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How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study

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ABSTRACT

Aims and objectives: Gaining insight in how people living with chronic conditions experience primary healthcare within their informal network.

Background: The primary healthcare system is challenged by the increasing number of people living with chronic conditions. To strengthen chronic care management, literature and policy plans point to a person-centered approach of care (PCC). A first step to identify an appropriate strategy to implement PCC, is to gain more insight into the care experiences of these people and their informal caregivers.

Design: A phenomenological-hermeneutical philosophy is used. The study is in line with the Consolidated Criteria for Reporting Qualitative Research Guidelines (COREQ).

Method: In-depth, semi-structured interviews with people living with chronic conditions and informal caregiver dyads (PCDs) (n=16; 32 individuals) were conducted. An open-ended interview guide was used to elaborate on the PCDs' experiences regarding primary care. A purposive, maximal variation sampling was applied to recruit the participants.

Results: Based on sixteen PCDs' reflections, ten themes were identified presenting their experiences with primary care and described quality care as: 'listening and giving attention to what people with chronic conditions want, to what they strive for, and above all to promote their autonomy in a context wherein they are supported by a team of formal caregivers, family, and friends.

Conclusion: To meet the PCDs' needs, self-management should be addressed in an interprofessional environment in which the PCD is an important partner. The findings may facilitate a shift to encourage PCDs in their strengths by enabling them to share their personal goals and by working towards meaningful activities in team collaboration.

Relevance to clinical practice: Three strategies – self-management support, goal-oriented care, and interprofessional collaboration - have been suggested to improve the PCDs primary care experiences. These strategies could guide nursing practice in using more and improve high-quality of nursing care.

Keywords: primary care, chronic illness, qualitative study, lived experiences, phenomenological-hermeneutical, nursing practice

What does this paper contribute to the wider global clinical community?

- Primary care providers and especially nurses play a crucial role in the lives of people with chronic conditions and their informal caregivers as they support them in performing essential activities (e.g., taking medication, showering, etc.). Our findings suggest the need to reconsider the roles and responsibilities of primary care providers to encourage and also support people living with chronic conditions in performing meaningful activities (e.g., gardening, knitting).
- Care for people with chronic conditions and their informal caregivers, should pay attention to their needs, what they strive for, and promote their autonomy in a context where they are supported by a team of formal caregivers, family, and friends. By addressing these elements, people with chronic conditions and their informal caregivers can experience high-quality of care.

INTRODUCTION

As a result of the increasing number of people with chronic conditions high quality and accessible primary health care is required to improve coordination and continuity of care (Bodenheimer, Wagner, & Grumbach, 2002; Borgès Da Silva et al., 2018; Dessers & Vrijhoef, 2017; Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004; Haggerty et al., 2008). Moreover, a person-centered care (PCC) approach is needed since each individual has different experiences towards primary healthcare (Bodenheimer et al., 2002; Wagner et al., 2005). The main objective of this study is to gain in-depth insight into the daily lives of people living with chronic conditions and their informal caregivers, support they need regarding primary care, and the organization of primary care.

BACKGROUND

In Europe, more than 50 million people have multiple chronic conditions (van der Heide et al., 2015). In Belgium, this is estimated at one-third of the national population and is increasing each year (Van der Heyden, 2018). Chronic conditions, defined as conditions lasting at least one year and requiring ongoing medical attention and usually limiting daily living activities (Hajat & Stein, 2018), are associated with higher mortality, reduced functional status, and increased rate of consultations in health care and medication use (Cassell et al., 2018; Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004; Niessen & Squire, 2019).

In 2007, the World Health Organization (WHO) formulated a response to the increasing prevalence of chronic conditions by recommending a reorganization of current healthcare systems towards a PCC approach. This approach emphasizes the needs of people with chronic conditions to be informed about their conditions and empowered in promoting and protecting their own health (World Health Organization. Regional Office for the Western, 2007). PCC is currently considered the key concept for primary health care settings. It not only includes the person during the care process, but also guides the care providers to respect choices and autonomy of people with chronic conditions (Kogan, Wilber, & Mosqueda, 2016; Smeets, Kroese, Ruwaard, Hameleers, & Elissen, 2020). Therefore, PCC requires that health providers have good knowledge of their needs and preferences (Kogan et al., 2016).

Scientific literature has shown the importance of being listened to, being appreciated, feeling safe, and independent (Foo, Sundram, & Legido-Quigley, 2020; Kuluski et al., 2019). Numerous studies have analyzed people's experiences of primary healthcare using various research methods in a variety of populations (Burt et al., 2017; Norwood, Correia, Veiga, & Watson, 2019; Salisbury, Wallace & Montgomery, 2010). This has led to a large heterogeneity and findings, many of which are context- and care-specific (e.g., end-of life care, self-management, treatment, involvement in shared-decision making, health outcome prioritization/ goal-setting, healthcare service delivery, and screening/ diagnostic testing) (Gonzalez et al., 2019). To our knowledge, Kuluski et al. (2019) are the only research group who have performed qualitative research with people with multimorbidity and informal caregivers to capture their priorities more broadly, without focusing on specific issues (Kuluski et al., 2019).

In addition to the literature, the relevance of listening to people with chronic conditions ~~patients~~ is expressed in governmental plans, local, and worldwide. In Flanders (the Dutch speaking part of Belgium), the primary care system is currently undergoing a transition from acute to chronic care including a shift towards PCC based on the WHO global strategy (WHO, 2015). This shift is based on three pillars: 1) people must be empowered to participate in their care processes, 2) care delivery should be adapted to the needs of people with chronic conditions, and 3) informal caregivers are an essential pillar in the outpatient care processes, especially for vulnerable older persons (Morgan & Yoder, 2012; Plöthner, Schmidt, De Jong, Zeidler, & Damm, 2019). Informal caregivers should be considered as full partners in care and should have the possibility to provide input into the care process of their relatives (Organization, 2015). Including the perspectives of both the people with chronic conditions and their informal caregivers could contribute to integrated care systems that enable PCC (Kodner, 2002; Kodner & Spreeuwenberg, 2002; Toscan, Mairs, Hinton, Stolee, & Team, 2012).

Although, both the literature and governmental plans describe the importance of the PCC system, the translation into practice has not yet been realized (WHO, 2015). To succeed in this transition, an important prerequisite is to gain more in-depth insights into care experiences of people living with chronic conditions and their informal caregivers. This applies not only to the Flemish context, but also worldwide, as primary care is undergoing a shift from acute to chronic care (WHO, 2015). In this shift, nurses are being given a prominent role, as they seem to be key figures in the lives of people living with chronic conditions and their informal caregivers (Sousa et al., 2021). In addition, nurses are getting more and more involved in primary care (e.g., home environments, general practices) to deal with the increasing number of people with chronic diseases and support them in living autonomously for as long as possible (Mustafa, Adams, Bareham, & Carryer, 2021). Because Flanders is currently undertaking a reorganization of primary care, this context is a relevant opportunity to expand knowledge on how people with chronic conditions and their informal caregivers experience primary care. In addition, most available Flemish studies are performed in the hospital settings instead of primary care settings (Van Humbeeck et al., 2020; Van Wilder et al., 2020) and of the diversity of people and conditions is poorly addressed, since most studies focus on one specific disease or population (Forman et al., 2018). Therefore, our study aims to get a broad picture of primary care experiences of diverse populations of people living with chronic conditions in Flanders.

To support the shift towards PCC in Flanders, the Primary Care Academy (PCA), a consortium of four universities, six universities of applied sciences, patient representatives and White-Yellow Cross (Flemish home care organization), has been established. The PCA aims to strengthen the capacity of primary care by developing interventions, optimal roadmaps, and hands-on toolkits for primary care policies, practice, and education. The PCA adopted therefore the guidelines of the Medical Research Council (MRC) (Craig et al., 2008). The study reported here is a first step in the entire project and aims to contribute to the identification of an appropriate theory to implement PCC in the Flemish primary care context (Craig et al., 2008). The phenomenon under investigation in this study is the daily life of people living with chronic conditions and their informal caregivers, what support they need from their primary care providers, and how primary care is organized. The corresponding research question is: how do people living with chronic conditions and their informal caregivers experience primary healthcare in Flanders?

METHODOLOGY

DESIGN

This study used a qualitative study design with a phenomenological-hermeneutical philosophy following Lindseth and Norberg (Lindseth & Norberg, 2004). The combination of both epistemological backgrounds (phenomenology and hermeneutics) allowed us to examine the meaning of the experiences of people living with chronic conditions and their informal caregivers with primary care (phenomenology) as well as to interpret the transcripts describing this phenomenon (hermeneutics). In this study, the phenomenon under investigation is the daily life of people living with chronic conditions and their informal caregivers, what support they need from their primary care providers, and how primary care is organized. It responds to the ongoing transition from acute to chronic care, especially in primary care. This study complies with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Supplementary File 1) (Tong, Sainsbury, & Craig, 2007).

RESEARCH TEAM

This study is conducted by a team of researchers with different professional backgrounds: occupational therapists (DB, F, Drs; DVdV, M, PhD & PDV, F, PhD), pharmacists (MMS, M, Drs & LT, F, Drs), registered nurse (MLH, F, PhD), and gerontologist (PDV). This ensures a diverse and broad perspective when analyzing the data of PCDs.

PARTICIPANTS AND SAMPLING METHOD

In total 32 individuals, comprising 16 people with chronic conditions informal caregivers dyads (PCDs), consent to participate. The informal caregivers were proxies of the people with chronic conditions and provided voluntary support by helping them with essential or meaningful activities. To recruit these PCDs, a maximal variation, purposeful sampling was used. The sampling was based on the definition of people with complex care needs operationalized by Iglesias (2018) (Iglesias et al., 2018). Participants were included when they met the following main criteria: a) having a single severe chronic condition or multimorbidity, b) having the support of an informal caregiver, and c) getting support from three or more primary care and welfare providers (e.g., family doctor, pharmacists, social workers, etc.). Maximum variation was sought when the participants met one of the following additional criteria: d) taking four or more different medications related to their chronic conditions, or e) having a higher need of care, or f) having a

low socio-economic situation, or g) lacking health literacy, or h) showing the need for more care according to at least one member of the primary care team. Inclusion criteria were selected to recruit people with chronic conditions that could serve as exemplars due to their chronicity and the frequent and ongoing interactions they have with a range of health professionals. Participants were excluded when they were: a) under the age of 18, b) legally incapable, c) incapable to reason about care (e.g., severe mental illness, cognitive impairment), d) incapable of being interviewed for 1 hour, e) unable to provide informed consent, and f) terminally ill.

People with chronic conditions were recruited using flyers distributed via health and welfare organizations, and family doctors, the latter being the central contact point for the patients and researchers. Upon giving oral informed consent to the family doctor, people with chronic conditions indicated their main informal caregiver. All participants who were contacted were interviewed. Then, researchers contacted the person with chronic conditions or informal caregiver to introduce the study and schedule the interview. Written, informed consent was obtained before the start of the interview.

DATA COLLECTION

A qualitative, semi-structured interview technique was chosen to explore the PCDs' point of view and their unique care experiences reflecting their care situation. Prior to constructing the interview guide, gaps in literature regarding primary care were identified. Thereafter, several brainstorm sessions were organized with the authors to develop this interview guide and to collect sufficient data about the care experiences, preferences, and needs of people with chronic conditions and their informal caregivers. Interviews were conducted with PCDs with the focus on the care experiences of people with chronic conditions. The informal caregiver was able to complete the answers or help to elaborate on the questions, which could possibly result in deeper insight in the care experiences, as described by Morgan et al. 2013 (Morgan, Ataie, Carder, & Hoffman, 2013).

The semi-structured in-depth interviews started with the daily life and activities of the PCDs during the last week using the question: 'Tell me. What did your last week look like, and 'What did you do?'. These opening questions were followed by topics covering the care experiences of people with chronic conditions, support they receive from formal and informal caregivers, the way PCDs are involved in their care, and their care needs. By using eliciting probes, the PCDs were encouraged to elaborate and deepen their answers.

The interviews were conducted between January 2020 and August 2020; physical interviews at home environments of the person with chronic conditions, or by videocall due to COVID-19 measures imposed by the Flemish and national government. The interviews were conducted by the three principal researchers who were trained in qualitative research techniques (DB, MMS, LT). Data collection and analysis were done simultaneously to confirm or refute the preliminary findings until data saturation. This strategy allowed identification of specific gaps for which more information was needed and to tailor the focus of the interviews with the remaining PCDs. No member check was performed and transcripts were not returned to the participants. Before data collection and analysis, the researchers performed reflexive bracketing to decrease the influence

of pre-conceived understanding. This approach reduced the risk of confirmation bias by the researchers and thus increased the neutrality (Lincoln & Guba, 1988).

DATA ANALYSIS

The interviews were audio-recorded, transcribed verbatim, and combined with non-verbal observations such as emotions. No software program was used to manage the data and interviews were coded manually. Analysis according to the three-step method of Lindseth and Norberg (2004) was conducted: 1) naïve understanding, 2) structural analysis, and 3) comprehensive understanding. All steps were guided by an inductive logic. To describe the naïve understanding, the principal researchers (DB, MMS, LT) read the entire interviews and formulated an initial and personal understanding. These individual naïve understandings were discussed with the co-authors (MLH, DVdV,, PDV) and gave rise to one overall naïve understanding. Subsequently, a structural analysis was conducted for which data were broken down into meaning units and condensations resulting in themes as shown in Table 1. Meaning units were parts of transcript containing information about experiences towards primary care. The structural analysis was an iterative process containing three stages. First, one interview was analyzed together by the three principal researchers to gain common insights in the data. Second, five more interviews were analyzed simultaneously by two researchers to serve as validators for each other. These analyses resulted in a preliminary overview of the themes and were presented to the co-authors to serve as extra validation to increase credibility. Third, ten more interviews were conducted, analyzed individually, and integrated with the first analysis. Based on these three stages, preliminary themes were presented, discussed, and reformulated in final themes by all the authors. In the last stage of the structural analysis, the themes were presented to all senior researchers of the Primary Care Academy (PCA) and discussed until consensus was reached. Finally, the comprehensive understanding was developed to create an overarching reflection of the results related to the themes of the structural analysis. All the three steps were guided by an inductive logic.

ETHICAL CONSIDERATIONS

Approval was obtained from the Ethical Committee of Antwerp University Hospital with the file number (B300201942302). The study was in accordance with the principles outlined in the Declaration of Helsinki. The participants received verbal and written information about the purpose and methods of the study. The informed consents were approved by the above-mentioned Ethical Committee. People with chronic conditions and their informal caregivers were informed that participation was voluntary, and that confidentiality would be ensured. All participants gave written informed consent in advance.

RESULTS

A total of 16 PCDs, comprising 32 individuals (16 people with chronic conditions and 16 informal caregivers) were interviewed (characteristics presented in Table 1). No participants refused to be interviewed. People with chronic conditions had a mean age of 67.5 years; of which 11 were female, and 13 were retired. For informal caregivers the mean age was 66.8 years, and 11 of the 16 PCDs were living together. Since this study is based on the shared input during the interviews from the PCDs, the results are presented as shared views and experiences. Therefore, the word

'PCDs' or 'participants' are used to emphasize that the results of both people living with chronic conditions and informal caregivers. When their views were different, this is explicitly indicated using the words 'people with chronic conditions' or 'informal caregivers'.

Table 1. Overview of the participants' characteristics

Characteristic	Patients (N=16)	Informal caregivers (N=16)
Sex, <i>N</i>		
Female	11	9
Male	5	7
Age in years (range)	67.5 (44-89)	66.8 (45-82)
Civil registration, <i>N</i>		
Single	4	1
Married	12	15
Relationship of informal caregiver with patient (CH = cohabiting)		
Partner		10 (CH = 10)
Parent		2 (CH=1)
Child		4
Employment		
Employed	0	1
Unemployed	0	1
Unemployed due to disability	3	3
Retired	13	11
Inclusion criteria (multiple criteria possible)		
Taking four or more types of medications	11	
Having a higher need for care	6	
Having a low socio-economic situation	3	
Lacking health literacy	3	
Showing the need for more care according to at least one member of the care team	2	

NAÏVE UNDERSTANDING

The interviews showed that the people with chronic conditions preferred to live at home and stay engaged in meaningful activities despite their chronic conditions. Their informal caregivers confirmed these preferences. The people living with chronic conditions expressed the needs for regular support for performing meaningful and essential activities from their informal and formal caregivers. In addition to the central (in)formal caregivers, the broader social environment, such as family members and friends, played a significant role in terms of practical support and for listening. Furthermore, the narratives showed that the independence of people with chronic conditions increased by reorganizing activities and adapting them to their current capabilities with or without the use of assistive devices. Elaborating on the competences and skills of the care professional, PCDs expected a sufficient level of professional expertise of them, encompassing both practical and emotional skills. In fact, PCDs longed for more personal contact and the feeling

of being heard, through open communication with formal caregivers. This open communication seemed to be facilitated when PCDs were actively involved and experienced co-determination in care-related decisions. PCDs also mentioned that (interprofessional) communication could connect different partners in their care to facilitate coordination. Finally, PCDs experienced major barriers that impede caregivers to deliver high quality of care as they face for example barriers regarding reimbursements.

STRUCTURAL ANALYSIS

The structural analysis was based on condensing the meaning units and reorganizing into themes (see Table 2 for an excerpt from an analysis) and resulted in ten themes, which are presented in Table 3 and highlighted with illustrative quotations from different PCDs interviews. Each quote indicates whether the information was from a person living with chronic conditions (P) or informal caregiver (IC) and is added with the number as indicated in the table.

Table 2 Example of structural analysis of a meaning unit

Meaning unit	Condensation	Themes
“Yes, the homecare nurse is coming every week to help me shower, then she puts me in the shower.”	Homecare nurse helps with showering.	Performance of essential activities supported by a team of (in)formal caregivers.
“... in the morning, I always have to wait for the homecare nurse. They come always at different times to help me dress. So, I always have to wait...”	Waiting for the homecare nurse who comes always at different times.	Care coordination as part of care continuity.
“We are knitting blankets for the children hospital... I am looking forward to Saturday... The hospital has asked to make blankets in the colors of the minions...”	Knitting blankets for the children hospital and looking forward to handing over them.	Meaningful activities to create a fulfilling life.

1. Autonomy to be in charge of health and welfare decisions
2. Meaningful activities to create a fulfilling life
3. Performance of essential activities supported by a team of (in)formal caregivers
4. Supportive network to participate in society
5. Practical and psychosocial support to manage meaningful and essential activities
6. Balance between practical and emotional formal caregivers' skills
7. Patient-provider dialogue to achieve open communication
8. Involvement of people living with chronic conditions to facilitate 'care decision-making'
9. Care coordination as part of care continuity
10. Barriers to provide good care

Table 3 Overview of the themes

1. Autonomy to be in charge of health and welfare decisions

Autonomy was expressed as a main life goal for the people with chronic conditions and their informal caregivers. They experienced autonomy as the ability to engage in activities they can carry out themselves, the ability to make their own decisions, and the freedom to go wherever they want to go. The analysis showed that PCDs strived to remain in charge of their own lives. When they felt no longer autonomous, they experienced the fear to lose individuality and their uniqueness.

"I have always been someone who was independent, did everything myself, never asked for help. For me, it is a huge step to ask someone, my son or family, for help [e.g., help with dressing]. Just putting my walking aid downstairs for a moment is very difficult. I feel my independence slipping away, I find it annoying. I try to do all that by myself, but then I am so tired." (P - P14)

While the PCDs expressed their wish to stay autonomous for as long as possible, they also feared to be placed in a nursing home. To experience a feeling of prolonged autonomy and independent life, PCDs replied within the constraints of their own possibilities to stay home, for example through acquiring assistive devices to increase mobility.

"I am afraid of going to a nursing home. You will no longer be independent. Everything is arranged for you. Goh... As long as you live at home, you can do everything you want. Sometimes we [informal care giver to partner] say to each other: 'Let's hope she [patient] doesn't have to go to a nursing home.'" (IC - P4)

2. Meaningful activities to create a fulfilling life

When PCDs were asked to define a good day, they mostly reflected upon their engagement in meaningful activities (e.g., from knitting blankets for the children's hospital to going to flea markets, etc.). These activities created fulfillment and purpose for both people with chronic conditions and their informal caregivers. The performance of meaningful activities confronted PCDs with the deterioration of the person with chronic conditions since the extent of disabilities played an important role in how these activities were done. Therefore, PCDs had to find mutual connection in their activities, and were challenged to rearrange their activities, or discover new ones.

"We are still rearranging [e.g., restructuring activities]. Now I have to cook in several times while I used to do once... I also do some woodwork for a few hours in the hobby room and do some gardening. We rearrange ourselves to the things I am still able to do." (P – P10)

It was mainly the informal caregivers who had a hard time maintaining his/ her meaningful activities because they had to spend a lot of time providing care. A variety of coping strategies were reported by the people with chronic conditions some changed their lifestyles according to their abilities and stated that this did not affect their happiness. They were grateful and are *'taking the day as it comes'* (P - P6). These PCDs showed a positive outlook and realistic vision on the future.

"I'm actually someone who always looks for the positive in the negative. For example, I say: 'now I have the chance to see the sun going down'. Instead of earlier, while I used to be working or helping at home. Now this is no longer possible." (P – P6)

Others experienced feelings of dejection, losing interest in activities and expressed that they *"had nothing to strive for anymore"* (P- P5). These people with chronic conditions longed nostalgically for old times and regretted that they were not able to perform the activities they used to perform earlier.

"My mood...is not to talk about. How do I have to call it... Close to depression. I fight against it. I said to myself 'there are people who are worse off'. Then I start thinking what could be worse... Right? It is not fun. I am... sad..." (P– P5)

3. Performance of essential activities supported by a team of (in)formal caregivers

In addition to meaningful activities, PCDs also expressed they had to perform essential activities to make it through the day. Essential activities included showering and dressing, but also, for example, going to the physiotherapist and pain clinic.

Some people with chronic conditions were able to perform these essential activities autonomously, others needed support from their informal caregiver who was seen as indispensable to cope with their situation in various ways. Informal caregivers offered practical (e.g., household chores) as well as psychosocial support (e.g., offering a listening ear) but also tried to entertain the ones who they cared for by taking them out and going on excursions together. For these reasons, informal caregivers were described as *"key figures"* (P - P2).

“Concerning showering. Since her fall, she [p] never takes a shower by herself anymore and has to use a chair. And if she had to bend down to wash herself I [IC] stood behind her and held her like this [places her hands in her side].” (IC – P2)

Although informal caregivers “*did their utmost*” (IC - P2), support from formal caregivers (e.g., physiotherapist, home nurse, general practitioner) remained inevitable. They offer not only medical support, but also give advice and education (e.g., how to increase mobility). Formal caregivers supported people with chronic conditions with essential activities (e.g., dressing). With some, PCDs had bonded over the years, resulting in a strong connection. According to the PCDs, the good formal caregivers aimed to assist PCDs to live their lives to the fullest and as autonomously as possible. With the help of formal caregivers in essential activities, people with chronic conditions could use their energy more efficiently to perform meaningful activities.

4. Practical and psychosocial support to manage meaningful and essential activities

An important role emerged for practical and psychosocial support. Practical support was often related to assistive devices (e.g., a walking aid, a wheelchair, handles in the bathroom, and a stair lift). For PCDs, those devices were considered essential in remaining independent in their daily activities. In some cases, greater adjustments, such as home-modifications, were essential to allow people with chronic conditions to continue living in their own houses. For this reason, modifications were positively received, but required financial resources or homeowners willing to make the necessary changes.

“The homeowner has installed a walk-in shower, so I don’t have to climb [over the bathtub which was removed] over and we have also installed a sauna [for the pain]. I think that is fantastic...I go in there once or twice a week.” (P – P11)

PCDs expressed that psychosocial support, for example finding distractions in shared leisure activities was equally important as practical support. Some PCDs found also support in talking with peers through which “*they found an equal (Patient - P4)*”. Peers listened based on their own expertise or were “*companions (P4)*” to undertake activities to forget about worries. In contrast, other PCDs found contact with peers conflictive, because they were faced with their own functional deterioration compared to the observed better functioning of these peers.

“I have a good contact with a fellow MS [Multiple Sclerosis] patient, who is worse off than me. Sometimes I invite her to come over and relax in the garden. We are both interested in culture. We exchange experiences, things we’ve been through [e.g., visit to a museum] ...We don’t talk about our disease.” (P - P9)

Another aspect raised by the participants was digital tools for the treatment and control of chronic conditions that have changed a lot. The use of applications, Internet, and social media offered support. However, they often doubted the reliability of the outcomes. Therefore, this innovative support was experienced by the participants as novel, but not providing yet enough trust to consider reliable.

5. Supportive network to participate in society

The social environment of PCDs varied from family members and friends to neighbors. Yet others had limited social contacts and had to rely mainly on themselves. The way this social environment was organized determined the amount of support PCDs received.

“They all [family e.g., children] live nearby. Yes, otherwise I wouldn’t be able to live here, if they would live further away [family is helping her with daily activities]. I would enjoy staying here until I die. In my small house...” (P – P4)

The proximity of family members, in which the PCDs put trust, resulted for them in a sense of stability and the possibility to live as autonomous as possible. However, the impact was strongly dependent on the availability, the work-life balance, the financial situation, and the health condition of their family members.

“Because my sister has her own family, she must take care of her household and her work, she can’t take care of me on her own. That’s a bit disappointing... I’ve already discussed with my mother...when I will be alone later that I would like to have someone to support me in cooking...” (P – P7)

The social environment had a positive impact on the situation of the people with chronic conditions but some PCDs also faced a decrease in social contacts as the functional capabilities decreased. In addition, PCDs experienced a feeling of being excluded from society due to external reasons e.g., inaccessible public places, family and friends who do not have the opportunity to invite PCDs for a visit because their house is not accessible. These external factors hampered PCDs to spontaneously interact with others and to go wherever they want to go, reflecting a lack of autonomy. Also, not every PCD could rely on a supportive network and expressed to *“living on an island (IC - P13)”* hampering the management of meaningful and essential activities.

6. Combination of emotional support and practical skills to fulfill the needs of people with chronic conditions

Previous themes illustrated the need for PCDs to be supported by formal caregivers in essential activities. However, in addition to the need for practical information, PCDs required emotional support from formal caregivers. They expressed the need for balance between practical and emotional caregivers’ skills. From the narrative analysis, practical skills could be described as having theoretical knowledge and skills to provide the appropriate and technical treatment, expressed by PCDs as *“formal caregivers have to do their job.” (Patient - P15)*. Whereas emotional skills gave PCDs the feeling of being heard and treated as a person ‘who has an illness’ instead of ‘who is the illness’.

“The most important thing is to build a relationship of trust. This isn’t possible if there is no understanding or empathy from the caregiver to the person with chronic conditions ...Authenticity...That a caregiver also shows a piece of himself, also show that he is human. Professionalism and knowledge are also extremely important and that is where I set a high standard, the importance of education and continuing learning.” (IC – P12)

When reflecting on the emotional support, PCDs expected their formal caregivers to ask adequate questions, have a level of increased empathy, be authentic as a person, and pay attention to the person as a whole. Formal caregivers should also be able to “*intuit the needs of people with chronic conditions*” (P- P14)”, to “*discover their unexpressed needs*” (P - P14), and to adapt their treatment approach to the personality of the person with chronic conditions. When PCDs experienced a lack of empathy they tended to change to another formal caregiver.

7. Dialogue between people with chronic conditions and providers to achieve open communication

“*Communication goes both ways (IC - P15)*” reflects the need for a dialogue between the PCDs and their formal caregivers. People with chronic conditions experienced that they want to share their story; formal caregivers in turn must provide the right context for them to share their concerns. For this, trust was of utmost importance. PCDs gained trust when time was offered, when there was a longstanding relationship with the formal caregiver, or when they gained a second opinion to confirm a previous diagnosis.

“*It is not that familiar as in e.g., the rehabilitation center ... You miss tenderness. In the rehab center they take time to talk about how you feel and what you want to do. I think that is important. They provide time and space to you share our problems.*” (P – P16)

Open communication was also improved when adequate information was offered, expressing honesty about the diagnosis, treatment options, treatment method, and medication regime. In the following quote, a person with chronic conditions reflected on a situation when she did not receive adequate information to share her own diagnosis with her family.

“*How I was supposed to tell my husband and my children [just after receiving the diagnosis of MS]? The doctor said: ‘there is Internet and a library Miss.’ So, I started looking on the Internet.*” (P – P6)

In addition, the physical context in which the communication occurs must allow and facilitate open and personal communication (e.g., using a laptop to take notes was indicated as a main obstacle hampering a trustfulness open conversation).

8. Involvement to facilitate ‘care decision-making’

People with chronic conditions expressed the wish to be involved in their care processes, for example by participating in the search for the best treatment. Involvement gave them a sense of safety that made them feel respected and gave assurance that the treatment was for their own good, which in turn increased the adherence. As a result, trust towards their informal caregiver and their decision-making was facilitated.

“*I am someone who enters a discussion with the medical doctor about my health... with my family doctor and my neurologist. I want to hear the various options which I will go for.*” (P – P6)

Participants were convinced that active involvement in their care process created different prescribing by the caregiver.

"If I go to the family doctor, he asks whether we would try this medication, or we prefer something else. So yes, I'm involved in the decisions." (P – P3)

9. Care coordination as part of care continuity

Participants received support from a broad range of providers to handle their conditions. It was important for them that those formal caregivers worked together and communicate with each other. This means that care must be *"well-coordinated (IC - P8)"*.

Coordination was also mentioned as essential to ensure care continuity. This included communication among (in)formal caregivers and people with chronic conditions. PCDs preferred interaction with the entire team that contributed to better care and a more personal approach. Also, care coordination was mentioned in the context of the follow-up of previous diagnostic tests. Nowadays, *"it is all in the computer (IC - P2)"* and facilitated by electronic and shared patients' records.

"Caregivers must dare to broaden their view and look beyond their own discipline. They must open up to have contact with other caregivers, so they become one. In that case, the person with chronic conditions would be supported by a network of caregivers." (P – P12)

Although participants expressed the need for coordinated care, they experienced a lack of coordination and communication among professionals from different organizations and levels. For example, they experienced too little communication from the hospital towards the family doctor when someone was discharged. People living with chronic conditions desired better follow-up, especially from their family doctor, who should be aware of recent events that they experienced. The PCDs suggested a home visit from their family doctor immediately after being discharged from the hospital as a possible way to guarantee a better follow-up.

"And the family doctor comes on a home visit. He said to her: 'see you in 4 - 6 weeks'. How is this possible?!? She [P] just left the hospital, with all her worries and he said, till 4-6 weeks! Someone should, after leaving the hospital with a severe disease or so, warn the family doctor. Now you have to call him [FD] yourself which can take 2-3 weeks." (IC - P3)

In addition to better follow-up, PCDs needed structure and certainty from their formal caregivers. In the case of home nurses, people with chronic conditions preferred the same nurse on the same hour to help them with their morning routines. This contributed to personal contact and trust bonding between the patient and the home nurse because they were continuously building on a sustainable relationship.

10. Barriers to provide quality care

Administrative procedures (e.g., application for refunds) were expressed as the main barrier to quality care. For example, PCDs got bogged down in bureaucracy when they applied for reimbursements of assistive devices. The use of applications took too much time and effort and were often too complex to understand resulting in inconsistent information to make the right decisions.

“Why should I prove that I have disabilities? It was not my first application. They [insurance company] do not realize that my condition is progressive. It was only after the renovation of our bathroom that they [insurance company] asked for a proof of invalidity...I got negative response...Then I had to defend myself and all they asked was why I have chosen a specific system...Now I am already waiting for nine months for an electric wheelchair...It always take so long...” (P – P15)

The struggle with administrative procedures led to sadness and frustration on top of the negative feelings some PCDs already experienced as a result of having the chronic condition. PCDs also experienced difficulties in finding leisure activities, contact with peers, or finding advice for modifications to their house and transport. PCDs felt on their own in finding their way through procedures and expressed this as *“a full-time job (IC - P15)”*. If support was provided, PCDs could focus on activities that give purpose to life.

COMPREHENSIVE UNDERSTANDING

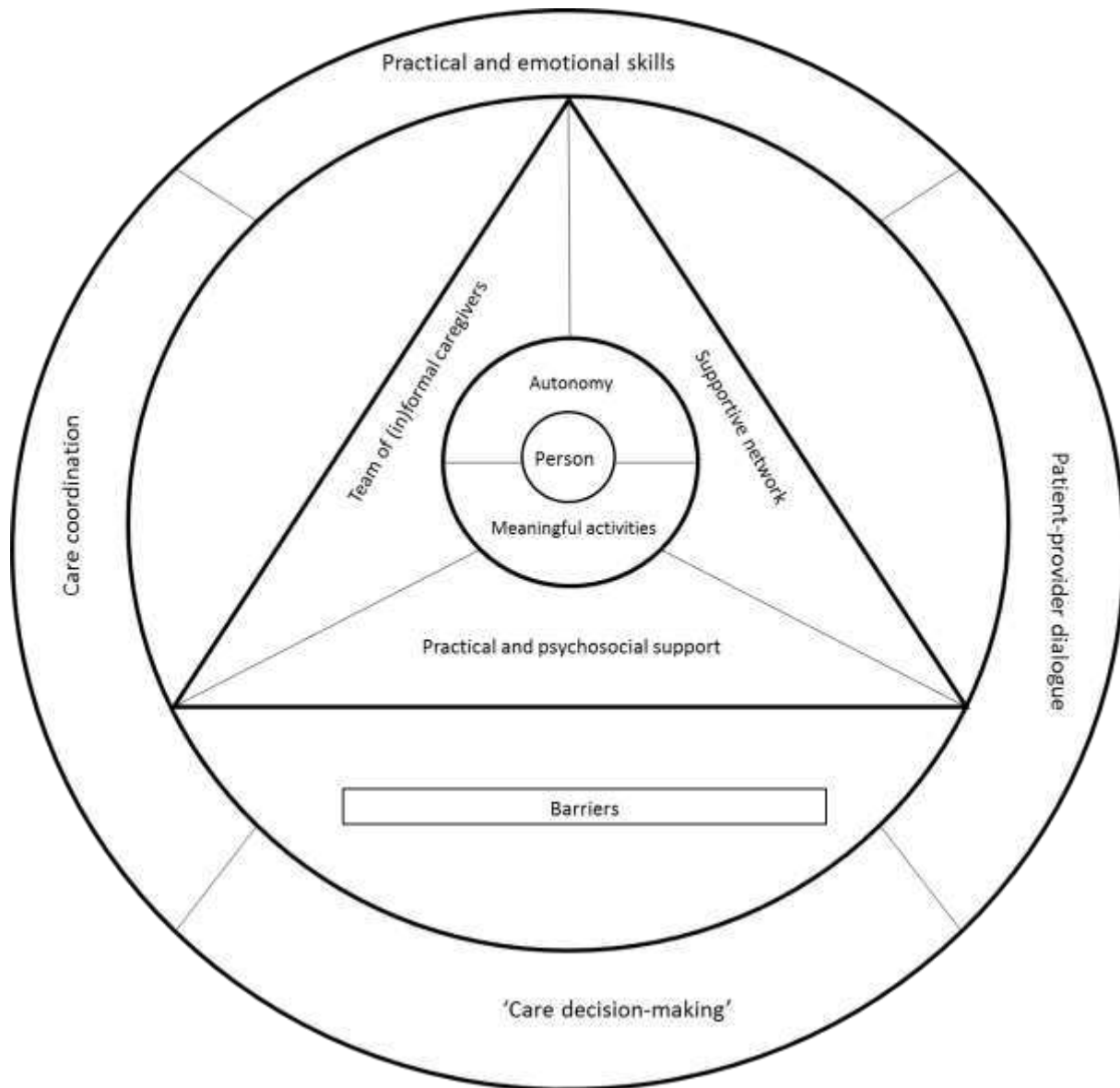
The naïve understanding and the identified themes from the structural analysis were re-read as a whole to see how they interrelated and to formulate a comprehensive understanding. By doing so, patterns between the themes and thus the lived experiences of people living with chronic conditions regarding their care situation were articulated. This allowed us to visualize the associations among the different themes, illustrated in Figure 1.

When someone is diagnosed with a chronic disease, this illness does not stop the person from being an individual human and having needs and preferences. PCDs expressed that it is of paramount importance that health care providers are capable to go beyond the level of purely functional and essential activities (e.g., washing, bathing, and clothing) to the level of meaningful activities and encounters. Although essential activities were necessary to get through the day – and for some it can even mean the beginning of their day – it was very important to find meaning in several ways: meaning in activities one performs, meaning in one’s relationships with family and friends, but also meaning in the relationship with one’s caregivers, and finally meaning in life. The search for meaning determined how people with chronic conditions interacted and coped with their conditions; a constant balance between what was strictly necessary on the one hand and what gave satisfaction and meaning in life on the other. The latter led to a satisfying care process that emphasizes the diagnosis and treatment adding that extra level of being treated as a person. Reading the person and being able to ask the unasked question to discover the unexpressed needs of people with chronic conditions, determined a ‘quality caregiver’.

PCDs expected formal caregivers to change how they delivered care and required that they look beyond their professional perspective of logical care solutions and assumptions. They should acquire skills to intuit the needs of people with chronic conditions. This intuitive ‘reading’ made these people feeling seen, heard, and committed in their care process. Quality care was described by the PCDs as listening and giving attention to what they want, to what they strive for, and above all to promote their autonomy in a context wherein they are supported by a team of formal caregivers, family, and friends. These elements could be found in care that starts from personal and meaningful goals in which care was delivered based on the needs and preferences of people living with chronic conditions and informal caregivers, while supporting their self-management,

as prioritized goals, and encouraging them to live their life regardless their chronic conditions. Citing the PCDs, this could only be reached in a strong interprofessional collaboration in which the team worked together – among each other and with the PCDs- to that what was important to them.

Figure 1 schematic representation of the themes



DISCUSSION

This study provides a broad picture about the daily life of people living with chronic conditions and their informal caregivers, what support they need from primary care providers, and how primary care is organized.

PCDs reflected on the importance of being autonomous, demonstrated by performing meaningful and essential activities. Therefore, PCDs needed support from a social environment of family and friends, formal caregivers, and in some cases assistive devices. Throughout these activities and relationships, their personal values should be mirrored. Consequently, PCDs expected to be treated as an equal partner that includes open communication. All this should take place in a context where collaboration among the PCDs and formal caregivers was facilitated. According to the PCDs, quality care was described as: *'listening and giving attention to what the people with chronic conditions want, to what they strive for, and above all to promote their autonomy in a context wherein they are supported by a team of formal caregivers, family, and friends.*

These findings confirm other recent studies exploring the needs and preferences of people with chronic conditions. This is not surprising as the aim of this study was to start 'tabula rasa' and truly explore the experiences from the PCDs themselves. Common themes seem to be the need for person-centered open communication (Epstein & Street, 2011; Hashim, 2017; Noël, Frueh, Larme, & Pugh, 2005; Timpel et al., 2017; Zoffmann, Harder, & Kirkevold, 2008; Zoffmann et al., 2016), involvement in the care process (Epstein & Street, 2011; Timpel et al., 2017), a supportive network (Lopez Hartmann et al., 2016), and adequate multidisciplinary coordination (Berntsen et al., 2018). Despite similarities in results, these studies were slightly different since previous studies have focused on the experiences of people with chronic conditions and not of PCDs. However, informal caregivers should be considered as full partners in care and their presence could improve the research process for people with chronic conditions who lack communication skills (Dixe et al., 2019; Epping-Jordan et al., 2004; Norouzinia, Aghabarari, Shiri, Karimi, & Samami, 2015; Organization, 2010; van Dongen, Habets, Beurskens, & van Bokhoven, 2017). Based on our observations, the presence of informal caregivers allowed people with chronic conditions to elaborate more on their care experiences, because they felt supported, which allowed us to gain more insight.

While most of the studies focused on specific components of care (e.g., collaboration, communication), we addressed the large majority of health and social needs of people with chronic conditions from a wide range of chronic conditions (Morgan, Barroso, Bateman, Dixson, & Brown, 2020; Rocque & Leanza, 2015). This was done intentionally to recruit participants with diverse health profiles resulting in contrasting cases. As far as we know, only a few studies such as Lim et al. (2017) have included broad study populations and their needs. Lim et al. (2017) performed interviews with people suffering from multiple chronic conditions and defined six domains essential for well-being and health (principles, relationships, emotions, activities, abilities, and possessions). Their findings are similar to our ten themes and also emphasize the importance of activities (e.g., reading, gardening, and self-care) and having significant connections with others (e.g., family, friends, and the community) (Lim et al., 2017).

Our findings show that PCDs want to engage in meaningful activities, going beyond what they call the essential activities, to create fulfillment and purpose in life. Each *“individual needs to have the opportunity to engage in activities that foster meaning and satisfaction, the so called ‘occupational well-being’”* (Doble & Santha, 2008). Engaging in meaningful activities enables quality of life and - even more - impacts morbidity and mortality (De Vriendt, Cornelis, Vanbosseghem, Desmet, & Van de Velde, 2019). In other words, it is important that the care process pay attention to meaningful activities and not only to essential activities (White, Lentin, & Farnworth, 2013). To create purpose in life, autonomy appeared to be an important requirement. More specifically, PCDs expressed the wish to stay autonomous by making shared decisions in which they take responsibility and experience freedom by choosing where they want to go. This shared decision-making throughout care delivery is one of the activities of a person-centered process of care and could be facilitated by nurses, among others (McCormack & McCance, 2006). These findings also correspond to the multiple aspects of autonomy Bassett and colleagues described such as having freedom of choice, taking responsibility, retaining independence in daily activities, and living independently (Bassett, Bourbonnais, & McDowell, 2007). The feeling of autonomy could also be fostered by having agency over activities, and from a broader perspective over health and chronic conditions. This means that individuals should experience a sense of control over what, when, and how to engage in activities, including care activities (Doble & Santha, 2008; Entwistle, Carter, Cribb, & McCaffery, 2010).

PCDs found control in surrounding themselves by a broad supportive network, such as the formal caregivers and their social environment of family and friends. To keep up in their environments and to participate in society, they relied on practical support (e.g., assistive devices). In addition to using practical support, they received psychosocial support from peers who listened and made them feel safer and less lonely. These findings are in line with the literature which indicates that the presence of these networks has a positive influence on personal welfare status (e.g. loneliness) (Dodds, 2016; Marmot & Bell, 2012). Our research shows that psychosocial support is necessary to remain independent in daily living. PCDs tried to reorganize their lives and reinvent themselves by making use of their remaining capabilities, for example, by searching for activities they are still able to perform. People with chronic conditions adapt their activities to compensate their limitations and changed behaviors caused by their conditions (Gignac, Cott, & Badley, 2000; Ridgeway et al., 2014). In our study, we found that PCDs also tried to maintain, change, or create new meaningful behaviors in activities and life roles. Based on this reasoning, PCDs could engage in role-management (Lorig & Holman, 2003). This approach corresponds with the SOC-model (selection, optimization, and compensation) of Baltes (Baltes & Baltes, 1990), wherein ageing people carefully select activities they still can perform. Throughout these meaningful activities and relationships with formal caregivers, we found that it is important that the PCDs' personality and authenticity is mirrored. Therefore, personal values of people with chronic conditions should be highlighted in developing, sharing, and follow-up in the care plan (McGilton et al., 2018). This can be achieved by approaching PCDs as equal partners in care, although this is often hampered by a lack of time, among other factors, during visits with the caregiver (Berntsen et al., 2018; Noël et al., 2005). Being treated as a whole person, is beneficial for people with chronic conditions. It can increase their satisfaction, enhance the relationship with their providers, and lead to better understanding and more knowledge regarding their own health (Feder et al., 2019; Mold, 2017).

To be treated as a person, people with chronic conditions expressed the need for balance between practical and emotional caregivers' skills. To meet their needs and preferences providers should have a level of empathy and pay attention to the whole person (McCormack & McCance, 2006). PCDs want to share their story with their formal caregivers. Gaining trust is a key achievement to perform communication between people with chronic conditions and providers. In addition, the ability to be able "*to intuit their needs*" and to recognize what they feel was indicated as an important skill, which can only be applied if an open communication between them and the provider is achieved. These findings correspond with findings from literature where communication skills and especially "*empathy*" are considered as the most important skills that caregivers should master to perform 'quality care' (McCormack & McCance, 2006). Being in empathetic contexts allows people with chronic conditions to feel safer and to express their thoughts and problems that concern them (Moudatsou, Stavropoulou, Philalithis, & Koukouli, 2020). In addition, Franklin et al. (2019) showed that the caregivers' communication style is important to collaborate and negotiate on what people with chronic conditions prioritize (Franklin et al., 2019). Formal caregivers are not exclusively communicating with the PCDs, but they constantly communicate with multiple other (in)formal caregivers. A recent editorial briefing by Kuluski explores these communication and relationships themes, identifying them as the core components of PCC (Kuluski, 2020). When reflecting on formal relationships, people with chronic conditions indicated that they receive support from a broad range of providers to handle their conditions. They want well-coordinated care, which is essential to ensure continuity of care. They also often experience a lack of coordination and communication among professionals working in primary care and hospitals. They require better follow-up after being discharged from the hospital, (Clarke et al., 2015; Ricci-Cabello et al., 2016). The importance of the care environment to deliver PCC was also described by McComarck (2004), who indicates that the environment has a major impact on the operationalization of PCC and has the greatest potential to limit or facilitate PCC (McCormack, 2004). Interprofessional collaboration facilitates the integration of health workers and allows them to engage any individual whose skills can help achieve local health goals (Hiss, Armbruster, Gillard, & McClure, 2007). To do so, health professionals need a shared vision and goals (Barry & Edgman-Levitan, 2012) and can be enhanced by using a PCC approach (K. Kuluski & Guilcher, 2019; S. Morgan & Yoder, 2012).

Strengths and limitations

This study has several limitations. Firstly, by sampling mostly older and retired participants with certain functional limitations, our results could not be generalized to the entire population and cannot be transferred to other populations and contexts beyond this specific group we interviewed and met the inclusion criteria (e.g., working population or people with chronic conditions transitioning to the labor market). However, this sample could be considered as a clinical representative sample in the primary care context of Flanders, where most people with chronic conditions are elderly people (Van der Heyden, 2018). Notwithstanding it might be interesting to include more participants to capture the experiences of other ages, cultures, etc.

Secondly, there are limitations with the data collection. Due to the covid-19 pandemic, we had to switch to video interviews which changed the context and created consequences (e.g. less non-verbal observations, lack of concentration)(Cater, 2011; Deakin & Wakefield, 2014). Furthermore, the performance of PCDs interviews could have inhibited people with chronic conditions to share

information that they would not want their informal caregiver to know. This limitation was addressed by giving people with chronic conditions the freedom to indicate their informal caregiver by which they felt most comfortable. The strategy of PCDs interviews also enabled us to improve the fluency of the interview for people with chronic conditions who lack communication skills. Through the open nature of the interview questions, PCDs were enabled to reflect not only on their care experiences, but also on their daily life with a chronic condition. Furthermore, interviews were conducted by the three first authors, all of whom are experienced in qualitative interviewing people with chronic conditions. No member check was performed and transcripts were not returned to the participants. However, data collection continued until saturation was reached; in the last interviews, no new information for the themes appeared (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008; Norouzinia et al., 2015).

It is common in qualitative research that the presence of a researcher influences the interpretation of the data. This risk of bias was minimized by triangulating researchers from different backgrounds (e.g., occupational therapists, pharmacists, nurses, gerontologists) and by conducting and analyzing interviews together in team of at least two researchers. This triangulation and intensive cooperation increased credibility and reduced the risk of bias to interpret the data based on pre-conceived understanding and personal opinions. Furthermore, the findings were debriefed in an iterative process, increasing the reflexivity and critical awareness for members of the consortium, which included a broad range of healthcare professionals. In the first stage, the three principal researchers (DB, MMS, LT) analyzed the interviews separately, afterwards they compared their findings. In a second stage, these preliminary results were presented and discussed with the co-authors (MLH, DVdV, PDV) until consensus was reached. In a third stage, the findings were presented to other senior researchers of the PCA consortium and then the process began again if no consensus was reached. This stepwise approach decreased the risk of confirmation bias.

Relevance for clinical practice

Primary care providers and especially nurses play a crucial role in the PCDs' lives as they support performing essential activities (e.g., taking medication, showering, etc.). Our findings suggest reconsidering nurses' roles and responsibilities to encourage and also support people living with chronic conditions in performing meaningful activities (e.g., gardening, knitting). From an academic point of view, the shift towards the support of people with chronic conditions while considering their strengths, listening to their goals, and collaboration with the entire team is already being made (Damarell, Morgan, & Tieman, 2020). To support among others nurses in further implementation of this shift into practice, possible strategies could include (1) a focus on self-management support to achieve an autonomous life (Audulv, Asplund, & Norbergh, 2012; Schulman-Green et al., 2012), (2) care processes with a focus on personal and meaningful life goals of people with chronic conditions (Tinetti et al., 2019), and (3) interprofessional collaboration including the individual as a partner to ensure care continuity (Reeves, Pelone, Harrison, Goldman, & Zwarenstein, 2017).

Conclusion

For people living with chronic conditions and their informal caregivers, it is important to be supported in their autonomy enabling them to engage in activities, both meaningful and essential.

They should be supported in their self-management to deal with the consequences of chronic conditions. To meet these needs and to enable self-management at its fullest, care should be tailored to the individual with a focus on personal and meaningful life goals. Care should be organized in a context of interprofessional collaboration in which the person with chronic condition should be considered as an important partner and a whole person. This entails paying attention to what the person with chronic conditions want, to what they strive for, and to promote their autonomy in a context wherein they are supported by a team of formal caregivers, family and friends. Only then we are moving towards the translation of the basic PCC principles into practice.

SUPPLEMENTARY FILE 1: THE CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE RESEARCH (COREQ)

DECLARATIONS

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