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Symptoms and feelings valued by patients after a percutaneous coronary intervention: a discrete-choice experiment to inform development of a new patient-reported outcome

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ABSTRACT

Objective To inform the development of a patient-reported outcome measure, the aim of this study was to identify which symptoms and feelings following percutaneous coronary intervention (PCI) are most important to patients.

Design Discrete-choice experiment consisting of two hypothetical scenarios of 10 symptoms and feelings (pain or discomfort; shortness of breath; concern/worry about heart problems; tiredness; confidence to do usual activities; ability to do usual activities; happiness; sleep disturbance; dizziness or light-headedness and bruising) experienced after PCI, described by three levels (never, some of the time, most of the time). Preference weights were estimated using a conditional logit model.

Setting Four Australian public hospitals that contribute to the Victorian Cardiac Outcomes Registry (VCOR) and a private insurer's claim database.

Participants 138 people aged >18 years who had undergone a PCI in the previous 6 months.

Main outcome measures Patient preferences via trade-offs between 10 feelings and symptoms.

Results Of the 138 individuals recruited, 129 (93%) completed all 16 choice sets. Conditional logit parameter estimates were mostly monotonic (eg, moving to worse levels for each individual symptom and feeling made the option less attractive). When comparing the magnitude of the coefficients (based on the coefficient of the worst level relative to best level in each item), feeling unhappy was the symptom or feeling that most influenced perception of a least-preferred PCI outcome (OR 0.42, 95% CI 0.34 to 0.51, p<0.0001) and the least influential was bruising (OR 0.81, 95% CI 0.67 to 0.99, p=0.04).

Conclusion This study provides new insights into how patients value symptoms and feelings they experience following a PCI.

Strengths and limitations of this study

- ► This study design used a discrete-choice experiment (DCE), which quantifies the relative value as well as order of importance of each individual symptom and feeling, unlike simple ranking methods.
- ► There was no correlation between individual symptoms and feelings or overlap between scenarios as the DCE design was orthogonal and balanced.
- ► Interaction effects cannot be accurately estimated as the study design selected choice sets assuming an additive model.

INTRODUCTION

Worldwide, coronary artery disease (CAD) is the leading cause of death, and will continue to be until at least 2030.[1] Percutaneous coronary intervention (PCI) and coronary artery bypass graft (CABG) surgery are among the most common major medical procedures performed in North America, Europe and the UK.[2 3] While PCI is less invasive than CABG, long-term benefits over optimal medical management for patients with chronic stable CAD remain unknown.[4] The effectiveness of PCI is also questionable in terms of quality of life and cost benefits if repeat revascularisation is required, and in patients with multivessel disease.[5–9] Measuring patient-reported outcomes may provide greater insight into the health and well-being of patients following PCI.

There is growing recognition that understanding outcomes from the view of the patient, rather than relying on clinical end points alone, offers the potential to improve cardiac care.[10 11] The International Consortium for Health Outcomes Measurement (ICHOM) Standard Set for CAD has identified five outcomes that matter most to patients with CAD: (1) health-related quality of life; (2) functional status; (3) depression;

(4) dyspnoea and (5) angina.[12] It recommends three patient reported outcome measures (PROMs) totalling 11 items be used with patients with CAD to measure these outcomes. While these recommendations are based on advice from a group of leading physicians, measurement experts and patients, the number of items across different instruments is likely to limit uptake. A more concise, single tool may be developed to improve clinical utility and decreases respondent burden.

PROMs quantify information about the symptoms and feelings a patient is experiencing, providing insights into their overall health state. PROMs seek information directly from patients without interpretation of their response by a clinician or anyone else. They are used to assess treatment effectiveness and are a tool to improve the quality of clinician-patient interactions, facilitating shared decision-making and patient-centred care.[13] Their use is recommended in clinical trials of interventions for patients with cardiovascular disease by key stakeholders including the American Heart Association[14 15] and is a requirement of health service funders in the UK and the USA.[16] Cardiovascular registries focus on improving quality of care by reporting process and outcome measures. The most commonly collected and reported outcomes are in-hospital and 30-day mortality and complications.[12] Some collect generic quality of life measures but cardiac-specific PROMs are not routinely collected. The length of existing cardiac PROMs (up to 160 items)[17 18] may be a key factor in their limited uptake. In addition, a previous review highlighted that the patient perspective had often been overlooked in the development of PROMs for patients who had undergone elective coronary revascularisation.[17] As such, instruments were not necessarily reflective of outcomes most important to patients, including only two of the three PROMs recommended by ICHOM.[12 19]

One method for obtaining quantitative information about patient perspectives is via a discrete-choice experiment (DCE). DCEs involve respondents making choices in reply to a series of hypothetical scenarios. For example, a respondent is presented with two health profiles (scenario A and scenario B), which have varying levels of symptoms (eg, no pain, some shortness of breath, severe bruising vs severe pain, no shortness of breath, no bruising), and the respondent selects which health profile they would prefer. The participant responds to a series of paired scenarios with varying combinations of symptoms. The design and analysis provides information on trade-offs that the respondents are willing to make for different symptoms, for example, how much pain would a patient be willing to endure to experience less shortness of breath. As such, DCEs go beyond ranking exercises by providing information on relative strength of preference and trade-offs. Additionally, they enable interactions between respondent characteristics and outcomes to be explored and provide an in-depth assessment of preferences.[20] DCEs have not previously been applied in the development of cardiac PROMs.

In addition to response burden and a lack of patient involvement in the design and development of existing cardiac PROMs, generic quality of life instruments may have measurement flaws when applied to PCI populations. By example, the Victorian Cardiac Outcomes Registry (VCOR) collects the 5-item Euroqol (EQ-5D) at the 30-day telephone follow-up of patients undergoing PCI.[21] Analysis of data shows that at 30 days post procedure, approximately 80% of patients report having no problems with personal care, mobility, usual activities, pain/discomfort or anxiety/depression.[22] This suggests that either patients are generally feeling and doing well after PCI, or more likely, that the EQ-5D has a ceiling effect in the PCI population. An opportunity exists to develop a new PROM for patients undergoing PCI that is based on patient perspective, is concise, useable and has sound measurement properties.

The primary aim of this study was to quantify the importance of symptoms and feelings commonly experienced by patients following PCI, using a DCE to inform the development of a PROM.

Specifically, the objectives were to:

1. Elicit relative value of each symptom and feeling including trade-offs;
2. Examine patient characteristics that could influence the perceived value of each symptom and feeling and
3. Provide recommendations for symptoms and feelings that could be included in a new PROM.

METHODS

This study was step 3 of a larger project that aimed to develop a PROM for patients undergoing PCI (figure 1).

The results from steps 1 and 2 were considered in the designing of the DCE, to inform:

1. The symptoms and feelings of interest (literature review, focus groups and interviews) and
2. Setting levels for symptoms and feelings (literature review, focus groups and interviews; expert opinion).

Literature review, focus groups and interviews (steps 1 and 2)

A systematic search of the peer-reviewed literature was undertaken to identify existing cardiac PROMs.[17] Twenty-seven PROMs were identified yielding 430 symptoms and feelings that were used to develop topic guides for the focus groups and interviews. Further details on the methods and results of the literature review have been published elsewhere (refer to Peeters *et al*[17]).

Eight focus groups (n=27) and five one-one interviews were conducted with people aged ≥18 years who had undergone a PCI in the last 6 months. Sessions explored: (1) the relevance and importance of symptoms and feelings identified from the literature review and (2) additional symptoms and feelings not identified by the search. They were semi-structured, and followed a topic guide to stimulate discussion about symptoms and feelings that were important to patients and identify the potential range of variation in each symptom and feeling

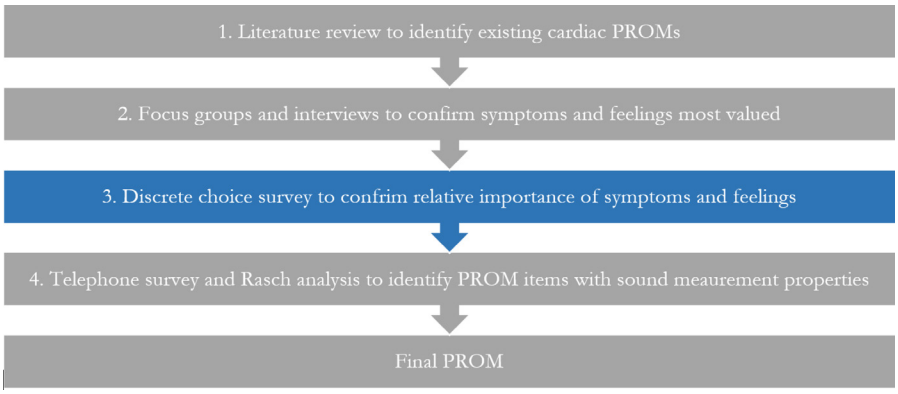


Figure 1 A four-step mixed-methods approach to develop and validate a new cardiac patient-reported outcome measure (PROM).

(levels). Example levels were presented and their appropriateness discussed. The range of levels of each item was intended to: (1) span the clinically relevant range of symptoms and feelings that has been seen, or might be expected to be seen, in clinical trials or clinical practice; (2) ensure differences in levels encompass the range of improvements in symptoms and feelings that potentially could be seen in clinical trials or clinical practice and (3) reflect the maximum range over which respondents are willing to accept trade-offs among symptoms and feelings. Further details on the methods and results from these focus groups and interviews have been published elsewhere (refer to Ayton *et al*[23]). Ten symptoms and feelings with a 3–4 level response option were confirmed as being most important to patients. These results were presented to an expert panel (consisting of cardiologists, nurses, health services researchers and allied health professionals), who agreed on the symptoms and feelings identified and the assignment of three levels to each symptom/feeling (table 1).

Construction of choice sets

It was not feasible to present an individual with all possible combinations from the 10 symptoms and feelings with three levels in table 1 (full factorial design: 3^{10}=59 049 combinations). Therefore, experimental design techniques were used to draw a subset of symptom and feeling combinations to be used in the DCE. We employed NGENE (V.1.1.2) to develop the design. We developed a candidate set of choice sets, where any 4 of the 10 symptoms and feelings were constrained to be the same between the two options (and as shown in figure 2, the symptoms and feelings that do differ are highlighted to demonstrate differences between options). We then constructed a D-efficient design (i.e., identified a subset of the full-choice design) from those candidate choice sets.[20] In addition to the assumption about the degree of overlap, we also excluded certain pairwise combinations of levels to ensure implausible combinations were not used.[24] The implausible combination we excluded was feeling short of breath most of the time when exerting

Table 1 Final set of symptoms and feelings and levels for the discrete choice experiment

Item	Level 1 (worse)	Level 2	Level 3 (better)
Pain or discomfort when exerting (eg, carrying groceries, climbing, stairs, brisk walking)	Most of the time	Some of the time	Never
Shortness of breath when exerting (eg, carrying groceries, climbing stairs, brisk walking)	Most of the time	Some of the time	Never
Concerned or worried about heart problem	Most of the time	Some of the time	Never
Tiredness when doing usual activities (eg, work, social activities, domestic work)	Most of the time	Some of the time	Never
Lacking confidence to do usual activities (eg, work, social activities domestic work)	Most of them	Some of the time	Never
Physically unable to do usual activities (eg, work, social activities, domestic work)	Most of the time	Some of the time	Never
Feeling unhappy	Most of the time	Some of the time	Never
Trouble falling or staying asleep	Most of the time	Some of the time	Never
Dizziness or light-headedness	Most of the time	Some of the time	Never
Bruising	Most of the time	Some of the time	Never

Choice 2 of 16

Consider the following 2 scenarios after your stent procedure. Which scenario would you prefer?

Symptoms and feelings	Scenario A	Scenario B
Feeling pain or discomfort when exerting myself (e.g. carrying groceries, climbing stairs, brisk walking)	Some of the time	Most of the time
Feeling short of breath when exerting myself (e.g. carrying groceries, climbing stairs, brisk walking)	Most of the time	Never
Feeling concerned or worried about my heart problems	Most of the time	Some of the time
Feeling tired when doing my usual activities (e.g. work, social activities, domestic work)	Never	Most of the time
Lacking confidence to do my usual activities (e.g. work, social activities, domestic work)	Most of the time	Some of the time
I am physically unable to do my usual activities (e.g. work, social activities, domestic work)	Some of the time	Some of the time
Feeling unhappy	Most of the time	Most of the time
Having trouble falling or staying asleep	Some of the time	Some of the time
Feeling dizzy or light-headed	Most of the time	Some of the time
Bothered by bruising	Most of the time	Most of the time
Please tick the box under the scenario that you would prefer:	**Scenario A** ☐	**Scenario B** ☐

Figure 2 Example choice set of the discrete choice experiment. Each participant was presented with 16 different choice sets. Six of the 10 dimensions differed between scenarios in each choice set and that these were highlighted in blue so that the participant could easily identify differences between scenarios.

yourself (eg, carrying groceries, climbing stairs, brisk walking) but never physically unable to complete usual activities (eg, work, social activities, domestic work).

The final design consisted of 240 choice sets, from which each respondent was randomly assigned to one of 15 versions which consisted of a block of 16 choice sets. The resulting design was nearly orthogonal and balanced in terms of the number of times each level of an item was seen in a scenario. The final design is reported in online supplementary appendix 1. To avoid confusion with participants, the choice sets were labelled as 'scenario A' and 'scenario B'. For each choice set, the respondent was asked which scenario they would prefer to experience 1 month after having a PCI. An example of a choice task is shown in figure 2.

Survey design and pilot testing

The survey contained two components. Section 1 included 11 demographic questions on characteristics of respondents (sex, age, living status, education, comorbidities, heart disorders, emergency/elective PCI, date of procedure) used to assess the representativeness of the sample against VCOR.[21] Section 1 also included 11 general health questions. Section 2 was the DCE survey as described above.

Once developed, the survey was pilot tested with eight patients undergoing PCI through one-one interviews. These patients had initially expressed interest in participating in interviews or focus groups for the prior stage of this research; however, they were unable to participate at the required time. Patients who had indicated that they were willing to be later contacted for the DCE component of the research were contacted to participate in the pilot testing of the survey. The results were used to establish a dissemination approach (paper version and online version) and refine the comprehension and wording of the survey. During the interviews, a researcher asked patients to 'think aloud' as they completed the survey, while the researcher observed. Once completed, patients were asked a series of debriefing questions to determine the feasibility of completing the survey; whether they understood the DCE questions and instructions and if any relevant symptoms and feelings were omitted. After each participant interview, changes to the DCE were made based on patient comments and tested in the subsequent interview. The final two pilot patients raised no issues with the survey.

Study sample

In accounting for the number of choice sets, alternatives and analysis cells, the equation of Johnson and Orme[25] was used to calculate a required sample size of 46. A review undertaken by de Bekker-Grob *et al*[26] found that 41% (n=69) of health-related studies using DCE analysis had a sample size of 100–300. Therefore, we aimed to obtain 100–150 returned survey responses.

Participant recruitment

Our study sample included cardiac patients aged ≥18 years who had undergone a PCI in the previous 6 months; there were no exclusion criteria. Potential participants were

identified by review of hospital records from four Australian hospitals; and a private insurer's claim database. A participant information sheet and letter with a link to the online survey were sent out to potential participants. Hardcopy surveys were sent to participants on request. Hardcopy surveys were also distributed at cardiac rehabilitation sessions run by one of the hospitals. Data collection took place between October 2016 and May 2017. No identifying information was collected. Completion and return of the survey implied consent.

Analysis

We assessed the representativeness of the sample relative to the VCOR population with X^2 tests for categorical characteristics and a t-test for continuous characteristics. Choice data were analysed using a conditional logit model. These regression models are commonly used when the dependent variable is binary such as for a choice—an individual's preference for A or B.[27] To obtain robust variance estimates and account for the possible correlation of non-independent responses to the 16 scenarios presented to each individual, we applied Stata's cluster-correlated robust estimate of variance. In this model, the dependent variable was the choice; the explanatory variables included the levels of the individual symptoms and feelings shown in table 1. All analyses were conducted using Stata IC V.14. In interpreting the regression results, the sign of the coefficient reflected whether the dimension had a positive or a negative effect on preference compared with the base level. Since this base was never having the symptom or feeling, we expected a priori for coefficients to be negative due to the negative wording of symptoms and feelings (eg, pain most of the time was expected to have been a less preferred outcome than never having pain). To infer relative importance of each of the individual symptoms and feelings to participants, the magnitude of the coefficients (based on the worst level relative to the best level) were compared.

To explore heterogeneity of response scale, whereby responses may vary due to non-observable participant characteristics, we employed a heteroscedastic conditional logit model.[27] Analyses included categorical covariates (such as age, emergency procedure and sex) in the model one by one. For this, age was divided into two categories (70 years and over or under 70), emergency procedure (yes or no) and sex (female or male). Statistically significant covariates (defined as $p<0.05$) were then included and non-significant covariates were excluded from this model. The value of accounting for how much covariates affected the model fit was tested using Akaike information criterion (AIC), and the complimentary Bayesian information criterion (BIC). The results from the analysis were presented to a group of clinical experts (cardiologists, cardiac nurse, VCOR registry members, health services managers) to ensure clinical applicability and acceptability.

Patient involvement

Patients were not directly involved in the development of the research questions, study design or conduct. A lay summary of our findings from this and all studies from this project will be available for VCOR participants and the public at https://vcor.org.au.

RESULTS

Patient characteristics

A total of 1056 surveys were distributed to potential participants; 1032 surveys via post and 24 distributed at cardiac rehabilitation sessions. A total of 139 surveys were returned representing a response rate of 13%. One survey was excluded (recruited via the private health insurer) as the patient had a CABG and not a PCI. All patients started the first DCE choice set and 129 (93 %) completed all 16 choice sets, with a total of 138 surveys included in the analysis.

Of the 138 patients, the majority were male (n=102; 74%); and were aged under 70 years (n=75, 54%). Seventy were retired (51%). For 70% of patients (n=96), this was their first stent procedure; and 34% of these were an elective procedure (n=47). Demographics and self-reported health characteristics are presented in table 2. The study sample is representative of the patient demographics from the VCOR in relation to sex (77% male), age (mean 66, SD 12.0), recurrent PCI (32.7%), emergency procedure (60%) and elective procedure (36%).[21]

Objective 1: eliciting relative value of each symptom and feeling and trade-offs

The results for the conditional logit model are reported in table 3. There is a logical ordering of levels within the majority of symptoms and feelings—monotonic construction (ie, moving to worse levels in each individual symptom and feeling made the option less attractive) (table 2). Each movement away from the 'never' level (level 1) for each item is negative and absolutely larger, except level 2 for *tiredness, shortness of breath and bruising*. However, these non-monotonicities (non-logical ordering of levels) were not statistically significant. Out of a possible 20 coefficients, 12 are statistically significant in the model. Both levels 2 and 3 were statistically significant for three symptoms and feelings (*pain, lacking confidence to do usual activities* and *trouble falling asleep*).

When comparing the magnitude of the coefficients to infer relative importance of the item to participants (based on the worst level relative to the best level), the most important item was *feeling unhappy* (OR 0.42, 95% CI 0.34 to 0.51, $p<0.0001$). The negative coefficient indicates feeling unhappy was the symptom or feeling that most influenced perception of a least-preferred PCI outcome. Next important were *physically being able to do daily activities* (OR 0.48, 95% CI 0.39 to 0.6, $p<0.0001$) and least

Table 2 Demographic and clinical characteristics of participating patients

Characteristic	Study participants (n=138)
Male, n (%)	102 (73.9)
Age, mean SD	67 (10.8)
Living alone, n (%)	33 (23.9)
Education, n (%)	
Primary school	8 (5.8)
High school	39 (28.3)
Trade/certificate/diploma	47 (34.1)
University	44 (31.9)
Working status, n (%)	
Full-time	32 (23.2)
Part-time/casual	16 (11.6)
Retired	70 (50.7)
No paid work	20 (14.5)
Privately insured, n (%)	80 (58.0)
Time since PCI (months), mean (SD)	4.33 (2.0)
First PCI, n (%)	96 (69.6)
Type of procedure	
Emergency procedure, n (%)	86 (62.3)
Elective procedure, n (%)	47 (34.1)
Do not know, n (%)	5 (3.6)
Top five comorbidities, n (%)	
Arthritis	43 (31.2)
Diabetes	35 (25.4)
Depression	23 (16.7)
Asthma	20 (14.5)
Macular degeneration or cataracts	18 (13.0)
Health rating, n (%)	
Poor	2 (1.5)
Fair	28 (20.3)
Good	42 (30.4)
Very good	46 (33.3)
Excellent	19 (13.8)

important was *bruising* (OR 0.81, 95% CI 0.67 to 0.99, p=0.04).

Objective 2: examining patient characteristics that could influence the perceived value of each symptom and feeling

Age (under 70 vs 70 years and older), sex and procedure type (emergency vs elective) were added to the model one by one. Age and sex were statistically significant covariates (p<0.05). However, there was no statistically significant variation in item preferences between elective and emergency patient groups (p=0.45). Figure 3 shows the relative importance of each of the items for the unadjusted and adjusted (adjusted for age and sex) models. In general, the coefficients of the two models are similar. Of note, the AIC and BIC (tests for best model fit) were both slightly reduced when accounting for age and sex in the model (indicating the adjusted model is considered to be a better fit model).

Objective 3: recommended symptoms and feelings to be included in a PROM

The ORs for each of the symptoms and feelings was presented to the clinical expert group. The clinical experts felt that *bruising* could be removed as an item; however, *shortness of breath* should be included as it is an important clinical indicator of recovery. The coefficients for *tiredness* (OR 0.61, 95% CI 0.51 to 0.73, p<0.0001) and *trouble falling asleep or staying asleep* (OR 0.59, 95% CI 0.49 to 0.71, p<0.0001) were the next least important. In addition, it is possible that there may be interaction in preferences for these two symptoms and feelings, as they may be measuring similar constructs. Hence, we deferred to the results from the focus groups and interviews (step 2, figure 1), where participants described how their medications post-PCI impacted on sleep quality which led to feelings of tiredness and fatigue.[23] Therefore, it was recommended, to retain only *trouble falling asleep or staying asleep*. The clinical expert group recommendations resulted in a final set of eight symptoms and feelings for future assessment of a PROM for patients undergoing PCI.

DISCUSSION

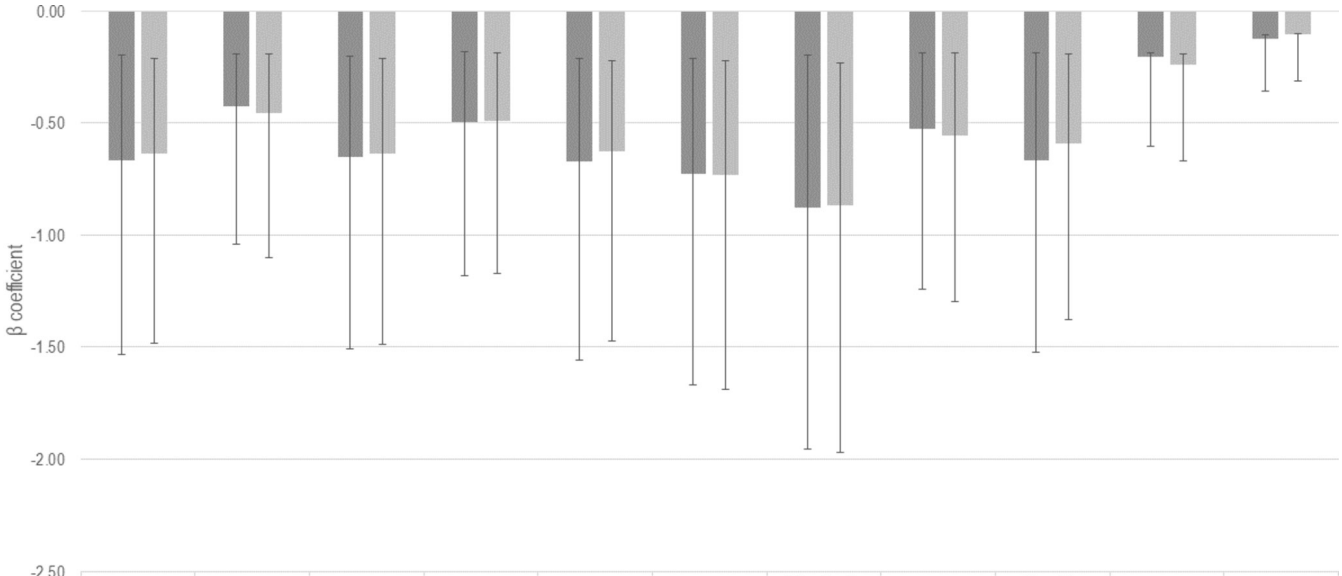
In this study, eight symptoms and feelings were identified as being important to patients undergoing PCI, compared with the ICHOM recommended 11 items from three separate cardiac PROMs, highlighting the potential for a new briefer cardiac PROM. The most important symptoms and feelings to patients following a PCI were *feeling unhappy*, followed by *physically being able to do usual activities*. The least important was *bruising*. There was some overlap between symptoms and feelings identified as most important to patients with CAD by ICHOM and this study, specifically feeling unhappy, physically being able to do usual activities, pain and discomfort on exertion and shortness of breath. However, this study identified additional symptoms and feelings as important—sleep difficulties, dizziness, confidence to do usual activities and concern or worry about heart problems. These findings suggest that there is opportunity to improve the measurement of patient-reported outcomes in patients undergoing PCI by incorporating the findings from this study. Further analysis will confirm which of the eight items have sound measurement properties and if in combination they provide a reliable and valid measure of patient-reported outcome post-PCI.

The finding of this study that feeling unhappy was the most influential symptom or feeling in patients' assessment of their health outcome following PCI is consistent with previous studies. Epidemiological studies report that 25%–50% of people experience depression

Table 3 Conditional logit regression results from discrete-choice experiment

Symptoms and feelings	Level	OR	95% CI	P values
Pain or discomfort	Never	*Reference level*		
	Some of the time	0.78	(0.64 to 0.94)	0.01
	Most of the time	0.51	(0.42 to 0.63)	<0.0001
Shortness of breath	Never	*Reference level*		
	Some of the time	1.12	(0.93 to 1.36)	0.24
	Most of the time	0.65	(0.54 to 0.79)	<0.0001
Concerned or worried about heart problem	Never	*Reference level*		
	Some of the time	0.85	(0.70 to 1.03)	0.09
	Most of the time	0.52	(0.43 to 0.63)	<0.0001
Tiredness	Never	*Reference level*		
	Some of the time	1.03	(0.86 to 1.24)	0.75
	Most of the time	0.61	(0.51 to 0.73)	<0.0001
Confidence to do usual activities	Never	*Reference level*		
	Some of the time	0.64	(0.52 to 0.78)	<0.0001
	Most of the time	0.51	(0.41 to 0.63)	<0.0001
Physically able to do usual activities	Never	*Reference level*		
	Some of the time	0.87	(0.71 to 1.06)	0.18
	Most of the time	0.48	(0.39 to 0.6)	<0.0001
Feeling unhappy	Never	*Reference level*		
	Some of the time	0.89	(0.73 to 1.07)	0.22
	Most of the time	0.42	(0.34 to 0.51)	<0.0001
Trouble falling or staying asleep	Never	*Reference level*		
	Some of the time	0.84	(0.69 to 1.03)	0.09
	Most of the time	0.59	(0.49 to 0.71)	<0.0001
Dizziness or light-headedness	Never	*Reference level*		
	Some of the time	0.86	(0.73 to 1.03)	0.11
	Most of the time	0.51	(0.42 to 0.62)	<0.0001
Bruising	Never	*Reference level*		
	Some of the time	1.01	(0.85 to 1.21)	0.87
	Most of the time	0.81	(0.67 to 0.99)	0.04

and 24%–72% experience anxiety in the 3 months after PCI.[28–30] The feelings of depression are prevalent, and they are associated with an increased risk of mortality and revascularisation post-PCI.[31] The reason for these psychological symptoms are posited to be due to lack of knowledge and information provided about the disease and the procedure, low health literacy, feeling physically unwell after a PCI and fears of adverse outcomes.[28] Prior research has also indicated that the PCI may lead to increased sympathetic activity and inflammation, which may lead to anxiety and depression.[28] These feelings may affect a patient's daily life and work activities and also impact on perceptions of overall satisfaction of the treatment. Assessing feelings of anxiety and depression following a PCI may assist in the identification of unmet care needs and facilitate discussions about need for psychological interventions for some patients. One novel finding by this study was that patients resonated with the wording of being unhappy over depression, which may indicate a preference for non-clinical terminology to describe their emotional states. Prior research has indicated that lay accounts of mental health do not tend to recognise emotional distress as a medical problem, rather the feelings are seen as part of normal life.[32] Most existing PROMs focus on depression as opposed to feeling unhappy. By example, of the three PROMs recommended in the ICHOM Standard Set for CAD, none include questions about happiness, but they do contain questions about depression.[12] The Set identifies depression as one of the outcomes that matters most to cardiac patients and recommends this be assessed via the Patient Health Questionnaire.[12] The findings of this study suggest happiness may be the more meaningful feeling to assess than depression.



	Pain or discomfort	Shortness of breath	Concerned or worried about heart	Problem	Tiredness	Confidence to do usual activities	Physically able to do usual activities	Feeling unhappy	Trouble falling or staying asleep	Dizziness or light-headedness	Bruising
Unadjusted	-0.67	-0.43	-0.65	-0.50	-0.67	-0.73	-0.88	-0.53	-0.67	-0.21	-0.12
Adjusted	-0.63	-0.45	-0.64	-0.49	-0.63	-0.73	-0.87	-0.56	-0.59	-0.24	-0.10

Figure 3 Conditional logit regression results from discrete-choice experiment (unadjusted vs adjusted for age and gender).

It was an important finding of this study that symptom and feeling value did not appear to vary across elective and emergency patient groups, indicating that PROMs that include the eight recommended outcomes are likely to be applicable to both patient groups. There is limited prior research that has explored the validity of PROMs across emergency and elective cardiac patients.

Common symptoms and feelings included in existing cardiac-specific PROMs include physical ability, pain, depression, concern or worry about heart problems, shortness of breath (dyspnoea) and tiredness. These symptoms and feelings were ranked highly in the DCE by participants, except for shortness of breath, which was ranked the second least important item. Patients felt that shortness of breath was a less important item following PCI, despite shortness of breath being a key clinical symptom of heart disease. Shortness of breath has also been recommended as a core item for cardiac instruments to measure, which explains its common appearance in previous cardiac PROMs.[12] Interestingly, in our survey, we questioned patients about pain and discomfort when exerting (eg, carrying groceries, climbing, stairs, brisk walking), whereas previous PROMs specify the area of pain (eg, chest, shoulders, legs).[15] During step 2 of this study, participants did speak about chest pain (angina); however, they identified that angina manifested as pain in other areas of the body (jaw, shoulder, arm) and also was experienced as 'discomfort' rather than pain.[23] Therefore, in order to make the PROM as brief as possible, we decided to include only one question about pain and make it a generic pain question including the discomfort aspect. As PROMs are generally completed by the patients themselves to avoid interpretation by a clinician or other health provider, it is essential that PROMs are acceptable and easily interpretable.

This study has a number of strengths. DCE have an advantage over simple ranking methods as they quantify the relative value, as well as order of importance of each individual item.[33 34] The DCE was initially pilot tested with eight patients to gauge whether the survey was easy to complete and what adjustments were required to improve usability. Our DCE design was both orthogonal and balanced, which ensured there was no correlation between individual symptoms and feelings or overlap between scenarios. The thorough development of the DCE, including literature review, focus groups and survey piloting, ensured optimal selection of symptoms and feelings evaluated in this DCE. After completing the DCE, participants were also asked if they felt any key symptoms or feelings were missing from the list and none was identified. The engagement of clinicians and registry staff in both the design and interpretation of the findings has aimed to optimise the utility of the PROM. However, there were some limitations of the design to be considered. The DCE asked participants to consider 16 choice sets each with two different health scenarios containing 10 symptoms and feelings per scenario. A large amount of information can be difficult to simultaneously consider and, as such, participants may not have fully deliberated all information or symptoms and feelings. Similar surveys have also included a large number of symptoms and feelings (e.g., the survey by Norman *et al*[18] included 11 symptoms and feelings, and a survey by Rowen *et al*[24]

included 8 symptoms and feelings). It is possible that there may be interaction in preferences for some of the symptoms and feelings, for example, tiredness and sleep. Nevertheless, the study design selected choice sets assuming an additive model, meaning that interaction effects cannot be accurately estimated. A low response rate was observed in this study (13%). Still, participant characteristics were found to be similar to the VCOR population and thus likely to be representative of this clinical group, although they may differ in terms of other unmeasured characteristics. The low response rate also limited statistical power to undertake subgroup analyses of individual conditions (such as angina, myocardial infarct). Participants with different conditions may perceive such factors differently, warranting further investigation in future studies.

CONCLUSION

Understanding the symptoms and feelings most valued by patients following PCI provides valuable data to inform the establishment a new PROM for patients undergoing PCI. The results from this study have been used as part of a larger mixed-methods project to develop a PROM. The DCE analysis led to the 10-item PROM being reduced to 8 symptoms and feelings. DCEs are a useful method to adopt in the development of PROMs. The symptoms and feelings identified by this study will be tested in further analysis to confirm which combination of items should be included in a new PROM for patients follow PCI.

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