Patient-Centered Primary Care for Patients with Multimorbidity

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General introduction

GENERAL INTRODUCTION

Current primary care is not tailored to the needs of patients with multimorbidity; patient-centered care (PCC) may improve primary care for this population (Damarell, Morgan, & Tieman, 2020; Institute of Medicine [IOM], 2001; Poitras, Maltais, Bestard-Denommé, Stewart, & Fortin, 2018; Rijken, Struckmann, Dyakova, Melchiorre, Rissanen, & van Ginneken, 2013). However, we lack a clear understanding of what primary PCC for patients with multimorbidity looks like in practice, and evidence for its added value. This thesis presents an evaluation of a PCC improvement program for patients with multimorbidity implemented in a primary care setting.

Introduction to patients with multimorbidity

Worldwide, multimorbidity has become a major concern in healthcare, accompanied with many challenges in healthcare delivery (World Health Organization [WHO], 2011). Multimorbidity is defined as the co-existence of two or more chronic conditions in a patient (Johnston, Crilly, Black, Prescott, & Mercer, 2019). In the Netherlands, its prevalence has been increasing and this trend is expected to continue in coming years (Uijen & van de Lisdonk, 2008; Tacken et al., 2011; Van Oostrom et al., 2016), indicating the need to address this concern. Multimorbidity is associated with increasing age, female sex, and lower socio-economic status (Chen, Karimi, & Rutten-van Mölken, 2020; Marengoni et al., 2011; Violan et al., 2014). Patients with multimorbidity often have significantly lesser well-being and quality of life, functional impairments, increased healthcare utilisation, and a greater risk of mortality than do patients without chronic conditions (Fortin, Lapointe, Hudon, Vanasse, Ntetu, & Maltais, 2004; Makovski, Schmitz, Zeegers, Stranges, & van den Akker, 2019; Marengoni et al., 2011; Nunes, Flores, Milke, Thume, & Facchini, 2016). Currently, healthcare delivery is often not optimally designed and cannot adequately respond to the burden of multimorbidity.

Current primary care delivery to patients with multimorbidity in the Netherlands

In the Netherlands, healthcare delivery to patients with multimorbidity occurs mainly in primary care settings. The Dutch primary healthcare system is based on the hierarchical gatekeeper model (Kringos, Boerma, Hutchinson, Saltman, & WHO, 2015). According to this model, general practitioners (GPs) coordinate primary care delivery to patients with chronic conditions (Kroneman, Boerma, van den Berg, Groenewegen, de Jong, & van Ginneken, 2016), although multiple healthcare professionals in diverse settings (e.g. physiotherapists, specialists in hospitals, dieticians) are often also involved. Care delivery to patients with multimorbidity is often considered to be difficult and complex (Damarell et al., 2020; Navickas, Petric, Feigl & Seychell, 2016). Although combinations of chronic conditions are originally medically related, the problems of patients with multimorbidity tend to expand over multiple domains (i.e. social, medical and mental), necessitating a focus on these patients' overall well-being (Raad Volksgezondheid en Samenleving [RVS], 2020). However, current primary care has a historically based focus on acute care, and thus is not adequately responsive for patients with chronic conditions (Rijken et al., 2013). For example, healthcare professionals work with single-disease–oriented guidelines, which renders decision making about the best treatment for patients with multiple conditions difficult (Damarell et al., 2020). Additionally, care delivery across settings and disciplines is often fragmented, resulting in poor patient outcomes (Damarell et al., 2020; Sinnott, Mc Hugh, Browne & Bradley, 2013). Patients with multimorbidity desire less-fragmented and better-coordinated care (Gill, Kuluski, Jaakkimainen, Naganathan, Upshur, & Wodchis, 2014; Mason et al., 2016), indicating the need for a new approach to care delivery with better tailoring to their needs.

Patient-centered care and co-creation of care

PCC may be valuable for the improvement of primary care for patients with multimorbidity (Damarell et al., 2020). PCC involves the delivery of care in a manner that respects individual patients' values, needs and preferences and ensures that these factors guide all clinical decisions (IOM, 2001). It is a holistic concept with eight dimensions defined by the Picker Institute (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Picker Institute, n.d.; Figure 1): (1) patient preferences, (2) information and education, (3) access to care, (4) emotional support, (5) family and friends, (6) continuity and transition, (7) coordination of care and (8) physical comfort.

As patients with multiple chronic conditions must live with these conditions for the rest of their lives, they should be considered to be experts in their care (RVS, 2020). As only 1% of these patients' time is spent in healthcare settings, with 99% spent in living daily with their conditions, these patients often have strong preferences related not only to medical aspects, but also to quality of life (RVS, 2020). The central positioning of patients with multimorbidity in their care delivery could thus contribute greatly to the tailoring of care to their needs. To achieve this goal, the provision of *information and*

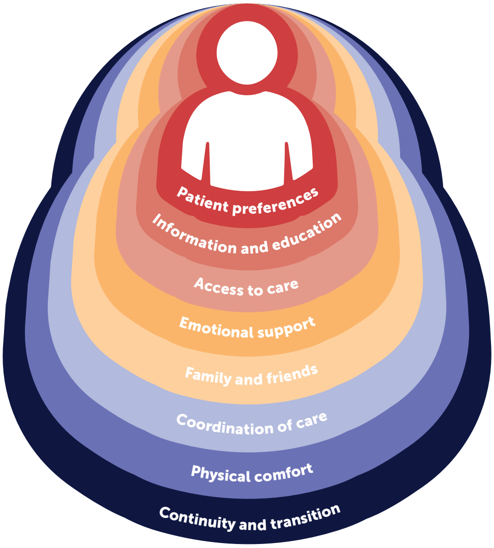

Figure 1. The eight dimensions of patient-centered care

education about all aspects of their care is important. Additionally, because of their long-term use of healthcare, *access to care* is important, in terms of financial considerations and accessibility (e.g. easy appointment scheduling and short wait times). In addition to having physical limitations (e.g. shortness of breath and sleeping problems), patients with multimorbidity often experience depression and anxiety (Read, Sharpe, Modini, & Dear, 2017; Vancampfort, Koyanagi, Hallgren, Probst, & Stubbs, 2017). Thus, the adaptation of care delivery to offer *physical comfort* and adequate *emotional support* is relevant. As having multiple chronic conditions impacts not only patients, but also their surroundings (Amer Nordin, Mohd Hairi, Choo, & Hairi, 2019), *family and friends* should be involved in care delivery. As care delivery to patients with multimorbidity often involves multiple healthcare professionals, within single organizations (*coordination of care)* and across healthcare disciplines (*continuity and transition)*, the alignment of care plans and healthcare professionals' awareness of their and others' roles in such delivery are important to avoid the fragmentation of care (Hujala, Taskinen, Rissanen, & van Ginneken, 2017; Tinetti, Fired & Boyd, 2012). The organization of care delivery based on these eight dimensions of PCC is associated with improved organizational and patient outcomes, such as increased job satisfaction among healthcare professionals and increased quality of life and satisfaction with care among patients (Rathert, Wyrwich, & Boren, 2013).

Investment in patient-centered interaction and communication to establish productive interactions between patients and healthcare professionals, often referred to as co-creation of care, may also be important (Cramm & Nieboer, 2015). Co-creation of care is based on a framework of relational coordination, which can be described as a mutually reinforcing process between the quality of communication and relationships (Bolton, Logan, & Gittell, 2021). Timely, problem-solving, frequent and accurate communication between a patient and a healthcare professional reinforces their relationship (which is based on shared knowledge, shared goals and mutual respect), and vice versa (Figure 2). Co-creation of care is especially important in situations characterised by uncertainty, complexity and time constraints (Bolton et al., 2021; Gittell, Godfrey, & Thistlethwaite, 2006). Care delivery to patients with multimorbidity often involves

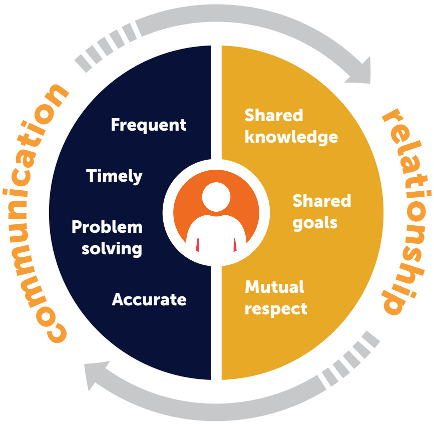

Figure 2. Co-creation of care: The mutually reinforcing process of communication and relationship between the healthcare professional and the patient.

such situations, as these patients have complex care needs, time is often too limited to address all aspects of their conditions and reliance on single-disease guidelines creates uncertainty regarding the best treatment options for all combinations of chronic conditions (Damarell et al., 2020; Sinnott et al., 2013). Thus, co-creation of care may be especially relevant to the delivery of care to patients with multimorbidity.

Although PCC is often viewed as being potentially valuable in addressing the burden of multimorbidity in primary care, we lack a clear understanding of what primary PCC for patients with multimorbidity looks like in practice and evidence for its added value. Thus, the following research aims were established for this thesis.

Research aims

The main objective of this thesis was to investigate the importance of PCC for patients with multimorbidity in the primary care setting. The three research aims were:

1. to identify the views of patients with multimorbidity on PCC delivery,
2. to identify the relationships of PCC and co-creation of care to the well-being of patients with multimorbidity in the primary care setting and
3. to describe the organization of primary PCC for patients with multimorbidity.

Research setting

For this thesis, the ‘Anders denken, anders doen’ PCC improvement program was evaluated as implemented in seven primary care practices in Noord-Brabant, the Netherlands. This program was initiated in 2017 by Zorggroep RCH Midden Brabant BV, a cooperative of 160 primary care practices in the Netherlands. Its main objective was to improve primary PCC delivery to patients with multimorbidity. All patients involved in this study had two or more chronic conditions (asthma, chronic obstructive pulmonary disease [COPD], diabetes, coronary and vascular diseases).

Outline of the thesis

To tailor care delivery to the preferences of patients with multimorbidity, these patients’ views on PCC and the relative importance of the eight PCC dimensions must be explored. Chapter 2 describes these views, which suggest that not all patients with multimorbidity require the same type of care delivery, and that not all aspects of PCC delivery are equally important to all patients. In chapters 3 and 4, baseline measurements of PCC and co-creation of care are provided, and their cross-sectional (chapter 3) and longitudinal (chapter 4) relationships to the well-being and satisfaction with care of patients with multimorbidity are described. The findings presented in these two chapters suggest that greater tailoring of care to the needs of patients with multimorbidity through attention to PCC and co-creation of care may contribute to the improvement of patient outcomes.

Although evidence of the effects of PCC provision is abundant, a clear understanding of what it looks like in practice is lacking. Thus, how primary PCC can be improved for patients with multimorbidity is described in chapters 5 and 6. Chapter 5 describes the PCC improvement program and its intervention components, and provides qualitative insight on the organization of PCC according to healthcare professionals. Chapter 6 reveals barriers to effective and sustainable PCC implementation for patients with multimorbidity at the patient, organizational and national levels, according to primary healthcare professionals. Chapter 7 contains an overall discussion of the main thesis findings, theoretical and methodological considerations, implications for policy and practice and recommendations for future research.

REFERENCES

Amer Nordin, A., Mohd Hairi, F., Choo, W. Y., & Hairi, N. N. (2019). Care recipient multimorbidity and health impacts on informal caregivers: A systematic review. *The Gerontologist, 59*(5), e611-e628.

Bolton, R., Logan, C., & Gittell, J. H. (2021). Revisiting relational coordination: a systematic review. *The Journal of Applied Behavioral Science*, *57*(3), 290-322.

Chen, Y. H., Karimi, M., & Rutten-van Mölken, M. P. (2020). The disease burden of multimorbidity and its interaction with educational level. *PloS One*, *15*(12), e0243275.

Cramm, J. M., & Nieboer, A. P. (2015). The importance of productive patient–professional interaction for the well-being of chronically ill patients. *Quality of Life Research*, *24*(4), 897-903.

Damarell, R. A., Morgan, D. D., & Tieman, J. J. (2020). General practitioner strategies for managing patients with multimorbidity: A systematic review and thematic synthesis of qualitative research. *BMC Family Practice, 21*(1), 1-23.

Fortin, M., Lapointe, L., Hudon, C., Vanasse, A., Ntetu, A. L., & Maltais, D. (2004). Multimorbidity and quality of life in primary care: a systematic review. *Health and Quality of life Outcomes*, *2*(1), 1-12.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T.L. (1993). *Through the patient's eyes: understanding and promoting patient-centered care.* Jossey-Bass Publishers.

Gill, A., Kuluski, K., Jaakkimainen, L., Naganathan, G., Upshur, R., Wodchis, W.P. (2014) "Where Do We Go From Here?" Health system frustrations expressed by patients with multimorbidity, their caregivers and family physicians. *Healthcare Policy/Politiques de Sante*, *9*(4), 73-89.

Gittell, J. H., Godfrey, M., & Thistlethwaite, J. (2013). Interprofessional collaborative practice and relational roordination: Improving healthcare through relationships. *Journal of Interprofessional Care, 27*(4), 210-213.

Hujala, A., Taskinen, H., Rissanen, S., Richardson, E., & van Ginneken, E. (2017). *How to support integration to promote care for people with multimorbidity in Europe?* World Health Organization, Regional Office for Europe.

Institute of Medicine (2001). *Crossing the quality chasm: a new health system for the 21st century.* National academy press.

Johnston, M. C., Crilly, M., Black, C., Prescott, G. J., & Mercer, S. W. (2019). Defining and measuring multimorbidity: a systematic review of systematic reviews. *European Journal of Public Health*, *29*(1), 182-189.

Kringos, D. S., Boerma, W. G., Hutchinson, A., Saltman, R. B., & World Health Organization. (2015). *Building primary care in a changing Europe*. World Health Organization. Regional Office for Europe.

Kroneman, M., Boerma, W., van den Berg, M., Groenewegen, P., de Jong, J., & van Ginneken, E. (2016). Netherlands: Health system review. *Health Systems in Transition, 18*(2), 1-240.

Makovski, T. T., Schmitz, S., Zeegers, M. P., Stranges, S., & van den Akker, M. (2019). Multimorbidity and quality of life: systematic literature review and meta-analysis. *Ageing Research Reviews*, *53*, 100903.

Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., ... & Fratiglioni, L. (2011). Aging with multimorbidity: a systematic review of the literature. *Ageing Research Reviews*, *10*(4), 430-439.

Mason, B., Nanton, V., Epiphaniou, E., Murray, S. A., Donaldson, A., Shipman, C., ... & Boyd, K. (2016). 'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers. *BMJ Supportive & Palliative Care*, *6*(1), 60-65.

Navickas, R., Petric, V., Feigl, A. B., & Seychell, M. (2016). Multimorbidity: What do we know? What should we do? *Journal of Comorbidity, 6*(1), 4-11.

Nunes, B. P., Flores, T. R., Mielke, G. I., Thumé, E., & Facchini, L. A. (2016). Multimorbidity and mortality in older adults: a systematic review and meta-analysis. *Archives of Gerontology and Geriatrics*, *67*, 130-138.

Picker Institute. (n.d.). *Principles of person-centred care.* https://www.picker.org/about-us/picker-principles-of-person-centred-care.

Poitras, M. E., Maltais, M. E., Bestard-Denommé, L., Stewart, M., & Fortin, M. (2018). What are the effective elements in patient-centered and multimorbidity care? A scoping review. *BMC Health Services Research*, *18*(1), 1-9.

Raad Volksgezondheid en Samenleving. (2020). *Hoor mij nou! Samen begrijpen, proberen, reflecteren en leren bij complexe zorgvragen. https://www.raadrvs.nl/documenten/publicaties/2020/10/15/hoor-mij-nou*

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review, 70*(4), 351-379.

Read, J. R., Sharpe, L., Modini, M., & Dear, B. F. (2017). Multimorbidity and depression: A systematic review and meta-analysis. *Journal of Affective Disorders, 221*, 36-46.

Rijken, M., Struckmann, V., Dyakova, M., Melchiorre, M. G., Rissanen, S., & van Ginneken, E. (2013). ICA-RE4EU: Improving care for people with multiple chronic conditions in Europe. *Eurohealth*, *19*(3), 29-31.

Sinnott, C., Mc Hugh, S., Browne, J., & Bradley, C. (2013). GPs' perspectives on the management of patients with multimorbidity: Systematic review and synthesis of qualitative research. *BMJ Open, 3*(9), e003610-2013-003610.

Tacken, M. A., Opstelten, W., Vossen, I., Smeele, I. J., Calsbeek, H., Jacobs, J. E., & Braspenning, J. C. (2011). Increased multimorbidity in patients in general practice in the period 2003-2009. [Toename multimorbiditeit bij patienten in de huisartsenpraktijk in de periode 2003-2009]. *Nederlands Tijdschrift Voor Geneeskunde, 155*(26), A3109.

Tinetti, M. E., Fried, T. R., & Boyd, C. M. (2012). Designing health care for the most common chronic condition—multimorbidity. *Jama, 307*(23), 2493-2494.

Uijen, A. A., & van de Lisdonk, E. H. (2008). Multimorbidity in primary care: Prevalence and trend over the last 20 years. *The European Journal of General Practice, 14*(1), 28-32.

Vancampfort, D., Koyanagi, A., Hallgren, M., Probst, M., & Stubbs, B. (2017). The relationship between chronic physical conditions, multimorbidity and anxiety in the general population: A global perspective across 42 countries. *General Hospital Psychiatry, 45*, 1-6.

Van Oostrom, S. H., Gijsen, R., Stirbu, I., Korevaar, J. C., Schellevis, F. G., Picavet, H. S. J., & Hoeymans, N. (2016). Time trends in prevalence of chronic diseases and multimorbidity not only due to aging: Data from general practices and health surveys. *PloS One, 11*(8), e0160264.

Violan, C., Foguet-Boreu, Q., Flores-Mateo, G., Salisbury, C., Blom, J., Freitag, M., ... & Valderas, J. M. (2014). Prevalence, determinants and patterns of multimorbidity in primary care: a systematic review of observational studies. *PloS One*, *9*(7), e102149.

World Health Organization (2011). Global status report on noncommunicable diseases 2010. Geneva: WHO.

Patient preferences

Information and education

Physical comfort

Access to care

Emotional support

Family and friends

Coordination of care

Continuity and transition

Chapter 2

Views of patients with multimorbidity on what is important for patient-centered care in the primary care setting

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ABSTRACT

Background

Patient-centered care (PCC) has been proposed as the way forward in improving primary care for patients with multimorbidity. However, it is not clear what PCC exactly looks like in practice for patients with multimorbidity. A better understanding of multi-morbid patients' views on what PCC should look like and which elements are most important may help to improve care delivery for this vulnerable population. The present study thus aimed to identify views of patients with multimorbidity on the relative importance of PCC aspects in a Dutch primary care setting.

Methods

Interviews were conducted with 16 patients with multimorbidity using Q-methodology, which combines quantitative and qualitative analyses. The participants ranked 28 statements about the eight dimensions of PCC (patients' preferences, information and education, access to care, emotional support, family and friends, continuity and transition, physical comfort, and coordination of care) by relative importance. By-person factor analysis using centroid factor extraction and varimax rotation were used to reveal factors that represent viewpoints. Qualitative interview data were used to interpret the viewpoints.

Results

The analyses revealed three factors representing three distinct viewpoints of patients with multimorbidity on what is important for patient-centered care in the primary care setting. Patients with viewpoint 1 are *prepared proactive patients* who seem to be well-off and want to be in charge of their own care. To do so, they seek medical information and prefer to be supported by a strongly coordinated multidisciplinary team of healthcare professionals. Patients with viewpoint 2 are *everyday patients* who visit GPs and require well-coordinated, respectful, and supportive care. Patients with viewpoint 3 are *vulnerable patients* who are less resourceful in terms of communication skills and finances, and thus require accessible care and professionals taking the lead while treating them with dignity and respect.

Conclusions

The findings of this study suggest that not all patients with multimorbidity require the same type of care delivery, and that not all aspects of PCC delivery are equally important to all patients.

BACKGROUND

Increasing numbers of people face the burden of multimorbidity (World Health Organization, 2008; Van Oostrom et al., 2012). We define multimorbidity as the co-existence of two or more chronic conditions in one patient. Patients with multimorbidity are often considered to constitute a vulnerable and complex population with a high risk of mortality and high utilization of care, and they often are less satisfied with their care (Fortin et al., 2004; Navickas, Petric, Feigl, & Seychell, 2016). Moreover, a systematic review showed that quality of life decreases with an increasing number of diseases (Makovski, Schmitz, Zeegers, Stranges, & van den Akker, 2019). In the Netherlands, general practitioners (GPs) coordinate care for patients with multimorbidity (Kroneman et al., 2016). However, the organization of high-quality primary care for this patient population is currently a great challenge in healthcare delivery. Primary care falls short of adequate and optimal care delivery for these patients, for whom single disease–oriented guidelines are not the most suitable (Lugtenberg, Burgers, Clancy, Westert, & Schneider, 2011; Osborn, Moulds, Squires, Doty, & Anderson, 2014). According to GPs, care delivery for this patient population is complex and demanding: There is a high medical complexity, clinical uncertainty on what is the best treatment, lack of communication between health and social care providers, and it is hard to always reach agreement on patient preferences regarding treatment goals (Søndergaard et al., 2015). This represents a missed opportunity, as the primary care setting is precisely the context identified as being most appropriate for effective management of patients with multimorbidity (Aronson, 2015).

Patient-centered care (PCC) has been proposed to be the way forward in improving primary care for patients with multimorbidity (Kuipers, Cramm, & Nieboer, 2019). The aims of PCC are to put patients at the center of their healthcare and to let them be in charge. PCC is associated with higher levels of social and physical well-being, and satisfaction with care, among patients with multimorbidity (Kuipers et al., 2019). The Picker Institute proposed eight dimensions of PCC (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). First, the *patients' preferences* dimension entails the treatment of patients with dignity and respect, taking their preferences into account and stimulating patients to set and achieve their own treatment goals. As PCC prioritizes placing patients in charge of their own care, the *information and education* dimension is also important to assure that patients should be well informed about all aspects of their care, regardless of their educational and migration backgrounds, or potential language barriers. Furthermore, patients must have good *access to care*, for example through easily made appointments, short wait times before consultations and accessible buildings. *Physical comfort* is also part of PCC because it is important to reduce potential feelings of pain, fatigue, shortness of breath, and lack of sleep. Other important aspects of physical comfort in GP practices are ensuring privacy, availability of comfortable chairs, and clean (waiting) rooms. PCC also entails *emotional support* since living with multiple chronic conditions is often accompanied by anxiety and depression (Read, Sharpe, Modini, & Dear, 2017; Vancampfort, Koyanagi, Hallgren, Probst, & Stubbs, 2017), and impacts patients' private lives, such as their social relations or their jobs. However, chronic conditions often impact not only patients, but also their *family and friends*. PCC takes relatives into account, addressing their needs and questions, and involves the provision of adequate support to involve family members and friends in the care process. The *continuity and transition* dimension of PCC is important because multiple healthcare providers are often involved in care for patients with multimorbidity. Information must be transferred adequately and referred patients must be well informed about where to go and why. Finally, to ensure the *coordination of care* among healthcare professionals within an organization (in this case, a GP practice) frequent deliberation in multidisciplinary team meetings is important, and patients should know who is coordinating their care and/or have a first point of contact (Cramm & Nieboer, 2017). Organizations with higher scores on these eight dimensions also report better organizational and patient outcomes (Rathert, Wyrwich, & Boren, 2013; Institute of Medicine., 2001). Although many organizations claim to be patient-centered, in reality this is not always the case. PCC delivery is often found to be more difficult for certain patient populations, among others low educated patients and ethnic minorities while these patients are precisely the ones who could really benefit from PCC (Rademakers, Delnoij, Nijman, & De Boer, 2012; Renzaho, Romios, Crock, & Sønderlund, 2013; Swenson et al., 2004).

Despite the thorough scientific description of PCC, it is still not clear what PCC looks like in practice for patients with multimorbidity. The views and experiences of such patients are needed to identify the elements of PCC and its delivery that are most important to them, which may help to improve care delivery for this vulnerable population. Bayliss and colleagues (2008) have examined how patients with multimorbidity describe ideal processes of care, that indeed entail patient-centeredness and individualized ways of care delivery; among others continuity in relationships with healthcare providers, clear communication, and accessible care. However, patients with multimorbidity are often described as one patient population, but as in single disease patients there are also differences among patients with multimorbidity. Rijken and van der Heide (2019) found three subgroups of Dutch patients with multimorbidity based on their background characteristics, medical characteristics and resources. This variety of patients with multimorbidity requires different needs and ways of care delivery (Rijken & van der Heide, 2019). Thus, this is the first study to examine viewpoints of patients with multimorbidity on the relative importance of PCC delivery-related aspects in a Dutch primary care setting.

METHODS

Setting: the role of GPs in the Netherlands

Primary care systems in Europe vary widely, with different impacts on healthcare delivery design. The Netherlands has a strong primary care system based on a professional hierarchical gatekeeper model (Kringos, Boerma, Hutchinson, & Saltman, 2015). GPs have a central role in primary care, although a wide variety of care providers (e.g., dentists, pharmacists, dieticians, physiotherapists, and psychologists) are also involved. GPs function as gatekeepers, such that hospital and specialist care is often inaccessible without GP referral. Dutch GPs are often readily accessible (Kringos et al., 2015; Kroneman et al., 2016); appointments can usually be made within two working days, and most GP-delivered care is covered by healthcare insurers (i.e., at no cost to patients). A standard consultation lasts 10 minutes (Verheij et al., 2010). For chronic conditions, however, often double consultations are scheduled. Each citizen is obligated to have basic health insurance (covering GP services), which can be complemented (voluntarily) by extra services, such as physiotherapy and/or dentistry (De Bakker & Groenewegen, 2009). Dutch GPs are in most cases non-interventionist; they handle 93% of all problems within primary care, only 4% of patients is referred to secondary care (Kroneman et al., 2016). Most Dutch GPs are self-employed (Kringos et al., 2015). They coordinate mental healthcare (e.g. emotional support) as well as care for chronic diseases (e.g., diabetes, asthma, chronic obstructive pulmonary disease (COPD)) (Kroneman et al., 2016). Patients can choose their own GP (Kroneman et al., 2016); so, patients are often treated by the same GP every time they visit the GP practice.

Participants

This study is part of a larger evaluation study investigating PCC for patients with multimorbidity in the primary care setting in Noord-Brabant, the Netherlands (Kuipers, Cramm, & Nieboer, 2019). In this larger evaluation study, a mixed-methods design was used to compare primary care practices aiming to improve PCC (intervention practices) with those providing care as usual (control practices). Patients were eligible to participate in this study when they had two or more registered chronic conditions (i.e. asthma, diabetes, COPD, coronary and vascular disease). Patients with multimorbidity from intervention practices who filled in a questionnaire were asked if they were willing to take part in the current study. Those who were willing to participate were contacted by telephone; they were given an in-depth explanation of the study and appointments were made to participate. Of 30 respondents who were willing to participate, 9 patients were ineligible due to visibility impairment (*n*=2), illness preventing participation (*n*=2), dementia (*n*=1), and the inability to schedule an appointment (*n*=4). Thus, a total of 17 patients consented to participate in the study. After the exclusion of one additional patient who could not complete the study tasks because she could not understand the instructions and statements, data from 16 patients were included in the analyses. Data saturation was reached.

In addition, four meetings with all healthcare professionals and researchers involved in the larger evaluation study were hosted. During these meetings the healthcare professionals (GPs and nurse practitioners) could share experiences and learn from each other. Furthermore, during these meetings preliminary research results were shared and validated.

The medical ethics committee of the Erasmus Medical Centre, Rotterdam, the Netherlands, determined that the rules laid down in the Medical Research Involving Human Subjects Act did not apply to this study (protocol no. METC_2018_021). Written consent was obtained from all participants.

Q methodology

In this exploratory qualitative study, we used Q methodology to identify the perspectives of patients with multimorbidity on which aspects of PCC are important. This approach combines quantitative and qualitative methods to examine subjectivity (Watts & Stenner, 2012). It is used to explore respondents' personal experiences, tastes, values, and beliefs (Baker, 2006). Q methodology has been used in research on primary care services (Honey, Bryant, Murray, Hill, & House, 2013; Shabila, Al-Tawil, Al-Hadithi, & Sondorp, 2014) and PCC (Berghout, van Exel, Leensvaart, & Cramm, 2015; Cramm, Leensvaart, Berghout, & van Exel, 2015). A Q-methodology study entails the following three steps: (a) design of the Q-set, (b) administering the Q-sort, and (c) statistical analysis and factor interpretation.

Q-set design

The perspectives of patients with multimorbidity on the importance of PCC aspects are generated by the placement of statements according to their relative importance. These statements about a subject matter are often referred to as the Q-set. An important characteristic of a Q-set is that it should fully cover the subject; PCC. Therefore, the current Q-set was developed based on the 36-item patient-centered primary care instrument (Cramm & Nieboer, 2017). It is not necessary to base a Q-set on a valid instrument, but we made use of the instrument because it assesses the eight dimensions of PCC among patients with multimorbidity, and thus fully covers PCC. The number of statements in a Q-set depends on the subject matter. However, having too many statements is often considered demanding for participants (Watts & Stenner, 2012). As patients with multimorbidity are often considered to be vulnerable, we decided to minimize the Q-set and use only three or four statements per dimension to reduce the complexity of the Q-sort and to shorten the interview time; the final Q-set consisted of 28 statements on PCC. The research team decided which items were merged (because they covered similar topics) to preserve the full coverage of PCC. To ensure comprehensibility and applicability, the Q-set was tested in a pilot study with two participants, and neither participant mentioned the need to include additional statements nor did they mention unclarities. Thus, agreement was reached on a final set of 28 statements (Table 2).

Administering the Q sort (procedure)

All interviews for the Q-study took place at the participants' homes. The interviews lasted 45–90 minutes each and were conducted by the first author (SK). A script was used to ensure consistency. All interviews were recorded with participants' permission. The participants were asked to rank the 28 statements according to their perceived importance for PCC in primary care. The statements were presented to the respondents on printed cards. After global instruction, the respondents were asked to read each of the statements and place it into one of three piles representing aspects of PCC that they consider to be "unimportant," "neutral," and "important." The respondents were then asked to elaborate on their decisions. Then, the statements were sorted using a standardized Q-grid (Figure 1) ranging from –3 (least important) to +3 (most important). First, respondents were asked to select the two statements that they considered to be most important from the "important" pile and to place them in the +3 column. Second, the respondents chose the four statements that were most important from the remaining cards in the "important" pile and placed them in the +2 column. This process was repeated for the "unimportant" pile, with the cards placed in the –3 and –2 columns. Lastly, cards from the "neutral" pile were placed in the remaining columns. When all cards are placed in the Q-grid, this is called a Q-sort. After completing the Q-sort, the respondents were asked to elaborate on their placement of statements in the four outer columns. All comments during the placements of the cards and the elaboration were transcribed verbatim.

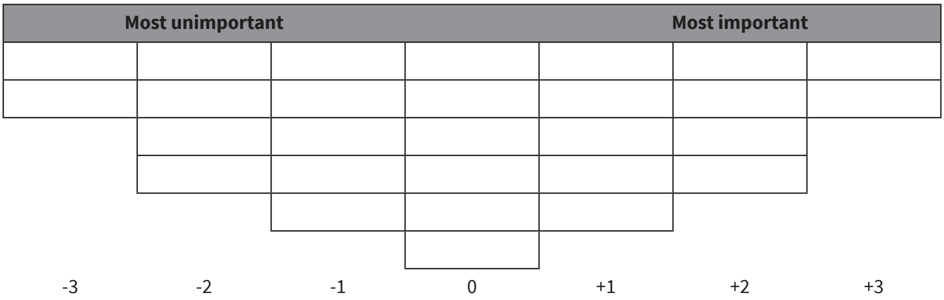


Figure 1. the Q-grid

Statistical analysis

To make the methodology clear for all readers, this section is divided in three steps; 1. How to get factors out of Q-sorts, 2. Making factor arrays out of factors, and 3. How to interpret factor arrays. The PQ Method software was used to perform the statistical analysis (Schmolck & Atkinson, 2002).

How to get factors out of Q-sorts

All Q-sorts were manually imported in PQmethod. A correlation is used to simply measure the association or degree of (dis)agreement between the Q-sorts. All Q-sorts were intercorrelated. These correlations were subjected to a by-person factor analysis using centroid factor extraction and varimax factor rotation to reduce it to groups of participants who have ranked the statements in similar ways; these groups are also known as factors. The Kaiser–Guttman criterion was used to determine the number of factors extracted (Guttman, 1954; Kaiser, 1960). A factor represents a viewpoint of patients with multimorbidity about which aspects of PCC they consider to be important.

Making factor arrays out of factors

A factor thus represents a viewpoint, where some statements about PCC have higher loadings (e.g. a higher relative importance) compared to others. All Q-sorts that belong to a factor are merged by weighted averaging to form a so-called factor array; an ideal-typical Q-sort (see Table 2 for the factor arrays in this study).

How to interpret factor arrays

Thus, a factor array shows us which aspects of PCC are most important according to different viewpoints. It is this factor array that is the basis of different forms of factor interpretation. The aim of factor interpretation is to fully understand and explain the shared viewpoints. First, the patterning of items in the factor array was examined. Second, the comments and explanations that respondents gave during the Q-sort and follow-up interviews were used alongside. Specific attention was given to distinguishing statements (those placed in the +3 and –3 columns, e.g. where the viewpoints disagree). The interpretation of qualitative data helped to explain why a statement was important and to describe types of patients with similar perspectives.

RESULTS

Sixteen respondents participated in the study. Their sociodemographic characteristics are presented in Table 1. Their mean age was 72 years (range, 56–88 years). Nine participants were male and seven were female. Education levels ranged from primary school to university; three were low educated (primary school or less), 13 were high educated (ranging from secondary school to university). Nine participants were married, two were single, one was divorced, and four were widowed.

Table 1 Sociodemographic characteristics of study participants (*n* = 16)

Characteristic	Mean (range) or percentage
Age (years)	72.13 (56–88)
Gender (male)	56%
Education (low*)	18.8%
Marital status	
Single	12.5%
Married	56.25%
Divorced	6.25%
Widowed	25%

*primary education or less

The analyses revealed three factors that each represent a viewpoint. The factors explained 41% of the study variance. Data from 14 respondents were associated significantly with one of the three factors. Factors 1–3 were defined by data from six, five, and three respondents, respectively. Each factor is represented by a factor array, a composite Q-sort that represents the ideal/typical Q-sort, or shared perspectives/viewpoints. The factor arrays are shown in Table 2. Below, the three viewpoints are described with use of factor interpretation and follow-up interview data. In Q-methodology, each factor is given a name that captures the essence of the viewpoint (in this study 1) the prepared proactive patient, 2) the everyday patient, and 3) the vulnerable patient). Each viewpoint section starts with a detailed description supported by quotations, and ends with a brief summary of the viewpoint. Consensus statements, ranked similarly on all factors, are also provided.

Viewpoint 1: the prepared, proactive patient

This is the viewpoint of six patients, of whom four are male (67%), all high educated (100%), four married (67%), two widowed (33%), and the mean age of the patients holding this viewpoint is 73 years old.

Patients holding viewpoint 1 consider the information and education dimension of PCC to be important. To be in charge of their own care and well prepared for GP visits, they need to be informed about all aspects of their care (statement 22, +3), and they want to be informed about where to go and why when they are referred to other care providers (statement 12, +2).

Table 2 Statements and factor loadings

#		Factor 1	Factor 2	Factor 3
Patient preferences				
1	Being treated with dignity and respect	–1	3	3
2	Taking into account my wishes and preferences	–1	–1	0
3	Taking into account the influence that the treatment can have on my life	1	1	–1
4	Being supported to achieve my treatment goals	1	1	–2
Physical comfort				
5	Giving attention to my physical comfort (such as the management of pain, shortness of breath)	2	2	0
6	Clean and comfortable (waiting) rooms	–2	0	–1
7	Sufficient privacy in the treatment room(s) and at the counter	–1	0	0
Coordination of care				
8	That everyone is well informed; only having to tell my story once	0	–2	3
9	Well attuned care among the practitioners involved	2	2	0
10	A contact person who knows everything about my illness and care	3	–3	0
11	Being able to easily contact someone with questions	1	2	1
Continuity of care				
12	Being well informed about where to go and why when referred to another care provider (specialist/dietician/physiotherapist)	2	0	2
13	With a referral, all my information is passed on correctly	1	0	1
14	Advice (such as on medication) from different practitioners (medical specialists and family doctor) is well attuned	2	2	1
Emotional support				
15	Emotional support	–3	1	–1
16	Paying attention to possible feelings of fear, gloom, and anxiety	–2	1	–2
17	Paying attention to the impact of my health on my private life (family, relatives, work, social life)	–3	–1	–2
Access to care				
18	Not having problems going from my home to my family doctor and back again	0	–2	2
19	Free, available care and medication (without extra payment)	–2	–1	2
20	Easily and quickly scheduling an appointment	0	1	2
21	Not having to wait long before it is my turn at an appointment	–1	–2	0
Information and education				
22	Being well informed	3	0	–1
23	A good explanation for all the information I receive	0	0	1
24	Easy access to my own data (lab results, medication overview, referrals)	1	–1	–1
25	Being able to ask all the questions I want	0	3	1
Family and friends				
26	Involving relatives in my treatment	–2	–2	–3
27	Giving attention to care and support provided by family members	0	–3	–2
28	Giving attention to possible questions or needs from my family members	–1	–1	–3

> “Very important, yes, of course. The family doctor has to find out where the distress is coming from, and whether I have to go to a lung specialist or a nephrologist. And when she refers me, I have to know why I have to go to that specific specialist.” (Respondent 1, statement 12)

These patients have a strong focus on care related to their physical comfort (statement 5, +2). They consider their GPs’ main task to be the maintenance of their physical comfort, through pain management and the treatment of shortness of breath.

> “I find that promoting my physical comfort is at the heart of what I can expect from a general practitioner.” (Respondent 1, statement 5)

They consider, however, aspects of physical comfort that are not related to their physical health, such as the comfort of GP waiting rooms (statement 6, –1), to be less important.

> “Of course, the waiting room shouldn’t be dirty, but it’s not comfortable here. And I don’t mind.” (Respondent 1, statement 6)

Furthermore, these patients do not consider privacy (e.g., in GP waiting rooms) to be an important aspect of PCC. For instance, they do not mind when others hear them speak about their illnesses (statement 7, –2).

> “I don’t mind when everyone knows what’s wrong with me.” (Respondent 9, statement 7)

Patients holding this viewpoint prefer a well-coordinated multidisciplinary team of healthcare professionals with a central contact person who knows everything about their illness and care (statement 10, +3), and they prefer care to be well attuned among the professionals involved (statement 9, +2).

> “I think that you should have someone who has insight into your health and care. That’s probably because I haven’t been so well informed myself for a number of years. But then at least they know what’s going on. Yes, I think that’s very important.” (Respondent 2, statement 10)

These patients also seem to be financially well-off. They have no problem paying for costs not covered by their insurance when required to receive good care (statement 19, –2).

> “Sometimes you have to take medicines, but you have to pay extra. But you really need them, so that is not an issue. But I know I might be in different circumstances compared to others, because you have to be able to make it financially as well.” (Respondent 16, statement 19)

Summary

Patients with this viewpoint like to be in charge, and will, when possible, contribute to their own care delivery. During GP visits, they are often well prepared and focus primarily on the medical aspects of their care, seeking (new) information about their conditions. These patients do not consider emotional support to be the responsibility of GPs; the main focus should be on patients’ physical health. They like to be supported by a well-coordinated multidisciplinary team of healthcare professionals, and they seem to be well-off and down-to-earth.

Viewpoint 2: the everyday patient

This is the viewpoint of five patients, of whom two are male (40%), four high educated (80%), two married (20%), two single (20%), one widowed (20%), and the mean age of patients holding this viewpoint is 65 years old.

Patients holding viewpoint 2 highly value the patients’ preferences dimension of PCC. They want to be taken seriously and to establish good relationships with healthcare professionals (statement 1, +3).

> “That’s very important. Because whether you are a millionaire or a farmer, you should be respected anyhow.” (Respondent 11, statement 1)

According to these patients, the ability to ask any question (statement 25, +3) is an important aspect of a trusting relationship with one’s healthcare professional (statement 25, +3). They feel that barriers to open communication will negatively impact care delivery and, thus, the quality of care.

> “If you go to a doctor with a certain threshold, so if I’m afraid to ask certain things, I don’t think a doctor can treat me well. But if I come with a certain ailment and I don’t show the back of my tongue about what I feel or what I think I feel, how should they act correctly? When I go to my doctor, I must indeed feel myself in such a relaxed way that I can and dare say anything. Even if they don’t agree, or I don’t agree with them, it has to be possible to talk with each other.” (Respondent 14, statement 25)

In contrast to those holding viewpoint 1, these patients do not need a central contact person who knows everything about their care (statement 10, –3). These two patient groups, however, interpreted this statement differently. Patients with viewpoint 2 consider a central contact person to be yet another care provider, whereas those with viewpoint 1 consider this person to be more of a case manager. Patients with viewpoint 2 want to handle all communication themselves, to speak for themselves and avoid misinterpretation.

> “Why do I need a contact person who knows about my illness or treatment? I can say for myself what I want and what I don’t want.” (Respondent 11, statement 10)

> “Another contact. The more contacts, the more things go wrong. Now I have two short lines; the nurse practitioner, the GP, and them together, who of course also communicate about me. I also know what is being communicated, which is important. If there is another contact, how will I be sure that they’ll communicate it to the third party the way I want, or whether they correctly interpret my answers and my questions?” (Respondent 14, statement 10)

In accordance with those holding viewpoint 1, patients holding viewpoint 2 consider the PCC dimension of access to care to be less important. They do not mind waiting for their appointments because they value their GPs’ help and they grant other patients this valued time as well, even if that means longer wait times (statement 21, –2).

> “No, I don’t mind. Occasionally you experience that someone needs more time. And I don’t mind. Especially when it’s urgent.” (Respondent 4, statement 21)

In addition, they do not consider traveling to their GPs’ offices to be an important issue (statement 18, –2).

> “I can get there easily, because I have a part-time taxi pass. And otherwise I can take the bus, but then I have to walk a bit through the forest.” (Respondent 6, statement 18)

Continuity of care is important for patients with this viewpoint. These patients do not mind cooperating with care providers to guarantee continuity of care; when needed, they do not mind telling their stories several times (statement 8, –2).

> "I don't think that's important, because I want to tell my story if necessary, to the right healthcare provider. I think that if you have something, you want to give an explanation at that moment and ask questions that fit in with that moment. You can read everything in the file, but that doesn't have to apply at that moment. This may also include things that you have processed and let go of again." (Respondent 15, statement 8)

Advice from the different healthcare providers involved in care for patients with multimorbidity can be difficult to align. Such alignment, for example regarding medication (statement 14, +2), is important for patients holding viewpoint 2 to ensure that they receive safe, high-quality care. They find contradictory advice to be counterproductive.

> "The GP gave me advice, but the therapist gave contradictory advice. Another therapist gave the same advice as the GP. The advice [of the first therapist] was nonsense advice and the second therapist agreed, it would only be counterproductive." (Respondent 14, statement 14)

> "Yes, I think that's very important. I also get medication sometimes. I don't take that much, only three. But I'm paying close attention to other packaging. Do they contain the same medicines that I had? That's what I asked the other day at the pharmacy. You get different boxes every time, but they explained that is because they are cheaper and they contain the same medicines that I must have. So that's important, because you don't know if all those other medicines will work the same way." (Respondent 6, statement 14)

Summary

Patients with this viewpoint represent the average patient who visits the GP. Similar to patients with viewpoint 1, these patients prefer to be supported by a well-coordinated multidisciplinary team. They seem to be less informed about their conditions than are patients holding viewpoint 1, and thus feel that the ability to easily turn to their healthcare professionals with all of their questions is important. In addition, they want to receive relevant medical information and advice concerning their conditions and care. Furthermore, they highly value trusting relationships with their healthcare professionals and want to be treated with dignity and respect.

Viewpoint 3: the vulnerable patient

This is the viewpoint of three patients, of whom two are male (67%), two married (67%), one divorced (33%), one high educated (33%), and the mean age of patients holding this viewpoint is 79 years old.

Like those with viewpoint 2, patients holding viewpoint 3 value the patients' preferences dimension of PCC, as they feel strongly that being taken seriously and being treated with dignity and respect by their healthcare professionals are important (statement 1, +3).

> "Yes, that's important. You are a human being. You just want to be treated normally." (Respondent 7, statement 1)

These patients also agree that access to care is very important; they greatly value being able to travel to their GPs' offices without problems (statement 18, +2) and being able to schedule appointments easily and within a reasonable timeframe (statement 20, +2).

> "Yes, I have a problem with that [traveling to the GP practice]. I can get there, but I have to leave my mobility scooter outside. Then I have to go upstairs with the elevator and then I have to walk a bit. And a bit in the waiting room and to the toilet as well. I can't do that." (Respondent 7, statement 18)

The affordability of care is also important to these patients, who seem to have fewer financial resources than do those holding viewpoint 1. For example, the need to pay costs not covered by insurance is an issue for patients holding viewpoint 3 (statement 19, +2).

> "Yes, altogether I have 70 euros a week. I have my General Old-Age Pensions Act money, but that's not much." (Respondent 7, statement 19)

Another patient agreed on this statement as well.

> "Yes, I think that's important. The care is already so expensive, we already pay so much per month [for the health insurance]." (Respondent 8, statement 19)

These patients seem less capable of truly comprehending information, and experience more difficulties in communicating with healthcare professionals than do patients with viewpoints 1 and 2. Shared decision making with patients holding viewpoint 3 is thus more challenging. As a result, these patients do not want to set their own treatment goals; they would rather leave this task to their healthcare professionals (statement 4, −2).

> “The doctor determines what needs to be done. These doctors have an understanding of treatment goals.” (Respondent 12, statement 4)
>
> “All those terms are so difficult. No, you just have to say; that’s what you need. Not all those Latin words. I just want to be treated as I am.” (Respondent 7, statement 4)

Given their struggles with communicating, these patients are often asked to re-tell their stories, which they dislike (statement, 8, +3).

> “It would be nice if I didn’t have to tell them every time. Every time I come, every time, I have to say; I have these medicines.” (Respondent 7, statement 8)

Summary

Patients with this viewpoint need more support regarding their care than do patients with viewpoints 1 and 2. These patients seem to be vulnerable in terms of communication skills and finances. They are aware of their lack of resources; they are looking for affordable and accessible care provided by healthcare professionals who take them seriously and treat them with dignity and respect. They are less focused on the way in which care is delivered than are patients with viewpoints 1 and 2; in their opinion, such matters fall under the expertise of their GPs and nursing practitioners.

Consensus among viewpoints

Although the three patient viewpoints differ from each other, they contain agreement on some elements of PCC. All viewpoints consider three aspects of continuity of care to be important for PCC: being well informed about where to go and why when referred to other care providers (statement 12), accurate transfer of information upon referral (statement 13), and alignment of advice from different practitioners (statement 14). Patients also agree on the importance of two aspects of coordination of care: attunement of care among all practitioners involved (statement 9) and the ability to easily contact someone with questions (statement 11). Patients think that attention should be paid to the influences of treatments on their lives (statement 3), but do not need all of their wishes and preferences to be taken into account (statement 2). Finally, almost all patients classified good explanation of all relevant information (statement 23) as neutral.

Within all viewpoints, patients consider two PCC dimensions to be less important: emotional support, and family and friends. First, patients do not think that emotional support is a key task of GPs; they would rather seek such support elsewhere (statement 15, –3/1/–1). The impact of their health on their private lives (statement 17, –3/–1/–2) and possible feelings of fear, gloom, and anxiety (statement 16, –2/1/–2) were less important than other aspects of PCC to all patients. Some patients do not seem to have given much thought to whether emotional problems should be discussed with their GPs, and some patients' chronic diseases have not really affected them emotionally.

> "I don't think it's that important. This [emotional support] has absolutely nothing to do with my illness." (Respondent 12, statement 15)

Second, patients do not wish to involve their family members or friends in their care at present (statement 26, –2/–2/–3) because they do not want to bother others, because they feel that their condition is a private matter, or because they simply feel that they can handle their care on their own. Thus, they also feel that attention to the needs and support provided by their relatives is not important (statement 27, 0/–3/–2); statement 28, –1/–1/–3). However, they believe that involving family and friends could be beneficial in more severe stages of illness (e.g., cancer, terminal illness). During these stages, optimal provision of emotional support becomes a crucial aspect of PCC.

> "I'll take care of it myself. I have severe COPD, but it's never been so severe that my family should be informed by my GP. Maybe if I ever get terminally ill, it would be important someday." (Respondent 14, statement 27)

DISCUSSION

This study aimed to explore the relative importance of PCC-related aspects in a primary care setting according to patients with multimorbidity in Noord-Brabant, the Netherlands. Three viewpoints regarding these aspects were identified. Patients with viewpoint 1 are the *prepared proactive patients* who seem to be well-off and want to be in charge of their own care. To do so, they seek medical information and prefer to be supported by a strongly coordinated multidisciplinary team of healthcare professionals. Patients with viewpoint 2 are *everyday patients* who visit GPs, and are in need of well-coordinated, respectful, and supportive care. Patients with viewpoint 3 are *vulnerable patients* who are less resourceful in terms of communication skills and finances, and are thus in need of accessible care and professionals' lead taking while treating them with dignity and respect.

The findings of this study suggest that not all patients with multimorbidity are in need of the same type of care delivery, and that the PCC dimensions are not equally important to all patients. This is in accordance with a study by Rijken and Van der Heide (2019) that identified subgroups of patients with multimorbidity based on their care needs and support. Rijken and Van der Heide (2019) showed that subgroups of patients with multimorbidity can be identified based on differences with regard to, among others, physical functioning, social functioning, mental health, and emotional functioning. Interestingly, differences still existed after controlling for physical condition and age. Background characteristics, medical characteristics and resources were examined as well. Though we did not use an instrument to measure these aspects in this study, we did gather qualitative data on these characteristics. One of the groups in the study from Rijken and van der Heide (2019) is limited with regard to financial resources, and communicative skills, which seems to correspond with our group 3 'the vulnerable patient'. Our findings are also in accordance with those of previous research examining the influence of health literacy on primary care needs. Health literacy encompasses several resources conferring the capacity to meet the complex demands of healthcare management (Sørensen et al., 2012); it is fundamental for patients who want to be in charge of their own care (Keleher & Hagger, 2007). The needs of patients with low and high health literacy differ in relation to the ability to manage their own care, for example with regard to communication and information provision. Our results provide insight that can guide the design of PCC with adjustment according to the diversity of care needs of patients with multimorbidity. We recommend further research to explore whether the adjustment of care according to these different viewpoints results in better patient outcomes.

Our results also showed that patients consider the dimensions 'family and friends' and 'emotional support' to be less important within all three viewpoints. Patients' ranking of the involvement of family and friends as less important than other PCC dimensions may reflect their perceived disease severity. They indicated that this dimension may become more important in more severe stages of illness, including terminal illness. These results may be related to previous findings that patients with chronic illnesses involve their family members and friends more often when their care needs are complex and when they are more vulnerable to worse health outcomes (Rosland, Piette, Choi, & Heisler, 2011; Wolff & Boyd, 2015).

Many participants in our study did not consider emotional support to be a key GP task, although the 2014 reform of mental healthcare in the Netherlands designates it as such (Kroneman et al., 2016). A possible explanation for this result is that patients are simply not used to this change in the GP role. Although patients do not expect emotional support from their GPs, they need such support in general. Coping with multiple chronic diseases is often accompanied by psychological burden, and patients with chronic conditions are at increased risk of developing depression and anxiety (Kunik et al., 2005; Van Manen et al., 2002). This emotional burden necessitates good PCC.

This study has several limitations. First, our sample may be considered small. However, a large sample is not required for the application of Q-methodology, and our sample size is similar to those of other Q-studies (Kelly, Moher, & Clifford, 2016; Kibblewhite, Hegarty, Stebbings, & Treharne, 2017). Data saturation and the representation of all viewpoints are more important than the sample size. We achieved data saturation (respondents gave no additional answers or explanations during final interviews), with the identification of three viewpoints. On presentation of the preliminary study results to all involved professionals (GPs and nurse practitioners), the professionals recognized the three viewpoints and agreed that they fully described this patient population; in their expert opinions, no viewpoint was missing. Therefore, the sample size in this study should not be considered problematic. It should be noted that since data saturation is somewhat subjective, further studies would be necessary to make sure no viewpoints are missing. Second, during interpretation of our findings it should be taken into account that our sample may still be biased, since those excluded from the study, or the non-responders from the larger evaluation study, may have been in poorer health compared to those who participated in the Q-study. We do not have health literacy scores or deprivation scores of the participants. Third, using Q-methodology forced us to exclude participants, because some were too ill to participate, and some visible impairments made it impossible for participants to read the cards and rank them according to their relative importance. Fourth, the generalizability of our results may be limited, as this study was conducted in Noord-Brabant, the Netherlands. Therefore, further research in other regions and countries with different primary care systems is needed to confirm and expand on our study findings. Since the Netherlands has a strong primary care system, it is possible that a replication of this study in a country with a different primary care system may result in different study findings. Moreover, Q-methodological findings do not allow for generalizability to an entire population what makes it more difficult to draw conclusions. However, this does not mean that findings based on Q-methodology cannot have wider implications (Thomas & Baas, 1992). Fifth, it should be considered that the qualitative part of this study has a risk of bias towards the researcher that conducted the interviews and selected the statements. We tried to minimize this bias by using a script for all interviews. However, and that is directly the strength of Q-methodology, both quantitative and qualitative analyses revealed similar results. Finally, the lesser communication skills of patients with viewpoint 3 impacted our findings, as these patients had greater difficulty elaborating on their Q-sorts and thus provided less-rich qualitative descriptions of their views than did patients with viewpoints 1 and 2. Patients with viewpoint 3 did, however, have strong opinions about which aspects of PCC they considered to be more and less important for their care, and had no problem Q-sorting the statements.

Conclusions

Using Q-methodology, we identified three viewpoints held by patients with multimorbidity on the important aspects of PCC delivery in the primary care setting, representing [1] the prepared proactive patient, [2] the everyday patient, and [3] the vulnerable patient. The results of this study are important for improving care delivery for patients with multimorbidity in primary care. The findings of this study suggest that not all patients with multimorbidity require the same type of care delivery, and that not all aspects of PCC delivery are equally important to all patients. This knowledge is important for healthcare professionals in the primary care setting to be able to tailor their care to the needs of patients with multimorbidity to ensure the best possible outcomes for their patients. The results can make GPs more aware of the viewpoints on PCC-related aspects and provide more insight in what PCC may look like in practice for this specific patient population.

REFERENCES

Aronson, L. (2015). Necessary steps: How health care fails older patients, and how it can be done better. *Health Affairs, 34*(3), 528-532.

Baker, R. M. (2006). Economic rationality and health and lifestyle choices for people with diabetes. *Social Science & Medicine, 63*(9), 2341-2353.

Bayliss, E. A., Edwards, A. E., Steiner, J. F., & Main, D. S. (2008). Processes of care desired by elderly patients with multimorbidities. *Family Practice, 25*(4), 287-293.

Berghout, M., van Exel, J., Leensvaart, L., & Cramm, J. M. (2015). Healthcare professionals' views on patient-centered care in hospitals. *BMC Health Services Research, 15*(1), 385.

Cramm, J. M., Leensvaart, L., Berghout, M., & van Exel, J. (2015). Exploring views on what is important for patient-centred care in end-stage renal disease using Q methodology. *BMC Nephrology, 16*(1), 74.

Cramm, J. M., & Nieboer, A. P. (2017). Validation of an instrument to assess the delivery of patient-centred care to people with intellectual disabilities as perceived by professionals. *BMC Health Services Research, 17*(1), 472.

Cramm, J. M., Kuipers, S. J., & Nieboer, A. P. (2019). Persoonsgerichte zorg voor patiënten met multimorbiditeit in de huisartsenpraktijk. *Rotterdam: Erasmus School of Health Policy & Management*.

De Bakker, D. H., & Groenewegen, P. P. (2009). *Primary care in the Netherlands: Current situation and trends.* Utrecht: NIVEL.

Fortin, M., Lapointe, L., Hudon, C., Vanasse, A., Ntetu, A. L., & Maltais, D. (2004). Multimorbidity and quality of life in primary care: A systematic review. *Health and Quality of Life Outcomes, 2*(1), 51.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T.L. (1993). *Through the patient's eyes: understanding and promoting patient-centered care.* Jossey-Bass Publishers.

Guttman, L. (1954). Some necessary conditions for common-factor analysis. *Psychometrika, 19*(2), 149-161.

Honey, S., Bryant, L. D., Murray, J., Hill, K., & House, A. (2013). Differences in the perceived role of the healthcare provider in delivering vascular health checks: A Q methodology study. *BMC Family Practice, 14*(1), 172.

Kaiser, H. F. (1960). The application of electronic computers to factor analysis. *Educational and Psychological Measurement, 20*(1), 141-151.

Keleher, H., & Hagger, V. (2007). Health literacy in primary health care. *Australian Journal of Primary Health, 13*(2), 24-30.

Kelly, S. E., Moher, D., & Clifford, T. J. (2016). Expediting evidence synthesis for healthcare decision-making: Exploring attitudes and perceptions towards rapid reviews using Q methodology. *PeerJ, 4*, e2522.

Kibblewhite, J. R., Hegarty, R. S., Stebbings, S., & Treharne, G. J. (2017). The role of enjoyment in exercise for people with arthritis: Four different viewpoints from a q-methodology study. *Musculoskeletal Care, 15*(4), 324-332.

Kringos, D. S., Boerma, W. G., Hutchinson, A., Saltman, R. B., & World Health Organization. (2015). *Building primary care in a changing Europe*. World Health Organization. Regional Office for Europe.

Kroneman, M., Boerma, W., van den Berg, M., Groenewegen, P., de Jong, J., & van Ginneken, E. (2016). Netherlands: Health system review. *Health Systems in Transition, 18*(2), 1-240.

Kuipers, S. J., Cramm, J. M., & Nieboer, A. P. (2019). The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multimorbidity in the primary care setting. *BMC Health Services Research, 19*(1), 13.

Kunik, M. E., Roundy, K., Veazey, C., Souchek, J., Richardson, P., Wray, N. P., & Stanley, M. A. (2005). Surprisingly high prevalence of anxiety and depression in chronic breathing disorders. *Chest, 127*(4), 1205-1211.

Lugtenberg, M., Burgers, J. S., Clancy, C., Westert, G. P., & Schneider, E. C. (2011). Current guidelines have limited applicability to patients with comorbid conditions: A systematic analysis of evidence-based guidelines. *PloS One, 6*(10), e25987.

Makovski, T. T., Schmitz, S., Zeegers, M. P., Stranges, S., & van den Akker, M. (2019). Multimorbidity and quality of life: systematic literature review and meta-analysis. *Ageing Research Reviews*, *53*, 100903.

Navickas, R., Petric, V., Feigl, A. B., & Seychell, M. (2016). Multimorbidity: What do we know? what should we do? *Journal of Comorbidity, 6*(1), 4-11.

Osborn, R., Moulds, D., Squires, D., Doty, M. M., & Anderson, C. (2014). International survey of older adults finds shortcomings in access, coordination, and patient-centered care. *Health Affairs, 33*(12), 2247-2255.

Rademakers, J., Delnoij, D., Nijman, J., & De Boer, D. (2012). Educational inequalities in patient-centred care: Patients' preferences and experiences. *BMC Health Services Research, 12*(1), 261.

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review, 70*(4), 351-379.

Read, J. R., Sharpe, L., Modini, M., & Dear, B. F. (2017). Multimorbidity and depression: A systematic review and meta-analysis. *Journal of Affective Disorders, 221*, 36-46.

Renzaho, A., Romios, P., Crock, C., & Sønderlund, A. (2013). The effectiveness of cultural competence programs in ethnic minority patient-centered health care—a systematic review of the literature. *International Journal for Quality in Health Care, 25*(3), 261-269.

Institute of Medicine (2001). *Crossing the quality chasm: a new health system for the 21st century.* National academy press.

Rijken, M., & van der Heide, I. (2019). Identifying subgroups of persons with multimorbidity based on their needs for care and support. *BMC Family Practice, 20*(1), 1-10.

Rosland, A. M., Piette, J. D., Choi, H., & Heisler, M. (2011). Family and friend participation in primary care visits of patients with diabetes or heart failure: Patient and physician determinants and experiences. *Medical Care, 49*(1), 37-45.

Schmolck, P., & Atkinson, J. (2002). PQMethod (version 2.11) [computer software]. Available at http://schmolck.org/qmethod/#PQMethod

Shabila, N. P., Al-Tawil, N. G., Al-Hadithi, T. S., & Sondorp, E. (2014). Using Q-methodology to explore people's health seeking behavior and perception of the quality of primary care services. *BMC Public Health, 14*(1), 2.

Søndergaard, E., Willadsen, T. G., Guassora, A. D., Vestergaard, M., Tomasdottir, M. O., Borgquist, L., . . . Reventlow, S. (2015). Problems and challenges in relation to the treatment of patients with multimorbidity: General practitioners' views and attitudes. *Scandinavian Journal of Primary Health Care, 33*(2), 121-126.

Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health, 12*(1), 80.

Swenson, S. L., Buell, S., Zettler, P., White, M., Ruston, D. C., & Lo, B. (2004). Patient-centered communication. *Journal of General Internal Medicine, 19*(11), 1069-1079.

Thomas, D. B., & Baas, L. R. (1992). The issue of generalization in Q methodology: "Reliable schematics" revisited. *Operant Subjectivity, 16*(1), 18-36.

Van Manen, J., Bindels, P., Dekker, F., IJzermans, C., Van der Zee, J., & Schade, E. (2002). Risk of depression in patients with chronic obstructive pulmonary disease and its determinants. *Thorax, 57*(5), 412-416.

Van Oostrom, S. H., Picavet, H. S. J., van Gelder, B. M., Lemmens, L. C., Hoeymans, N., van Dijk, C. E., . . . Baan, C. A. (2012). Multimorbidity and comorbidity in the Dutch population–data from general practices. *BMC Public Health, 12*(1), 715.

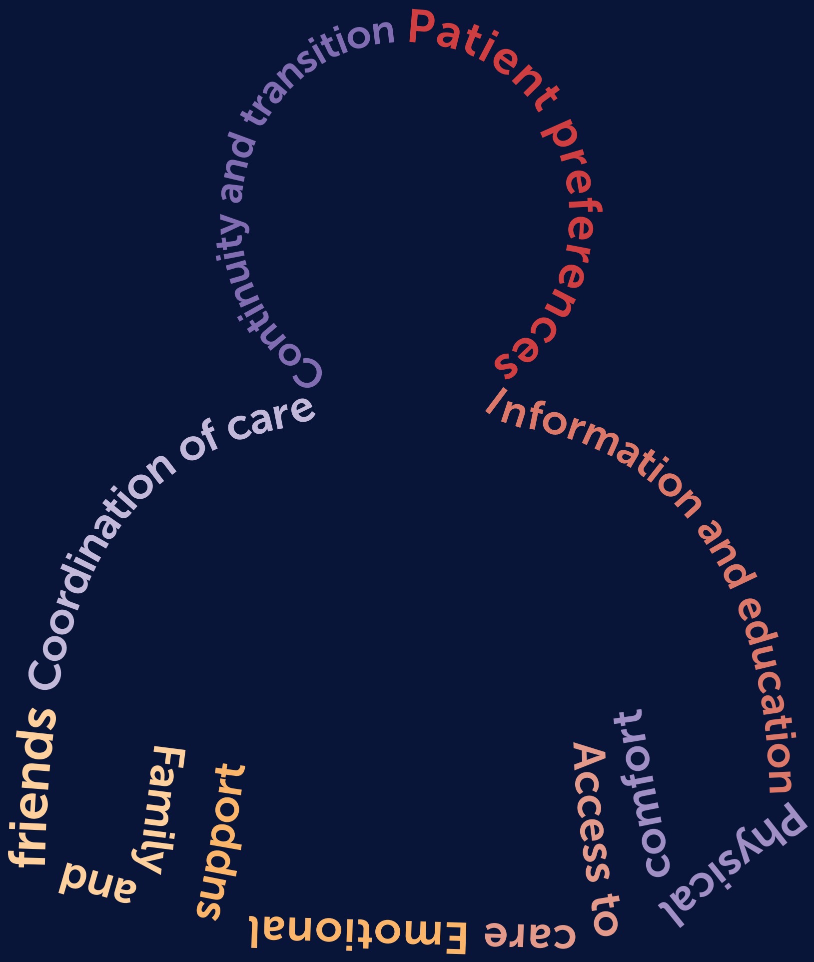
Vancampfort, D., Koyanagi, A., Hallgren, M., Probst, M., & Stubbs, B. (2017). The relationship between chronic physical conditions, multimorbidity and anxiety in the general population: A global perspective across 42 countries. *General Hospital Psychiatry, 45*, 1-6.

Verheij, R., Van Dijk, C., Abrahamse, H., Davids, R., Wennekes, L., Van den Hoogen, H., . . . Van Althuis, T. (2010). Landelijk informatie netwerk huisartsenzorg (LINH) kerncijfers 2008. *Utrecht, the Netherlands: NIVEL.*

Watts, S., & Stenner, P. (2012). *Doing Q methodological research: Theory, method & interpretation.* Sage.

Wolff, J. L., & Boyd, C. M. (2015). A look at person-centered and family-centered care among older adults: Results from a national survey. *Journal of General Internal Medicine, 30*(10), 1497-1504.

World Health Organization. (2008). *The world health report 2008: primary health care now more than ever*. World Health Organization.


Patient preferences
Information and education
Physical comfort
Access to care
Emotional support
Family and friends
Coordination of care
Continuity and transition

Chapter 3

The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multimorbidity in the primary care setting

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ABSTRACT

Background

Patients with multimorbidity have complex care needs that often make healthcare delivery difficult and costly to manage. Current healthcare delivery is not tailored to the needs of patients with multimorbidity, although multimorbidity poses a heavy burden on patients and is related to adverse outcomes. Patient-centered care and co-creation of care are expected to improve outcomes, but the relationships among patient-centered care, co-creation of care, physical well-being, social well-being, and satisfaction with care among patients with multimorbidity are not known.

Methods

In 2017, a cross-sectional survey was conducted among 216 (of 394 eligible participants; 55% response rate) patients with multimorbidity from seven primary care practices in Noord-Brabant, the Netherlands. Correlation and regression analyses were performed to identify relationships among patient-centered care, co-creation of care, physical well-being, social well-being, and satisfaction with care.

Results

The mean age of the patients was 74.46 ± 10.64 (range, 47–94) years. Less than half (40.8%) of the patients were male, 43.3% were single, and 39.3% were less educated. Patient-centered care and co-creation of care were correlated significantly with patients' physical well-being, social well-being, and satisfaction with care (all $p \leq 0.001$). Patient-centered care was associated with social well-being ($B = 0.387$, $p \leq 0.001$), physical well-being ($B = 0.368$, $p \leq 0.001$) and satisfaction with care ($B = 0.425$, $p \leq 0.001$). Co-creation of care was associated with social well-being ($B = 0.112$, $p = 0.006$) and satisfaction with care ($B = 0.119$, $p = 0.007$).

Conclusions

Patient-centered care and co-creation of care were associated positively with satisfaction with care and the physical and social well-being of patients with multimorbidity in the primary care setting. Making care more tailored to the needs of patients with multimorbidity by paying attention to patient-centered care and co-creation of care may contribute to better outcomes.

BACKGROUND

Because of aging populations, the prevalence of multimorbidity has grown tremendously and is expected to increase even further in the near future (Van Oostrom et al, 2012; World Health Organization [WHO], 2008). This increase poses a challenge, as patients with multimorbidity have complex care needs that often make adequate healthcare delivery difficult and costly to manage (Navickas, Petric, & Feigl, 2016). Most current healthcare systems are single disease–oriented and thus not adequately responsive to patients with multiple diseases and combinations of complex care needs. Healthcare for patients with multimorbidity involves following multiple disease-specific guidelines that do not take aspects of multimorbidity into account, resulting in a deficiency of evidence regarding best treatment (Lugtenberg, Burgers, Clancy, Westert, & Schneider, 2011; Tinetti, Bogardus, & Agostini, 2004)). Current care delivery is not tailored to the needs of patients with multimorbidity (Van der Heide et al., 2018), despite the heavy burden that multimorbidity places on these patients. This burden is often related to adverse patient outcomes, leading to a greater risk of mortality and increased healthcare utilization and cost (Lehnert et al., 2011). As a result, patients with multimorbidity report lower quality of life and well-being, and less satisfaction with care (Fortin, Lapointe, Hudon, Vanasse, Ntetu, & Maltais, 2004; Navickas et al. 2016). Making care more patient-centered may be the way forward.

Patient-centered care (PCC) has the potential to make care more tailored to the needs of patients with multimorbidity. PCC can be defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Institute of Medicine [IOM], 2001). Previous studies have investigated patients’ perspectives on PCC and distinguished eight dimensions: (1) patients’ preferences, (2) information and education, (3) access to care, (4) emotional support, (5) family and friends, (6) continuity and transition, (7) physical comfort, and (8) coordination of care (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). According to a systematic review conducted by Rathert, Wyrwich, and Boren (2013), organizations that are more patient-centered also have more positive outcomes, such as greater satisfaction with care, greater job satisfaction among healthcare professionals, increased quality and safety of care, and greater quality of life and well-being of patients. However, the systematic review included mainly studies conducted in hospital settings; very few were conducted in primary care settings and they did not specifically target patients with multimorbidity. Although PCC is expected to be beneficial for patients with multimorbidity, the relevance of its eight dimensions for these patients in the primary care setting is not known. Given that PCC may differ among settings (Rathert et al., 2013), investigation of its effects on patients with multimorbidity in the primary care setting is important.

Co-creation of care

In addition to the eight dimensions of PCC, which inform us how patient-centered organizations are, examination of co-creation of care is important. Co-creation of care is based on the quality of relationships characterized by patient-centered interaction and communication, which is also important for improving outcomes (Den Boer, Nieboer, & Cramm, 2017; Van der Meer, Nieboer, Finkenflugel, & Cramm, 2018). Co-creation of care is the establishment of productive interactions between patients and healthcare professionals (Den Boer et al., 2018). Productive interactions are defined as timely, accurate, and problem-solving ways of communication (Gittell, 2002). According to Gittell (2002), three relational dimensions are particularly important for establishing such productive interactions: shared goals, shared knowledge, and mutual respect. Co-creation is especially important in situations characterized by complex tasks, uncertainty, and time constraints. A meta-synthesis by Cottrell and Yardley (2015) showed that patients, general practitioners (GPs), and medical interns experience the complexity of managing care for patients with multimorbidity, and they face difficulties and uncertainties in finding the type of care necessary to meet all of these patients' needs and wishes. Moreover, GPs find that care delivery to patients with multimorbidity is often time consuming because of single-disease-oriented systems and their accompanying logistics. These difficult and complex issues thus make the co-creation of care potentially valuable in the context of care delivery to patients with multimorbidity. Co-creation of care is expected to lead to better outcomes among these patients.

PCC and patient outcomes

Physical and social well-being and satisfaction with care are important outcomes for patients with multimorbidity (Van der Heide et al., 2018). Programs that improve the quality of primary care are associated with better outcomes, such as improved physical well-being, but are not able to prevent the decline in social well-being of patients with chronic illnesses (Cramm & Nieboer, 2016b). Making chronic care more patient-centered is expected to enable patients to manage their own health and quality of life, thereby improving their physical and social well-being and satisfaction with care (Cramm & Nieboer, 2016b). Rathert and colleagues (2013) reported positive relationships between PCC and patients' well-being and satisfaction with care, but their review did not include studies of patients with multimorbidity in the primary care setting. The relationships among PCC, co-creation of care, patients' well-being (physical and social), and patients' satisfaction with care remain unexamined among patients with multimorbidity.

Study aim

Although we hypothesize positive associations among PCC, co-creation of care, physical and social well-being, and satisfaction with care among patients with multimorbidity, research supporting these expectations is still lacking. Therefore, this study aimed to explore the current level of PCC delivery to patients with multimorbidity in the primary care setting and the relationships among patient-centered care, co-creation of care, satisfaction with care, and physical and social well-being of patients with multimorbidity.

METHODS

This study included multi-morbid patients from seven primary care practices in Noord-Brabant, the Netherlands. All patients with two or more registered chronic conditions (*n* = 413) were eligible to participate. Exclusion criteria were: too ill to participate or recently moved (and as a result no longer treated by the primary care practices under study). Based on information received from the GP, patient or their informal caregiver nineteen patients were not eligible to participate (death (*n* = 4), terminal illness (*n* = 2), incorrect address (*n* = 5), recent move (*n* = 2), inability to fill in the questionnaire due to poor cognitive functioning (*n* = 2), recent stroke (*n* = 1), or poor eyesight (*n* = 3)). Questionnaires were sent by mail to all remaining participants (*n* = 394). After a few weeks, reminders were sent to non-respondents. Another few weeks later, second reminders and duplicates of the questionnaire were sent to non-respondents. When no response was received after the second reminder, we called non-respondents for whom telephone numbers were available. In total, 216 patients filled in the questionnaire and consented to participate in the study. Thus, the response rate was 55% (216 out of 394 respondents). A sample size calculation revealed that 110 participants would be required in order to detect small to medium effects with 95% power and a type 1 error rate of 5% (Faul, Erdfelder, Lang & Buchner, 2007). Having 216 respondents is therefore sufficient for valid results.

The medical ethics committee of the Erasmus Medical Centre, Rotterdam, the Netherlands, reviewed the research proposal (file number METC_2018_021) and decided that the rules laid down in the Dutch Medical Research Involving Human Subjects Act did not apply. Our research did not have a RCT design, participants were not subjected to procedures such as taking a blood sample, the research was not carried out with the intention of contributing to medical knowledge (e.g. etiology, pathogenesis, signs/symptoms, diagnosis) by systematically collecting and analyzing data. The main aim of the research was to investigate experiences of participants with care delivery, a process evaluation to improve quality of care delivery, which does not fall under the scope of Medical Research Involving Human Subjects Act (WMO) (see http://www.ccmo.nl/en/your-research-does-it-fall-under-the-wmo). Written consent was obtained from all participants.

Measures

PCC for patients with multimorbidity in the primary care setting

PCC for patients with multimorbidity in the primary care setting was measured using the 36-item patient-centered primary care (PCPC) instrument, which assesses the eight dimensions of PCC (Cramm & Nieboer, 2018). The PCPC instrument builds on our earlier work, in which we investigated the eight dimensions of PCC in hospital and long-term care settings (Berghout, Van Exel, Leensvaart, & Cramm, 2015; Cramm, Leensvaart, Berghout, & Van Exel, 2015; Cramm & Nieboer, 2017). Responses of patients were measured on a 5-point scale ranging from 1 (totally disagree) to 5 (totally agree), with higher scores indicating greater PCC. Scores for each of the eight dimensions of PCC were derived by calculating the average score for all items in that particular dimension. The overall score of PCC, in turn, was derived by calculating the average score for the eight dimensions (mean of the eight subscales calculated in the previous step). In this study, the Cronbach's alpha value for this instrument was 0.89, indicating good reliability.

Well-being

Well-being was measured with the 15-item version of the Social Production Function Instrument for the Level of Well-being (SPF-ILs) (Nieboer, Lindenberg, Boomsma, & Bruggen, 2005). Levels of physical (comfort and stimulation) and social (status, behavioral confirmation, and affection) well-being were measured. Responses of patients were measured on a 4-point scale ranging from 1 to 4, with higher scores indicating greater well-being. Scores for physical and social well-being were derived by calculating the average score for all items in that particular subsection of items. In this study, the Cronbach's alpha value for both physical and social well-being, measured with the SPF-ILs, was 0.83, indicating good reliability.

Co-creation of care

Co-creation of care was measured with the relational co-production instrument (Gittell, 2010). The instrument consists of seven items measuring four aspects of communication (timely, accurate, frequent, and problem-solving) and three aspects of the relationship (shared goals, shared knowledge, and mutual respect) between patients with multimorbidity and the healthcare professionals treating them (GPs, nurse practitioners, and specialists). Responses of patients were measured on a 5-point Likert-scale ranging from 1 (never) to 5 (always), with higher scores indicating better co-creation of care. Scores for co-creation of care were derived by calculating the average score for all items in this instrument. In this study, the Cronbach's alpha value for this instrument was 0.93, indicating excellent reliability.

Satisfaction with care

The adjusted version of the Satisfaction with Stroke Care questionnaire (SASC) was used to measure patients' satisfaction with care (Boter, De Haan, & Rinkel, 2003). Although the original 8-item SASC was used among stroke patients, this instrument contains generic questions about satisfaction with care and is not restricted to patients receiving stroke care. The SASC instrument is therefore often used in various patient populations in the hospital setting (Baumann, Rat, Mainard, Cuny, & Guillemin, 2011; Bredart et al., 2003; Poder & Vone, 2009; Von Essen ,Larsson, Oberg, & Sjoden, 2002). Given that the instrument was developed to assess satisfaction with care in the hospital setting, we did slightly adjust items for the primary care setting (e.g. 'The doctors have done everything they can to make me well again' was changed into 'The staff has done everything they can to make me well again'). Furthermore, we removed irrelevant or overlapping items (e.g. 'The hospitalization process went smoothly' and 'I have been treated with kindness and respect by the staff at the hospital'), which resulted in a final set of 6 items: 'I have received all the information I want about the causes and nature of my illness(es)', 'The staff has done everything they can to make me well again', 'I am satisfied with the type of treatment they have given me (e. g. physiotherapy, occupational therapy)', 'I have had enough therapy (e.g. physiotherapy, occupational therapy)', 'I am happy about the effect treatments had on my disease progression', and 'I am satisfied with the treatment provided by the general practitioner who I visit'. Responses of patients were measured on a 4-point scale ranging from 1 (totally disagree) to 4 (totally agree), with higher scores indicating greater satisfaction with care. Satisfaction with care scores were derived by calculating the average score for all 6 items. In this study, the Cronbach's alpha value for this instrument was 0.89, indicating good reliability.

Background characteristics

Patients were also asked to provide information on background characteristics, such as age, gender, education, and marital status. Dummy variables were created for marital status (1, living alone, widowed or divorced; 0, married/living with partner) and education (1, primary education or less; 0, preparatory school for vocational secondary education or higher).

Statistical analyses

SPSS software (version 23; IBM Corporation, Armonk, NY, USA) was used to analyze the data. Descriptive statistics were applied to all variables and involved the calculation of *n*s, means, minimums, maximums, standard deviations (SDs), and/or percentages. Pearson correlation analyses were performed to identify associations between PCC and background characteristics, co-creation of care, satisfaction with care, and physical and social well-being of patients with multimorbidity. Regression analyses were performed to investigate multivariate relationships among these variables. Two-sided p values ≤ 0.05 were considered to be significant.

As data were missing for some PCC items due to occasional inapplicability, we additionally employed multiple imputation techniques (Markov chain Monte Carlo) and performed the regression analyses on pooled results based on the five imputed datasets (n = 216 each). Predictive mean matching was used as an imputation model to ensure that imputed values preserved the actual range of each variable.

RESULTS

Table 1 displays the background characteristics of the patients. Their mean age was 74.46 ± 10.64 (range, 47–94) years. Less than half (40.8%) of the patients were male, 43.3% were single, and 39.3% had low educational levels.

Table 1 Descriptive statistics (n = 216)

Characteristic	Mean ± standard deviation (range) or percentage
Age (years)	74.44 ± 10.64 (47–94)
Gender (male)	40.8%
Education (low)	39.3%
Marital status (single)	43.3%
Patient-centered care	3.84 ± 0.47 (1.7–5)
Preferences	3.96 ± 0.63 (1–5)
Physical comfort	3.92 ± 0.57 (1.8–5)
Coordination	3.92 ± 0.61 (2–5)
Emotional support	3.45 ± 0.75 (1–5)
Access to care	3.99 ± 0.56 (1.67–5)
Continuity and transition	3.97 ± 0.58 (2–5)
Information and education	3.89 ± 0.56 (2–5)
Family and friends	3.57 ± 1.01 (1–5)
Co-creation of care	3.61 ± 0.85 (1–5)
General practitioner	3.78 ± 0.88 (1–5)
Nurse practitioner	3.63 ± 1.03 (1–5)
Specialist	3.12 ± 1.32 (1–5)
Satisfaction with care	3.13 ± 0.45 (1.5–4)
Social well-being	2.71 ± 0.53 (1.44–4)
Physical well-being	2.55 ± 0.62 (1–4)

Note: Based on imputed data.

The mean overall score for the level of PCC in the primary care practices was 3.84 ± 0.47. PCC dimension scores ranged from 3.45 (SD 0.75) to 3.99 (SD 0.56). The mean scores for the emotional support and family and friends dimensions were relatively low (3.45 and 3.57, respectively). The mean score for co-creation of care was 3.61 ± 0.85. GPs received the highest co-creation of care score (3.78 ± 0.88), followed by nurse practitioners (3.63 ± 1.03) and specialists (3.12 ± 1.32). The mean satisfaction with care score was 3.13 ± 0.45. The mean scores for social and physical well-being were 2.71 ± 0.53 and 2.55 ± 0.62, respectively; these scores were lower than those obtained among patients with chronic obstructive pulmonary disease (COPD), cardiovascular disease (CVD), and diabetes (see Appendix Supplementary Table 1).

Table 2 shows the percentage of patients who (completely) agreed with each PCC item (if applicable). About half of patients agreed with the items in the emotional support dimension. In the patient preferences dimension, about three-fourths of patients agreed with the items “I was helped to determine my own treatment goals,” “I felt supported to achieve my treatment goals,” and “I received advice that I really could use.” In the physical comfort dimension, 60% of patients felt that attention was given to fatigue and insomnia, 74.3% felt that the waiting rooms were comfortable, and 71.5% felt that they had sufficient privacy in the treatment room and at the counter. An important issue in the access to care dimension seems to be waiting time; slightly more than 30% of patients felt that they had been waiting too long to be seen by care providers. In the information and education dimension, about half of the patients felt that their own data was easily accessible. Finally, there is room for improvement in the friends and family dimension, especially concerning the items “attention was given to care and support provided by family members” and “attention was given to possible questions from my family members.” When applicable, more than one-third of respondents were dissatisfied about the way in which care providers involved family and friends.

The results of the correlation analysis are displayed in Table 3. PCC and co-creation of care were correlated significantly with patients’ physical well-being, social well-being, and satisfaction with care (all $p \leq 0.001$). In addition, a weak negative correlation was found between satisfaction with care and single marital status ($r = -0.148$, $p = 0.033$). Physical well-being was correlated negatively with age ($r = -0.165$, $p = 0.016$). A weak positive correlation was found between physical well-being and male gender ($r = 0.152$, $p = 0.029$). All eight dimensions of PCC were correlated significantly with patients’ physical well-being, social well-being, and satisfaction with care (Table 4). Finally, a positive relationship was found between PCC and co-creation of care ($r = 0.442$, $p < 0.001$).

Table 2 Percentages of respondents' agreement with patient-centered care items

Patient-centered care item	(Completely) agree (%)
Patient preferences	
I felt taken seriously	89.2
My wishes and preferences were taken into account when choosing a treatment	80.4
I was involved in decisions about my treatment	85.7
The influence that the treatment can have on my life was taken into account	80.4
I was helped to determine my own treatment goals	73.5
I felt supported to achieve my treatment goals	77.0
I received advice that I really could use	79.0
Physical comfort	
Attention was given to my physical comfort (such as the management of pain, shortness of breath)	84.7*
Attention was paid to fatigue and insomnia	60.8*
The (waiting) rooms were clean	90.0
The (waiting) rooms were comfortable	74.3
In the treatment room(s) and at the counter there was sufficient privacy	71.5
Coordination of care	
Everyone was well informed; I only had to tell my story once	81.5*
The care was well attuned among the practitioners involved	81.7*
I knew who was coordinating my care	71.9
I could easily contact someone with questions	79.4
Continuity and transition	
When being referred to another care provider (specialist/dietician/physiotherapist) I was well informed about where to go and why	86.0*
With a referral, all my information was passed on correctly	82.2*
Advice (such as medication) from different practitioners (medical specialists and family doctor) was well attuned to each other	78.7*
Treatment from the family doctor is in line with treatment from other care providers	84.7*
Emotional support	
Emotional support was also provided	53.0
Attention was paid to possible feelings of fear, gloom, and anxiety	54.5
I was made aware of the possibilities for more intensive emotional support	32.4
Attention was paid to the impact of my health on my private life (family, relatives, work, social life)	52.0
Access to care	
It was no problem to go from my home to my family doctor and back again	80.4
The general practice was easily accessible	94.7
I could easily schedule an appointment quickly	85.6
On a visit I didn't have to wait long before it was my turn	69.4
I could easily request a prescription refill	93.3

Table 2 Percentages of respondents' agreement with patient-centered care items (continued)

Patient-centered care item	(Completely) agree (%)
Information and education	
I was well informed	87.5
The information I received was well explained	85.1
I had easy access to my own data (lab results, medication overview, referrals)	55.2
I could ask all the questions I wanted	89.6
Family and friends	
With my consent, relatives were involved in my treatment	70.5*
Attention was given to care and support provided by family members	57.4*
Attention was given to possible questions from my family members	63.3*

Note: Based on non-imputed data. *If applicable

Table 3 Associations between patients' characteristics, patient-centered care, co-creation of care and satisfaction and social and physical well-being (*n* = 216)

Variable	Satisfaction with care		Social well-being		Physical well-being	
	r	*p*	*r*	*p*	*r*	*p*
Age (years)	–0.121	0.080	–0.006	0.927	–0.165	0.016
Gender (male)	0.110	0.155	0.057	0.407	0.152	0.029
Marital status (single)	–0.148	0.033	–0.011	0.870	–0.129	0.064
Education (low)	–0.080	0.263	–0.050	0.473	–0.131	0.064
Patient-centered care	0.501	<0.001	0.446	<0.001	0.392	<0.001
Co-creation of care	0.389	<0.001	0.334	<0.001	0.217	0.001

Note: Based on imputed data.

Table 4 Relationships of the eight patient-centered care dimensions and co-creation of care with satisfaction and social and physical well-being (*n* = 216)

PCC dimension or co-creation of care	Satisfaction with care		Social well-being		Physical well-being	
	r	*p*	*r*	*p*	*r*	*p*
Patients' preferences	0.446	<0.001	0.324	<0.001	0.333	<0.001
Physical comfort	0.371	<0.001	0.367	<0.001	0.325	<0.001
Coordination of care	0.475	<0.001	0.363	<0.001	0.294	<0.001
Emotional support	0.309	<0.001	0.307	<0.001	0.183	0.011
Access to care	0.454	<0.001	0.324	<0.001	0.333	<0.001
Continuity and transition	0.442	<0.001	0.335	<0.001	0.203	0.010
Information and education	0.416	<0.001	0.398	<0.001	0.280	<0.001
Family and friends	0.308	<0.001	0.332	<0.001	0.202	0.013
Overall PCC	0.501	<0.001	0.446	<0.001	0.329	<0.001
Co-creation of care	0.389	<0.001	0.334	<0.001	0.217	<0.001

Note: Based on imputed data. PCC, patient-centered care.

The results of the multivariate regression analyses are presented in Table 5. After controlling for background characteristics, PCC was associated with social well-being (*B* = 0.387, *p* ≤ 0.001), physical well-being (*B* = 0.368, *p* ≤ 0.001), and satisfaction with care (*B* = 0.425, *p* ≤ 0.001). Co-creation of care was associated with social well-being (*B* = 0.112, *p* = 0.006) and satisfaction with care (*B* = 0.119, *p* = 0.007). Although we found a significant association between co-creation of care and physical well-being in the bivariate analysis, this effect dissipated in the multivariate analysis (*B* = 0.062, *p* = 0.249). The significant associations of background characteristics with satisfaction with care and physical well-being also dissipated in the multivariate analysis.

Table 5 Multivariate relationships of variables with satisfaction with care, social well-being, and physical well-being (*n* = 216)

Variable	Satisfaction with care		Social well-being		Physical well-being	
	B (SE)	*p*	*B* (SE)	*p*	*B* (SE)	*p*
Age	0.004 (0.003)	0.210	0.000 (0.003)	0.932	–0.005 (0.004)	0.241
Gender	0.019 (0.059)	0.785	0.018 (0.072)	0.770	0.107 (0.086)	0.210
Marital status	–0.055 (0.070)	0.648	0.051 (0.062)	0.233	–0.038 (0.088)	0.667
Education	–0.068 (0.080)	0.397	–0.061 (0.062)	0.326	–0.099 (0.095)	0.297
Patient-centered care	0.425 (0.078)	≤0.001	0.387 (0.069)	≤0.001	0.368 (0.097)	≤0.001
Co-creation of care	0.119 (0.044)	0.007	0.112 (0.039)	0.006	0.062 (0.054)	0.249

Note: Based on imputed data.
Adjusted R^2 social well-being: 0.18
Adjusted R^2 physical well-being: 0.11
Adjusted R^2 satisfaction with care: 0.31

DISCUSSION

This study demonstrated that the eight dimensions of PCC and co-creation of care are important for satisfaction with care, physical well-being, and social well-being among patients with multimorbidity in the primary care setting in Noord-Brabant, the Netherlands. Although similar findings have been obtained among patients in hospital settings (Rathert et al., 2013) and for care delivery to people with intellectual disabilities (Van der Meer et al., 2018), this study is the first to show the importance of both PCC and co-creation of care for patients with multimorbidity in the primary care setting. This patient population experiences lower levels of social and physical well-being than do patients with single chronic diseases, such as COPD, CVD, and diabetes (Cramm & Nieboer, 2014; Cramm & Nieboer, 2015; Cramm & Nieboer, 2016a). Patients with multimorbidity differ in many other aspects from patients with single chronic diseases. Hopman, Schellevis, and Rijken (2016) showed that patients with multimorbidity are more often male and less educated, and that they experience more problems in health domains such as mobility, usual activities, and pain/discomfort. Thus, care needs to be made more patient-centered and tailored to the needs of patients with multimorbidity.

Although the overall level of PCC in the primary care practices included in this study was sufficient, there is room for improvement in two dimensions in particular: family and friends, and emotional support. More than one-quarter of all patients with multimorbidity in this study were not completely satisfied with aspects of the involvement of family and friends in their care. Moreover, this dimension was not considered to be applicable for almost half of the study population; 43% of patients were single, which could reflect an absence of family members who could be involved in the care process. Chronically ill patients who are married or have partners are more likely to bring these partners to GP visits (Rosland, Piette, Choi & Heisler, 2011). Furthermore, previous studies have shown that two-thirds of care providers endorse barriers to the participation of family and friends in patients' care processes; they are concerned about privacy rules, they experience the involvement of family and friends as burdensome, and/or they are uncertain about their skills for such involvement (Rosland et al., 2011).

About half of the patients surveyed in this study did not experience sufficient levels of emotional support from their care providers. Kenning and colleagues (Kenning, Fisher, Bee, Bower, & Convertry, 2013) revealed a discrepancy between the expectations and experiences of patients with multimorbidity and their care providers in the primary care setting. Further research should focus on how emotional support should be provided to meet patients' needs.

In the bivariate analyses, co-creation of care was related positively to satisfaction with care, physical well-being, and social well-being. However, the effect of physical well-being dissipated in the multivariate analyses. The stronger association between co-creation of care and social well-being could be explained by the fact that the former focuses mainly on social aspects, namely the quality of a relationship (Gittell, 2002). The key elements of co-creation of care (shared goals, shared knowledge, mutual respect) enable the realization of social well-being goals. To illustrate, mutual respect between patients and care providers may result in higher levels of status for patients, as when they receive compliments from care providers on how they are dealing with their conditions relative to other patients or compared to how they used to deal with their conditions. Acknowledging a patient's specific care needs may result in more affectionate and trusting interactions with the care provider, fulfilling the patient's need for affection and behavioral confirmation. Co-creation of care may add to social well-being through the quality of patient-centered interaction and communication. However, when a patient's physical health deteriorates, this quality is unlikely to improve or change his/her physical status. Currently, most researchers do not consider physical and social well-being separately; rather, they combine the concepts into a single overall well-being or quality of life score. The findings of this study demonstrate the importance of separately examining physical and social well-being in future research on PCC and co-creation of care.

This study has several limitations that should be taken into account when interpreting our findings. First, the cross-sectional design prevented us from determining the causality of relationships. Second, this study was conducted in Noord-Brabant, a region in the Netherlands; research in other regions and/or countries is needed to confirm our study findings. Third, this study assessed the experiences of patients with multimorbidity, which does not guarantee the objectivity of observations and measurements; however, subjective experiences and self-rated health are important predictors of health outcomes, such as morbidity and mortality (Idler & Benyamini, 1997). The final limitation is the response rate. Although the response rate of 55% might be considered as low, it is higher compared to other studies in which the respondents also received a questionnaire by mail (Buttle & Thomas, 1997; Picavet, 2001) and much higher compared to earlier studies using the same strategy among chronically ill patients (31% response rate) (Peters et al., 2018). Our sample still may be biased which could have affected our study findings; non-responders may have been in poorer health compared to those who did fill in the questionnaire.

Conclusions

PCC and co-creation of care are associated positively with satisfaction with care and the physical and social well-being of patients with multimorbidity in the primary care setting. These findings are important because current care delivery is not tailored to the needs of patients with multimorbidity, although multimorbidity is often related to adverse patient outcomes. Making care more tailored to the needs of these patients by paying attention to PCC and co-creation of care may contribute to better outcomes.

REFERENCES

Baumann, C., Rat, A., Mainard, D., Cuny, C., & Guillemin, F. (2011). Importance of patient satisfaction with care in predicting osteoarthritis-specific health-related quality of life one year after total joint arthroplasty. *Quality of Life Research, 20*(10), 1581-1588.

Berghout, M., van Exel, J., Leensvaart, L., & Cramm, J. M. (2015). Healthcare professionals' views on patient-centered care in hospitals. *BMC Health Services Research, 15*(1), 385.

Boter, H., de Haan, R. J., & Rinkel, G. J. (2003). Clinimetric evaluation of a satisfaction-with-stroke-care questionnaire. *Journal of Neurology, 250*(5), 534-541.

Brédart, A., Robertson, C., Razavi, D., Batel-Copel, L., Larsson, G., Lichosik, D., ... & De Haes, J. C. J. M. (2003). Patients' satisfaction ratings and their desire for care improvement across oncology settings from France, Italy, Poland and Sweden. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *12*(1), 68-77.

Buttle, F., & Thomas, G. (1997). Questionnaire colour and mail survey response rate. *Journal of the Market Research Society*, *39*(4), 625-627.

Cottrell, E., & Yardley, S. (2015). Lived experiences of multimorbidity: An interpretative meta-synthesis of patients', general practitioners' and trainees' perceptions. *Chronic Illness*, *11*(4), 279-303.

Cramm, J. M., & Nieboer, A. P. (2014). The effects of social and physical functioning and self-management abilities on well-being among patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes. *Applied Research in Quality of Life*, *9*(1), 113-121.

Cramm, J. M., Leensvaart, L., Berghout, M., & van Exel, J. (2015). Exploring views on what is important for patient-centred care in end-stage renal disease using Q methodology. *BMC Nephrology, 16*(1), 74.

Cramm, J. M., & Nieboer, A. P. (2015). Chronically ill patients' self-management abilities to maintain overall well-being: what is needed to take the next step in the primary care setting?.*BMC Family Practice*, *16*(1), 1-8.

Cramm, J. M., & Nieboer, A. P. (2016a). The changing nature of chronic care and coproduction of care between primary care professionals and patients with COPD and their informal caregivers. *International Journal of Chronic Obstructive Pulmonary Disease*, *11*, 175-182.

Cramm, J. M., & Nieboer, A. P. (2016b). Is "disease management" the answer to our problems? no! population health management and (disease) prevention require "management of overall well-being". *BMC Health Services Research, 16*(1), 1-6.

Cramm, J. M., & Nieboer, A. P. (2017). Validation of an instrument to assess the delivery of patient-centred care to people with intellectual disabilities as perceived by professionals. *BMC Health Services Research, 17*(1), 472.

Cramm, J. M., & Nieboer, A. P. (2018). Validation of an instrument for the assessment of patient-centred care among patients with multimorbidity in the primary care setting: The 36-item patient-centred primary care instrument. *BMC Family Practice, 19*(1), 143

Den Boer, J., Nieboer, A. P., & Cramm, J. M. (2017). A cross-sectional study investigating patient-centred care, co-creation of care, well-being and job satisfaction among nurses. *Journal of Nursing Management*, *25*(7), 577-584.

Essen, L. V., Larsson, G., Öberg, K., & Sjödén, P. O. (2002). 'Satisfaction with care': associations with health-related quality of life and psychosocial function among Swedish patients with endocrine gastrointestinal tumours. *European Journal of Cancer Care*, *11*(2), 91-99.

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). A flexible statistical power analysis program for the social, behavioral and biomedical sciences. *Behavior Research Method, 39*(2), 175-191.

Fortin, M., Lapointe, L., Hudon, C., Vanasse, A., Ntetu, A. L., & Maltais, D. (2004). Multimorbidity and quality of life in primary care: a systematic review. *Health and Quality of life Outcomes*, *2*(1), 1-12.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T.L. (1993). *Through the patient's eyes: understanding and promoting patient-centered care.* Jossey-Bass Publishers.

Gittell, J. H. (2002). Relationships between service providers and their impact on customers. *Journal of Service Research, 4*(4), 299-311.

Gittell, J. H. (2011). *Relational coordination: Guidelines for theory, measurement and analysis*. Waltham, MA: Brandeis University.

Hopman, P., Schellevis, F. G., & Rijken, M. (2016). Health-related needs of people with multiple chronic diseases: differences and underlying factors. *Quality of Life Research*, *25*(3), 651-660.

Idler, E. L., & Benyamini, Y. (1997). Self-rated health and mortality: a review of twenty-seven community studies. *Journal of Health and Social Behavior*, 38(1), 21-37.

Institute of Medicine (2001). *Crossing the quality chasm: a new health system for the 21st century.* National academy press*.*

Kenning, C., Fisher, L., Bee, P., Bower, P., & Coventry, P. (2013). Primary care practitioner and patient understanding of the concepts of multimorbidity and self-management: A qualitative study. *SAGE Open Medicine*, *1*, 2050312113510001.

Lehnert, T., Heider, D., Leicht, H., Heinrich, S., Corrieri, S., Luppa, M., ... & König, H. H. (2011). Health care utilization and costs of elderly persons with multiple chronic conditions. *Medical Care Research and Review*, *68*(4), 387-420.

Lugtenberg, M., Burgers, J. S., Clancy, C., Westert, G. P., & Schneider, E. C. (2011). Current guidelines have limited applicability to patients with comorbid conditions: A systematic analysis of evidence-based guidelines. *PloS One, 6*(10), e25987.

Navickas, R., Petric, V., Feigl, A. B., & Seychell, M. (2016). Multimorbidity: What do we know? what should we do? *Journal of Comorbidity, 6*(1), 4-11.

Nieboer, A., Lindenberg, S., Boomsma, A., & Bruggen, A. C. V. (2005). Dimensions of well-being and their measurement: The SPF-IL scale. *Social Indicators Research, 73*(3), 313-353.

Peters, M., Kelly, L., Potter, C. M., Jenkinson, C., Gibbons, E., Forder, J., & Fitzpatrick, R. (2018). Quality of life and burden of morbidity in primary care users with multimorbidity. *Patient Related Outcome Measures, 9*, 103-113.

Picavet, H. S. J. (2001). National health surveys by mail or home interview: effects on response. *Journal of Epidemiology & Community Health*, *55*(6), 408-413.

Pöder, U., & von Essen, L. (2009). Perceptions of support among Swedish parents of children on cancer treatment: a prospective, longitudinal study. *European Journal of Cancer Care*, *18*(4), 350-357.

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review, 70*(4), 351-379.

Rosland, A. M., Piette, J. D., Choi, H., & Heisler, M. (2011). Family and friend participation in primary care visits of patients with diabetes or heart failure: Patient and physician determinants and experiences. *Medical Care, 49*(1), 37-45.

Tinetti, M. E., Bogardus, S. T.,Jr, & Agostini, J. V. (2004). Potential pitfalls of disease-specific guidelines for patients with multiple conditions. *The New England Journal of Medicine, 351*(27), 2870-2874.

Van der Heide, I., Snoeijs, S., Quattrini, S., Struckmann, V., Hujala, A., Schellevis, F., & Rijken, M. (2018). Patient-centeredness of integrated care programs for people with multimorbidity. Results from the European ICARE4EU project. *Health Policy, 122*(1), 36-43.

Van Oostrom, S. H., Picavet, H. S. J., van Gelder, B. M., Lemmens, L. C., Hoeymans, N., van Dijk, C. E., .. Baan, C. A. (2012). Multimorbidity and comorbidity in the dutch population–data from general practices. *BMC Public Health, 12*(1), 715.

Van der Meer, L., Nieboer, A. P., Finkenflügel, H., & Cramm, J. M. (2018). The importance of person-centred care and co-creation of care for the well-being and job satisfaction of professionals working with people with intellectual disabilities. *Scandinavian Journal of Caring Sciences, 32*(1), 76-81.

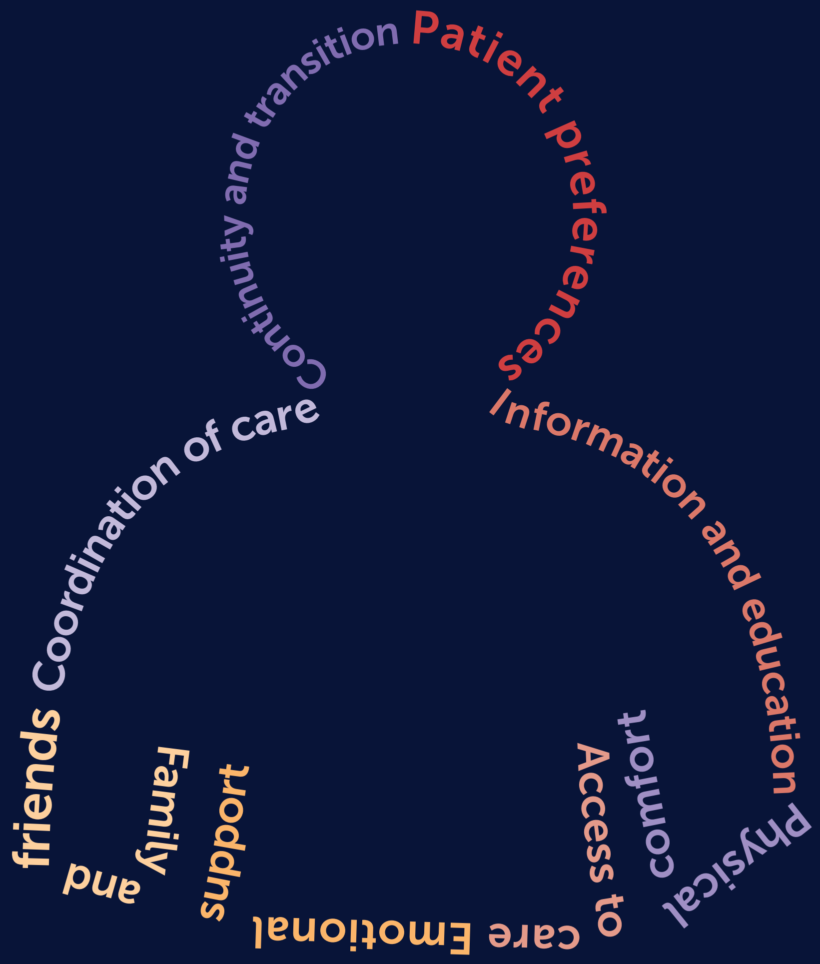
World Health Organization. (2008). *The world health report 2008: primary health care now more than ever*. World Health Organization.

APPENDIX

Supplementary Table 1 Descriptive statistics of physical and social well-being in patient populations with multimorbidity, COPD, CVRM, and diabetes

	Multimorbidity		COPD		CVRM		Diabetes	
Statistic	Physical well-being	Social well-being	Physical well-being	Social well-being	Physical well-being	Social well-being	Physical well-being	Social well-being
n	216	216	400	390	439	439	135	134
Mean ± standard deviation (range)	2.55 ± 0.62 (1–4)	2.71 ± 0.53 (1.44–4)	2.76 ± 0.58 (1–4)	2.81 ± 0.55 (1–4)	2.78 ± 0.52 (1.5–4)	2.79 ± 0.49 (1–4)	2.79 ± 0.49 (1–4)	2.82 ± 0.47 (1.33–4)

Note: Well-being data for patients with COPD (Chronic Obstructive Pulmonary Disease), CVRM (Cardio Vascular Risk Management), and diabetes are derived from 2012 surveys of chronically ill patients enrolled in Dutch disease management programs; the 15-item version of the Social Production Function Instrument for the Level of Well-being short version was used to assess physical and social well-being. This survey was part of a larger study of the effectiveness of disease management programs in the Netherlands [Lemmens, K. M., Rutten-Van Mölken, M. P., Cramm, J. M., Huijsman, R., Bal, R. A., & Nieboer, A. P. (2011). Evaluation of a large scale implementation of disease management programmes in various Dutch regions: a study protocol. *BMC health services research*, *11*(1), 1-9.].



Patient preferences

Information and education

Physical comfort

Access to care

Emotional support

Family and friends

Coordination of care

Continuity and transition

Chapter 4

The need for co-creation of care with multimorbidity patients—A longitudinal perspective

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ABSTRACT

Background

Primary care delivery for multimorbid patients is complex, due to single disease–oriented guidelines, complex care needs, time constraints and the involvement of multiple healthcare professionals. Co-creation of care, based on the quality of communication and relationships between healthcare professionals and patients, may therefore be valuable. This longitudinal study investigates the relationships of co-creation of care to physical and social well-being and satisfaction with care among multimorbid patients in primary care.

Methods

In 2017 and 2018, longitudinal surveys were conducted among multimorbid patients from seven primary care practices in Noord-Brabant, the Netherlands (n = 138, age = 73.50 ± 9.99). Paired sample t-tests and multivariate regression analyses were performed.

Results

Co-creation of care improved significantly over time (t = 2.25, p = 0.026), as did social well-being (t = 2.31, p = 0.022) and physical well-being (t = 2.72, p = 0.007) but not satisfaction with care (t = 0.18, p = 0.858). Improvements in co-creation of care from T0 to T1 were associated with social well-being (B = 0.157, p = 0.002), physical well-being (B = 0.216, p = 0.000) and satisfaction with care (B = 0.240, p = 0.000).

Conclusions

Thus, investment in co-creation of care by primary care practices may lead to better outcomes for multimorbid patients.

BACKGROUND

The global prevalence of multimorbidity is increasing (Uijen & van de Lisdonk, 2008). As multimorbidity is associated with age, its prevalence is expected to increase even further in the near future due to populational ageing (World Health Organization, 2008; Van Oostrom et al., 2012). Multimorbidity is often described as the co-existence of two or more chronic conditions in one patient (Fortin, Bravo, Hudon, Vanasse, & Lapointe, 2005). It has been associated with poorer health outcomes, such as reduced functional capacity and quality of life, as well as increased healthcare use (Bayliss, Bayliss, Ware, & Steiner, 2004; Brettschneider et al., 2013; Fortin et al., 2004; Makovski, Schmitz, Zeegers, Stranges, & van den Akker, 2019; Palladino, Pennino, Finbarr, Millett, & Triassi, 2019; Van Oostrom et al., 2014).

In the Netherlands, most care delivery for patients with multimorbidity is managed by general practitioners (GPs) in the primary care setting (Kroneman et al., 2016). The management of care delivery for this patient population is complex; it is costly and difficult due to patients' complex care needs (Navickas, Petric, Feigl, & Seychell, 2016), and the single-disease orientation of many guidelines and protocols results in uncertainty about what best care is for patients with multiple diseases (Lugtenberg, Burgers, Clancy, Westert, & Schneider, 2011; Sinnott, Mc Hugh, Browne, & Bradley, 2013; Tinetti, Bogardus, & Agostini, 2004). Thus, patients with multimorbidity receive care that is often fragmented and not tailored to their needs, which may result in irrelevant or potentially unsafe treatment (American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity, 2012; Sinnott et al., 2013). Care management for patients with multimorbidity is also complex because time constraints often result in suboptimal approaches to care delivery (Sinnott et al., 2013). Most consultations last 10–20 minutes, and most of this time is used to efficiently discuss all medically related aspects of patients' multiple chronic conditions. Other aspects, such as the impacts on patients' private lives, family members and friends, are somewhat overlooked (Weiner & Schwartz, 2016). Finally, care management is more difficult when multiple healthcare professionals are involved, which is often the case for patients with multimorbidity. The quality of a patient's experience of communication among his/her healthcare professionals deteriorates with an increasing number of conditions (Fung et al., 2008), and poor communication may contribute to the fragmentation of care (Sinnott et al., 2013). To improve outcomes for patients with multimorbidity, these complexities and uncertainties concerning the management of care delivery must be adequately addressed and minimised.

Co-creation of care may be valuable for the improvement of care delivery to patients with multimorbidity (Cramm & Nieboer, 2015; Den Boer, Nieboer, & Cramm, 2017; Kuipers, Cramm, & Nieboer, 2019; van der Meer, Nieboer, Finkenflügel, & Cramm, 2018), as it is especially suitable for situations involving complexity, uncertainty and time constraints (Gittell, 2011). Co-creation of care is based on high-quality and mutually reinforcing communication and relationships between healthcare professionals and patients. In the context of the co-creation of care, good communication is characterised as timely, accurate, frequent and problem solving, and good relationships are characterised by shared knowledge, shared goals and mutual respect (Gittell, 2011; Gittell, Godfrey, & Thistlethwaite, 2013). Frequent (follow-up) meetings between healthcare professionals and patients, at which accurate information is communicated, increase the likelihood of information sharing on personal and medical levels (shared knowledge). Although the sharing of personal information is very important for the setting of treatment goals and alignment of treatment to patients' wants and needs, it does not always occur (Joensson, Guassora, Freil, & Reventlow, 2018). This situation represents a missed opportunity, as not all treatment goals need to be related only to medical aspects, or to all of a patient's conditions. Moreover, given perceived time constraints, time does not have to be spent on goals that are not important to the patient. Improved healthcare professional–patient communication and relationships also increase patients' treatment adherence (Ha & Longnecker, 2010; Kerse et al., 2004), and thereby outcomes. In addition, many patients who report good communication and relationships with their healthcare professionals are more satisfied with care (De Waard et al., 2018; Ha & Longnecker, 2010; Ward, 2018) and perceive higher levels of well-being (Peimani, Nasli-Esfahani, & Sadeghi, 2018). Many studies of well-being, however, have not distinguished social and physical well-being. As patients with multimorbidity encounter not only the physical consequences (clinical aspects) of their diseases, but also social consequences due to, for example, coping problems and the impacts of their diseases on their personal lives and loved ones, social and physical well-being were examined separately in the present study to enable an understanding of which aspects of well-being are associated with co-creation of care. As overall well-being can be seen as the joint production of social and physical well-being (Ormel, Lindenberg, Steverink, & Verbrugge, 1999), an understanding of the influence of co-creation of care on both well-being domains may contribute to the improvement of care for patients with multimorbidity through better alignment with patients' needs.

To our knowledge, only one study involving patients with multimorbidity in the primary care setting has revealed positive relationships of co-creation of care with satisfaction with care and (social and physical) well-being, using a cross-sectional design (Kuipers et al., 2019). The present study adds to that knowledge by using a longitudinal design.

Insight on long-term outcomes and whether improvements in co-creation of care over time are also associated with satisfaction with care and physical and social well-being could aid the improvement of healthcare for this patient population. This is the first longitudinal study investigating the relationships of the co-creation of care with physical and social well-being and satisfaction with care among patients with multimorbidity in the primary care setting.

METHODS

Participants and procedure

This study included patients with multimorbidity (two or more registered chronic conditions, that is asthma, diabetes, COPD, coronary and vascular diseases) from seven primary care practices in Noord-Brabant, the Netherlands. These practices are part of a cooperative of GPs from 160 primary care practices in the Netherlands called 'Zorggroep RCH Midden Brabant BV'. They were selected because they were considered to be the best practices in this cooperative and because they expressed enthusiasm about further improvement. The participating GP practices identified all eligible patients and provided us with their names and addresses.

In 2017 (T0), a questionnaire was sent to study participants by mail. Those who did not respond after 3 weeks received reminders by mail. Another 3 weeks later, a second reminder and another copy of the questionnaire were sent by mail to remaining non-responders. Thereafter, a reminder by telephone was given to non-responders for whom telephone numbers were known. Of 413 potential study participants, 19 patients were not eligible to participate due to incorrect addresses (*n* = 5), death (*n* = 4), poor eyesight (*n* = 3), terminal illness (*n* = 2), recent relocation (*n* = 2), inability to fill in the questionnaire due to poor cognitive function (*n* = 2) and recent stroke (*n* = 1), as reported by the patients, their GPs and/or informal caregivers. Of the remaining 394 participants, 216 completed the questionnaire at T0 (55% response rate).

Between T0 and T1, 59 participants dropped out (as reported by the primary care practices) due to death, nursing home or hospice admission, inability to fill in the questionnaire due to poor cognitive function and no longer being treated at the primary care practices. In 2018 (T1), 335 questionnaires were sent to the remaining participants. As at T0, reminders were sent to non-responders after 3 and 6 weeks. Again, 19 patients were not eligible to participate due to incorrect addresses (*n* = 5), death (*n* = 5), poor cognitive function/dementia (*n* = 5), nursing home admission (*n* = 2) and inability to fill in the questionnaire (*n* = 2). Of the remaining 315 participants, 169 completed the questionnaire at T1 (54% response rate). Overall, 138 participants filled in the questionnaires at both T0 and T1; thus, the attrition rate was 36%. A sample size calculation revealed that 124 participants would be required in order to detect small to medium effects with 80% power and a type 1 error rate of 5%. Having 138 respondents is therefore sufficient for valid results.

The medical ethics committee of Erasmus Medical Centre, Rotterdam, the Netherlands, approved the research proposal for this study (file no. METC_2018_021). The committee determined that the rules imposed by the Dutch Medical Research Involving Human Subjects Act did not apply. Written informed consent was obtained from all participants.

Study design and setting

This study was part of a larger longitudinal study in which healthcare professionals from the seven primary care practices in Noord-Brabant, the Netherlands, participated in five ‘knowledge’ workshops and four ‘get togethers’ during a year, with the aim of motivating them to deliver more patient-centered care and improve co-creation of care. The knowledge workshops provided information about and training in several interventions (Box 1). These interventions were implemented in the primary care practices. Furthermore, most healthcare professionals made videos of one of their consultations, which were later discussed with a trainer to determine how they could improve their patient-centredness and co-creation of care. All healthcare professionals and the researchers involved in the larger longitudinal study attended the ‘get togethers’, during which experiences with the interventions and preliminary research results were shared and validated.

Measures

Background characteristics

Patients were asked to provide information on their background characteristics, such as age, gender, education and marital status. We dichotomised marital status (1, living alone, widowed or divorced; 0, married/living with partner) and education (1, primary education or less; 0, preparatory school for vocational secondary education or higher).

Co-creation of care

Following previous research, we used the relational co-production instrument to assess co-creation of care (Gittell, 2011). This instrument of 7 items is used to evaluate aspects of communication (whether it is timely, accurate, frequent and problem solving), and the healthcare professional–patient relationship (shared goals, shared knowledge and mutual respect). Example questions are ‘How often do you communicate with your GP/nurse practitioner/specialist?’ and ‘To what extent do these people (GP/nurse practitioner/specialist) share your goals?’.

Box 1. Interventions used most frequently in participating primary care practices.

Intervention	Description
Coaching on the job	During two workshops, a coach helped all healthcare professionals employed at two practices improve their patient-centeredness All daily care activities, from appointment making via internet/telephone to front desk work, provision of advice, and consultation structure, were evaluated, and required points of improvement were discussed.
Shared decision making	During one workshop, professionals were trained to use shared decision making during consultations to 1) prepare patients for the decision-making process (e.g. by informing them of consultation goals), 2) determine goals (e.g. jointly explore patients' situations, share relevant medical information and formulate goals), 3) agree on action points (e.g. by discussing all options) and 4) act and evaluate (e.g. by acting on agreements and reflecting on progression).
Training in illiteracy recognition	This training focused on how healthcare professionals can recognise illiterate patients and adjust their communication accordingly during consultations, answering of the telephone by triage assistants, and at the front desk. For example, the teach-back method can be used to make sure patients understand all information provided, and informational materials can be adjusted.
Three good questions	This intervention is based on a Dutch national campaign that aims to reassure patients that their wishes, anxieties and needs matter during healthcare consultations. The three good questions that patients can ask their healthcare professionals are 1) What are my options?, 2) What are the pros and cons of those options? and 3) What does that mean in my situation? To make patients more aware of their role during consultations, the practices provided fliers with the three questions at the front desk and in the waiting room, and showed the questions on a screen in the waiting room.
Motivational interviewing	Training in a directive, patient-centered approach to counselling that prepares patients for behaviour changes and helps to resolve ambivalence.
Diary keeping	All healthcare professionals kept diaries on how they improved/changed their care delivery during the year (e.g. listening to the patient for 1 minute at the beginning of a consultation before talking, making sure the patient's question is the central starting point of the consultation, and not judging or interpreting the patient's feelings without asking.

Responses are given on a scale ranging from 1 (never) to 5 (always), with higher mean scores representing better co-creation of care. In this study, Cronbach's alpha values for the relational co-production instrument at T0 and T1 were 0.93 and 0.96, respectively, indicating good reliability. Change in co-creation of care was measured by subtracting the mean score at T0 from that at T1.

Well-being

Well-being was assessed at T0 and T1 using the 15-item version of the Social Production Function Instrument for the Level of Well-being short (SPF-ILs) (Nieboer, Lindenberg, Boomsma, & Bruggen, 2005). This instrument is used to measure levels of physical (comfort and stimulation) and social (behavioural confirmation, affection and status) well-being. Example questions are 'Do you feel that people really love you?' and 'Are your activities challenging to you?'. Responses are given on a scale ranging from 1 (never) to 4 (always), with higher mean scores representing greater well-being. In this study, Cronbach's alpha values for the SPF-ILs at T0 and T1 were 0.88 and .087, respectively, indicating good reliability.

Satisfaction with care

Satisfaction with care was measured using the 6-item version of the Satisfaction with Stroke Care (SASC) questionnaire (Boter, de Haan, & Rinkel, 2003). The use of this instrument is not restricted to stroke patients, as it contains general questions about satisfaction with care; the SASC questionnaire has been used for various patient populations in the hospital setting (Baumann, Rat, Mainard, Cuny, & Guillemin, 2011; Pöder & von Essen, 2009), and adjusted versions have been used in other care settings (Hakobyan, Nieboer, Finkenflügel, & Cramm, 2019; Kuipers et al., 2019). Example items are 'The staff has done everything they can to make me well again', 'I am happy about the effect treatments had on my disease progression' and 'I have received all the information I want about the causes and nature of my illness(es)'. Responses are given on a scale ranging from 1 (totally disagree) to 4 (totally agree), with higher mean scores representing greater satisfaction with care. In this study, Cronbach's alpha values for the SASC instrument at T0 and T1 were 0.87 and 0.92, respectively, indicating good reliability.

Statistical analyses

We used SPSS software (version 23; IBM Corporation, Armonk, NY, USA) to analyse the data. First, we calculated descriptive statistics [frequencies, percentages, means, ranges and/or standard deviations (SDs)] for all variables to characterise the study population. Second, paired-sample *t* tests were used to investigate improvements over time (differences between T0 and T1) in co-creation of care, physical and social well-being and satisfaction with care. Third, regression analyses were performed to investigate multivariate relationships among these variables. As age, gender, marital status and education are known to be related to well-being and satisfaction with care, we controlled for these variables in the multivariate regression analysis (Carr & Springer, 2010; Pinquart & Sörensen, 2001; Saatci et al., 2010; Spasojevic, Hrabac, & Huseinagic, 2015)]. Results were considered to be significant when two-sided *p* values were ≤0.05.

Because some data on aspects underlying co-creation of care were missing, we performed additional regression analyses with imputed data produced with the Markov Chain monte Carlo imputation technique (*n* = 138). As these analyses yielded similar results, only the results of the original analyses are presented in the tables. Furthermore, we checked for multilevel nesting within the GP practices. We found no variance at the GP practice level (data available on reasonable request), indicating that nesting did not affect our conclusions.

RESULTS

Table 1 presents an overview of the background characteristics of the 138 patients with multimorbidity who filled in questionnaires at both T0 and T1. The mean age of the respondents at T1 was 73.50 (range 48.45–94.32, SD = 9.99) years; 42.2% of respondents were male, 37.2% were single and 33.8% had low educational levels. The mean scores for co-creation of care and satisfaction with care were 3.86 ± 0.80 and 3.20 ± 0.43, respectively, and those for social and physical well-being were 2.90 ± 0.47 and 2.80 ± 0.55, respectively.

Table 1. Descriptive statistics at T1.

	Mean ± standard deviation (range/absolute number) or percentage
Age (years)	73.50 ± 9.99 (48.45-94.32)
Gender (male)	42.2% (58)
Marital status (single)	37.2% (51)
Education level (low)	33.8% (46)
Satisfaction with care	3.20 ± 0.43 (2-4)
Social well-being	2.90 ± 0.47 (1.56-3.78)
Physical well-being	2.80 ± 0.55 (1-4)
Co-creation of care	3.86 ± 0.80 (1-5)

Note. The analysis included only data from respondents who filled in questionnaires at both T0 and T1 (n = 138).

Co-creation of care improved significantly over time (t = 2.25, p = 0.026; Table 2). To better understand this improvement, we also performed paired-sample t tests for individual aspects underlying co-creation of care. All aspects underlying co-creation of care improved over time, although only two improvements were significant: frequent communication (t = 2.94, p = 0.004) and timely communication (t = 2.51, p = 0.013). Mean scores for these two aspects were lower than those of the other aspects at T0 (3.2 and 3.51, respectively). In Table 3, the results of the paired sample t tests of the dependent variables (social well-being, physical well-being, and satisfaction with care) are presented. Improvement over time was also observed for social well-being (t = 2.31, p = 0.022) and physical well-being (t = 2.72, p = 0.007), but not for satisfaction with care (t = 0.18, p = 0.858).

The results of the multivariate regression analysis are presented in Table 4. Improvement in the co-creation of care over time (T1 – T0) was related significantly to social well-being (β = 0.288, p = 0.002). The inclusion of background characteristics, social well-being at baseline, co-creation of care at baseline and the change in co-creation of care over time explained 42.6% of the variance in social well-being (r^2 = 0.426, F = 11.255).

Table 2. Paired sample *t* tests (aspects of) co-creation of care.

		T0		T1		Paired difference		
Variable	N	Mean	SD	Mean	SD	*t*	df	*p*
Co-creation of care	135	3.70	0.88	3.87	0.78	2.25	134	0.026
Frequent communication	135	3.20	0.84	3.44	0.87	2.94	134	0.004
Timely communication	132	3.51	1.05	3.75	0.90	2.51	131	0.013
Accurate communication	131	3.86	1.01	4.01	0.86	1.68	130	0.095
Problem-solving communication	124	3.95	1.07	4.10	0.83	1.44	123	0.153
Shared knowledge	121	3.81	1.10	3.91	0.94	0.852	120	0.396
Mutual respect	114	3.95	1.06	4.12	0.88	1.54	113	0.127
Shared goals	116	3.92	1.05	4.06	0.94	1.38	115	0.171

Table 3. Paired sample *t* tests social well-being, physical well-being and satisfaction with care.

		T0		T1		Paired difference		
Variable	N	Mean	SD	Mean	SD	*t*	df	*p*
Social well-being	132	2.80	0.50	2.90	0.47	2.31	131	0.022
Physical well-being	135	2.67	0.57	2.79	0.55	2.72	134	0.007
Satisfaction with care	125	3.19	0.50	3.20	0.42	0.18	124	0.858

Table 4. Multivariate relationships between co-creation of care, satisfaction with care, social and physical well-being over time**.**

	Social well-being				Physical well-being				Satisfaction with care			
	B	SE	β	*p*	*B*	SE	β	*p*	*B*	SE	β	*p*
(Constant)	1.395	0.378		0.000	1.788	0.421		0.000	2.603	0.424		0.000
Outcome at T0*	0.593	0.074	0.617	0.000	0.584	0.071	0.612	0.000	0.054	0.088	0.060	0.544
Age	0.007	0.004	0.153	0.054	0.009	0.004	0.169	0.030	0.004	0.004	0.096	0.307
Gender	0.017	0.077	0.017	0.825	0.063	0.86	0.57	0.465	0.064	0.081	0.074	0.434
Marital status	0.105	0.080	0.106	0.191	0.047	0.090	0.041	0.604	0.021	0.085	0.024	0.802
Education	0.215	0.080	0.210	0.008	0.149	0.090	0.126	0.102	0.129	0.086	0.142	0.136
Co-creation of care	0.065	0.050	0.120	0.202	0.013	0.056	0.021	0.818	0.165	0.062	0.326	0.008
Change in co-creation of care over time	0.157	0.050	0.288	0.002	0.216	0.56	0.345	0.000	0.240	0.054	0.501	0.000

*'Outcome' refers to satisfaction with care, social well-being and physical well-being.

Improvement in the co-creation of care was also related significantly to physical well-being ($\beta = 0.345$, $p \leq 0.000$). The inclusion of background characteristics, physical well-being at baseline, co-creation of care at baseline and the change in co-creation of care over time explained 44.5% of the variance in physical well-being ($r^2 = 0.445$, $F = 12.470$). The co-creation of care at baseline and improvement therein were related significantly to satisfaction with care ($\beta = 0.326$, $p = 0.008$ and $\beta = 0.501$, $p \leq 0.000$, respectively). The inclusion of background characteristics, satisfaction with care at baseline, co-creation of care at baseline and changes in co-creation of care over time explained 19.5% of the variance in satisfaction with care ($r^2 = 0.195$, $F = 3.603$).

DISCUSSION

This study was the first to investigate longitudinal relationships between co-creation of care, physical well-being, social well-being and satisfaction with care among patients with multimorbidity in the primary care setting in Noord-Brabant, the Netherlands. Our findings clearly show that improvements in co-creation of care, as perceived by patients with multimorbidity, benefit these patients' physical well-being, social well-being and satisfaction with care, highlighting the value of investment in co-creation of care in the primary care setting.

Patients participating in this study perceived that co-creation of care improved significantly over time, likely due to the GP practices' investment during the 1-year study period. For example, the shared decision-making intervention likely contributed to the establishment of shared goals, the 'three good questions' intervention likely contributed to the generation of shared knowledge, and the illiteracy training likely improved communication between healthcare professionals and patients. The findings of this study do not, however, provide insight into which specific interventions contributed to the improvements in co-creation of care; further research is recommended to identify interventions that most effectively improve the co-creation of primary care, and the reasons for this effectiveness. Nevertheless, given the variation among patients with multimorbidity in their needs for support and care (Rijken & van der Heide, 2019) goals and the need to co-create, we emphasise the need to invest in a variety of interventions to make sure that the co-creation of care is well adjusted and personalised for all patients.

Although this study revealed overall improvement in co-creation of care, only frequent and timely communication improved significantly over time. The primary care practices that participated in this study are among the best-performing practices in their region (they were selected for this reason), which is reflected in the high baseline scores for the co-creation of care. Thus, the ceiling effect may explain the non-significant improvement in some underlying elements. Scores for frequent and timely communication were lower than those for other aspects, and thus may have been easier to improve. Examination of the effects of investment in co-creation of care by average- and/or low-scoring GP practices would be of interest. We expect that the effects of investment in co-creation of care would be greater in average- and low-scoring GP practices, where improvement would be easier to achieve. However, motivating these practices to invest in co-creation of care would probably be more difficult than for the practices included in this study.

The social and physical well-being of patients with multimorbidity also improved over time, and changes in co-creation of care contributed to this improvement. Co-creation of care at baseline and changes therein were related to patients' satisfaction with care, but the mean satisfaction with care score did not improve significantly over time. Although there was no improvement in satisfaction with care over time based on the group mean, the change in co-creation of care may have caused individual variation in satisfaction with care which may explain the significant longitudinal relationship found.

Improvement in co-creation of care also showed significant longitudinal relationships with the social and physical well-being of patients with multimorbidity. These findings are in accordance with our expectations, and in partial agreement with cross-sectional data showing that the co-creation of care was related to the social well-being and satisfaction with care (but not physical well-being) of patients with multimorbidity in a primary care setting (Kuipers et al., 2019). The discrepancy in the physical well-being findings may be explained by the improbability that the main elements of co-creation of care (communication and relationship quality) immediately enable the realisation of physical well-being goals; they may, however, have a cumulative effect in the long term (Street, Makoul, Arora, & Epstein, 2009). Street and colleagues (2009) also suggested that communication can lead to improved physical health when conversations improve the understanding of patients' conditions (e.g., enable correct diagnoses) and better alignment of treatments to patients' situations and conditions. The findings of this study reinforce the need for GP practices to continue to invest in co-creation of care to improve physical well-being, as well as social well-being and satisfaction with care, among patients with multimorbidity.

This study has several limitations that should be considered. First, as it was conducted in Noord-Brabant, the Netherlands, the generalisability of our findings may be limited; further research in other countries and/or regions is recommended. Second, each chronic condition, and combinations thereof, may have affected the study outcomes. We lacked information about individual participants' conditions, aside from the presence of some combination of asthma, diabetes, COPD and coronary and vascular diseases, as the GP practices were not allowed to share this information due to privacy concerns. Third, we do not have information on drug therapy or activities of daily living, which may have an influence on our study outcomes. Fourth, only patients who filled in the questionnaire at both T0 and T1 were included in this study; 36% (*n* = 78) of patients filled in the questionnaire only at baseline and were excluded. The attrition rate could be considered a limitation to this study. Attrition rates tend to be associated positively with increased age, poor functioning, cognitive impairment and unmarried status (Chatfield, Brayne, & Matthews, 2005). Patients with multimorbidity constitute a vulnerable population, which could explain the high attrition rate. This dropout may have affected our findings, given the existence of significant differences in health and well-being between patients who dropped out and the remaining sample: at baseline, those who dropped out were significantly older and lower educated, significantly more of them were single, and they had significantly lower scores for physical and social well-being, satisfaction with care and the co-creation of care. The more favourable evaluation of co-creation of care by the remaining sample may have caused underestimation of improvement in co-creation of care, as improvement could have been greater in the total sample.

Conclusions

In this study, improvement in co-creation of care was related positively to the physical and social well-being and satisfaction with care of patients with multimorbidity in primary care. The findings of this study are important because the management of care delivery to this patient population is often considered to be complex. They indicate the value of investment in co-creation of care to improve outcomes for patients with multimorbidity in the primary care setting.

REFERENCES

American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity. (2012). Patient-centered care for older adults with multiple chronic conditions: A stepwise approach from the American geriatrics society. *Journal of the American Geriatrics Society, 60*(10), 1957-1968.

Baumann, C., Rat, A., Mainard, D., Cuny, C., & Guillemin, F. (2011). Importance of patient satisfaction with care in predicting osteoarthritis-specific health-related quality of life one year after total joint arthroplasty. *Quality of Life Research, 20*(10), 1581-1588.

Bayliss, E. A., Bayliss, M. S., Ware, J. E., & Steiner, J. F. (2004). Predicting declines in physical function in persons with multiple chronic medical conditions: What we can learn from the medical problem list. *Health and Quality of Life Outcomes, 2*(1), 47.

Boter, H., de Haan, R. J., & Rinkel, G. J. (2003). Clinimetric evaluation of a satisfaction-with-stroke-care questionnaire. *Journal of Neurology, 250*(5), 534-541.

Brettschneider, C., Leicht, H., Bickel, H., Dahlhaus, A., Fuchs, A., Gensichen, J., . . . Schön, G. (2013). Relative impact of multimorbid chronic conditions on health-related quality of life–results from the MultiCare cohort study. *PloS One, 8*(6), e66742.

Carr, D., & Springer, K. W. (2010). Advances in families and health research in the 21st century. *Journal of Marriage and Family, 72*(3), 743-761.

Chatfield, M. D., Brayne, C. E., & Matthews, F. E. (2005). A systematic literature review of attrition between waves in longitudinal studies in the elderly shows a consistent pattern of dropout between differing studies. *Journal of Clinical Epidemiology*, *58*(1), 13-19.

Cramm, J. M., & Nieboer, A. P. (2015). The importance of productive patient–professional interaction for the well-being of chronically ill patients. *Quality of Life Research, 24*(4), 897-903.

De Waard, C. S., Poot, A. J., den Elzen, W. P., Wind, A. W., Caljouw, M. A., & Gussekloo, J. (2018). Perceived doctor-patient relationship and satisfaction with general practitioner care in older persons in residential homes. *Scandinavian Journal of Primary Health Care, 36*(2), 189-197.

Den Boer, J., Nieboer, A. P., & Cramm, J. M. (2017). A cross-sectional study investigating patient-centred care, co-creation of care, well-being and job satisfaction among nurses. *Journal of Nursing Management, 25*(7), 577-584.

Fortin, M., Lapointe, L., Hudon, C., Vanasse, A., Ntetu, A. L., & Maltais, D. (2004). Multimorbidity and quality of life in primary care: A systematic review. *Health and Quality of Life Outcomes, 2*(1), 51.

Fortin, M., Bravo, G., Hudon, C., Vanasse, A., & Lapointe, L. (2005). Prevalence of multimorbidity among adults seen in family practice. *Annals of Family Medicine, 3*(3), 223-228.

Fung, C. H., Setodji, C. M., Kung, F., Keesey, J., Asch, S. M., Adams, J., & McGlynn, E. A. (2008). The relationship between multimorbidity and patients' ratings of communication. *Journal of General Internal Medicine, 23*(6), 788-793.

Gittell, J. H. (2011). *Relational coordination: Guidelines for theory, measurement and analysis.* Waltham, MA: Brandeis University.

Gittell, J. H., Godfrey, M., & Thistlethwaite, J. (2013). Interprofessional collaborative practice and relational coordination: Improving healthcare through relationships. *Journal of interprofessional care, 27*(3), 210-213.

Ha, J. F., & Longnecker, N. (2010). Doctor-patient communication: A review. *The Ochsner Journal, 10*(1), 38-43.

Hakobyan, L., Nieboer, A. P., Finkenflügel, H., & Cramm, J. M. (2019). The significance of person-centered care for satisfaction with care and well-Being among informal caregivers of persons with severe intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities, 17*(1), 31-42.

Joensson, A. B. R., Guassora, A. D., Freil, M., & Reventlow, S. (2018). What the doctor doesn't know: Discarded patient knowledge of older adults with multimorbidity. *Chronic Illness, 16*(3), 212-225.

Kerse, N., Buetow, S., Mainous, A. G.,3rd, Young, G., Coster, G., & Arroll, B. (2004). Physician-patient relationship and medication compliance: A primary care investigation. *Annals of Family Medicine, 2*(5), 455-461.

Kroneman, M., Boerma, W., van den Berg, M., Groenewegen, P., de Jong, J., & van Ginneken, E. (2016). Netherlands: Health system review. *Health Systems in Transition, 18*(2), 1-240.

Kuipers, S. J., Cramm, J. M., & Nieboer, A. P. (2019). The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multimorbidity in the primary care setting. *BMC Health Services Research, 19*(1), 13.

Lugtenberg, M., Burgers, J. S., Clancy, C., Westert, G. P., & Schneider, E. C. (2011). Current guidelines have limited applicability to patients with comorbid conditions: A systematic analysis of evidence-based guidelines. *PloS One, 6*(10), e25987.

Makovski, T. T., Schmitz, S., Zeegers, M. P., Stranges, S., & van den Akker, M. (2019). Multimorbidity and quality of life: systematic literature review and meta-analysis. *Ageing research reviews*, *53*, 100903.

Navickas, R., Petric, V., Feigl, A. B., & Seychell, M. (2016). Multimorbidity: What do we know? what should we do? *Journal of Comorbidity, 6*(1), 4-11.

Nieboer, A., Lindenberg, S., Boomsma, A., & Bruggen, A. C. V. (2005). Dimensions of well-being and their measurement: The SPF-IL scale. *Social Indicators Research, 73*(3), 313-353.

Ormel, J., Lindenberg, S., Steverink, N., & Verbrugge, L. M. (1999). Subjective well-being and social production functions. *Social Indicators Research, 46*(1), 61-90.

Palladino, R., Pennino, F., Finbarr, M., Millett, C., & Triassi, M. (2019). Multimorbidity and health outcomes in older adults in ten European health systems, 2006–15. *Health Affairs, 38*(4), 613-623.

Peimani, M., Nasli-Esfahani, E., & Sadeghi, R. (2018). Patients' perceptions of patient–provider communication and diabetes care: A systematic review of quantitative and qualitative studies. *Chronic Illness,* 16*(1), 3-22.*

Pinquart, M., & Sörensen, S. (2001). Gender differences in self-concept and psychological well-being in old age: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 56*(4), 195-213.

Pöder, U., & von Essen, L. (2009). Perceptions of support among Swedish parents of children on cancer treatment: A prospective, longitudinal study. *European Journal of Cancer Care, 18*(4), 350-357.

Saatci, E., Tahmiscioglu, G., Bozdemir, N., Akpinar, E., Ozcan, S., & Kurdak, H. (2010). The well-being and treatment satisfaction of diabetic patients in primary care. *Health and Quality of Life Outcomes, 8*(1), 67.

Sinnott, C., Mc Hugh, S., Browne, J., & Bradley, C. (2013). GPs' perspectives on the management of patients with multimorbidity: Systematic review and synthesis of qualitative research. *BMJ Open, 3*(9), e003610-2013-003610.

Spasojevic, N., Hrabac, B., & Huseinagic, S. (2015). Patient's satisfaction with health care: A questionnaire study of different aspects of care. *Materia Socio-Medica, 27*(4), 220-224.

Street Jr, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? pathways linking clinician–patient communication to health outcomes. *Patient Education and Counseling, 74*(3), 295-301.

Tinetti, M. E., Bogardus, S. T.,Jr, & Agostini, J. V. (2004). Potential pitfalls of disease-specific guidelines for patients with multiple conditions. *The New England Journal of Medicine, 351*(27), 2870-2874.

Uijen, A. A., & Van de Lisdonk, E. H.. (2008). Multimorbidity in primary care: Prevalence and trend over the last 20 years. *The European Journal of General Practice, 14*(1), 28-32.

Van der Meer, L., Nieboer, A. P., Finkenflügel, H., & Cramm, J. M. (2018). The importance of person-centred care and co-creation of care for the well-being and job satisfaction of professionals working with people with intellectual disabilities. *Scandinavian Journal of Caring Sciences, 32*(1), 76-81.

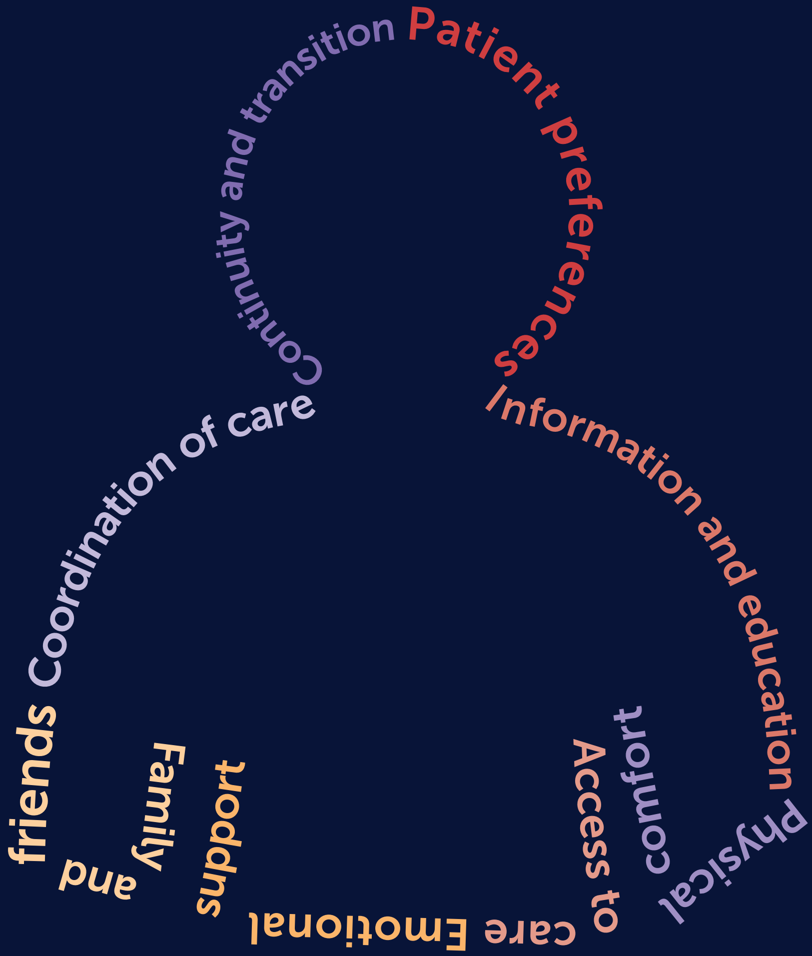
Van Oostrom, S. H., Picavet, H. S. J., De Bruin, S. R., Stirbu, I., Korevaar, J. C., Schellevis, F. G., & Baan, C. A. (2014). Multimorbidity of chronic diseases and health care utilization in general practice. *BMC Family Practice, 15*(1), 61.

Van Oostrom, S. H., Picavet, H. S. J., van Gelder, B. M., Lemmens, L. C., Hoeymans, N., van Dijk, C. E., . . . Baan, C. A. (2012). Multimorbidity and comorbidity in the Dutch population–data from general practices. *BMC Public Health, 12*(1), 715.

Ward, P. (2018). Trust and communication in a doctor-patient relationship: A literature review. *Archivos De Medicina, 3*(3), 36.

Weiner, S. J., & Schwartz, A. (2016). Contextual errors in medical decision making: Overlooked and understudied. *Academic Medicine, 91*(5), 657-662.

World Health Organization. (2008). *The world health report 2008: primary health care now more than ever*. World Health Organization.


Patient preferences
Information and education
Physical comfort
Access to care
Emotional support
Family and friends
Coordination of care
Continuity and transition

Chapter 5

Making care more patient centered; experiences of healthcare professionals and patients with multimorbidity in the primary care setting

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ABSTRACT

Background

The present study describes how primary care can be improved for patients with multimorbidity, based on the evaluation of a patient-centered care (PCC) improvement program designed to foster the eight PCC dimensions (patient preferences, information and education, access to care, physical comfort, coordination of care, continuity and transition, emotional support, and family and friends). This study characterizes the interventions implemented in practice as part of the PCC improvement program and describes the experiences of healthcare professionals and patients with the resulting PCC delivery.

Methods

This study employed a mixed-methods design. Semi-structured interviews were conducted with nine general practitioners and nurse practitioners from seven primary care practices in Noord-Brabant, the Netherlands, that participated in the program (which included interventions and workshops). The qualitative interview data were examined using thematic analysis. A longitudinal survey was conducted with 138 patients with multimorbidity from these practices to assess perceived improvements in PCC and its underlying dimensions. Paired sample t tests were performed to compare survey responses obtained at a 1-year interval corresponding to program implementation.

Results

The PCC improvement program is described, and themes necessary for PCC improvement according to healthcare professionals were generated [e.g. Aligning information to patients' needs and backgrounds, adapting a coaching role]. PCC experiences of patients with multimorbidity improved significantly during the year in which the PCC interventions were implemented ($t = 2.66$, $p = 0.005$).

Conclusions

This study revealed how primary PCC can be improved for patients with multimorbidity. It emphasizes the importance of investing in PCC improvement programs to tailor care delivery to heterogenous patients with multimorbidity with diverse care needs. This study generates new perspectives on care delivery and highlights opportunities for its improvement according to the eight dimensions of PCC for patients with multimorbidity in a primary care setting.

BACKGROUND

Primary care organizations throughout the world strive to make their care more patient centered, defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Institute of Medicine, 2001). To achieve this goal, an organization must fulfill the eight dimensions of patient-centered care (PCC; also referred to as person-centered care) defined by the Picker Institute (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993): 1) patient preferences, 2) information and education, 3) access to care, 4) physical comfort, 5) coordination of care, 6) continuity and transition, 7) emotional support, and 8) family and friends (Box 1, method section) (Davis, Schoenbaum & Audet, 2005; Gerteis et al., 1993). Evidence for the effects of PCC provision is clear; healthcare organizations with higher dimensional PCC scores report better patient and organizational outcomes (Kuipers, Cramm, & Nieboer, 2019; Rathert, Wyrwich, & Boren, 2013). However, despite international agreement about the importance of PCC, considerable consensus on its definition, and a common understanding of how it would ideally look, knowledge about the types of PCC interventions implemented in the primary care setting and about whether these interventions generate more positive patient experiences is insufficient (Davis et al., 2005).

Although primary PCC provision is desirable for all populations, it may be especially valuable for patients with multimorbidity. Multimorbidity is often described as the coexistence of two or more chronic conditions (Fortin, Bravo, Hudon, Vanasse, & Lapointe, 2005). Patients with multimorbidity often report poor health and quality of life, functional impairment, and frailty, and have a greater risk of mortality (Fortin, Lapointe, Hudon, Vanasse, Ntetu, & Maltais, 2004; Makovski, Schmitz, Zeegers, Stranges, & Van den Akker, 2019; Marengoni et al., 2011; Nunes, Flores, Mielke, Thume, & Facchine, 2016; Vetrano et al., 2019;). Most primary care delivery follows single disease–oriented guidelines; multiple disease–oriented guidelines would be beneficial to avoid the fragmentation of care for patients with multimorbidity (Lugtenberg, Burgers, Clancy, Westert, & Schneider, 2011; Tinetti, Bogardus, & Agostini, 2004). Moreover, the complex care needs of these patients render their management very time consuming and expensive (Navickas, Petric, Feigl, & Seychell, 2016). As care delivery must be tailored to their needs to improve outcomes, primary PCC is important for this patient population.

Study objectives

In the present study, we aimed to describe how primary care could be improved for patients with multimorbidity by evaluating a program designed to improve PCC delivery to these patients in general practitioners’ (GPs’) practices in the Netherlands. The implementation of this program provided a unique opportunity to characterize PCC delivery in practice and healthcare professionals' and patients' experiences with this care. Specifically, the aims of this study are to 1) identify the interventions that were part of the PCC improvement program, 2) characterize the experiences of healthcare professionals with the program implementation, and 3) determine whether the program implementation is associated with more positive patient-centered experiences among patients with multimorbidity.

METHODS

Setting

The "Zorggroep RCH Midden Brabant BV" is a cooperative that invests in the improvement of PCC delivery in the 160 primary care practices of its GP members in the Netherlands. In 2017, it started the PCC improvement program for patients with multimorbidity, based on the eight PCC dimensions (Table 1), in seven GP practices in Noord-Brabant that were considered to be most patient centered and known to be most enthusiastic about further improving PCC.

During 1 year of the PCC improvement program implementation in 2017 and 2018, healthcare professionals from the GP practices attended four meetings and several workshops covering a variety of patient-centered interventions (Box 2, result section). The meetings focused primarily on increasing participants' knowledge about the PCC dimensions, and provided opportunities for participants to reflect on and share their experiences with PCC implementation in practice. During the PCC improvement program, a toolbox of interventions was provided to the involved healthcare professionals, which were taught during workshops. Throughout the program, and in line with the concept of PCC, investment in a variety of interventions was emphasized, given the variation within individual GP practices and among patients with multimorbidity and their needs.

Study design and data collection

A mixed-methods design was used to describe and evaluate the PCC improvement program and to capture the experiences of healthcare professionals and patients with multimorbidity. The qualitative data described the PCC improvement program and healthcare professionals' experiences with it, and the quantitative data described improvements in patients' experiences. The first author conducted interviews (~1 hour each) with nine healthcare professionals who participated in the PCC improvement program (four GPs and five nurse practitioners, selected by purposive sampling). Ten interviews were scheduled, but one interview was cancelled due to the participant's illness.

Table 1. The eight dimensions of patient-centered care

PCC dimension	Description
Patient preferences	Healthcare professionals treat patients with dignity and respect and involve them in decisions regarding their care. They support patients in setting and achieving treatment goals, e.g., via individualized care plans based on patients' needs, wishes, and preferences.
Information and education	To empower them to be in charge of their care, patients are informed about all aspects of their care and have access to their medical records. The information provided is suitable for all education levels, migration backgrounds, languages, and ages, among others. The need for informative and open communication between patients and healthcare professionals is recognized.
Access to care	Healthcare is affordable, and medical buildings are easily accessible for all patients (including, e.g., those who are blind and those who use wheelchairs or walkers). Appointment scheduling is easy and wait times are short.
Physical comfort	Healthcare professionals pay attention to patients' physical comfort by, e.g., providing pain management and addressing sleep problems and shortness of breath. Physical comfort is optimized at the organizational level via the provision of comfortable, clean (waiting) rooms and sufficient privacy.
Coordination of care	The organization's team of healthcare professionals is well informed about the care delivered to their patients, and care delivery is well coordinated, e.g., via frequent team meetings. Patients know who is coordinating their care and whom they can contact when they have questions about their care.
Continuity and transition	When multiple healthcare professionals are involved in care provision to a patient, they all transfer information regularly and adequately, and ensure that their care delivery and advice are well coordinated. When patients are referred to healthcare professionals in other disciplines, they know where to go and why.
Emotional support	Healthcare professionals offer emotional support to patients when needed, by paying attention to patients' possible fear, depression, and anxiety, and the impacts of chronic conditions on patients' private lives. Patients are made aware of their ability to obtain emotional support, e.g., from social workers or peer groups.
Family and friends	As many conditions impact not only patients, but also their family members and friends, healthcare professionals involve these individuals in the care process (with patients' consent). They provide support and address any questions and needs regarding patients' care.

The interviews were conducted at the GP practices in January and February 2018. All participants were familiar with the researcher, whom they had met at PCC improvement program meetings, and the goals of the study. The interviews were semi-structured according to the PCC dimensions. Only the researcher and interviewee were present during each session. The interviews were recorded digitally, with the participants' permission, and transcribed verbatim. The researcher used a script to ensure consistency across interviews.

In order to identify whether the PCC improvement program was associated with more positive experiences among patients with multimorbidity, a survey was sent, at baseline (T0) and 1 year later (T1), by mail to patients with multimorbidity [two or more registered conditions, i.e., asthma, chronic obstructive pulmonary disease (COPD), diabetes, coronary and vascular conditions] from the participating practices. PCC experience was assessed using the 36-item patient-centered primary care instrument, validated for patients with multimorbidity (Cramm & Nieboer, 2018). Seven items of this instrument covered patient preferences; five items each covered physical comfort and access to care; four items each covered coordination of care, continuity and transition, emotional support, and information and education; and three items covered family and friends. Responses are given on a scale ranging from one (totally disagree) to five (totally agree), with higher mean scores indicating a greater degree of PCC. Average dimension scores were calculated in the presence of responses to at least two-thirds of items, and average total scores were calculated in the presence of at least six dimension scores. In this study, the Cronbach's alpha value for this instrument at T0 and T1 was 0.96, indicating good reliability. We also asked participating patients to provide information on their background characteristics, such as age, gender, education level (1, primary education or less; 0, preparatory school for vocational secondary education or more), and marital status (1, living alone, widowed, or divorced; 0, married/living with partner).

Data analysis

Inductive thematic analysis was performed with the interview data, as described by Braun and Clarke (2006). First, the interviews were transcribed verbatim and the full transcripts were read for familiarization with the data. Second, the transcript content was classified according to the eight dimensions of PCC. Using ATLAS.ti, (version 8.4.18; ATLAS.ti Scientific Software Development GmbH), the first author then coded and categorized the dimension-classified content. Finally, the authors generated themes that represented needs for PCC improvement in primary care for patients with multimorbidity in each dimension identified by healthcare professionals. All codes and themes were discussed among all of the authors until agreement was reached. The themes were also discussed during a meeting of all PCC improvement program participants. The healthcare professionals recognized all themes raised, and no additional theme emerged during this meeting.

For analysis of the patient survey data, descriptive statistics (means, ranges, standard deviations, frequencies, and percentages) were first generated for all variables. Only data of patients that filled in the questionnaire at both T0 and T1 were analyzed (n=138). Then, we used paired-sample *t* tests to compare PCC total and dimension scores at T0 and T1. As improvement was expected, we conducted one-sided tests. The significance level was set at 0.05. Reliability was assessed using Cronbach's alpha. The statistical analyses were performed using SPSS software (version 26; IBM Corporation, Armonk, NY, USA).

RESULTS

Study participants

In total, 22 healthcare professionals from the seven GP practices participated in the PCC delivery improvement program. Nine of these professionals [four GPs and five nurse practitioners (NPs)] were interviewed. At T0, 413 patients were eligible to participate in the survey; 19 of these patients were excluded due to incorrect addresses (*n* = 5), death (*n* = 4), visual impairment (*n* = 3), recent moves with deregistration from the GP practices (*n* = 2), admission to a nursing home/hospice because of a terminal illness (*n* = 2), dementia/cognitive decline (*n* = 2), and hemorrhage (*n* = 1). Of the 394 remaining patients, 216 filled in the survey (55% response rate). Between T0 and T1, 59 patients dropped out because of death, admission to a nursing home, and deregistration from the GP practices. At T1, 335 patients were eligible to participate; 19 of these patients were excluded due to incorrect addresses (*n* = 5), death (*n* = 5), dementia/cognitive decline (*n* = 5), admission to a nursing home (*n* = 2), and inability to fill in the survey (*n* = 2). Of the remaining 315 patients, 169 filled in the survey (54% response rate). The overall attrition rate was 36%; 138 participants filled in the questionnaire at both T0 and T1.

Intervention components of the PCC improvement program

During the PCC improvement program, a toolbox of interventions was provided to the involved healthcare professionals (Table 2). The healthcare professionals reported that participation in the PCC improvement program led them to select various interventions that they would like to implement. For example, health literacy recognition training was a priority intervention for a GP practice where many patients with immigrant backgrounds were treated, whereas other interventions were more important for other practices. The interventions of choice were explained and taught during multiple workshops. For example, an “evaluation of PCC on the job” workshop was held to help all participating healthcare professionals improve all eight dimensions of PCC; among other topics, practice interiors and privacy, documentation, management of wait times, and information provision during consultations were discussed. Other workshops aimed to contribute to the information and education dimension and facilitate informative, efficient and open communication between patients and healthcare professionals, such as by using the teach-back method, emphasizing the importance of listening to patients’ needs, checking whether they properly understand information, and adjusting information provision as needed, which is especially valuable for patients with low health literacy. All interventions offered during program implementation are described in Table 2.

Table 2. PCC interventions for healthcare professionals in the primary care setting

PCC intervention	Description
Consultation videotaping	A workshop aiming to improve the coaching role of healthcare professionals during consultations by discussing video recordings of consultations with patients.
Evaluation of PCC on the job	A workshop aiming to help all healthcare professionals employed at an organization to improve their patient-centeredness. All daily care activities, from appointment making via internet/telephone to front desk work, provision of advice, and consultation structure, are evaluated.
Listening	A workshop aiming to help healthcare professionals understand patients' questions and needs at the start of consultation by listening to patients first, instead of immediately asking questions.
Motivational interviewing	A training session in a directive, patient-centered approach to counseling that prepares patients for behavior changes. With motivational interviewing, attention is payed to building a strong patient–provider relationship and working toward patient autonomy and responsibility during the care process.
NIVEA	A workshop aiming to help healthcare professionals avoid judgement or interpretation of patients' feelings without asking for clarification or further information.
Shared decision making	A workshop aiming to train healthcare professionals to use shared decision making during consultations to 1) prepare patients for the decision-making process (e.g., by informing them of consultation goals), 2) determine goals (e.g., jointly explore patients' situations, share relevant medical information, and formulate goals), 3) agree on action points (e.g., by discussing all options), and 4) act and evaluate (e.g., by acting on agreements and reflecting on progression).
Teach-back method	A workshop in which healthcare professionals learn to always check whether patients fully understand the information provided by asking patients to explain/repeat what they have just been told. This approach provides healthcare professionals with better insight on whether their information provision is adjusted adequately to patients' skills, and whether patients remember the right elements.
Three good questions	An intervention based on a Dutch national campaign that aims to reassure patients that their wishes, anxieties, and needs matter during healthcare consultations. The 'three good questions' that patients can ask their healthcare professionals are 1) What are my options? 2) What are the pros and cons of those options? and 3) What does that mean in my situation?
Topic list	An intervention exploring areas in which patients need support. The topic list is sent to patients before consultations; it contains depictions of pain and topics such as stress and lack of sleep. The list makes patients aware of the range of topics that they can discuss with their healthcare professionals.
Training in illiteracy recognition	A training session focusing on healthcare professionals' recognition of illiterate patients and adjustment of their communication accordingly during consultations. The training also addresses such recognition by triage assistants and front desk staff when answering the telephone.

PCC, patient-centered care; NIVEA, niet invullen voor een ander [do not interpret the feelings of a patient without asking].

Experiences of healthcare professionals with PCC improvement

The healthcare professionals reported that the program meetings and interventions improved their PCC delivery. These improvements are described below according to the PCC dimensions, with the provision of supporting quotations from the NP and GP interviewees. The main themes are also depicted in table 3.

Table 3. Overview of how to organize patient-centered care (PCC) for patients with multimorbidity

PCC Dimension	Theme
Patient preferences	- From a paternalistic to a coaching role - From protocols to patient preferences - From generic to individualized care plans
Access to care	- Close monitoring of patients with multimorbidity - Providing consultation options - Wait time management
Physical comfort	- Moving beyond physical complaints - Physical comfort at the GP practice
Family and friends	- Creating understanding among family members and friends of patients with multimorbidity
Emotional support	- Recognizing the emotional impact of multimorbidity - Providing emotional support
Information and education	- Aligning information to patients' needs and backgrounds - Helping patients to understand their own medical data - Repeating (assumingly already well-known) information
Coordination of care (within the GP practice)	- From working alone to teamwork - Adequate information transfer within a team - Organizing team meetings to coordinate care delivery
Continuity and transition (across healthcare settings)	- Multidisciplinary teamwork - Adequate information transfer across healthcare settings - Organizing multidisciplinary meetings to coordinate care plans - Proximity of multidisciplinary healthcare professionals

Patient preferences

From a paternalistic to a coaching role

According to the healthcare professionals, PCC for patients with multimorbidity contributes to patients' well-being when it is based on individuals' wishes, needs, and abilities. Thus, the professionals felt that they should involve patients in their care and decision-making processes, and stimulate patients to set and achieve their own treatment goals. According to the GPs, this approach requires more of a coaching role than the paternalistic role that they used to play, with the aim of supporting individual patients' achievement of their own goals.

> "In the past, we used to let people come and draw blood for all kinds of tests, and thus, we thought, provided good care for that patient. And now we look more and more at what suits the patient; what does the patient need? Some measure several values themselves, such as blood pressure or sugar levels, and someone who is well regulated may not need to come as often as someone else. So it is more patient centered, meaning that the patients decide for themselves what their goals are and how often they need support, instead of us telling them 'you have to come so often and this is what we are going to do.' We have more of a coaching role now." (GP7)

To be able to take on a coaching role, the healthcare professionals emphasized the importance of listening to patients first, as needs and wishes differ among patients. At the beginning of the program, the professionals believed that such listening was a basic communication skill that they already possessed, but during the program they found that it was more difficult than expected. The healthcare professionals learned to be silent at the start of consultations and to listen to patients' needs for at least 1 minute. They concluded that this approach is more efficient than one in which they begin by providing solutions without precisely understanding the problem.

> "Suppose I sit here on the edge of my chair and do not let the patient finish, but immediately start asking counter-questions. The result is that he or she does not feel heard, because in the end I have not asked what he or she wants to know from me. Instead, I come up with solutions, without knowing what the real question is. The calmer you are, the more serenity you radiate, the more open you stay, the more information you get, and the faster it goes. That is the trick." (GP1)

The healthcare professionals also reported that they send questionnaires covering disease-related topics to patients before follow-up consultations, to prompt them to think about what they wished to discuss with their GPs and/or NPs. The NPs reported that this approach helped patients formulate and express their individual preferences and needs, and made them more in charge of their care.

> "I use this list especially with cardiovascular risk management and with diabetic patients. I usually tell them: 'The list contains all kinds of aspects that can affect your health. Your illness, but also how you feel and how healthy you feel. Is there anything on this list that makes you think that is just something I would like to talk about, because I have a problem with that or I have a question about it?'" (NP2)

From protocols to patient preferences

According to the healthcare professionals, care delivery according to patients' preferences requires flexibility concerning protocols and guidelines that they used to follow. For example, protocols mandate a fixed number of follow-up consultations per year for patients with diabetes, but some patients with multimorbidity prefer fewer follow-ups, as they consider themselves to be experts in diabetes, given that they have lived with it all of their lives and can manage everything themselves.

> “With diabetes, we have check-ups four times a year, but a number of patients tell me: ‘I have had diabetes for twenty years now. Everything has already been said, it is all going very well. I feel good, the check-ups are good, why do I have to come four times a year?” It used to be protocol based, but now we are reducing that number. ‘How many times would you like? When? Whom would you like to see?’” (GP1)

From generic to individualized care plans
The healthcare professionals reported that they had begun to formulate individualized care plans together with patients, stimulated by the goals of shared decision making and consideration of patients’ preferences, wishes, and needs. They reported that difficulties could arise when patients’ care preferences contradicted their own, but emphasized the importance of following the former, as long as all options and potential side effects are discussed.

> “I will always explain why the protocol or standard says that a certain choice is best, but I do respect the patient’s choice. As long as I have pointed out to the patient what the possible risks might be.” (NP3)

Information and education
Aligning information to patients’ needs and backgrounds
The healthcare professionals acknowledged that provision of the right information and education to patients is crucial. They recognized that patients’ levels of understanding/education and preferred form of information provision vary, rendering the alignment of information provision to individual patients important. They also acknowledged the difficulty of doing so, as patients’ health literacy and/or resources can be difficult to recognize. The program’s training in illiteracy recognition and the teach-back method helped them to recognize patients’ needs. These professionals also spoke of the importance of helping patients to distinguish trustworthy from unreliable sources, as patients also gather information elsewhere.

> “I always ask the patients what they like; I can give information verbally or in a letter so that they can read it again later. I also ask them how they look for information themselves. One patient goes neurotically through all the forums, while another thinks you cannot look anything up on the internet. Then I tell them that it is good to use different sources of information, but that they have to assess the value of those sources. Some patients can do that and others cannot. So, I often help them to determine where to find relevant information.” (GP4)

Helping patients to understand their own medical data

The healthcare professionals realized that if patients had access to their own medical data, they had to help them understand it. Examples that facilitated patients' understanding were the addition of "smileys" (color-coded happy/sad face icons) to medical records to indicate that values are (not) good, and the drawing of visual graphs during consultations.

> "Patients do not know how to see if their values are good, but now there are smileys. An LDL of 2.5 comes with a green smiling face. And the patient is invited to email if it is orange or red. And if they want to email anyway, even when it is green, that is all right, if they still want confirmation. I think that is pretty much the future." (NP3)

> "Just the values, they do not understand of course. And they are not to blame, because those sugar values are developed internationally, and I find that difficult too. So, I try to show in graphs what happens, but not only with the sugar, also with the blood pressure or weight. And you can put two graphs together and then say 'okay, your weight has risen, but your sugar rises along with it. When the weight goes down, the sugar goes down as well.' So then one can see what is happening there. And that is a lot of fun actually." (NP6)

Repeating (assumingly already well-known) information

The healthcare professionals emphasized the power of repetition for patients with multimorbidity. Although these patients' conditions are chronic and they perform most actions (e.g., insulin injection) practically automatically, the professionals emphasized the value of checking whether the patients are still performing the actions correctly.

> "I think that for some patients, things do become a habit, insulin therapy for example. Then it is wise to repeat it once more. Because you often assume that people know it all, that is also the case when using an inhaler with a spacer, for example. Now I often hand out again the leaflet that says how to do it. Then I will go through it briefly. And then they say 'oh, I don't actually do it like that,' or they do not know that they have to clean the puffer as well. Even though they have done it like that for years, I just say it again." (NP8)

Access to care

Close monitoring of patients with multimorbidity

The healthcare professionals emphasized the importance of closely monitoring all patients with multimorbidity to ensure that they receive the care they need. Thus, they reported that they schedule follow-up appointments (even those farther in the future, for patients who prefer less follow-up) directly after consultations. Reminders are sent, and patients who do not attend follow-up appointments are contacted by telephone to schedule new appointments.

> “The people who I see always leave here with a new appointment. And if someone for example cancels an appointment through the assistant, they get a reminder; or if they don’t show up, I call them. And if they do not answer, I send them a letter. At the time of their checkup every two months we monitor whether they are back in the picture again; if not, they will receive another reminder. And once every three months we also get an overview from the healthcare service provider, which also keeps track of when people are in danger of getting lost to follow-up.” (NP2)

Providing consultation options

The healthcare professionals reported that they offer a variety of (follow-up) consultation options to enable tailoring to patients’ preferences and needs, e.g., to account for their work hours or physical ability to come to the GP practice. Some consultations, e.g., those at which measurements must be taken, need to be conducted in person, but others, e.g., those held to provide information and regular check-ups, can be done by telephone or online.

> “Telephone consultations are not just for my own convenience, but for both sides. If patients come here just to tell me something which takes two minutes, it is also annoying for the patient. And for me it just takes the same time when I can help them over the phone. I ask them sometimes: ‘you can come here, but we can also do it over the phone.’ We leave the choice up to the patient. Only a new blood pressure measurement, well, that is not possible over the phone.” (NP3)

> “Some patients find it [consultation by email] very pleasurable. Other patients really just want the personal contact, either by phone or physically.” (GP5)

Wait time management

The healthcare professionals reported that their GP practices pay attention to patient wait times before in-person consultation and on the telephone. One practice improved this aspect by extending the hours during which they could be reached by telephone, and then closely monitoring telephone accessibility to determine where further improvement was needed. The professionals also emphasized the importance of expectation management by informing patients how long they must wait.

> "To the annoyance of the assistants, our phone is always open. We could switch on the answering machine, but we do not want to. Even at lunchtime the phone is answered and we monitor it every day. Daily at five o'clock, I get a list with the day's waiting times. And once every week we have a meeting about the telephone times and we would like to see that more than 90% is answered within two minutes. The emergency line is always within 30 seconds." (GP4)

> "It helps to inform patients about the waiting times. When people see how long it takes, they know where they stand." (NP9)

Physical comfort

Moving beyond physical complaints

The healthcare professionals reported that physical disease aspects, including comfort (e.g., pain, sleeping problems), were predominant topics of discussion, by the professionals and patients with multimorbidity, during consultations, as patients must cope with these aspects daily and as physical complaints are traditional foci of primary care delivery. With greater knowledge about PCC, however, the professionals realized that physical aspects differ among patients and are not the only components of physical comfort; they reported that they had begun to also ask, for example, about the suitability and comfort of use of the materials needed for disease management (e.g., insulin injection).

> "I think that physical comfort has always been a goal in primary care. And as a nurse practitioner, you pay a lot of attention to what kind of obstacles patients experience as a result of their condition. And that is often somatically oriented, i.e., focused on physical comfort." (NP2)

> "Physical comfort often looms large in the patient's perception. That's what bothers them the most, so when they visit for check-ups, the first thing they say is 'I am in pain.' This is also much more important to them

> than all kinds of other factors that may be much worse compared to the pain. But they feel the pain now and that must be resolved now as well." (GP4)

> "There are a number of things that you ask by default, such as 'how short of breath have you been?,' 'does the cough bother you?,' 'does it interfere with your social contacts?.' But also, the questions to diabetics: 'Are your injections comfortable enough?,' 'Are your materials suitable?,' 'Do you sleep well?.' A lot is about physical comfort." (NP2)

Physical comfort at the GP practice
During the study period, the healthcare professionals made many improvements to their practice interiors to ensure patients' comfort and privacy, based on suggestions provided during the "evaluation of PCC on the job" workshop and those shared by other participants. Examples are the provision of comfortable chairs and creation of a nice atmosphere in the waiting room, and the separation of the front desk from the waiting room.

> "We just have got everything brand new. We tested a lot of chairs, and we have got half of them with cushions and half without. All very washable, because people very quickly find it dirty. Everything is built according to the latest requirements; everything is easily accessible for wheelchairs, everything is height adjustable; for example, the examination table goes from very low to very high. All aisles are wide, and also in the corners there are special recesses for stretchers. The ambulance entrance is completely on a straight line that is the shortest possible route. The walking routes are such that people enter and leave as quietly as possible. And the partition at the reception desk is there so that others cannot see who they need to visit, be it a psychologist or a doctor. And next to the desk, there is also a special room, so that people cannot listen in, and if something private is asked at the desk. That is a soundproof room so they can get the results there. And of course, the large toilet facility for the disabled. And at the back of the toilet a hatch to deposit urine samples, so no one can see that you turn in pee." (GP4)

> "We have addressed the privacy issue, and in particular that you can overhear others. At first, the phone calls were audible in the waiting room, but after installing a glass wall this was a lot less." (NP2)

> "Learning about this aspect was really an experience. Sometimes you come across people who are very fat and are supposed to sit in such a small chair, but then say 'I will just stand here.' Now I realize it is not a comfortable chair for them." (NP8)

Coordination of care within the GP practice

From working alone to teamwork

To improve the coordination of care within their GP practices (i.e., among GPs, NPs, front desk workers, and triage nurses involved in care delivery to patients with multimorbidity), and thus also improve patients' satisfaction with care, the healthcare professionals recognized the importance of knowing what their colleagues are doing for patients; they also admitted that they did not always have this knowledge. Thus, they began to observe each other's consultations to gain insight into colleagues' expertise and contributions to patient care, which allowed them to better coordinate their own care delivery and/or ask for help.

> "We would like to use each other's expertise. So, for example, an assistant walks into my office at lunchtime to ask me about a patient. Like, 'would you like to help me determine how I could deal with this issue?'" (NP2)

Adequate transfer of information within a team

The healthcare professionals recognized the importance of all-encompassing documentation and efficient information transfer to achieve teamwork and adequate knowledge of all team members' contributions. They noted that every aspect of patient care should be well documented in a system accessible to all healthcare professionals at the practice, who can read this information in preparing for patient consultations. For example, NPs explained that they prepared for consultations by reading GPs' notes from previous consultations. Professionals from one GP practice mentioned that they also check each other's work to avoid mishaps, not out of distrust, but mainly to make sure that documentation that is important for accurate care delivery is not overlooked.

> "It is very important for me to see what the GP has written down. When someone comes for a consultation, I check in advance what has happened to that person since the last time I saw the patient. That may be on a completely different level, but all the information, including that from the consultations with the GP, is important." (NP2)

> "We also verify all phone calls with the assistants: everyone who called today is on the authorization list. Other practices do not do that, because

> they say ‘but I trust my assistants.’ I do trust my assistants, because we have really good assistants, but even still, things are not always as they should be.” (GP4)

Organizing team meetings to coordinate care delivery

The GPs and NPs reported that they often organized team meetings with all practice professionals to ensure that care is well coordinated. In one practice, daily morning meetings were held to align care delivery and discuss important content or questions that would likely arise during that day.

> “The cooperation with the general practitioners is fine. We casually enter each other’s rooms or I schedule a brief telephone consultation, and there is a structured low-threshold team meeting with the general practitioners and also with the assistants. They do not have anything to do with chronic care, but they do plan the appointments and receive patients.” (NP9)

> “I always prepare my agenda; I check all the results in advance or any items I already promised I would discuss. Every morning we go through all that. Every day we have a start-of-day meeting with the whole team. And also with the assistants present. Details about patients or the practice are discussed there.” (NP3)

Continuity and transition among healthcare disciplines

Multidisciplinary teamwork

The professionals recognized that in the provision of care to patients with multimorbidity, working with care providers from disciplines (e.g., psychologists, dieticians, physiotherapists, hospital specialists, social workers) strengthens the continuity of care and aids the detection of patients’ problems and the delivery of tailored care.

> “It is nice that when you are worried about something you can ask ‘gosh think along, do you have any other points of view?’ That you just start thinking along from your own expertise. Because a psychologist might think very differently from a psychiatrist and a nurse practitioner.” (GP7)

> “In cooperation with the district nursing service, we get a much better understanding of what the most profound problems are for a patient in a home situation. Sometimes this is not necessarily pain or shortness of breath, but for example, no good contact with the children anymore or loneliness or no daytime activities at all, or that the house is neglected.

> And that way you can take a much broader look at what that patient needs.” (GP5)

Adequate information transfer across healthcare settings

Similar to the need for an efficient intra-practice information system, the healthcare professionals indicated the importance of efficient information transfer among all healthcare organizations involved in the care of patients with multimorbidity. They reported that they used a chain-like system in which all involved professionals shared information about their part of care delivery to individual patients, which helped to coordinate care and ensure its continuity.

> “The other professionals do not literally see the information in our system. However, they can communicate through our chain information system. This is an automation system for communicating with chain partners. And you can open up bits of information and close up bits of information, so that only relevant information goes to the healthcare professional who needs it.” (GP1)

Organizing multidisciplinary meetings to coordinate care plans

To stimulate care continuity, the healthcare professionals organized meetings with professionals from other involved healthcare disciplines. During these meetings, they used each other’s expertise to coordinate care plans and discuss patients’ progress.

> “We start by making a care plan and then the various disciplines are complementing. Various people may well contribute something. I myself, a doctor, a geriatrics specialist, and also home care can contribute something. It is solution focused, but also thinking along. That’s how we try to complete the picture.” (NP2)

Proximity of multidisciplinary healthcare professionals

The healthcare professionals indicated that multidisciplinary teamwork is more efficient when other involved professionals work in the same neighborhood, village, or metropolitan area.

> “We are really trying to work together with professionals in the neighborhood. So, we do not go to someone on the other side of town, because that does not work.” (NP8)

> "I must say that the lines with the district nurses and the paramedics are actually very short, because here in a village you actually know everyone. We meet once a month in a home team meeting where we also specifically highlight the vulnerable patients." (GP5)

Emotional support

Recognizing the emotional impact of multimorbidity

Although the healthcare professionals indicated that emotional support was not a regular topic of discussion during consultations, and that such discussions occurred more often with NPs than with GPs, they emphasized the importance of considering the potential impacts of chronic conditions on the feelings and private lives of patients with multimorbidity, as these effects may influence clinical aspects of patients' conditions. They acknowledged, however, that they sometimes struggled with discussing emotional aspects. They indicated that they used the consultation time primarily to discuss all physical aspects accompanying chronic conditions, especially for patients with multimorbidity. The professionals reported that the use of topic lists provided more insight into the emotional aspects important to patients.

> "It is a well-known fact that if people with diabetes are very emotional or stressed, then those sugar values can go up." (NP8).

> "Someone with severe COPD and rheumatism can be very limited in his mobility. Such a patient can also become very sad. Therefore, I think that a lot of people also find a sense of support and comfort important. Sometimes patients really develop depression. Of course, you must talk about that too." (GP5)

> "Yes, any chronic care protocol includes a section on how the patient experiences his illness, how he deals with it. So, it is part of it. It's just a tricky part. Because sometimes it can take a lot of time to go into it deeply." (GP1)

Providing emotional support

The healthcare professionals noted that the emotional support that patients are determined to need is often provided by mental health NPs. They also emphasized the importance of adjusting this support to accommodate patients' needs and preferences, as emotional problems can be difficult to discuss; trust is very important. The healthcare professionals reported that they sometimes struggled with the provision of adequate emotional support, and thus actively sought other resources (e.g., peer support groups, social workers, and psychologists) or helped patients to do so based on their wishes and needs.

> “We have different mental health nurse practitioners, with different backgrounds. On purpose actually. So that for certain cases we have the option to better assess who suits whom. We have both a man and a woman. We have a psychologist, a social worker, and we have a psychiatric nurse.” (GP7)

> “There are a number of people with COPD here who work out with the physiotherapists twice a week in a group, and get a lot of emotional support from it. From the other people in the group, but also from the physiotherapist. It just shows that everyone finds support in something or with someone else. As long as there is enough variety, so that people eventually end up somewhere where they feel supported.” (GP5)

Family and friends

Creating understanding among family members and friends of patients with multimorbidity

The healthcare professionals agreed that the involvement of family members and friends in the delivery of care to patients with multimorbidity is important, mainly because chronic illnesses are part of these patients’ lives. They also noted that helping people close to patients understand the patients’ conditions is important. However, the healthcare professionals acknowledged that they did not always try to achieve such involvement, as they struggled with the determination of when patients would like their family members or friends to be involved, and whether relatives have questions or needs concerning care delivery. The healthcare professionals reported various ways in which they involved relatives in care delivery, such as by making house visits to map out patients’ situations and asking whether relatives can attend consultations; in addition, they noted that relatives sometimes took the initiative in contacting the healthcare professionals.

> “We know that patients spend less than 1% of their time here in the consulting room and spend much more time at home with family and friends.” (GP5)

> “Family needs to come along to the consultation as well and be educated in order to understand why something is important. Someone with heart failure, for example, should not eat salt. But then the food does not taste

> good. So, then I explain to the family member who is cooking what it means if he/she always adds salt to the food, and that this can lead to a hospital visit. It is also a matter of great ignorance in the family." (GP4)

Overall, the healthcare professionals felt that the PCC improvement program, including the intervention toolbox and workshops, generated new perspectives on care delivery and options for the improvement of the eight dimensions of PCC. In the next paragraph, we discuss whether these improvements yielded more positive PCC experiences for patients with multimorbidity.

Experiences of patients with multimorbidity with PCC improvement

The mean age of the 138 patients who filled in the questionnaire at T0 and T1 was 73.50 (range, 48.45–94.32) years; 42.2% were male, 37.2% were single, and 33.8% had low educational levels. Table 3 shows that the patients perceived that PCC improved significantly over the study period ($t(109) = 2.66$, $p = 0.005$). Specifically, they perceived significant improvement in the physical comfort ($t(117) = 1.80$, $p = 0.037$), emotional support ($t(122) = 2.35$, $p = 0.010$), continuity and transition ($t(86) = 2.37$, $p = 0.010$), and family and friends ($t(41) = 2.20$, $p = 0.017$) dimensions (Table 4). Improvement of the coordination of care dimension was only marginally significant ($t(115) = 1.51$, $p = 0.068$). Patient preferences, access to care and information and education did not improve over time ($t(133) = 0.44$, $p = 0.332$; $t(129) = - 0.54$, $p = 0.296$; $t(132) = 0.54$, $p = 0.294$, respectively).

Table 4 Patient-perceived quality of primary patient-centered care

PCC dimension	n	Score (mean ± standard deviation)		T0 vs. T1		
		T0	T1	t	df	p
Overall	110	3.90 ± 0.49	4.03 ± 0.43	2.66	109	0.005
Patient preferences	134	4.05 ± 0.61	4.07 ± 0.56	0.44	133	0.332
Physical comfort	118	3.96 ± 0.59	4.07 ± 0.49	1.80	117	0.037
Coordination of care	116	3.97 ± 0.61	4.06 ± 0.52	1.51	115	0.068
Emotional support	123	3.55 ± 0.74	3.73 ± 0.69	2.35	122	0.010
Access to care	130	4.12 ± 0.57	4.10 ± 0.49	-0.54	129	0.296
Continuity and transition	87	4.05 ± 0.59	4.21 ± 0.51	2.37	86	0.010
Information and education	133	3.97 ± 0.56	4.00 ± 0.46	0.54	132	0.294
Family and friends	42	3.72 ± 1.07	4.08 ± 0.76	2.20	41	0.017

DISCUSSION

With the present study, we aimed to describe how primary PCC for patients with multimorbidity can be improved by evaluating a PCC improvement program implemented in the Netherlands using a mixed-methods design; the qualitative data describe how PCC can be improved according to healthcare professionals, and the quantitative data describe whether patients with multimorbidity experienced improvements during the implementation of the PCC improvement program.

Our findings emphasize the importance of investing in PCC improvement programs, including the provision of an intervention “toolbox” and workshops, for the tailoring of care delivery to heterogenous population of patients with multimorbidity with diverse care needs. They are in line with findings suggesting that the PCC dimensions are not equally important to all patients with multimorbidity, and that subgroups of these patients can be identified based on care needs (Kuipers, Nieboer, & Cramm, 2020; Rijken & Van der Heide, 2019). We found that the program provided healthcare professionals with new perspectives on care delivery and opportunities to make improvements in the eight PCC dimensions. These professionals’ experiences with PCC improvement were not correlated one-to-one with the interventions implemented but were closely tied to all lessons learned during program participation. The changes implemented in GP practices based on the program also improved patients with multimorbidity’s experiences with PCC delivery. As patient experiences have been associated with clinical effectiveness, patient safety, and health outcomes this is relevant for further improving care delivery for patients with multimorbidity (Doyle, Lennox, & Bell, 2013).

This study shows that within the patient preferences dimension of PCC it is important that healthcare professionals adopt a coaching role to support patients’ goal achievement, listen to patient preferences, and formulate individualized care plans. The adoption of these practices does not mean that PCC cannot be evidence based; the two approaches can be integrated, although the manner in which this is done may differ among organizations (Engle et al., 2021). For example, healthcare professionals should continue to discuss disease guidelines based on strong evidence for specific treatment options with patients.

According to this study, to improve the information and education dimension, the alignment of information to patients’ needs and backgrounds, helping patients to understand their medical data, and repeating (assumed to be well-known) information is important. Although the healthcare professionals emphasized the importance of supporting patients in being in charge of their own care, many patients with multimorbidity have reported that they feel unable to oversee all aspects of their care and that they require support (Van der Aa, Van den Broeke, Stronks, & Plochg, 2017). However, our patient survey revealed that patients participating in this study did not experience significant improvement in this dimension, thus further improvement is needed.

Regarding the access to care dimension, healthcare professionals in this study recognized the importance of close patient monitoring, the provision of various consultation options, and the management of wait times. These findings are in line with the reported preferences of patients with multimorbidity, who have been found to make appointments with their GPs only when their symptoms are beyond their self-management abilities; thus, they prefer quick access to their care providers, and for some preferably via email instead of telephone due to long telephone wait times (Bayliss, Edwards, Steiner, & Main, 2008).

Identified themes in the physical comfort dimension include healthcare professionals' recognition that they devote the majority of their attention to the clinical aspects of disease during consultations, as chronic conditions are often accompanied by pain, shortness of breath, and lack of sleep (Koyanagi, et al, 2014; Scherer et al., 2016). However, according to this study, providing physical comfort also entails suitability and comfort of the materials needed for disease management. The healthcare professionals also reported that they had made many improvements to their practice facilities related to patients' physical comfort and privacy, based on the PCC improvement program content. Previous studies have revealed the importance of the waiting room physical environment in primary care for the quality of care and patients' satisfaction with care (Arneill & Devlin, 2002). Indeed, in this study, patients' survey responses indicated that the GP practice improvements improved their experiences.

Themes related to the coordination of care within the GP practice raised by the healthcare professionals include the need for teamwork and efficient information transfer, including the holding of practice-wide meetings. These findings are in line with relational coordination theory, which holds that effective coordination depends on the mutually reinforcing interaction of (timely, frequently, accurate, and problem-solving) communication and relationships (based on shared goals, shared knowledge, and mutual respect) between service providers (Gittell, 2002). For example, healthcare professionals' knowledge of each other's contributions to care delivery leads to mutual respect, frequent team meetings entail frequent and timely communication leading to shared goals, and efficient information transfer provides shared knowledge and accurate communication. The patients with multimorbidity surveyed in this study, however, perceived only marginal improvement in the coordination of care. Future research should focus on how patient experiences with coordination of care can be improved further.

Similarly, healthcare professionals participating in this study reported their efforts to work in multidisciplinary teams, with frequent meetings of all professionals involved in individual patients' care to coordinate care plans, and multi-disciplinary information transfer; these aspects fall within the continuity and transition dimension of PCC. The continuity of care is often found to improve patients' outcomes and satisfaction with care (Van Walraven, Oake, Jennings, & Forster, 2010), and is typically managed mainly by GPs as the clinical leaders of multidisciplinary teams (Saint-Pierre, Herskovic, & Sepulveda, 2018). Frequent discussion of this role and its importance during the PCC improvement program may have led to GPs' improved adherence to the role, and thereby the improved organization of multidisciplinary teamwork. This inference is supported by patients' indication of significant improvement in the continuity and transition dimension of PCC in their survey responses.

The healthcare professionals stressed the importance of emotional support, a PCC dimension, as patients' multiple chronic conditions often affect their private lives and social relationships; at the same time, they acknowledged that they had difficulty discussing such topics and providing adequate support. Research has shown that multimorbidity is often accompanied by anxiety and depression (Read, Sharpe, Modini & Dear, 2017; Vancampfort, Koyanage, Hallgren, Probst, & Stubbs, 2017). The professionals' difficulty with this dimension may reflect their lack of initial training in asking patients about their general emotional status, and/or due to patients' reluctance to discuss their emotional problems. The latter is in line with the findings that stigma often prevents patients from disclosing emotional problems to their healthcare professionals, and that patients do not always believe that their GPs can adequately manage these problems (Priest, Vize, Roberts, Roberts, & Tylee, 1996; Prior, Wood, Lewis, & Pill, 2003). Although patients' responses to the survey conducted as part of this study show significant improvement in this dimension, the emotional support score was lower than scores for other dimensions at T1, indicating that further improvement is needed. These results suggest that the emotional support component of the PCC improvement program examined in this study was insufficient. Several potential interventions targeting emotional support have been described: they include multiple peer support interventions for patients with chronic conditions (Embuldeniya et al., 2013) and effective self-management support interventions that include strategies for coping with stress and chronic conditions (Dineen-Griffin, Garcia-Cardenas, Williams, & Benrimoj, 2019). Future research should investigate whether the implementation of similar interventions would result in (further) PCC improvement, as perceived by patients with multimorbidity, and whether patients expect GPs and NPs to treat emotional aspects of their status, or whether taking these problems seriously and providing options for treatment elsewhere would be sufficient.

Finally, regarding the family and friends' dimension of PCC, improving PCC includes the importance of helping patients' family members and friends understand the patients' conditions and potentially play roles in care delivery. Although the PCC improvement program did not include a workshop on the involvement of relatives in care delivery, significantly improved patient experiences were found in this dimension, presumably due to healthcare professionals' improved application in practice after acquiring knowledge and theory-based perspectives. Interventions entailing strategies to involve family members and friends, among others described in a systematic review of family-centered approaches for adults with chronic conditions (Deek et al., 2016), may further improve the experiences of patients with multimorbidity.

In addition to identifying components needed for the improvement of the eight dimensions of PCC, the healthcare professionals who participated in this study identified difficulties with PCC delivery, such as the adjustment of information provision and education to patients' needs and the provision of adequate emotional support. Although this study was not designed to explicitly describe barriers to PCC delivery, those described in the literature include healthcare professionals' lack of knowledge, skills, and time (Van der Heide et al, 2018). Future research should investigate whether these barriers also apply in the implementation of the PCC improvement program examined in this study.

In summary, this study yielded a characterization of how primary PCC can be improved. The overview of the interventions implemented could be useful for GP practices aiming to invest in PCC. Furthermore, healthcare professionals' descriptions of their experiences provided insight into the nature of PCC for patients with multimorbidity in practice. Survey data showed that the PCC experiences of patients with multimorbidity improved significantly during the year in which the PCC interventions were implemented, demonstrating the value of the program as a guiding framework for the further improvement of PCC delivery to these patients.

Study limitations and suggestions for future research

Several limitations of this study should be considered when interpreting its results. First, as the program examined was implemented in the Noord-Brabant region of the Netherlands, the generalizability of the results may be limited. Future research should investigate the experiences of healthcare professionals and patients with the implementation of similar PCC improvement programs in other regions and countries. Second, although patients perceived a significant overall improvement in PCC, their survey responses showed no significant improvement in the information and education, access to care, or patient preferences dimension. These results may be explained by the ceiling effect, as the GP practices that participated in this program are among the best-performing practices in their region, with high baseline PCC scores and little room for improvement on a 1–5 Likert scale. The program may yield even better results in GP practices with lower baseline PCC scores; future research should investigate its implementation in average- and low-scoring (Dutch) GP practices. Third, the study design did not allow for the testing of direct relationships between interventions and outcomes. Given the goal of the PCC improvement program, this was not a study aim; however, the program's intervention "toolbox" is not exhaustive, and interventions can be added and/or removed according to specific GP practices' needs. Fourth, confounding variables may have influenced patients' experiences with PCC during the 1-year study period. However, taking into account the efforts made by the healthcare professionals, investments made in the improvement of PCC were likely the main contributors to the observed improvements in patient experiences. Finally, the Netherlands has a strong primary care system (Kringos, Boerma, Hutchinson, & Saltman, 2015) which is a prerequisite for PCC development (World Health Organization, 2008). This should be taken into account while determining the applicability of the PCC improvement program in other countries.

Conclusions

The findings of this study indicate how primary care can be improved for patients with multimorbidity in the Netherlands, including interventions and a focus on PCC themes identified by healthcare professionals. PCC experiences of patients with multimorbidity improved significantly during the year in which the PCC interventions were implemented. The results of this study are valuable for the further improvement of PCC delivery to patients with multimorbidity in the primary care setting.

REFERENCES

Arneill, A. B., & Devlin, A. S. (2002). Perceived quality of care: The influence of the waiting room environment. *Journal of Environmental Psychology*, *22*(4), 345-360.

Bayliss, E. A., Edwards, A. E., Steiner, J. F., & Main, D. S. (2008). Processes of care desired by elderly patients with multimorbidities. *Family Practice, 25*(4), 287-293.

Braun, V.,& Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Cramm, J. M., & Nieboer, A. P. (2018). Validation of an instrument for the assessment of patient-centred care among patients with multimorbidity in the primary care setting: The 36-item patient-centred primary care instrument. *BMC Family Practice, 19*(1), 143.

Davis, K., Schoenbaum, S. C., & Audet, A. (2005). A 2020 vision of patient-centered primary care. *Journal of General Internal Medicine, 20*(10), 953-957.

Deek, H., Hamilton, S., Brown, N., Inglis, S. C., Digiacomo, M., Newton, P. J., . . . FAMILY Project Investigators. (2016). Family-centred approaches to healthcare interventions in chronic diseases in adults: A quantitative systematic review. *Journal of Advanced Nursing, 72*(5), 968-979.

Dineen-Griffin, S., Garcia-Cardenas, V., Williams, K., & Benrimoj, S. I. (2019). Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. *PloS One, 14*(8), e0220116.

Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open, 3*(1), e001570.

Embuldeniya, G., Veinot, P., Bell, E., Bell, M., Nyhof-Young, J., Sale, J. E., & Britten, N. (2013). The experience and impact of chronic disease peer support interventions: A qualitative synthesis. *Patient Education and Counseling, 92*(1), 3-12.

Engle, R. L., Mohr, D. C., Holmes, S. K., Seibert, M. N., Afable, M., Leyson, J., & Meterko, M. (2021). Evidence-based practice and patient-centered care: Doing both well. *Health Care Management Review*, *46*(3), 174.

Fortin, M., Lapointe, L., Hudon, C., Vanasse, A., Ntetu, A. L., & Maltais, D. (2004). Multimorbidity and quality of life in primary care: A systematic review. *Health and Quality of Life Outcomes, 2*(1), 51.

Fortin, M., Bravo, G., Hudon, C., Vanasse, A., & Lapointe, L. (2005). Prevalence of multimorbidity among adults seen in family practice. *Annals of Family Medicine, 3*(3), 223-228.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T.L. (1993). *Through the patient's eyes: understanding and promoting patient-centered care.* Jossey-Bass Publishers.

Gittell, J. H. (2002). Relationships between service providers and their impact on customers. *Journal of Service Research, 4*(4), 299-311.

Koyanagi, A., Garin, N., Olaya, B., Ayuso-Mateos, J. L., Chatterji, S., Leonardi, M., . . . Haro, J. M. (2014). Chronic conditions and sleep problems among adults aged 50 years or over in nine countries: A multi-country study. *PloS One, 9*(12), e114742.

Kringos, D. S., Boerma, W. G., Hutchinson, A., Saltman, R. B., & World Health Organization. (2015). *Building primary care in a changing Europe*. World Health Organization. Regional Office for Europe.

Kuipers, S. J., Cramm, J. M., & Nieboer, A. P. (2019). The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multimorbidity in the primary care setting. *BMC Health Services Research, 19*(1), 13.

Kuipers, S. J., Nieboer, A. P., & Cramm, J. M. (2020). Views of patients with multimorbidity on what is important for patient-centered care in the primary care setting. *BMC Family Practice*, *21*(1), 1-12.

Lugtenberg, M., Burgers, J. S., Clancy, C., Westert, G. P., & Schneider, E. C. (2011). Current guidelines have limited applicability to patients with comorbid conditions: A systematic analysis of evidence-based guidelines. *PloS One, 6*(10), e25987.

Makovski, T. T., Schmitz, S., Zeegers, M. P., Stranges, S., & van den Akker, M. (2019). Multimorbidity and quality of life: systematic literature review and meta-analysis. *Ageing Research Reviews*, *53*, 100903.

Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., . . . Fratiglioni, L. (2011). Aging with multimorbidity: A systematic review of the literature. *Ageing Research Reviews, 10*(4), 430-439.

Navickas, R., Petric, V., Feigl, A. B., & Seychell, M. (2016). Multimorbidity: What do we know? what should we do? *Journal of Comorbidity, 6*(1), 4-11.

Nunes, B. P., Flores, T. R., Mielke, G. I., Thume, E., & Facchini, L. A. (2016). Multimorbidity and mortality in older adults: A systematic review and meta-analysis. *Archives of Gerontology and Geriatrics, 67*, 130-138.

Priest, R. G., Vize, C., Roberts, A., Roberts, M., & Tylee, A. (1996). Lay people's attitudes to treatment of depression: Results of opinion poll for defeat depression campaign just before its launch. *BMJ, 313*(7061), 858-859.

Prior, L., Wood, F., Lewis, G., & Pill, R. (2003). Stigma revisited, disclosure of emotional problems in primary care consultations in wales. *Social Science & Medicine, 56*(10), 2191-2200.

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review, 70*(4), 351-379.

Read, J. R., Sharpe, L., Modini, M., & Dear, B. F. (2017). Multimorbidity and depression: A systematic review and meta-analysis. *Journal of Affective Disorders, 221*, 36-46.

Institute of Medicine (2001). *Crossing the quality chasm: a new health system for the 21st century.* National Academy Press.

Rijken, M., & Van der Heide, I. (2019). Identifying subgroups of persons with multimorbidity based on their needs for care and support. *BMC Family Practice, 20*(1), 1-10.

Saint-Pierre, C., Herskovic, V., & Sepúlveda, M. (2018). Multidisciplinary collaboration in primary care: A systematic review. *Family Practice, 35*(2), 132-141.

Scherer, M., Hansen, H., Gensichen, J., Mergenthal, K., Riedel-Heller, S., Weyerer, S., . . . Schön, G. (2016). Association between multimorbidity patterns and chronic pain in elderly primary care patients: A cross-sectional observational study. *BMC Family Practice, 17*(1), 68.

Tinetti, M. E., Bogardus, S. T.,Jr, & Agostini, J. V. (2004). Potential pitfalls of disease-specific guidelines for patients with multiple conditions. *The New England Journal of Medicine, 351*(27), 2870-2874.

Van der Aa, M. J., van den Broeke, J. R., Stronks, K., & Plochg, T. (2017). Patients with multimorbidity and their experiences with the healthcare process: A scoping review. *Journal of Comorbidity, 7*(1), 11-21.

Van der Heide, I., Snoeijs, S., Quattrini, S., Struckmann, V., Hujala, A., Schellevis, F., & Rijken, M. (2018). Patient-centeredness of integrated care programs for people with multimorbidity. Results from the European ICARE4EU project. *Health Policy, 122*(1), 36-43.

Van Walraven, C., Oake, N., Jennings, A., & Forster, A. J. (2010). The association between continuity of care and outcomes: A systematic and critical review. *Journal of Evaluation in Clinical Practice, 16*(5), 947-956.

Vancampfort, D., Koyanagi, A., Hallgren, M., Probst, M., & Stubbs, B. (2017). The relationship between chronic physical conditions, multimorbidity and anxiety in the general population: A global perspective across 42 countries. *General Hospital Psychiatry, 45*, 1-6.

Vetrano, D. L., Palmer, K., Marengoni, A., Marzetti, E., Lattanzio, F., Roller-Wirnsberger, R., . . . Onder, G. (2019). Frailty and multimorbidity: A systematic review and meta-analysis. *The Journals of Gerontology: Series A, 74*(5), 659-666.

World Health Organization. (2008) *People-centred health care: technical papers: International symposium on people-centred health care: Reorienting Health Systems in the 21st Century*, The Tokyo International Forum.


Patient preferences
Information and education
Physical comfort
Access to care
Emotional support
Family and friends
Coordination of care
Continuity and transition

Chapter 6

Easier said than done: Healthcare professionals' barriers to the provision of patient-centered primary care to patients with multimorbidity

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ABSTRACT

Background

Patient-centered care (PCC) has the potential to entail tailored primary care delivery according to the needs of patients with multimorbidity (two or more co-existing chronic conditions). To make primary care for these patients more patient centered, insight on healthcare professionals' perceived PCC implementation barriers is needed.

Methods

In this study, healthcare professionals' perceived barriers to primary PCC delivery to patients with multimorbidity were investigated using a constructivist qualitative design based on semi-structured interviews with nine general and nurse practitioners from seven general practices in the Netherlands. Purposive sampling was used, and the interview content was analyzed to generate themes representing experienced barriers.

Results

Barriers were identified in all eight PCC dimensions (patient preferences, information and education, access to care, physical comfort, emotional support, family and friends, continuity and transition, and coordination of care). They include difficulties achieving mutual understanding between patients and healthcare professionals, professionals' lack of training and education in new skills, data protection laws that impede adequate documentation and information sharing, time pressure, and conflicting financial incentives.

Conclusions

These barriers pose true challenges to effective, sustainable PCC implementation at the patient, organizational, and national levels. Further improvement of primary care delivery to patients with multimorbidity is needed to overcome these barriers.

BACKGROUND

Patient (or person)-centered care (PCC) receives a great deal of attention and has been adopted widely in healthcare organizations throughout the world (Jayadevappa & Chhatre, 2011; McMillan et al., 2013; Park, Lee, Jeong, Jeong, & Go, 2018; Rathert, Wyrwich, & Boren, 2013; Institute of Medicine, 2001; World Health Organization, 2008). In the past two decades, many interventions have been implemented to make healthcare organizations more patient centered. Commonly implemented PCC interventions for patients entail patient empowerment, physical support, and information provision; those for healthcare professionals focus mainly on education and training and improvement of the continuity and coordination of care (Park et al., 2018).

With such efforts, most organizations claim to be patient centered; the reality, however, is more nuanced (Davis et al., 2006; Matthews, Stanhope, Choy-Brown, & Doherty, 2018; Tondora, Miller, & Davidson, 2012). In theory, PCC should be delivered using a comprehensive approach, with multiple interventions tailored specifically to the needs of the most vulnerable groups in society (e.g., patients with less education, migration backgrounds, or low health literacy) (Rathert et al., 2013); in practice, achieving this goal remains a huge struggle (De Boer, Delnoij, & Rademakers, 2013; Filler, Jameel, & Gagliardi, 2020; Rademakers, Delnoij, Nijman, & De Boer, 2012). This nuanced picture of PCC in practice is especially relevant for primary care delivery to patients with multimorbidity (two or more co-existing chronic conditions (Johnston, Crilly, Black, Prescott, & Mercer, 2019)), who are often considered to form one of the most vulnerable groups in society (Hujala, Taskinen, & Rissanen, 2017). Globally, more than half of people aged >65 years have multiple chronic conditions, which are treated mainly in the primary care setting (Marengoni et al., 2011; Violan et al., 2014). Patients with multimorbidity are often older, with lower socioeconomic status and fewer health literacy skills (Violan et al., 2014). Multimorbidity is also more prevalent among patients with migration backgrounds than among those without migration backgrounds (Verest et al., 2019). Furthermore, multimorbidity is often related to adverse patient outcomes, such as poor health, low quality of life, functional impairment, and a greater risk of mortality (Makovski, Schmitz, Zeegers, Stranges, & van den Akker, 2019; Marengoni et al., 2011; Nunes, Flores, Mielke, Thume, & Facchini, 2016; Vetrano et al., 2019).

Current primary care delivery is not optimally tailored to the needs of patients with multimorbidity; PCC has the potential to overcome this obstacle (Kuipers, Cramm, & Nieboer, 2019; Reuben & Tinetti, 2012; Van der Heide et al., 2018). The Picker Institute developed an eight-dimension framework that describes all aspects of PCC (Gerteis, 1993) (Figure 1): (1) patient preferences, (2) information and education, (3) access to care, (4) physical comfort, (5) emotional support, (6) family and friends, (7) coordination of care, and (8) continuity and transition.

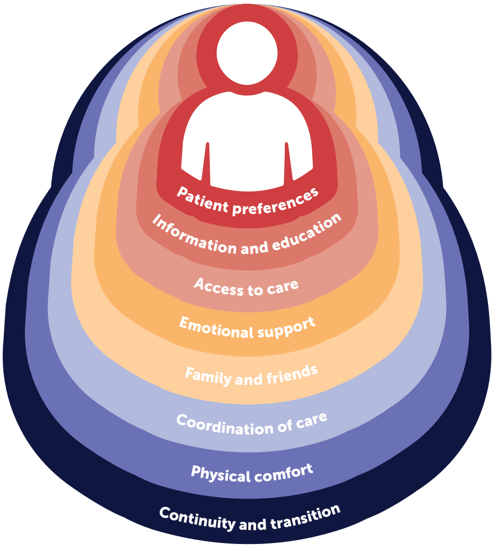


Figure 1. The eight dimensions of patient-centered care

According to this framework, PCC delivery to patients with multimorbidity requires, among other efforts, that healthcare professionals strive to support patients in the setting and achievement of treatment goals guided by *patient preferences*. Patients with multimorbidity can be viewed as being experts on their diseases (Haslam, 2015) who should be empowered by healthcare professionals to be in charge of their own care. To do so, healthcare professionals should provide *information and education* that is accessible and understandable to all, regardless of education, age, educational background, or health literacy. Furthermore, PCC emphasizes the need for good *access to care*, meaning, among other characteristics, affordability and the accessibility of buildings to all patients, including those with mobility limitations. Moreover, as having many chronic conditions is often accompanied by physical problems, and as the perceived quality of the physical comfort (e.g., spatial layout) offered in healthcare settings affects the perceived quality of care, attention should be paid to patients' *physical comfort* (e.g., management of sleeping problems, pain, shortness of breath; provision of comfortable facilities) (Zhang, Tzortzopoulos, & Kagioglou, 2019). Having multiple chronic conditions impacts patients' lives, social relations, and/or jobs, and is often accompanied by feelings of anxiety and depression (Read, Sharpe, Modini, & Dear, 2017; Vancampfort, Koyanagi, Hallgren, Probst, & Stubbs, 2017). Thus, to be patient centered, healthcare professionals should offer *emotional support* to patients. Furthermore, chronic illnesses affect not only patients, but also their *family and friends* (Nordin, Haire, Choo, & Hairi, 2019). With PCC, healthcare professionals should involve these individuals in the care process, as they also have roles in care delivery and support (van Nistelrooij, Visse, Spekkink, & de Lange, 2017). Finally, care delivery to patients with multimorbidity often involves multiple healthcare professionals, within organizations (*coordination of care*) and across healthcare disciplines (*continuity and transition*). To ensure PCC, all healthcare professionals involved in care delivery to a multimorbid patient should be well informed, which involves regular and adequate transfer of information, and care delivery should be aligned to avoid fragmentation (Hujala, Taskinen, & Rissanen, 2017; Tinetti, Fried, & Boyd, 2012).

In practice, the Picker Institute's framework [24] is often used for the development of PCC guidelines and interventions. An example of such interventions is the establishment of patient-centered medical homes, which serves as a model for high-quality primary care that is considered to be more effective than standard care for patients with chronic conditions (Jackson et al., 2013). A systematic review has shown that the organization of care according to these eight dimensions of PCC results in better organizational and patient outcomes (Rathert et al., 2013).

Although a clear vision of PCC for patients with multimorbidity has been developed (Kuipers, Nieboer, & Cramm, 2021), PCC implementation in practice is not always straightforward. Barriers occasionally hamper adequate PCC delivery or prevent PCC implementation entirely. Healthcare professionals in management positions frequently mention the lack of time and funding as obstacles (Van der Heide et al., 2018). Multimorbid patients often have complex problems and needs, which take much time and effort to identify (Rijken & van der Heide, 2019). The identification of the problems at hand and the care and support required is particularly difficult for patients with low health literacy and/or education levels (Heijmans, Brabers, & Rademakers, 2018; Raad Volksgezondheid en Samenleving, 2020). In addition, patients with multimorbidity form a heterogenous population requiring more than one type of PCC delivery (Kuipers, Nieboer, & Cramm, 2020). Furthermore, most healthcare systems remain single disease oriented, and thus not adequately responsive to the needs of patients with multiple chronic conditions (Lugtenberg, Burgers, Clancy, Westert, & Schneider, 2011), resulting in complications in practice (Damarell, Morgan, & Tieman, 2020). This situation reflects the need for and added value of PCC, as well as the challenges faced in its implementation. Despite agreement about the importance of PCC for patients with multimorbidity in the primary care setting, the realization of PCC in practice remains difficult. Although healthcare professionals' perspectives of primary care delivery for patients with multimorbidity have been investigated (Austad, Hetlevik, Mjølstad, & Helvik, 2016; Damarell et al., 2020; Freilich, Nilsson, Ekstedt, & Flink, 2020; Macdonald et al., 2018), evidence from healthcare professionals regarding the sources of difficulties with PCC implementation for these patients is scarce. Thus, the identification of barriers to such implementation is a first step toward further improvement in practice.

Study aim

To make primary care for patients with multimorbidity more patient centered, insight on perceived barriers to PCC delivery for this population is needed. Thus, the present study was conducted to investigate such barriers, as perceived by healthcare professionals in a primary care setting.

METHODS

Study design

This study was conducted using a constructivist qualitative research design (Given, 2008). Data from semi-structured interviews were analyzed to identify barriers to PCC delivery for patients with multimorbidity in the primary care setting, as perceived by healthcare professionals (general practitioners (GPs) and nurse practitioners (NPs)). Its methodology is described according to the consolidated criteria for reporting a qualitative research checklist (e.g., participant selection, setting, data collection, analysis) (Tong, Sainsbury, & Craig, 2007).

Setting and participants

All participating healthcare professionals, from seven GP practices in Noord-Brabant, the Netherlands, participated in a 1-year-long (2017–2018) PCC improvement program initiated by a regional cooperative of GPs (Zorggroep RCH Midden Brabant BV). The program's aim was to improve primary PCC delivery to patients with multimorbidity. Participants attended meetings for the improvement of their knowledge about PCC and the sharing of their experiences with PCC implementation in practice. A toolbox of interventions for PCC improvement was provided, and participants were instructed in its use in several workshops (the PCC improvement program and intervention toolbox have been described in detail previously (Kuipers, SJ et al., 2021)). The first and third authors (SK and JC) were present at all program meetings.

At the end of the program, interviews were conducted to identify perceived barriers to PCC delivery for patients with multimorbidity in the primary care setting. This approach is similar to that used in previous qualitative studies of barriers to primary care delivery (Allory et al., 2020; Mc Namara et al., 2017). Sampling was purposive, with the intent of interviewing at least one GP and one NP per practice. The practices selected healthcare professionals for participation. As three practices had the same healthcare team, 10 interviews were planned. One interview was cancelled due to the participant's illness. Thus, nine healthcare professionals (four GPs and five NPs; one male and eight females), comprising 43% of PCC improvement program participants, agreed to participate and were interviewed. After these interviews, the authors presented the themes to the healthcare professionals, and together, the group decided that no additional interview was needed, as all themes were recognized and no additional theme emerged. For the same reason, no repeat interview was conducted.

Ethics

The medical ethics committee of Erasmus Medical Centre, Rotterdam, the Netherlands, determined that the rules stipulated in the Medical Research Involving Human Subjects Act did not apply to this study (protocol no. MEC-2018-021).

Data collection

In January and February 2018, the first author conducted semi-structured interviews lasting about 1 h each. Each interview was conducted at the GP practice of the interviewee, with only the researcher and participant present. All interviewees were familiar with the purpose of the research and with the interviewer, with whom they had established relationships during prior program meetings. During the interviews, the eight PCC dimensions were used as a guide for consistency. Open questions (without a predetermined set of questions) were used to investigate the interviewees' conceptualizations of each dimension of PCC, and of what could be further improved. Verbal informed consent was obtained from all participants. With the participants' permission, the interviews were recorded digitally. No fieldnotes were made during the interviews.

Data analysis

Reflexive thematic analysis was applied to the data, based on the steps defined by Braun and Clarke (2006), to identify patterns of meaning across the dataset. The authors analyzed the data inductively; coding and theme development were directed by its content. To identify patterns of meaning, six steps were defined for the analysis (Figure 2). First, all interviews were transcribed verbatim (~3.5 h per transcript), and the first author read the full transcripts to familiarize herself with the data. The respondents did not read the transcripts. Second, the first author coded the content using ATLAS.ti, (version 8.4.18; ATLAS.ti Scientific Software Development GmbH). Third, all authors examined the codes and identified themes in each PCC dimension representing barriers to PCC delivery for patients with multimorbidity in the primary care setting identified by the respondents. Fourth, all authors reviewed and refined the themes, discussing their scope and names until agreement was reached (triangulation). Finally, to validate the findings, all themes were discussed during a meeting, with all 22 healthcare professionals participating in the PCC improvement program; the professionals recognized the themes raised, and no additional theme emerged during this meeting.

RESULTS

Descriptive statistics of the participants are presented in Table 1.

Table 1. Descriptive statistics.

Participant	Gender	Age (Years)	Employment at Organization	Workhours/Week
GP 1	Male	52	≥10 years	≥36 h
GP 2	Female	42	≥10 years	≥36 h
GP 3	Female	53	5–10 years	≥36 h
GP 4	Female	37	3–5 years	29–36 h
NP 1	Female	57	≥10 years	≥36 h
NP 2	Female	37	3–5 years	≥36 h
NP 3	Female	38	≤1 year	≤16 h
NP 4	Female	61	≥10 years	≥36 h
NP 5	Female	46	3–5 years	≥36 h
Overall (years/% of all participants)	89%	47	33.3% ≥10 years	56% ≥36 h

GP: General practitioner, NP: Nurse practitioner

The healthcare professionals identified barriers (themes) in all eight PCC dimensions (Table 2). The barriers are presented by dimension, but described below in no specific order, as all of the dimensions are important for the improvement of PCC.

Table 2. Overview of barriers to patient-centered care (PCC) for patients with multimorbidity

PCC Dimension	Barriers
Patient preferences	- Taking on a coaching role takes time and calls for additional skills - The need for mutual understanding of patients' needs - Not all patients want to be actively involved
Access to care	- Agreements with healthcare insurers do not fully support PCC - Community support is not always (financially) accessible for patients
Physical comfort	- Struggles with the offering of physical comfort at GP practices
Family and friends	- Unfamiliarity with the involvement of family member and friends in regular consultations - Consultation time is often too limited for the involvement of family members and friends - Contradicting needs and wishes of patients and their family members and friends
Emotional support	- Patients visit GP practices due to physical, rather than emotional, problems - Healthcare professionals do not always address emotional problems - Healthcare professionals feel that it is not their task to provide emotional support, and that time is limited
Information and education	- Information does not always match the situation of multimorbid patients - Variation in patients' health literacy makes the alignment of information and education difficult
Coordination of care	- Larger numbers of team members add complexity to the coordination of care - The team atmosphere is crucial for improvement in an organization
Continuity and transition	- A longer care chain entails risks - Data protection laws impede adequate documentation and information sharing - Information and communications technology systems are not optimally designed to ensure care continuity and transition

Patient preferences

Taking on a coaching role takes time and calls for additional skills

The consideration of patients' preferences, wishes, and needs in care delivery often requires a shift from paternalistic consulting toward a coaching role for healthcare professionals. According to the interviewees, this shift is not always easy. The assumption of this new role, and the exploration of patients' preferences, take time.

> "I have been working as a practitioner for many years and I have my ways, so I also have to get used to a change and a new approach to healthcare delivery." (NP1)

Moreover, this shift requires additional communication skills and techniques to enable healthcare professionals to explore patients' preferences and support them in goalsetting. Not all healthcare professionals, however, have been trained or acquired these new skills, which makes PCC delivery challenging. Furthermore, not all healthcare professionals are willing to make this change.

> "I still get very easily into sending mode. Sometimes you just convey certain information without having properly tested where the patient's needs lie." (GP1)

The need for mutual understanding of patients' needs

For adequate PCC delivery, a mutual understanding of patients' needs and priorities is crucial; the interviewees reported that achieving such understanding can be challenging. For example, the exploration of patient needs and preferences is more difficult when there is a language barrier or cultural difference.

> "Sometimes a language barrier or culture also makes it difficult. With a language barrier, patients do not always understand what is going on and that they have a say too. And culture also often does determine how people cope with their disease process. Often, they are used to me telling them what is wrong, what they have to do, and then they do it." (GP4)

Not all patients want to be actively involved

The exploration of patients' wishes and needs is also more difficult when patients do not want to be actively involved in care delivery. Some patients have difficulties being proactive, sharing their perspectives, or setting goals concerning their care. They prefer care as usual, with goalsetting done mainly by their healthcare professionals. The receipt of care as usual can be considered as a patient preference, although healthcare professionals sometimes struggle with this factor.

> “It can also be that the patient comes to me with very different expectations and does not feel the need to express what he wants, but adopts more of a consuming attitude: “well, just tell me how the blood sugar is and whether the blood pressure is okay and I will be satisfied.” Then it is difficult to find out what people really want with their health.” (GP1)

Access to care

Agreements with healthcare insurers do not fully support PCC

The interviewees emphasized that the time needed to deliver PCC, especially to patients with multimorbidity, should not be underestimated. As NPs often have flexible consultation times, this barrier applies mainly to GPs. Most consultations with GPs last 10–20 min, which is a short period of time for patients with complex care needs. Blood pressure or glucose measurement and/or the discussion of other physical complaints often take up most of this time. Financial arrangements with healthcare insurers have restricted consultation durations, limiting multimorbid patients’ access to care. Spending more time with patients than agreed upon with health insurers is not rewarded. These agreements are thus perceived as barriers to PCC delivery, as the time pressure means that healthcare professionals cannot always discuss patients’ care preferences or set goals with them.

> “What I find very strange is that if you tailor your care to the needs of the patient, help and invest in them well, then you get penalized very badly financially for that.” (GP2)

> “If I have only ten minutes, I go much less deeply than if I have double the time. Then I can ask a lot more thoroughly what the patient means and list all the options. Sure, I always try to do that, but really teaching the patients to make and set their own goals goes a bit further than that.” (GP4)

Another example is the healthcare insurers’ predetermination of the number of follow-up visits for multimorbid patients. With PCC, this number should be determined according to patients’ preferences, but this is currently difficult, as the insurers take the performance of fewer follow-up visits to represent low-quality care delivery and do not provide reimbursement for visits beyond the number agreed upon.

> “Well, if the patient says “I like it so much here I will come back next week,” you also have a problem. Because then he comes next week and the week after that, but you only get paid for two or three contacts a year. And that, of course, averages out. The health insurance company only looks at the

> care that was delivered. And if you get paid twice and you see him ten times, they would rather see that, than if you get paid three times and you only see him once.” (GP1)

Community support is not always (financially) accessible for patients

Healthcare professionals often use community support elements, such as taxi rides to GP appointments for patients with mobility limitations, as part of good PCC provision. However, these services are not always (financially) accessible for patients, as they are often not reimbursed.

> “Exercise programs can make a huge contribution to care. But people do not get reimbursed for it, and there is still a group of people with small budgets who cannot afford it themselves. In order to provide PCC, sometimes a bit of professional guidance to get and stay in motion is also very much needed. I think that is a real gap in the regulations.” (NP1)

Physical comfort

Struggles with the offering of physical comfort at GP practices

The interviewees acknowledged the importance of offering physical comfort at GP practices, but noted that they struggle with what to provide and what is considered to be sufficient (i.e., what exactly is “comfortable”). Moreover, they sometimes have limited options for comfort provision. For example, space limitations can make the provision of adequate privacy via separate waiting rooms and a separate front desk difficult. Furthermore, some interviewees expressed awareness that physical comfort (e.g., swinging doors) was suboptimal at their practices, but had no concrete plan to solve this problem.

> “My consultation room is upstairs where you can only get to by stairs. That is not ideal for some patients. But the lack of space forces me to do this. Sometimes when people cannot manage it, I make house calls and some of the people we know about we try to schedule them for a day when we have a free consultation room downstairs. But this is becoming increasingly difficult because we are indeed short of space. I realize that we also have swing doors as a front door, which is not very handy with the wheelchair.” (NP5)

Family and friends

Unfamiliarity with the involvement of family members and friends in regular consultations

The interviewees stated that they struggle with the involvement of multimorbid patients' family members and friends in care delivery, including consultations, because they are simply not used to doing so. In addition, not all interviewees were aware of the benefits of this practice in terms of patient outcomes.

> "Well we can always do better, but I do not know how. Then you have to learn yourself to bring up those kinds of things [private situations] more often. But I do not quite see how to do that in an ordinary consultation. I only do that in exceptional cases. I do not ask the standard diabetic patient how things are at home. I will bring it up, but not every three months, I think." (NP2)

Consultation time is often too limited for the involvement of family members and friends

The GPs and NPs also stated that they often do not involve patients' relatives due to the time required to do so and to pay attention to and address their needs and questions. As their consultation times for this patient population are often limited, GPs choose to pay more attention to other aspects of care delivery.

> "The time is too limited. And if there is a problem, you would like to do something with it. And wanting to do something with it means the more things you bring up, the more problems there are, the more time you need to find a solution for all those problems." (GP1)

Contradicting needs and wishes of patients and their family members and friends

The interviewees explained that family members' preferences sometimes contradict those of patients, which contributes to the difficulty of involving relatives in care delivery.

> "Involving family is sometimes difficult. Sometimes I do get phone calls from [patients'] children. Sometimes that is nice, sometimes it is not. If several children are involved in the care delivery, and all want something different, it sometimes creates difficult situations." (NP5)

Emotional support

Patients visit GP practices due to physical, rather than emotional, problems

The interviewees recognized that not all patients think that their GP practice is the place to discuss emotional issues or the impacts of chronic diseases on one's private life. Although some patients know that the exploration of such issues is the task of mental-health NPs, they do not believe it to be the task of GPs. This perspective may impede the provision of adequate emotional support to patients who need it.

> "Sometimes you also see that there is some doubt if they [patients] can say it here, because how will we [healthcare professionals] think of it [an emotional problem]." (GP1)

Healthcare professionals do no always address emotional problems

The interviewees acknowledged that they do not always address possible emotional problems accompanying multimorbidity.

> "Of course, I do not always ask about it [emotional problems]. Yes, if people start talking about it themselves, I do listen. I do my best with that, or I suggest the accessible mental healthcare nurse practitioner. But there is not always attention to emotional aspects. Someone with diabetes with good values is doing well. Then I am not going to actively ask whether he is also under stress." (NP2)

Furthermore, not all interviewees felt comfortable discussing emotional aspects accompanying patients' diseases, such as depressive feelings or anxiety.

> "Well, there will undoubtedly be intrinsic factors in myself as well, on account of which I may be more likely to discuss certain things rather than other topics. I also bring my own person into a conversation. So that can be a barrier." (NP1)

Healthcare professionals feel that it is not their task to provide emotional support, and that time is limited

The GPs interviewed also noted the lack of clear boundaries for the provision of emotional support, whether the recognition of problems is sufficient or more is needed. This factor is related to time pressure; the interviewees stated that they do not want patients to believe that they can make appointments solely to discuss emotional problems, as they feel that this is not their role and that time is limited.

> “I do not have time myself to talk for half an hour every week, but the mental healthcare nurse practitioner does. Some people do like that, other people say no I do not want that, I just want to talk about it here. And then I think, no way I am going to free up my schedule to talk for half an hour every week. We also have to set boundaries.” (GP2)

> “If a patient is very sad, you cannot say “well, the time is up.” You do not do that. So yes, that also makes the planning of the consultation hours difficult, because they come for something and if everything else comes along, which is quite often, then it runs late. And you cannot schedule everyone for half an hour, because even if you were to work twenty-four hours a day, you still would not have seen all the patients. So, you always have to choose and share. And that is just annoying. You can never do the best for everyone and that is very frustrating.” (GP2)

Information and education

Information does not always match the situations of multimorbid patients

The interviewees emphasized the importance and difficulty of providing information specific to multimorbidity, as disease-specific information on comorbidities does not always exist.

> “I would like to give more psycho-education, so people get more specific information. But that is difficult to do for such a wide range of conditions. There are so many things that play a role in multimorbidity.” (GP4)

Variation is patients’ health literacy makes the alignment of information and education difficult

Not only healthcare professionals, but also patients, need to possess skills to explore their preferences. Patients need to have health literacy and communication skills to share preferences and information and set goals. Thus, the interviewees found the lack of such skills to impede PCC delivery.

> “You will see that patients with multimorbidity are often older people. And older people often look up to the doctor as well. And have a little less knowledge, they think, of all kinds of diseases, while of course that is not the case. Because they have been on Earth much longer than I have. But the elderly are more sensitive to it. The younger people can decide much easier, and often find a lot of information on the internet to make a targeted choice.” (GP1)

The interviewees noted that health literacy skills vary greatly in this patient population, making the adjustment of information provision to individual patients difficult. It can be difficult to recognize what patients need to gain better health literacy skills, and to determine whether patients have truly understood the information provided.

> "And as to low literacy, here in the village it is not too bad, but for someone who barely finished secondary school or did not finish it at all, it is obviously quite difficult to think about conditions, pills, solutions and options, to make a choice. And then it seems as if you have to be smart to make a good choice, but someone who is less educated can do that just as well. Provided that the information fits well. And of course, there is a barrier in that. Because as professionals we communicate on a completely different level. We use much more complicated words and terms that do not always come across." (GP1)

The interviewees mentioned that the development and use of multiple resources (e.g., brochures) adapted to all education levels and language backgrounds would aid the provision of good information aligned with patients' needs and characteristics. Although such materials exist, the interviewees did not use them often.

> "I could perhaps do more with the foreign people here in the district in terms of informational material. Because I do that a lot in Dutch now. Of course, they are often accompanied by someone who can speak Dutch, but then it all goes through an intermediary. And I think there are enough materials in other languages as well that are not yet available at the thuisarts website [which provides disease-specific information to patients]." (NP2)

Coordination of care

Larger numbers of team members add complexity to the coordination of care

According to the interviewees, adequate PCC delivery requires all practice team members to believe in the added value of this approach. They noted that the coordination of care differs between small and large teams in GP practices. For PCC, the same team should be involved in every instance of care delivery to a patient. However, coordination becomes more complex with the addition of team members (e.g., multiple assistants at the front desk, part-time workers).

> "We were looking at how to divide the patients among three nurse practitioners. At first we had one nurse practitioner, and then of course there

> was nothing to divide. But now we have more. And one works only so many hours part time and the other works only so many hours part time. So, it all just has to fit, but coordinating this can be quite a challenge." (GP1)

> "For a patient, it is quite difficult. Having your own general practitioner and a nurse practitioner is manageable. But there are also eight assistants they have to deal with, and I think that can be confusing. That could be organized better." (NP1)

The team atmosphere is crucial for improvement in an organization

The interviewees emphasized the importance of the team's morale and atmosphere for the adoption of a new approach. When no safe environment to provide feedback and ask critical questions exists, improvement is difficult.

> "It is enjoyable to watch each other's work and you can get a lot of tips and find many improvements by doing so. But feedback is sometimes given in such a way that makes it come across as hurtful or threatening. There must also be a sense of safety." (GP1)

Continuity and transition

A longer care chain entails risks

In many cases, healthcare professionals from diverse disciplines in various healthcare settings (e.g., primary, hospital, community, and social care) are involved in care delivery to patients with multimorbidity. The interviewees noted that this situation may hinder the continuity of care; longer chains of care are more vulnerable to disruption.

> "Because there are many healthcare settings involved, there are many links and each link is vulnerable. If I verbally pass something on to you and you pass it on to someone else and they pass it on to their colleague. After ten people, look what finally emerges." (GP1)

To ensure the continuity of care, collaboration among healthcare settings is very important. The GPs interviewed stated that they tried to take leading roles in managing the continuity and transition of care, but emphasized that this was easier said than done. The part-time work schedules of many healthcare professionals render the continuity of care even more difficult, due to difficulties with the scheduling of meetings and alignment of advice. Furthermore, the interviewees stated that they did not always know the expertise of professionals in other disciplines, especially those outside of the healthcare setting (i.e., in the community or social domain), which makes the transition of information and referral difficult.

> “I think that as a GP I have a particular task when people see several specialists and those specialists are not always well informed about each other’s goals and treatments. Patients sometimes lose their way because of this, because they feel that there is not enough holistic collaboration. My job is to call or consult with the specialist or refer someone who is a bit older to a geriatrician. And then I sometimes ask specifically whether the geriatrician could take over the check-ups from the various specialists. But that is often not the case. If someone is a very specific rheumatologist or a patient has a cardiac or pulmonary condition, you do not let those specialists go easily. Then you sometimes have to call more often to get things coordinated. I think that takes a lot of energy. And it takes a lot of energy from the patient as well.” (GP3)

> “More and more people work part time. So, in any case you also get more and more people within the chain who are not always available at the time that you work.” (GP1)

Data protection laws impede adequate documentation and information sharing

The interviewees identified data protection laws as barriers to PCC, and in particular to the continuity and transition of care. Good, complete documentation shared among all healthcare professionals involved in a patient’s care is important, but these laws prohibit the sharing of some information with professionals in all disciplines, resulting in the loss of (relevant) information. Medical information may be transferred only between medical doctors, and cannot be shared with paramedics, who are members of multidisciplinary teams providing PCC. The laws also make information sharing during multidisciplinary team meetings difficult.

> “We have a pharmacy here in the building. I am not allowed to just hand over a list to the pharmacy saying these are all the people with heart failure, could you please check if the medication is okay. Because that is a data leak. So, I have to ask permission from each individual patient to tell the pharmacy that they have heart failure. And then if the patient says yes, then it is allowed. Otherwise it is not. So, you have to take a lot of steps to get there.” (GP2)

> “We are only allowed to transfer information to another physician. So, not all the allied healthcare professionals are allowed to have certain information, because that is all protected. We also have a chain information system, but everyone’s information is open to a limited extent. Most healthcare professionals involved really only get the referral and no additional information is allowed.” (GP2)

The data protection laws also complicate communication with healthcare professionals involved in a patient’s care, as the (unprotected) exchange of emails is not permitted. This situation often results in a loss of efficiency in seeking to achieve continuity of care.

> “Email traffic in primary care really needs to be implemented safely at breakneck speed, although it is apparently very difficult. This is really a shortcoming. This would allow us to communicate even better with the patient. For me as a NP, the GP is ultimately responsible, so I have to regularly consult with the GP and then call the patient back. The patient also has to stay at home especially for that phone call. With an email you can save a lot of time, but it will also help the patient since he can read everything back at leisure. If you start with medication, the patient has to pick it up at the pharmacy, take it at a certain time for a certain amount of time. That is a lot of information, and putting that in an email might be more convenient.” (NP3)

Information and communication technology systems are not optimally designed to ensure care continuity and transition

According to the interviewees, the data information systems used within the organization and for the entire care chain are not optimally designed to function concurrently. Given the use of two different systems, not all relevant information is transferred adequately to all professionals on multidisciplinary care teams. This situation complicates communication among all healthcare providers involved and may result in the fragmentation of care.

> “When I report on diabetes care, all the doctors involved can just see it in the chain information system [CIS]. But within the practice we work with a GP information system (GIS), but those two systems do not always work well together. For example, when patients last visited the optometrist. Nine times out of ten, the data is correctly processed in CIS but sometimes it does not come across well in GIS. So, for example, they go to their GP for an annual check-up and the GP asks when was the last time they saw the

> optometrist? Sometimes the patient cannot remember, so the GP looks in GIS and cannot find the report. Then they have to ask me to look in CIS to look it up. This is not very efficient.” (NP5)

DISCUSSION

This study was performed to investigate barriers to PCC delivery to patients with multimorbidity, as perceived by healthcare professionals in a primary care setting. Although the participating healthcare professionals acknowledged the value of PCC in this context, they identified barriers in all eight PCC dimensions.

Patient preferences

According to the study findings, healthcare professionals face difficulties in making the shift from a paternalistic consulting to a coaching role; the assumption of a new role takes time, and additional skills are necessary to, for example, thoroughly explore patient preferences. Such changes of mindset have been mentioned frequently as barriers to PCC implementation (Luxford, Safran, & Delbanco, 2011). Furthermore, although patient-centered communication encompasses several skills, such as the expression of empathy and shared decision making (Hashim, 2017), many healthcare professionals are not trained in such skills and do not realize that their possession could help them improve their patient-centered communication (Hashim, 2017; Levinson, Lesser, & Epstein, 2010). Communication training could achieve this goal (Maatouk-Bürmann et al., 2016), potentially enabling healthcare professionals to gain a better understanding of their patients’ conditions and care needs, in turn resulting in better treatment alignment (Street Jr, Makoul, Arora, & Epstein, 2009). Healthcare professionals also encounter barriers with regard to patient preferences (e.g., language barriers) when creating mutual understanding with their patients. Language barriers perceived by patients and healthcare professionals have been found to impede PCC delivery to immigrant and refugee women (Filler et al., 2020).

In addition, healthcare professionals who participated in this study reported feeling that not all patients want to be actively involved in their care and/or have difficulties with goalsetting. Patients have been found to differ in their proactivity and skills for active PCC involvement (Kuipers et al., 2020). Although a patient’s preference for care as usual should be respected, we emphasize the need for thorough examination of whether the patient truly does not want to be in charge of his or her care, or whether the selection of care as usual is simply easier for him or her, as he or she may have difficulties with expressing his or her needs or preferences. The latter reflects the need for extra support from healthcare professionals to identify patients' needs and preferences.

Access to care

In the *access to care* dimension, healthcare professionals reported the lack of reimbursement for care provided as a barrier to effective PCC implementation. PCC often requires that healthcare professionals spend more time and exert more effort during consultations and in additional training sessions and workshops, and that they collaborate with professionals in other healthcare disciplines. The lack of financial structures supporting such activities may hamper the sustainability and widespread embedding of PCC into care systems in the long term. Concerns similar to those identified in this study have been raised by many healthcare professionals participating in programs aiming to improve the quality of primary care (e.g., integrated primary care for community-dwelling frail older persons, interventions based on the chronic care model) (Kadu & Stolee, 2015; Vestjens, Cramm, & Nieboer, 2018). Supporting financial structures are often described as prerequisites for the effective and sustainable implementation of healthcare delivery (Fleuren, Paulussen, Van Dommelen, & Van Buuren, 2014; Grol, Wensing, Eccles, & Davis, 2013). In addition, as the financial resources of patients with multimorbidity vary (Rijken & van der Heide, 2019), the creation of supportive financial structures also accounts for community support that may be inaccessible to patients with fewer resources.

Physical comfort

The healthcare professionals reported that they struggled with how to provide physical comfort in their GP practices. A systematic review revealed differences in preferences regarding essential aspects of physical comfort provided in healthcare organizations among departments and occupants (Eijkelenboom & Bluyssen, 2019). Additional research is needed to identify specific aspects of physical comfort preferred by patients with multimorbidity.

Family and friends

The study participants reported several barriers in this dimension. They acknowledged that they had difficulty involving patients' relatives in care delivery because they are simply not used to doing so, and not all healthcare professionals were aware of the benefits of doing so. Patients with chronic diseases have been found to involve their family members and friends more often when their care needs become too complex to self-manage and when worse health outcomes become more likely (Rosland, Piette, Choi, & Heisler, 2011; Wolff & Boyd, 2015). The study participants also reported that their consultation time is too limited to incorporate all aspects of PCC. As patients with multimorbidity often have physical complaints, most of the professionals' attention is devoted to these problems, leaving limited time to address relatives' needs and questions (Damarell et al., 2020; Riffin, Wolff, Estill, Prabhu, & Pillemer, 2020). Finally, the healthcare professionals experienced difficulties when they faced contradicting needs of patients and their family members. In another study, patient–family disagreements also were identified as a barrier to family involvement in primary care (Riffin, Wolff, Butterworth, Adelman, & Pillemer, 2020).

Emotional support

This study revealed that patients with multimorbidity do not think their GPs' tasks include the discussion of emotional aspects of their conditions, as has previous research (Kuipers et al., 2020). GPs likely feel the same, although a 2014 mental healthcare reform in the Netherlands designated emotional support as a GP task (Kroneman et al., 2016). The aforementioned barrier that consultation time is often spent fully on the addressing of the physical aspects of patients' conditions also applies to this dimension. However, as patients with multimorbidity often experience high emotional burdens related to their conditions, emotional support of these patients should receive more attention (Read et al., 2017; Vancampfort et al., 2017).

Information and education

Healthcare professionals participating in this study emphasized the importance of patients' possession of health literacy and communication skills, which allows them to participate in PCC delivery. The alignment of information provided with multimorbid patients' needs and backgrounds has been shown to be important to increase patient-centeredness (Kuipers, SJ et al., 2021). This study revealed wide variation in such literacy and skills among patients with multimorbidity. This is in accordance with the previous identification of subgroups of patients with multimorbidity based on personal resources such as communication and health literacy skills (Rijken & Van der Heide, 2019). Moreover, health literacy skills are often considered to be fundamental for patients who want to be in charge of their care (Keleher & Hagger, 2007). Previous research provides insight in how PCC delivery can be aligned to the (differences in) care needs of patients with multimorbidity (Kuipers et al., 2020). Furthermore, this study revealed a barrier related to the provision of information to patients with multimorbidity, as most available information is disease specific. The same barrier was identified in a systematic review describing the challenges that GPs face in managing patients with multimorbidity (Damarell et al., 2020).

Coordination of care

According to the study participants, optimal PCC delivery requires that all healthcare professionals in an organization are motivated to achieve change and improvement, and that the environment is supportive. When not all such professionals are motivated or able to change, improvement may be difficult. Consequently, larger teams may add complexity to the achievement of improvement. According to Fleuren et al. (2014), organizational size, colleagues' support, and the extent to which the task orientation beliefs of healthcare professionals fit the innovation goals are important determinants for healthcare innovation.

Continuity and transition

The study participants reported three barriers in the *continuity and transition* dimension. They reported that adequate information sharing is difficult to achieve when working with large teams of healthcare professionals across multiple settings. A study investigating how GP practices should organize their care for patients with multimorbidity to increase patient-centeredness showed that multidisciplinary work is very important and can be strengthened by the organization of multidisciplinary meetings (Kuipers et al., 2021). A systematic review showed that fragmentation between primary and secondary care poses a major challenge to the provision of care to patients with multimorbidity (Damarell et al., 2020). Second, the study participants reported that data protection laws restrict information sharing among healthcare professionals from multiple disciplines involved in individual patients' care. Third, they emphasized that data information systems within organizations and for entire care chains are not optimally designed for concurrent functioning. Previous studies have revealed similar challenges to the continuity of care (Berwick & Gaines, 2018; Kruse, Stein, Thomas, & Kaur, 2018). The inadequacy of information and communications technology systems may endanger the continuity of care, which is especially important for patients with multimorbidity, many of whom require multidisciplinary healthcare teams. Optimal technology and supportive laws are often described as prerequisites for the effective and sustainable implementation of healthcare delivery (Fleuren et al., 2014; Grol et al., 2013).

Practical implications and future research

The barriers identified in this study pose true challenges in the effort to effectively and sustainably implement PCC at the patient, organizational, and national levels. At the patient level, most identified barriers were related to the variation in patients' care needs and health literacy skills. These differences should be considered when developing care plans according to the PCC framework. At the organizational level, this study showed that not all healthcare professionals are aware of and/or trained in all elements of PCC delivery. Training and education of healthcare professionals should be initiated to increase their awareness and skills related to patient-centered communication, the involvement of patients' family members and friends, and the discussion of patients' emotional status, thereby improving care delivery to patients with multimorbidity. At the national level, challenges are related to data protection laws that restrict information sharing among healthcare settings, and to the lack of financial structures supporting PCC implementation; both of these factors are considered to be prerequisites for the effective and sustainable implementation of healthcare delivery (Fleuren et al., 2014; Grol et al., 2013). Future research and policies should focus on meeting organizational preconditions to enable investment in preventive care across the lifespan and to make PCC the best way forward.

Limitations

Several limitations of this study should be considered when interpreting its results. First, the generalizability of the results may be limited, as this study was conducted with primary healthcare professionals in the Noord-Brabant region of the Netherlands. Future research should investigate the experiences of healthcare professionals with regard to barriers to PCC implementation in other regions, countries, and healthcare settings. Second, the sample of nine healthcare professionals may be considered to be small. However, this sample size is similar to those used in other qualitative health and well-being studies (Duguay, Gallagher, & Fortin, 2014; Eckerström et al., 2019; Sørensen, Groven, Gjelsvik, Almendingen, & Garnweidner-Holme, 2020; Uittenbroek, van der Mei, Sijrike F, Slotman, Reijneveld, & Wynia, 2018). We selected it carefully, inviting 50% of all healthcare professionals from the GP practices participating in the PCC improvement program. Furthermore, the data are rich and were discussed during a meeting with all PCC program participants for validation; all healthcare professionals agreed with the findings, and no new theme was raised.

Conclusions

PCC has the potential to entail the tailored delivery of primary care according to the needs of patients with multimorbidity. PCC implementation in practice, however, is often difficult due to the existence of barriers. At the patient, organizational, and national levels, barriers were identified in all eight dimensions of PCC (patient preferences, information and education, access to care, physical comfort, emotional support, family and friends, continuity and transition, and coordination of care) in this study. They include difficulties with the achievement of mutual understanding between patients and healthcare professionals, the lack of healthcare professionals' training and education in new skills, data protection laws that impede adequate documentation and information sharing, time pressure, and conflicting financial incentives. These barriers pose true challenges to effective and sustainable PCC implementation for patients with multimorbidity.

REFERENCES

Allory, E., Lucas, H., Maury, A., Garlantezec, R., Kendir, C., Chapron, A., & Fiquet, L. (2020). Perspectives of deprived patients on diabetes self-management programmes delivered by the local primary care team: A qualitative study on facilitators and barriers for participation, in france. *BMC Health Services Research, 20*(1), 1-9.

Austad, B., Hetlevik, I., Mjølstad, B. P., & Helvik, A. (2016). Applying clinical guidelines in general practice: A qualitative study of potential complications. *BMC Family Practice, 17*(1), 1-8.

Berwick, D. M., & Gaines, M. E. (2018). How HIPAA harms care, and how to stop it. *Jama, 320*(3), 229-230.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-10.

Damarell, R. A., Morgan, D. D., & Tieman, J. J. (2020). General practitioner strategies for managing patients with multimorbidity: A systematic review and thematic synthesis of qualitative research. *BMC Family Practice, 21*(1), 1-23.

Davis, D. A., Mazmanian, P. E., Fordis, M., Van Harrison, R., Thorpe, K. E., & Perrier, L. (2006). Accuracy of physician self-assessment compared with observed measures of competence: A systematic review. *Jama, 296*(9), 1094-1102.

De Boer, D., Delnoij, D., & Rademakers, J. (2013). The importance of patient-centered care for various patient groups. *Patient Education and Counseling, 90*(3), 405-410.

Duguay, C., Gallagher, F., & Fortin, M. (2014). The experience of adults with multimorbidity: A qualitative study. *Journal of Comorbidity, 4*(1), 11-21.

Eckerström, J., Allenius, E., Helleman, M., Flyckt, L., Perseius, K., & Omerov, P. (2019). Brief admission (BA) for patients with emotional instability and self-harm: Nurses' perspectives-person-centred care in clinical practice. *International Journal of Qualitative Studies on Health and Well-Being, 14*(1), 1667133.

Eijkelenboom, A., & Bluyssen, P. M. (2019). Comfort and health of patients and staff, related to the physical environment of different departments in hospitals: A literature review. *Intelligent Buildings International,* 1-19.

Filler, T., Jameel, B., & Gagliardi, A. R. (2020). Barriers and facilitators of patient centered care for immigrant and refugee women: A scoping review. *BMC Public Health, 20*(1), 1-12.

Fleuren, M. A., Paulussen, T. G., Van Dommelen, P., & Van Buuren, S. (2014). Towards a measurement instrument for determinants of innovations. *International Journal for Quality in Health Care, 26*(5), 501-510.

Freilich, J., Nilsson, G. H., Ekstedt, M., & Flink, M. (2020). "Standing on common ground"-a qualitative study of self-management support for patients with multimorbidity in primary health care. *BMC Family Practice, 21*(1), 1-12.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T.L. (1993). *Through the patient's eyes: understanding and promoting patient-centered care.* Jossey-Bass Publishers.

Given, L. M. (2008). *The sage encyclopedia of qualitative research methods.* Sage publications.

Grol, R., Wensing, M., Eccles, M., & Davis, D. (2013). *Improving patient care: the implementation of change in health care*. John Wiley & Sons.

Hashim, M. J. (2017). Patient-centered communication: Basic skills. *American Family Physician, 95*(1), 29-34.

Haslam, D. (2015). "You're an expert in me": The Role of the Generalist Doctor in the Management of Patients with Multimorbidity. *Journal of Multimorbidity and Comorbidity, 5*(1), 132-134.

Heijmans, M., Brabers, A., & Rademakers, J. (2018). *Health literacy in Nederland*. Utrecht: NIVEL.

Hujala, A., Taskinen, H., Rissanen, S., Richardson, E., & van Ginneken, E. (2017). *How to support integration to promote care for people with multimorbidity in Europe?*. World Health Organization, Regional Office for Europe.

Jackson, G. L., Powers, B. J., Chatterjee, R., Prvu Bettger, J., Kemper, A. R., Hasselblad, V., . . . Kendrick, A. S. (2013). The patient-centered medical home: A systematic review. *Annals of Internal Medicine, 158*(3), 169-178.

Jayadevappa, R., & Chhatre, S. (2011). Patient centered care-a conceptual model and review of the state of the art. *The Open Health Services and Policy Journal, 4*(1), 15-25.

Johnston, M. C., Crilly, M., Black, C., Prescott, G. J., & Mercer, S. W. (2019). Defining and measuring multimorbidity: A systematic review of systematic reviews. *European Journal of Public Health, 29*(1), 182-189.

Kadu, M. K., & Stolee, P. (2015). Facilitators and barriers of implementing the chronic care model in primary care: A systematic review. *BMC Family Practice, 16*(1), 12.

Keleher, H., & Hagger, V. (2007). Health literacy in primary health care. *Australian Journal of Primary Health, 13*(2), 24-30.

Kroneman, M., Boerma, W., van den Berg, M., Groenewegen, P., de Jong, J., & van Ginneken, E. (2016). Netherlands: Health system review. *Health Systems in Transition, 18*(2), 1-240.

Kruse, C. S., Stein, A., Thomas, H., & Kaur, H. (2018). The use of electronic health records to support population health: A systematic review of the literature. *Journal of Medical Systems, 42*(11), 214.

Kuipers, S. J., Cramm, J. M., & Nieboer, A. P. (2019). The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multimorbidity in the primary care setting. *BMC Health Services Research, 19*(1), 13.

Kuipers, S. J., Nieboer, A. P., & Cramm, J. M. (2020). Views of patients with multimorbidity on what is important for patient-centered care in the primary care setting. *BMC Family Practice, 21*, 1-12.

Kuipers, S. J., Nieboer, A. P., & Cramm, J. M. (2021). Making care more patient centered; experiences of healthcare professionals and patients with multimorbidity in the primary care setting. *BMC Family Practice, 22*(70), 1-15.

Levinson, W., Lesser, C. S., & Epstein, R. M. (2010). Developing physician communication skills for patient-centered care. *Health Affairs, 29*(7), 1310-1318.

Lugtenberg, M., Burgers, J. S., Clancy, C., Westert, G. P., & Schneider, E. C. (2011). Current guidelines have limited applicability to patients with comorbid conditions: A systematic analysis of evidence-based guidelines. *PloS One, 6*(10), e25987.

Luxford, K., Safran, D. G., & Delbanco, T. (2011). Promoting patient-centered care: A qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *International Journal for Quality in Health Care, 23*(5), 510-515.

Maatouk-Bürmann, B., Ringel, N., Spang, J., Weiss, C., Möltner, A., Riemann, U., . . . Jünger, J. (2016). Improving patient-centered communication: Results of a randomized controlled trial. *Patient Education and Counseling, 99*(1), 117-124.

Macdonald, G. G., Townsend, A. F., Adam, P., Li, L. C., Kerr, S., McDonald, M., & Backman, C. L. (2018). eHealth technologies, multimorbidity, and the office visit: Qualitative interview study on the perspectives of physicians and nurses. *Journal of Medical Internet Research, 20*(1), e8983.

Makovski, T. T., Schmitz, S., Zeegers, M. P., Stranges, S., & van den Akker, M. (2019). Multimorbidity and quality of life: systematic literature review and meta-analysis. *Ageing Research Reviews*, *53*, 100903.

Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., . . . Fratiglioni, L. (2011). Aging with multimorbidity: A systematic review of the literature. *Ageing Research Reviews, 10*(4), 430-439.

Matthews, E. B., Stanhope, V., Choy-Brown, M., & Doherty, M. (2018). Do providers know what they do not know? A correlational study of knowledge acquisition and person-centered care. *Community Mental Health Journal, 54*(5), 514-520.

Mc Namara, K. P., Breken, B. D., Alzubaidi, H. T., Bell, J. S., Dunbar, J. A., Walker, C., & Hernan, A. (2017). Health professional perspectives on the management of multimorbidity and polypharmacy for older patients in Australia. *Age and Ageing, 46*(2), 291-299.

McMillan, S. S., Kendall, E., Sav, A., King, M. A., Whitty, J. A., Kelly, F., & Wheeler, A. J. (2013). Patient-centered approaches to health care: A systematic review of randomized controlled trials. *Medical Care Research and Review, 70*(6), 567-596.

Nordin, A. A., Hairi, M. F., Choo, W. Y., & Hairi, N. N. (2019). Care recipient multimorbidity and health impacts on informal caregivers: A systematic review. *The Gerontologist, 59*(5), e611-e628.

Nunes, B. P., Flores, T. R., Mielke, G. I., Thume, E., & Facchini, L. A. (2016). Multimorbidity and mortality in older adults: A systematic review and meta-analysis. *Archives of Gerontology and Geriatrics, 67*, 130-138.

Park, M., Lee, M., Jeong, H., Jeong, M., & Go, Y. (2018). Patient-and family-centered care interventions for improving the quality of health care: A review of systematic reviews. *International Journal of Nursing Studies, 87*, 69-83.

Raad Volksgezondheid en Samenleving. (2020). *Hoor mij nou! Samen begrijpen, proberen, reflecteren en leren bij complexe zorgvragen. https://www.raadrvs.nl/documenten/publicaties/2020/10/15/hoor-mij-nou*

Rademakers, J., Delnoij, D., Nijman, J., & De Boer, D. (2012). Educational inequalities in patient-centred care: Patients' preferences and experiences. *BMC Health Services Research, 12*(1), 261.

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review, 70*(4), 351-379.

Read, J. R., Sharpe, L., Modini, M., & Dear, B. F. (2017). Multimorbidity and depression: A systematic review and meta-analysis. *Journal of Affective Disorders, 221*, 36-46.

Reuben, D. B., & Tinetti, M. E. (2012). Goal-oriented patient care--an alternative health outcomes paradigm. *The New England Journal of Medicine, 366*(9), 777.

Institute of Medicine (2001). *Crossing the quality chasm: a new health system for the 21st century.* National academy press.

Riffin, C., Wolff, J. L., Butterworth, J., Adelman, R. D., & Pillemer, K. A. (2020). Challenges and approaches to involving family caregivers in primary care. *Patient Education and Counseling, 104*(7), 1644-1651.

Riffin, C., Wolff, J. L., Estill, M., Prabhu, S., & Pillemer, K. A. (2020). Caregiver needs assessment in primary care: Views of clinicians, staff, patients, and caregivers. *Journal of the American Geriatrics Society, 68*(6), 1262-1270.

Rijken, M., & van der Heide, I. (2019). Identifying subgroups of persons with multimorbidity based on their needs for care and support. *BMC Family Practice, 20*(1), 1-10.

Rosland, A. M., Piette, J. D., Choi, H., & Heisler, M. (2011). Family and friend participation in primary care visits of patients with diabetes or heart failure: Patient and physician determinants and experiences. *Medical Care, 49*(1), 37-45.

Sørensen, M., Groven, K. S., Gjelsvik, B., Almendingen, K., & Garnweidner-Holme, L. (2020). Experiences of self-management support in patients with diabetes and multimorbidity: A qualitative study in Norwegian general practice. *Primary Health Care Research & Development, 21,* e44.

Street Jr, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? pathways linking clinician–patient communication to health outcomes. *Patient Education and Counseling, 74*(3), 295-301.

Tinetti, M. E., Fried, T. R., & Boyd, C. M. (2012). Designing health care for the most common chronic condition—multimorbidity. *Jama, 307*(23), 2493-2494.

Tondora, J., Miller, R., & Davidson, L. (2012). The top ten concerns about person-centered care planning in mental health systems. *International Journal of Person Centered Medicine, 2*(3), 410-420.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357.

Uittenbroek, R. J., van der Mei, Sijrike F, Slotman, K., Reijneveld, S. A., & Wynia, K. (2018). Experiences of case managers in providing person-centered and integrated care based on the chronic care model: A qualitative study on embrace. *PloS One, 13*(11), e0207109.

Van der Heide, I., Snoeijs, S., Quattrini, S., Struckmann, V., Hujala, A., Schellevis, F., & Rijken, M. (2018). Patient-centeredness of integrated care programs for people with multimorbidity. Results from the European ICARE4EU project. *Health Policy, 122*(1), 36-43.

Van Nistelrooij, I., Visse, M., Spekkink, A., & de Lange, J. (2017). How shared is shared decision-making? A care-ethical view on the role of partner and family. *Journal of Medical Ethics, 43*(9), 637-644.

Vancampfort, D., Koyanagi, A., Hallgren, M., Probst, M., & Stubbs, B. (2017). The relationship between chronic physical conditions, multimorbidity and anxiety in the general population: A global perspective across 42 countries. *General Hospital Psychiatry, 45*, 1-6.

Verest, W. J., Galenkamp, H., Spek, B., Snijder, M. B., Stronks, K., & van Valkengoed, I. G. (2019). Do ethnic inequalities in multimorbidity reflect ethnic differences in socioeconomic status? the HELIUS study. *European Journal of Public Health, 29*(4), 687-693.

Vestjens, L., Cramm, J. M., & Nieboer, A. P. (2018). An integrated primary care approach for frail community-dwelling older persons: A step forward in improving the quality of care. *BMC Health Services Research, 18*(1), 28.

Vetrano, D. L., Palmer, K., Marengoni, A., Marzetti, E., Lattanzio, F., Roller-Wirnsberger, R., . . . Onder, G. (2019). Frailty and multimorbidity: A systematic review and meta-analysis. *The Journals of Gerontology: Series A, 74*(5), 659-666.

Violan, C., Foguet-Boreu, Q., Flores-Mateo, G., Salisbury, C., Blom, J., Freitag, M., . . . Valderas, J. M. (2014). Prevalence, determinants and patterns of multimorbidity in primary care: A systematic review of observational studies. *PloS One, 9*(7), e102149.

Wolff, J. L., & Boyd, C. M. (2015). A look at person-centered and family-centered care among older adults: Results from a national survey. *Journal of General Internal Medicine, 30*(10), 1497-1504.

World Health Organization. (2008). *The world health report 2008: primary health care now more than ever*. World Health Organization.

Zhang, Y., Tzortzopoulos, P., & Kagioglou, M. (2019). Healing built-environment effects on health outcomes: Environment–occupant–health framework. *Building Research & Information, 47*(6), 747-766.

Patient preferences

Information and education

Physical comfort

Access to care

Emotional support

Family and friends

Coordination of care

Continuity and transition

Chapter 7

General discussion

GENERAL DISCUSSION

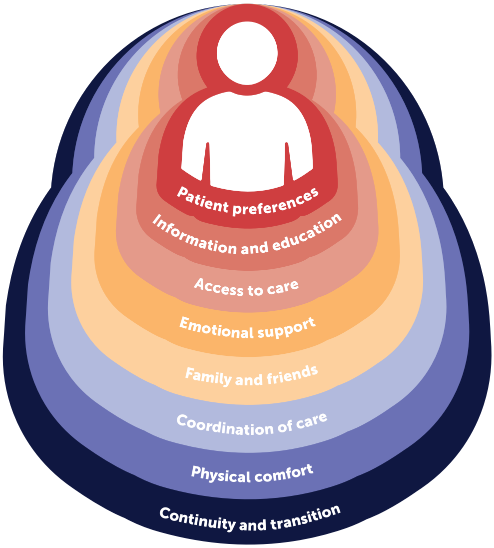


Figure 1. The eight dimensions of patient-centered care

The main objective of this thesis was to investigate the importance of the eight dimensions of PCC identified by the Picker Institute (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Picker Institute, n.d.; Figure 1) for patients with multimorbidity in a primary care setting. The *patient preferences* dimension refers to the taking of patients' needs and preferences into account, treating them with dignity and respect, and supporting them to set and achieve their own goals. The *information and education* dimension encompasses the provision of information to patients about all aspects of their care, and the alignment of this information with patients' educational and migration backgrounds. *Access to care* refers to wait time management, appointment scheduling and the accessibility of buildings. The *physical comfort* dimension refers to the adequate management of the physical aspects of conditions (e.g. fatigue, shortness of breath, lack of sleep), ensuring patients' privacy and providing comfortable and clean (waiting) rooms. *Emotional support* encompasses the management of the emotional aspects of patients' conditions, such as anxiety and depression, and the impacts of their multiple chronic conditions on their private lives (e.g. social relationships or jobs). The *family and friends* dimension refers to the acknowledgement of the impacts of multimorbidity on patients' family members and friends, and the provision of adequate support to involve them in the care process. As multiple healthcare professionals are often involved in care delivery to patients with multimorbidity, *continuity and transition* entail the adequate transfer of information between healthcare settings and the *coordination of care* entails the alignment of care delivery among healthcare professionals within an organisation. These eight dimensions formed the basis of the research conducted for this thesis. In the research described in the first part of the thesis, the views of patients with multimorbidity on the eight dimensions of PCC were identified; in the research described in the second part, relationships of these dimensions and the co-creation of care with the well-being of these patients were examined in a primary care setting. The third part of the thesis consists of a thorough description of how to implement and organise the eight PCC dimensions in the primary care setting for patients with multimorbidity. In this chapter, the main findings of these parts of the thesis research are discussed.

Figure 2. The eight dimensions of patient-centered care

Main research findings

Research aim 1: to identify the views of patients with multimorbidity on PCC delivery

For the tailoring of care delivery to the preferences of patients with multimorbidity, these patients' views on PCC and the relative importance of the eight PCC dimensions must be explored. Research has demonstrated the importance of these eight dimensions, but their relative importance may vary among patients with different care needs and personal situations. The findings reported in chapter 2 show that not all patients with multimorbidity require the same type of care delivery, and enable the grouping of patients according to their perspectives as (1) prepared and proactive, (2) everyday and (3) vulnerable patients.

Relative to patients with other viewpoints, *prepared proactive patients* are well-off and down-to-earth, and want to be in charge of their care. They find the *information and education* dimension of PCC to be important, as they seek medical information about all aspects of their care. According to a previous study, most patients want to have active roles in their care processes, but the extent to which they want to or are able to differs (Rademakers, 2013). In line with our findings, these differences have been found to be based on motivation, self-confidence and patients' (medical) knowledge (Hibbard, Mahoney, Stockard, & Tusler, 2005). Patients holding this viewpoint also consider *physical comfort* (i.e. the physical aspects of their conditions) and *continuity and transition* to be important; they like to be supported by well-coordinated multidisciplinary teams of healthcare professionals. According to previous research, patients with multimorbidity agree on the need for good coordination to reduce the fragmentation of care (Gill, Kuluski, Jaakimainen, Naganathan, Upshur, & Wodchis, 2014; Mason et al., 2016).

Everyday patients highly value aspects related to the *patient preferences* dimension of PCC; they want to be taken seriously and establish good and trusting relationships with healthcare professionals, and they feel that poor communication will negatively impact care delivery. Trust and communication are often considered important in healthcare professional–patient relationships, as they are related to better and more effective treatment, increased satisfaction with care and improved patient adherence (Chandra, Mohammadnezhad, & Ward, 2018). Furthermore, like *prepared proactive patients*, *everyday patients* consider *continuity and transition* to be important, as they need supported guidance throughout their care processes.

Unlike patients with other viewpoints, v*ulnerable patients* consider a*ccess to care* to be important, as they have more difficulty, for example, paying healthcare costs not covered by insurance. In the Netherlands, poverty is more prevalent among people with than among those without chronic illnesses (Van Agt, Stronks, & Mackenbach, 2000), indicating the relevance of this viewpoint. Like *everyday patients*, *vulnerable patients* feel that being taken seriously and being treated with dignity and respect (i.e. *patient preferences)* are important. Relative to patients with the other viewpoints, *vulnerable patients* are less resourceful in terms of communication skills and comprehension of the *information and education* provided to them. In the Netherlands, more than one-third of all patients have difficulty understanding and processing information about their care, often referred to as low health literacy (Heijmans, Brabers, & Rademakers, 2018) and considered to reflect a mismatch between patients and their care delivery (Rademakers, 2016). PCC has the potential to address this discrepancy.

The research described in chapter 2 also showed that all patients, regardless of their viewpoints, considered the *family and friends* and *emotional support* dimensions of PCC to be less important than other dimensions. The study participants indicated that the involvement of relatives may become more important in the more severe stages of their conditions, which is in line with findings that patients with chronic conditions involve their relatives more often when their care needs become more complex and when they are more vulnerable to worse health outcomes (Rosland, Piette, Choi, & Heisler, 2011; Wolff & Boyd, 2015). The lower ranking of *emotional support* may reflect findings from a systematic review, which showed that patients feel that GPs cannot sufficiently manage emotional problems, and that stigma or guilt about taking up consultation time may prevent patients from disclosing these problems (Parker, Byng, Dickens, Kinsey, & McCabe, 2020).

The heterogeneity of the care needs, personal resources and background characteristics of patients with multimorbidity (Rijken & Van der Heide, 2019) may make individualized care delivery more complex. The use of Q methodology in the research described in chapter 2 enabled us to gain a foothold in this matter, as it enabled us to characterise variation in the relative importance of the eight PCC dimensions among patients. Although the identification of common patient viewpoints may provide some guidance and make PCC more manageable in practice, PCC still requires the tailoring of care to individual patients' needs and preferences.

Research aim 2: to identify the relationships of PCC and co-creation of care to the well-being of patients with multimorbidity in the primary care setting

The research conducted to fulfil this aim provided insight on cross-sectional and longitudinal associations of PCC and co-creation of care with patients' well-being and satisfaction with care. GP practices participating in the study described in chapter 3 showed good performance on PCC at baseline. The Netherlands has a strong primary care system (Kringos, Boerma, Hutchinson, Saltman, & WHO, 2015), although it has historically focused on acute care. This situation implies that there is room for improvement and that the tailoring of care to the needs of patients with multimorbidity may lead to even better performance in all PCC dimensions. The participating practices' scores for the *emotional support* and *family and friends* dimensions were lower than those for the other PCC dimensions, indicating the need for improvement in these dimensions particularly. Almost two-thirds of all healthcare professionals consider the involvement of family members and friends in patients' care processes to be difficult due to aspects such as privacy concerns, the extra burden of doing so and uncertainty about their skills to do so (Rosland et al., 2011).

Positive cross-sectional relationships of PCC to the physical and social well-being and satisfaction with care of patients with multimorbidity were identified in this research, as in other patient populations and healthcare settings (Rathert, Wyrwich, & Boren, 2013; Van der Meer, Nieboer, Finkenflügel, & Cramm, 2018). The tailoring of care to *patients' preferences* and needs, the offering of *information and education* on the self-management of their conditions and the provision of *physical comfort* may enable the realization of patients' physical well-being goals. The acknowledgement of *patients' preferences* and provision of *emotional support* when needed may enable the realization of their social well-being goals. As having multiple chronic conditions is often related to adverse patient outcomes (Marengoni et al., 2011), these findings suggest that further improvement of these PCC dimensions may contribute to the improvement of patient outcomes.

The research described in chapters 3 and 4 also showed that co-creation of care was related to the satisfaction with care and physical and social well-being of patients with multimorbidity. Co-creation of care is based on patient-centered interaction and communication for the establishment of productive interactions between patients and healthcare professionals (Cramm & Nieboer, 2015a). According to Street (2013), communication can directly and indirectly improve patients' health. Many patients with multimorbidity have expressed frustration with poor patient–provider communication (Gill et al., 2014). In practice, the degree to which GPs value the need for co-creation of care differs; some GPs recognize the importance of shared goals and their assumption of advisor roles in caring for patients with multimorbidity, whereas others remain focused on clinical issues without prioritizing patient preferences (Damarell, Morgan, & Tieman, 2020). In chapter 4, intervention components of the implemented PCC improvement program that likely contributed to the experienced improvement of co-creation of care during the 1-year study period are described. For example, an intervention focused on shared decision making likely contributed to the establishment of shared goals, and training in illiteracy recognition and motivational interviewing likely improved communication between healthcare professionals and their patients.

Cross-sectional and longitudinal relationships were found between co-creation of care and the social well-being of patients with multimorbidity. The relational components of co-creation of care (shared goals, shared knowledge and mutual respect) contribute to the realization of social well-being goals (affection, behavioural confirmation and status), as described by SPF theory. To illustrate, the establishment of mutual respect may be expressed by healthcare professionals' complimenting of patients on their progress in dealing with their multimorbidity, resulting in increased status. Moreover, sharing information about patients' specific care needs and setting treatment goals based on those needs may result in trusting and affectionate patient–provider interactions, and thus in more affection and behavioural confirmation. Hence, co-creation of care may contribute to the realization of social well-being through high-quality patient-centered interaction and communication.

Furthermore, cross-sectional and longitudinal relationships were found between co-creation of care and the physical well-being of patients with multimorbidity. Whereas the significance of the cross-sectional association dissipated in multivariate analyses, the longitudinal association was strong. These findings are in accord with previous research showing that patient–healthcare professional relationships and communication do not directly affect patients' physical well-being (i.e. mutual respect will not change patients' pain or shortness of breath), but that improved understanding of patients' care needs and better alignment of treatments to their individual situations and preferences are expected to have long-term effects (Street, Makoul, Arora & Epstein, 2009; Street, 2013).

The research described in chapters 3 and 4 indicates that PCC and co-creation of care are associated positively with the satisfaction with care and physical and social well-being of patients with multimorbidity in the primary care setting. Making care more tailored to the needs of these patients by paying attention to PCC and co-creation of care may contribute to better patient outcomes.

Research aim 3: to describe the organization of primary PCC for patients with multimorbidity

The PCC improvement program and healthcare professionals' and patients' experiences with it are described in detail in chapter 5. The findings of the study described in that chapter emphasize the importance of investing in a variety of PCC interventions, given the heterogeneity of care needs among patients with multimorbidity. Furthermore, the organization of PCC entails improvements in all eight PCC dimensions, including healthcare professionals' assumption of a coaching role instead of a paternalistic role, the alignment of information with patients' needs and backgrounds, the adequate transfer of information across healthcare settings, the provision of emotional support and the creation of understanding among the family members and friends of patients with multimorbidity. These findings are in accord with those of previous descriptions and evaluations of PCC and related interventions, which identify similar aspects of PCC organization: patient empowerment, physical support and information provision for interventions targeting patients, and education, training and improvement of the continuity and coordination of care for those targeting healthcare professionals (Damarell et al., 2020; Park, Lee, Jeong, Jeong, & Go, 2018). The improvements made during the PCC improvement program examined in this research contributed to the improved experiences of patients with multimorbidity with PCC delivery, demonstrating the value of such an approach for further improvement of primary PCC delivery to these patients.

Whether PCC and evidence-based healthcare are similar or mutually exclusive approaches has been debated (Bensing, 2000; Lacy & Backer, 2008). The findings described in chapter 5 demonstrate that these two approaches can be united, for example by creating individualised treatment plans with patients while discussing disease guidelines providing strong evidence for specific treatment options. This finding is in line with the previous determination that PCC and evidence-based care can be integrated (Engle et al., 2021).

In practice, PCC organization can be difficult. Several factors can impede innovation in healthcare. Insight on perceived barriers to PCC is needed to realize its sustainable implementation; the research described in chapter 6 revealed barriers to the provision of PCC to patients with multimorbidity on patient, organization and national levels, according to healthcare professionals. Similar barriers on three levels (micro, meso and macro) were identified previously (Vennedey, Hower, Hillen, Ansmann, Kuntz, & Stock, 2020).

At the patient level, most barriers identified in the thesis research were related to the characteristics of patients with multimorbidity, such as their care needs and health literacy. A previous study showed that GPs perceive complexity most when patients' multimorbidity interacts with their frailty or personal resources (e.g. social, economic and cultural factors) (Damarell et al., 2020). This complexity demands the flexibility and adaptability of healthcare professionals seeking to align care delivery to patients' preferences. It also emphasizes the importance of eliciting patients' goals and preferences, which is often thought to be an intuitive process based on healthcare professional–patient relationships (Kristensen, Due, Hølge-Hazelton, Guassora, & Waldorff, 2018).

Two main barriers at the organizational level were identified. According to the healthcare professionals participating in the research, optimal PCC delivery requires that all healthcare professionals in an organization be motivated to achieve change and improvement. The lack of motivation is a frequently mentioned barrier to PCC implementation (Luxford, Safran, & Delbanco, 2011). Second, not all healthcare professionals were aware of and/or trained in all elements of PCC delivery. This finding is in line with previous research showing that additional training and education to improve healthcare professionals' communication skills are needed to achieve care provision aligned with patients' preferences and values (Back, Fromme, & Meier, 2019), and that many GPs do not feel sufficiently qualified to ask about the emotional and social needs of patients and their family members (Stumm et al., 2019).

At the national level, two main barriers to effective PCC implementation were identified. The first barrier is the inadequate *continuity and transition* of information among healthcare professionals from multiple disciplines involved in individual patients' care; data protection laws restrict information sharing among healthcare settings, and data information systems within organizations and for entire care chains are not optimally designed for concurrent functioning. Previous studies have revealed similar barriers to the continuity of care (Berwick & Gaines, 2018; Kruse, Stein, Thomas & Kaur, 2018). This problem is especially relevant for patients with multimorbidity, whose care delivery often involves multidisciplinary teams potentially using suboptimal information and communications technology systems. The second barrier identified was that current national financial incentives for primary care are insufficiently supportive of prevention across the lifespan. Healthcare professionals reported that the lack of reimbursement for care provided impaired effective PCC implementation. PCC often requires that healthcare professionals spend more time and exert more effort during consultations and in additional training and workshops, and that they collaborate with professionals in other healthcare disciplines. The lack of supportive financial structures to do so may hamper the sustainability and widespread embedding of PCC into care systems in the long term. The overcoming of such national-level challenges has been described as prerequisite for effective and sustainable healthcare delivery (Fleuren, Paulussen, Van Dommelen, & Van Buuren, 2014; Grol, Wnesing, Eccles, & Davis, 2013).

Theoretical reflections

The Picker Institute's PCC framework (Gerteis et al., 1993; Picker Institute, n.d.) aids the identification of aspects associated with PCC, but does not enable investigation of the theoretical mechanisms of PCC or the interaction among its dimensions. However, interaction between dimensions may be arguable, as accessible and affordable care can be considered to be a prerequisite to referral to other healthcare professionals, and the examination of patients' needs and desire to take on a proactive role might be needed to determine which information and education should be provided. Solid information about interactions among PCC dimensions could facilitate effective PCC implementation in practice. Such interactions were not examined in this thesis, which should be taken into account when interpreting the results. However, the research described in chapter 2 revealed differences in the relative importance of PCC dimensions among patients with multimorbidity. The thesis research also revealed independent associations of all PCC dimensions with patient outcomes, indicating that measures taken in all dimensions would contribute separately to the improvement of care delivery to patients with multimorbidity, regardless of the potential existence of interaction among dimensions.

SPF theory underlay the assessment of patients' well-being in the research conducted for this thesis. This theory provides insight into the theoretical mechanisms driving contributors to well-being. It can be used, for example, to show how resources (in this context, PCC and the co-creation of care) can contribute to the fulfilment of patients' social and physical well-being needs (Ormel, Lindenberg, Steverink, & Vonkorff, 1997; Ormel, Lindenberg, Steverink, & Verbrugge, 1999; Nieboer, Lindenberg, Boomsma, & Bruggen, 2005; Nieboer & Cramm, 2018). To illustrate, PCC can be supportive when patients' chronic illness–related functional limitations hamper the fulfilment of their need for stimulation or engagement in social activities, and the co-creation of care enables the realization of social well-being goals through patient-centered interaction and communication. In addition, SPF theory enables the separate assessment of social and physical well-being needs (Nieboer et al., 2005; Nieboer & Cramm, 2018). These concepts have been combined into single overall well-being or quality of life scores in many studies, but the research conducted for this thesis demonstrates the importance of their separate assessment in the context of care delivery to patients with multimorbidity.

Methodological considerations

Study design

The thesis research had a mixed-methods design, with the combined analysis of quantitative and qualitative data. Multiple research methods were used to investigate the importance of PCC for patients with multimorbidity in a primary care setting. The use of Q methodology allowed us to explore patients' experiences, values and beliefs with regard to the relative importance of the PCC dimensions. The survey provided insight to (improvements in) PCC and the co-creation of care, and their relationships to patients' well-being and satisfaction with care. The interviews with healthcare professionals enabled us to gain a deeper understanding of what PCC in practice entails, and which further improvements are needed. This combined use of multiple research methods is a considerable strength of this thesis research, as it enabled the development of a more thorough understanding of primary PCC for patients with multimorbidity.

Setting and participants

This research was conducted with healthcare professionals and patients with multimorbidity from seven GP practices in Noord-Brabant, the Netherlands. Zorggroep RCH Midden Brabant BV, a cooperative of 160 primary care practices, initiated the PCC improvement programme and selected GP practices for participation in this research. These practices were among the best-performing practices in the region, and were considered to be the most motivated to improve.

The GPs selected patients with multimorbidity for participation in the research; all patients registered with two or more chronic conditions were included (n = 416). Asthma, COPD, diabetes, and coronary and vascular diseases, used for patient selection in this research, are among the conditions encountered most frequently in patients with multimorbidity in the Dutch primary care system (Van Oostrom et al., 2012), although multimorbidity often involves other conditions as well. This factor must be taken into account when interpreting the results of the thesis research.

Methodological limitations

A limitation to the overall design of this research is the lack of inclusion of control GP practices, which made it difficult to examine whether the PCC improvement program itself led to improvements in PCC, or whether regular improvements in primary care and increased attention to PCC and the overall improvement of care delivery to patients with multimorbidity contributed to improvement over time (also for patients not enrolled in the program). However, previous research on disease management programs for patients with (multiple) chronic conditions showed that improvements in the quality of care and the interventions implemented did not prevent structural declines in these patients' social well-being (Cramm & Nieboer, 2015b; Cramm & Nieboer, 2016). Whereas disease management programs focus mainly on the quality of care and patients' physical quality of life (Cramm & Nieboer, 2015b), PCC programs tend to focus on overall quality of life. The improvements in the physical and social well-being of patients with multimorbidity observed in the thesis research suggest that the interventions implemented are valuable for the further improvement of care delivery to this patient population.

Another limitation of this research is that patients with cognitive decline, institutionalized patients and those who did not speak Dutch were not included. In addition, participants' health literacy was not examined; those with low health literacy may not have participated in the research, as they may have had difficulty filling out the survey. In the Q-methodological study, however, some patients had difficulty elaborating on their choices and provided less-rich qualitative descriptions of their views than did other patients. This observation suggests that patients with lesser health literacy were included. However, the opportunity to assess specific PCC measures and well-being in relation to health literacy was missed in this research. PCC is often considered to be more important for patients with lesser health literacy skills, and would be expected to be associated even more strongly with these patients' well-being (Murugesu, Heijmans, Fransen, & Rademakers, 2018). Thus, if the patient samples for the thesis research had greater health literacy than did patients who dropped out, the importance of PCC may have been underestimated.

As expected, survey attrition rates were high (45% in the cross-sectional study and 36% in the longitudinal study). Attrition rates are associated with increasing age, poor functioning, cognitive impairment and living without a partner (Chatfield, Brayne, & Matthews, 2005). Indeed, in the study described in chapter 4, patients who dropped out were significantly older and less educated, more were unmarried, and they had lower well-being scores than did patients who filled out the survey. The attrition rates in these studies are comparable to those in other studies including patients with multimorbidity (Mujica-Mota et al., 2015; Peters et al., 2018).

Furthermore, the samples in the studies based on interviews with healthcare professionals were small (*n* = 9). However, they comprised almost 50% of all healthcare professionals from the GP practices participating in the PCC improvement program, and thus can be considered to be reliable. Moreover, the data are rich, data saturation was reached and all findings were validated by presenting the results to a larger group of healthcare professionals. Furthermore, the sample size is comparable to those in other qualitative studies conducted with healthcare professionals in GP practices in the Netherlands (Bertels et al., 2019; Eilers, Krabbe, & de Melker, 2015).

Finally, the PCC improvement program was initiated with some of the best-performing GP practices in Noord-Brabant, the Netherlands. To facilitate the national implementation of PCC, average-/low-scoring GP practices should also be included in such programs. The PCC improvement program is expected to yield even better results in these practices, as lower baseline PCC scores provide more room for improvement. However, motivating these GP practices to participate in such initiatives may be more difficult, especially as most motivational resources are financial incentives, and the lack of financial resources is a barrier to PCC.

Implications for practice

The findings presented in this thesis show that investment in the eight dimensions of PCC is valuable for the improvement of primary care delivery to patients with multimorbidity. These patients are vulnerable, and their needs are currently not adequately managed within primary care (Damarell et al., 2020). The thesis research demonstrated the importance of primary PCC for the maintenance of the well-being of patients with multimorbidity. Investment in PCC enables the tailoring of care delivery to these patients' individual needs. The thesis research provides insight into intervention components and the experiences of healthcare professionals participating in a PCC improvement program that can support GP practices' efforts to make their care more patient-centered. Furthermore, it provides insight into barriers impeding PCC implementation in practice, providing guidance for policymakers regarding the steps that need to be taken to encourage the provision of preventive care across the lifespan and to implement PCC in practice. To stimulate the effective and sustainable implementation of PCC, national conditions (i.e. financial incentives and digitalization) should be supportive. A related question is whether investment in PCC in countries without solid primary care systems is desirable. The existence of a strong primary care system is considered to be prerequisite for PCC development (WHO, 2008).

Recommendations for future research

Future research in this area should explore how interventions that contribute to PCC improvement can best be implemented in practice. The thesis research reveals the importance of investing in multiple interventions, as intervention impacts may differ among patients, but this factor may make it more difficult to envision what PCC might look like in practice. Information about the effectiveness of individual interventions could better guide PCC implementation. For example, if a specific intervention is known to contribute to the improvement of *information and education* scores and outcomes (e.g. understanding of information, goalsetting) among patients with low health literacy, GP practices with large populations of such patients might be interested in investing in it.

The PCC improvement program was initiated with some of the best-performing GP practices in the study region; to investigate how PCC can best be implemented nationally, low-/average-scoring GP practices should also be included in research. The PCC improvement program may lead to larger improvements in GP practices with lower PCC scores at baseline. Thus, future research should explore GP practices' performance in the eight PCC dimensions, and how GP practices across the performance spectrum could be motivated to implement PCC for patients with multimorbidity and be supported in this effort.

This thesis research was conducted in a specific region, with a selected sample of GP practices. Future research should focus on how the further deployment of primary PCC should be initiated. Furthermore, the investigation of whether PCC contributes to outcome improvement for other patient populations in GP practices would be of interest. Such a contribution would further support the investment in PCC.

Conclusions

Investment in the eight dimensions of PCC is valuable for the improvement of primary care delivery to patients with multimorbidity, who constitute a vulnerable population with complex care needs. Primary PCC enables the maintenance of these patients' well-being and satisfaction with care. Although not all patients with multimorbidity require the same type of care delivery, PCC enables the tailoring of care delivery to individual patients' needs. The research conducted for this thesis provides new perspectives on care delivery to patients with multimorbidity, and describes possible approaches and interventions that facilitate such care delivery. Barriers at the patient, organisational and national levels may impede effective implementation of PCC, which should be overcome to stimulate the tailoring of care to the needs of patients with multimorbidity and make PCC the best way forward.

REFERENCES

Back, A. L., Fromme, E. K., & Meier, D. E. (2019). Training clinicians with communication skills needed to match medical treatments to patient values. *Journal of the American Geriatrics Society*, *67*(S2), S435-S441.

Bensing, J. (2000). Bridging the gap.: The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counseling*, *39*(1), 17-25.

Bertels, L., van der Heijden, S., Hoogsteyns, M., Dekker, E., van Asselt, K., van Weert, H., & Knottnerus, B. (2019). GPs' perspectives on colorectal cancer screening and their potential influence on FIT-positive patients: an exploratory qualitative study from a Dutch context. *BJGP Open*, *3*(1), 18X101631.

Berwick, D. M., & Gaines, M. E. (2018). How HIPAA harms care, and how to stop it. *Jama*, *320*(3), 229-230.

Chandra, S., Mohammadnezhad, M., Ward, P. (2018). Trust and communication in a doctor-patient relationship: a literature review. *Journal of Healthcare Communications*, *3*(3), 36.

Chatfield, M. D., Brayne, C. E., & Matthews, F. E. (2005). A systematic literature review of attrition between waves in longitudinal studies in the elderly shows a consistent pattern of dropout between differing studies. *Journal of Clinical Epidemiology, 58*(1), 13-19.

Cramm, J. M., & Nieboer, A. P. (2015a). The importance of productive patient–professional interaction for the well-being of chronically ill patients. *Quality of Life Research*, *24*(4), 897-903.

Cramm, J. M., & Nieboer, A. P. (2015b). Disease management: The need for a focus on broader self-management abilities and quality of life. *Population Health Management, 18*(4), 246-255.

Cramm, J. M., & Nieboer, A. P. (2016). Is "disease management" the answer to our problems? no! population health management and (disease) prevention require "management of overall well-being". *BMC Health Services Research, 16*(1), 1-6.

Damarell, R. A., Morgan, D. D., & Tieman, J. J. (2020). General practitioner strategies for managing patients with multimorbidity: A systematic review and thematic synthesis of qualitative research. *BMC Family Practice, 21*(1), 1-23.

Eilers, R., Krabbe, P. F., & de Melker, H. E. (2015). Attitudes of Dutch general practitioners towards vaccinating the elderly: less is more?. *BMC Family Practice*, *16*(1), 1-7.

Engle, R. L., Mohr, D. C., Holmes, S. K., Seibert, M. N., Afable, M., Leyson, J., & Meterko, M. (2021). Evidence-based practice and patient-centered care: Doing both well. *Health Care Management Review*, *46*(3), 174.

Fleuren, M. A., Paulussen, T. G., Van Dommelen, P., & Van Buuren, S. (2014). Towards a measurement instrument for determinants of innovations. *International Journal for Quality in Health Care*, *26*(5), 501-510.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T.L. (1993). *Through the patient's eyes: understanding and promoting patient-centered care.* Jossey-Bass Publishers.

Gill, A., Kuluski, K., Jaakkimainen, L., Naganathan, G., Upshur, R., Wodchis, W.P. (2014) "Where Do We Go From Here?" Health system frustrations expressed by patients with multimorbidity, their caregivers and family physicians. *Healthcare Policy/Politiques de Sante*, *9*(4), 73-89.

Grol, R., Wensing, M., Eccles, M., & Davis, D. (2013). *Improving patient care: the implementation of change in health care*. John Wiley & Sons.

Heijmans, M., Brabers, A., & Rademakers, J. (2018). *Health literacy in Nederland*. Utrecht: NIVEL.

Hibbard, J. H., Mahoney, E. R., Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the patient activation measure. *Health Services Research, 40*(6), 1918-1930.

Kringos, D. S., Boerma, W. G., Hutchinson, A., Saltman, R. B., & World Health Organization. (2015). *Building primary care in a changing Europe*. World Health Organization. Regional Office for Europe.

Kristensen, M. A. T., Due, T. D., Hølge-Hazelton, B., Guassora, A. D., & Waldorff, F. B. (2018). 'More constricting than inspiring'—GPs find chronic care programmes of limited clinical utility. A qualitative study. *BJGP Open*, *2*(2), 18X101591.

Kruse, C. S., Stein, A., Thomas, H., & Kaur, H. (2018). The use of electronic health records to support population health: a systematic review of the literature. *Journal of Medical Systems*, *42*(11), 1-16.

Lacy, N. L., & Backer, E. L. (2008). Evidence-based and patient-centered care: results from an STFM group project. *Family Medicine*, *40*(6), 417.

Luxford, K., Safran, D. G., & Delbanco, T. (2011). Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *International Journal for Quality in Health Care*, *23*(5), 510-515.

Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., ... & Fratiglioni, L. (2011). Aging with multimorbidity: a systematic review of the literature. *Ageing Research Reviews*, *10*(4), 430-439.

Mason, B., Nanton, V., Epiphaniou, E., Murray, S. A., Donaldson, A., Shipman, C., ... & Boyd, K. (2016). 'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers. *BMJ Supportive & Palliative care*, *6*(1), 60-65.

Mujica-Mota, R. E., Roberts, M., Abel, G., Elliott, M., Lyratzopoulos, G., Roland, M., & Campbell, J. (2015). Common patterns of morbidity and multimorbidity and their impact on health-related quality of life: Evidence from a national survey. *Quality of Life Research, 24*(4), 909-918.

Murugesu, L., Heijmans, M., Fransen, M., & Rademakers, J. (2018). *Beter omgaan met beperkte gezondheidsvaardigheden in de curatieve zorg: Kennis, methoden en tools.* Utrecht: NIVEL.

Nieboer, A., Lindenberg, S., Boomsma, A., & Bruggen, A. C. V. (2005). Dimensions of well-being and their measurement: the SPF-IL scale. *Social Indicators Research*, *73*(3), 313-353.

Nieboer, A. P., & Cramm, J. M. (2018). How do older people achieve well-being? Validation of the Social Production Function Instrument for the level of well-being–short (SPF-ILs). *Social Science & Medicine*, *211*, 304-313.

Ormel, J., Lindenberg, S., Steverink, N., & Vonkorff, M. (1997). Quality of life and social production functions: A framework for understanding health effects. *Social Science & Medicine*, *45*(7), 1051-1063.

Ormel, J., Lindenberg, S., Steverink, N., & Verbrugge, L. M. (1999). Subjective well-being and social production functions. *Social Indicators Research, 46*(1), 61-90.

Park, M., Lee, M., Jeong, H., Jeong, M., & Go, Y. (2018). Patient-and family-centered care interventions for improving the quality of health care: a review of systematic reviews. *International Journal of Nursing Studies*, *87*, 69-83.

Parker, D., Byng, R., Dickens, C., Kinsey, D., & McCabe, R. (2020). Barriers and facilitators to GP–patient communication about emotional concerns in UK primary care: a systematic review. *Family Practice*, *37*(4), 434-444.

Peters, M., Kelly, L., Potter, C. M., Jenkinson, C., Gibbons, E., Forder, J., & Fitzpatrick, R. (2018). Quality of life and burden of morbidity in primary care users with multimorbidity. *Patient Related Outcome Measures, 9*, 103-113.

Picker Institute. (n.d.). *Principles of person centred care.* https://www.picker.org/about-us/picker-principles-of-person-centred-care.

Rademakers, J. (2013). *De Nederlandse patiënt en zorggebruiker in beeld*. Utrecht: Nivel.

Rademakers, J. (2016*). De actieve patiënt als utopie*. Maastricht University.

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: a systematic review of the literature. *Medical Care Research and Review*, *70*(4), 351-379.

Rijken, M., & van der Heide, I. (2019). Identifying subgroups of persons with multimorbidity based on their needs for care and support. *BMC Family Practice*, *20*(1), 1-10.

Rosland, A. M., Piette, J. D., Choi, H., & Heisler, M. (2011). Family and friend participation in primary care visits of patients with diabetes or heart failure: Patient and physician determinants and experiences. *Medical Care, 49*(1), 37-45.

Street Jr, R. L. (2013). How clinician–patient communication contributes to health improvement: modeling pathways from talk to outcome. *Patient Education and Counseling*, *92*(3), 286-291.

Street Jr, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? pathways linking clinician–patient communication to health outcomes. *Patient Education and Counseling, 74*(3), 295-301.

Stumm, J., Thierbach, C., Peter, L., Schnitzer, S., Dini, L., Heintze, C., & Döpfmer, S. (2019). Coordination of care for multimorbid patients from the perspective of general practitioners–a qualitative study. *BMC Family Practice*, *20*(1), 1-11.

Van Agt, H.M., Stronks, K., & Mackenbach, (2000). Chronic illness and poverty in the Netherlands. *The European Journal of Public Health*, *10*(3), 197-200.

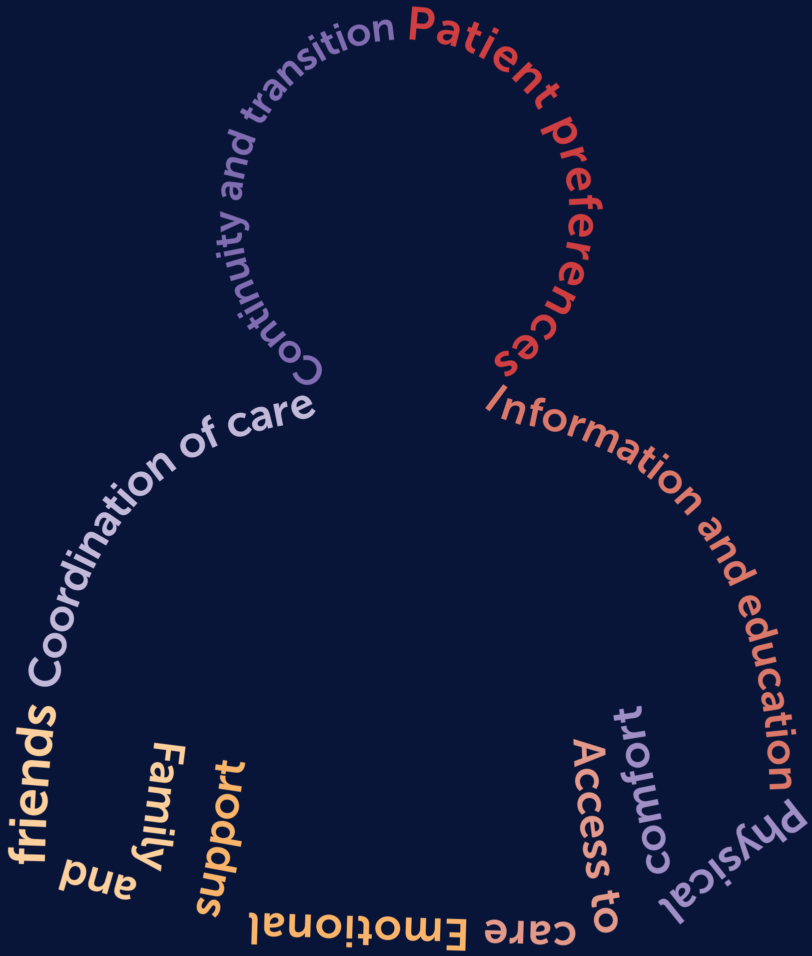
Van der Meer, L., Nieboer, A. P., Finkenflügel, H., & Cramm, J. M. (2018). The importance of person-centred care and co-creation of care for the well-being and job satisfaction of professionals working with people with intellectual disabilities. *Scandinavian Journal of Caring Sciences, 32*(1), 76-81.

Van Oostrom, S. H., Picavet, H. S. J., Van Gelder, B. M., Lemmens, L. C., Hoeymans, N., Van Dijk, C. E., ... & Baan, C. A. (2012). Multimorbidity and comorbidity in the Dutch population–data from general practices. *BMC Public Health*, *12*(1), 1-9.

Vennedey, V., Hower, K. I., Hillen, H., Ansmann, L., Kuntz, L., & Stock, S. (2020). Patients' perspectives of facilitators and barriers to patient-centred care: insights from qualitative patient interviews. *BMJ Open*, *10*(5), e033449.

Wolff, J. L., & Boyd, C. M. (2015). A look at person-centered and family-centered care among older adults: Results from a national survey. *Journal of General Internal Medicine, 30*(10), 1497-1504.

World Health Organization. (2008) *People-centred health care: technical papers: International symposium on people-centred health care: Reorienting Health Systems in the 21st Century*, The Tokyo International Forum.


Patient preferences
Information and education
Physical comfort
Access to care
Emotional support
Family and friends
Coordination of care
Continuity and transition

Summary
Samenvatting
Dankwoord
Curriculum Vitae
About the author

SUMMARY

Current primary care is not tailored to the needs of patients with multimorbidity; patient-centered care (PCC) could potentially be beneficial for improving primary care for this patient population However, there is no clear understanding of what patient-centered primary care for patients with multimorbidity looks like in practice, and we lack evidence about the added value of such an approach for this specific patient population and setting. The main objective of this thesis was to investigate the importance of PCC for patients with multimorbidity in a primary care setting.

In order to tailor care delivery to the preferences of patients with multimorbidity, it is necessary to explore their views on PCC and the relative importance of the eight PCC dimensions. The research presented in chapter 2 used a Q-methodological design, which combines quantitative and qualitative analyses, to explore perspectives of patients with multimorbidity regarding the relative importance of the PCC dimensions. The analyses revealed three factors representing three distinct viewpoints of patients with multimorbidity on what is important for patient-centered care in the primary care setting. Patients with viewpoint 1 are prepared proactive patients who seem to be well-off and want to be in charge of their own care. To do so, they seek medical information and prefer to be supported by a strongly coordinated multidisciplinary team of healthcare professionals. Patients with viewpoint 2 are everyday patients who visit GPs and require well-coordinated, respectful, and supportive care. Patients with viewpoint 3 are vulnerable patients who are less resourceful in terms of communication skills and finances, and thus require accessible care and professionals taking the lead while treating them with dignity and respect. The findings of this chapter suggest that not all patients with multimorbidity require the same type of care delivery, and that not all aspects of PCC delivery are equally important to all patients.

Patient-centered care and co-creation of care are expected to improve patient outcomes, but the relationships among patient-centered care, co-creation of care, physical well-being, social well-being, and satisfaction with care among patients with multimorbidity are not known. The research presented in chapter 3 described the results of a cross-sectional survey among 216 patients with multimorbidity. Correlation and regression analyses were performed to identify relationships among patient-centered care, co-creation of care, physical well-being, social well-being, and satisfaction with care. The results showed that patient-centered care and co-creation of care were associated positively with satisfaction with care and the physical and social well-being of patients with multimorbidity in the primary care setting. Making care more tailored to the needs

of patients with multimorbidity by paying attention to patient-centered care and co-creation of care may thus contribute to better outcomes.

Chapter 4 presented research further assessing these relationships by investigating longitudinal relationships between co-creation of care and well-being and satisfaction with care among 138 patients with multimorbidity in a primary care setting. Primary care delivery for multimorbid patients is complex, due to single disease–oriented guidelines, complex care needs, time constraints and the involvement of multiple healthcare professionals. Co-creation of care, based on the quality of communication and relationships between healthcare professionals and patients, may therefore be valuable. The findings of this study indicated that improvements in co-creation of care were associated with patients' social and physical well-being, and satisfaction with care. Thus, investment in co-creation of care by primary care practices may lead to better outcomes for multimorbid patients.

Although evidence of the effects of PCC provision is rich, a clear understanding of what it looks like in practice is lacking. The research presented in chapter 5 described a PCC improvement program and its intervention components, and provided qualitative insights in the experiences of healthcare professionals with the resulting PCC delivery. The research presented in chapter 5 employed a mixed-methods design. Semi-structured interviews with healthcare professionals were conducted to assess their experiences with PCC (n=9) and a longitudinal survey was conducted among patients with multimorbidity (n=138) to assess improvements in PCC during the implementation of the PCC improvement program. This chapter revealed how primary PCC can be improved for patients with multimorbidity, and showed that PCC, as perceived by patients, improved significantly during the year in which the PCC interventions were implemented. Themes associated with PCC delivery include shifting from a paternalistic to a coaching role, aligning information to patients' needs and backgrounds, adequate information transfer within a team and across healthcare settings, and creating understanding among patients' family members and friends. This study generated new perspectives on care delivery and highlighted opportunities for its improvement according to the eight dimensions of PCC for patients with multimorbidity in a primary care setting.

Unfortunately, organizing PCC in practice is easier said than done. Chapter 6 investigated healthcare professionals' perceived barriers to primary PCC delivery to patients with multimorbidity using a constructivist qualitative design based on semi-structured interviews with nine general and nurse practitioners from seven general practices in the Netherlands. Barriers were identified in all eight PCC dimensions. They include difficulties achieving mutual understanding between patients and healthcare professionals,

professionals' lack of training and education in new skills, data protection laws that impede adequate documentation and information sharing, time pressure, and conflicting financial incentives. These barriers pose true challenges to effective, sustainable PCC implementation at the patient, organizational, and national levels. Further improvement of primary care delivery to patients with multimorbidity is needed to overcome these barriers.

Chapter 7 provides a description and discussion on the main findings of this thesis. Furthermore, the theoretical considerations are reflected upon. Among others, it reflects upon how the PCC framework does not allow for understanding the theoretical mechanisms of PCC, nor for investigating interaction or potential order of importance between dimensions. The methodological considerations, including limitations such as the absence of control practices, are also presented. Recommendations for future research are described, such as identifying how a further deployment of PCC in practice should be initiated. Finally, practical implications of this thesis are described that substantiate the value of investing in the eight dimensions of PCC for further improvement of primary care delivery for patients with multimorbidity.

This thesis demonstrated that investing in the eight dimensions of PCC is valuable in improving primary care delivery for patients with multimorbidity. Patients with multimorbidity are a vulnerable patient population with complex care needs. Primary PCC enables maintaining their well-being and satisfaction with care. Although not all patients with multimorbidity are in need of the same type of care delivery, PCC enables tailoring care delivery to these patients' individual care needs. This thesis provided new perspectives on care delivery for patients with multimorbidity, and described possibilities and interventions to do so. Unfortunately, barriers at patient, organizational and national level may impede effective implementation of PCC, which should be overcome in order to stimulate tailoring care to the needs of patients with multimorbidity and make PCC the best way forward.

SAMENVATTING

De huidige eerstelijnszorg is niet afgestemd op de behoeften van patiënten met multimorbiditeit. Het leveren van persoonsgerichte zorg zou bij kunnen dragen aan het verbeteren van de eerstelijnszorg voor deze patiëntenpopulatie. Er is echter geen duidelijke visie op hoe persoonsgerichte eerstelijnszorg voor patiënten met multimorbiditeit er in de praktijk uitziet, en er ontbreekt sluitend bewijs over de toegevoegde waarde van een dergelijke benadering voor deze specifieke patiëntenpopulatie en setting. De belangrijkste doelstelling van dit proefschrift was om het belang van persoonsgerichte zorg voor patiënten met multimorbiditeit in de huisartsenpraktijk te onderzoeken.

Alvorens de zorgverlening te kunnen afstemmen op de voorkeuren van patiënten met multimorbiditeit, is het nodig om hun perspectieven omtrent persoonsgerichte zorg en het relatieve belang van de acht dimensies van persoonsgerichte zorg te identificeren. Het onderzoek in hoofdstuk 2 heeft door middel van een Q-methodologisch design (een combinatie van kwantitatieve en kwalitatieve analyses) perspectieven van patiënten met multimorbiditeit ten aanzien van het relatieve belang van de dimensies van persoonsgerichte zorg onderzocht. Uit de analyses kwamen drie factoren naar voren die drie verschillende visies van patiënten met multimorbiditeit representeren over wat zij belangrijk vinden met betrekking tot persoonsgerichte zorg in de huisartsenpraktijk. Patiënten met visie 1 zijn goed voorbereide en proactieve patiënten die zelf verantwoordelijkheid willen dragen over hun zorg. Daartoe zoeken zij medische informatie en worden bij voorkeur ondersteund door een sterk gecoördineerd multidisciplinair team van zorgverleners. Patiënten met visie 2 zijn alledaagse patiënten die de huisarts bezoeken en behoefte hebben aan goed gecoördineerde, respectvolle en ondersteunende zorg. Patiënten met visie 3 zijn kwetsbare patiënten die minder vaardig zijn op het gebied van communicatie en informatieverwerking, en het financieel minder breed lijken te hebben. Zij hebben zodoende behoefte hebben aan toegankelijke zorg en professionals die de leiding nemen en hen met waardigheid en respect behandelen. De bevindingen van dit hoofdstuk suggereren dat niet alle patiënten met multimorbiditeit dezelfde vorm van zorgverlening behoeven, en dat niet alle aspecten van persoonsgerichte zorg voor alle patiënten even belangrijk zijn.

Ondanks dat er wordt verwacht dat persoonsgerichte zorg en co-creatie van zorg bij zullen dragen aan patiëntuitkomsten, zijn de relaties tussen persoonsgerichte zorg, co-creatie van zorg, lichamelijk- en sociaal welbevinden, en tevredenheid met zorg onder patiënten met multimorbiditeit tot op heden niet bekend. Het onderzoek in hoofdstuk 3 presenteert de resultaten van een cross-sectioneel onderzoek onder 216 patiënten met multimorbiditeit. Correlatie- en regressieanalyses werden uitgevoerd om relaties tussen persoonsgerichte zorg, co-creatie van zorg, lichamelijk- en sociaal welbevinden, en tevredenheid met zorg te achterhalen. De resultaten tonen aan dat patiëntgerichte zorg en co-creatie van zorg positief geassocieerd zijn met tevredenheid over de zorg en het lichamelijk- en sociaal welbevinden van patiënten met multimorbiditeit in de huisartsenpraktijk. Persoonsgerichte zorg voor en co-creatie van zorg met patiënten met multimorbiditeit kan dus bijdragen aan betere uitkomsten voor de patiënt.

Hoofdstuk 4 beschrijft een studie waarbij longitudinale relaties werden onderzocht tussen co-creatie van zorg en welbevinden en tevredenheid met zorg bij 138 patiënten met multimorbiditeit in de huisartsenpraktijk. Eerstelijnszorg voor multimorbide patiënten is complex, vanwege ziekte specifieke richtlijnen, complexe zorgbehoeften, tijdsbeperkingen en de betrokkenheid van meerdere zorgverleners. Co-creatie van zorg, gebaseerd op de kwaliteit van communicatie en relaties tussen zorgverleners en patiënten, kan daarom waardevol zijn. De bevindingen van deze studie tonen aan dat verbeteringen in co-creatie van zorg geassocieerd zijn met het lichamelijke- en sociale welbevinden van patiënten, en met de tevredenheid met de zorg. Investeren in co-creatie van zorg door huisartsenpraktijken kan dus leiden tot betere uitkomsten voor multimorbide patiënten.

Hoewel er veel bewijs is voor de effecten van persoonsgerichte zorg, ontbreekt het aan een duidelijk begrip van hoe het in de praktijk moet worden vormgegeven. Het onderzoek in hoofdstuk 5 beschrijft een verbeterprogramma voor persoonsgerichte zorg, waarbij de nadruk werd gelegd op het beschrijven van de interventiecomponenten van het programma. Daarnaast geeft het onderzoek kwalitatieve inzichten in de ervaringen van zorgverleners met persoonsgerichte zorg. Bij dit onderzoek is een mixed-methods design toegepast. Semigestructureerde interviews met negen zorgverleners werden uitgevoerd om hun ervaringen met persoonsgerichte zorg te inventariseren, en een longitudinaal onderzoek werd uitgevoerd onder 138 patiënten met multimorbiditeit om verbeteringen in PCC gedurende de implementatie van het verbeterprogramma vast te stellen. Dit onderzoek laat zien hoe persoonsgerichte zorg voor patiënten met multimorbiditeit kan worden georganiseerd, en heeft aangetoond dat patiëntervaringen met persoonsgerichte zorg significant zijn verbeterd gedurende het jaar waarin de interventies werden geïmplementeerd. Volgens de zorgverleners betreft het organiseren van persoonsgerichte zorg onder andere een verschuiving van een paternalistische naar een coachende rol, afstemming van informatie op de behoeften en achtergronden van patiënten, een adequate informatieoverdracht binnen een team en over zorgdisciplines heen, en het creëren van begrip onder familieleden en vrienden van patiënten. Deze studie biedt nieuwe perspectieven op de zorgverlening voor patiënten met multimorbiditeit in de huisartsenpraktijk en mogelijkheden voor verbetering volgens de acht dimensies van persoonsgerichte zorg.

Helaas is het organiseren van persoonsgerichte zorg in de praktijk gemakkelijker gezegd dan gedaan. Hoofdstuk 6 onderzoekt de barrières die zorgverleners ervaren bij het leveren van persoonsgerichte zorg aan patiënten met multimorbiditeit. Hierbij werd gebruik gemaakt van een kwalitatief design gebaseerd op semigestructureerd interviews met negen huisartsen en praktijkondersteuners. Er worden barrières beschreven binnen alle acht dimensies van persoonsgerichte zorg. Het gaat onder meer om de moeite om wederzijds begrip te bereiken tussen patiënten en zorgverleners, een gebrek aan training en opleiding van de zorgverleners in nieuwe vaardigheden, gegevensbeschermingswetten die adequate documentatie en informatie-uitwisseling belemmeren, tijdsdruk, en conflicterende financiële prikkels. Deze barrières vormen uitdagingen voor een doeltreffende en duurzame implementatie van persoonsgerichte zorg op patiënten-, organisatie- en nationaal niveau. Verdere verbetering van de eerstelijnszorgverlening aan patiënten met multimorbiditeit is nodig om deze barrières te overwinnen.

Hoofdstuk 7 geeft een beschrijving van en een beschouwing over de belangrijkste bevindingen van dit proefschrift. Verder wordt er gereflecteerd op de theoretische overwegingen. Er wordt onder andere gereflecteerd op hoe het raamwerk van PCC het noch mogelijk maakt om de theoretische mechanismen van PCC te begrijpen, noch om de interactie tussen of de prioritering van de dimensies te onderzoeken. De methodologische overwegingen, met inbegrip van beperkingen zoals de afwezigheid van controlepraktijken, worden eveneens gepresenteerd. Aanbevelingen voor toekomstig onderzoek worden beschreven, zoals de vraag hoe een verdere uitrol van persoonsgerichte zorg in de praktijk zou moeten worden geïnitieerd. Tenslotte worden praktische implicaties van dit proefschrift beschreven die het belang onderbouwen van investeren in de acht dimensies van persoonsgerichte zorg voor verdere verbetering van de eerstelijnszorgverlening voor patiënten met multimorbiditeit.

Dit proefschrift heeft aangetoond dat het investeren in de acht dimensies van persoonsgerichte zorg waardevol is voor het verbeteren van de eerstelijnszorgverlening aan patiënten met multimorbiditeit. Patiënten met multimorbiditeit zijn een kwetsbare patiëntenpopulatie met complexe zorgbehoeften. Persoonsgerichte zorg maakt het mogelijk dat zij hun welbevinden en tevredenheid met de zorg behouden. Hoewel niet alle patiënten met multimorbiditeit hetzelfde type zorg nodig hebben, maakt persoonsgerichte zorg het mogelijk om de zorgverlening af te stemmen op de individuele zorgbehoeften van deze patiënten. Dit proefschrift biedt nieuwe perspectieven op zorgverlening aan patiënten met multimorbiditeit, en beschrijft mogelijkheden en interventies om dit te doen. Helaas kunnen belemmeringen op patiënten-, organisatorisch en nationaal niveau een effectieve implementatie van PCC in de weg staan. Deze belemmeringen moeten worden weggenomen om het afstemmen van zorg op de behoeften van patiënten met multimorbiditeit te bevorderen en een verdere uitrol van persoonsgerichte zorg te bewerkstelligen.

DANKWOORD

Vier jaar is een lange periode. Het is immers een zevende deel van mijn leven, maar ook de tijd die doorgaans wordt uitgetrokken voor het afronden van een proefschrift. Wanneer je aan het begin staat, lijken deze vier jaar een lange en vooral eindeloze periode voor de afwisselende werking tussen schrijven en denken. Met de eindstreep in zicht verandert echter het perspectief. Wanneer je deze tijd vol benut biedt het ook mogelijkheden om je persoonlijk en professioneel te ontwikkelen, mooie samenwerkingen tot stand te brengen, vrienden voor het leven te maken, en kennis toe te voegen aan deze wondere wereld vol ontdekkingen. Het heeft inderdaad vier jaar gekost om al mijn data te verzamelen en artikelen te lezen en te publiceren, maar met name vier jaar opgeleverd om kennis en kracht te ontwikkelen, te ontdekken en te bundelen tot het boek dat u nu in uw handen heeft.

Persoonsgerichte zorg staat als onderwerp centraal in mijn proefschrift, maar heeft ook centraal gestaan in de begeleiding die ik heb ontvangen in de afgelopen vier jaar. Anna en Jane, ik wil jullie uit de grond van mijn hart bedanken voor jullie toegewijde supervisie. Een persoonsgerichte aanpak op de werkvloer is niet zo vanzelfsprekend als dat jullie het soms doen voorkomen. Jullie hebben altijd het welzijn van jullie PhD studenten vooropgesteld, en daarbinnen gezocht naar individuele uitdagingen, sterke punten, en hoe jullie het beste ondersteuning konden bieden aan wat er op dat moment nodig was. Jullie geoefende samenwerking is een schoolvoorbeeld van co-creatie. Jullie vullen elkaar naadloos aan en vormen een front waar ik altijd op heb kunnen bouwen. Jullie hebben me niet alleen de waarde van het onderzoek geleerd, maar ook laten zien waar mijn individuele waardes liggen. Ik kijk terug op een fijne samenwerking met ruimte voor vragen, humor, en bovenal eerlijkheid. Ik had het niet anders gewild. Bedankt voor alles.

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Sanne Kuipers

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Presentation at European Health Management Association digital conference: "The need for co-creation of care with multimorbidity patients – a longitudinal perspective", Rotterdam (the Netherlands)	2021
Presentation at International Conference on Integrated Care: "Patient-centered care for patients with multimorbidity in primary care", San Sebastian (Spain)	2019
Presentation at RCH midden-Brabant: "Evaluatie persoonsgerichte zorg voor patiënten met multimorbiditeit in de huisartsenzorg", Tilburg (the Netherlands)	2019
Presentation at Thebe "congres 100 jarig bestaan": "Persoonsgerichte zorg voor patiënten met multimorbiditeit in de huisartsenzorg", Breda (the Netherlands)	2019
Presentation at Thebe "congres 100 jarig bestaan": "Persoonsgerichte zorg voor patiënten met multimorbiditeit in de huisartsenzorg", Moergestel (the Netherlands)	2019
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Teaching activities	
Bachelor Health Policy and Management	
Zorgen voor later - Tutor workgroups	2019-2021
Zorgen voor later - Supervised work	2019-2021
Thesis supervision	2019-2020
Master Healthcare Management	
Patient Centred Care Delivery - Lecturer	2018-2020
Patient Centred Care Delivery -Tutor workgroups	2017-2020

International publications

Kuipers, S. J., Nieboer, A. P., & Cramm, J. M. (2021). Easier said than done: Healthcare professionals' barriers to the provision of patient-centered primary care to patients with multimorbidity. *International Journal of Environmental Research and Public Health*, *18*(11), 6057.

Kuipers, S. J., Nieboer, A. P., & Cramm, J. M. (2021). Making care more patient centered; experiences of healthcare professionals and patients with multimorbidity in the primary care setting. *BMC Family Practice*, *22*(1), 1-15.

Kuipers, S. J., Nieboer, A. P., & Cramm, J. M. (2020). The need for co-creation of care with multimorbidity patients—A longitudinal perspective. *International Journal of Environmental Research and Public Health*, *17*(9), 3201.

Kuipers, S. J., Nieboer, A. P., & Cramm, J. M. (2020). Views of patients with multimorbidity on what is important for patient-centered care in the primary care setting. *BMC Family Practice*, *21*, 1-12.

Kuipers, S. J., Cramm, J. M, & Nieboer, A. P. (2019). The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multimorbidity in the primary care setting. *BMC Health Services Research, 19*(1):13.

Dutch report

Cramm, J. M., Kuipers, S. J., & Nieboer, A.P. (2019). *Persoonsgerichte zorg voor patiënten met multimorbiditeit in de huisartsenpraktijk.* Erasmus School of Health Policy & Management, Rotterdam.

Additional activities

Board member PhD council ESHPM	2019-2020
Member activity committee ESHPM	2018-2019

ABOUT THE AUTHOR

Sanne Kuipers was born in Deventer on the 5th of March in 1993. She studied Psychology (with a specialization in neuropsychology) at the University of Groningen. She continued her education at Leiden University and obtained a master's degree in Vitality and Ageing (cum laude) in 2017. After graduation, Sanne started her PhD trajectory at the department of socio-medical sciences at the Erasmus School of Health Policy & Management (ESHPM; Erasmus University Rotterdam). She evaluated a program for improving patient-centered primary care for patients with multimorbidity, which resulted in this thesis. The results of her research were published in international journals, presented at international conferences, and shared during workshops with Dutch healthcare professionals. Next to conducting research, she taught various courses, such as 'Patient-centered care delivery' and 'Zorgen voor later'. In addition, Sanne served as a board member of the ESHPM PhD council. Currently, she works as a project manager within the innovation program 'Zorg van Waarde' at the Albert Schweitzer hospital in Dordrecht.

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