

# Comparison of Patient and Proxy Assessment of Patient-Centeredness in the Care of Coronary Heart Disease: A Cross Sectional Survey Using the PACIC-SI I. I

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## Abstract

**Introduction:** When making medical care more patient-centered, surveys on patients' and their relatives' experiences can be helpful in identifying opportunities for improvement. In cases where the targeted patients are unable to express their own perspective, for example, due to them being too young or suffering from severe impairments, proxies can serve as substitutes. Proxies are frequently used in care planning and consent. Nevertheless, it is unclear whether patients' assessments of how patient-centered their medical care is are similar to those of their proxies. This study aims to assess the level of consistency between patients' and their proxies' assessments using an adapted version of the Patient Assessment of Chronic Illness Care (PACIC) short form questionnaire.

**Methods:** In a cross-sectional study, patients with coronary heart disease were recruited at cardiologists' offices, rehabilitation clinics and hospitals. Participants were surveyed with regard to the perceived level of patient-centeredness during their care using an adapted version of the German PACIC short form (PACIC-SI I. I). Correlations in the assessments made by each patient and their respective proxy were analyzed. On the level of the patients group and the relatives group differences between mean ratings for each item were compared using paired t-tests.

**Results:** In total, 74 pairs of patients and proxies submitted the completed questionnaire. On the level of the individual patient/proxy pairs, no correlation, or significant but low correlation, was found between the ratings. On the group level, patients' and their proxies' item ratings were similar in the interpretation of averages, but still demonstrated statistically significant differences. Overall, patients rated their care as more patient-centered than their proxies did.

**Conclusion:** The study shows that, on the individual level, proxies' ratings do not necessarily reflect the patients' assessment of PCC. On the group level, the assessments of relatives regarding PCC are similar to those of the patients.

**Trial registration** German clinical trials register (Deutsches Register Klinischer Studien, DRKS) Registration Number: DRKS00012434 (URL: [https://www.drks.de/drks\\_web/navigate.do?navigationId=trial.HTML&TRIAL\\_ID=DRKS00012434](https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00012434))

## Keywords

proxy, patient-centeredness, coronary artery disease, chronic illness, survey

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## Introduction

Refining care structures, processes and interventions based on the concept of patient-centered care (PCC) has become increasingly important in recent decades. In 1968, Balint described PCC as considering each patient as a “unique human-being” (p. 269) instead of regarding them purely as an illness to treat.<sup>1</sup> Later, the Institute of Medicine refined and

specified the definition to the currently widely accepted definition of PCC as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (p. 5).<sup>2</sup> There are several models for the determinants and activities involved in PCC; these provide practical guidance on redesigning healthcare with PCC in mind. Relevant elements



include coordinated, proactive, integrated and continuous care, prepared care teams, and shared decision-making.<sup>3-9</sup> While the provision of PCC is relevant to all patients, those with chronic illnesses in particular often require healthcare services from a number of different providers; the coordination and provision of these tasks is a continuous process.<sup>10</sup> One practical example of care models based on the concept of PCC is disease management programs, which involve regular scheduled meetings with the patient, agreed treatment plans, and self-management support. In addition to such formalized programs, patient-centeredness during care can also be increased by regularly assessing the patients' care experiences and identifying areas for improvement. Survey instruments have been developed and tested to assess levels of patient-centeredness. One of the most widely used survey instruments in this field is the *Patient Assessment of Chronic Illness Care* (PACIC).<sup>11</sup> This instrument has been tested extensively and adapted for use in various countries and patient groups, including in its short forms.<sup>12-14</sup> These instruments are applied as self-report questionnaires to be completed by the patients. In many situations, patients cannot be surveyed directly with regard to their experiences of healthcare or patient-centeredness. In such cases in medical care and health services research, proxy surveys are commonly applied. Parents are asked to report on the health status and symptoms of their children, as these may not be able to self-report. Likewise, for patients who are unable to express their own will, for example, due to severe cognitive or physical impairments, proxies are required during care planning and consent in order to represent the patients' interests. Alongside medical reasons such as these, relatives or other proxies are also asked for their assessment of the situation because of the major role they play in the care process, especially during care for chronic illnesses. Their assessment of the patient's healthcare has value in itself, as they are often heavily involved in the care process.

Chronically ill patients, such as those with coronary heart disease (CHD), require care from a number of different providers and professionals, including medication, non-drug medical and psychological interventions, and lifestyle changes, such as adjustments in diet and physical activity.<sup>15</sup> These requirements make them a group who can profit from various PCC activities and, in most cases, who can be surveyed directly.<sup>16</sup> As a result of these characteristics, people with CHD represent an appropriate target group for assessing whether patients' assessments of the

level of patient-centeredness in their medical care are similar to those of their proxies. This study aims to assess the correlation between CHD patients' assessments of PCC in their healthcare and those of their proxies.

## Methods

### Study Design and Setting

This study was conducted within the Cologne Research and Development Network (CoRe-Net), which consists of scientists, patient organizations, health and social care organizations (HSCOs), municipality representatives and other stakeholders in the region of Cologne, Germany.<sup>17</sup> Currently 4 projects are affiliated with CoRe-Net. The data collected and presented in this article originate from the research project MenDis-CHD (Mental disorders in patients with coronary heart disease).<sup>18</sup> Members of MenDis-CHD contributed to the development and conduct of this study. The study has been approved by the Ethics Committee of the Medical Faculty of the University of Cologne (reference number: 17-220). All the participants provided written, informed consent. A cross-sectional, questionnaire-based survey was conducted among the patients, the patients' partners/relatives (proxies living in same household), and their physicians in order to assess the current quality of care for patients with CHD and the prevalence of mental-health-related comorbidities. This paper reports on the surveys' analyses of patient-centeredness as rated by patients and their proxies in relation to the care received from their primary care provider (either their general practitioner or their cardiologist).

### Participants and Recruitment

Patients were eligible for this study if they suffered from an angiographically documented CHD, had been treated for stable angina pectoris or acute coronary syndromes, or had received percutaneous coronary intervention or bypass surgery. Additionally, the patients and their proxies had to be at least 18 years old, able to provide informed consent, and able to speak German with a sufficient level of proficiency. Anyone living in the same household as the patient (eg, child, spouse or partner) was eligible to act as a proxy for this study. Patients and proxies were excluded if they suffered from severe or unstable physical or mental conditions

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that would hinder study participation. Patients were recruited at 2 hospitals, 2 rehabilitation clinics, and 3 cardiologists' offices. When provided with informed consent to do so by the patient, the researchers contacted the proxies and provided them with the study information, consent forms and questionnaire. Proxies who accompanied the patients to the doctor were given the materials in person; otherwise the materials were sent by post. Patients completed the questionnaire at the site of recruitment.

### Questionnaire and Data Collection

The data presented in this article were collected using a self-report questionnaire for patients and proxies, though a researcher was present at the site of recruitment to answer any questions while the patients completed the questionnaire. The researchers were clinical psychologists. All the proxies completed the questionnaire individually, either during waiting times at the recruitment sites or at their homes. The questionnaire included socio-demographic questions and an adapted version of the PACIC-S11.<sup>12</sup> We used the items from the German version of the PACIC-S11<sup>12</sup> and combined them with the five-point answer scale from the original long version of the German PACIC,<sup>13</sup> which ranges from "almost never" to "almost always." This scale was deemed more comprehensible in pretests, and this combination was also used in other short forms of the PACIC.<sup>19</sup> For the proxy survey, the items of the questionnaire were re-phrased as follows: sentences such as "Within the last 6 months, how often was *I* given choices about treatment to think about?" (patient questionnaire) were changed to "Within the last 6 months, how often was *your relative* given choices about treatment to think about?" (proxy questionnaire). In the last item, both the patients and the proxies were asked about their level of satisfaction with the care the patient had received; this question could be answered on a scale from "Not at all satisfied" to "Completely satisfied". A detailed validation of the adapted versions of the PACIC-S11.1 will be published elsewhere.

### Data Analysis

Patient characteristics were analyzed using descriptive statistics such as frequency counts. Data from the adapted PACIC-S11.1 were handled as numerical values, with 1 corresponding to "almost never" / "not at all satisfied" and 5 corresponding to "almost always" / "completely satisfied." Correlations in the assessments made by each patient and their respective proxies were analyzed using the Spearman correlation coefficient ( $r_s$ ).<sup>12</sup> The correlation coefficient can range from  $-1$  (perfect negative correlation) to  $1$  (perfect positive correlation), whereby  $0$  corresponds to no correlation. A correlation between  $> 0$  and  $< \pm 0.3$  was considered

poor,  $\pm 0.3$  to  $< \pm 0.6$  was considered fair,  $\pm 0.6$  to  $< \pm 0.8$  was considered moderate, and  $\pm 0.8$  to  $< 1$  was considered very strong.<sup>20</sup> Differences between the mean ratings of the patient group and the proxy group for each item were compared using paired *t*-tests. Results were considered significant if  $P < .05$ . All the analyses were performed using IBM SPSS Statistics for Windows, Version 25 (IBM Corp., Armonk, NY, USA).

## Results

### Participant Characteristics

After providing written, informed consent, 364 patients were surveyed in this study. Of these, 262 agreed to forward the survey to their proxy. The main reason why patients did not agree to forward the questionnaire to their relatives was a reluctance to overburden their relatives, since the patients already considered themselves a burden to their loved ones. In total, 74 proxies completed the survey and submitted written, informed consent to the study. The majority of the proxies were the patients' spouses and partners (81.1%) or children (14.9%). 78.4% of the patients were male (proxies: 20.3%). The average patient age was 68.3 years old (proxies: 63.5), and most were married and living with their partner (79.7%). The majority of both patients (83.8%) and proxies (78.4%) possessed German social health insurance. More than half (52.7%) of the patients had a permanent degree of disability. Additional characteristics of the samples are provided in Table 1.

### Comparison Between the Patient and Proxy Groups

The patients' and their proxies' ratings of PCC are displayed in Table 2 and Figure 1. On the group level, the assessments of the patients and those of their proxies differed significantly in 4 out of 12 items (Items 2, 4, 8, 12). On average, 9 out of 12 items were rated higher by patients than by proxies. Patients reported the highest score (4.46 out of 5) for satisfaction that their care was well-organized (Item 2). Proxies rated the item "given a copy of their treatment plan" (Item 4) highest, with a score of 4.35. Both patients and proxies rated the item "being encouraged to get to a specific group or class to help me cope with the chronic condition" lowest (Item 5, 2.28 and 2.45 out of 5 respectively). Overall, the patients reported that they were "rather satisfied" to "completely satisfied" with their care (Item 12, 4.27 out of 5). Proxies reported that they were "moderately satisfied" to "rather satisfied" (3.91 out of 5). There was no significant difference between the item ratings of the overall sample of 364 patients and those of the subsample of patients who had a proxy ( $N = 74$ ).

**Table 1.** Sample Characteristics (N=74 Pairs of Patient and Proxy).

	Patients n (%)	Proxies n (%)
Relationship with patient		
Spouse/significant other		60 (81.08)
Child		11 (14.86)
Other relationship (eg, friend)		3 (4.05)
Sex		
Male	58 (78.38)	15 (20.27)
Female	16 (21.62)	59 (79.73)
Age (in years)	68.34 (10.24 <sup>a</sup> )	63.54 (13.65 <sup>a</sup> )
Family status		
Living with partner (married)	59 (79.73)	64 (86.49)
Living with partner (not married)	6 (8.11)	8 (10.81)
Single	0 (0.00)	1 (1.35)
Divorced	4 (5.41)	1 (1.35)
Widowed	5 (6.76)	0 (0.00)
Total number of persons in household		
1	10 (13.51)	2 (2.70)
2	49 (66.22)	58 (78.38)
3	8 (10.81)	5 (6.76)
4	5 (6.76)	7 (9.46)
5	2 (2.70)	2 (2.70)
Professional qualification		
None	3 (4.05)	9 (12.16)
Vocational training	44 (59.46)	34 (45.95)
College degree	17 (22.97)	11 (14.86)
University degree	13 (17.57)	18 (24.32)
Other	6 (8.11)	8 (10.81)
Health insurance		
Social health insurance	62 (83.78)	58 (78.38)
Private supplementary insurance	2 (2.70)	2 (2.70)
Private health insurance	10 (13.51)	14 (18.92)
Nursing grade		
Yes	4 (5.41)	1 (1.35)
No	70 (94.59)	73 (98.65)
Degree of disability		
Yes	39 (52.70)	16 (21.62)
No	35 (47.30)	58 (78.38)

<sup>a</sup>Standard deviation.

### Comparison Between Individual Patient/Proxy Pairs

The correlation between specific patients' assessments of their PCC and those of and their paired proxies ratings are shown in Table 3. Fair correlations were observed for overall satisfaction with care (Item 12;  $r_s = 0.53$ ) and for the items "being contacted after a visit to see how things were going" (Item 10;  $r_s = 0.42$ ), "being given a copy of my

treatment plan" (Item 2;  $r_s = 0.35$ ), and "being asked about my health habits" (Item 6;  $r_s = 0.33$ ). All of these correlations were significant. For the remaining 8 items, the correlation between patients' ratings and those of their proxies was poor, though it was still significant for 5 of these items.

### Discussion

This study used the PACIC-S11.1 to assess the correlation between assessments of patient-centered care among patients with CHD and their proxies. Significant correlation between patient and proxy ratings was observed for 7 of the 12 items in the questionnaire. Nevertheless, both these significant correlations and the insignificant correlations were below  $<\pm 0.6$ , indicating a poor to fair agreement between individual patients and their proxies with regard to assessments of PCC. After overall satisfaction, the highest correlation among patient/proxy pairs was found for the items "given a copy of my treatment plan" and "being contacted after a visit." This might be due to the fact that both of these aspects can often be directly observed by proxies, for example, if a medication plan is lying around the house or they hear the patient take a phone call from their physician. All the other aspects would require active communication between the patients and their proxies, or for the proxies to have accompanied the patients during visits to their doctors. Our data collection did not include a metric for frequency of communication or attendance of the patients' healthcare appointments. However, the inclusion criterion of living in the same household as the patient is assumed to ensure a higher involvement in care and communication between patient and proxy than could be guaranteed using more distant proxies.

There was also a significant statistical difference in the mean group ratings per item, though these were close to each other for all items in terms of interpretation. The group proxy ratings therefore seem to be an adequate reflection of the overall level of patient-centeredness experienced by the patients. The concordance between the patient and proxy group ratings was also observed in factors such as the assessment of health-related quality of life.<sup>21,22</sup> Overall, the group of patients in our study tended to rate the patient-centeredness of their care higher than their proxies, as was observed in a study on health-related quality of life.<sup>23</sup> This might be due to the fact that patients perceive their care directly, while their proxies might not be present at all of their healthcare appointments or kept up to date about them. This is supported by the findings of another study, which linked decreasing correlation in ratings with decreases in the frequency of contact between the patient and their proxy.<sup>24</sup> Additionally, previous studies have noted that children provide lower ratings than spouses for nursing care, and also for the coordination and quality of care.<sup>24</sup> Our sample of proxies includes both spouses and children, but due to

**Table 2.** Patients’ and Proxies’ Rating of PCC (N=74 Pairs of Patient and Proxy).

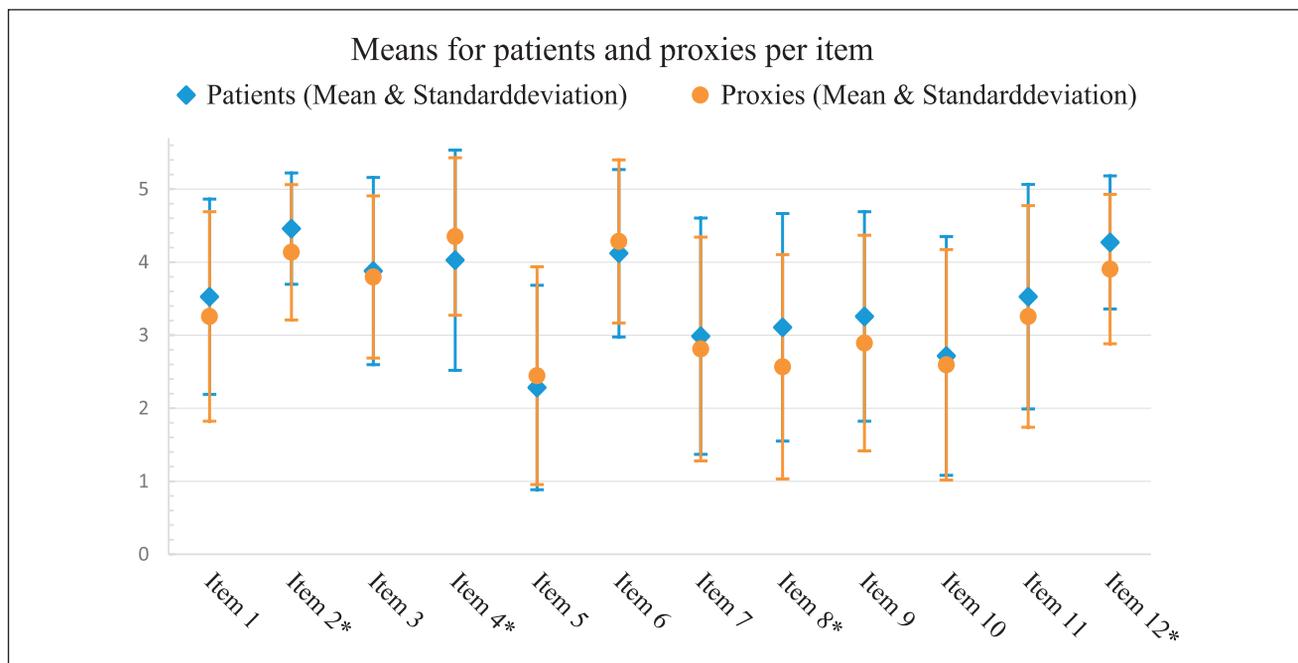
Item	How often was I ( <i>your relative</i> ) . . .	Patients’ mean <sup>a</sup>	SD <sup>c</sup>	Proxies’ mean <sup>a</sup>	SD <sup>c</sup>	P value
1	. . .given choices about treatment to think about?	3.53	1.34	3.26	1.43	0.21
2	. . .satisfied that my care was well organized?	4.46	0.76	4.14	0.93	0.01
3	. . .helped to set specific goals to improve my eating or exercise?	3.88	1.28	3.80	1.11	0.62
4	. . .given a copy of my treatment plan?	4.03	1.51	4.35	1.08	<0.05 <sup>d</sup>
5	. . .encouraged to get to a specific group or class to help me cope with my chronic condition?	2.28	1.40	2.45	1.49	0.43
6	. . .asked questions either directly or on a survey about my health habits?	4.12	1.15	4.28	1.12	0.35
7	. . .helped to make a treatment plan that I could carry out in my daily life?	2.99	1.62	2.81	1.53	0.50
8	. . .helped to plan ahead so I could take care of my conditions even in hard times?	3.11	1.56	2.57	1.54	0.02
9	. . .asked how my chronic conditions affect my life?	3.26	1.43	2.89	1.48	0.12
10	. . .contacted after a visit to see how things were going?	2.72	1.64	2.60	1.58	0.55
11	. . .told how visits with other types of doctors, like an eye doctor or surgeon, helped my treatment?	3.53	1.54	3.26	1.52	0.23
12	Overall, how satisfied are you with the medical care of your chronic disease?	4.27 <sup>b</sup>	0.91	3.91 <sup>b</sup>	1.02	<0.01

<sup>a</sup>Codings of answer categories: 1 =almost never, 2=generally not, 3=sometimes, 4=most of the time, 5=almost always.

<sup>b</sup>Codings of answer categories: 1 =not at all satisfied, 2=generally not satisfied, 3=moderately satisfied, 4=rather satisfied, 5 =completely satisfied.

<sup>c</sup>SD: Standard deviation.

<sup>d</sup>P value =.048.



**Figure 1.** Means for patients and proxies per item (N=74 patients and N=74 proxies).

\*=significantly different ratings (P < .05).

the small sample size, it was not possible to assess differences in correlation. It is likely that patients have closer contact with their spouses than with their children, and

exclusively using spouses as proxies might have yielded higher correlation in assessments of PCC on both the group level and the individual patient/proxy pair level. Another

**Table 3.** Correlation Between Individual Pairs of Patient and Proxy (N=74 Pairs of Patient and Proxy).

Item	How often was I ( <i>your relative</i> ) . . .	Correlation coefficient ( $r_s$ ) <sup>a</sup>	P value
1	. . .given choices about treatment to think about?	0.09	0.47
2	. . .satisfied that my care was well organized?	0.23	0.05
3	. . .helped to set specific goals to improve my eating or exercise?	0.28	0.02
4	. . .given a copy of my treatment plan?	0.35	<0.01
5	. . .encouraged to get to a specific group or class to help me cope with my chronic condition?	0.27	0.02
6	. . .asked questions, either directly or on a survey about my health habits?	0.33	<0.01
7	. . .helped to make a treatment plan that I could carry out in my daily life?	-0.01	0.95
8	. . .helped to plan ahead so I could take care of my conditions even in hard times?	0.24	0.04
9	. . .asked how my chronic condition affect my life?	0.08	0.50
10	. . .contacted after a visit to see how things were going?	0.42	<0.01
11	. . .told how visits with other types of doctors, like an eye doctor or surgeon, helped my treatment?	0.25	0.04
12	Overall, how satisfied are you with the medical care of your chronic disease?	0.53	<0.01

<sup>a</sup>Spearman correlation coefficient.

explanation for the tendency of proxies to rate PCC lower than the patients themselves might be that the patients completed the questionnaire in a setting where the researchers were present, and therefore tended to provide more socially acceptable ratings. Other studies have also produced mixed results in terms of correlation between patient and proxy ratings, with some studies reporting better agreement on health status and symptom-related questions, while others report better agreement regarding frequency, quality and/or organization of care.<sup>25-27</sup> Overall, the differences in ratings highlight the need to encourage patients' relatives and/or friends to become closely involved in disease management and care planning at an early stage in practice. If the patient's health status deteriorates, the person who takes on the role of their legal representative will need to be aware of the patient's wishes and preferences when making decisions on their behalf. Future research should also identify the expectations of relatives and friends in order to aid their active involvement in the care process. In addition to providing practical support, for example, with regard to adjusting diet or physical activity behavior, this might also strengthen the mutual emotional support between the patient and those close to them.

As in our study, participants in a Dutch study that used the PACIC also rated the organization of care (Item 2) highest.<sup>28,29</sup> The availability of regularly updated treatment guidelines for CHD and a disease management program in Germany might contribute to the general satisfaction rating for care organization observed in this study. Comparisons with other studies that use the PACIC questionnaire are difficult, as most studies use the long version and report on the long version's subscales, as opposed to on individual items.<sup>30</sup> Using the short version to survey participants can be particularly useful due to the added value it provides if

a patient's cognitive or physical ability to complete a questionnaire is limited, or if the study's overall data collection process includes a number of different instruments.

### Strengths and Limitations

Our study has several limitations. Firstly, the generalizability of our results is limited due to the study's small sample size. The planned overall sample size for patients in this study was reached, but only around 70% of these patients were willing to forward the questionnaire to relatives or allow the research team to do so, as they already feared that they were overburdening their partners or relatives due to the disease alone. Secondly, the mode of questionnaire administration differed between patients and proxies, as the patients completed the questionnaire in the presence of an interviewer and proxies did not necessarily attend the physician visit. This might bias the patients' toward providing more socially acceptable—and thus higher—ratings with regard to patient-centeredness. As the overall patient survey included instruments that required interviewer-led data collection, this was unavoidable. Finally, we did not conduct a separate survey on the expectations of patients and their proxies toward care. Such expectations might shape the retrospective assessment of patient-centeredness during care, and divergence might bias assessments. The strengths of our study include the fact that the patients were recruited in a variety of healthcare settings, including hospitals, rehabilitation clinics and local cardiologists' offices. This ensures a wide range of states of disease, settings and treatment experiences. As such, our results provide a better reflection of the care situation as a whole, rather than just a part of the care process. Due to the use of interviewer-assisted data collection and individual personal or telephone contact with

patients and proxies, there was no data missing from any of the questionnaires that were available for inclusion in the analysis. As such, data imputation was not necessary.

## Conclusion

Proxy surveys of relatives using the PACIC-S11.1 seem to be a suitable means of assessing the level of patient-centeredness in the care of overall groups of patients undergoing medical care for CHD. However, the limited correlation between individual patients' ratings and those of their proxies should be taken into account when surveying proxies instead of patients. As a result of this, proxy ratings for PCC using the PACIC-S11.1 should mainly be considered in situations where direct patient ratings are not possible, and not as a substitute for patient ratings. Future research on patient and proxy agreement should address factors that might modify correlation in ratings. These might include subgroup analyses for different family relationships between patient and proxy, the perceived closeness of the relationship, and the frequency with which the proxy accompanies the patient to their doctors' appointments.

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## Authors' Contributions

CA, FJ, FV, and SS designed the study. All authors refined the methods. HM and SP collected the data. AS and VV analysed and interpreted the data. VV drafted the manuscript. All authors critically read and revised the manuscript and approved the final version.

## Declaration of Conflicting Interests

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

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