

Heart Failure Reviews

Palliative care needs-assessment and measurement tools used in patients with heart failure: a systematic mixed-studies review with narrative synthesis

--Manuscript Draft--

Manuscript Number:	HREV-D-20-00072R2	
Full Title:	Palliative care needs-assessment and measurement tools used in patients with heart failure: a systematic mixed-studies review with narrative synthesis	
Article Type:	Unsolicited Articles	
Keywords:	Palliative care; Heart failure; Needs-assessment; Needs-measurement; Systematic Review; Mixed-studies review; Narrative synthesis	
Order of Authors:	Bader Nael Remawi	
	Amy Gadoud	
	Iain Malcolm James Murphy	
	Nancy Preston	
Corresponding Author:	Bader Nael Remawi Lancaster University Lancaster, Lancashire UNITED KINGDOM	
Corresponding Author Secondary Information:		
Corresponding Author's Institution:	Lancaster University	
Corresponding Author's Secondary Institution:		
First Author:	Bader Nael Remawi	
First Author Secondary Information:		
Order of Authors Secondary Information:		
Funding Information:	Lancaster University (GB) (not applicable)	Mr. Bader Nael Remawi
	British Council (not applicable)	Mr. Bader Nael Remawi
Abstract:	<p>Patients with heart failure have comparable illness burden and palliative care needs to those with cancer. However, few of them are offered timely palliative care. One main barrier is the difficulty in identifying those who require palliative care. Several palliative care needs-assessment/measurement tools were used to help identify these patients and assess/measure their needs, but it is not known which one is the most appropriate for this population. This review aimed to identify the most appropriate palliative care needs-assessment/measurement tools for patients with heart failure. Cochrane Library, MEDLINE Complete, AMED, PsycINFO, CINAHL Complete, EMBASE, ETHOS, websites of the identified tools, and references and citations of the included studies were searched from inception to 25 June 2020. Studies were included if they evaluated palliative care needs-assessment/measurement tools for heart failure populations in terms of development, psychometrics, or palliative care patient/needs identification. Twenty-seven papers were included regarding nineteen studies, most of which were quantitative and observational. Six tools were identified and compared according to their content and context of use, development, psychometrics, and clinical applications in identifying patients with palliative care needs. Despite limited evidence, the Needs Assessment Tool: Progressive Disease – Heart Failure (NAT:PD-HF) is the most appropriate palliative care needs-assessment tool for use in heart failure populations. It covers most of the patient needs and has the best psychometric properties and evidence of identification ability and appropriateness. Psychometric testing of the tools in patients with heart failure and evaluating the tools to identify those with palliative care needs require more investigation.</p>	

Response to Reviewers:

Dear Editor/Reviewer,

Thank you for your time and effort in providing a second feedback for our submitted manuscript (HREV-D-20-00072R1). Our responses to the reviewer comments are outlined below. You can also find information on where the changes that we made can be found in the manuscript and other documents (e.g. tables). The lines of the submitted manuscript text were given numbers to facilitate tracking the made changes according to the reviewer comments. The length of the revised manuscript does not differ considerably from the previous version.

Reviewer Comment-1:

Abstract: The abstract still does not make the distinction between assessment and measurement tools. This is easily done e.g. "Several palliative care need assessment and/or measurement toolsthis review.. the most appropriate pc needs assessment and/or measurement tools... etc." If you are stuck for word count then you could just put "needs assessment/measurement tools". Obviously, in relation to the NAT, it is correct to refer to it as an assessment tool.

Our Response:

We agree with the reviewer comment.

- The distinction between needs-assessment and needs-measurement tools have now been made explicit in the Abstract as well as the Title. As the reviewer suggested and to keep the word count low, we used "needs assessment/measurement" instead of "needs assessment and/or measurement".

Locations of Change:

- Title [Page 1, Lines 1-3]
- Abstract [Page 1, Lines 5-22]

Reviewer Comment-2:

The issue of patient identification and needs identification is now clear. As with the suggestion for the abstract - do make sure that the distinction between needs identification and needs measurement is also made. This is in relation to the purpose of the tool.

Our Response:

We agree with the reviewer comment.

- The distinction between needs-assessment and needs-measurement have now been made explicit throughout the manuscript. We replaced "needs-assessment tools" with "needs-assessment/measurement tools" where appropriate.
- A new table was added (Table 4) to classify the tools into patient vs needs identification tools and needs assessment vs needs measurement tools. A footnote was added to alert the reader that the classification should not be considered rigid as there can be some overlap.
Note: Table 4 in the previous submitted version is now Table 5.

Locations of Change:

- Throughout the manuscript
- Table 4

Reviewer Sub-Comment-2A:

Suggested places where/how this could be clarified are shown below - but the manuscript should be checked for others:

"...other tools are primarily used to provide a more holistic assessment of those unmet needs (needs-identification tools) [31]."

Suggest add, something along the lines of, "Further, some tools are designed to assess the needs as clinical decision aids, (What are they? How should they be managed?) whilst others are designed to identify and measure them (What are they? How bad are they?)."

Our Response:

- A separate paragraph has now been added to the Introduction to differentiate between patient-identification and needs-identification on one hand, and between needs-assessment and needs-measurement on the other hand. In this paragraph,

details have been added regarding the definition of needs-measurement tools and clinical decision aids, issues with needs-measurement tools, and practicalities of clinical decision aids.

- Note: as new references were introduced in this paragraph, the in-text citations in Table 2, as well as those in the manuscript, were modified.

Locations of Change:

- Introduction [Page 3, Lines 68-83]

Reviewer Sub-Comment-2B:

See comment re strengths and weaknesses below

Our Response:

Refer to our response in 3B. below

Reviewer Comment-3:

Just a couple of things to tighten in the discussion:

Reviewer Sub-Comment-3A:

"Secondly, worsening of health status over time is expected in patients with heart failure [8]."

Suggest add - and without a control group it is not possible to see signal of benefit over time; deterioration may have happened faster without the intervention.

Our Response:

We agree with the review comment.

- The suggested sentence was added to the text.

Locations of Change:

- Discussion [Page 19, Lines 570-572]

Reviewer Sub-Comment-3B:

Strengths and limitations - the distinction between the needs assessment and needs measurement is still not made here (although the non-mutual exclusivity is now clearer further back in the discussion). These are apples and pears, and the psychometric approaches for each are not directly comparable. So to imply (maybe this is not the intended message) that the NAT:PD-HF is good example, perhaps, only because the others had not had so much psychometric testing does not make sense; they have different, though overlapping, purposes.

Our Response:

- We deleted the sentence "NAT:PD-HF superiority is partly due to other tools not undergoing psychometric testing" and replaced it with "Given that the tools serve different purposes, their psychometric properties are not directly comparable. Nonetheless, no tool had been tested as widely as NAT:PD-HF".

- Under (Strengths and Limitations), we clarified that "Needs-assessment tools are distinct from needs-measurement tools and they have different, though overlapping, purposes; therefore, the psychometric approaches for each are not directly comparable".

- Under (Implications for research, practice and policy), we added that "Healthcare professionals should be aware of the different roles that needs-assessment/measurement tools can play and consider combining them where appropriate".

Locations of Change:

- Discussion [Page 18, Lines 538-539]

- Discussion [Page 20, Lines 618-620]

- Discussion [Page 21, Lines 643-644]

SPRINGER NATURE

Disclosure of potential conflicts of interest

Authors must disclose all relationships or interests that could have direct or potential influence or impart bias on the work. Although an author may not feel there is any conflict, disclosure of all relationships and interests provides a more complete and transparent process, leading to an accurate and objective assessment of the work. Awareness of real or perceived conflicts of interest is a perspective to which the readers are entitled. This is not meant to imply that a financial relationship with an organization that sponsored the research or compensation received for consultancy work is inappropriate. For examples of potential conflicts of interests *that are directly or indirectly related to the research* please visit:

www.springer.com/gp/authors-editors/journal-author/journal-author-helpdesk/publishing-ethics/14214

Corresponding authors of papers submitted to Heart Failure Reviews [include name of journal] must complete this form and disclose any real or perceived conflict of interest. The corresponding author signs on behalf of all authors.

The corresponding author will include a statement in that reflects what is recorded in the potential conflict of interest disclosure form. Please check the Instructions for Authors where to put the statement which may be different dependent on the type of peer review used for the journal. Please note that you cannot save the form once completed. Please print upon completion, sign, and scan to keep a copy for your files.

The corresponding author should be prepared to send the potential conflict of interest disclosure form if requested during peer review or after publication on behalf of all authors (if applicable).

We have no potential conflict of interest.

Category of disclosure	Description of Interest/Arrangement

Article title Palliative Care Needs Assessment Tools Used in Patients with Heart Failure : a Systematic Mixed-Studies Review with Narrative Synthesis

Manuscript No. (if you know it) _____

Corresponding author name Bader Remawi

Herewith I confirm, on behalf of all authors, that the information provided is accurate.

Author signature  Date 24th March 2020

Dear Dr Goldstein and Dr Sabbah,

I would like to submit the manuscript entitled "*Palliative care needs-assessment tools used in patients with heart failure: a systematic mixed-studies review with narrative synthesis*" to be considered for publication as a review article in Heart Failure Reviews journal.

The significant burden of heart failure on patients is well documented. Most will need a palliative care approach at some point in their disease trajectory to relieve their suffering. Palliative care needs-assessment tools can help to identify those who require palliative care and assess their holistic needs (physical, psychosocial, and spiritual). Consequently, those identified needs can be addressed by healthcare professionals to improve the quality of life of their patients. Although several tools were used in patients with heart failure, it is not known which one is the most appropriate for this population. This review aims to extract and compare these tools according to their intended use and content, development, psychometrics, and clinical applications in identifying patients with palliative care needs.

We conducted a systematic review to answer the research question. Both quantitative and qualitative studies were included, and their findings were analyzed using narrative synthesis. Six tools were extracted and compared. Among these, the Needs Assessment Tool: Progressive Disease – Heart Failure (NAT:PD-HF) was found to be the most appropriate palliative care needs-assessment tool for use in heart failure populations, although more evidence is required. It covers most of the patient needs, has the best psychometric properties, and has good identification ability.

According to the review findings and until more data become available, healthcare professionals are advised to use NAT:PD-HF to identify heart failure populations with palliative care needs. Researchers should further evaluate the tools' psychometric properties and their applications in identifying those with palliative care needs. We believe these findings will be of interest to the journal readers as the journal aims to develop links between basic science and clinical care. Palliative care is an integral component of heart failure interdisciplinary care and is recommended to be provided alongside standard therapy. The first step for integrating palliative care is identifying those who need it, and this is where needs-assessment tools play a major role.

We confirm that this manuscript has not been published elsewhere and is not under consideration by another journal. All authors have approved the manuscript and agree with its submission to Heart Failure Reviews.

Please let me know of your decision at your earliest convenience.

With my best regards,

Sincerely yours,

Bader Remawi (corresponding author)

Date: 27 March 2020

Palliative care needs-assessment tools used in patients with heart failure: a systematic mixed-studies review with narrative synthesis

Authors

Bader Nael Remawi¹ (corresponding author)

Email address: b.remawi@lancaster.ac.uk

ORCID iD: 0000-0002-3208-4419

Dr. Amy Gadoud^{1,2}, ORCID iD: 0000-0001-6351-1535

Dr. Iain Malcolm James Murphy^{1,3}, ORCID iD: 0000-0002-7151-1735

Prof. Nancy Preston², ORCID iD: 0000-0003-2659-2342

Declarations

Author contributions

Bader Remawi, Nancy Preston, and Amy Gadoud contributed to the study conception and design. The literature search was performed by Bader Remawi. Bader Remawi and Iain Murphy screened the studies, extracted relevant data, and appraised the quality of the included studies. Nancy Preston and Amy Gadoud provided their input when required to solve any discrepancy. Synthesizing and analyzing the evidence were carried out by Bader Remawi. The review was drafted by Bader Remawi and critically revised by Nancy Preston and Amy Gadoud.

Compliance with ethical standards

The manuscript does not contain clinical studies or patient data.

Funding

This review was part of a research project for Bader Remawi who is funded by the British Council to pursue his PhD study at Lancaster University which contributes the value of the academic fees.

Conflict of interest

The authors declare that they have no conflict of interest.

Consent

Not applicable

Consent, Data and/or Code availability

Not applicable

¹ Lancaster Medical School, Faculty of Health and Medicine, Lancaster University, Lancaster, LA1 4YG, UK

² International Observatory on End of life Care, Faculty of Health and Medicine, Lancaster University, Lancaster, LA1 4YG, UK

³ Trinity Hospice and Palliative Care Services, Low Moor Road, Blackpool, FY2 0BG, UK

[Click here to view linked References](#)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1 Palliative care needs-assessment and measurement tools used in 2 patients with heart failure: a systematic mixed-studies review with 3 narrative synthesis

4 Abstract

5 Patients with heart failure have comparable illness burden and palliative care needs to those with cancer.
6 However, few of them are offered timely palliative care. One main barrier is the difficulty in identifying
7 those who require palliative care. Several palliative care needs-assessment/measurement tools were used
8 to help identify these patients and assess/measure their needs, but it is not known which one is the most
9 appropriate for this population. This review aimed to identify the most appropriate palliative care needs-
10 assessment/measurement tools for patients with heart failure. Cochrane Library, MEDLINE Complete,
11 AMED, PsycINFO, CINAHL Complete, EMBASE, EThOS, websites of the identified tools, and references and
12 citations of the included studies were searched from inception to 25 June 2020. Studies were included if
13 they evaluated palliative care needs-assessment/measurement tools for heart failure populations in
14 terms of development, psychometrics, or palliative care patient/needs identification. Twenty-seven
15 papers were included regarding nineteen studies, most of which were quantitative and observational. Six
16 tools were identified and compared according to their content and context of use, development,
17 psychometrics, and clinical applications in identifying patients with palliative care needs. Despite limited
18 evidence, the Needs Assessment Tool: Progressive Disease – Heart Failure (NAT:PD-HF) is the most
19 appropriate palliative care needs-assessment tool for use in heart failure populations. It covers most of
20 the patient needs and has the best psychometric properties and evidence of identification ability and
21 appropriateness. Psychometric testing of the tools in patients with heart failure and evaluating the tools
22 to identify those with palliative care needs require more investigation.

23 24 Introduction

25 Palliative care is defined by the World Health Organization (WHO) as *“an approach that improves the*
26 *quality of life of patients and their families facing the problem associated with life-threatening illness...”*
27 [1]. It is a team-based, holistic approach that aims to address the multidimensional needs of patients and
28 families; physical, psychological, social, and spiritual [1]. The basic palliative care needs of patients are

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

29 managed by the patient’s usual care team (for example, primary care practitioner, cardiologist, heart
30 failure nurse), while more complex needs are managed by a multidisciplinary specialist team with
31 extensive training in palliative care [2,3].

32
33 Patients with heart failure have a significant symptom burden and palliative care needs [4,5], which are
34 comparable to those with cancer [6,7]. Several guidelines call for integrating palliative care into their
35 standard heart failure management [8-10]. Providing palliative care to these patients results in an
36 improvement in their physical and psychological symptoms, quality of life, and satisfaction; increase in
37 documentation of care preferences; and decrease in the use of medical service [11-13]. Despite this,
38 patients with heart failure have less access to palliative care than those with cancer, and most of their
39 palliative care consultations occur late in their life [14]. There are many barriers to providing palliative
40 care to patients with heart failure [15,16]. One major barrier is the difficulty in identifying those who need
41 palliative care [17].

42
43 Using structured research tools can aid in identifying patients with heart failure who need palliative care
44 [18]. Generally, these tools fall in one of two categories; those predicting end of life (prognostic tools),
45 and those assessing/measuring patient needs (needs-assessment/measurement tools) [18]. Given the
46 unpredictable trajectory of heart failure, prognostic tools are of limited value for identifying patients with
47 a high risk of mortality who can benefit from palliative care [19]. The National Institute for Health and
48 Care Excellence (NICE) guidelines do not recommend their use to determine if patients with heart failure
49 need palliative care referral [20]. These tools do not correlate strongly with the palliative care needs of
50 heart failure populations [19], nor do they account for the improvement in their quality of life [21]. On
51 the other side, tools that focus on assessing/measuring patient needs, instead of predicting prognosis, are
52 more appropriate for the timely initiation of palliative care for patients with heart failure [18,22]. These
53 tools can identify patient needs early before evidence of poor prognosis [23], provide a systematic
54 assessment/measurement of patients’ needs which are often underreported by patients or
55 assessed/measured differently by healthcare professionals [24,25], facilitate discussion with the care
56 team, and elicit patient preferences and goals of care [26].

57
58 Despite their advantages, some challenges exist for the use of palliative care needs-
59 assessment/measurement tools in heart failure populations. These tools require further evaluation to
60 determine their ability to enhance the timely introduction of palliative care in these patients [18].

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

61 Furthermore, most of these tools have not been widely implemented and few have been specifically
62 developed and validated for non-cancer conditions [27,28]. Several factors should be taken into
63 consideration when selecting the most appropriate palliative care needs-assessment/measurement tool,
64 including the aim of assessment, target patients, patient capabilities, clinical settings, administration
65 mode, and its psychometric and practicality properties [27]; the latter defined as the burden of completing
66 the tool on respondents (acceptability) and administrators (feasibility) [29,30].

67
68 The intended use of the tools is another important factor to guide the selection of appropriate tools [31].
69 While some tools are mainly used as screening instruments to identify patients who require palliative care
70 based on their deteriorating health and potential palliative care needs (patient-identification tools),
71 others are primarily used to provide a more holistic evaluation of those unmet needs (needs-identification
72 tools) [32]. Furthermore, while some tools are designed to measure patient needs (needs-measurement
73 tools), others are designed to assess these needs as clinical decision aids (needs-assessment tools) [33].
74 Needs-measurement tools enable screening, monitoring, and scoring patient needs over time to track
75 changes in health status and evaluate the effectiveness and quality of provided care [34]. When used
76 alone, these tools may not trigger healthcare professionals to act on the identified needs as they may lack
77 the skills and knowledge to interpret the scores [35,36]. Therefore, they may have little contribution to
78 clinical decision making on their own [37]. On the other hand, needs-assessment tools, as clinical decision
79 aids, facilitate the evaluation of patient needs, assignment of actions to address those needs, and
80 understanding of care options and outcomes [33,38]. These tools are ideally used as adjuncts to patient
81 counseling to assist healthcare professionals in making the most appropriate decisions on patient care
82 [33]. They are not intended to be prescriptive or used as an endpoint in themselves, but rather as a
83 support and starting point for patient-centered care [33].

84
85 Comparisons between palliative care needs-assessment/measurement tools used in heart failure
86 populations are lacking. It is not known which tools are better for palliative care patient/needs
87 identification and which have the best psychometric and practicality evidence in these patients. There are
88 no systematic reviews to critique these tools in identifying patients with heart failure who have palliative
89 care needs. Three systematic reviews demonstrated tools that could be used to identify palliative care
90 patients in primary care settings [28,32,39]. However, these were not specific to heart failure populations
91 and limited to one setting. Another review of palliative care needs-assessment tools used in patients with
92 chronic heart failure was not systematic, nor did it compare the psychometric properties in detail [18]. A

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

93 comprehensive comparison between palliative care needs-assessment/measurement tools used in heart
94 failure populations is needed to determine the most appropriate tools for identifying patients who require
95 palliative care and assessing/measuring their needs. Subsequently, these needs can be acted upon to
96 improve patients' quality of life.

97
98 **Review question**
99 *What are the most appropriate palliative care needs-assessment/measurement tools for use in patients*
100 *with heart failure?*

101
102 **Review objectives**

- 103 1. Identify palliative care needs-assessment/measurement tools used to identify patients with heart
104 failure who have palliative care needs.
- 105 2. Compare these tools regarding their content (included items, length, addressed need domains) and
106 context of use (clinical settings, completion method).
- 107 3. Compare the development and intended use of the tools.
- 108 4. Compare the psychometric and practicality properties of the tools in patients with heart failure.
- 109 5. Compare the clinical applications of the tools in identifying patients with heart failure who have
110 palliative care needs.

111
112 **Methods**

113 The review protocol was registered with the International Prospective Register of Systematic Reviews
114 (PROSPERO) on December 2018 under registration number CRD42018118376. Quantitative, qualitative,
115 and mixed-methods studies were included in the review to maximize the evidence on using the tools in
116 patients with heart failure, where limited research is available [40]. The review was written following the
117 guidance of the *adapted Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)*
118 *for reporting systematic reviews of qualitative and quantitative evidence* [41]. Covidence online software
119 programme was used to facilitate systematic review management.

120
121 **Inclusion/exclusion criteria**

122 Studies were included if they met all these criteria:

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

- 123 • Included adults 18 years of age or older with a primary diagnosis of heart failure.
- 124 • Evaluated palliative care needs-assessment/measurement tools, defined as structured multi-item
125 research instruments developed for identifying palliative care patients/needs.
- 126 • Evaluated more commonly used tools, defined as those which were used for identifying heart failure
127 populations with palliative care needs in more than one study retrieved through the review search.
- 128 • Aimed to evaluate the tools in terms of development, psychometrics or practicality, or palliative care
129 patient/needs identification.
- 130 • Primary empirical quantitative, qualitative, or mixed-methods studies where quantitative and
131 qualitative data were combined for data collection and/or analysis.
- 132 • Published in English or Arabic.

133 Studies that evaluated guidelines, pathways, and individual items were excluded. Case reports, opinion
134 pieces, editorials, commentaries, letters, retrospective studies, reviews, and secondary research were also
135 excluded.

137 Search strategy

138 A sensitive search strategy was applied to retrieve relevant studies and tools after consulting experienced
139 librarians. Cochrane Library, MEDLINE Complete (EBSCO), AMED (EBSCO), PsycINFO (EBSCO), CINAHL
140 Complete (EBSCO), and EMBASE (Ovid) were searched from inception to 25 June 2020. The following
141 secondary resources were also searched: websites of the retrieved tools where available; EThOS for
142 United Kingdom's (UK's) doctoral research theses; and citing and cited articles of the included studies.
143 Search terms for *palliative care*, *heart failure*, and *tool* were combined in each database using both free-
144 text terms and Medical Subject Headings (MeSH) where available (Table 1). The search strategy for
145 EMBASE (Ovid) is presented in Supplemental Table 1. Duplicates were removed from the retrieved records
146 using EndNote X8 and Covidence.

148 Study/tool selection

149 Titles and abstracts of retrieved studies were screened by the main author (BR). A second reviewer (IM)
150 screened 10% of them independently. The agreement rate for the studies screened was 97% which
151 demonstrated a high level of agreement. Full texts of potentially relevant studies were screened by BR to
152 determine their eligibility, while IM screened 25% of those independently as the agreement rate was 80%.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

153 Discrepancies were resolved through discussion which helped identify screening issues and discuss the
154 inclusion criteria. A third reviewer (AG or NP) was consulted when necessary.

155
156 [Data collection](#)

157 Data extraction tables were created for the included studies. They were piloted first on a sample of studies
158 and continuously amended until the final versions were developed. Extracted data included study design,
159 objectives, population, settings, and country; method of and reason for tools' development; results of
160 psychometric and practicality testing; method of identifying patients requiring palliative care and their
161 needs; and results of tools' applications in palliative patient/needs identification. Relevant data were
162 extracted from the included papers by BR. IM extracted data from about half of the papers independently.
163 All disagreements were resolved through discussion which helped identify extraction issues and refine the
164 data extraction tables. There was no need to refer to the third reviewer. First authors of the included
165 studies were contacted by email to clarify vague information if necessary, and all of them responded. Data
166 were also extracted from the tools themselves and their associated guides if available. Extracted data
167 included primary instruments from which the tools were adapted, settings of use, completion method
168 and time, and involved items and need domains. The latest edition/version of each tool at the time of
169 synthesizing the evidence was compared to the others.

170
171 [Criteria to assess tools' psychometrics and practicality](#)

172 The psychometric and practicality properties of the included tools were assessed by BR using the Oxford
173 Patient-Reported Outcome Measures (PROMs) Group criteria for selecting PROMs in clinical trials [31].
174 Although the tools in this review were not all PROMs, this seemed the most appropriate tool to use as it
175 provides detailed guidance on how to assess each of these criteria. Among the eight criteria suggested by
176 the Oxford PROMs Group, the five which have been more often used and cited on standard checklists and
177 discussions were compared: Acceptability, Feasibility, Reliability, Validity, and Responsiveness [31].

178
179 [Quality appraisal](#)

180 To assess the quality of the heterogeneous studies (quantitative, qualitative, and mixed methods), Hawker
181 et al.'s tool for appraising disparate data was used [42]. This instrument assesses the quality of studies
182 based on nine criteria which can be scored from one (very poor) to four (good). The minimum and
183 maximum possible scores per study are nine and 36, respectively. The methodological quality of the

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

184 included studies was described and considered in the synthesis stage. Studies were not excluded based
185 on their methodological rigor or assigned scores. Quality assessment of the included papers was
186 performed by BR, while IM assessed the quality of about half of them independently. Disagreements were
187 resolved through discussion which helped identify quality appraisal issues and critique the studies more
188 thoroughly. There was no need to refer to the third reviewer.

190 Synthesis method

191 Narrative synthesis, guided by Popay et al.'s framework, was used to synthesize the findings from the
192 heterogeneous studies [43]. Tools were described narratively, and studies were tabulated and grouped
193 according to the evaluated tool and their application to discover patterns within and across the groups.
194 Subsequently, relationships were explored within and between the studies. The synthesis process was
195 then critiqued where the limitations of the synthesis methodology, influence of low-quality studies on the
196 synthesis results, made assumptions, and areas for future research were highlighted. Synthesizing the
197 evidence from the included studies was carried out by BR.

199 Results

200 Study selection

201 The search strategy for the primary and secondary resources retrieved a total of 46,212 records, which
202 were reduced to 33,135 after removing duplicates. The titles/abstracts of these papers were screened for
203 relevance and meeting the inclusion criteria, resulting in 308 papers for full-text screening. Among these,
204 27 papers were included in the review about 19 studies. The included studies differ in their design; ten
205 were quantitative [19,44-54], one qualitative [55], and eight of mixed-methods design [26,56-68]. All
206 studies were observational except for one interventional study [61-64], one pilot study [59], and one
207 feasibility study [26,56]. The PRISMA flow diagram of study selection is presented in Fig. 1 [69].

208
209 The included papers were classified into three categories based on how the included tools were evaluated:
210 development studies; psychometrics/practicality studies; and palliative care patient/needs identification
211 studies (identification studies) (Table 2). Some studies fitted into more than one category as they were
212 used for more than one purpose. There were five development studies, five psychometrics/practicality

1
2
3
4 213 studies, and 17 identification studies. Quality scores of studies ranged from 22 to 35 with a median of 29,
5
6 214 indicating moderate to good quality.

7
8 215
9
10 216 1. Identifying palliative care needs-assessment/measurement tools used to identify
11
12 217 patients with heart failure who have palliative care needs

13
14 218 Several tools were found that had been or could be used for identifying patients with heart failure who
15
16 219 require palliative care. Among these, six palliative care needs-assessment/measurement tools were
17
18 220 identified as per the inclusion criteria and compared:

- 19
20 221 1. Integrated Palliative care Outcome Scale (IPOS) [55]
21
22 222 2. Gold Standards Framework - Proactive Identification Guidance (GSF-PIG) [70]
23
24 223 3. Radboud Indicators for Palliative Care Needs (RADPAC) [60]
25
26 224 4. Supportive and Palliative Care Indicators Tool (SPICT) [65]
27
28 225 5. Needs Assessment Tool: Progressive Disease - Heart Failure (NAT:PD-HF) [58]
29
30 226 6. Necesidades Paliativas - Palliative Needs (NECPAL) [66]

31 227
32
33 228 2. Comparing the tools regarding their content and context of use

34
35 229 The main features and comparisons of the tools are displayed in Table 3. All tools were based on previous
36
37 230 tools that informed their development except RADPAC, which was informed by extracting indicators used
38
39 231 for identifying patients with palliative care needs from the literature [60]. Some tools were derived from
40
41 232 each other which explains their similarities.

42 233
43
44 234 **Included items**

45 235 The tools include different items to identify patients with palliative care needs. GSF-PIG and NECPAL
46
47 236 include the surprise question (*would you be surprised if the patient dies in next year?*) as the first step for
48
49 237 identification [71], followed by general and disease-specific indicators of health decline. SPICT does not
50
51 238 have the surprise question but includes general and disease-specific indicators, while RADPAC has only
52
53 239 disease-specific indicators. In all these tools, a set of indicators specific to heart failure, or heart disease,
54
55 240 exists. On the other hand, IPOS and NAT:PD-HF do not have indicators for patient-identification. Instead,
56
57 241 they include items that evaluate a variety of patient needs. IPOS consists of open-ended questions about
58
59 242 patient main problems and unlisted symptoms alongside closed-ended questions on patient and caregiver
60
61 243 needs which are answered using a Likert scale. It provides a total score which gives information on the

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

244 overall patient needs. NAT:PD-HF consists of four sections that address patient and caregiver needs:
245 *priority referral for further assessment, patient wellbeing, caregiver/family ability to care for patient, and*
246 *caregiver wellbeing.* Needs identified in the last three sections can be rated according to their significance:
247 *none, some/potential, and significant.* Moreover, actions are suggested for these needs: *direct*
248 *management by the healthcare professional, management by another care team member, and referral to*
249 *members outside the team.*

250

251 **Clinical settings**

252 Only NAT:PD-HF is specific for use in patients with heart failure [58]. All other tools can be used in multiple
253 diseases. RADPAC was developed for use in primary care [60], while the other tools can be used in
254 different healthcare settings.

255

256 **Completion method**

257 Other than IPOS which has a version for staff completion and another for patient completion, all tools
258 were designed to be completed by healthcare professionals with interaction from patients or informal
259 caregivers. All tools have a subjective element of completion where healthcare professionals use their
260 clinical judgement (*for example, to assess symptoms severity or health decline*) or where
261 patients/caregivers provide their input (*for example, to request for palliative care or rate their symptoms*).
262 Furthermore, GSF-PIG, RADPAC, SPICT, and NECPAL require information from patients' medical records
263 such as the number of hospitalizations and weight.

264

265 **Length**

266 The length of tools varies with a range of seven items for completion (RADPAC) to 20 items (NAT:PD-HF).
267 IPOS and NAT:PD-HF contain more items than other tools and although they may take longer to complete,
268 they provide a more comprehensive evaluation of patient needs. SPICT and NECPAL need less than eight
269 minutes to fill [72-74]. IPOS patient version takes about eight minutes for completion while the staff
270 version takes about two to five minutes [75]. NAT:PD-HF needs about five to ten minutes [27], although
271 its Dutch translation needed an average of 26 minutes to be completed by heart failure nurses who were
272 untrained in palliative care [59].

273

274 **Addressed need domains**

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

275 NAT:PD-HF covers more palliative care needs than any other tool, including the key need domains
276 advocated by the WHO; physical, psychological, social, and spiritual [1]. It is the only tool that asks if
277 patients have issues in managing their medication and treatment regimens. IPOS is also comprehensive
278 and addresses most of the need domains contained in NAT:PD-HF. NECPAL misses the spiritual issues,
279 while GSF-PIG, RADPAC, and SPICT address mainly the physical symptoms of patients.

280
281 In summary, NAT:PD-HF and IPOS outweigh other tools regarding the content and context of use. Both
282 can be used in multiple clinical settings, completed in a reasonable time frame without reviewing patient
283 medical records, provide a comprehensive assessment/measurement of patient and informal caregiver
284 needs, and address more palliative care needs than other tools. Compared to NAT:PD-HF, IPOS has a
285 patient version for completion which can decrease staff burden, includes open questions which enable
286 patients to outline their main problems and unlisted symptoms, and requires less time for filling. However,
287 unlike NAT:PD-HF, IPOS does not explicitly address treatment complexity among patient needs, neither
288 does it have a correspondent action to be taken for the identified concerns.

289 3. Comparing the development and intended use of the tools

290
291 None of the tools was originally developed for use in patients with heart failure. Only NAT:PD-HF was
292 adapted specifically for use in these patients from a similar tool for patients with cancer [58]. All other
293 tools are generic but have been used for patients with heart failure. A heart failure specific version of IPOS
294 has not been formally tested yet [76]. All tools were developed in high-income countries, and half of them
295 (IPOS, GSF-PIG, SPICT) were developed in the UK. The clinical expertise of healthcare professionals
296 contributed to tools' development. Similarly, literature reviews were conducted to aid in the development
297 of all tools except GSF-PIG [70]. Interestingly, all tools have an original development paper except GSF-
298 PIG. In conclusion, GSF-PIG underperforms compared to other tools in this comparison aspect.

299
300 GSF-PIG, RADPAC, SPICT, and NECPAL were developed to identify patients who require palliative care
301 (*Patient-identification tools*) [60,65,66,70], while IPOS and NAT:PD-HF were developed to provide a more
302 comprehensive evaluation of the palliative care needs of patients (*needs-identification tools*) [55,58]. The
303 patient-identification tools were mainly developed as *clinical decision aids* which can be used during
304 patient consultation to decide whether patients require palliative care and subsequently to prompt more
305 holistic needs-assessment/measurement. SPICT, for example, is recommended to be used alongside IPOS
306 to get a more complete picture on patient needs [77]. IPOS, on the other hand, was developed as an

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

307 *outcome measure* to identify and score patient symptoms and concerns. It does not provide
308 recommendations on how to address the identified needs and thus clinical decision support tools are
309 needed to interpret its scores [33]. NAT:PD-HF is not an outcome measure. It is mainly used as a clinical
310 decision aid during patient consultation to classify the level of concern (none, some, significant) and triage
311 actions for each identified need (managed directly, managed by other care team member, referral
312 required). The main purpose and intended use of the tools are summarized in Table 4.

4. Comparing the psychometric and practicality properties of the tools in patients with heart failure

316 In the general population, IPOS and SPICT have the best evidence of validity, reliability, and practicality
317 [55,65,72,73,78-84], followed by NECPAL and RADPAC [60,66], while no formal validation studies were
318 found for GSF-PIG. Still, the psychometric and practicality properties of the tools were rarely assessed in
319 heart failure populations (Table 5). Only NAT:PD-HF (Original NAT:PD-HF), its Dutch translation (Dutch
320 NAT:PD-HF), IPOS (Original IPOS), and its German translation (German IPOS) had their practicality
321 properties tested in these patients [56-59]. Besides, only Original NAT:PD-HF and Dutch NAT:PD-HF had
322 some of their psychometric properties tested in this population [51,58,59].

324 **Acceptability:** Acceptability of the tools to patients was only tested for Original NAT:PD-HF, Dutch
325 NAT:PD-HF, Original IPOS, and German IPOS. Although acceptability of NAT:PD-HF versions was not
326 directly assessed from the perspective of patients, it was assessed using other parameters such as *time to*
327 *complete* and *translation and cultural applicability* [31]. Overall, both IPOS versions and Original NAT:PD-
328 HF were acceptable, with more evidence in favor of IPOS [56-58]. On the contrary, Dutch NAT:PD-HF had
329 negative evidence of acceptability [59].

331 **Feasibility:** Feasibility of the tools for healthcare professionals was only tested for Original NAT:PD-HF,
332 Dutch NAT:PD-HF, and Original IPOS. While Original IPOS and Original NAT:PD-HF were feasible (easy to
333 complete in a short time) [56,58], Dutch NAT:PD-HF had negative evidence of feasibility [59].

335 **Reliability:** Reliability was only assessed for Original NAT:PD-HF [58]. Results of testing inter-rater
336 reliability showed good agreement between the raters for each tool item. Internal consistency and test-
337 retest reliability were not tested.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Validity: Validity was only assessed for Original NAT:PD-HF and Dutch NAT:PD-HF. Original NAT:PD-HF showed good face, content, and concurrent (construct) validity [51,58]. Construct validity was tested in one study by identifying the correlation between the items in the NAT:PD-HF *patient wellbeing* section and corresponding items from the Heart Failure Needs Assessment Questionnaire (HFNAQ) [58]. In another study which was not designed to test the tool psychometrics, a statistically significant relationship was found between having a *significant* concern on any item in the NAT:PD-HF *patient wellbeing* section and the construct of specialist palliative care needs as defined by the authors (persistently severe impairment of any of four PROMs without improvement, or severe impairment immediately preceding death) ($p = 0.008$) [51]. The other tool sections were not tested for construct validity in both studies. In contrast to Original NAT:PD-HF, Dutch NAT:PD-HF showed poor construct and criterion validity [59]. These were tested by identifying the correlation between some items of Dutch NAT:PD-HF and three outcome measures: Dutch Edmonton Symptom Assessment System (ESAS), Australia-modified Karnofsky Performance Scale (AKPS), and Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC). Of note, the evaluating study was a pilot study and not designed to test the tool's validity.

Responsiveness: Responsiveness was not evaluated for any tool.

In conclusion, Original NAT:PD-HF is the most extensively tested and psychometrically robust tool in heart failure populations. It is the only tool validated in this population and has some evidence of reliability. Also, it is feasible for healthcare professionals and has some evidence of acceptability to patients. Although IPOS has more acceptability evidence than NAT:PD-HF, its psychometrics have not been tested in heart failure populations. Psychometrics and practicality of the other tools were not tested at all in this population.

5. Comparing the clinical applications of the tools in identifying patients with heart failure who have palliative care needs

The characteristics of the identification studies are shown in Supplemental Table 2. Detailed results of the tools' applications in identifying heart failure populations with palliative care needs are presented in Supplemental Table 3.

Breadth of tools' application in heart failure populations

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

370 Few identification studies were found for each tool. GSF-PIG and NECPAL were the most commonly
371 evaluated (four studies each) [19,44-47,52-54,66-68], followed by SPICT and NAT:PD-HF [48-51,58,59,65]
372 (three studies each), IPOS (two studies) [26,56,57], and lastly RADPAC (one study) [61-64]. GSF-PIG was
373 evaluated in more countries than other tools (four countries), followed by NAT:PD-HF (three countries).
374 NECPAL was evaluated in diverse healthcare settings, while IPOS, GSF-PIG, SPICT, and NAT:PD-HF were
375 evaluated for inpatients and outpatients. More patients with heart failure were screened by NAT:PD-HF
376 and NECPAL compared to other tools. Baseline data for the tools-screened patients were described in
377 more detail in NAT:PD-HF and IPOS studies. While NAT:PD-HF was evaluated for several types and classes
378 of heart failure and was the only tool evaluated for those with acute on chronic heart failure, patients
379 who lacked the cognitive capacity to participate or consent were excluded from its studies.

380
381 **Use for palliative care patient/needs identification**

382 All tools were used to identify palliative patients (patient-identification) and evaluate their needs (needs-
383 identification) except RADPAC which was mainly applied by the authors to identify palliative patients [61-
384 63]. When used for patient-identification, GSF-PIG (in one study) and RADPAC were combined with a more
385 comprehensive needs-assessment/measurement tool [45,46,61,62].

386
387 **Ability and appropriateness of the tools for palliative care patient/needs identification**

388 *Proportion of identified patients*

389 The proportion of patients with heart failure identified by the tools for palliative care among those
390 screened was considered as an indicator of their *identification ability*. This could not be calculated in many
391 studies because of missing or vague data and the lack of a clear gold standard of what a palliative care
392 patient is. RADPAC-trained primary practitioners identified only 6% of patients with heart failure in a
393 randomized controlled trial [62]. One-year after training, these trained practitioners did not identify any
394 patient, while those untrained identified more patients shortly after RADPAC administration [63]. SPICT
395 identified only a few patients with heart failure although the proportion in one study was misleadingly
396 high because of the small sample size [48]. GSF-PIG identified 86% of patients with heart failure in one
397 study [19], while NECPAL identified 32%, 55%, and 91% in three studies [53,54,67]. IPOS and NAT:PD-HF
398 identified 56% and 26% of patients with heart failure for specialist palliative care, respectively [51,57].
399 NAT:PD-HF identified 100% of patients for palliative care in another study [59].

400
401 *Baseline health characteristics and morbidity outcomes of identified patients*

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

402 This was considered as an indicator of the *appropriateness of identification* by the tools. However, it was
403 not reported in most studies. The tool is robust if the patients it identified for palliative care had evidence
404 of poor health. Poor health at baseline; evidenced by poor scoring in patient outcome measures, long or
405 frequent hospitalizations, old age, and/or New York Heart Association (NYHA) class III-IV, was shown for
406 many patients identified by IPOS [57], GSF-PIG [19,45,46], NAT:PD-HF [51,59], and NECPAL [53,54].
407 Likewise, better health at baseline, evidenced by NYHA class I-II, was observed in many patients who
408 reported few significant psychological, social, and spiritual concerns in NAT:PD-HF [58]. Morbidity
409 outcomes at follow-up periods of identified patients were only presented briefly in one GSF-PIG study,
410 where identified patients did not have significantly more hospitalizations within a one-year follow-up
411 period as would have been expected [19].

412
413 **Impact of the tools**

414 Three tools were incorporated into palliative care interventions where healthcare professionals were
415 trained on using the tools to identify, and subsequently act on, the palliative care needs of patients
416 [56,59,61,62]. IPOS, RADPAC, and Dutch NAT:PD-HF had no significant positive impact on patients with
417 heart failure or their informal caregivers. The IPOS-based intervention resulted in mild improvement in
418 the quality of life, symptom burden, and depression; though this was often transient and got worse at
419 further follow-up periods [56]. Similarly; symptom burden, physical functioning, care dependency, and
420 caregiver burden were not significantly improved after the Dutch NAT:PD-HF intervention and health
421 status got significantly worse [59]. Additionally, it did not influence the recording of advance directives or
422 hospital and emergency room visits. Of note, the studies that evaluated the intervention effect of IPOS
423 and Dutch NAT:PD-HF were pilot/feasibility studies and not designed to test their effectiveness [56,59].
424 In contrast, the RADPAC intervention effect was evaluated in a cluster randomized controlled trial where
425 primary care practitioners used the tool to identify patients with palliative care needs [61,62]. RADPAC
426 intervention did not result in a significant difference between deceased patients of RADPAC-trained
427 practitioners and those of untrained practitioners in the number of contacts with out of hours primary
428 care service (primary outcome measure), contacts with own primary care practitioner, hospitalizations,
429 and place of death (secondary outcome measures). In a post-hoc analysis, identified patients from the
430 trained group (only two with heart failure) had significantly better secondary outcome measures
431 compared to all other patients, but the primary measure was not different.

432
433 **Perspectives of healthcare professionals and patients on using the tools for identification**

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

434 The three interventions described above were followed by interviews with healthcare professionals
435 and/or patients to evaluate their perspectives on using the tools for identification [26,59,64]. The
436 emerged themes were mainly positive for IPOS and RADPAC and negative for Dutch NAT:PD-HF. A
437 common positive theme on IPOS and RADPAC was the identification of palliative needs (IPOS) and patients
438 (RADPAC), though identifying those with heart failure was considered difficult by RADPAC. Dutch NAT:PD-
439 HF was not found helpful to communicate about palliative care, while IPOS was found to facilitate patient-
440 nurse communication although many patients did not consider it to have any clinical effect. Patient
441 perspectives were only evaluated for IPOS while healthcare professionals were interviewed in all studies.

442
443 In summary, NAT:PD-HF outperformed other tools in the clinical applications in palliative patient/needs
444 identification though this needs further testing. NAT:PD-HF has relatively wide application in heart failure
445 populations and it was used for both patient-identification and needs-identification. NAT:PD-HF was able
446 to identify high proportions of patients with heart failure who have palliative care needs and most
447 importantly, those identified had poor health at baseline, indicating a proper identification. The original
448 NAT:PD-HF was not incorporated into an intervention in contrary to its Dutch translation. Like IPOS and
449 RADPAC, Dutch NAT:PD-HF lacked a significant positive impact on patients/informal caregivers. Unlike
450 these two tools, healthcare professionals were not positive in their comments on Dutch NAT:PD-HF and
451 they listed many barriers for its use.

453 Discussion

454 This is the first systematic review that comprehensively compares palliative care needs-
455 assessment/measurement tools used in patients with heart failure. The main review question was to
456 determine the most appropriate palliative care needs-assessment/measurement tools for use in heart
457 failure populations to inform clinical practice. Six tools were identified and compared according to their
458 content and context of use, development, psychometrics and practicality, and applications in identifying
459 patients with palliative care needs. Based on the limited available evidence, NAT:PD-HF is the most
460 appropriate palliative care needs-assessment tool for heart failure populations, though more studies are
461 needed to confirm this. IPOS is promising and shares many advantages of NAT:PD-HF but it is less
462 commonly studied in this population [76]. Generalizability of the review results is limited by the small
463 number of tool-evaluating studies and the heterogeneity of populations, interventions, outcomes, and
464 health settings.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

465

The results of this review are concordant with the recent European Association for Palliative Care (EAPC) position statement where a comprehensive palliative care needs-assessment tool was suggested to identify patients with unmet needs [9]. NAT:PD-HF, being validated for patients with heart failure, was suggested as an example of such a tool but this was not based on detailed comparisons with other tools. IPOS was also suggested as a trigger to initiate palliative care but categorized separately as a symptoms-assessment tool. SPICT was considered a patient-identification tool that does not detail individual needs. Although SPICT was recommended over other tools in one review to identify palliative patients, this was concluded for the general population in primary care, and neither NAT:PD-HF nor IPOS was included in that review [39].

475

NAT:PD-HF was not identified in three previous systematic reviews that looked for tools used to identify general populations with palliative care needs in primary care [28,32,39]. It was probably seen as a needs-identification rather than a patient-identification tool. Indeed, NAT:PD-HF was developed for identifying patient needs rather than screening patients who require palliative care, although it has been used for both purposes [51,58,59]. Another non-systematic review of palliative care needs-assessment in patients with chronic heart failure included NAT:PD-HF but it did not seek which tool is the most appropriate for this population [18].

483

The tools have different items to identify patients with palliative care needs, including the surprise question, indicators of deterioration, and reported symptoms and concerns. The potential use of the surprise question as a simple method for identifying patients with palliative care needs had been acknowledged [85,86]. However, RADPAC developers did not recommend it to trigger end of life discussions [60], and although it was included in SPICT original versions it was removed later. Apart from this question, the items of some tools (GSF-PIG, RADPAC, and SPICT) address mainly patient physical symptoms. These tools may not be able to identify relatively asymptomatic patients with a high risk of dying [87,88]. Therefore, a more comprehensive needs-assessment/measurement tool like NAT:PD-HF or IPOS would be more appropriate to use in this population.

493

The length of time to complete the tools should be accounted for to prevent staff/patient burden [27]. Reasons for the differences between the tools in time for completion include the tool purpose, number of items, and completion method [27,39]. NAT:PD-HF and IPOS aim to identify the multidimensional

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

497 palliative care needs of patients and hence they have the largest number of items to complete. All items
498 require clinical judgement or patient/informal caregiver input which may increase completion time [39].
499 The *action taken* section of NAT:PD-HF may contribute to the longer time needed to fill the tool compared
500 to IPOS, but it may also prompt staff to think about how to act on the identified needs. IPOS does not
501 have such section and it may just be filled and filed without having a clinical effect [26]. IPOS patient
502 version (PROM) can be used outside the consultation time where each question is answered to provide a
503 score measure for each concern and symptom. Conversely, although NAT:PD-HF takes a relatively few
504 minutes to complete the form itself, it represents information obtained throughout a longer clinical
505 assessment. This may explain the long time needed to complete its Dutch translation (26 minutes) [59].
506 Interestingly, the original cancer version of NAT:PD-HF (NAT:PD-C) did not prolong the average
507 consultation time (18 minutes) indicating that the tool items are normally evaluated during consultations
508 [89]. The other tools (GSF-PIG, RADPAC, SPICT, and NECPAL) are clinical consultation aids, like NAT:PD-HF,
509 but they require screening medical records in addition to subjective judgements. No data about time for
510 completion were available on the latest version of these tools at the time of synthesizing the evidence.

511
512 Regarding tools' development, GSF-PIG, SPICT, and NECPAL were derived from prognostic tools but the
513 focus has been shifted from determining prognosis to assessing needs for recognizing eligible patients for
514 palliative care. This is supported by the results of a study where a high level of need was observed among
515 patients identified by GSF-PIG although few of them died within a 12-month follow-up period [19]. Indeed,
516 GSF-PIG was renamed from *Prognostic Indicator Guidance* to *Proactive Identification Guidance* although
517 the tool content only showed minimal changes [70]. Likewise, the aim of SPICT was changed from
518 "*identifying people at risk of deteriorating and dying*" to "*identify people whose health is deteriorating*
519 *[and] assess them for unmet supportive and palliative care needs...*" [77]. Despite these endeavors, these
520 tools are still used to determine prognosis which informs patient eligibility for palliative care [19,78,90].

521
522 The tools are not necessarily mutually exclusive; indeed, they can be used for different, and possibly
523 complementary, purposes. One scenario is the use of one tool to screen for patients who require palliative
524 care (patient-identification), followed by another tool to evaluate their needs more comprehensively
525 (needs-identification) [32]. In this case, the patient-identification tool provides a quick snapshot of patient
526 needs, while the needs-identification tool provides a more complete picture and holistic evaluation of
527 these needs [27]. Another scenario is the use of one tool to measure general patient needs over time and
528 another tool to identify specific needs and triage action to meet those needs [91]. IPOS, as a generic

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

529 outcome measure which provides a total score and individual scores of patient needs, could provide a
530 general summary of patient needs which could be then assessed in more detail using the heart failure
531 specific tool NAT:PD-HF by determining the level of concern for each need and assigning actions to address
532 those needs. Another possible use of the tools is to identify patients with specialist palliative care needs
533 to be included in a randomized controlled trial of specialist palliative care versus standard care [92].
534 Providing a specialist palliative care intervention to those identified to have specialist palliative care needs
535 is necessary to avoid diluting the effect size. This issue is common in heart failure research where patients
536 with specialist palliative care needs are not differentiated from patients without these needs.

537
538 Given that the tools serve different purposes, their psychometric properties are not directly comparable.
539 Nonetheless, no tool had been tested as widely as NAT:PD-HF. Original NAT:PD-HF has good validity and
540 interrater reliability and was acceptable to staff and patients [51,58]. The poor psychometric and
541 practicality properties of Dutch NAT:PD-HF have several possible reasons [59]. Firstly, although the tool
542 was translated using a forward-backward procedure, cultural adaptation was not adopted upon
543 translation. Cultural adaptation is needed when a tool is used in another country and language to maintain
544 its content validity [93], and poor translation may create an inequivalent tool to the original one [93,94].
545 Secondly, the evaluating study was not designed as a primary psychometric study and its focus was not to
546 test construct and criterion validity. Nonetheless, the correlation between some Dutch NAT:PD-HF items
547 and three outcome measures was examined in an exploratory secondary analysis, and the results provided
548 information on both validity types. Thirdly, the small sample size was a contributor to the lack of
549 relationship between the constructs. Lastly, the heart failure nurses who administered the tool to patients
550 lacked skills, knowledge, training, and experience in palliative care which led to difficulties in
551 understanding the tool questions. This suggests that implementation issues may affect the tools' ability
552 to identify patient needs.

553
554 Two approaches were suggested in this review to evaluate the tools in identifying patients with palliative
555 care needs. The first approach is to assess their identification ability by calculating the proportion of
556 identified palliative patients (the more patients identified, the better is the tool). It was noted that a high
557 proportion of identified patients may not always reflect a good tool's identification ability. Proportions
558 may be misleadingly high or low if the tool is used by untrained or unskilled staff or if few patients are
559 screened [48,49]. Also, a low proportion may reflect less severe disease rather than weak identification
560 ability. Therefore, a better approach to evaluate the tools is to assess the appropriateness of identification

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

561 by evaluating the health status of identified patients. Issues with identification were suggested for
562 RACPAC and NECPAL. RADPAC-trained primary care practitioners identified a few patients for palliative
563 care [62], most likely because the tool covers only physical patient needs so it could not identify those
564 with psychosocial and spiritual needs. For NECPAL, more than 90% of patients with a negative answer to
565 the surprise question were identified by the tool across all the evaluating studies [52-54,67], which may
566 suggest a little added value of the detailed NECPAL compared to the surprise question alone.

567
568 The lack of intervention effect of IPOS and Dutch NAT:PD-HF on health outcomes have many possible
569 reasons [56,59]. Firstly, the evaluating studies were not designed to test effectiveness. Secondly,
570 worsening of health status over time is expected in patients with heart failure [8]. Without a control group,
571 it is not possible to see a signal of benefit over time; deterioration may have happened faster without the
572 intervention. Lastly, the actions taken by the nurses to address the identified patient needs might be
573 inappropriate as they were not offered clinical guidelines on how to act upon the results of the tools. The
574 interviews with heart failure nurses and patients after the IPOS intervention revealed that it could not
575 trigger nurses to act on the identified needs [26]. The several barriers listed for Dutch NAT:PD-HF by
576 interviewed heart failure nurses indicate the improper translation of the tool and lack of palliative care
577 knowledge among nurses [59]. For RADPAC intervention, the lack of significant effect was justified by the
578 small proportion of identified patients and identifying practitioners [61,62]. The difficulty in identifying
579 palliative patients with heart failure as reported by the interviewed primary care practitioners after the
580 intervention revealed a tool identification problem [64].

581
582 To be clinically relevant, palliative care needs-assessment/measurement tools should be successfully
583 implemented in practice by healthcare professionals. Barriers to implementation include high workload
584 of healthcare professionals and limited resources and capacities; lack of expertise, knowledge, education,
585 and training about palliative care in heart failure; and lack of communication skills with patients and
586 informal caregivers [32,59]. Additional barriers adopted from similar discussions on implementing
587 advance care planning in heart failure care, where needs-assessment is a key element [95], exist on
588 different levels. These include lack of support at the health system and institutional level; lack of an
589 electronic information-recording and exchange system; lack of public education about palliative care; fear
590 of losing hope and causing concern if palliative care is discussed with patients and informal caregivers;
591 lack of trust and a long relationship with patients and informal caregivers to enable palliative care
592 discussions; unstable physical, cognitive, and emotional conditions of patients; emotional impact on

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

593 healthcare professionals when discussing palliative care; misconception that palliative care discussions
594 reflect treatment failure; and lack of collaboration between healthcare professionals and consensus on
595 who should fill the tool and assess the needs [96-98]. It is essential to overcome these barriers because
596 no matter how well-developed, valid, acceptable, and feasible the tools are, they would be ineffective in
597 clinical practice if no attention is paid to implementation issues. Successful implementation of the tools
598 would facilitate the timely identification of patients with palliative care needs and subsequent access to
599 palliative care services [32].

600

601 [Strengths and limitations](#)

602 This review adopted a systematic method to search for relevant evidence, screen retrieved studies and
603 tools, extract data from included ones, assess their quality, and synthesize their findings. A broad search
604 strategy was used to retrieve most of the relevant studies. The review was not restricted to quantitative
605 or qualitative studies as both were sought. It was written following the adapted PRISMA reporting
606 guideline to enhance transparency [41]. The choice of the most appropriate tools was based on
607 comprehensive comparisons according to predetermined criteria. Although NAT:PD-HF was suggested as
608 an example of a good needs-assessment tool in the EAPC statement and another review, this was not
609 based on such comparisons [9,18].

610

611 The review has some limitations. Firstly, tools were excluded if they were not developed for palliative care
612 patient/needs identification or used for identifying heart failure populations with palliative care needs in
613 a single study retrieved through the review search. Including these tools in the review could have altered
614 its findings. Secondly, the second reviewer was only partly involved in study screening, data extraction,
615 and quality appraisal. He was not involved in assessing the tools' psychometric and practicality properties
616 and synthesizing the evidence. Thirdly, the psychometric and practicality properties of the tools were
617 assessed using the Oxford PROMs Group criteria although all tools, except IPOS patient version, were
618 clinical decision aids rather than PROMs. Needs-assessment tools are distinct from needs-measurement
619 tools and they have different, though overlapping, purposes; therefore, the psychometric approaches for
620 each are not directly comparable. The purpose and method of validation differ between these tool types
621 and the psychometric items of responsiveness, although not assessed, may not apply to clinical decision
622 aids. Fourthly, despite adopting a sensitive search strategy, some studies and tools might be missed as
623 with any systematic review. Studies published in non-English or non-Arabic languages were not searched,
624 and few grey literature sources were sought. Indeed, palliative care and heart failure studies are difficult

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

625 to retrieve because of their inconsistent terminology [99,100]. The term *heart disease* was used in some
626 included studies and this was assumed to be equivalent to *heart failure* unless indicated otherwise.

627
628 Methodological limitations include the subjective nature of narrative synthesis which may affect
629 transparency and reproducibility [101], though this was mitigated by adapting Popay et al.'s framework
630 [43]; lack of consensus on the best tool for concomitantly appraising quantitative, qualitative, and mixed-
631 methods studies [102], though the commonly cited Hawker et al.'s tool was used; and assignment of a
632 total quality score for each study which is not agreed by some researchers [42]. Studies were not excluded
633 based on their quality score. However, excluding lower-quality studies would not have changed the
634 answer to the review question, especially that NAT:PD-HF and IPOS studies scored in the upper range of
635 the scale and would not have been excluded.

636 637 Implications for research, practice, and policy

638 The tools need further assessment of their psychometric and practicality properties in patients with heart
639 failure. Further evaluation of the tools for identifying heart failure populations with palliative care needs
640 is also needed. Future studies should include a larger number of patients, evaluate patients with different
641 types of heart failure and in multiple health settings, and adequately report the baseline data and health
642 outcomes for identified patients. Cultural adaptation should be included in the tools' translation to create
643 tools equivalent to the original ones. Healthcare professionals should be aware of the different roles that
644 needs-assessment/measurement tools can play and consider combining them where appropriate. Until
645 more data become available, they are advised to use NAT:PD-HF to identify heart failure populations with
646 palliative care needs. This should be followed by acting to address these needs and consequently improve
647 health outcomes. Policymakers should adopt a needs-based approach for identifying patients requiring
648 palliative care and integrate needs-assessment/measurement tools into the practice of healthcare
649 professionals. Particular attention should be paid to implementation issues to enhance the clinical
650 effectiveness of the tools in practice.

651 652 Conclusion

653 Six palliative care needs-assessment/measurement tools used in patients with heart failure were
654 identified and compared according to their content and context of use, development, psychometrics and
655 practicality, and applications in identifying palliative care patients and needs. The tools are not necessarily
656 mutually exclusive as they may serve different purposes including patient-identification, needs-

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

657 identification, needs-measurement, and needs-assessment (decision aids). Comparison results suggested
658 that NAT:PD-HF is the most appropriate palliative care needs-assessment tool for use in heart failure
659 populations. It covers most of the patient needs and has the best psychometric properties and evidence
660 of identification ability and appropriateness. However, this conclusion is based on limited evidence. Four
661 retrieved tools lack studies on their psychometric and practicality properties in heart failure populations,
662 and one of these (GSF-PIG) even lacks a research development paper. Nevertheless, NAT:PD-HF is
663 preliminarily recommended for use in patients with heart failure, but it requires further testing and
664 validation. IPOS has some similar advantages to NAT:PD-HF but less evidence is available on its use in
665 heart failure populations.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Figure's caption (and key)

Fig. 1 PRISMA flow diagram of study selection

HF: Heart Failure, PC: Palliative Care

Compliance with ethical standards

This article does not contain any studies with human participants or animals performed by any of the authors.

Disclosures

Funding

This review was part of a research project for Bader Remawi who is funded by the British Council to pursue his PhD study at Lancaster University which contributes the value of the academic fees.

Conflict of interest

The authors declare that they have no conflict of interest.

References

1. Sepúlveda C, Marlin A, Yoshida T, Ullrich A (2002) Palliative care: the World Health Organization's global perspective. *J Pain Symptom Manage* 24(2):91-96. [https://doi.org/10.1016/s0885-3924\(02\)00440-2](https://doi.org/10.1016/s0885-3924(02)00440-2)
2. Quill TE, Abernethy AP (2013) Generalist plus specialist palliative care - creating a more sustainable model. *N Engl J Med* 368(13):1173-1175. <https://doi.org/10.1056/NEJMp1215620>
3. Gelfman LP, Kavalieratos D, Teuteberg WG, Lala A, Goldstein NE (2017) Primary palliative care for heart failure: what is it? How do we implement it? *Heart Fail Rev* 22(5):611-620. <https://doi.org/10.1007/s10741-017-9604-9>
4. Chan HY, Yu DS, Leung DY, Chan AW, Hui E (2016) Quality of life and palliative care needs of elderly patients with advanced heart failure. *J Geriatr Cardiol* 13(5):420-424. <https://doi.org/10.11909/j.issn.1671-5411.2016.05.016>
5. Cagle JG, Bunting M, Kelemen A, Lee J, Terry D, Harris R (2017) Psychosocial needs and interventions for heart failure patients and families receiving palliative care support: a systematic review. *Heart Fail Rev* 22(5):565-580. <https://doi.org/10.1007/s10741-017-9596-5>
6. O'leary N (2009) The comparative palliative care needs of those with heart failure and cancer patients. *Curr Opin Support Palliat Care* 3(4):241-246. <https://doi.org/10.1097/SPC.0b013e328332e808>
7. Bekelman DB, Rumsfeld JS, Havranek EP, Yamashita TE, Hutt E, Gottlieb SH et al (2009) Symptom burden, depression, and spiritual well-being: a comparison of heart failure and advanced cancer patients. *J Gen Intern Med* 24(5):592-598. <https://doi.org/10.1007/s11606-009-0931-y>
8. Jaarsma T, Beattie JM, Ryder M, Rutten FH, McDonagh T, Mohacsi P et al (2009) 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* 11(5):433-443. <https://doi.org/10.1093/eurjhf/hfp041>
9. Sobanski PZ, Alt-Epping B, Currow DC, Goodlin SJ, Grodzicki T, Hogg K et al (2020) Palliative care for people living with heart failure: European Association for Palliative Care Task Force expert position statement. *Cardiovasc Res* 116(1):12-27. <https://doi.org/10.1093/cvr/cvz200>
10. Braun LT, Grady KL, Kutner JS, Adler E, Berlinger N, Boss R et al (2016) Palliative care and cardiovascular disease and stroke: a policy statement from the American Heart Association/American Stroke Association. *Circulation* 134(11):e198-e225. <https://doi.org/10.1161/CIR.0000000000000438>
11. Diop MS, Rudolph JL, Zimmerman KM, Richter MA, Skarf LM (2017) Palliative care interventions for patients with heart failure: a systematic review and meta-analysis. *J Palliat Med* 20(1):84-92. <https://doi.org/10.1089/jpm.2016.0330>
12. Datla S, Verberkt CA, Hoye A, Janssen DJ, Johnson MJ (2019) Multi-disciplinary palliative care is effective in people with symptomatic heart failure: a systematic review and narrative synthesis. *Palliat Med* 33(8):1003-1016. <https://doi.org/10.1177/0269216319859148>

- 1
2
3
4 715 13. Zhou K, Mao Y (2019) Palliative care in heart failure: a meta-analysis of randomized controlled trials.
5 716 Herz 44(5):440-444. <https://doi.org/10.1007/s00059-017-4677-8>
- 7 717 14. Gadoud A, Kane E, Oliver SE, Johnson MJ, Macleod U, Allgar V (2020) Palliative care for non-cancer
8 718 conditions in primary care: a time trend analysis in the UK (2009-2014). BMJ Support Palliat Care.
9 719 <https://doi.org/10.1136/bmjspcare-2019-001833>
- 11 720 15. Selman L, Harding R, Beynon T, Hodson F, Hazeldine C, Coady E et al (2007) Modelling services to
12 721 meet the palliative care needs of chronic heart failure patients and their families: current practice in the
13 722 UK. Palliat Med 21(5):385-390. <https://doi.org/10.1177/0269216307077698>
- 16 723 16. Gelfman LP, Kalman J, Goldstein NE (2014) Engaging heart failure clinicians to increase palliative care
17 724 referrals: overcoming barriers, improving techniques. J Palliat Med 17(7):753-760.
18 725 <https://doi.org/10.1089/jpm.2013.0675>
- 20 726 17. Gadoud A, Jenkins SM, Hogg KJ (2013) Palliative care for people with heart failure: summary of
21 727 current evidence and future direction. Palliat Med 27(9):822-828.
22 728 <https://doi.org/10.1177/0269216313494960>
- 25 729 18. Janssen DJ, Johnson MJ, Spruit MA (2018) Palliative care needs assessment in chronic heart failure.
26 730 Curr Opin Support Palliat Care 12(1):25-31. <https://doi.org/10.1097/SPC.0000000000000317>
- 28 731 19. Haga K, Murray S, Reid J, Ness A, O'Donnell M, Yellowlees D et al (2012) Identifying community
29 732 based chronic heart failure patients in the last year of life: a comparison of the Gold Standards
30 733 Framework Prognostic Indicator Guide and the Seattle Heart Failure Model. Heart 98(7):579-583.
31 734 <https://doi.org/10.1136/heartjnl-2011-301021>
- 34 735 20. National Institute for Health and Care Excellence (2018) Chronic heart failure in adults: diagnosis and
35 736 management. National Institute for Health and Care Excellence, London.
36 737 <https://www.nice.org.uk/guidance/ng106>. Accessed 20 Mar 2020
- 38 738 21. Passantino A, Guida P, Parisi G, Iacoviello M, Scrutinio D (2018) Critical appraisal of multivariable
39 739 prognostic scores in heart failure: development, validation and clinical utility. Adv Exp Med Biol
40 740 1067:387-403. https://doi.org/10.1007/5584_2017_135
- 43 741 22. Hogg KJ, Jenkins SM (2012) Prognostication or identification of palliative needs in advanced heart
44 742 failure: where should the focus lie? Heart 98(7):523-524. <https://doi.org/10.1136/heartjnl-2012-301753>
- 46 743 23. Gadoud AC, Johnson MJ (2014) Response: what tools are available to identify patients with palliative
47 744 care needs in primary care: a systematic literature review and survey of European practice? BMJ Support
48 745 Palliat Care 4(2):130. <https://doi.org/10.1136/bmjspcare-2014-000706>
- 50 746 24. Ekman I, Ehrenberg A (2002) Fatigued elderly patients with chronic heart failure: do patient reports
51 747 and nurse recordings correspond? Int J Nurs Terminol Classif 13(4):127-136.
52 748 <https://doi.org/10.1111/j.1744-618x.2002.tb00416.x>
- 55 749 25. Ekman I, Cleland JG, Andersson B, Swedberg K (2005) Exploring symptoms in chronic heart failure.
56 750 Eur J Heart Fail 7(5):699-703. <https://doi.org/10.1016/j.ejheart.2005.07.003>

- 1
2
3
4 751 26. Kane PM, Ellis-Smith CI, Daveson BA, Ryan K, Mahon NG, McAdam B et al (2018) Understanding how
5 752 a palliative-specific patient-reported outcome intervention works to facilitate patient-centred care in
6 753 advanced heart failure: a qualitative study. *Palliat Med* 32(1):143-155.
7 754 <https://doi.org/10.1177/0269216317738161>
8
9
10 755 27. Girgis A, Waller A (2015) Palliative care needs assessment tools. In: Cherny N, Fallon M, Kaasa S,
11 756 Portenoy RK, Currow DC (eds) *Oxford textbook of palliative medicine*, 5th edn. Oxford University Press,
12 757 Oxford, pp 363-375
13
14 758 28. Maas EA, Murray SA, Engels Y, Campbell C (2013) What tools are available to identify patients with
15 759 palliative care needs in primary care: a systematic literature review and survey of European practice.
16 760 *BMJ Support Palliat Care* 3(4):444-451. <https://doi.org/10.1136/bmjspcare-2013-000527>
17
18 761 29. Ware JE Jr, Brook RH, Davies AR, Lohr KN (1981) Choosing measures of health status for individuals
19 762 in general populations. *Am J Public Health* 71(6):620-625. <https://doi.org/10.2105/ajph.71.6.620>
20
21 763 30. Deyo AR, Patrick LD (1989) Barriers to the use of health status measures in clinical investigation,
22 764 patient care, and policy research. *Med Care* 27(3 Suppl):S254-S268. [https://doi.org/10.1097/00005650-](https://doi.org/10.1097/00005650-198903001-00020)
23 765 [198903001-00020](https://doi.org/10.1097/00005650-198903001-00020)
24
25 766 31. Fitzpatrick R, Davey C, Buxton MJ, Jones DR (1998) Evaluating patient-based outcome measures for
26 767 use in clinical trials. *Health Technol Assess* 2(14):i-iv,1-74. <https://doi.org/10.3310/hta2140>
27
28 768 32. ElMokhallalati Y, Bradley SH, Chapman E, Ziegler L, Murtagh FE, Johnson MJ et al (2020)
29 769 Identification of patients with potential palliative care needs: a systematic review of screening tools in
30 770 primary care. *Palliat Med*. <https://doi.org/10.1177/0269216320929552>
31
32 771 33. van Vliet LM, Harding R, Bausewein C, Payne S, Higginson IJ (2015) How should we manage
33 772 information needs, family anxiety, depression, and breathlessness for those affected by advanced
34 773 disease: development of a Clinical Decision Support Tool using a Delphi design. *BMC Med* 13:263.
35 774 <https://doi.org/10.1186/s12916-015-0449-6>
36
37 775 34. Greenhalgh J (2009) The applications of PROs in clinical practice: what are they, do they work, and
38 776 why? *Qual Life Res* 18(1):115-123. <https://doi.org/10.1007/s11136-008-9430-6>
39
40 777 35. Simon ST, Higginson IJ, Harding R, Daveson BA, Gysels M, Deliens L et al (2012) Enhancing patient-
41 778 reported outcome measurement in research and practice of palliative and end-of-life care. *Support Care*
42 779 *Cancer* 20(7):1573-1578. <https://doi.org/10.1007/s00520-012-1436-5>
43
44 780 36. Daveson BA, Simon ST, Benalia H, Downing J, Higginson IJ, Harding R et al (2012) Are we heading in
45 781 the same direction? European and African doctors' and nurses' views and experiences regarding
46 782 outcome measurement in palliative care. *Palliat Med* 26(3):242-249.
47 783 <https://doi.org/10.1177/0269216311409614>
48
49 784 37. Greenhalgh J, Long AF, Flynn R (2005) The use of patient reported outcome measures in routine
50 785 clinical practice: lack of impact or lack of theory? *Soc Sci Med* 60(4):833-843.
51 786 <https://doi.org/10.1016/j.socscimed.2004.06.022>
52
53 787 38. O'Connor AM (2007) Using decision aids to help patients navigate the "grey zone" of medical
54 788 decision-making. *CMAJ* 176(11):1597-1598. <https://doi.org/10.1503/cmaj.070490>
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4 789 39. Walsh RI, Mitchell G, Francis L, van Driel ML (2015) What diagnostic tools exist for the early
5 790 identification of palliative care patients in general practice? A systematic review. *J Palliat Care* 31(2):118-
6 791 123. <https://doi.org/10.1177/082585971503100208>
8
9 792 40. Hong QN, Pluye P, Bujold M, Wassef M (2017) Convergent and sequential synthesis designs:
10 793 implications for conducting and reporting systematic reviews of qualitative and quantitative evidence.
11 794 *Syst Rev* 6(1):61. <https://doi.org/10.1186/s13643-017-0454-2>
12
13 795 41. Pluye P, Hong QN, Vedel I (2016) Report mixed studies reviews. McGill University, Department of
14 796 Family Medicine.
15 797 <http://toolkit4mixedstudiesreviews.pbworks.com/w/page/66154236/Report%20mixed%20studies%20r>
16 798 [eviews](http://toolkit4mixedstudiesreviews.pbworks.com/w/page/66154236/Report%20mixed%20studies%20r). Accessed 4 Jul 2019
18
19 799 42. Hawker S, Payne S, Kerr C, Hardey M, Powell J (2002) Appraising the evidence: reviewing disparate
20 800 data systematically. *Qual Health Res* 12(9):1284-1299. <https://doi.org/10.1177/1049732302238251>
22
23 801 43. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M et al (2006) Guidance on the conduct
24 802 of narrative synthesis in systematic reviews: a product from the ESRC Methods Programme. Lancaster
25 803 University, Institute for Health Research
26
27 804 44. Milnes S, Orford NR, Berkeley L, Lambert N, Simpson N, Elderkin T et al (2019) A prospective
28 805 observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a
29 806 tertiary regional Australian hospital. *BMJ Support Palliat Care* 9(1):92-99.
30 807 <https://doi.org/10.1136/bmjspcare-2015-000864>
32
33 808 45. Ryan T, Ingleton C, Gardiner C, Parker C, Gott M, Noble B (2013) Symptom burden, palliative care
34 809 need and predictors of physical and psychological discomfort in two UK hospitals. *BMC Palliat Care*
35 810 12:11. <https://doi.org/10.1186/1472-684X-12-11>
36
37 811 46. Gardiner C, Gott M, Ingleton C, Seymour J, Cobb M, Noble B et al (2013) Extent of palliative care
38 812 need in the acute hospital setting: a survey of two acute hospitals in the UK. *Palliat Med* 27(1):76-83.
39 813 <https://doi.org/10.1177/0269216312447592>
41
42 814 47. Pandini S, Defendi S, Scirè C, Fiorini F, Fiorini G (2016) Biases in palliative care access for elderly
43 815 patients dying in hospital: a prospective study in acute care. *Prog Palliat Care* 24(6):310-314.
44 816 <https://doi.org/10.1080/09699260.2016.1230973>
45
46 817 48. Hamano J, Oishi A, Kizawa Y (2018) Identified palliative care approach needs with SPICT in family
47 818 practice: a preliminary observational study. *J Palliat Med* 21(7):992-998.
48 819 <https://doi.org/10.1089/jpm.2017.0491>
50
51 820 49. Hamano J, Oishi A, Kizawa Y (2019) Prevalence and characteristics of patients being at risk of
52 821 deteriorating and dying in primary care. *J Pain Symptom Manage* 57(2):266-272.e1.
53 822 <https://doi.org/10.1016/j.jpainsymman.2018.11.006>
54
55 823 50. Campbell RT, Jackson CE, Wright A, Gardner RS, Ford I, Davidson PM et al (2015) Palliative care
56 824 needs in patients hospitalized with heart failure (PCHF) study: rationale and design. *ESC Heart Fail*
57 825 2(1):25-36. <https://doi.org/10.1002/ehf2.12027>
59
60
61
62
63
64
65

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

51. Campbell RT, Petrie MC, Jackson CE, Jhund PS, Wright A, Gardner RS et al (2018) Which patients with heart failure should receive specialist palliative care? *Eur J Heart Fail* 20(9):1338-1347. <https://doi.org/10.1002/ejhf.1240>

52. de-la-Rica-Escuín M, García-Barrecheguren A, Monche-Palacín AM (2019) Assessment of the needs for palliative care in advanced chronic patients on discharge. *Enferm Clin* 29(1):18-26. <https://doi.org/10.1016/j.enfcli.2018.07.004>

53. Orzechowski R, Galvão AL, Nunes TD, Campos LS (2019) Palliative care need in patients with advanced heart failure hospitalized in a tertiary hospital. *Rev Esc Enferm USP* 53:e03413. <https://doi.org/10.1590/S1980-220X2018015403413>

54. Gastelurrutia P, Zamora E, Domingo M, Ruiz S, González-Costello J, Gómez-Batiste X (2019) Palliative care needs in heart failure. A multicenter study using the NECPAL questionnaire. *Rev Esp Cardiol (Engl Ed)* 72(10):870-872. <https://doi.org/10.1016/j.rec.2019.01.009>

55. Schildmann EK, Groeneveld EI, Denzel J, Brown A, Bernhardt F, Bailey K et al (2016) 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* 30(6):599-610. <https://doi.org/10.1177/0269216315608348>

56. Kane PM, Daveson BA, Ryan K, Ellis-Smith CI, Mahon NG, McAdam B et al (2017) Feasibility and acceptability of a patient-reported outcome intervention in chronic heart failure. *BMJ Support Palliat Care* 7(4):470-479. <https://doi.org/10.1136/bmjspcare-2017-001355>

57. Roch C, Palzer J, Zetzl T, Störk S, Frantz S, van Oorschot B (2020) Utility of the integrated palliative care outcome scale (IPOS): a cross-sectional study in hospitalised patients with heart failure. *Eur J Cardiovasc Nurs*. <https://doi.org/10.1177/1474515120919386>

58. Waller A, Girgis A, Davidson PM, Newton PJ, Lecathelinais C, MacDonald PS et al (2013) Facilitating needs-based support and palliative care for people with chronic heart failure: preliminary evidence for the acceptability, inter-rater reliability, and validity of a needs assessment tool. *J Pain Symptom Manage* 45(5):912-925. <https://doi.org/10.1016/j.jpainsymman.2012.05.009>

59. Janssen DJ, Boyne J, Currow DC, Schols JM, Johnson MJ, La Rocca HP (2019) Timely recognition of palliative care needs of patients with advanced chronic heart failure: a pilot study of a Dutch translation of the Needs Assessment Tool: Progressive Disease - Heart Failure (NAT:PD-HF). *Eur J Cardiovasc Nurs* 18(5):375-388. <https://doi.org/10.1177/1474515119831510>

60. Thoonsen B, Engels Y, van Rijswijk E, Verhagen S, van Weel C, Groot M et al (2012) Early identification of palliative care patients in general practice: development of RADboud indicators for Palliative Care Needs (RADPAC). *Br J Gen Pract* 62(602):e625-e631. <https://doi.org/10.3399/bjgp12X654597>

61. Thoonsen B, Groot M, Engels Y, Prins J, Verhagen S, Galesloot C et al (2011) Early identification of and proactive palliative care for patients in general practice, incentive and methods of a randomized controlled trial. *BMC Fam Pract* 12:123. <https://doi.org/10.1186/1471-2296-12-123>

1
2
3
4 863 62. Thoonsen B, Vissers K, Verhagen S, Prins J, Bor H, van Weel C et al (2015) Training general
5 864 practitioners in early identification and anticipatory palliative care planning: a randomized controlled
6 trial. BMC Fam Pract 16:126. <https://doi.org/10.1186/s12875-015-0342-6>
7 865
8
9 866 63. Thoonsen B, Gerritzen SH, Vissers KC, Verhagen S, van Weel C, Groot M et al (2019) Training general
10 867 practitioners contributes to the identification of palliative patients and to multidimensional care
11 868 provision: secondary outcomes of an RCT. BMJ Support Palliat Care 9(1):e18.
12
13 869 <https://doi.org/10.1136/bmjspcare-2015-001031>
14
15 870 64. Thoonsen B, Groot M, Verhagen S, van Weel C, Vissers K, Engels Y (2016) Timely identification of
16 871 palliative patients and anticipatory care planning by GPs: practical application of tools and a training
17 872 programme. BMC Palliat Care 15:39. <https://doi.org/10.1186/s12904-016-0112-9>
18
19 873 65. Hight G, Crawford D, Murray SA, Boyd K (2014) Development and evaluation of the supportive and
20 874 palliative care indicators tool (SPICT): a mixed-methods study. BMJ Support Palliat Care 4(3):285-290.
21 875 <https://doi.org/10.1136/bmjspcare-2013-000488>
22
23 876 66. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X et al (2013) Identifying
24 877 patients with chronic conditions in need of palliative care in the general population: development of the
25 878 NECPAL tool and preliminary prevalence rates in Catalonia. BMJ Support Palliat Care 3(3):300-308.
26 879 <https://doi.org/10.1136/bmjspcare-2012-000211>
27
28 880 67. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X et al (2014) Prevalence and
29 881 characteristics of patients with advanced chronic conditions in need of palliative care in the general
30 882 population: a cross-sectional study. Palliat Med 28(4):302-311.
31 883 <https://doi.org/10.1177/0269216313518266>
32
33 884 68. Amblàs-Novellas J, Murray SA, Espauella J, Martori JC, Oller R, Martínez-Muñoz M et al (2016)
34 885 Identifying patients with advanced chronic conditions for a progressive palliative care approach: a cross-
35 886 sectional study of prognostic indicators related to end-of-life trajectories. BMJ open 6(9):e012340.
36 887 <https://doi.org/10.1136/bmjopen-2016-012340>
37
38 888 69. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group (2009) Preferred reporting items for
39 889 systematic reviews and meta-analyses: the PRISMA statement. Ann Intern Med 151(4):264-269.
40 890 <https://doi.org/10.7326/0003-4819-151-4-200908180-00135>
41
42 891 70. National Gold Standards Framework Centre. The gold standards framework.
43 892 <http://www.goldstandardsframework.org.uk/PIG>. Accessed 4 Jun 2019
44
45 893 71. Pattison M, Romer AL (2001) Improving care through the end of life: launching a primary care clinic-
46 894 based program. J Palliat Med 4(2):249-254. <https://doi.org/10.1089/109662101750290335>
47
48 895 72. Fachado AA, Martínez NS, Roselló MM, Rial JJ, Oliver EB, García RG et al (2018) Spanish adaptation
49 896 and validation of the supportive & palliative care indicators tool – SPICT-ESTM. Rev Saude Publica 52:3.
50 897 <https://doi.org/10.11606/s1518-8787.2018052000398>
51
52 898 73. Afshar K, Feichtner A, Boyd K, Murray S, Jünger S, Wiese B et al (2018) Systematic development and
53 899 adjustment of the German version of the Supportive and Palliative Care Indicators Tool (SPICT-DE). BMC
54 900 Palliat Care 17(1):27. <https://doi.org/10.1186/s12904-018-0283-7>
55
56
57
58
59
60
61
62
63
64
65

- 1
2
3
4 901 74. Rodríguez-Calero MÁ, Julià-Mora JM, Prieto-Alomar A (2016) Detection of palliative care needs in an
5 902 acute care hospital unit. Pilot study. *Enferm Clin* 26(4):238-242.
6
7 903 <https://doi.org/10.1016/j.enfcli.2015.11.004>
8
9 904 75. Bausewein C, Schildmann E, Rosenbruch J, Haberland B, Tänzler S, Ramsenthaler C (2018) Starting
10 905 from scratch: implementing outcome measurement in clinical practice. *Ann Palliat Med* 7(Suppl 3):S253-
11 906 S261. <https://doi.org/10.21037/apm.2018.06.08>
12
13 907 76. Oriani A, Guo P, Gadoud A, Dunleavy L, Kane P, Murtagh FEM (2019) What are the main symptoms
14 908 and concerns reported by patients with advanced chronic heart failure?-a secondary analysis of the
15 909 Palliative care Outcome Scale (POS) and Integrated Palliative care Outcome Scale (IPOS). *Ann Palliat Med*
16 910 8(5):775-780. <https://doi.org/10.21037/apm.2019.08.10>
17
18
19 911 77. The University of Edinburgh. SPiCT Supportive And Palliative Care Indicators Tool.
20 912 <https://www.spict.org.uk/>. Accessed 11 Oct 2019
21
22 913 78. De Bock R, Van Den Noortgate N, Piers R (2018) Validation of the Supportive and Palliative Care
23 914 Indicators Tool in a geriatric population. *J Palliat Med* 21(2):220-224.
24 915 <https://doi.org/10.1089/jpm.2017.0205>
25
26 916 79. Pham L, Arnby M, Benkel I, Dahlqvist Jonsson P, Källstrand J, Molander U et al (2019) Early
27 917 integration of palliative care: translation, cross-cultural adaptation and content validity of the
28 918 Supportive and Palliative Care Indicators Tool in a Swedish healthcare context. *Scand J Caring Sci*.
29 919 <https://doi.org/10.1111/scs.12781>
30
31
32 920 80. Murtagh FE, Ramsenthaler C, Firth A, Groeneveld EI, Lovell N, Simon ST et al (2019) A brief, patient-
33 921 and proxy-reported outcome measure in advanced illness: validity, reliability and responsiveness of the
34 922 Integrated Palliative care Outcome Scale (IPOS). *Palliat Med* 33(8):1045-1057.
35 923 <https://doi.org/10.1177/0269216319854264>
36
37 924 81. Sterie AC, Bernard M (2019) Challenges in a six-phase process of questionnaire adaptation: findings
38 925 from the French translation of the Integrated Palliative care Outcome Scale. *BMC Palliat Care* 18(1):38.
39 926 <https://doi.org/10.1186/s12904-019-0422-9>
40
41 927 82. Veronese S, Rabitti E, Costantini M, Valle A, Higginson I (2019) Translation and cognitive testing of
42 928 the Italian Integrated Palliative Outcome Scale (IPOS) among patients and healthcare professionals. *PLoS*
43 929 *One* 14(1):e0208536. <https://doi.org/10.1371/journal.pone.0208536>
44
45
46 930 83. Beck I, Olsson Möller U, Malmström M, Klarare A, Samuelsson H, Lundh Hagelin C et al (2017)
47 931 Translation and cultural adaptation of the Integrated Palliative care Outcome Scale including cognitive
48 932 interviewing with patients and staff. *BMC Palliat Care* 16(1):49. [https://doi.org/10.1186/s12904-017-](https://doi.org/10.1186/s12904-017-0232-x)
49 933 [0232-x](https://doi.org/10.1186/s12904-017-0232-x)
50
51
52 934 84. Sakurai H, Miyashita M, Imai K, Miyamoto S, Otani H, Oishi A et al (2019) Validation of the Integrated
53 935 Palliative care Outcome Scale (IPOS) - Japanese Version. *Jpn J Clin Oncol* 49(3):257-262.
54 936 <https://doi.org/10.1093/jjco/hvy203>
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4 937 85. Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NK (2017) The "surprise question" for
5 938 predicting death in seriously ill patients: a systematic review and meta-analysis. CMAJ 189(13):E484-
6 939 E493. <https://doi.org/10.1503/cmaj.160775>
7
8
9 940 86. White N, Kupeli N, Vickerstaff V, Stone P (2017) How accurate is the 'Surprise Question' at identifying
10 941 patients at the end of life? A systematic review and meta-analysis. BMC Med 15(1):139.
11 942 <https://doi.org/10.1186/s12916-017-0907-4>
12
13 943 87. Cleland JG, Chattopadhyay S, Khand A, Houghton T, Kaye GC (2002) Prevalence and incidence of
14 944 arrhythmias and sudden death in heart failure. Heart Fail Rev 7(3):229-242.
15 945 <https://doi.org/10.1023/a:1020024122726>
16
17 946 88. MERIT-HF Study Group (1999) Effect of metoprolol CR/XL in chronic heart failure: Metoprolol CR/XL
18 947 Randomised Intervention Trial in Congestive Heart Failure (MERIT-HF). Lancet 353(9169):2001-2007.
19 948 [https://doi.org/10.1016/S0140-6736\(99\)04440-2](https://doi.org/10.1016/S0140-6736(99)04440-2)
20
21 949 89. Waller A, Girgis A, Johnson C, Lecathelinais C, Sibbritt D, Seldon M et al (2012) Implications of a
22 950 needs assessment intervention for people with progressive cancer: impact on clinical assessment,
23 951 response and service utilisation. Psychooncology 21(5):550-557. <https://doi.org/10.1002/pon.1933>
24
25 952 90. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X et al (2017) Utility of the
26 953 NECPAL CCOMS-ICO© tool and the Surprise Question as screening tools for early palliative care and to
27 954 predict mortality in patients with advanced chronic conditions: a cohort study. Palliat Med 31(8):754-
28 955 763. <https://doi.org/10.1177/0269216316676647>
29
30 956 91. Johnson MJ. Systematic identification and triage of palliative care needs of patients and family
31 957 carers. Hull York Medical School.
32 958 <http://www.yhscn.nhs.uk/media/End%20of%20Life%20Care/Presentations%20Posters/Needs%20Asses>
33 959 [sment.pdf](http://www.yhscn.nhs.uk/media/End%20of%20Life%20Care/Presentations%20Posters/Needs%20Asses). Accessed 14 Jun 2020
34
35 960 92. Kluger BM, Miyasaki J, Katz M, Galifianakis N, Hall K, Pantilat S et al (2020) Comparison of integrated
36 961 outpatient palliative care with standard care in patients with Parkinson disease and related disorders: a
37 962 randomized clinical trial. JAMA Neurol 77(5):551-560. <https://doi.org/10.1001/jamaneurol.2019.4992>
38
39 963 93. Guillemin F, Bombardier C, Beaton D (1993) Cross-cultural adaptation of health-related quality of life
40 964 measures: literature review and proposed guidelines. J Clin Epidemiol 46(12):1417-1432.
41 965 [https://doi.org/10.1016/0895-4356\(93\)90142-n](https://doi.org/10.1016/0895-4356(93)90142-n)
42
43 966 94. Herdman M, Fox-Rushby J, Badia X (1998) A model of equivalence in the cultural adaptation of
44 967 HRQoL instruments: the universalist approach. Qual Life Res 7(4):323-335.
45 968 <https://doi.org/10.1023/a:1024985930536>
46
47 969 95. Rietjens JA, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M et al (2017) Definition
48 970 and recommendations for advance care planning: an international consensus supported by the
49 971 European Association for Palliative Care. Lancet Oncol 18(9):e543-e551. <https://doi.org/10.1016/s1470->
50 972 [2045\(17\)30582-x](https://doi.org/10.1016/s1470-2045(17)30582-x)
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

96. Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AH (2018) Overview of systematic reviews of advance care planning: summary of evidence and global lessons. *J Pain Symptom Manage* 56(3):436-459.e25. <https://doi.org/10.1016/j.jpainsymman.2018.05.016>

97. Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AH (2019) State of advance care planning research: a descriptive overview of systematic reviews. *Palliat Support Care* 17(2):234-244. <https://doi.org/10.1017/s1478951518000500>

98. Schichtel M, Wee B, MacArtney JI, Collins S (2019) Clinician barriers and facilitators to heart failure advance care plans: a systematic literature review and qualitative evidence synthesis. *BMJ Support Palliat Care*. <https://doi.org/10.1136/bmjspcare-2018-001747>

99. Rietjens JA, Bramer WM, Geijteman EC, van der Heide A, Oldenmenger WH (2019) Development and validation of search filters to find articles on palliative care in bibliographic databases. *Palliat Med* 33(4):470-474. <https://doi.org/10.1177/0269216318824275>

100. Fitzsimons D, Strachan PH (2012) Overcoming the challenges of conducting research with people who have advanced heart failure and palliative care needs. *Eur J Cardiovasc Nurs* 11(2):248-254. <https://doi.org/10.1016/j.ejcnurse.2010.12.002>

101. Booth A, Sutton A, Papaioannou D (2016) Synthesising and analysing quantitative studies. In: Booth A, Sutton A, Papaioannou D (eds) *Systematic approaches to a successful literature review*, 2nd edn. Sage, London, pp 171-214

102. Pluye P, Gagnon MP, Griffiths F, Johnson-Lafleur J (2009) A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *Int J Nurs Stud* 46(4):529-546. <https://doi.org/10.1016/j.ijnurstu.2009.01.009>

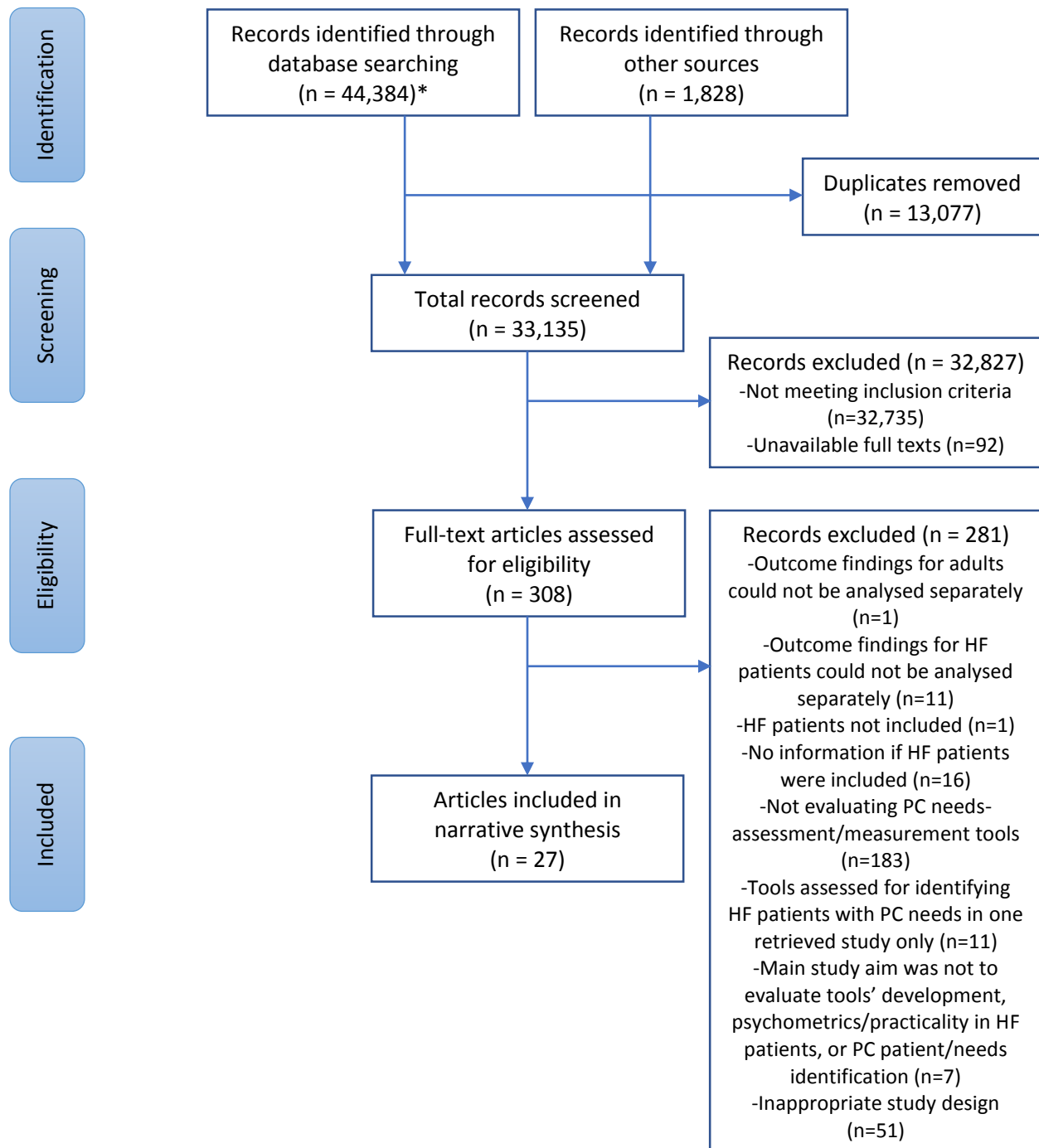


Fig. 1 PRISMA flow diagram of study selection

HF: Heart Failure, PC: Palliative Care

* Cochrane Library, MEDLINE Complete, AMED, PsycINFO, CINAHL Complete, and EMBASE were originally searched from inception to 4 January 2019. The latest search update was run in these databases on 25 June 2020 except for CINAHL Complete because of end of subscription

Table 1 Key search terms used in the review

	Key Search terms*
Concept-1	Palliative care OR Terminal care OR Long-term care OR End of life care OR Hospice OR Advance care planning
Concept-2	Heart failure OR Cardiac failure OR Ventricular dysfunction OR Low cardiac output OR Dilated cardiomyopathy OR Congestive cardiomyopathy OR Cardiogenic shock
Concept-3	Tool OR Survey OR Questionnaire OR Checklist OR Inventory OR Scale OR Instrument OR Indicator OR Measure OR Index OR Model OR Criteria OR Calculator OR Score
Filters/limits	
Population	Human
Language	English or Arabic
Study design	Empirical research
Date	No limits
Settings	No limits

* These terms are not exhaustive. An example of a comprehensive search strategy for EMBASE (Ovid) is shown in Supplemental Table 1

Table 2 List of the included tools and corresponding evaluation studies with their overall quality scores using Hawker et al.'s tool

Tool	Development	Quality score*	Psychometrics/ Practicality#	Quality score*	Identification	Quality score*
IPOS	Schildmann et al. 2016 [55]	32	Kane et al. 2017 [56]	29	Kane et al. 2017 [56]	29
					Kane et al. 2018 [26] (<i>follow-up paper</i>)	30
			Roch et al. 2020 [57]	28	Roch et al. 2020 [57]	28
GSF-PIG	--	--	--	--	Milnes et al. 2019 [44]	27
					Haga et al. 2012 [19]	30
					Gardiner et al. 2013 [46]	28
					Ryan et al. 2013 [45] (<i>follow-up paper</i>)	30
					Pandini et al. 2016 [47]	24
RADPAC	Thoonsen et al. 2012 [60]	27	--	--	Thoonsen et al. 2011 [61] (<i>protocol</i>)	NA
					Thoonsen et al. 2015 [62]	32
					Thoonsen et al. 2019 [63] (<i>follow-up paper</i>)	32
					Thoonsen et al. 2016 [64] (<i>follow-up paper</i>)	29
SPICT	Highet et al. 2014 [65]	27	--	--	Highet et al. 2014 [65]	27
					Hamano et al. 2018 [48]	26
					Hamano et al. 2019 [49]	29
NAT:PD-HF	Waller et al. 2013 [58]	30	Waller et al. 2013 [58]	30	Waller et al. 2013 [58]	30
			Janssen et al. 2019 [59]	35	Janssen et al. 2019 [59]	35
			Campbell et al. 2018 [51]	28	Campbell et al. 2015 [50] (<i>protocol</i>)	NA
NECPAL	Gómez-Batiste et al. 2013 [66]	24	--	--	Gómez-Batiste et al. 2013 [66]	24
					Gómez-Batiste et al. 2014 [67] (<i>follow-up paper</i>)	30
					Ambllàs-Novellas et al. 2016 [68] (<i>follow-up paper</i>)	29
					de-la-Rica-Escuín et al. 2019 [52]	30
					Orzechowski et al. 2019 [53]	23
Gastelurrutia et al. 2019 [54]	22					

NA: Not Applicable. These papers are study protocols with no results to critique and therefore could not be assigned a total score in Hawker et al.'s tool

* Scores are out of 36

Some studies in this column were not designed to test psychometrics/practicality but some data on these aspects were indirectly provided

Table 3 Main features and comparisons of the tools

Tool	IPOS version-1	GSF-PIG 6th edition, 2016	RADPAC original version	SPICT April 2019	NAT:PD-HF original version	NECPAL version-3.1, 2017
Main tools from which the tool was adapted	POS, POS-S, APCA African POS	NHPCO tool	--	NHPCO tool, GSF-PIG, PPS, PPI	PC-NAT	GSF-PIG, SPICT
Generic vs HF-Specific	Generic	Generic	Generic	Generic	HF-Specific	Generic
Clinical settings						
Diseases for which the tool can be used	Multiple (including heart failure)	Multiple (including heart disease)	Multiple (cancer, congestive heart failure, COPD)	Multiple (including heart/vascular disease)	Chronic heart failure	Multiple (including chronic heart disease)
Clinical settings for tool use	Multiple	Multiple	Primary care/ General practice	Multiple	Multiple	Multiple
Completion method						
Completed by	Healthcare professionals (staff version), Patients (patient version)	Healthcare professionals	Primary care practitioners	Healthcare professionals	Healthcare professionals	Healthcare professionals
Objective vs Subjective*	Subjective	Objective, Subjective	Objective, Subjective	Objective, Subjective	Subjective	Objective, Subjective
Items						
Surprise Question	X	✓	X	X	X	✓
General indicators of health decline or PC need	X	✓	X	✓	X	✓
Disease-specific indicators of health decline or PC need	X	✓	✓	✓	X	✓
Open questions	✓	X	X	X	X	X
Length						
Number of items (for HF patients)	17 (+ 2 open questions)	17	7	9	20	18

Tool	IPOS version-1	GSF-PIG 6th edition, 2016	RADPAC original version	SPICT April 2019	NAT:PD-HF original version	NECPAL version-3.1, 2017
Average time for completion	Staff version: 2 – 5 minutes Patient version: 8 minutes	--	--	-- (Older versions: 5 – 7.5 minutes)	5 – 10 min. (Dutch version: 26 minutes)	-- (Older version: 2 – 8 minutes)
Minimal criteria to identify HF patients who require PC	--	SQ+, or general indicators, or two HF-specific indicators	--	Any general indicator or the HF-specific indicator	--	SQ+ plus any other parameter
Need domains						
Physical	✓	✓	✓	✓	✓	✓
Psychological	✓	✓	X	X	✓	✓
Social	✓	X	X	X	✓	✓
Spiritual	✓	X	X	X	✓	X
Others	Informal carer, Information, Financial/ Personal	--	--	Informal carer	Informal carer, Information, Financial/ Legal, Treatment regimens	--

APCA: African Palliative Care Association, COPD: Chronic Obstructive Pulmonary Disease, HF: Heart Failure, NHPCO: National Hospice and Palliative Care Organization, PC: Palliative Care, PC-NAT: Palliative Care-Needs Assessment Tool, POS: Palliative care Outcome Scale, POS-S: Palliative care Outcome Scale-Symptoms, PPI: Palliative Prognostic Index, PPS: Palliative Performance Scale, SQ+: a negative answer to the Surprise Question (healthcare professionals would not be surprised if the patient dies within the next year)

* Objective: Medical records. Subjective: Clinical judgement or patient/informal caregiver input

Table 4 Main purpose and intended use of the tools

Tool*	IPOS <i>version-1</i>	GSF-PIG <i>6th edition, 2016</i>	RADPAC <i>original version</i>	SPICT <i>April 2019</i>	NAT:PD-HF <i>original version</i>	NECPAL <i>version-3.1, 2017</i>
Patient identification		✓	✓	✓		✓
Needs identification	✓				✓	
Needs assessment/ Decision aids		✓	✓	✓	✓	✓
Needs measurement	✓					

* This classification should not be considered rigid as there can be some overlap in these applications

Table 5 Psychometric and practicality properties of the tools in patients with heart failure, using the Oxford Patient-Reported Outcome Measures Group criteria

	Acceptability	Feasibility	Reliability	Validity	Responsiveness
Original IPOS (patient version-1, 7-day recall)	+++	+++	0	0	0
German IPOS (patient version, 3-day recall)	++	0	0	0	0
GSF-PIG	0	0	0	0	0
RADPAC	0	0	0	0	0
SPICT	0	0	0	0	0
Japanese SPICT (SPICT-J)	0	0	0	0	0
Original NAT:PD-HF	+	+++	+	++	0
Dutch NAT:PD-HF	-	-	0	-	0
NECPAL	0	0	0	0	0

- = evidence does not support criteria

0 = not reported or no evidence in favor

+ = some limited evidence in favor

++ = some good evidence in favor, but some aspects do not meet criteria or some aspects not reported

+++ = good evidence in favor



Click here to access/download

Supplementary Material

Electronic Supplementary Material_ Revised
Revised.docx