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A deeper understanding of patient-centred care and satisfaction with care requires investigation of patients' experiences with actual care, ideal care, and the gap between them

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3 **A deeper understanding of patient-centred care and satisfaction with care requires**
4 **investigation of patients' experiences with actual care, ideal care, and the gap between**
5 **them**
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ABSTRACT

Objective This study aimed to identify relationships among the actual level of patient-centred care (PCC), the care gap (ideal level of PCC versus actual care delivery), and satisfaction with care.

Design This study was a cross-sectional survey.

Setting This study was conducted at two locations of a Dutch hospital (Nieuwegein and Leidsche Rijn Utrecht).

Participants Patients visiting the outpatient clinics for heart failure, chronic obstructive disease (COPD), and cancer in March–May 2017 were asked to fill in a questionnaire.

Inclusion criteria were diagnosis with COPD, heart failure, or cancer and clinic visitation for a regular appointment. A total of 186 patients filled in the questionnaire.

Primary and secondary outcome measures Outcomes evaluated were the actual level of PCC, the care gap, and satisfaction with care.

Results About half (45%) of the respondents were female, 38% had low educational levels, and 31% were single. Respondents' mean age was 67.83 ± 10.02 (range, 16–94) years.

Patients' experiences with actual care delivery and their conceptualisation of the ideal type of care differed significantly, representing care gaps, in all PCC dimensions. After controlling for background characteristics, patients' experiences with actual delivery and the care gap were related significantly to patients' satisfaction with care ($\beta=0.17$ and $\beta=-0.41$, respectively).

Conclusions Patients' experiences with actual delivery and the care gap are important for patients' satisfaction with care.

Strengths and limitations of this study

- Investigation of patients' experiences with actual care, ideal care, and the gap between them
- Given the cross-sectional nature of the study, we were able to assess only relationships among study variables.
- A longitudinal study design is needed to investigate these relationships over time.
- We included only patients with chronic obstructive pulmonary disease, heart failure, and cancer.
- We used subjective measures only.

INTRODUCTION

Internationally, patient satisfaction is playing an increasingly important role in care-quality reforms and healthcare delivery in general. Satisfied patients are more likely to be compliant and co-operative and to complete treatment regimens. Hence, patient satisfaction has been identified as the way forward to improve health, reduce costs, and implement reform.^{1 2}

Hospitals are therefore refocusing healthcare delivery and organisational policies toward patients to improve the quality of care. Research, for example, shows that to improve satisfaction with care among patients, healthcare staff need to respect and respond to patients' choices, needs, and preferences and to involve their family members, elements which are at the core of patient-centred care (PCC).³

Since the Institute of Medicine (IOM) identified PCC as one of the six dimensions of improving the quality of care,⁴ interest in PCC has grown tremendously. In 2001, the IOM defined PCC as: 'Healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.'⁵ Although many definitions and models have been developed to describe PCC, the dimensions identified by the Picker Institute have been the most influential. This might be due to the researchers' use of a combination of empirical research and involvement of patients' points of view in developing this model. Their in-depth extensive research, wherein patients were asked to assess PCC, resulted in the identification of the following eight dimensions: 'respect for patient preferences', 'coordination of care', 'information and education', 'physical comfort', 'emotional support', 'involvement of family and friends', 'transition and continuity', and 'access to care'.³

A large body of evidence shows that organisations which implement a constellation of interventions aimed at multiple sets of these eight dimensions [e.g. training healthcare

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3 professionals in PCC consultation (particularly communication and negotiation skills),
4 incorporating patients' individualised needs and expectations into care plans, use of a
5 comprehensive and individualised discharge plan] achieve higher levels of satisfaction with
6 care among their patients.³ Although previous research has provided insight on the
7 relationships between specific PCC interventions (e.g. computerised assessment and goal
8 setting for patients, patient-centred consultation, healthcare provider counselling, specially
9 designed physical environments, hospital discharge planning to secure smooth transitions)
10 and outcomes, we lack insight into patients' experiences in terms of the eight PCC
11 dimensions and how they relate to their satisfaction with care.
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22 Research on satisfaction with care and quality of care indicates clearly that the
23 investigation of patients' experiences with care is not straightforward. Although the quality of
24 care can be measured in multiple ways, patients' experiences are increasingly used to assess
25 the quality of care delivery.⁶ Measuring satisfaction with care and experiences with quality of
26 care has, however, been criticised as being unclear in terms of what is actually being
27 measured or determined, and as failing to discriminate effectively between good and bad
28 practice.^{7 8} Jenkinson and colleagues,⁹ for example, evaluated patient experiences 1 month
29 after hospital discharge and found that even some of the 55% of patients who rated their care
30 as being excellent (assessed in terms of patient satisfaction) cited serious inpatient care
31 problems. Although the patients in their study were generally satisfied with care delivery,
32 some aspects of this delivery did not meet their expectations and led to disappointment.
33 Satisfaction with care was only partially explained by patients' experiences with actual care.
34 Investigation of the discrepancy between expected or ideal care and the actual care received
35 is expected to better explain the relationship between patients' experiences and satisfaction
36 with care.¹⁰ Investigating and truly understanding patient experiences is a highly complex
37 matter which calls for more detailed assessment. Clearly, asking only about patient
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3 satisfaction is not enough. Based on the study of Jenkinson and colleagues,⁹ we may conclude
4 that satisfaction with care reflects whether care meets a certain standard or norm, whereas
5 examination of actual experiences with care delivery and identification of the aspects of care
6 that do not meet patients' expectations provide a more detailed and fuller picture. To increase
7 our understanding of patient experiences with PCC, we thus need to ask patients about their
8 experiences with actual care, their conceptualisation of ideal care, and the gap between them.
9
10 Given that better experiences with care delivery also result in better patient and
11 organisational outcomes,^{6 11} investigation of the interplay between (disappointing) care
12 experiences and satisfaction with care would be of value. Earlier research among chronically
13 ill adolescents revealed the importance of disentangling experiences in light of patients'
14 experiences with actual care and the care gap (difference between actual and ideal care).¹²
15
16 Investigating the relationships among satisfaction with care, actual experiences with care, and
17 the care gap will provide insight into whether these experiences are actually important, and if
18 so, how important they are. We currently lack such knowledge in the PCC literature.
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20 Therefore, this study aimed to identify relationships among the actual level of PCC, the care
21 gap (ideal level of PCC versus actual care delivery), and satisfaction with care.
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40 **METHODS**

41 This study was conducted at two locations of St. Antonius Hospital (Nieuwegein and
42 Leidsche Rijn Utrecht). Patients visiting the outpatient clinics for heart failure, chronic
43 obstructive pulmonary disease (COPD), and cancer in March–May 2017 were asked to fill in
44 a questionnaire. Inclusion criteria were diagnosis with COPD, heart failure, or cancer and
45 visitation of the outpatient clinic for a regular appointment. Diagnoses and reasons for
46 patients' visits were listed on the outpatient clinic schedules and the physicians they were
47 visiting. Patients on these schedules were screened for eligibility, and those who fulfilled the
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3 criteria were asked to participate in the study. Informed consent was obtained from all
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5 participants.
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8 9 **Measures**

10 11 *Actual experience with care*

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13 Respondents were asked about their actual experiences with the extent to which each of the
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15 eight dimensions of PCC was fulfilled. Response categories were ‘not at all’ (1), ‘a bit’ (2),
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17 ‘somewhat’ (3), ‘very much so’ (4), and ‘extensively’ (5). Higher scores indicated greater
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19 occurrence of the PCC dimension. The Cronbach’s alpha value for this instrument was 0.80,
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21 indicating good reliability.
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24 25 26 *Ideal care*

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28 Respondents were also asked about their ideal type of care and how important they thought
29
30 each of the eight dimensions of PCC really was. They rated their level of agreement on a
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32 five-point scale ranging from 1 (‘not important at all’) to 5 (‘very important’). Care fitting
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34 what patients thought to be important was considered to constitute ideal care. The Cronbach’s
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36 alpha value for this instrument was 0.91, indicating excellent reliability.
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39 40 41 *The care gap*

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43 The care gap was assessed by calculating the difference in each respondent’s scores for the
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45 ideal type of care and their actual care experience in each PCC dimension. The Cronbach’s
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47 alpha value for these items were 0.86, indicating good reliability.
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50 51 52 *Satisfaction with care*

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3 Respondents were asked to rate their overall satisfaction with the care provided in the
4 outpatient clinics on a 0–10 scale, where 0 represented the worst hospital possible and 10
5 represented the best hospital possible. This question was taken from the Hospital Consumer
6 Assessment of Healthcare Providers and Systems (HCAHPS) survey. The Centers for
7 Medicare & Medicaid Services partnered with the Agency for Healthcare Research and
8 Quality, another agency in the federal Department of Health and Human Services, to develop
9 the HCAHPS (www.hcahpsonline.org).
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20 ***Background variables***

21 Patients were additionally asked about their age, gender, marital status, education level,
22 medication intake (number of medications), comorbidity, and which outpatient clinic they
23 visited (for COPD, heart failure, or cancer).
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31 **Statistical analyses**

32 First, descriptive statistics were used to characterise the study population, patients'
33 assessments of the eight dimensions of PCC (actual experiences, ideal type of care, and the
34 gap between them), and their satisfaction with care in each outpatient clinic. The chi-squared
35 test and analysis of variance were used to detect differences among outpatient clinics.
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41 Second, paired-sample *t* tests were used to investigate differences between ideal and actual
42 care by PCC dimension. Third, we employed correlation analyses to investigate associations
43 among background characteristics, ideal care, actual care, the care gap, and satisfaction with
44 care. Fourth, we used a linear regression model to investigate multivariate relationships
45 among background characteristics, actual care, the care gap, and satisfaction with care (with
46 listwise deletion of missing cases). Results were considered significant when two-sided *p*
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3 values were ≤ 0.05 . The SPSS software (version 23; IBM Corporation, Armonk, NY, USA)
4
5 was used for the analyses.
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8 9 **RESULTS**

10 Table 1 displays the characteristics of the 186 patients who completed the questionnaire.

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12 About half (45%) of the respondents were female, 38% had low educational levels, and 31%
13
14 were single. Respondents' mean age was 67.83 ± 10.02 (range, 16–94) years.
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17 These results show no difference in experiences with care (ideal care, actual care, and the
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19 care gap) or satisfaction with care. Patients with heart failure were older and more of these
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21 patients were male compared with patients with COPD and cancer.
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Table 1 Descriptive statistics for study participants

Characteristic	COPD (n=71)	Heart failure (n=50)	Cancer (n=65)	p ^a	Total (N=186)
Age (years)	63.0 ± 13.0	69.0 ± 12.2	63.2 ± 14.1	0.03	64.7 ± 13.4
Gender (male)	45.1%	66.0%	50.8%	0.07	52.7%
Marital status (married)	69.0%	66.0%	66.2%	0.92	67.2%
Education (years)	12.4 ± 3.9	10.7 ± 4.1	12.1 ± 3.8	0.08	11.8 ± 4.0
Comorbidities (# of additional diseases)	2.0 ± 1.2	2.7 ± 1.3	1.7 ± 1.0	<0.001	2.1 ± 1.2
Medication (# of medicines taken)	3.9 ± 1.5	4.8 ± 0.7	3.3 ± 1.8	<0.001	3.9 ± 1.6
Ideal care	3.0 ± 0.6	3.2 ± 0.5	3.1 ± 0.5	0.122	3.1 ± 0.5
Actual care	2.3 ± 0.8	2.5 ± 0.8	2.6 ± 0.8	0.238	2.4 ± 0.8
Care gap (ideal versus actual care)	0.6 ± 0.7	0.7 ± 0.7	0.5 ± 0.8	0.592	0.6 ± 0.7
Satisfaction with care	8.1 ± 1.2	8.2 ± 1.0	8.3 ± 0.8	0.501	8.2 ± 1.0

Data are expressed as mean ± standard deviation or percentage. ^aDifference among groups, chi-squared test or analysis of variance. COPD = chronic obstructive pulmonary disease.

Table 2 displays care gap data for the eight PCC dimensions. These results clearly show that patients' experiences with actual care delivery and their views of the ideal type of care differed significantly, revealing care gaps, in all dimensions.

Table 2 Care gaps (actual versus ideal care) experienced by patients in the eight dimensions of patient-centred care

Dimension	Actual care	Ideal care	Care gap (mean difference)	<i>p</i> ^a
Patient preferences (<i>n</i> =169)	2.45 ± 0.94	3.04 ± 0.85	-0.59 ± 0.88	<0.001
Information and education (<i>n</i> =175)	2.9 ± 0.92	3.60 ± 0.64	-0.70 ± 0.99	<0.001
Co-ordination of care (<i>n</i> =175)	2.69 ± 0.98	3.50 ± 0.66	-0.81 ± 1.11	<0.001
Emotional support (<i>n</i> =167)	1.93 ± 1.12	2.32 ± 0.99	-0.38 ± 1.05	<0.001
Physical comfort (<i>n</i> =167)	2.49 ± 0.97	3.13 ± 0.83	-0.64 ± 1.05	<0.001
Family and friends (<i>n</i> =169)	2.07 ± 1.22	2.50 ± 1.06	-0.44 ± 0.94	<0.001
Transition of care (<i>n</i> =175)	2.57 ± 1.07	3.21 ± 0.76	-0.63 ± 1.11	<0.001
Access to care (<i>n</i> =172)	2.54 ± 1.05	3.17 ± 0.77	-0.63 ± 1.10	<0.001

Data are expressed as mean ± standard deviation. ^aDifference between actual and ideal care, paired-sample *t* test.

Table 3 shows associations of study variables. Satisfaction with care was related significantly to actual experiences with care ($r=0.41$, $p<0.001$) and the care gap ($r=-0.37$, $p<0.001$). No significant association was found between any background characteristic and satisfaction with care.

Table 3 Associations among background characteristics, ideal care, actual care, the care gap, and satisfaction with care

	1	2	3	4	5	6	7	8	9	10	11	12
1. Age (years)												
2. Gender (male)	0.18**											
3. Marital status (married)	0.02	0.16*										
4. Education (years)	-0.30***	-0.02	0.14									
5. COPD	-0.10	-0.12	0.03	0.11								
6. Cancer	-0.08	-0.03	-0.02	0.05	-0.58***							
7. Heart failure	0.20**	0.16*	-0.02	-0.17**	-0.48***	-0.44***						
8. Comorbidities (# of additional diseases)	0.30***	0.02	-0.01	-0.24**	-0.04	-0.25***	0.31***					
9. Medication (# of medicines taken)	0.33***	0.11	0.06	-0.20**	0.00	-0.31***	0.33***	0.42***				
10. Ideal care	0.13	-0.22**	-0.05	-0.00	-0.15*	0.06	0.10	0.12	0.12			
11. Actual care	0.08	-0.04	-0.01	-0.04	-0.12	0.11	0.02	-0.04	0.11	0.48***		

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12. Care gap (ideal versus actual care)	0.02	-0.14	-0.03	0.05	0.01	-0.07	0.06	0.11	-0.04	0.22**	-0.75***	
13. Satisfaction with care	-0.07	-0.08	-0.05	-0.06	-0.09	-0.09	0.02	-0.08	-0.11	0.08	0.41***	-0.37***

*** $p \leq 0.001$, ** $p \leq 0.01$, * $p \leq 0.05$ (two-tailed). COPD = chronic obstructive pulmonary disease.

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Table 4 shows multivariate relationships among the study variables. After controlling for background characteristics, patients' experiences with actual delivery and the care gap were related significantly to their satisfaction with care ($\beta=0.17$ and $\beta=-0.41$, respectively). No significant relationship was found between any background characteristic and satisfaction with care.

Table 4 Multivariate relationships between background characteristics, actual care, the care gap (ideal care versus actual care), and satisfaction with care ($n=155$)

Independent variable	Satisfaction with care		
	β	B (SE)	<i>p</i>
Age (years)	-0.07	-0.01 (0.01)	0.396
Gender (male)	-0.07	-0.13 (0.16)	0.416
Marital status (married)	-0.00	-0.00 (0.16)	0.989
Education (years)	-0.07	-0.02 (0.02)	0.366
COPD*	-0.13	-0.27 (0.20)	0.184
Cancer*	-0.11	-0.23 (0.22)	0.291
Comorbidities (# of additional diseases)	-0.04	-0.03 (0.07)	0.644
Medication (# of medicines taken)	-0.14	-0.09 (0.06)	0.123
Actual care	0.17	0.32 (0.15)	0.036
Care gap (ideal care versus actual care)	-0.41	-0.57 (0.11)	<0.001

*Reference category, heart failure. Results are based on listwise deletion of missing cases.

Pairwise deletion and mean substitution of missing cases yielded similar results. COPD = chronic obstructive pulmonary disease.

DISCUSSION

This study aimed to identify relationships among the actual level of PCC, the care gap (ideal level of PCC versus actual care delivery), and satisfaction with care among patients in three outpatient clinics (for COPD, heart failure, and cancer). Importantly, we found that patients' experiences with actual care delivery and their conceptualisation of the ideal type of care differed significantly in all eight PCC dimensions. The study results clearly show that patients experienced care gaps in all of these dimensions, and that their actual experiences

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3 and the care gap were related significantly to their satisfaction with care, even after
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5 controlling for background characteristics. While we already knew that a constellation of
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7 interventions aimed at multiple PCC dimensions resulted in increased patient satisfaction
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9 with care,³ this research additionally shows that patients' (positive and disappointing)
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11 experiences with care delivery are associated positively with care satisfaction. Investigation
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13 of the care gap especially adds value when actual care is also taken into account. In line with
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15 the findings of Sonneveld and colleagues¹² for chronically ill adolescents, this research shows
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17 the importance of asking chronically ill adult patients about their experiences with actual
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19 care, ideal care, and the gap between them to truly understand the relationships of these
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21 experiences to care satisfaction. The identification of PCC dimensions in need of
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23 improvement (evidenced by higher gap scores) can be a first step in organisations' efforts to
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25 further improve levels of patient-centredness and satisfaction with care. Research clearly
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27 shows that poor experiences with access to care are associated with mortality,¹³ and that lack
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29 of integration among various silos and inadequate communication among providers during
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31 transition of care delay the delivery of appropriate healthcare services, leading to poor health
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33 outcomes and higher costs.¹⁴
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38 This study has several limitations. First, given its cross-sectional nature, we were able to
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40 assess only relationships, not causality. A longitudinal study design is needed to investigate
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42 relationships over time. Second, we included only patients with COPD, heart failure, and
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44 cancer. Given that our findings are in line with those of Sonneveld and colleagues¹² and that
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46 the type of chronic disease did not affect patients' experiences or satisfaction with care, we
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48 are confident that the inclusion of patients with only three chronic diseases did not influence
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50 our study findings.
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53 From this study, we can conclude that patients' experiences with actual care delivery and
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55 the care gap are important for patients' satisfaction with care. A deeper understanding of PCC
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3 and satisfaction with care thus requires investigation of patients' experiences with actual care,
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5 ideal care, and the gap between them.
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A cross-sectional research conducted in the Netherlands to identify relationships among the actual level of patient-centred care, the care gap (ideal versus actual care delivery), and satisfaction with care

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ABSTRACT

Objective This study aimed to identify relationships among the actual level of patient-centred care (PCC), the care gap (ideal level of PCC versus actual care delivery), and satisfaction with care.

Design This study was a cross-sectional survey.

Setting This study was conducted at two locations of a Dutch hospital (Nieuwegein and Leidsche Rijn Utrecht).

Participants Patients visiting the outpatient clinics for heart failure, chronic obstructive disease (COPD), and cancer in March–May 2017 were asked to fill in a questionnaire.

Inclusion criteria were diagnosis with COPD, heart failure, or cancer and clinic visitation for a regular appointment. A total of 186 patients filled in the questionnaire.

Primary and secondary outcome measures Outcomes evaluated were the actual level of PCC, the care gap, and satisfaction with care.

Results About half (45%) of the respondents were female, 38% had low educational levels, and 31% were single. Respondents' mean age was 67.83 ± 10.02 (range, 16–94) years.

Patients' experiences with actual care delivery and their conceptualisation of the ideal type of care differed significantly, representing care gaps, in all PCC dimensions. After controlling for background characteristics, patients' experiences with actual delivery and the care gap were related significantly to patients' satisfaction with care ($\beta=0.17$ and $\beta=-0.41$, respectively).

Conclusions Patients' experiences with the actual level of PCC and the care gap are important for patients' satisfaction with care.

Strengths and limitations of this study

- Given the cross-sectional nature of the study, we were able to assess only relationships among study variables.
- A longitudinal study design is needed to investigate these relationships over time.
- We included only patients with chronic obstructive pulmonary disease, heart failure, and cancer.
- We used subjective measures only.

INTRODUCTION

Internationally, patient satisfaction is playing an increasingly important role in care-quality reforms and healthcare delivery in general. Satisfied patients are more likely to be compliant and co-operative and to complete treatment regimens. Hence, patient satisfaction has been identified as the way forward to improve health, reduce costs, and implement reform.^{1 2}

Hospitals are therefore refocusing healthcare delivery and organisational policies toward patients to improve the quality of care. Research, for example, shows that to improve satisfaction with care among patients, healthcare staff need to respect and respond to patients' choices, needs, and preferences and to involve their family members, elements which are at the core of patient-centred care (PCC).³

Since the Institute of Medicine (IOM) identified PCC as one of the six dimensions of improving the quality of care,⁴ interest in PCC has grown tremendously. In 2001, the IOM defined PCC as: 'Healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.'⁵ Although many definitions and models have been developed to describe PCC, the dimensions identified by the Picker Institute have been the most influential. This might be due to the researchers' use of a combination of empirical research and involvement of patients' points of view in developing this model. Their in-depth extensive research, wherein patients were asked to assess PCC, resulted in the identification of the following eight dimensions: 'respect for patient preferences', 'coordination of care', 'information and education', 'physical comfort', 'emotional support', 'involvement of family and friends', 'transition and continuity', and 'access to care'.³

A large body of evidence shows that organisations which implement a constellation of interventions aimed at multiple sets of these eight dimensions [e.g. training healthcare

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3 professionals in PCC consultation (particularly communication and negotiation skills),
4 incorporating patients' individualised needs and expectations into care plans, use of a
5 comprehensive and individualised discharge plan] achieve higher levels of satisfaction with
6 care among their patients.³ Although previous research has provided insight on the
7 relationships between specific PCC interventions (e.g. computerised assessment and goal
8 setting for patients, patient-centred consultation, healthcare provider counselling, specially
9 designed physical environments, hospital discharge planning to secure smooth transitions)
10 and outcomes, we lack insight into patients' experiences in terms of the eight PCC
11 dimensions and how they relate to their satisfaction with care.
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24 Research on satisfaction with care and quality of care indicates clearly that the
25 investigation of patients' experiences with care is not straightforward. Although the quality of
26 care can be measured in multiple ways, patients' experiences are increasingly used to assess
27 the quality of care delivery.⁶ Measuring satisfaction with care and experiences with quality of
28 care has, however, been criticised as being unclear in terms of what is actually being
29 measured or determined, and as failing to discriminate effectively between good and bad
30 practice.^{7 8} Jenkinson and colleagues,⁹ for example, evaluated patient experiences 1 month
31 after hospital discharge and found that even some of the 55% of patients who rated their care
32 as being excellent (assessed in terms of patient satisfaction) cited serious inpatient care
33 problems. Although the patients in their study were generally satisfied with care delivery,
34 some aspects of this delivery did not meet their expectations and led to disappointment.
35 Satisfaction with care was only partially explained by patients' experiences with actual care.
36 Investigation of the discrepancy between expected or ideal care and the actual care received
37 is expected to better explain the relationship between patients' experiences and satisfaction
38 with care.¹⁰ Investigating and truly understanding patient experiences is a highly complex
39 matter which calls for more detailed assessment. Clearly, asking only about patient
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3 satisfaction is not enough. Based on the study of Jenkinson and colleagues,⁹ we may conclude
4 that satisfaction with care reflects whether care meets a certain standard or norm, whereas
5 examination of actual experiences with care delivery and identification of the aspects of care
6 that do not meet patients' expectations provide a more detailed and fuller picture. To increase
7 our understanding of patient experiences with PCC, we thus need to ask patients about their
8 experiences with actual care, their conceptualisation of ideal care, and the gap between them.
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10 Given that better experiences with care delivery also result in better patient and
11 organisational outcomes,^{6 11} investigation of the interplay between (disappointing) care
12 experiences and satisfaction with care would be of value. Earlier research among chronically
13 ill adolescents revealed the importance of disentangling experiences in light of patients'
14 experiences with actual care and the care gap (difference between actual and ideal care).¹²
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16 Investigating the relationships among satisfaction with care, actual experiences with care, and
17 the care gap will provide insight into whether these experiences are actually important, and if
18 so, how important they are. We currently lack such knowledge in the PCC literature.
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20 Therefore, this study aimed to identify relationships among the actual level of PCC, the care
21 gap (ideal level of PCC versus actual care delivery), and satisfaction with care.
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43 **METHODS**

44 This study was conducted at two locations of St. Antonius Hospital (Nieuwegein and
45 Leidsche Rijn Utrecht). Patients visiting the outpatient clinics for heart failure, chronic
46 obstructive pulmonary disease (COPD), and cancer were asked by nurses to fill in a
47 questionnaire after visiting their physician during a few days in April 2017. In every
48 outpatient clinic nurses received the questionnaire from us and were asked to include patients
49 who were eligible for the study. Inclusion criteria were diagnosis with COPD, heart failure,
50 or cancer and visitation of the outpatient clinic for a regular appointment. Diagnoses and
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3 reasons for patients' visits were listed on the outpatient clinic schedules and the physicians
4 they were visiting. Patients on these schedules were screened for eligibility, and those who
5 fulfilled the criteria were asked to participate in the study by the nurses. Approximately 240
6 questionnaires were distributed of which a total of 186 patients actually filled in the
7 questionnaires. Informed consent was obtained from all participants.
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17 **Measures**

18 *Actual experience with care*

19 Respondents were asked about their actual experiences with the extent to which each of the
20 eight dimensions of PCC was fulfilled. Response categories were 'not at all' (1), 'a bit' (2),
21 'somewhat' (3), 'very much so' (4), and 'extensively' (5). Higher scores indicated greater
22 occurrence of the PCC dimension. The Cronbach's alpha value for this instrument was 0.80,
23 indicating good reliability.
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35 *Ideal care*

36 Respondents were also asked about their ideal type of care and how important they thought
37 each of the eight dimensions of PCC really was. They rated their level of agreement on a
38 five-point scale ranging from 1 ('not important at all') to 5 ('very important'). Care fitting
39 what patients thought to be important was considered to constitute ideal care. The Cronbach's
40 alpha value for this instrument was 0.91, indicating excellent reliability.
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51 *The care gap*

52 The care gap was assessed by calculating the difference in each respondent's scores for the
53 ideal type of care and their actual care experience in each PCC dimension. The Cronbach's
54 alpha value for these items were 0.86, indicating good reliability.
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Satisfaction with care

Respondents were asked to rate their overall satisfaction with the care provided in the outpatient clinics on a 0–10 scale, where 0 represented the worst hospital possible and 10 represented the best hospital possible. This question was taken from the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. The Centers for Medicare & Medicaid Services partnered with the Agency for Healthcare Research and Quality, another agency in the federal Department of Health and Human Services, to develop the HCAHPS (www.hcahpsonline.org).

The Medical research Ethics Committee United (MEC-U) determined that the rules stipulated in the Dutch Medical Research Involving Human Subjects Act did not apply to this study (file number W17.019) (see <http://www.ccmo.nl/en/your-research-does-it-fall-under-the-wmo>). 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 analysing 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).

Background variables

Patients were additionally asked about their age, gender, marital status, education level, medication intake (number of medications), comorbidity, and which outpatient clinic they visited (for COPD, heart failure, or cancer).

Statistical analyses

First, descriptive statistics were used to characterise the study population, patients' assessments of the eight dimensions of PCC (actual experiences, ideal type of care, and the gap between them), and their satisfaction with care in each outpatient clinic. The chi-squared test and analysis of variance were used to detect differences among outpatient clinics.

Second, paired-sample *t* tests were used to investigate differences between ideal and actual care by PCC dimension. Third, we employed correlation analyses to investigate associations among background characteristics, ideal care, actual care, the care gap, and satisfaction with care. Fourth, we used a linear regression model to investigate multivariate relationships among background characteristics, actual care, the care gap, and satisfaction with care (with listwise deletion of missing cases). Results were considered significant when two-sided *p* values were ≤ 0.05 . The SPSS software (version 23; IBM Corporation, Armonk, NY, USA) was used for the analyses.

Patient and public involvement

Patients were not involved in setting up the study design, the recruitment of patients, development of the research questions or outcomes measures.

RESULTS

Table 1 displays the characteristics of the 186 patients who completed the questionnaire.

About half (45%) of the respondents were female, 38% had low educational levels, and 31% were single. Respondents' mean age was 67.83 ± 10.02 (range, 16–94) years.

These results show no difference in experiences with care (ideal care, actual care, and the care gap) or satisfaction with care between heart failure, COPD and cancer patients. Patients

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3 with heart failure were older and more of these patients were male compared with patients
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5 with COPD and cancer.
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Table 1 Descriptive statistics for study participants

Characteristic	COPD (n=71)	Heart failure (n=50)	Cancer (n=65)	p ^a	Total (N=186)
Age (years)	63.0 ± 13.0	69.0 ± 12.2	63.2 ± 14.1	0.03	64.7 ± 13.4
Gender (male)	45.1%	66.0%	50.8%	0.07	52.7%
Marital status (married)	69.0%	66.0%	66.2%	0.92	67.2%
Education (years)	12.4 ± 3.9	10.7 ± 4.1	12.1 ± 3.8	0.08	11.8 ± 4.0
Comorbidities (# of additional diseases)	2.0 ± 1.2	2.7 ± 1.3	1.7 ± 1.0	<0.001	2.1 ± 1.2
Medication (# of medicines taken)	3.9 ± 1.5	4.8 ± 0.7	3.3 ± 1.8	<0.001	3.9 ± 1.6
Ideal care	3.0 ± 0.6	3.2 ± 0.5	3.1 ± 0.5	0.122	3.1 ± 0.5
Actual care	2.3 ± 0.8	2.5 ± 0.8	2.6 ± 0.8	0.238	2.4 ± 0.8
Care gap (ideal versus actual care)	0.6 ± 0.7	0.7 ± 0.7	0.5 ± 0.8	0.592	0.6 ± 0.7
Satisfaction with care	8.1 ± 1.2	8.2 ± 1.0	8.3 ± 0.8	0.501	8.2 ± 1.0

Data are expressed as mean ± standard deviation or percentage. ^aDifference among groups, chi-squared test or analysis of variance. COPD = chronic obstructive pulmonary disease.

Table 2 displays care gap data for the eight PCC dimensions. These results clearly show that patients' experiences with actual care delivery and their views of the ideal type of care differed significantly, revealing care gaps, in all dimensions.

Table 2 Care gaps (actual versus ideal care) experienced by patients in the eight dimensions of patient-centred care

Dimension	Actual care	Ideal care	Care gap (mean difference)	<i>p</i> ^a
Patient preferences (<i>n</i> =169)	2.45 ± 0.94	3.04 ± 0.85	-0.59 ± 0.88	<0.001
Information and education (<i>n</i> =175)	2.9 ± 0.92	3.60 ± 0.64	-0.70 ± 0.99	<0.001
Co-ordination of care (<i>n</i> =175)	2.69 ± 0.98	3.50 ± 0.66	-0.81 ± 1.11	<0.001
Emotional support (<i>n</i> =167)	1.93 ± 1.12	2.32 ± 0.99	-0.38 ± 1.05	<0.001
Physical comfort (<i>n</i> =167)	2.49 ± 0.97	3.13 ± 0.83	-0.64 ± 1.05	<0.001
Family and friends (<i>n</i> =169)	2.07 ± 1.22	2.50 ± 1.06	-0.44 ± 0.94	<0.001
Transition of care (<i>n</i> =175)	2.57 ± 1.07	3.21 ± 0.76	-0.63 ± 1.11	<0.001
Access to care (<i>n</i> =172)	2.54 ± 1.05	3.17 ± 0.77	-0.63 ± 1.10	<0.001

Data are expressed as mean ± standard deviation. ^aDifference between actual and ideal care, paired-sample *t* test.

Table 3 shows associations of study variables. Satisfaction with care was related significantly to actual experiences with care ($r=0.41$, $p<0.001$) and the care gap ($r=-0.37$, $p<0.001$). No significant association was found between any background characteristic and satisfaction with care.

Table 3 Associations among background characteristics, ideal care, actual care, the care gap, and satisfaction with care

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	Age (years)	Gender (male)	Marital status (married)	Education (years)	COPD	Cancer	Heart failure	Comor- bidities	Medica- tion	Ideal care	Actual care	Care gap
1. Age (years)												
2. Gender (male)	0.18**											
3. Marital status (married)	0.02	0.16*										
4. Education (years)	-0.30***	-0.02	0.14									
5. COPD	-0.10	-0.12	0.03	0.11								
6. Cancer	-0.08	-0.03	-0.02	0.05	-0.58***							
7. Heart failure	0.20**	0.16*	-0.02	-0.17**	-0.48***	-0.44***						
8. Comorbidities (# of additional diseases)	0.30***	0.02	-0.01	-0.24**	-0.04	-0.25***	0.31***					
9. Medication (# of medicines taken)	0.33***	0.11	0.06	-0.20**	0.00	-0.31***	0.33***	0.42***				

10. Ideal care	0.13	-0.22**	-0.05	-0.00	-0.15*	0.06	0.10	0.12	0.11	0.48***		
11. Actual care	0.08	-0.04	-0.01	-0.04	-0.12	0.11	0.02	-0.04	0.04	0.22**	-0.75***	
12. Care gap (ideal versus actual care)	0.02	-0.14	-0.03	0.05	0.01	-0.07	0.06	0.11	0.11	0.08	0.41***	-0.37***
13. Satisfaction with care	-0.07	-0.08	-0.05	-0.06	-0.09	-0.09	0.02	-0.08				

*** $p \leq 0.001$, ** $p \leq 0.01$, * $p \leq 0.05$ (two-tailed). COPD = chronic obstructive pulmonary disease.

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Table 4 shows multivariate relationships among the study variables. After controlling for background characteristics, patients' experiences with actual delivery and the care gap were related significantly to their satisfaction with care ($\beta=0.17$ and $\beta=-0.41$, respectively). No significant relationship was found between any background characteristic and satisfaction with care.

Table 4 Multivariate relationships between background characteristics, actual care, the care gap (ideal care versus actual care), and satisfaction with care ($n=155$)

Independent variable	Satisfaction with care		
	β	B (SE)	<i>p</i>
Age (years)	-0.07	-0.01 (0.01)	0.396
Gender (male)	-0.07	-0.13 (0.16)	0.416
Marital status (married)	-0.00	-0.00 (0.16)	0.989
Education (years)	-0.07	-0.02 (0.02)	0.366
COPD*	-0.13	-0.27 (0.20)	0.184
Cancer*	-0.11	-0.23 (0.22)	0.291
Comorbidities (# of additional diseases)	-0.04	-0.03 (0.07)	0.644
Medication (# of medicines taken)	-0.14	-0.09 (0.06)	0.123
Actual care	0.17	0.32 (0.15)	0.036
Care gap (ideal care versus actual care)	-0.41	-0.57 (0.11)	<0.001

*Reference category, heart failure. Results are based on listwise deletion of missing cases.

Pairwise deletion and mean substitution of missing cases yielded similar results. COPD = chronic obstructive pulmonary disease.

DISCUSSION

This study aimed to identify relationships among the actual level of PCC, the care gap (ideal level of PCC versus actual care delivery), and satisfaction with care among patients in three outpatient clinics (for COPD, heart failure, and cancer). Importantly, we found that patients' experiences with actual care delivery and their conceptualisation of the ideal type of care differed significantly in all eight PCC dimensions. The study results clearly show that patients experienced care gaps in all of these dimensions, and that their actual experiences

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3 and the care gap were related significantly to their satisfaction with care, even after
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5 controlling for background characteristics. While we already knew that a constellation of
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7 interventions aimed at multiple PCC dimensions resulted in increased patient satisfaction
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9 with care,³ this research additionally shows that patients' (positive and disappointing)
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11 experiences with care delivery are associated positively with care satisfaction. Investigation
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13 of the care gap especially adds value when actual care is also taken into account. In line with
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15 the findings of Sonneveld and colleagues¹² for chronically ill adolescents, this research shows
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17 the importance of asking chronically ill adult patients about their experiences with actual
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19 care, ideal care, and the gap between them to truly understand the relationships of these
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21 experiences to care satisfaction. The identification of PCC dimensions in need of
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23 improvement (evidenced by higher gap scores) can be a first step in organisations' efforts to
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25 further improve levels of patient-centredness and satisfaction with care. Research clearly
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27 shows that poor experiences with access to care are associated with mortality,¹³ and that lack
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29 of integration among various silos and inadequate communication among providers during
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31 transition of care delay the delivery of appropriate healthcare services, leading to poor health
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33 outcomes and higher costs.¹⁴

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40 A noticeable finding are the relatively lower emotional support scores looking at both
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42 actual care as well as ideal care. This is in line with the study of Cramm and Nieboer¹⁵ who
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44 also investigated these eight dimensions of patient-centred care among multimorbidity
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46 patients. In their study multimorbidity patients also gave the lowest score to the emotional
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48 support dimension. Health care is known to struggle with achieving real gains in chronically
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50 ill patients' emotional or mental well-being because the focus is often mainly aimed at
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52 physical health and clinical outcomes only.^{16,17} Supporting patients' mental and emotional
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54 well-being needs presents a huge challenge in current care delivery^{18,19} as this study also
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3 Another important finding is that no significant associations were found between
4 patients' experiences with care and background variables (age, gender, marital status, type of
5 chronic disease, multimorbidity and medication intake). This is a noticeable finding given
6 that earlier research did show a relationship between background variables (such as age and
7 multimorbidity)^{20,21} and experiences with care. Although, this finding would suggest that care
8 gaps are pervasive across different specialties (diseases) and demographics, this study is first
9 of its kind and we are therefore cautious to draw such conclusions. Looking at earlier
10 research among multimorbidity patients we do know that to align with the clinical reality of
11 multimorbidity, care should evolve from a disease orientation to a patient goal orientation,
12 focused on maximizing the health goals of individual patients with unique sets of risks,
13 conditions, and priorities.²² The eight dimensions of PCC may be a way to deliver care in
14 such a way that it truly fits the needs and expectations of all patients regardless of their
15 background.

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33 This study has several limitations. First, given its cross-sectional nature, we were able to
34 assess only relationships, not causality. A longitudinal study design is needed to investigate
35 relationships over time. Second, we included only patients with COPD, heart failure, and
36 cancer. Given that our findings are in line with those of Sonneveld and colleagues¹² and that
37 the type of chronic disease did not affect patients' experiences or satisfaction with care, we
38 are confident that the inclusion of patients with only three chronic diseases did not influence
39 our study findings. Thirdly, not all eligible patients were systematically asked by nurses to
40 participate in the study. Due to these organizational impediments we were not able to keep a
41 record of the number of patients who were actually invited to participate by the nurses and
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56 From this study, we can conclude that patients' experiences with actual care delivery and
57 the care gap are important for patients' satisfaction with care. A deeper understanding of PCC
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3 and satisfaction with care thus requires investigation of patients' experiences with actual care,
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5 ideal care, and the gap between them.
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10 **A. contributor ship statement**

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12 Ferogh Mirzad and Anna Nieboer participated in the initial study design. Ferogh Mirzad
13 performed data collection. Jane Cramm, Ferogh Mirzad and Anna Nieboer analyzed the
14 collected data. Jane Cramm and Anna Nieboer drafted the manuscript and contributed to its
15 refinement. All authors read and approved the final version of the manuscript.
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20 **B. competing interests**

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22 There are no competing interests for any author.
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26 **C. funding**

27
28 There was no funding for this study.
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31 **D. data sharing statement**

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33 No additional data.
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STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No		Recommendation
Title and abstract	1	<i>v</i>	(a) Indicate the study's design with a commonly used term in the title or the abstract
		<i>v</i>	(b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction			
Background/rationale	2	<i>v</i>	Explain the scientific background and rationale for the investigation being reported
Objectives	3	<i>v</i>	State specific objectives, including any prespecified hypotheses
Methods			
Study design	4	<i>v</i>	Present key elements of study design early in the paper
Setting	5	<i>v</i>	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	<i>v</i>	(a) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	<i>v</i>	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	<i>v</i>	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	<i>v</i>	Describe any efforts to address potential sources of bias
Study size	10	-	Explain how the study size was arrived at
Quantitative variables	11	<i>v</i>	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	<i>v</i>	(a) Describe all statistical methods, including those used to control for confounding
		<i>v</i>	(b) Describe any methods used to examine subgroups and interactions
		<i>v</i>	(c) Explain how missing data were addressed
		<i>na</i>	(d) If applicable, describe analytical methods taking account of sampling strategy
		<i>na</i>	(e) Describe any sensitivity analyses
Results			
Participants	13*	<i>v</i>	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		-	(b) Give reasons for non-participation at each stage
		-	(c) Consider use of a flow diagram
Descriptive data	14*	<i>v</i>	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		<i>v</i>	(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	<i>v</i>	Report numbers of outcome events or summary measures
Main results	16	<i>v</i>	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included

		<i>na</i>	(b) Report category boundaries when continuous variables were categorized
		<i>na</i>	(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	<i>v</i>	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion			
Key results	18	<i>v</i>	Summarise key results with reference to study objectives
Limitations	19	<i>v</i>	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	<i>v</i>	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	<i>v</i>	Discuss the generalisability (external validity) of the study results
Other information			
Funding	22	<i>na</i>	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.