

Supplementary file 1 Identification of palliative domains, needs and questions in advanced CHF in existing tools (stage 1)

Domain number	Domain	Helpful input \$	Palliative care need (n=50)	Description of need
1	Physical aspects of care	SPICT RADPAC NAT:PD-HF CareQoL IPOS NECPAL HefPAC HFNAQ Qualitative research	1	Physical complaints such as pain, shortness of breath or fatigue
			2	Mobility problems
2	Psychological aspects of care	NAT:PD-HF CareQoL IPOS NECPAL HFNAQ Qualitative research	3	Psychological complaints such as gloom, anxiety, irritability, worrying
			4	Problems related to processing loss of health
			5	Low self-esteem

3	Social aspects of care	NAT:PD-HF CareQoL IPOS HFNAQ Qualitative research	6	Loneliness
			7	Lack of understanding by others
			8	Limited social and activity engagement
			9	Issues in finding a purposeful way of spending the day
			10	Problems related to processing loss of tasks or different roles at home
4	Spiritual aspects of care	RADPAC NAT:PD-HF IPOS HFNAQ Qualitative research Source: Society of mental caretakers: https://vgvz.nl/wp-content/uploads/2019/08/Indicaties-GV-eerstelijnszorg_Professionals_Definitief_Organisaties_Formulier_20190705.pdf	11	Life questions, why-questions or existential questions
			12	Questions about the meaning of life

			13	The need to talk about spiritual wishes
5	Care needs nearing the end of life	NAT:PD-HF Qualitative research*	14	Concerns about how to manage symptoms / symptom relief
			15	Fears of death and dying
			16	Questions and worries about supportive care for (bereaved) family member
6	Care needs related to grief and loss	NAT:PD-HF qualitative research	17	Problems related to processing loss
			18	Needs support with loss and grief
7	Cultural aspects of care	NAT:PD-HF Pharos "Lessons from conversations about life and death"/ Roukayya Oueslati Qualitative research	19	Cultural or religious background needs attention
			20	Language barrier is an issue
8	Financial aspects of care	NAT:PD-HF IPOS HFNAQ Qualitative research	21	Financial issues due to loss of work or disease-related expenses
			22	Housing conditions are not optimal
			23	Problems related to finding and using services
			24	Financial, housing or work support needs

			25	Needs help to find services to discuss financial issues
			26	Information about which services to call in for financial support
9	Medication aspects	NAT:PD-HF Qualitative research*	27	Questions about medication
			28	Needs support to know how to use medication
			29	Worries about medication
10	Patient information aspects	SPICT NAT:PD-HF IPOS HefPAC HFNAQ Qualitative research	30	Questions or worries about heart failure, the treatment and/or medication
			31	Questions about treatment
11	Informal care aspects	SPICT NAT:PD-HF HefPAC Qualitative research*	32	Worries about informal caregiver burden
			33	Information needs of the informal caregiver
			34	The informal caregiver needs support

			35	The informal caregiver has health issues
			36	The informal caregiver needs care
			37	Absence of informal caregiver
12	Being in safe hands/ structure and processes of care	NAT:PD-HF CareQoL HefPAC Qualitative research*	38	Worries about direct available care in case of acute deterioration
			39	Unclear which healthcare professional to contact and accessibility
			40	Worries about the continuity of care /information sharing
			41	Unsufficient trust in expertise of healthcare professionals
13	ACP - Advance care planning aspects	SPICT NAT:PD-HF HefPAC Qualitative research	42	Insufficient trust that the life- sustaining treatments and/or end of life care as discussed and agreed will be provided
			43	Care planning needs concerning life- sustaining treatments/ end of life care/ role of the legal representative
			44	Questions or worries about the future and heart failure
			45	Preferences about how, when and with whom information can be shared and discussed related to life- sustaining treatments/ end of life care

14	Aids and equipment aspects	SNAP	46	Needs or questions related to aids and home adaptations
		Qualitative research*	47	Needs help to find services related to aids and home adaptations
15	Getting out and about aspects	SNAP	48	Issues related to getting out and about and/or caredependency
		Qualitative research*	49	issues related to independency
			50	Mobility problems

§ Systematic review. The following tools were identified: the POS/IPOS (Integrated Palliative care Outcome Scale), the Needs Assessment Tools Progressive Disease – Heart Failure (NAT: PD-HF), the RAdboud indicators for Palliative Care Needs (RADPAC), the Heart Failure Needs Assessment Questionnaire (HFNAQ), the Care related Quality of Life for Chronic Heart Failure Questionnaire (CareQoL CHF), the Heart Failure Palliative Approach to Care (HeFPAC) and the Necesidades Paliativas (NECPAL).

* Qualitative research resulted in the identification of palliative care needs. In the other cases the qualitative research provided insight in exemplary cases of palliative care needs.

Domain of support need (n=13)	Description of the support need (n=19)	Questions (in Dutch)
Physical aspects	Physical complaints such as pain, shortness of breath, fatigue	<ul style="list-style-type: none"> ▪ Hebt u last van kortademigheid, vermoeidheid, pijn of andere lichamelijke klachten die u belemmeren bij het doen van uw dagelijkse bezigheden (zoals uw hobby (zorgverlener vul evt. hobby in))? ▪ Hebt u last van kortademigheid, vermoeidheid, pijn of andere lichamelijke klachten waar u zich zorgen over maakt? ▪ Wilt u dat er meer gedaan wordt aan uw lichamelijke klachten zoals pijn, kortademigheid, vermoeidheid of andere klachten dan nu gebeurt?
Psychological aspects	Psychological complaints such as gloom, anxiety, irritability, worrying	<ul style="list-style-type: none"> ▪ Hebt u last van somberheid, angst, prikkelbaarheid of piekeren?
Care needs related to grief and loss	Problems related to processing loss of health, function at work or limitations in leisure activities	<ul style="list-style-type: none"> ▪ Hebt u hulp nodig bij het accepteren van uw ziekte, uw beperkingen of verlies van werk of hobby? ▪ Heeft u begeleiding nodig bij positief leven met hartfalen? ▪ Heeft u begeleiding nodig bij het omgaan met hartfalen?
Social aspects	Loneliness	<ul style="list-style-type: none"> ▪ Hebt u het gevoel er alleen voor te staan? ▪ Heeft u last van eenzaamheid?
Social aspects	Lack of understanding by others	<ul style="list-style-type: none"> ▪ Hebt u het gevoel dat uw naasten uw situatie begrijpen?

		<ul style="list-style-type: none"> ▪ Voelt u zich begrepen door de mensen in uw omgeving?
Social aspects	Issues in finding a purposeful way of spending the day	<ul style="list-style-type: none"> ▪ Hebt u ondersteuning nodig om de dingen te kunnen doen die u graag doet? ▪ Hebt u hulp nodig om de dingen te kunnen doen die u graag doet?
Spiritual aspects	Life questions, why-questions or existential questions	<ul style="list-style-type: none"> ▪ Wilt u graag met iemand praten over levensvragen of 'waarom'-vragen?
Cultural background	Cultural or religious background needs attention	<ul style="list-style-type: none"> ▪ Is er iets over uw culturele achtergrond of geloof dat ik moet weten om u de juiste zorg te geven?
Financial issues related to care	Financial issues related to job loss/income and/or to disease-related expenses	<ul style="list-style-type: none"> ▪ Hebt u geldzorgen door uw ziekte? ▪ Maakt u zich zorgen over uw toekomst vanwege geldzorgen?
Issues related to treatment	Questions or issues related to the disease and the treatment	<ul style="list-style-type: none"> ▪ Hebt u vragen of zorgen over uw ziekte en/of uw behandeling?
Informal caregiver aspects	Informal caregiver burden	<ul style="list-style-type: none"> ▪ Vraag aan Patiënt: Heeft uw naaste ondersteuning nodig bij het zorgen voor u? ▪ Vraag aan Naaste: Voelt u zich belast door het zorgen voor uw naaste?

Informal caregiver aspects	Information needs of the informal caregiver	<ul style="list-style-type: none"> ▪ Vraag aan Naaste: Hebt u behoefte aan meer uitleg over de ziekte, behandeling of beschikbare voorzieningen? ▪ Vraag aan Naaste: Heeft u behoefte aan informatie over wat het hartfalen in de toekomst voor uw naaste zou kunnen betekenen? ▪ Vraag aan Patiënt: Heeft uw naaste behoefte aan meer uitleg over de ziekte, behandeling of beschikbare voorzieningen?
Informal caregiver aspects	Absence of informal caregiver	<ul style="list-style-type: none"> ▪ Is er iemand in uw omgeving die voor u kan zorgen als dat nodig is?
Feeling safe and cared for	Issues related to direct available care in case of acute deterioration	<ul style="list-style-type: none"> ▪ Weet u welke zorgverlener u kunt bellen als u opeens erger ziek wordt?
Advance care planning	Making agreements about life-sustaining treatments/ end of life care/ role of the legal representative	<ul style="list-style-type: none"> ▪ Weten uw artsen en naasten welke behandeling en zorg u wilt als u ernstig ziek wordt? ▪ Wilt u met uw arts(en) of naasten praten over de behandeling die u wilt als u ernstig ziek wordt?
Advance care planning	Questions or issues related to living with heart failure in the future	<ul style="list-style-type: none"> ▪ Hebt u vragen of zorgen over uw toekomst met hartfalen? ▪ Wilt u met uw arts praten over wat u kunt verwachten van uw toekomst met uw ziekte?
Aids and equipment	Needs or questions related to aids and home adaptations	<ul style="list-style-type: none"> ▪ Hebt u hulp nodig bij het krijgen van de juiste hulpmiddelen of aanpassingen in huis? ▪ Heeft u advies nodig over welke hulpmiddelen er beschikbaar zijn die u zouden kunnen helpen?

Getting out and about	Care dependance	<ul style="list-style-type: none">▪ Hebt u meer hulp nodig bij wassen, aankleden, boodschappen doen of het huishouden?
Getting out and about	Mobility problems	<ul style="list-style-type: none">▪ Hebt u problemen met lopen, fietsen of autorijden?▪ Hebt u hulp nodig bij u verplaatsen, zoals bij lopen, fietsen of autorijden?