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## Understanding how a palliative-specific patient reported outcome intervention works to facilitate patient-centred care in advanced heart failure: A qualitative study.

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### Abstract

**Background:** Palliative care needs of patients with chronic heart failure (CHF) are poorly recognised. Policy makers advise a patient-centred approach to holistically assess patients’ needs and care goals. Patient-reported outcome measures are proposed to facilitate patient-centred care.

**Aim:** To explore whether and how a palliative care-specific patient-reported outcome intervention involving the Integrated Palliative care Outcome Scale (IPOS) influences patients’ experience of patient-centred care in nurse-led CHF disease management clinics.

**Design:** A feasibility study using a parallel mixed methods embedded design was undertaken. The qualitative component which examined patients and nurses experience of the intervention is reported here. Semi-structured interviews were conducted and analysed using framework analysis.

**Setting/Participants:** Eligible patients attended nurse-led CHF disease management clinics in two tertiary referral centres in Ireland with New York Heart Association functional class (NYHA) II-IV. Nurses who led these clinics were eligible for inclusion.

**Results:** Eighteen patients and all four nurses involved in the nurse-led clinics were interviewed. Three key themes were identified; identification of unmet needs; holistic assessment; and patient empowerment. The intervention impacted on processes of care by enabling a shared understanding of patients’ symptoms and concerns; facilitating patient-nurse communication by focusing on these unmet needs; and empowering patients to become more involved in clinical discussions.

**Conclusions:** This IPOS-based intervention empowered patients to become more engaged in the clinical consultation and to highlight their unmet needs. This study adds to the evidence for the mechanism of action of PROMs to improve patient-centred care and will help inform outcome selection for future PROM research.

**Keywords:** Palliative Care; heart failure; patient-reported outcome measure; qualitative

## Introduction

Chronic heart failure (CHF) affects 1-2% of the adult population.<sup>1</sup> It is characterised by a high illness burden, compounded by poor symptom identification by patients and healthcare professionals.<sup>2</sup> CHF affects patients physically and psychosocially with loss of identity due to changes in status and independence,<sup>3</sup> thereby diminishing quality of life.<sup>4,5</sup> CHF patients can experience suboptimal communication particularly around psychological problems<sup>6</sup> and future care plans.<sup>7</sup> Policy makers advise a patient-centred approach for CHF involving an holistic assessment of patients' needs and identification of their preferences, priorities and goals for care;<sup>8-10</sup> an approach sharing a similar philosophy to palliative care.<sup>11</sup>

Patient-reported outcome measures (PROM) facilitate this patient-centred approach<sup>12</sup> by uncovering patients' problems<sup>13</sup> and may improve communication and patient care.<sup>14,15</sup> PROMs are patient-completed questionnaires proposed to provide a subjective assessment of patients' own health status.<sup>16</sup> In advanced conditions, PROM-based systematic symptom assessment significantly increases symptom identification compared to open-ended clinical questions.<sup>17</sup> Figure 1 illustrates the conceptual understanding of how patient-reported outcomes work to facilitate patient-centred care. Boxes on the left illustrate PROM impact on clinical decision-making. Boxes on the right illustrate how this facilitates patient-centred care. PROMs identify unrecognised problems,<sup>18,19</sup> capturing the ramifications of illness on patients' lives.<sup>20</sup> This prompts discussions about these problems,<sup>21,22</sup> helping to identify patients' priorities and preferences,<sup>14,23</sup> which inform their treatment plan.<sup>24,25</sup> Patients feel supported in having their needs, priorities and preferences recognised and addressed.<sup>15,26</sup> The full impact of PROMs on clinical practice has yet to be determined.<sup>24</sup>

[Figure 1]

The Integrated Palliative care Outcome Scale (IPOS) is a PROM developed with the construct that advanced disease globally affects patients' lives and is designed to identify physical, psychosocial and spiritual unmet needs.<sup>27</sup> CHF patients would benefit from such a

structured assessment,<sup>2</sup> providing an opportunity for their problems to be discussed in the clinical consultation.<sup>18</sup>

We undertook a feasibility and acceptability study using a parallel, mixed-methods embedded design of a palliative-specific PROM-based intervention (IPOS with nurse education and training) with CHF patients, reported elsewhere.<sup>28</sup> (feasibility REF) As part of this study, we conducted qualitative semi-structured interviews to explore the mechanism of action of this intervention in clinical practice<sup>18,29</sup> and in facilitating patient-centred care. We undertook a systematic literature review of CHF patient-centred interventions to identify common patient-centred care domains used in these interventions.<sup>11</sup> From this work, we developed a framework of patient-centred domains. This was used to explore specific patient-centred care related themes in the patients' and nurses' descriptions of the potential mechanism of action of the intervention, while also allowing for the emergence of new domains. This study aimed to explore if and how this palliative-specific PROM-based intervention facilitates patients' experience of patient-centred care in nurse-led CHF disease management clinics.

## Methods

### Design and Methodology

This qualitative study used semi-structured interviews. It was part of a wider feasibility study using a parallel, mixed methods embedded design,<sup>30</sup> reported elsewhere.<sup>28</sup> (feasibility REF) This paper reports solely on the qualitative findings.

### Setting and Sample

Eligible patients attended nurse-led CHF disease management clinics in two tertiary referral centres in Ireland and were participating in the feasibility study, reported elsewhere.

<sup>28</sup>(feasibility REF) Patients were purposively sampled and had advanced CHF; New York Heart Association functional class (NYHA) II-IV, with either systolic dysfunction or left ventricular ejection fraction of < 40% (HFrEF) or either one of heart failure symptoms in the presence of preserved systolic function  $\geq$  50% (HFpEF) or heart failure symptoms in the presence of mid-range systolic function: 40-49% (HFmrEF).

## **Recruitment**

Patients were purposively selected for age, sex, NYHA class and heart failure type (HFpEF or HFmrEF/HFrEF). They were invited to participate in a semi-structured interview to explore their perceptions of the role of the intervention. Qualitative sampling strategies use an inductive approach to explore in depth the range and complexity of the meanings and phenomena of the research question, rather than to achieve statistical generalisation.<sup>31,32</sup> Sampling ceased when no new emergent themes were generated from interview data.

Patients were interviewed at nurse-led clinics as they attended for appointments to minimise travel burden. Heart failure nurses who delivered the intervention were interviewed.

## **Intervention**

The IPOS with integrated heart failure nurse education and training was delivered alongside best standard care (Box 1). (Intervention description follows TIDieR guidelines.<sup>33</sup>) Once the nurses at each site had participated in education and training, they gave recruited patients the IPOS to complete at the subsequent clinic visit.

[Box 1]

## **Semi-structured qualitative interviews**

The interview topic guide (Appendix 1) was informed from patient-centred care literature and a systematic review of patient-centred care CHF interventions undertaken by the lead researcher (PMK),<sup>11</sup> and was reviewed by the Project Advisory Group. To explore the potential mechanism of action of the intervention, the topic guide included questions on the clinical value of the intervention and its role in the clinical interaction.

## **Data analysis**

Interviews were transcribed verbatim by an independent transcription company, anonymised and imported into MAXQDA software<sup>34</sup> to aid analysis using a framework approach.<sup>35</sup> Framework analysis is inductive but allows the inclusion of both *a priori* and emergent themes. *A priori* themes were drawn from the patient-centred framework

developed from the literature,<sup>11</sup> the interview topic guide and study objectives.<sup>36</sup> This matrix-based approach allowed emerging themes to be mapped to the patient-centred framework and for some adaptation. The interview transcripts were analysed by PMK and CES following the stages of framework analysis (familiarisation, thematic framework identification, indexing, charting, mapping and interpretation); consensus on themes and key findings were reached through discussion. The thematic framework was applied to the first four interviews and no additional themes were identified. Divergent cases were noted where emerging themes conflicted with more common themes to more comprehensively inform the qualitative analysis.

### **Ethics**

Ethics approval was obtained from Research Ethics Committees at study sites; Ref: 13/70 and Ref: 1/378/1579, and King's College London (Ref: BDM/ 13/14-25). Written informed consent was obtained from patients and participating nurses. A Project Advisory Group comprising expert clinicians, researchers and a service user reviewed study findings to inform the evaluation.

### **Results**

Eighteen out of twenty-five patients who completed the intervention and all four nurses involved in intervention delivery were interviewed. Table 1 reports patients' demographics and clinical characteristics. The nurses gave expressed consent for their views to be shared, but their details are not provided this information would be too granular and risk their identification. Interviews ranged from twenty-one to forty-four minutes (mean thirty-two minutes). We identified three key themes related to the mechanism of action; identification of unmet needs; holistic assessment; and patient empowerment.

[Table 1]

Each theme contains two subthemes. Patients and nurses were generally positive in their perceptions of the IPOS. They considered it a useful tool to comprehensively highlight unmet needs, while enabling patients to take a more active role in identifying their needs to the nurses.

## Identification of unmet needs

### **Symptom identification**

Patients acknowledged that CHF made them feel unwell but they were unable to describe this in more detail. They appreciated the list of symptoms included in the IPOS as these acted as a prompt for patients to self-assess what symptoms they were experiencing. One 89 year old woman conveyed a common experience reported by fourteen patients, that the list of symptoms in the IPOS helped identify symptoms patients had not identified in themselves.

*'I've had a lot of these things and I didn't realise, you know, "Constipation, poor appetite, nausea, weakness, lack of energy." But I would surprise myself that they would be relevant to the way I am feeling sometimes. ....I would tick quite a few of them.'* (Patient 07, Female, NYHA III, HFpEF)

### **Identifies patient perceived problems**

Nurses were surprised at the dissonance between their perception of optimal symptom control and the patients' perceptions. They were aware patients experienced refractory symptoms but thought they tolerated these. IPOS feedback helped the nurses realise that these symptoms could be a source of considerable distress. Scoring these symptoms highly on the IPOS gave patients the opportunity to revisit them again.

*'it [IPOS] showed what was most important for the patient. Like some of them came in, and they'd have shortness of breath as "severe" [graded on IPOS]. But they'd be just as they always are.. So it just showed that's a really big problem for that person, even though we've got them to their baseline, or as good as they can be, ...that we felt .. we had got under control, but it was still a big problem for them, .., it really led the conversation, but where the patient wanted to lead it.'* (Nurse 02)

## Holistic assessment

### Comprehensive review

The nurses acknowledged that their priorities to assess CHF-related physical symptoms differed the IPOS questions which was developed to assess symptoms and concerns in advanced disease. Nurses acknowledged that psycho-social concerns were frequently only considered at end-of-life and the IPOS allowed assessment of previously unidentified psycho-social issues. It provided a comprehensive review of patients' needs, particularly these psycho-social concerns, illustrating the far-reaching effects of CHF on patients' lives. The IPOS also helped them identify patients' issues within the demands of a busy clinic and complemented the nurses' priorities by assessing patients' palliative care symptoms and concerns.

*'It [IPOS] addresses a lot of things that affect people's lives, you know factoring [in] their financial .. burden. ....Then the physical component as well. So it did tap into their lives. And every part of your life.'* (Nurse 01)

*'I don't personally ask them myself, do they feel anxious or worried about their health? Now that is a question I would possibly ask when the patient's been readmitted, and we've exhausted all treatment options possibly referring them on for palliative care....*

*[IPOS] opens up the conversation again.... We can just lead people in the right directions, if they do feel they have issues...'* (Nurse 03)

Twelve patients spoke of the anxiety they and their caregivers experienced and thought that psychological distress should be assessed routinely to give patients the opportunity to discuss this. Patients acknowledged the suffering which CHF caused and thought the IPOS helped capture this distress, as illustrated by this 85 year old woman.

*'Because the sort of questions [on IPOS] weren't [nurse's] questions. Like usually they ask about .. my breathlessness .. how many pillows I sleep on and how is the fluid and how are my ankles and questions like that, medical things.....it [IPOS] shows how many people are*



*terribly worried and who have great pain and shows that sort of thing.'* (Patient 09, Female, NYHA III, HFmrEF)

### **Personalisation of IPOS**

Patients appreciated the IPOS open questions as these enabled them to highlight what was foremost of concern. Twenty-one of the twenty-five patients who received the intervention completed Question 1. The opportunity to individualise their responses resonated with patients. They felt more comfortable to highlight ongoing physical or psycho-social problems which they were tolerating but had previously omitted to mention. Patients, including this 82 year old man, frequently described how issues they included in these questions initiated discussions about bothersome problems, which was a source of reassurance.

*"What have your main problems or concerns over the past week?" [Q1 open IPOS question] I would say that's a very relevant question..... I would expect that the person dealing with me would have to ask me that question, would be able to relate to my answer and give me the necessary assurances I require, that's whatever they are.'* (Patient 20, Male, NYHA II, HFrEF )

### **Patient empowerment**

#### **Taking ownership**

Patients found CHF symptoms and associated polypharmacy complex to understand and frequently adopted a passive role, delegating responsibility to the nurses. Compounding this, some patients felt ill-equipped to engage with the nurses perceiving them as better educated, perhaps as many patients had only a secondary level education. Two patients were less inclined to ask questions or seek clarification, as they worried about being perceived as causing a nuisance, despite describing having a good rapport with the nurses. Ten patients acknowledged that they felt unable to articulate how they felt and the IPOS provided them with vocabulary to describe their experience, as illustrated by this 74 year old man.

*'I don't want to annoy someone, a silly thing. ..Maybe I'd make an old fool of myself ....That's maybe confidence again... It's just the normal things I do ask...I suppose you would find it*

*intimidating...you'll be saying, Maybe you shouldn't ask that question at all. .... It [IPOS] would be helpful ..... the words is there, that you're going through that. All, the whole lot of them [symptoms/concerns on IPOS]' (Patient 13, Male, NYHA III, HFrEF)*

All the patients recognised in the IPOS a description of their own experience of living with advanced disease. For the first time they felt able to take ownership of their own experience of CHF and be honest with themselves as to reality of their illness, as exemplified by this 72 year old woman.

*'they [symptoms/concerns] might be there at the back of your mind and the form [IPOS] brings it to the fore. And it [IPOS] makes you really look at it [symptoms/concerns], you know? It makes you question it.... it makes you face up to things, .. it's facing reality I suppose.'* (Patient 08, Female, NYHA III, HFrEF)

*'it would encourage people to care about their health much more, to do the right thing.'* (Patient 07, Female, NYHA III, HFpEF) (89y/o)

Attributing a score to each symptom or concern on the IPOS provided patients and nurses with feedback regarding its severity. This gave patients the impetus to want to improve their score. The patients felt empowered by this information and it helped them realise that they could take ownership over their symptoms and work to ameliorate them.

*'You never ever think of what's wrong with you and how you're feeling about it or has it improved, has it got worse, and should you do something different. I would think this [IPOS] is very good 'cause, as I said, it makes you pinpoint exactly how you're feeling-..and what you can do or what you can't do to improve it.....'* (Patient 10, Female, NYHA III, HFmrEF)

### **Enables discussion**

Eleven patients moved from being content with a passive role to actively wanting to understand more about their illness and medications so that they could help themselves. The IPOS symptoms and concerns validated their CHF experience and patients felt more in control for the first time. Nine patients felt empowered as they could now describe their

problems to the nurses and seek solutions. This gave them a confidence to more actively engage in discussions. One 72 year old woman illustrated this transformation which had resulted in her having a more coherent understanding of her CHF.

*'it [IPOS] started me thinking it did. Yeah....I need to know these things...and it's no good blaming them if I'm not asking. It's up to me for to do it...And I feel even this morning I'm going out now [leaving the clinic] and I am more content....because there's been things more explained to me.'* (Patient 08, Female, NYHA III, HFrEF)

The nurses and ten patients used IPOS feedback to prompt discussion about patients' needs, particularly concerning less commonly issues including psychological distress and financial needs. The nurses recognised how the IPOS gave patients a voice in the clinical interaction whereas before the focus had been on the nurses' agenda.

*'it's [IPOS] patient centred, ... it's the patient being allowed to voice their symptoms and their experiences, and how they feel.. and it'll also help with the interview afterwards .., we can discuss things, and it means we don't miss out on anything either. It covers everything.'* (Nurse 03)

Moving the focus of the clinical discussion to the patients' priorities presented both opportunities and challenges, as the IPOS highlighted less familiar issues for nurses to address. Nurses found the question regarding whether the patient felt at peace challenging as any future care planning generally only took place when patients had exhausted all treatment options. They were unsure as to what this question meant and found its potential broad sweep unsettling.

*Are they at peace with whatever they mean by that? (Nurse 01)*

They did recognise it as a useful marker as to whether a patient was becoming newly distressed. However, they openly admitted that they hoped patients wouldn't score it highly, as they felt unsure as to how to ascertain what patients' needs would be.

*'But it would be as difficult one to broach, I suppose it would open it up for you, and you could start the conversation. ..you could maybe guide them towards their priest, or maybe something like that. But, I think I'd only be able to discuss that with them....it would be a difficult one.'* (Nurse 02)

### Divergence

Divergent or contrasting reports were sought from the interviews. No patient reported either a positive or negative influence of the intervention on the clinical interaction. On direct questioning, patient participants were sometimes uncertain how nurses used the IPOS feedback, with five patients considering it as having no effect, four thought the nurse didn't use it and two couldn't remember if she had. Four patients attributed having a good rapport with the nurses as enabling them to mention symptoms without the IPOS. No patient reported an adverse clinical interaction, either related or unrelated to the IPOS.

Six patients did not want to take a more active role in discussions as they regarded the nurses as trained experts and trusted they would make the best decisions. Three patients worried that their input would undermine the optimal management of their health or considered themselves inadequately intelligent to participate in clinical discussions. Conversely, this delegation of responsibility to the nurses appeared to allow two patients to justify not adhering tightly to their treatment regime. Others considered their older age as reason enough to take a more passive role, as exemplified by this woman.

*"I feel that I should be accepting what's happening to me now at 90. I wouldn't kick up a row and say 'Oh why is that happening to me?' sure it's nearly time for me to say 'Bye-bye'."*

(Patient 07, Female, NYHA III, HFpEF)

Five patients did not regard the IPOS as providing any additional benefit to their interaction with the nurses. These patients included two who already took an active role in their own care and were involved in clinical decision-making, so they had skills which others described the IPOS as providing, as illustrated by this 74 year old lady.

*'[IPOS] wouldn't be necessary, I wouldn't think. Because any problems I have at the minute I'll discuss with the nurses.'* (Patient 13, Female, NYHA III, HFpEF)

One asymptomatic 52 year old man with no active CHF problems thought the intervention didn't add value to the consultation.

*'It wouldn't really have been... any benefit to me, really...I was just answering the questions and, probably the only thing I was thinking of was that I felt great'* (Patient 01, Male, NYHA III, HFrEF)

### Discussion

This study found that this palliative-specific PROM-based intervention facilitates patient-centred care by identifying patients' unmet needs which can then lead the clinical discussion. The intervention provided vocabulary prompts to describe symptoms and the open question facilitated personalised responses, empowering patients to become more actively involved in the clinical consultation. For some patients, the intervention acknowledged their illness experience, causing them to reflect on how CHF was affecting them and articulate this to the nurses. Nurses thought the intervention comprehensively identified unmet needs providing an opportunity to discuss complex issues including psychosocial and spiritual distress. There were no differences in findings relative to study site, heart failure type or NYHA class. Importantly, no adverse effects were reported with this intervention.

CHF patients under report their high symptom burden.<sup>2</sup> Consistent with growing evidence that PROMs improve identification of unrecognised problems<sup>19,37,38</sup>, the intervention prompted patients regarding potential symptoms and concerns, validating these as worthy of mention.

IPOS development involved patients with advanced disease<sup>27</sup> to appropriately reflect their symptoms and concerns.<sup>14</sup> This enhances its content validity,<sup>18,39</sup> together with the open questions which allow patients to individualise answers,<sup>22,40</sup> according to what concerning them, as described by patients in this study. The timing of a PROM relative to illness burden

may affect its impact on health outcomes<sup>41,42</sup> and perceived relevance to patients,<sup>38</sup> and with symptomatically stable patients considering it less relevant, as occurred in this study.

Psychological distress is common in CHF.<sup>43,44</sup> PROMs, including the IPOS,<sup>45</sup> are particularly effective in screening for this<sup>22</sup> and in facilitating more open communication.<sup>46</sup> Patients and nurses described the intervention as prompting discussions about psychological concerns where these were not routinely assessed. In this study, the nurses' expressed concern regarding the IPOS question '*Have you felt at peace?*' which they felt ill-equipped to address. Higher scores on this question may help initiate discussions around preparedness for adverse events<sup>47</sup> and future care planning,<sup>48</sup> areas often poorly addressed in CHF.<sup>49,50</sup> Having triggers to prompt these discussions would work to integrate a more patient-centred approach into CHF care<sup>46</sup> and prompt specialist palliative care input for more complex cases.

The Innovative Care for Chronic Conditions (ICCC) framework emphasises the need for patients to be informed, active participants in their own healthcare.<sup>51</sup> By validating their symptoms and providing symptom vocabulary, the intervention enabled patients to articulate their problems. These findings support the hypothesis that PROM completion improves patients' symptom description skills.<sup>26</sup> Some patients reported that taking a more active role in their care gave them a sense of control and improved their emotional well-being. PROMs have been shown to improve psychological and emotional well-being outcomes.<sup>15</sup> This has been attributed to patients feeling more supported by the action of PROM feedback with a resultant decrease in distress and anxiety.<sup>15,26,52</sup> CHF is characterised by uncertainty and loss of control causing emotional distress.<sup>53</sup> Patients in this study described having more control over their illness similar to other patient-centred care CHF interventions which have reduced uncertainty.<sup>54</sup> In this study, we have provided additional evidence on the mechanism of action of PROMs and how they may facilitate patient-centred care. We used PROMs rather than patient-reported experience measures as PROMs may be better at determining the natural course of a symptom or concern in order to better understand how and when interventions are valuable and/or have greatest impact.

Patients described how their unmet symptoms and concerns were identified through the intervention and were addressed in the clinical review. Despite this, they went on to report no impact of the intervention on the patient-nurse interaction. The reasons for this contradiction are likely to be multi-factorial. Interviews for logistical reasons were not undertaken on the day of intervention delivery, affecting patients' ability to fully recall events. Also, on reflection, these patients may have understood this question to mean if the nature of patient-nurse relationship had changed rather than the content of the clinical discussion. A recent review of the processes by which PROMS may improve patient care suggests they function more as a tool which enables patients to raise issues rather than changing the nature of patient-healthcare professional communication, which was the experience in this study.<sup>55</sup>

### **Limitations**

The lead researcher (PMK) was involved in study implementation and interviewed participants. This may have introduced bias as interviewees, particularly nurses, may have been less likely to offer criticisms. This study took place in hospitals where patients have access to nurse-led CHF disease management clinics which are arguably already patient-centred. Further exploration of this intervention in generalist settings would be useful to further inform the mechanism of action. There may be a selection bias as these patients were selected from those already participating in the feasibility study. All patients approached agreed to participate in the qualitative interviews. The number of nurses was small. It would be useful to explore further the value of the intervention from the healthcare professional's perspective, including other professional groups.

### **Conclusion**

This intervention identifies CHF patients' unmet needs by facilitating a more holistic assessment. By highlighting patient-perceived problems, the intervention allowed these to lead the clinical discussion and has the potential to act as a trigger for discussions around future care planning. After completing the intervention, some patients described themselves as motivated to take a more active role in their care. This study adds to the evidence for the mechanism of action of PROMs in improving patient-centred care and will help inform outcome selection for future PROM research.

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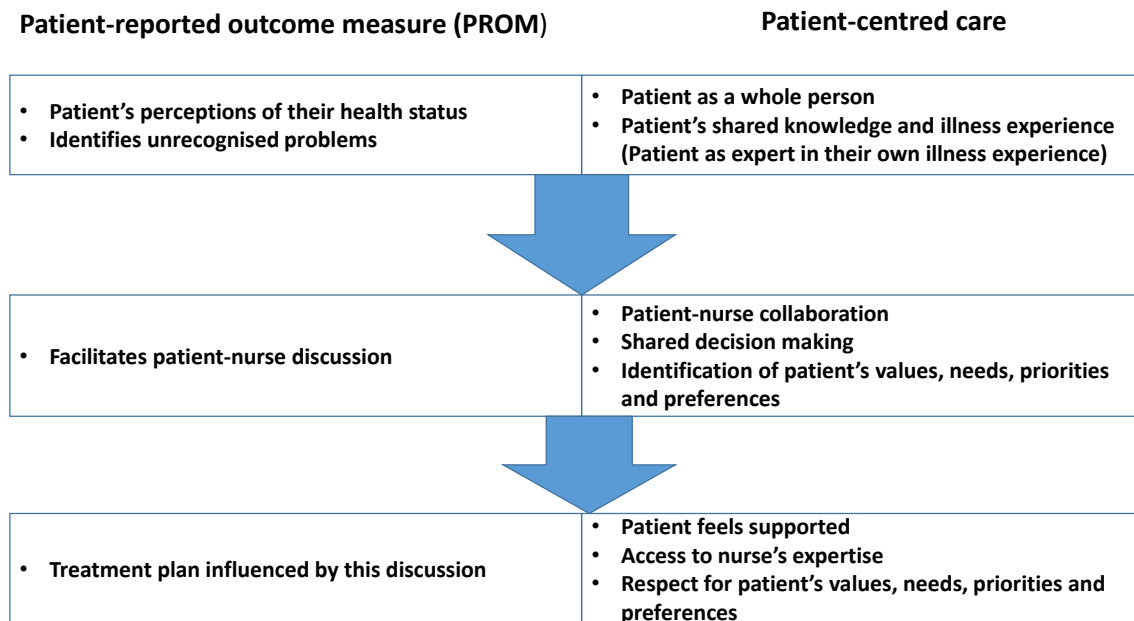
**Table 1 Patient demographics and clinical characteristics**

	<b>All patient participants n=18</b>
Male, n (%)	11 (61)
Age, y (mean $\pm$ SD)	75 $\pm$ 8.5
Educational level, n (%)	
Primary level only	7 (39)
Some/Completed secondary level	10 (55.6)
Some/completed university	1 (6)
NYHA functional class, n (%)	
II	4 (22)
III	13 (72)
IV	1 (6)
Type of heart failure, n (%)	
HFrEF	9 (50)
HFpEF and HFmrEF	9 (50)
Charlson Comorbidity Index (mean $\pm$ SD)	3.9 $\pm$ 1.4

Abbreviations: NYHA: New York Heart Association; HFrEF: Heart Failure reduced Ejection Fraction; HFpEF: Heart Failure preserved Ejection Fraction; HFmrEF: Heart Failure mid-range Ejection Fraction



**Figure 1 Visual representation of conceptual understanding of how patient-reported outcome measure facilitates patient-centred care**



## Box 1 Description of the intervention

### IPOS with integrated heart failure nurse education and training

#### **Aims and rationale**

The IPOS with integrated healthcare professional education and training aimed to provide a subjective assessment of patients' palliative symptoms and concerns, to improve their identification and management within the heart failure nursing clinical review. HFN education and training aimed to facilitate optimal IPOS use.<sup>22</sup> Following Knowles andragogy principles<sup>56</sup>, HFNs were involved in the education and training module development. Case studies underwent external expert review to ensure clinical accuracy for CHF patients. The IPOS has been designed to capture patients' palliative symptoms and concerns, which are well documented in CHF.<sup>57</sup> The IPOS parent PROM, the POS has been used in CHF.<sup>58,59</sup> The intervention was developed using the Medical Research Council guidance<sup>60</sup> and informed through a systematic review<sup>11</sup> using the best available evidence<sup>9,61</sup> and appropriate theory.<sup>18</sup>

#### **Content**

The intervention involved 2 components; the HFN education and training module and the IPOS. The module followed a heterogeneous pedagogical approach with 5 components; i) patient-centred care overview; ii) rationale for PROM use; iii) rationale for IPOS; iv) IPOS case studies; v) practicalities of IPOS use in the clinic. The IPOS has 10 questions with 2 open questions covering patients' main concerns and symptoms respectively, and a 5-point Likert scale (0-4) accompanying common symptoms, patient and family distress, existential well-being, sharing feelings with family, information available and practical concerns.<sup>27</sup> After module delivery, recruited patients completed the IPOS at their next clinic visit. HFNs then reviewed each patient with the completed IPOS. HFNs were advised to address individual items with scores  $\geq 3$ ; use their clinical discretion for individual scores  $\leq 2$ ; and assess any problems included in the open questions. No clinical guidelines were provided as HFNs were expected to use their clinical expertise in assessment and management of these symptoms/concerns, referring to other specialist services as they deemed appropriate. As the IPOS was used once with each patient, an overall IPOS score was not used.

#### **Personnel**

*Provider:* The primary researcher delivered the 1 hour education and training module at each study site once. The HFNs provided recruited patients with the IPOS.

*Supervision:* The primary researcher was on site when recruited patients attended the nurse-led CHF disease management clinic; prompted the HFNs to give patients the IPOS and to remind patients to complete both sides; and reminded HFNs to store completed IPOS in the provided repository.

#### **Format**

*Setting:* Patients completed the IPOS while waiting to be reviewed at the nurse-led CHF disease management clinic.

*Schedule and duration:* 25 patients completed the IPOS. On arrival to the clinic, HFNs provided patients with a paper copy of the IPOS on a clipboard with a pen.

#### **Delivery**

*Delivery methods:* The HFNs were advised where patients requested assistance to complete the IPOS not to paraphrase; not to give their own explanations of the questions; to adhere to the questionnaire text and not to prompt patients with potential answers. Only HFNs who had attended the module subsequently were involved in IPOS patient delivery and clinical use.

Abbreviations: IPOS: Integrated Palliative care Outcome Scale; HFN; Heart Failure Nurse; CHF: Chronic Heart Failure; POS: Palliative care Outcome Scale; PROM: Patient-Reported Outcome Measure.

## References

- 1 Townsend N, Bhatnagar P, Wilkins E, Wickramasinghe K, Rayner M. Cardiovascular disease statistics 2015. London: British Heart Foundation 2015. <https://www.bhf.org.uk/publications/statistics/cvd-stats-2015> (accessed 27th March, 2017).
- 2 Ekman I, Cleland, John G F, Andersson B, Swedberg K. Exploring symptoms in chronic heart failure. *Eur J Heart Fail* 2005; **7**: 699–703. doi:10.1016/j.ejheart.2005.07.003.
- 3 Leeming A, Murray SA, Kendall M. The impact of advanced heart failure on social, psychological and existential aspects and personhood. *Eur J Cardiovasc Nurs* 2014; **13**: 162–67. doi:10.1177/1474515114520771.
- 4 Murray SA, Boyd K, Kendall M. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ (Clinical research ed.)* 2002; **325**: 929–32.
- 5 Addington-Hall J, McCarthy M. Regional Study of Care for the Dying: methods and sample characteristics. *Palliat Med* 1995; **9**: 27–35. doi:10.1177/026921639500900105.
- 6 Selman L, Beynon T, Higginson IJ, Harding R. Psychological, social and spiritual distress at the end of life in heart failure patients. *Curr Opin Support Palliat Care* 2007; **1**: 260–66. doi:10.1097/SPC.0b013e3282f283a3.
- 7 Chattoo S, Atkin KM. Extending specialist palliative care to people with heart failure: Semantic, historical and practical limitations to policy guidelines. *Soc Sci Med* 2009; **69**: 147–53. doi:10.1016/j.socscimed.2009.02.025.
- 8 Allen LA, Stevenson LW, Grady KL, et al. Decision Making in Advanced Heart Failure: A Scientific Statement From the American Heart Association. *Circulation* 2012; **125**: 1928–52. doi:10.1161/CIR.0b013e31824f2173.
- 9 Jaarsma T, Beattie JM, Ryder M, et al. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2009; **11**: 433–43. doi:10.1093/eurjhf/hfp041.
- 10 World Health Organization. Innovative care for chronic conditions: building blocks for action. <http://www.who.int/chp/knowledge/publications/icccreport/en/> (accessed 24th June, 2015).
- 11 Kane P, Murtagh F, Ryan, K, et al. The gap between policy and practice: a systematic review of patient-centred care interventions in chronic heart failure. *Heart Fail Rev* 2015; **20**: 673–87. doi:10.1007/s10741-015-9508-5.
- 12 Greenhalgh J. The applications of PROs in clinical practice. what are they, do they work, and why? *Qual Life Res* 2009; **18**: 115–23. doi:10.1007/s11136-008-9430-6.
- 13 Higginson IJ, Carr AJ. Measuring quality of life - Using quality of life measures in the clinical setting. *BMJ* 2001; **322**: 1297–300. doi:10.1136/bmj.322.7297.1297.
- 14 Thompson DR, Ski CF, Garside J, Astin F. A review of health-related quality of life patient-reported outcome measures in cardiovascular nursing. *Eur J Cardiovasc Nurs* 2016; **15**: 114–25. doi:10.1177/1474515116637980.
- 15 Etkind SN, Daveson BA, Kwok W, et al. Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. *Journal of pain and symptom management* 2015; **49**: 611–24. doi:10.1016/j.jpainsymman.2014.07.010.

- 16 Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr AJ. The routine use of patient reported outcome measures in healthcare settings. *BMJ (Clinical research ed.)* 2010; **340**: c186. doi:10.1136/bmj.c186.
- 17 Homsí J, Walsh D, Rivera N, et al. Symptom evaluation in palliative medicine: patient report vs systematic assessment. *Support Care Cancer* 2006; **14**: 444–53. doi:10.1007/s00520-005-0009-2.
- 18 Greenhalgh J, Long AF, Flynn R. The use of patient reported outcome measures in routine clinical practice. lack of impact or lack of theory? *Soc Sci Med* 2005; **60**: 833–43. doi:10.1016/j.socscimed.2004.06.022.
- 19 Chen J, Ou L., Hollis S.J. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res* 2013: 211.
- 20 Stewart M. Towards a global definition of patient centred care. *BMJ* 2001; **322**: 444–45.
- 21 Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: A systematic review of qualitative research. *BMJ Qual Saf* 2014; **23**: 508–18. doi:10.1136/bmjqs-2013-002524.
- 22 Marshall S, Haywood K, Fitzpatrick R. Impact of patient -reported outcome measures on routine practice. a structured review. *J Eval Clin Pract* 2006; **12**: 559–68.
- 23 Valderas JM, Kotzeva A, Espallargues M, et al. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res* 2008; **17**: 179–93. doi:10.1007/s11136-007-9295-0.
- 24 Holmes MM, Lewith G, Newell D, Field J, Bishop FL. The impact of patient-reported outcome measures in clinical practice for pain: a systematic review. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2017; **26**: 245–57. doi:10.1007/s11136-016-1449-5.
- 25 Ravaud P, Keïta H, Porcher R, Durand-Stocco C, Desmonts JM, Mantz J. Randomized clinical trial to assess the effect of an educational programme designed to improve nurses' assessment and recording of postoperative pain. *Br J Surg* 2004; **91**: 692–98. doi:10.1002/bjs.4506.
- 26 Feldman-Stewart D, Brundage MD. A conceptual framework for patient-provider communication: a tool in the PRO research toolbox. *Qual Life Res* 2009; **18**: 109–14.
- 27 Schildmann EK, Groeneveld EI, Denzel J, et al. Discovering the hidden benefits of cognitive interviewing in two languages: The first phase of a validation study of the Integrated Palliative care Outcome Scale. *Palliat Med* 2016; **30**: 599–610. doi:10.1177/0269216315608348.
- 28 Kane PM, Murtagh FE, Ryan KR, et al. Strategies to address the shortcomings of commonly used advanced chronic heart failure descriptors to improve recruitment in palliative care research: A parallel mixed-methods feasibility study. *Palliat Med* 2017; **27**: 026921631770642. doi:10.1177/0269216317706426.
- 29 Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review--a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy* 2005; **10 Suppl 1**: 21–34. doi:10.1258/1355819054308530.
- 30 Creswell JW, Plano Clark, Vicki L. Designing and conducting mixed methods research. Los Angeles: Sage Publications, 2011.
- 31 Koffman J, Gao W, Goddard C, et al. Progression, symptoms and psychosocial concerns among those severely affected by multiple sclerosis: a mixed-methods cross-sectional

- study of Black Caribbean and White British people. *Plos One* 2013; **8**: e75431. doi:10.1371/journal.pone.0075431.
- 32 Strauss AL, Corbin JM. Basics of qualitative research. Grounded theory procedures and techniques. Newbury Park Calif: Sage Publications, 1990.
  - 33 Hoffmann TC, Glasziou PP, Boutron I, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ* 2014; **348**: g1687. doi:10.1136/bmj.g1687.
  - 34 VERBI Software. MAXQDA, software for qualitative data analysis. <http://www.maxqda.com/> (accessed 15th May, 2015).
  - 35 Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Analysis of Qualitative Data.
  - 36 Bowen DJ, Kreuter M, Spring B, et al. How we design feasibility studies. *Am J Prev Med* 2009; **36**: 452–57. doi:10.1016/j.amepre.2009.02.002.
  - 37 McKenna SP. Measuring patient-reported outcomes: moving beyond misplaced common sense to hard science. *BMC medicine* 2011; **9**: 86. doi:10.1186/1741-7015-9-86.
  - 38 Velikova G, Awad N, Coles-Gale R, Wright EP, Brown JM, Selby PJ. The clinical value of quality of life assessment in oncology practice—a qualitative study of patient and physician views. *Psycho-Oncology* 2008; **17**: 690–98. doi:10.1002/pon.1295.
  - 39 Lindblad AK, Ring L, Glimelius B, Hansson MG. Focus on the individual—quality of life assessments in oncology. *Acta Oncol* 2002; **41**: 507–16.
  - 40 Carr AJ, Higginson IJ. Are quality of life measures patient centred? *BMJ* 2001; **322**: 1357–60.
  - 41 McLachan SA, Allenby A, Matthews J, et al. Randomized trial of coordinated psychosocial interventions based on patient self-assessment versus standard care to improve the psychosocial functioning of patients with cancer. *J Clin Oncol* 2001; **19**: 4117–25.
  - 42 Hoekstra J, Vos R de, van Duijn, Nico P, Schade E, Bindels, Patrick J E. Using the symptom monitor in a randomized controlled trial: the effect on symptom prevalence and severity. *Journal of pain and symptom management* 2006; **31**: 22–30. doi:10.1016/j.jpainsymman.2005.06.014.
  - 43 Sears SF, Woodrow L, Cutitta K, Ford J, Shea JB, Cahill J. A patient's guide to living confidently with chronic heart failure. *Circulation* 2013; **127**: e525-8. doi:10.1161/CIRCULATIONAHA.112.000734.
  - 44 Dekker RL, Lennie TA, Albert NM, et al. Depressive Symptom Trajectory Predicts 1-Year Health-Related Quality of Life in Patients With Heart Failure. *J Card Fail* 2011; **17**: 755–63. doi:10.1016/j.cardfail.2011.04.016.
  - 45 Antunes B, Murtagh F, Bausewein C, Harding R, Higginson IJ. Screening for Depression in Advanced Disease: Psychometric Properties, Sensitivity, and Specificity of Two Items of the Palliative Care Outcome Scale (POS). *J Pain Symptom Manage* 2014. doi:10.1016/j.jpainsymman.2014.06.014.
  - 46 Thompson LE, Bekelman DB, Allen LA, Peterson PN. Patient-reported outcomes in heart failure: existing measures and future uses. *Curr Heart Fail Rep* 2015; **12**: 236–46. doi:10.1007/s11897-015-0253-9.
  - 47 McIlvennan CK, Allen LA. Palliative care in patients with heart failure. *BMJ* 2016; **353**: i1010. doi:10.1136/bmj.i1010.
  - 48 Denvir MA, Murray SA, Boyd KJ. Future care planning: a first step to palliative care for all patients with advanced heart disease. *Heart (British Cardiac Society)* 2015; **101**: 1002–07. doi:10.1136/heartjnl-2014-306724.

- 49 Meyers DE, Goodlin SJ. End-of-Life Decisions and Palliative Care in Advanced Heart Failure. *Can J Cardiol* 2016; **32**: 1148–56. doi:10.1016/j.cjca.2016.04.015.
- 50 Dunlay SM, Strand JJ. How to discuss goals of care with patients. *Trends in cardiovascular medicine* 2016; **26**: 36–43. doi:10.1016/j.tcm.2015.03.018.
- 51 Epping-Jordan JE, Pruitt SD, Bengoa R, Wagner EH. Improving the quality of health care for chronic conditions. *Qual Saf Health Care* 2004; **13**: 299–305. doi:10.1136/qshc.2004.010744.
- 52 Velikova G, Booth L, Smith AB, et al. Measuring Quality of Life in Routine Oncology Practice Improves Communication and Patient Well-Being: A Randomized Controlled Trial. *J Clin Oncol* 2004; **22**: 714–24. doi:10.1200/JCO.2004.06.078.
- 53 Winters CA. Heart failure: living with uncertainty. *Prog Cardiovasc Nurs* 1999; **14**: 85–91.
- 54 Dudas K, Olsson L, Wolf A, et al. Uncertainty in illness among patients with chronic heart failure is less in person-centred care than in usual care. *Eur J Cardiovasc Nurs* 2013; **12**: 521–28.
- 55 Greenhalgh J, Dalkin S, Gooding K, et al. Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care. *Health Services and Delivery Research* 2017; **5**: 1–163. doi:10.3310/hsdr05020.
- 56 Knowles M. *Androgogy in action. Applying modern principles of adult learning.* San Francisco: Jossey-Bass, 1984.
- 57 Bekelman DB, Hutt E, Masoudi FA, Kutner JS, Rumsfeld JS. Defining the role of palliative care in older adults with heart failure. *Int J Cardiol* 2008; **125**: 183–90. doi:10.1016/j.ijcard.2007.10.005.
- 58 Ma A, Reid J, Ness A, et al. Evaluation of the Palliative Care Outcome Scale (POS) in chronic heart failure patients. *BMJ Support & Palliat Care* 2011; **1**: A16. doi:10.1136/bmjspcare-2011-000020.48.
- 59 Malik FA, Gysels M, Higginson IJ. Living with breathlessness: a survey of caregivers of breathless patients with lung cancer or heart failure. *Palliat Med* 2013; **27**: 647–56. doi:10.1177/0269216313488812.
- 60 Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ (Clinical research ed.)* 2008; **337**: a1655. doi:10.1136/bmj.a1655.
- 61 Gadoud A, Jenkins, Shona M M, Hogg KJ. Palliative care for people with heart failure: summary of current evidence and future direction. *Palliat Med* 2013; **27**: 822–28. doi:10.1177/0269216313494960.