients' opinion;²⁷ d) exchange information from and towards the patient;^{14,16} and e) play an active role in decision-making.¹⁴⁻¹⁶ Roles of IC vary from passive observing to a highly active role.^{14,16,28}

To our knowledge, existing research has been limited to general patient-HCP-IC (known as triadic) communication research^{14,15} or research on communication with regard to specific patient types, such as cancer patients,²⁸⁻³¹ cognitive impaired,^{32,33} and vulnerable elderly.¹⁶ No research is available on roles of IC in triadic communication of HF- and COPD-patients. As roles of IC differ for each type of patient, insight is needed in these roles to adjust PTC and communication accordingly. Additionally, information is needed on how IC experience these roles.

AIM

The aim of this inquiry is to gain insight in roles informal caregivers see for themselves in communication with HCPs to reach patient-tailored care for their loved ones with HF or COPD. In this inquiry, HCPs are physicians, nurse practitioners and (practice) nurses.

METHOD

Design

A generic, qualitative study design was used. A qualitative design focusses on experiences, thoughts and views of IC on their roles in communication with HCPs.^{34,35} As we wanted to know how IC interpret and experience their roles, a generic design was appropriate.

Population and domain

Population of interest were all IC (≥ 18 years old) of HF- or COPD-patients in the north-eastern part of the Netherlands who are currently involved or were involved in the last year in communication between patients and HCPs. Exclusion criteria were IC a) of dying patients; b) of diagnosed cognitive impairment; c) unable to speak or hear; d) unable to speak in Dutch.

Data collection

Data was collected from January till May 2019. Main study parameter was roles IC see for themselves in communication between HCPs and their loved ones with HF or COPD. Purposeful sampling was used to achieve a maximum variation of IC.³⁴ Patient characteristics were collected to be able to reach maximum variation and gain insight in participants: sex, age, employment, education, residence, relationship to the patient and years of informal caregiving.

Semi-structured in-depth interviews were used. An interview-guide was used to ensure covering a specific set of topics in all interviews.^{34,36} The premiere interview guide was based on previous research on roles of IC in communication with HCPs.^{12,14–16,27,37} This interview guide was adapted after every fourth interview to make questions clearer and to gain deeper insight.^{34,38} Preliminary analysis was used to decide which areas should be examined in more detail.^{34,38} Table 1 shows final topics of the interview guide. Interviews lasted between 26 and 87 minutes. Interviews took place at participants' home or another location when preferred so. The interviews were recorded and transcribed verbatim. Observational notes were made to describe relevant impressions, ideas and thought.^{36,39} Data-collection and analysis took place simultaneously, as an iterative process.³⁴

[Table 1]

Following strategies were used to enhance quality.⁴⁰ First, to establish credibility, prolonged engagement was used, which means investment of sufficient time for collecting data to ensure saturation of key categories. This is also essential for building trust and rapport with participants.³⁶ Second, we took steps to foster reflexivity, which means the researcher is aware that the individual interviewer brings their unique background to the inquiry, by writing down fieldnotes.³⁶ Third, a member check was carried out to provide feedback from the participant. This was done by summarising, repeating and paraphrasing participants' words during the interview.^{34,36} Fourth, to establish transferability, peer debriefing was carried out to detect bias or inappropriate subjectivity.^{34,40} This was carried out within the research-group (JM, MU, LG, JK and LE) and with independent researchers (LvdV and VW) (appendix 2).

Data analysis

Software program Atlas.ti Scientific Software Development GmbH version: 8.4.14 (Evernote, Berlin, Germany) was used to analyse data. Data was analysed according to six steps of thematic analysis: a) recording and transcription; b) coding; c) theming; d) reviewing themes; e) defining and renaming themes and f) combining themes and answering the research question.^{41,42} Several strategies were used to enhance quality of data analysis. First, to establish confirmability, six out of twelve interviews were double coded by JM and another researcher (MU, LvdV, LE or JK). Codes of remaining interviews were reviewed and discussed after every fourth interview. Differences in decisions were discussed until consensus was achieved, purposing to gain objectivity and detect bias and inappropriate subjectivity.³⁴ Second, an inquiry audit took place between research-group members. Decisions were recorded in detail.³⁴

Procedures

Participants were recruited in collaboration with nurse practitioners, community nurses, outpatient clinics 'lung' and 'heart failure' and an IC-organisation. The research-group asked these professionals, who had direct contact with HF- and COPD-patients and their IC, to ask IC for participation. When the potential participant agreed, their personal details were given to the research-group and more information was given to them by phone by JM. When willing to participate, the participant information form and informed consent form were sent by e-mail and an appointment was made. The form was signed before start of the interview.

Ethical issues

This inquiry was conducted following the principles of the Declaration of Helsinki,⁴³ in accordance with good clinical practice, and in accordance with European General Protection Regulation.⁴⁴ The medical research ethics committee of Medisch Spectrum Twente Hospital confirmed that the Dutch Medical Research Involving Human Subjects Act was not applicable to this study. Verbal consent was given to HCPs to give their details to the research-group. Data was uploaded in a secured research cloud and will be stored for ten years.

RESULTS

Interviews were held with twelve participants, five spouses and eight children of a HF- or COPD-patient. Initial consent was given by one person who later refused to participate due to the death of her husband. Demographic details of participants and their loved ones are shown in table 2. From analysis, five main themes emerged: taking control in communication, decision-making, asking questions, practical support and intervening in the process of care. An overview of themes, according roles and which roles IC see for themselves is shown in table 3. Described roles are roles at time of the interview or roles IC had when their loved one died. During the length of caregiving, roles seemed to change in time. This change was independent from which HCPs they had consultations with.

[Table 2]

[Table 3]

Taking control

The non-controller leaves control in communication deliberately to his loved one, while he is still able to speak up for himself and to motivate his decision. The non-controller stated he would take more control in communication when the illness increased.

“As long as she is able. She wants to decide what she keeps under control herself. She doesn’t want to relinquish everything, because than she is totally driven by others.” (R10)

The second type, the controller, takes control in communication. Reasons for doing so are inability of the patient to take proper decisions, usually when cognitive problems are present or when the patient is too ill and physically incapable of making decisions.

“But the medical part of caregiving is left to me. They [other IC] want me to do that, because... My father as well [wants me to take control in communication with HCPs], so...” (R7)

The semi-controller leaves control to the patient but intervenes when he considers this necessary.

“It is not like I don’t say anything, I first leave it to hear. And finally, you are always asked if you have any questions or concerns. (...) So, she takes the lead, quite deliberately.” (R3)

Decision-making

Decision-making in communication with HCPs is done in several ways. The dominant decision-maker makes decisions for their loved one, whether in consultation with HCPs or other IC. This role often appears when cognitive problems are present or when a loved one is very ill.

“No, I’ll do that [make decisions]. Sometimes she does [accept that], sometimes she doesn’t, but it needs to be done this way.” (R1)

Most IC are joint decision-makers. Decisions are made in consultation with their loved one or triangular.

“We discussed everything, how we would do it.” (R6)

The advisor only advises in decision-making and leaves final decision-making to his loved one, even when he does not agree with this decision.

“She knows what she wants. And she makes it clear, this is how I want it and I am boss of my own body. (...) And I follow her decisions. (...) And it is possible I don’t agree with the decision. But this is how she wants it.” (R5)

The fourth type, the non-decider tells he has no part in decision-making because their loved one does not want intervening in decision-making by the IC or because the IC considers it important that their loved one makes decisions on his own.

Asking questions

IC do several things in directing questions to HCPs. The non-asker totally leaves asking questions to the patient. Most IC are included in the second type, the spokesperson. They

ask additional questions they deem necessary, because their loved one freezes up when the HCPs tells certain things, or the IC has different questions from their loved one.

“Because when you hear certain things, at least that is what I’ve noticed when my husband heard thing he didn’t appreciate. He just closed himself off and said yes and okay. And then I said, how exactly? Can you explain?” (R11)

The silent one is the IC who told he deliberately did not ask questions when he accompanied his spouse in consults because he was afraid he would hurt her in what he asked, for example he preferred not to ask his questions or to ask them to HCPs when his wife was outside the consulting room.

“It’s quite easy when you are there (...). I have the feeling I push my wife easily to the ground. And I mean, sometimes you say things you better not say.” (R12)

The last role is the asker, who asks all questions to HCPs in communication, while their loved one does not ask any questions.

Practical support

The driver accompanies to consultations because of the inability of their loved one to go alone. Reasons for this are because they need transport or because they are physically unable to visit the HCP alone.

IC tells that she attends in consultations with her mother only when consultations take place further away: “As long as she doesn’t need a car than it is not necessary.” (R4)

The second listener accompanies in consultations because information is memorized better when two persons attend consultations, and IC can inform other IC what was spoken about.

“After three or four years I joint him. (...) Because than I at least heard what that man [the physician] says. And now I still tell everybody to do that. (...) Go in pairs. With two you hear and memorize better.” (R11)

Intervening in the process of care

The first type is the realist. IC sometimes feel it necessary to add information to information their loved ones give to the HCP. They do this because their loved one does insufficiently feel the severity of their illness, is too modest, or sometimes exaggerates the situation.

“My mother tended to not fully tell what was going on. If she had a broken leg, so to speak, she would tell there was a little tedious in her leg or something like that. So, I felt the need to speak up for her and to sometimes blow the whistle.” (R8)

The lawyer feels the need to advocate for their loved ones, because their loved one doesn't understand what is said or doesn't distinguish the consequence of choices. Another reason for advocating is because of involvement of many different HCPs involved in the situation, who give unclear and inconsequent advice.

“It is a little bit a runaround. Then to the specialist. But that is how healthcare in the Netherlands is designed. When you have certain problems, we look at that problems, but we don't have a holistic view that is considered, like look at the whole patient.” (R8)

The initiator wants change of behavior for several reasons. First, they cannot persuade their loved ones themselves, so they request the HCP to do so. Second, they feel ignorant the way they must handle the situation and need the HCPs' knowledge.

“I am not a professional. (...) So, when I visit a physician, I want him to tell me what is going on. I do not want to find out myself what's the matter. Because then I might as well look on the internet what my disease is.” (R11)

Role-combinations

Although themes are described separately, they are interrelated. Table 3 shows which IC take which roles. It shows a tendency that taking control is always related to joint or dominant decision-making, being a spokesperson or asker and often intervening in process of care. In contrast, the non-controller is often available for practical support, less often intervenes in process of care and is often an advisor or non-decider.

Conditions of IC to fulfill their roles in communication with HCPs

IC state several conditions to fulfill their roles in communication with HCPs to tailor care: a) professional coordination for all involved HCPs to get one clear policy with respect to the holistic view; b) sufficient support from professionals and their environment (e.g. spouse and siblings); c) IC want to be involved in the process of care by professionals and d) proper decision of tasks between different IC.

DISCUSSION

This study shows five themes divided in sixteen roles IC see for themselves in communication with HCPs. Main themes are taking control, decision-making, asking questions, practical support and intervening in process of care.

In order to appreciate findings of this study, some limitations need to be considered. First, recruitment of sample took place only in the north-eastern part of the Netherlands. Therefore, transferability of this inquiry is poor.³⁶ Nevertheless, we are convinced that themes such as decision-making and taking control in communication will also emerge in repeated studies with another place of recruitment, while these themes also emerge in comparable studies conducted in other countries.^{14,33,45} Second, various things which happened during the interviews may have negatively influenced credibility.³⁶ Duration of one interview was 26 minutes, which is short for an in-depth interview. The planned duration of the interviews was 60 minutes, therefore less depth may have been achieved in this interview than wanted. Also, in this interview, the spouse of the IC of whom she was caregiving was present during this interview. This may have limited the IC in what she could say. Another interview took place with two participants at the same time. Both IC were informal caregiving of their mother. Although they both told different things about communication with HCPs, things one said may have influenced the other. During another interview, the partner of the participant suddenly attended the room. This may have distracted the participant, although she was not caregiving for her partner. Third, we deliberately decided to include some IC of persons who recently died, while researchers considered it valuable to know about roles in the entire process of care. However, this possibly led to recall bias.³⁶ Fourth, not all interviews were double coded, which may have influenced dependability. Nevertheless, all codes were reviewed within the research-group and checked on accuracy and consistency. Fifth, meaning saturation of data was aimed but not fully achieved due to the smaller number of participants included than planned. Meaning saturation normally is achieved within sixteen to 24 participants,³⁴ and in this study twelve participants were included. Particularly on the fifth theme no meaning saturation was achieved. Code saturation was achieved on all themes.

Some strengths also need consideration. First, consequent peer debriefing was carried out during the inquiry with independent researchers.^{34,40} We are convinced this detected inappropriate subjectivity and potential bias and thus led to a higher quality of the inquiry. Second, recruitment led to maximum variation of the sample. Spouses as well as children were recruited with a variation in age, length of informal caregiving and stage of illness.³⁶ Third, the qualitative character of this study allowed to gain insight in thoughts and

perspectives of participants, which was considered vital in answering the research question.³⁴ Fourth, this article was written according to the consolidated criteria for reporting qualitative research guideline, a high-quality checklist for explicit and comprehensive reporting of qualitative studies.⁴⁶

Compared to other studies, only three quantitative studies were found examining accompaniment in consultations of HF-patients.⁴⁷⁻⁴⁹ These studies show accompaniment to consultations is associated with higher self-care and self-management,⁴⁷ a greater patient satisfaction on communication,^{48,49} better understanding of advice⁴⁹ and more likely discuss difficult topics with HCPs.⁴⁹ Patients who were accompanied tend to be sicker compared to unaccompanied HF-patients.⁴⁷ No roles of IC derived from these inquiries, so no direct comparison can be made with our results.

Our study primarily states positive effects of accompanied patients in consultations, same as abovementioned studies on accompanied HF-patients.⁴⁷⁻⁴⁹ Our study showed higher PTC due to involvement of IC. We highlight the importance of IC involvement, as this has been expounded as one of six dimensions of PTC.⁵⁰ Furthermore, IC involvement leads to satisfaction in care.^{14,51} Our inquiry shows IC deliberately take certain roles to gain PTC, e.g. they deliberately intervene while they feel the need for this to gain better PTC. On contrary, it is possible they deliberately are low in intervening and taking control because they experience it as PTC to let patients make own choices without interference of others. Troy et al. and Wolff & Roter give reason to acknowledge some negative influences of IC accompanying loved ones in consultations.^{15,45} Negative influences are limiting exchange of information on specific topics such as psychosocial¹⁵ and sensitive information.⁴⁵ Furthermore, HCPs engage in less social conversations when patients are accompanied.¹⁵ These statements are supported by triadic research in cancer³⁰ and cognitive impaired patients.³³ Therefore, we need to stay critical, and always consider what is best to gain PTC.

This study was conducted on IC of HF- or COPD-patients, while we considered roles of IC different for each type of patient. After this inquiry, we can say that outcomes of our inquiry partly correspond with comparable research on triadic communication,^{14,16,33} and thus roles of IC of HF- or COPD-patients partly correspond with roles of IC of patients with other illnesses.^{14,16,31,33} Some specifics must be mentioned. First, emotional support didn't appear as a role in our inquiry, in contrast with other studies.^{14,31} It remains unclear why participants of this study didn't see a role in emotional support, as researchers examined that topic in interviews. A possible explanation is place of recruitment, people who live in the north-

eastern part of the Holland are quite level-headed and therefore may not easily point out their emotional needs. Second, corresponding themes are asking questions,^{16,31,33} decision-making^{14,16} and practical support.^{14,31} This seems reasonable while asking questions, decisions-making and practical support, e.g. driving, is not illness-related.

Outcomes of this inquiry are usable for several purposes. First, when IC attend in consultations with HCPs, it is essential for HCPs to keep in contact with the patient. Although patients may feel a companion is beneficial to consultations,^{33,52} still every HCP must be aware of speaking with the patient instead of speaking about the patient.^{33,53-55} Research shows patients don't see attendance of IC helpful when they don't feel free to speak because of attendance of their IC.^{53,55} Second, IC may consider their role often as a heavy burden and therefore, it is vital to explore their needs and to act upon findings.¹⁷⁻¹⁹ The burden of IC of HF- and COPD-patients intensifies with increase of severity of illness. Changes in role and lifestyle are often long-lasting and difficult, compared with a felt lack of knowledge.¹⁷ Therefore, the IC needs to feel he does not stand alone, e.g. by assessing their burden through an instrument, or by letting IC join care networks to gain tailored care for both patients and IC.

Additionally, further research is recommended. With results of this study, a quantitative follow-up study could be performed to design a tool. Next to this, a quantitative inquiry could focus on how often and in which circumstances those roles appear. Further research needs to be carried out to gain insight in how technology can be used to help IC fulfill their role, as several IC named use of technology in communication with HCPs could support them and their loved ones. Third, involvement of IC in communication becomes more complex when multiple IC are involved.³³ Therefore further research is recommended on how multiple IC may support or counteract each other.

CONCLUSION

This study describes which roles IC of loved ones with HF or COPD currently see for themselves in communication with HCPs to gain PTC. IC are of great importance in current society, especially when their loved one has chronic diseases such as HF or COPD. Roles of IC vary from highly active roles in communication to minimal or no interference in communication with HCPs. Several conditions are named by IC to be able to fulfill these roles, such as sufficient support and involvement in process of care by professionals.

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Table 1. Final interview topics

General questions about loved one of Informal caregiver

Involved HCPs

Description of own role as informal caregiver in communication with HCPs

in:

- Emotional support
- Practical support
- Asking questions
- Decision-making

Origin of current role

Reasons for taking certain roles in communication with HCPs

Possible change in their role as informal caregiver over time

Satisfaction/ acceptance

Possible wishes for change in roles

Possible needed support to fulfill current roles

HCPs = Healthcare Professionals.

Table 2. Patient characteristics of the study population

Informal caregiver							Loved one of informal caregiver	
Participant	Gender	Age	Education ^a	Employment ^b	Relationship to patient	Length of informal caregiving (years)	Age	Illness(es)
R1	Male	51	Middle	No employment, voluntary work	Son	18	75	COPD, HF, cognitive problems, RA
R2	Female	81	Low	No, housewife	Wife	30	84	COPD + HF
R3	Female	42	Middle	Yes	Daughter	6	71	COPD
R4	Female	70	Middle	No, retired	Daughter	35	90	COPD
R5	Female	63	Middle	No, housewife	Daughter	9	81	COPD
R6 ^c	Female	55	Middle	Yes	Wife	5	56 ^d	COPD
					Daughter	2	85	HF, cognitive problems
R7 ^e	Female	57	Middle	Yes	Daughter	3	81	HF, cognitive problems
							82	HF
R8	Female	43	High	Yes	Daughter	2	81 ^d	HF
R9	Female	51	High	Yes	Daughter	2	81 ^d	HF
R10	Male	69	Middle	No, retired	Husband	29	70	COPD, Bechterew's disease
R11	Male	66	Middle	No, retired	Wife	23	83 ^d	COPD + HF
R12	Male	74	Middle	No, retired	Husband	20	74	COPD

R = respondent; COPD = chronic obstructive pulmonary disease; HF = heart failure; RA = rheumatoid arthritis.

^a Low = primary school, lower secondary general, lower vocational; middle = higher secondary general education, intermediate vocational education = high: higher vocational education, university. ^b Employment at time of the interview. ^c Former informal caregiver of husband, currently informal caregiving of mother. ^d Age when loved one passed away.

^e Currently informal caregiving of both mother and father.

Table 3. Overview of themes and associated roles

Theme	Role	Which informal caregivers have these roles?
Taking control	The non-controller	R2 R4 R5 R10
	The controller	R1 R7 R6 ^b
	The semi-controller	R3 R6 ^a R8 R9 R11 R12
Decision-making	The dominant decision-maker	R1 R6 ^b R7
	The joint decision-maker	R3 R6 ^a R8 R9 R12
	The advisor	R2 R3 R11
	The non-decider	R4 R5 R10
Asking questions	The non-asker	R4
	The spokesperson	R1 R2 R3 R5 R6 ^a R8 R9 R10 R11
	The silent one	R12
	The asker	R7
Practical support	The driver	R1 R3 R4 R5 R6 ^b R7 R10 R12
	The second listener	R2 R3 R5 R6 ^a R11
Intervening in the process of care	The realist	R1 R3 R7 R8 R12
	The lawyer	R6 ^a R6 ^b R8 R9 R10
	The initiator	R6 ^b R7 R11

R = respondent.

^a R6 at time of informal caregiving of her husband. ^b R6 currently informal caregiving of her mother.

APPENDIX 1: LIST OF ABBREVIATIONS

COPD	chronic obstructive pulmonary disease
HCP	healthcare professional
HF	heart failure
IC	informal caregiver
PCC	patient centered care
PTC	patient tailored care

APPENDIX 2: ACKNOWLEDGEMENTS

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