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CLINICAL RESEARCH
Heart failure

End-of-life preferences of elderly patients with chronic heart failure

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Aims Elderly heart failure (HF) patients are assumed to prefer improved quality of life over longevity, but sufficient data are lacking. Therefore, we assessed the willingness to trade survival time for quality-of-life (QoL) and the preferences for resuscitation.

Methods and results At baseline and after 12 and 18 months, 622 HF patients aged ≥60 years (77 ± 8 years, 74% NYHA-class ≥III) participating in the Trial of Intensified vs. standard Medical therapy in Elderly patients with Congestive Heart Failure had prospective evaluation of end-of-life preferences by answering trade-off questions (willingness to accept a shorter life span in return for living without symptoms) and preferences for resuscitation if necessary. The time trade-off question was answered by 555 patients (89%), 74% of whom were not willing to trade survival time for improved QoL. This proportion increased over time (Month 12: 85%, Month 18: 87%, $P < 0.001$). In multivariable analysis, willingness to trade survival time increased with age, female sex, a reduced Duke Activity Status Index, Geriatric Depression Score, and history of gout, exercise intolerance, constipation and oedema, but even combining these variables did not result in reliable prediction. Of 603 (97%) patients expressing their resuscitation preference, 51% wished resuscitation, 39% did not, and 10% were undecided, with little changes over time. In 430 patients resuscitation orders were known; they differed from patients' preferences 32% of the time. End-of-life preferences were not correlated to 18-month outcome.

Conclusion Elderly HF patients are willing to address their end-of-life preferences. The majority prefers longevity over QoL and half wished resuscitation if necessary. Prediction of individual preferences was inaccurate. Trial Registration: isrctn.org Identifier: ISRCTN43596477

Keywords Heart failure • Survival • Ageing • End-of-life preferences • Quality of life

Asking patients about expectations and preferences regarding treatment is increasingly recognized as an important element in patient care.[1] This is particularly true for patients with chronic illnesses, in whom full recovery is not possible, but in whom quality-of-life (QoL) is considered a valuable goal of therapy. In chronic heart failure (CHF), several treatment modalities targeting different outcomes have become available. Some treatments improve both symptoms and prognosis. Some, such as inotropic agents or opioids, specifically focus on symptom relief, even at the expense of survival. And some focus only on prognosis, such as internal cardioverter-defibrillators (ICD) that reduce sudden cardiac death but do not affect symptoms and may even increase

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the number of CHF-related hospitalizations.[2] Although negative effects may be reduced by combining ICD with cardiac resynchronization in selected patients,[3] the question arises if pure reduction in mortality is the primary goal in all CHF patients or if patients would prefer symptom relief to survival.

This question is especially relevant since the average CHF patient is of advanced age with multiple co-morbidities.[4] Intuitively, it may be assumed that particularly elderly patients with severe symptomatic chronic disease would prefer a better QoL to prolonged survival. A significant proportion of younger patients were willing to trade survival time for perfect health.[5,6] Still, the assumption that older patients are more willing to trade survival time for QoL might be wrong, as sicker patients can express stronger preferences for life-prolonging treatments compared with healthier people.[7] Data giving insight into end-of-life preferences in elderly CHF patients, however, are lacking. Therefore, we aimed to investigate end-of-life and cardiopulmonary resuscitation (CPR) preferences in elderly CHF patients. In addition, predictive factors for willingness to trade survival time for better QoL and for wanting resuscitation if necessary were evaluated.

Methods

Setting and participants

Patients participating in the Trial of Intensified vs. standard Medical therapy in Elderly patients with Congestive Heart Failure (TIME-CHF; $n = 622$) were included in the analysis as described previously.[4,8] In short, TIME-CHF was a prospective randomized controlled multicentre trial addressing the management of elderly patients with CHF comparing a standard symptom-guided therapy with an intensified, N-terminal-pro-B-type natriuretic peptide (NT-BNP) guided medical therapy.

Patients aged $\geq$60 years, with symptomatic CHF (NYHA $\geq$II), a history of CHF hospitalization within the last year, and a NT-BNP level $>2\times$ the upper limit of normal were included and stratified into two age groups, i.e. 60–74 years ($n = 242$, mean age 69 ± 4 years) and $\geq$75 years ($n = 380$, mean age 82 ± 4 years). Some exclusion criteria applied,[4] but on average, the patients were similar to those included in large registries.[9,10] The ethics committee of each centre approved the study and each patient gave written informed consent for participation.

Baseline assessment included medical history, signs, and symptoms of CHF, QoL, and end-of-life preference questionnaires, laboratory results, and the 6 min walk test.

Quality of life was measured by structured, self-administered questionnaires [Minnesota Living with CHF (MLwHF),[11] Duke Activity Status Index (DASI),[12] and short form of the IQOLA SF-36 (SF-12)[13]]. Furthermore, Geriatric Depression Scale short form (GDS)[14] and the Hodkinson abbreviated mental test[15] were used.

Outcomes

End-of-life preferences were assessed by using a time trade-off (TTO) tool[6] and one question concerning CPR preference (yes, no, undecided). Both instruments were administered verbally after a descriptive introduction. Cardiopulmonary resuscitation preference was asked after explaining meaning and circumstances of CPR. To assess TTO, patients were asked whether they preferred living 2 years in their current state of health or living 1 year in excellent health. If 1 year in excellent health was chosen, the patients were asked whether they would prefer 2 years in their current state of health or 6 months in perfect health. If 2 years in the current state were chosen, then they were asked whether they would prefer 2 years in their current state of health or 18 months in perfect health. The series was continued until the point at which the choices were equivalent. This time point subtracted from 24 months yielded the number of months of survival time that the patient would be willing to trade.[6] End-of-life preferences were assessed at baseline, and at 12 and 18 months. In addition, CPR order during last hospitalization was assessed in patients who were included presently after discharge.

Statistical analysis

Results are shown as mean (SD), median (IQR), and numbers and percentages as appropriate. Patients were divided into four groups: not willing to trade any survival time, willing to trade $\leq$6 months, $>$6–12 months, and $>$12 months. Group comparisons were done using independent *t*-test, Mann–Whitney U-test, or Fisher's exact test, as appropriate. Multivariable analysis was done using logistic regression with stepwise backward procedure (inclusion $P \leq 0.05$, exclusion $P > 0.1$), including variables shown in *Table 1*. No imputation for missing data was performed. Changes over time were assessed by using Wilcoxon signed ranks and Friedman's ANOVA, as appropriate, using Bonferroni adjustment where required. Adjusting results for participating centres did not significantly influence results. Therefore, unadjusted analyses are presented. A two-sided *P*-value of 0.05 or less was considered to be statistically significant. Calculations were done using the commercially available statistical package SPSS 15.0.

Results

Baseline characteristics are shown in *Table 1*. Patients were elderly, severely symptomatic, and most had reduced left-ventricular systolic function (LVEF; 80% with LVEF$\leq$45%). Most had significant co-morbidities and QoL was considerably reduced. At baseline, 555 patients (89%) responded to the TTO question. Those not responding had more dementia, more co-morbidities, worse QoL, higher depression score, worse mental test, poorer results from the 6 min walk test, and lower haemoglobin levels (*Table 1*). During follow-up, the proportion of patients not answering the TTO interview increased [Month 12: 17% of patients alive ($n = 81$); Month 18: 16% ($n = 70$)]. Overall, 595 (96%) of the patients replied at least once to the TTO question. Of these, 32% ($n = 190$) expressed some willingness to accept a reduced survival time for better QoL on at least one occasion.

Willingness to trade survival time

At baseline, 74% of the patients were *not* willing to trade any survival time for excellent health (*Figure 1A*). Of the remaining patients, approximately equal groups were willing to trade up to 6 months, $>$6 months to 1 year, or more than 1 year. Patients aged $\geq$75 years were slightly more likely to be willing to trade than younger patients (29 vs. 20%, $P = 0.01$), whereas the proportion not responding to this question did not differ between the age groups (11% in both).

During follow-up, the proportion of patients willing to trade any survival time decreased (Month 12: $n = 62$ of 401, Month 18: $n = 48$ of 368, *Figure 2*, $P < 0.01$), with no differences between age groups. When considering all patients not responding to the question at Month 12 or withdrawing consent prior to this visit as

Table 1 Baseline characteristics

	All patients ($n = 622$)	Expressing EoL preferences ($n = 555$)	Not expressing EoL preferences ($n = 67$)	*P*-value
Female sex	253 (41%)	229 (41%)	24 (36%)	0.43
Age (years)	76.9 ± 7.6	76.8 ± 7.5	78.0 ± 7.8	0.19
BMI (m^2/kg)	25.6 ± 4.4	25.7 ± 4.4	25.0 ± 4.9	0.28
Cause of HF				0.46
CAD	330 (53%)	297 (54%)	33 (49%)	
DCM	89 (14%)	79 (14%)	10 (15%)	
HHD	173 (28%)	155 (28%)	18 (27%)	
Other	30 (5%)	24 (4%)	6 (9%)	
LVEF (%)	35.0 ± 13.0	34.9 ± 12.8	35.8 ± 14.7	0.60
LVEF >45%	123 (20%)	108 (19%)	15 (22%)	0.62
Hypertension	462 (74%)	410 (74%)	52 (78%)	0.56
Diabetes	222 (36%)	197 (36%)	25 (37%)	0.79
CVI/TIA	98 (16%)	86 (16%)	12 (18%)	0.60
Chronic obstructive pulmonary disease	124 (20%)	104 (19%)	20 (30%)	0.04
PAOD	124 (20%)	108 (20%)	16 (24%)	0.42
Cancer	86 (14%)	76 (14%)	10 (15%)	0.71
Dementia	28 (5%)	19 (3%)	9 (13%)	0.001
Depression	79 (13%)	70 (13%)	9 (13%)	0.85
Renal failure	355 (57%)	314 (57%)	41 (61%)	0.52
≥2 co-morbidities	459 (74%)	402 (72%)	57 (85%)	0.03
NYHA-class ≥III	473 (76%)	420 (76%)	53 (79%)	0.80
Angina	126 (21%)	108 (20%)	18 (28%)	0.14
6 m WT good effort	492 (79%)	453 (82%)	39 (58%)	<0.001
Systolic blood pressure	122 ± 20	122 ± 20	122 ± 21	0.87
Heart rate	76 ± 14	75 ± 14	77 ± 14	0.38
Creatinine	116 ± 38	115 ± 37	120 ± 50	0.52
Haemoglobin	131 ± 18	131 ± 18	127 ± 17	0.06
NT-BNP (pg/mL)	3836 (1916–6905)	3749 (1892–6847)	4165 (2338–8212)	0.25
DASI	7.2 (1.8–15.4)	7.2 (2.7–15.5)	4.5 (0.0–7.3)	0.001
Minnesota LHFQ	40 (25–55)	39 (25–54)	44 (34–61)	0.04
SF-12 physical	32 (26–39)	33 (27–40)	29 (22–36)	0.004
SF-12 mental	46 (378–55)	46 (37–56)	42 (33–52)	0.1
GDS	4 (2–6)	4 (2–6)	4 (3–8)	0.02
Hodkinson MT	9 (9–10)	10 (9–10)	9 (7–10)	<0.001

EOL, end-of-life; CAD, coronary artery disease; DCM, dilated cardiomyopathy; HHD, hypertensive heart disease; LVEF, left-ventricular ejection fraction; CVI/TIA, cerebrovascular insult or transient ischaemic attack; PAOD, peripheral arterial occlusive disease; 6 m WT, 6 min walk test; DASI, Duke Activity Status Index; LHFQ, Minnesota Living with Heart Failure Questionnaire; GDS, Geriatric Depression Score; MT, mental test.

willing to trade any survival time, the proportion of those *not* willing to trade would still be 72% (at Month 18, 75%).

Of the original 622 patients, 376 (60%) replied to the TTO question both at baseline and at Month 12 [117 (19%) died, 52 (8%) withdrew consent, 77 (12%) replied at only one time point]. Of these, the response was the same at both visits in 280 (75%) patients, with 263 (94%) not willing to trade any survival time (*Table 2*). A comparable picture was seen comparing the 339 patients who responded at both Months 12 and 18: no change in 280 (83%) patients, 22 (6%) patients with more, and 37 (11%) patients with less willingness to trade survival time, but the changes over time were no longer statistically significant ($P = 0.18$). Surviving patients replying only once to the question did not differ significantly from the others (data not shown).

Predictors of willingness to trade

Patients indicating any willingness to trade survival time for symptom-free living differed in many ways from those unwilling to trade. They were older, more often female, lived more often on their own and/or were not married, had more signs and symptoms of CHF and poorer QoL. A history of selected co-morbidities was also related to willingness to trade (*Table 3*).

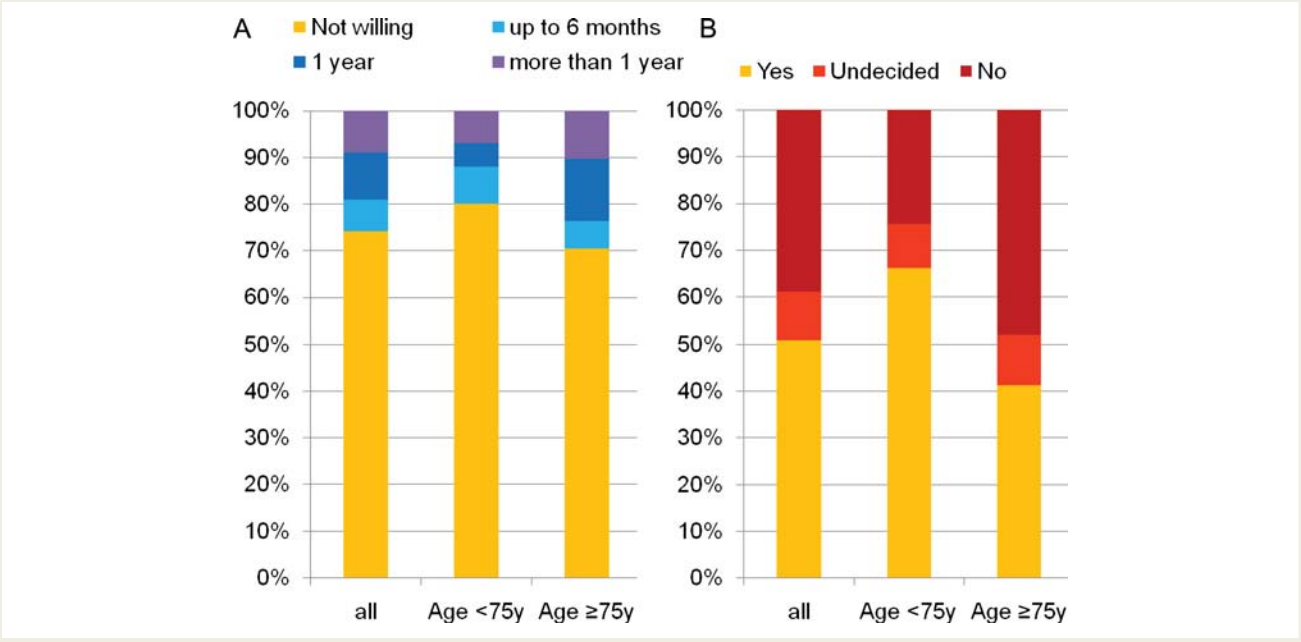

Figure 1 (*A*) Willingness to trade survival time for better health in the patient population replying to the time trade-off questions. Left column all patients ($n = 555$), middle column patients <75 ($n = 216$), and right column ≥75 years of age ($n = 339$). (*B*) Preference for cardiopulmonary resuscitation at baseline in the patient population replying to this question. Left column all patients ($n = 603$), middle <75 ($n = 234$) and right ≥75 years of age ($n = 369$).

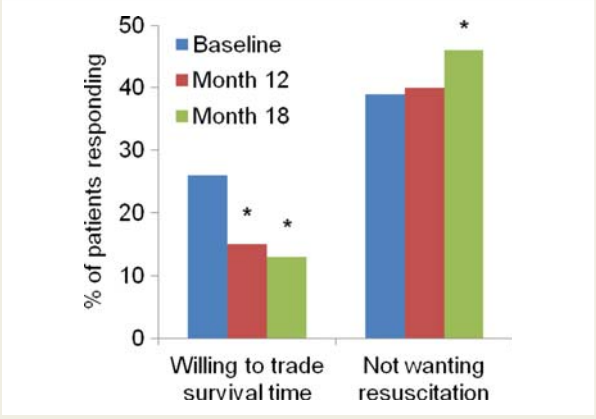

Figure 2 Changes in willingness to trade survival time (left) and not wanting resuscitation (right) over time. *$P < 0.01$ compared with baseline.

During follow-up, spouse of four patients died with little effect on end-of-life preferences.

Overall, 15 patients (2.4%) of the total study population had an ICD implanted, all of them were not willing to trade ($P = 0.03$). Because of the small number of patients with ICD, this was not considered in multivariable analysis.

In multivariable analysis, the following parameters were predictive of willingness to trade survival time: age [OR = 1.54 per 10 years, 95% confidence interval (CI) 1.13–2.10], reduced DASI (OR = 1.04 per score point, 95% CI 1.01–1.06), history of gout (OR = 2.40, 95% CI 1.22–4.70), female gender (OR = 1.74, 95% CI 1.12–2.72), GDS (OR = 1.10 per score point, 95% CI 1.02–1.18), exercise intolerance (OR = 1.43 per class on scale 0–3, 95% CI 1.08–1.89), constipation (OR = 1.23 per class on scale 0–3, 95% CI 1.01–1.50), and history of oedema (OR = 1.24 per class on scale 0–3, 1.01–1.52). The c-statistic of this multivariable logistic regression model was 0.710 (95% CI 0.657–0.763). The best cut-off was a probability of 33%, separating patients into those with a high ($n = 117$) and a low ($n = 404$) likelihood to accept a shorter survival time. However, even in the 'high likelihood' group, more than half of the patients (52%) preferred longevity vs. 83% in the low likelihood group ($P < 0.001$).

Table 2 Willingness to trade survival time for symptom-free status at baseline and 12-month follow-up

		Visit Month 12			
		No trade	**<6 months**	**6 m–1 year**	**>1 year**
Baseline visit	No trade	**263**	*11*	*9*	*8*
	<6 months	16	**3**	–	*2*
	6 m–1 year	21	1	**6**	*4*
	>1 year	17	2	5	**8**

Willingness to trade survival time for freedom of symptoms. Bold, unchanged ($n = 280$, 75%); italic, more willing to trade at Month 12 ($n = 30$, 8%); normal font, less willing to trade at Month 12 ($n = 62$, 17%).

Table 3 Comparison of patients willing and not-willing to trade survival time for quality of life

	Willing to trade (n = 143)	Not-willing to trade (n = 412)	P-value
Age	78.7 ± 7.6	76.1 ± 7.4	0.001
Female sex	78 (55%)	151 (37%)	<0.001
LVEF (%)	38 ± 13	34 ± 12	0.003
LVEF >45%	36 (25%)	72 (17%)	0.05
Main diagnosis			0.44
CAD	73 (51%)	224 (54%)	
DCM	16 (11%)	63 (15%)	
HHD	48 (34%)	107 (26%)	
Other	6 (4%)	18 (5%)	
Medical history			
Diabetes	56 (39%)	141 (34%)	0.31
CVI/TIA	20 (14%)	66 (16%)	0.60
Chronic obstructive pulmonary disease	30 (21%)	74 (18%)	0.46
PAOD	25 (17%)	83 (20%)	0.54
Cancer	20 (14%)	56 (14%)	0.89
Osteoporosis	23 (16%)	36 (9%)	0.02
Depression	26 (18%)	44 (11%)	0.03
Renal failure	78 (55%)	236 (57%)	0.63
Gout	20 (14%)	29 (7%)	0.02
Arthritis	43 (30%)	107 (26%)	0.38
Charlson Score	3 (2–4)	3 (2–4)	0.70
NYHA class (II/III/IV)	25/92/26 (17%/64%/18%)	110/251/51 (27%/61%/12%)	0.01
Angina (yes)	36 (26%)	72 (18%)	0.05
Orthopnea (0–3)	43/45/43/12 (30/32/30/8%)	136/158/80/38 (33/38/19/9%)	0.07
Oedema (0–3)	58/35/23/25 (41/25/16/18%)	234/84/56/37 (57/20/14/9%)	0.001
Ex. intolerance (0–3)	6/29/66/38 (4/21/48/27%)	38/128/177/68 (9/31/43/17%)	0.001
Constipation (0–3)	88/23/7/25 (62/16/5/17%)	314/38/24/33 (77/9/6/8%)	0.001
Clinical examination			
Rales (0–3)	62/55/21/5 (43/38/15/4%)	240/120/41/11 (58/29/10/3%)	0.006
Jugular vein (0–3)	50/34/35/20 (36/25/25/14%)	160/114/74/58 (39/28/18/14%)	0.32
Syst. BP (mmHg)	121 ± 19	122 ± 20	0.48
Heart rate rest (bpm)	78 ± 14	75 ± 14	0.03
NT-BNP (pg/mL)	3926 (1792–7089)	3654 (1904–6740)	0.63
Creatinine (μmol/L)	113 ± 37	116 ± 37	0.45
Haemoglobin (g/L)	127 ± 19	132 ± 18	0.003
6 min walk distance (m)	230 ± 112	277 ± 122	0.001
QoL/social status			
DASI	7.2 (0.0–15.2)	7.2 (2.8–15.5)	0.05
Minnesota LHFQ	41 (28–57)	39 (24–54)	0.10
SF-12 physical	30 (25–37)	34 (27–40)	0.001
SF-12 mental	45 (38–53)	46 (37–56)	0.60
GDS	4 (2–7)	3 (2–6)	0.002
Hodkinson MT	10 (9–10)	10 (9–10)	0.82
Married	68 (48%)	239 (58%)	0.03
Not alone	73 (51%)	268 (65%)	0.004

For abbreviations, see Table 1.

Resuscitation preferences

Most patients ($n = 603$, 97%) responded to the resuscitation question. At baseline, approximately one-third did not want CPR (*Figure 1B*). Age-influenced preference for CPR to a limited extent only (*Figure 1B*, $P < 0.001$).

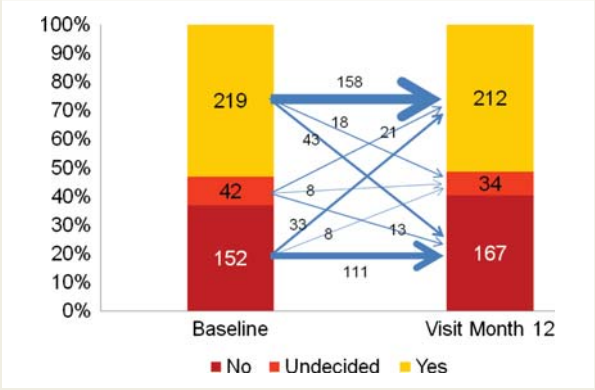

Figure 3 Comparison of cardiopulmonary resuscitation preference at baseline and at Month 12. Arrows indicate changes of individual patient preferences (numbers give number of patients). Size of arrows is related to number of patients in each category.

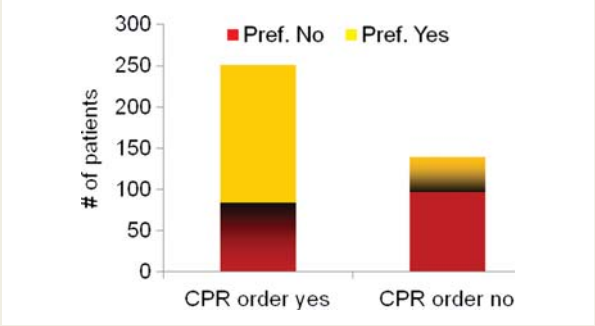

Figure 4 Comparison of preference for cardiopulmonary resuscitation and cardiopulmonary resuscitation orders at baseline (shaded = disagreement between cardiopulmonary resuscitation order and patient's preference).

The proportion not wanting resuscitation increased slightly over time (*Figure 2*, change over time $P = 0.01$). *Figure 3* depicts a comparison of the CPR preference at baseline and after 12 months ($P = 0.49$). At Month 18, compared with baseline, 238 patients out of 381 (62%) did not change their preference, 56 (15%) changed to wanting CPR, and 87 (23%) changed to not wanting CPR ($P < 0.01$). From the 15 patients with ICD implanted, 11 (73%) wanted to receive CPR ($P = 0.09$). Surviving patients replying only once to the question did not differ significantly from the others (data not shown).

Multivariable factors predictive for resuscitation preference were younger age (OR = 0.47 per each 10 year increase, 95% CI 0.28–0.78), male sex (OR = 2.13, 95% CI 1.42–3.19), lower GDS (OR = 0.92 per each score point increase, 0.86–0.97), being married (OR = 1.67, 95% CI 1.14–2.46), less orthostatic response (OR = 0.71 per class on scale 0–3, 95% CI 0.55–0.92), higher LVEF (OR = 1.19 per 10% increase, 95% CI 1.02–1.38), no history of anaemia (OR = 0.64, 95% CI 0.43–0.97), and history of syncope (OR = 2.16, 95% CI 1.05–4.42). Again, prediction of patients' preference was relatively inaccurate [c-statistic 0.741 (95% CI 0.700–0.782)].

Resuscitation preferences in relation to resuscitation orders

A total of 481 patients (77%) were included in the study presently after discharge from hospital. Of these, both CPR preferences at study entry and CPR orders from pre-randomization hospitalization were known for 430 patients (89%). For 390 patients with distinct CPR preferences, patient preferences (as answered to the study question) differed from the hospital records 32% of the time ($n = 126$; *Figure 4*). No predictors for disagreement could be identified (data not shown).

Relation of willingness to trade and wishing cardiopulmonary resuscitation with mortality

During follow-up, 20% of the patients died (*Table 4*). There were no significant differences in either all-cause mortality or cardiovascular mortality in relation to patients' willingness to trade survival time or wish to be resuscitated if necessary. However, non-cardiovascular deaths were more common in patients willing to trade survival time, with a similar trend in patients not wanting resuscitation (*Table 4*). No significant interaction with age or age group (< or ≥75 years) was seen.

Table 4 Mortality rate depending on end-of-life preferences

	Willing to trade survival time ($n = 555$)			Wanting CPR ($n = 603$)		
	Yes ($n = 143$)	No ($n = 412$)	*P*-value	Yes ($n = 307$)	No/undecided ($n = 296$)	*P*-value
All cause	33 (23%)	79 (19%)	0.33	58 (19%)	62 (21%)	0.54
CV	20 (14%)	68 (17%)	0.51	50 (16%)	44 (15%)	0.66
Non-CV	13 (9%)	11 (3%)	0.003	12 (3%)	14 (6%)	0.15

CV, cardiovascular.

Discussion

Patient-centred decision making and open communication with patients and their families are critical concepts in providing the highest quality of care.[16] This study addresses communication issues and describes important new findings regarding end-of-life preferences of elderly CHF patients with both reduced and preserved LVEF, exploring the willingness to trade survival time and resuscitation preferences and changes over 18 months. It also correlated resuscitation preferences with resuscitation orders.

Most patients showed a high willingness to answer these difficult questions, confirming previous findings.[6,17,18] Importantly, the majority preferred longevity over QoL, and half wished to be resuscitated if necessary. This was also true in very old patients, although the rates of willingness to trade in favour of longevity, and to be resuscitated, decreased with age. To some extent, the findings of this study are in contrast to the general belief[19] and some previous findings[5,20] that QoL is more important than longevity for elderly CHF patients, but confirm recently published results in younger patients.[6]

Previous studies on health values have focused on seriously ill patients,[21] who often had cancer,[22] were hospitalized,[23] or were living in a nursing home.[24] In patients with CHF, the focus was either on end-stage disease (e.g. patients confronted with cardiac transplantation[5]), younger patients,[6,20,23] or patients with various chronic diseases.[25] The vast majority of CHF patients, who are elderly, however, have received little attention. These previous studies found that health preferences may vary widely and may change over time not only in relation to changes in health status. The acceptability of a therapy which may result in reduced health seems to increase with time and this increase seems more likely in patients with a declining health status.[25] This response shift in relation to the disease trajectory inherent to the process of accommodating an illness has been subject to specific studies[26] and seems particularly relevant to life-threatening diseases. However, many of the previous studies[25] focused on the acceptability of burdensome treatment rather than the preference of longevity over QoL. With the availability of treatment to (solely) improve prognosis, as in CHF, the latter question may be more relevant. In fact, in the few patients having an ICD in our study, preferences were more in favour of longevity.

One possible explanation for the low willingness to trade survival time for better health may be that CHF patients tend to overestimate their life expectancy,[27] which may result in favouring more aggressive therapy.[28] However, this applies to younger patients, whereas patients with advanced age usually underestimate their life expectancy.[27] Given the high proportion of elderly patients preferring longevity, it is unlikely that overestimating life expectancy is the main explanation for our findings. In agreement with previous results,[6,29] the majority neither changed their willingness to trade survival time nor their preference regarding CPR over time. Still, there were patients who did change their preferences and these patients did not display characteristics that would help to identify them.

Besides severity of CHF and related symptoms, age, female sex, exercise intolerance, depression, and co-morbidities were relevant predictors of end-of-life preferences. Patients with normal LVEF showed more willingness to trade survival time, but this was largely explained by age and sex. In addition, psychosocial factors were relevant predictors. Other predictors, such as orthostatic response or constipation, were less obvious, suggesting that individual perception may vary considerably. Moreover, combining these characteristics did not allow for a reliable prediction. The findings, therefore, emphasize the importance of asking and incorporating the individual patient's wishes into decision making, irrespective of age, and to periodically repeat these discussions.[16]

The difficulty in communication is highlighted by the significant discordance between CPR orders and patients' wishes, reinforcing earlier findings that physicians' perceptions of patients' preferences are not always accurate.[29] Mismatches between preferences and treatment were shown, especially in the direction of patients receiving less aggressive care than they are willing to undergo[30] or very old CHF patients receiving more aggressive care than they desired.[31] Insufficient communication about death and prognosis may partly be due to physicians' self-perceived inability to predict mortality in advanced CHF,[18] or their concerns that such discussions will destroy hope.[17] This results in patients not receiving the treatment they prefer. Effective communication regarding end-of-life issues seems to rank among the most important topics in patients with advanced CHF, resulting in changes in preferences for life support.[32] Thus, expecting death in the near term should not detract from this discussion, but it should not be postponed until patients are end-stage as patients seem to prefer learning about their prognosis and its implications at a time of optimal cognitive function.[33]

Limitations

There are limitations to such an assessment, the most important being the hypothetical nature of the questions posed, which may be particularly difficult for very old patients to understand, a small proportion of which even having dementia, despite the fact that these questionnaires have been validated and used with success.[5,6] Importantly, excluding patients having reduced mental abilities as assessed by the Hodkinson abbreviated mental test did not influence results (data not shown). The population included in the study was primarily from middle European backgrounds and cultural differences in patients' willingness to engage in discussion regarding end-of-life preferences were not examined, limiting generalizability to patients from other socio-cultural backgrounds. In addition, it is inherent to studies that the study sample is selected and might not represent all patients. In particular, the results may not apply to patients who are sicker when being asked about their preferences. Still, as characteristics of our study population were comparable to those of large cohort studies,[9,10] our study population seems to be representative of a broad range of CHF patients.

Conclusion

Patients with CHF are willing to address their end-of-life preferences, often value longevity even at older age, but individual preferences are impossible to predict and may change over time, reinforcing the value of listening to patients to provide relevant insight and individualize care.[34] Openness and communication about prognosis, trajectories, and realistic treatment possibilities engender hope and allow patients to plan for their future.[17] This

applies to various decisions that confront CHF patients, but may be particularly important with respect to ICD implantation, turning off the device, and treatment with purely symptomatic medical therapy that may even reduce survival.

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Appendix

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TIME-CHF investigators see ref. 8.

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