

Supplementary Materials

Supplementary Methods contains more information on the RAND-36 and WPAI questionnaires, respectively. Supplementary Table 1 presents survey data on diagnosis stage and patients' treatment perception and understanding by NYHA class. Supplementary Table 2 presents patient narratives during qualitative interviews.

Supplementary Methods: additional information on the RAND-36 and WPAI questionnaires

RAND-36v1 Assessment

The RAND-36v1 is a generic health status and HRQoL assessment, including a total of 36 items to measure the eight domains over the prior four weeks: physical functioning (10 items), bodily pain (2 items), role of limitations due to physical health problems (4 items), role of limitations due to personal or emotional problems (3 items), emotional well-being (5 items), social functioning (2 items), energy/fatigue (4 items), and general health perceptions (5 items). It also includes a single item indicating perceived change in health status compared to a year ago. Each item is scored between 0 and 100, and domain scores are calculated by averaging the item scores belonging to the corresponding domain; higher scores indicate better function, state or well-being.¹ A linguistically validated Swedish version of RAND-36 was used in our study.² Updated RAND-36 reference data for the Swedish population was recently published by Ohlsson-Nevo et al³ and the present HF sample's levels of HRQoL were compared to these norm HRQoL scores.

WPAI Assessment

The WPAI⁴ assesses the impact of a disease on a patient's work productivity and daily activities during the past 7 days. It is a generic instrument that has been completed by a large number of patients in many different disease areas and can be used to compare work productivity across diseases. The WPAI has six items and generates the following four scores, where each is expressed as a percentage of work time missed or an activity impairment: absenteeism (work time missed),

presenteeism (impairment at work/reduced on-the-job effectiveness), work productivity loss (overall work impairment), and total activity impairment for life outside work. All subjects respond to the last item irrespective of their employment status, whereas only currently employed subjects respond to the former three items. For the current survey, a heart failure-specific Swedish version of the WPAI was developed in accordance with current industry standards.⁵

References

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3. Ohlsson-Nevo E, Hiyoshi A, Norén P, Möller M, Karlsson J. The Swedish RAND-36: psychometric characteristics and reference data from the Mid-Swed Health Survey. *J Patient Rep Outcomes.* 2021;5:66. doi: 10.1186/s41687-021-00331-z.
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Supplementary Tables

Supplementary Table 1 Survey data on diagnosis stage and patients' treatment perception and understanding by NYHA class

	NYHA ^a Class II n=49 (49%)			NYHA Class III/IV n=52 (51%)			Total N=101 (100%)		
Diagnosis stage									
<i>Did you see a cardiologist for the diagnosis of your chronic HF? n (%)</i>	Yes	No	Don't know	Yes	No	Don't know	Yes	No	Don't know
	40 (82)	8 (16)	1 (2)	41 (79)	7 (13)	4 (8)	81 (80)	15 (15)	5 (5)
<i>Where was the diagnosis made? n (%)</i>	Hospital	Primary	Neither	Hospital	Primary	Neither	Hospital	Primary	Neither
	38 (78)	11 (22)	0 (0)	42 (81)	10 (19)	0 (0)	80 (79)	21 (21)	0 (0)
<i>Has your heart been examined using an electrocardiogram (aka ECG)? n (%)</i>	Yes	No	Don't know	Yes	No	Don't know	Yes	No	Don't know
	49 (100)	0 (0)	0 (0)	49 (94)	0 (0)	3 (6)	98 (97)	0 (0)	3 (3)
<i>Has your heart been examined using ultrasound (aka echocardiography/Echo)? n (%)</i>	Yes	No	Don't know	Yes	No	Don't know	Yes	No	Don't know
	44 (90)	3 (6)	2 (4)	45 (86)	0 (0)	7 (13)	89 (88)	3 (3)	9 (9)
<i>Has your blood natriuretic peptide (aka BNP and/or NT-proBNP) level been tested? n (%)</i>	Yes	No	Don't know	Yes	No	Don't know	Yes	No	Don't know
	27 (55)	2 (4)	20 (41)	28 (54)	2 (4)	22 (42)	55 (54)	4 (4)	42 (42)
<i>Did you have this symptom prior to being diagnosed?</i>									
<i>Fatigue, n (%)</i>	26 (53)			25 (48)			51 (50)		
<i>Shortness of breath, n (%)</i>	18 (37)			22 (42)			40 (40)		
<i>Palpitations, n (%)</i>	17 (35)			16 (31)			33 (33)		
<i>Swollen ankles and legs, n (%)</i>	15 (31)			17 (33)			32 (32)		
<i>Chest pain, n (%)</i>	9 (18)			8 (15)			17 (17)		
Treatment perception and understanding									
<i>What type of clinic mainly manages your HF treatment? n (%)</i>	Hospital	Primary	Both	Hospital	Primary	Both	Hospital	Primary	Both
	25 (51)	14 (29)	10 (20)	24 (46)	23 (44)	5 (10)	49 (48)	37 (37)	15 (15)
<i>Do you understand how to take your HF treatments as prescribed? n (%)</i>	Clearly	Somewhat	No	Clearly	Somewhat	No	Clearly	Somewhat	No
	48 (98)	1 (2)	0 (0)	47 (90)	5 (10)	0 (0)	95 (94)	6 (6)	0 (0)
<i>Do you think you take your HF treatments according to the prescription? n (%)</i>	Strictly	Somewhat	No	Strictly	Somewhat	No	Strictly	Somewhat	No
	48 (98)	1 (2)	0 (0)	45 (86)	7 (13)	0 (0)	93 (92)	8 (8)	0 (0)
<i>To what extent do the</i>									

<i>treatments you take relieve your HF symptoms?</i>			
<i>Don't know, n (%)</i>	0 (0)	0 (0)	0 (0)
<i>Not at all, n (%)</i>	2 (4)	5 (10)	7 (7)
<i>A little bit, n (%)</i>	5 (10)	16 (31)	21 (21)
<i>Moderately, n (%)</i>	17 (35)	14 (27)	31 (31)
<i>Quite a bit, n (%)</i>	18 (37)	13 (25)	31 (31)
<i>Significantly, n (%)</i>	7 (14)	4 (8)	11 (11)

Notes: ^aPatients were classified according to NYHA class via their responses to the following screener item: “Please indicate how much you have been limited by heart failure (shortness of breath, fatigue, palpitations, or chest pain) over the past 2 weeks.” Response options: “Not limited at all: ordinary physical activity does not cause symptoms of heart failure” (non-eligible); “Slightly limited: comfortable at rest, but ordinary physical activity (eg, running, climbing stairs) results in symptoms of heart failure” (NYHA II); “Quite a bit limited: comfortable at rest, but less than ordinary activity (eg, walking uphill, dressing and undressing) causes symptoms of heart failure” (NYHA III); and, “Extremely limited: symptoms of heart failure even at rest” (NYHA IV).

Abbreviations: HF heart failure, NYHA New York Heart Association

Supplementary Table 2 Patient narratives during qualitative interviews

1	Experience at the time of diagnosis
	<p><i>“I could not walk further than 200–300 meters, then I had to stop and catch my breath. That’s how it started. Then it went well for a day or so because I didn’t really understand the seriousness then. It was the healthcare center...[...]”^a..., and they found this heart problem so they sent me to the emergency room at the hospital”. (Male, NYHA class II^b)</i></p> <p><i>“And then when I came to the hospital, they did a lot of tests and I had a high value of something called proBNP. So they had me admitted to the heart unit...[...]...and they sent me for an ultrasound and found the heart failure”. (Male, NYHA II)</i></p> <p><i>“At the heart clinic, I thought it worked great. Then I had contact with a heart failure</i></p>

	<p><i>coordinator who was very, very good, and she was easy to talk to, and we understood each other and everything. So she checked up regularly about how it was going". (Male, NYHA III)</i></p> <p><i>"Well of course in the acute phase everything feels really tough. A lot of anxiety about death that hits you out of nowhere...[...]... I felt incredibly safe and well taken care of while hospitalized. ...[...]... I mean, whatever happens they would be capable of taking care of it". (Male, NYHA II)</i></p> <p><i>"No, that, it wasn't a good thing to get it [the diagnosis], it wasn't. But on the other hand, I found out what the problems I had with energy were due to". (Male, NYHA III)</i></p> <p><i>"Yes, I was sad, of course because I understood then there was not much to do about heart failure, that the heart will never be the same. It is not possible to cure, you just have to try to stick to medication. So it was a shocking experience." (Female, NYHA III)</i></p> <p><i>"Well, actually, I may not have understood what it meant. Not really". (Female, NYHA III)</i></p>
2	Experience of disease journey and treatment decisions
	<p><i>"My cardiologist doctor made pretty much all the decisions... She often spoke to me and informed me, kept me up to speed, as did all other staff at the cardiology ICU where I was hospitalized for about a week. And my cardiologist doctor told me that 'We'll wait and see, we're going to try medications now at first, you might need a heart failure pacemaker in the future.'"</i></p> <p><i>(Male, NYHA II)</i></p>

“No, I didn’t experience getting any explanation or something like that. Instead, the fact was that I should take these pills. End of story”. (Female, NYHA III)

“...[...]... We haven’t discussed it [treatment], but we have been discussing weight and how other things felt, how the legs feel and so on, how much water the heart is able to pump out... of the body...[...]...so I was not allowed to drink more than a maximum of one and a half liters a day”. (Male, NYHA III)

“Well, I’ve called them to talk, and I’ve said that I have low blood pressure, I even got dizzy when I stood up so they changed the dosage, they lowered the dosage of the medications...[...]...Yes, it’s worked pretty well”. (Male, NYHA II)

“No, there were no alternatives. I don’t want to whine about the care staff in any way, they’ve been great in every way. But when it comes to heart failure, I haven’t received any proper information”... (Female, NYHA III)

“Forxiga[®] (dapagliflozin) is a relatively new medication. It’s for diabetes, but it’s supposed to help stabilize the heart without lowering your blood pressure, which is a challenge I have...[...]...And then Eliquis[®] [apixaban] is to stop blood clots”. (Male, NYHA III)

“Yes, at the start it [treatment] was a bit messy, I stored it all in a pharmacy bag, but now I have pill boxes. I know, I take it at eight and two and eight. Eight in the evening, eight in the morning and two in the afternoon”. (Male, NYHA II)

“What is difficult about Furix[®] (furosemide) is that it’s a diuretic—that you have to run to

	<p><i>the toilet</i>". (Female, NYHA III)</p> <p><i>"Slowly, but surely I have more energy. I walk a lot nowadays. And I have more and more energy"</i>. (Male, NYHA II)</p> <p><i>"Yes, in that sense I feel significantly better than I did before [i.e. response to treatment]"</i>. (Female, NYHA II)</p>
3	Experience of the impacts of heart failure
	<p><i>"Fatigue is always present. That's a way to put it: it is always present"</i>. (Female, NYHA II)</p> <p><i>"Yes, I feel it when I wake up ... when I wake up in the morning and sit up in bed"</i>. (Female, NYHA III)</p> <p><i>"Yes, it has gotten worse, it has, than it was in the beginning"</i>. (Female, NYHA III)</p> <p><i>"Every little uphill during cross-country skiing when you have to climb uphill wearing your skis, the thought alone makes me sweat. I don't dare to try that. So, it's been put on hold"</i>. (Male, NYHA II)</p> <p><i>"We love hiking, and we can't do that. We love skiing and we had to cancel our ski trip. It's too uncertain. ... And it's sad because it affects my wife and she might have to find others to do things with"</i>. (Male, NYHA III)</p> <p><i>"It's that I'm so damn tired. I get out of breath just by doing the smallest things...[...]... I'm</i></p>

no longer going for long walks with the dog, only short walks now. And when I walk to the shop, it's only 300 meters...[...].and I must stop in the middle and sit down on my walker and rest. So, it [fatigue] affects me". (Male, NYHA III)

"I can act like an average person, but I only pretend to be unaffected...[...].I started working 45 percent...[...].but I was exhausted after two or three months. They wanted me to keep going, and then I said, no, I must go down 10 percent...[...]. And I just got worse and worse. And then they asked, 'Do you want to continue?' 'No, I can't.' I said, '25% then,' and I was exhausted. ... And then I said, 'No, I'm not going to work anymore'...[...].I'm completely exhausted".

(Female, NYHA III)

"To go from such a creative environment with a lot of creative work to just staying home and doing nothing, I felt a bit of panic by the thought of that". (Female, NYHA III)

"Being outside and working in the garden is also impossible now". (Female, NYHA III)

"My wife has to do the majority of the housework while working full time since I don't have the energy to help. So I have a bad conscience at all times". (Male, NYHA III)

"Yes, I'm very tired. My ability to take initiative is bad and I don't have any energy. ...However, one does get depressed as well. ...It impacts me to the extent that I lack initiative. That is, if I sit down on a chair, I can remain there for hours without doing anything". (Female, NYHA III)

"I work with my diet through being vegan and I try to deal with my weight in different

	<p>ways". (Male, NYHA II)</p> <p><i>"I weigh myself every night and make sure I'm at the right level". (Male, NYHA IV)</i></p>
4	Experience of the healthcare system
	<p><i>"I think it worked incredibly well, there's nothing to complain about there. The heart clinic I was at has the right staff in the right place all the time". (Female, NYHA III)</i></p> <p><i>"The healthcare center, the visits there ... I'm happy to go there to leave samples and so on and get test results. To discuss heart problems with them ... It's unfortunately the case that most doctors you have met in 10 years you meet once and then you do not meet the same doctor again".</i></p> <p>(Male, NYHA III)</p> <p><i>"...I think there's a big shortcoming in this, that when you're referred to your healthcare center again, nothing happens after that". (Male, NYHA III)</i></p> <p><i>"Yes, and when I've had an operation, I've gotten special phone numbers to be able to reach that special unit at all hours of the day. It has felt very safe and nice". (Male, NYHA II)</i></p> <p><i>"I think I understand it [heart failure] pretty well anyway. There may be more to understand, but what I have read I think I understand the function of. Or the function of the failure, so to speak. If I understand it correctly is another matter". (Female, NYHA III)</i></p> <p><i>"Well, I know what's happening. That it [the heart] is not pumping correctly, but at the</i></p>

same time there are so many question marks that I'm not able to have this discussion with anyone. Like why do I have such a high pulse and... whether it's damaging for the heart or not that the pulse always is approximately 100? I miss that conversation with someone...[...]...I'm happy and thankful that I've gotten what I have gotten. But I cannot say that it's good today since I don't have any direct understanding or contact with anyone that knows my disease". (Female, NYHA III)

Moderator: *"Is there anything you think could be changed or improved to increase the security or trust [with respect to the healthcare practitioner(s)]?"*

Patient: *"Yes, maybe they should not talk in medical terms because you have to ask all the time what it means". (Female, NYHA III)*

Notes: ^a"[...]" denotes that words have been cut from quotes without altering the message. "..."
denotes silent pauses. ^bTwenty-one patients contributed to the reported 37 quotes (1, 2, 3 and 4
quotes each from 12, 5, 1, and 3 patient(s)).