ORIGINAL ARTICLE

Heart failure: Tools for nursing and medical treatment

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Abstract

Background: *To validate a structured interview designed to evaluate the healthcare and information needs of patients with heart failure (HF), who were also characterized by means of the Kansas City Cardiomyopathy Questionnaire (KCCQ) and the 36-item Short-Form Health Survey (SF-36).*

Methods: *Forty-five in- and outpatients with HF were administered a structured interview concerning their information and healthcare needs (together with the KCCQ and SF-36) with the aim of investigating the effects of healthcare models on their quality of life (QoL). Twenty--one patients were also involved in a one-week test-retest validity study carried out in order to verify reproducibility and stability by means of concordance and K statistics.*

Results: *The reproducibility of the structured interview was good or very good for all items, with a mean Kw of 0.59; the clarity and acceptability of most of the questions were good. Positive judgements of hospital care inversely related to the patients' New York Heart Association class. The subjects about which the patients sought greater information were diet, sleep, therapies and physical exercise, with cardiologists and general practitioners (GPs) being more involved than nurses. The most frequently discussed subject was diagnostic examinations. The questionnaire scores of our patients were generally lower than those reported in the literature, possibly because of their advanced age. However, it is difficult to believe that the quality of care was extraneous to their generally worse health-related QoL.*

Conclusions: *Our HF patients experienced a 'basic' healthcare model (hospitals, GPs, cardiologists) and judged them acceptable. Their ability to think critically about care was increasingly compromised as HF progressed and their health-related QoL decreased.* (Cardiol J 2011; 18, 4: 411–420)

Key words: heart failure, quality of life

Introduction

Socio-demographic changes and medical advances have profoundly altered healthcare needs in Italy and other Western countries by switching the emphasis from acute to frequently co-existing chronic diseases that affect an increasingly older population and absorb a growing proportion of public health costs. The primary requirement of offering patients clear points of reference throughout the process of care can be fulfilled by means of explicit management strategies shared by the different types of healthcare professionals, and supported at institutional level.

Heart failure (HF) is one of the chronic diseases with the highest impact on patient survival and

quality of life (QoL), and the fact that it affects 2–
–10 million patients and has an estimated 0.4–2%
prevalence within the general European population
[1] also means that it accounts for a considerable
amount of public health expenditure.

The aim of this study was to define the infor-
mation and healthcare priorities relating to patients
with HF by comparing their QoL as revealed by
means of specific (KCCQ, the Kansas City Cardio-
myopathy Questionnaire) and general (SF-36, the
36-item Short-Form Health Survey) instruments
with their perceived information and healthcare
needs as revealed by means of an *ad hoc* structured
interview and their clinical data. We evaluated the
reproducibility and construct validity of the inter-
view, as well as its applicability and comparability
with the published KCCQ and SF-36 data.

In order to be able to confront the long-term
healthcare needs of HF patients, it is necessary to
establish multi-disciplinary teams capable of opti-
mizing patient autonomy and costs. The scientific
literature [2–7] underlines the decisive role played
by specialist nurses in educating patients and their
relatives (e.g. by preparing information booklets and
forms for monitoring clinical parameters) and in-
forming and maintaining contacts with general prac-
titioners (GPs) before the patients are discharged.

Information/healthcare needs

It is clear from the literature that HF patients
do not generally have access to appropriate services,
and satisfying their needs and those of their pro-
fessional or other caregivers (the nurses or rela-
tives who support them emotionally and/or physi-
cally) requires the implementation of effective ser-
vice models [8].

The complexity of treating and costs of hospi-
talizing HF patients have necessarily led to the
development and assessment of various service
models primarily aimed at looking after them with-
in the community. These multi-disciplinary models
generally include giving information to patients and
caregivers, supervising drug administration, and
ensuring regular monitoring and some forms of in-
tervention by advanced practice nurses (APNs)
[9–16]. The main aims of all of these services are
to reduce the frequency of hospitalization, improve
cost/efficacy ratios, and increase the patients' func-
tional status.

Looking after elderly patients with HF means
providing physical, medical, behavioral and psycho-
logical assistance, and requires consideration of all
aspects of pharmacological and non-pharmacologi-
cal therapies [17]. However, the use of even the

most effective therapies to prolong the lives of such
patients does not necessarily improve their QoL
[18]. It is well known that they have considerable
difficulties in adjusting to their functional limitations
and coping with the problems of drug self-adminis-
tration [19] and drug-related side effects, as well as
the difficulties associated with co-morbidities and
the lack of psychosocial and/or rehabilitation ser-
vices [20].

Appropriate education programmes concerning
the treatment and possible complications of HF
have proved to be useful in improving patient au-
tonomy [21] in terms of monitoring symptoms,
checking body weight every day, adopting the best
strategies to deal with functional deterioration, and
understanding when it is necessary to consult
a healthcare professional [22]. A number of con-
trolled studies [23, 24], including one Italian expe-
rience [25], have found that such programs lead to
improvements but, in order to evaluate their effi-
cacy appropriately, it is necessary to use reliable
parameters and measuring instruments.

Methods

Study design

This observational cross-sectional study, which
was approved by the Ethics Committee of the Uni-
versity ASL of L'Aquila and conducted in accor-
dance with the principles set out in the Declaration
of Helsinki, was simultaneously carried out at Os-
pedale Civile S. Salvatore and the surgeries of va-
rious GPs in the town of L'Aquila, Italy. Patients
with HF were considered eligible for enrolment
after they had been carefully screened by a nurse
and two physicians, who checked their diagnosis-
-related group and the records of their GPs.

The patients were studied in relation to their
New York Health Association (NYHA) class, their
information and healthcare needs, and the effects
of healthcare modalities and other lifestyle charac-
teristics on their QoL.

The patients were administered the KCCQ
[26], the SF-36 [27], item 16 ('drug side effects') of
the Minnesota Living with Heart Failure Question-
naire (MLHF), and a structured interview.

The 23-item KCCQ, which was specifically
designed to monitor the health of patients with con-
gestive HF, analyzes the domains of symptoms and
symptom stability (frequency, severity and recent
changes), physical and social limitations, self-effi-
cacy, and the QoL. It is scored by assigning each
response an ordinal value, beginning with one for
the response implying the lowest level of functioning,

and summing the items within each domain. The scale scores are transformed into a 0–100 range by subtracting the lowest possible scale score, dividing by the range of the scale, and multiplying by 100. Higher scores indicate more favorable states [26]. Our patients were administered the Italian version [28], which was validated in a study of 50 patients that compared the results with those of the 21-item MLHF in which a six-point response scale is used to assess a patient's emotional and physical status [29].

The items of the SF-36 assess the QoL by means of eight scales: physical function, physical role (related to physical limitations), social function, bodily pain, general health, vitality, mental health, and emotional role; there is also a question concerning any change in health status during the course of the previous year. Higher scores reflect a better state of health. The SF-36 is widely used in Italy, and normative scores have been defined for the Italian population. For this reason, it was administered together with the Italian version of the KCCQ during the process of validation [30].

Item 16 of the MLHF was also included in order to complete the survey by collecting any unwanted effects of drug therapy [29].

The structured interview, developed by us, explored the main subjects of the study by means of prevalently qualitative variables: judgements concerning healthcare (questions 1 and 2), information received (questions 4 and 6), information not received (questions 5, 7 and 8), and healthcare needs (question 3). Questions 3, 4, 5, 6, 7 and 8 asked the patient to define an order of priority (1–5 or 1–6) for the different modalities listed, and the answers should therefore be considered exclusive. The answers to the question concerning the need for further information (question 8) ranged from a minimum of 'none' to a maximum of 'very much more'. The first phase of the study consisted of validating the interview in terms of stability, reproducibility and predictiveness.

The technical specifications included questions relating to demographic details (items 1–4), clinical status (5–7, 15, 19), the diagnostic work-up (8), pharmacological therapy (12–14), hospital admissions (9–11), and physical training (16–18).

Patients

Consecutive eligible patients were enrolled by the Divisione di Clinica Medica I and Cardiologia of Ospedale S. Salvatore in L'Aquila, and by GPs. The inclusion criteria were a diagnosis of HF based on the results of an echocardiographic examination, radiographic evidence of pulmonary congestion, and the presence of typical signs and symptoms; an age of at least 18 years; and classification in NYHA class I–IV. The exclusion criterion was the presence of a serious psychological disorder or other concomitant diseases (diabetes, severe renal insufficiency [creatinine ≥ 3 mg/dL]). Patients aged over 70 were not excluded because HF is frequent among the elderly, who also have more self-management difficulties and a greater need for healthcare services.

Validation study

The instruments were validated in a group of 21 patients with a diagnosis of HF who were contacted through their GPs because of the need to demonstrate the applicability of the instruments under the least favorable conditions (the sometimes limited availability of clinical documentation, time and attention). We evaluated the comprehensibility of the questions, the possibility of self-completing the KCCQ and SF-36, the time needed to do so, and the frequency of missing answers. The patients were re-tested one week later in order to assess the stability of their responses in the absence of any significant clinical changes.

We also evaluated the correspondence between the KCCQ and SF-36 scores by clinically significant groups and any action modifying the variables obtained using the interview (questions 1, 4 and 6). The KCCQ scores were compared with published data and those of the SF-36 in order to assess their consistency and reliability.

The KCCQ and SF-36 scores were analyzed in relation to clinical variables, the variables associated with a capacity for self-managing and coping with HF, and the variables indicating the quality of care and the people providing it.

Data analysis

Data was statistically analyzed using STATA 9 software. Cohen's K and percentage agreement were calculated for the validation study. The correlations between the different sets of scores and the qualitative variables were calculated using Pearson's correlation, and the between-score differences were assessed using a two-tailed Student's t test and Wilcoxon's rank-sum (Mann-Whitney) test. The associations between the variables were evaluated by means of the Kruskal-Wallis test.

Results

Table 1 shows the characteristics of the 45 enrolled patients (21 males, 24 females, mean age 77.5 years) by NYHA class: five were living in a resi-

Table 1. Demographic and clinical characteristics of the sample.

	NYHA class				Total sample
	I	II	III	IV	
Number	5	14	18	8	45
Male/female	3/2	3/11	10/8	5/3	21/24
Mean age	66.2	74.3	74.8	78.6	77.5
Education (years)	9.4	6.3	6.3	4.6	6.3
Single, no. (%)	1	6	5	2	14 (31%)
Mean EF (no. with % data available)	0.56 (5) 100%	0.56 (7) 50%	0.49 (14) 78%	0.34 (6) 75%	0.49 (32)
Mean duration of HF (years, with no. of patients providing data)	11 (5)	6.7 (14)	6.1 (18)	9.9 (8)	7.5
Admissions in last year (mean)	0.3	0.5	0.7	0.7	0.6
Mean number of drugs (% of patients in therapy)	2.5 (40%)	1.8 (100%)	1.9 (100%)	2 (100%)	1.9
Care no. (% positive judgments):					
Hospital	1 (2.8%)	12 (34.3%)	14 (40%)	8 (22.9%)	35/45
Home (IDC)	0	3 (42.9%)	3 (42.9%)	1 (14.2%)	7/7

NYHA — New York Health Association; EF — ejection fraction; HF — heart failure; IDC — Integrated Domiciliary Care

dential healthcare facility, 15 were being treated by a hospital department, and 25 were attending the surgeries of their GPs. The SF-36 and KCCQ were self-completed relatively easily by the patients after they had been explained by an interviewer. The structured interview proved to be more difficult to understand, despite explanations. The only question with missing replies was the structured interview question concerning Integrated Domiciliary Care, which was only answered by the seven patients who had actually received it and were therefore capable of expressing a judgement (which was positive in all cases).

In the validation study, the test/retest weighted K (Kw) and percentage agreement of the responses to the KCCQ, SF-36 and structured interview were measured using the questionnaires of 21 patients. A K value of > 0.75 is interpreted as excellent agreement, 0.6–0.75 as good, 0.40–0.60 as moderate, and < 0.4 as poor [31].

The Kw values for the KCCQ were high in relation to all of the items, as was the percentage agreement between the replies. The most concordant item was that relating to "limitation in doing yardwork, housework or carrying groceries", which had a Kw of 0.96 and 98.8% agreement. The mean Kw for all of the items as a whole was 0.82. The item extrapolated from the MLHF concerning the quantification of drug side-effects showed poor concordance, with a Kw of 0.27 and 84.8% agreement.

All of the items of the SF-36 also had high Kw and percentage agreement values. The items concerning "limitation in vigorous activities", "limita-tion in bending, kneeling or stooping", "limitation in the kind of work or other activities", "difficulty in performing the work as a result of any emotional problems" and "difficulty in performing the work or other regular daily activities as a result of physical health" were fully concordant, with a Kw of 1.00 and 100% agreement. The mean Kw for all of the items as a whole was 0.83.

Most of the items in the structured interview had fairly high Kw and percentage agreement values. The items concerning "information received from your APN" (Kw 0.78, 96.3% agreement), "information received from your GP" (Kw 0.79, 94.8% agreement), "management of treatment" (Kw 0.79, 91.1% agreement) and "information requested from your cardiologist" (Kw 0.78, 93.9% agreement) showed the greatest concordance. The mean Kw was 0.59.

In relation to information needs, the patients indicated "diet", "sleep" and "therapies" (about which respectively 19, 18 and 17 subjects requested "a lot/very much more" information), followed by "physical exercise", requested by 16 subjects.

The healthcare professionals mainly involved in the requests for information were "cardiologists" (18 patients, 11 of whom had received exhaustive replies) and "GPs" (17 patients, 15 of whom had received exhaustive replies); two patients had asked for information from a "nurse", one of whom judged the replies exhaustive.

The subject that aroused the greatest interest was "routine diagnostic examinations", with information being requested by 16 patients and obtained by 12.

The priority physical needs as reported by 44 patients were "support for everyday activities" (indicated by 14) and "physiotherapy" (indicated by 13). The priority relational needs as reported by 43 patients was "support for relatives" and "support for drug self-administration", both indicated by 15 patients. The 43 patients who assessed management needs gave priority to "treatment" (12 patients) and "disease-related bureaucratic requirements" (11 patients).

Table 2 shows that the patients in NYHA class I had the highest KCCQ scores for all domains; those in classes II–IV had progressively lower scores. The differences between the classes were statistically significant (Mann-Whitney test). There were significant differences between the KCCQ and SF-36 scores for the different domains, particularly between classes I and II (Table 2). The SF-36 scores followed the same trend. The patients in class I had the highest scores for physical functioning, with mean values of 84, whereas those in class IV had the minimum of 0; the mean value for the patients as a whole was 29.

Table 3 shows the linear correlation coefficients between the individual domains of the KCCQ and SF-36, together with their statistical significance. The KCCQ physical limitation scale generally correlated well with the SF-36 (optimally with physical function), and the social limitation scale optimally correlated with the physical function scale of the SF-36. The SF-36 vitality scale correlated well with the KCCQ scores. There was no correlation between the item extrapolated from the MLHF questionnaire (attempting to quantify drug side-effects) and the SF-36 (Table 3).

We compared our scores with the published total scores [26, 29, 30] and the scores of the different NYHA classes [28], bearing in mind that higher scores indicate a better status. In relation to the KCCQ domains, Miani et al. [28] reported cumula-

Table 2. Differences in mean SF-36 and KCCQ scores by NYHA class.

	NYHA class		
	I/II	II/III	III/IV
KCCQ			
Self-efficacy	−0.7	13.5	5
Physical limitation	33.4*	8.4	4
Symptoms	19.1**	21.4**	7.8
Symptoms stability	23.4	19.7	11.8
Social limitation	41.6*	16.1	−4.1
Quality of life	14.4	21*	−8.9
SF-36			
Physical function	51.1*	15	4.6
Physical role	56*	9**	0
Bodily pain	23.1	−14.7	12.1
Mental health	7.1	−4.9	2.8
Emotional role	33.8	18.8	7.4
Social function	19	9.1	3.8
Vitality	19.7	5.1	4.2
General health	15.1	7.9	−11.9

*p < 0.01; **p < 0.05

tive values for patients in classes I and II that were lower only in the case of symptoms and social limitation, whereas those of the class III patients were higher in all of the domains. Green et al. [26] reported higher total scores than those recorded by us for functional limitation (PL: 34.7 vs 33.6) and self-efficacy (SE: 67.6 vs 63.6). The total SF-36 score recorded by Apolone et al. [30] reflected generally higher scale scores, and only the bodily pain score of our sample was lower (47.6 vs 68.2). Shively et al. [32] reported total scores for physical role, general health and mental health, only the last of which was lower than that recorded by us (41.6 vs 44).

Multiple regression analysis revealed significant interdependence between the dependent variable of NYHA class and the physical function score

Table 3. Correlation coefficients (r) between SF-36 and KCCQ scores.

	SF-36							
	Physical function	Physical role	Emotional role	Bodily pain	Vitality	Mental health	Social function	General health
KCCQ								
Physical limitation	0.86*	0.48#	0.18	0.55*	0.62*	0.47#	0.55*	0.35†
Symptoms	0.49#	0.43#	0.35†	0.08	0.54*	0.34†	0.42#	0.27
Symptoms stability	0.36#	0.40†	0.10	0.08	0.33#	0.21	0.06	0.25
Social limitation	0.77*	0.51#	0.21	0.44#	0.56*	0.43#	0.59*	0.42#
Self-efficacy	~0.20	−0.008	0.06	0.04	0.19	0.28	0.19	0.10
Quality of life	0.50#	0.43#	0.26	0.22	0.55*	0.41#	0.48#	0.51#
MLHF	0.24	0.06	−0.02	0.23	0.04	0.27	0.25	−0.06

*p ≤ 0.0001; #p < 0.005; †p < 0.05

Table 4. Multiple regression parameters.
Dependent variable: NYHA class

Explanatory variables	Coefficient	P
SF-36: Physical function	–0.017	0.017
KCCQ: symptoms	–0.013	0.034
KCCQ: self-efficacy	–0.11	0.056

(p = 0.017). There was a similar interaction between NYHA class and KCCQ symptoms (p = 0.034) and self-efficacy scores (p = 0.056) (Table 4). The Kruskal-Wallis test showed a significant relationship between NYHA class and symptoms (p = 0.002), QoL (p = 0.03), symptom stability (p = 0.04), physical limitation (p = 0.01) and social limitation (p = 0.006) of the KCCQ, and physical function (p = 0.005) and physical role (p = 0.03) of the SF-36.

In relation to the items of the structured interview, the KCCQ symptoms scale interacted significantly with "assistance in moving around" and the physical limitation scale with "managing relations with healthcare professionals" and "the need for information". The symptom stability scale interacted significantly (Kruskal-Wallis test) with "diuresis and catheter care", the self-efficacy scale with "managing disease-related bureaucratic requirements" and the QoL with "support for everyday activities". The SF-36 mental health scale interacted significantly with "support for marital relations", "the need for information" and "managing relations with healthcare professionals", and general health interacted with "support for social relations".

Discussion

The rapid increase in the prevalence of HF has made it necessary to reconsider the effectiveness of models of patient management and monitoring in terms of survival, the QoL, and reducing emergency hospital admissions and iatrogenic disease.

There is no consensus concerning the most efficacious and cost-effective model. This is partly because of diverse healthcare services in different countries. However, all public health systems are paying increasing attention to the contribution that nursing professionals of various levels (specialists, APNs, etc.) make to ensure optimal patient management also in terms of resources [33].

This study considered the instruments for measuring health-related quality of life (HRQoL) are useful in evaluating healthcare interventions and models of care.

The mean age of the enrolled patients was relatively old for a study of this type, but it is worth noting that the KCCQ validation studies [23, 26] did not exclude patients aged 70-plus, not least because most HF patients are elderly. Our patients also had relatively less severe disease than those in other validation studies [26, 28] insofar as the great majority (26/32) had an ejection fraction of no less than 49%. Their average duration of education was low (six years), and 30% lived alone.

Validity of the findings

Our results show that the reproducibility of the KCCQ and SF-36 was optimal, while that of the structured interview was moderate; item 16 of the MLHF (drug side-effects) was not very reproducible; Heo et al. [34] reported that it does not contribute much to the MLHF score. Although the mean K value of the structured interview was acceptable (0.59) and all of the items showed > 75% agreement, analysis of the questions with a K value of < 0.4 showed that information about therapy was the most aleatory term in defining the quality of care and healthcare needs. In other words, it acts in an unstructured and inconstant manner if it does not have a clear and explicit association with prognosis, and leads to uncertainty in the patients' responses to the items investigating it. Furthermore, it is likely that the lack of adequate information induces HF patients not to recognise undesired drug effects, or at least to underestimate them [9–13].

Information and healthcare needs

Experience of Integrated Domiciliary Care and living in an Assisted Healthcare Residence seem to be determinant factors for expressing a favorable opinion of these forms of care [17, 21, 22, 35]. The positive judgement of hospital care expressed by most of the patients was inversely associated with their NYHA class (Table 1).

The patients identified "diet", "therapies", "sleep" and "physical exercise" as subjects about which more information was needed (although only a minority actually requested it), and these seem to be mainly related to the role of healthcare professionals identified as referents and the subjects they usually deal with [36]. Most of this information is provided by "cardiologists" and "GPs", whereas the "nurses" of various types (APNs, specialists or general) seem to play a secondary role, probably due to the fact that patients are less aware of a nurse's responsibilities.

Patients ask more questions about "routine diagnostic examinations", another subject most fre-

quently dealt with by healthcare professionals, in an attempt to discover more about their state of health.

Experience of the care received also seems to facilitate the identification of healthcare needs. The scenarios of care described in the international literature [4–8, 37] and referred to in the introduction seem to be totally extraneous to our patients. Consequently, although the interview was reproducible and there were very few missing answers, it was also relatively unhelpful in defining patient expectations.

HRQoL

The validity of the KCCQ and SF-36 questionnaires was confirmed by the steadily decreasing scores related to the NYHA class. The original study by Green et al. [26] showed that the KCCQ was more sensitive to clinical changes than the MLHF and SF-36, and the fact that the between--class differences in KCCQ scores were more frequently significant indicates its greater discriminatory power (Table 2). The patients in class I had the highest scores, probably because of their better clinical condition. The KCCQ results do not overlap those of the SF-36, except perhaps for the physical limitation and, partially, the social limitation dimensions; whereas the emotional role scale of the SF-36 had practically no relationship with the domains investigated by the KCCQ except for symptoms (Table 3).

Pathological conditions naturally had a determining effect on the physical dimension of the SF-36, except for the scale relating to pain, which is not a typical symptom of HF. The scales relating to the other domains were less affected, and multiple regression analyses (Table 4) showed that only the physical function scale of the SF-36, and the symptoms and self-efficacy scales of the KCCQ, significantly correlated with NYHA class.

Our patients' scores were generally lower than those reported in the literature, although no quantitative evaluation is possible because the articles [22, 28, 30, 32] do not give the standard deviation of the mean scores, and some of them group together different classes, preventing any direct comparison. The class-related KCCQ scores reported by Miani et al. [28] are higher than ours, as are the physical limitation and self-efficacy scores reported by Green et al. [25]; furthermore, the total SF-36 scores reported by Apolone et al. [30] are generally better than ours, whereas the physical role scores reported by Shively et al. [32] are better, and those relating to mental health and general health are substantially the same.

It is possible that the differences between our scores and the published data were due to the advanced age of our sample. However, it is unlikely that the quality of care had no effect on the generally worse HRQoL of our patients even though they had a better ejection fraction than those in the other studies [26, 28, 30, 32]. This possible indirect effect of the mode of care corresponds to the relative absence of specific requests for greater autonomy in managing the disease and its treatment.

Limitations of the study

Our study has a number of limitations that should be acknowledged. Firstly, the study population was small and not a randomized sample of patients with HF. The enrolled patients had chronic HF and were already receiving optimal medical therapy. However, these two limitations only affect the clinical relevance of our findings, and not the study's aim of validating the instruments used in a specific setting and population.

Finally, we did not determine the minimal clinically important difference in the KCCQ, SF-36 and structured interview scores. More experience in different clinical settings will throw further light on this question.

Conclusions

Our study demonstrated the good performance of the instruments used in our sample of patients, who were not specifically selected in terms of second-level healthcare, age or education. It confirmed the external validity of the KCCQ and SF-36 in relation to NYHA class and published data, and this was also negatively confirmed by the findings of the structured interview, which seemed to reflect the healthcare experiences of the patients rather than their expectations.

This last aspect reinforces the pertinence, relevance and usefulness of further studies of the role of qualified nurses in the management of HF patients, especially because the expected future increase in the prevalence of HF and the availability of qualified nurses make it likely that clinical and economic considerations will require multi-professional care models.

Acknowledgements

References

1. Mostered A, Hoes AW, de Bruyne MC et al. Prevalence of heart failure and left ventricular dysfunction in the general population. Eur Heart J, 1999; 20: 447–455.

2. Strombery A. Educating nurses and patients to manage heart failure. Dept of Cardiology of Cardiovascular Linkoping Sweden. Eur J Cardiovasc Nurs, 2002; 1: 33–40.

3. Blue L. Improving outcomes in chronic heart failure. Publishing Group, BMJ, London 2001.

4. Smith K. Increasing roles for nurses. Eur J Cardiovasc Nurs, 2002: 1: 19–21.

5. Stewart S. Caring for older patients with chronic cardiac disease, an increasing challenge for cardiac nurses in the 21st century. Eur J Cardiovasc Nurs, 2002, 1: 11–13.

6. Fridlund B. The role of the nurses in cardiac rehabilitation programmes. Eur J Cardiovasc Nurs, 2002; 1: 15–18.

7. Measuring and Improving Quality of Care AHA/ACC Conference Proceedings. Measuring and Improving Quality of Care: A Report From the American Heart Association/American College of Cardiology First Scientific Forum on Assessment of Healthcare Quality in Cardiovascular Disease and Stroke. Circulation, 2000; 101: 1483–1493.

8. Boyd KJ, Murray SA, Kendall M et al. Living with advanced heart failure: A prospective, community based study of patients and their carers. Eur J Heart Fail, 2004; 6: 585–591.

9. Harkness KI, Tranmer JE. Measurement of the caregiving experience in caregivers of persons living with heart failure: A review of current instruments. J Cardiac Fail, 2007; 13: 577–587.

10. Rich MW, Beckham V, Wittemberg C et al. A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. NEJM, 1995; 333: 1190–1195.

11. West JA, Miller NH, Parker K et al. A comprehensive management system for heart failure improves clinical outcomes and reduces medical resource utilisation. Am J Cardiol, 1997; 79: 58–63.

12. Cline CMJ, Israelsson BYA, Willenheimer RB et al. Cost effective management programme for heart failure reduces hospitalisation. Heart, 1998; 80: 442–446.

13. Blue L, Langley-Evans A, McMurray JJV. Randomised controlled trial of a specialist nurse intervention in heart failure. Br Med J, 2001; 323: 715–718.

14. Stewart AL, Greenfield S, Hays RD. Functional status and well-being of patients with chronic conditions. Results from the Medical Outcomes Study. J Am Med Assoc, 1989; Y262: 907–913.

15. Patel H, Shafazand M, Ekman I, Hojgard S, Swedberg K, Schaufelberger M. Home care an option in worsening chronic heart failure. A pilot study to evaluate feasibility, quality adjusted life years and cost-effectiveness. Eur J Heart Fail, 2008; 10: 675–681.

16. Barbareschi G, Sanderman R, Lesman Leegte I, Van Veldhuisen DJ, Jaarsma T. Educational level and the quality of life of heart failure patients: A longitudinal study. J Card Fail, 2011; 17: 47–53.

17. Grady KL, Dracup K, Kennedy G et al. Team management of patients with heart failure: A statement for healthcare professionals from the Cardiovascular Nursing Council of the American Heart Association. Circulation, 2000; 102: 2443–2456.

18. Dobre D, de Jongste JL, Haaijer-Ruskamp FM et al. The enigma of quality of life in patients with heart failure. Int J Cardiol, 2008; 125: 407–409.

19. Rogers A, Addington-Hall J, McCoy ASM et al. A qualitative study of chronic heart failure patients' understanding of their symptoms and drug therapy. Eur Heart Fail, 2002; 4: 283–287.

20. Pattenden JF, Roberts H, Lewin RJP. Living with heart failure; patient and carer perspectives. Eur J Cardiovasc Nurs, 2007; 6: 273–279.

21. Jaarsma T, Halfens R, Tan F et al. Self-care and quality of life in patients with advanced heart failure: The effect of a supportive educational intervention. Heart Lung, 2000; 29: 319–330.

22. Dunbar SB, Jacobson LH, Deaton C. Heart failure: Strategies to enhance patient self-management. AACN Clin Issues, 1998; 9: 244–256.

23. Martensson J, Stromberg A, Dahlstrom U et al. Patients with heart failure in primary health care: effects of a nurse-led intervention on health-related quality of life and depression. Eur J Heart Fail, 2005; 7: 393–403.

24. Cruz FD, Issa VS, Ayub-Ferreira SM et al. Effect of a sequential education and monitoring programme on quality of life components in heart failure. Eur J Heart Fail, 2010; 12: 1009–1015.

25. Chinaglia A, Gaschino C, Asteggiano R et al. Fattibilità ed efficacia di un programma di assistenza integrate tra ospedale e territorio basata su un ambulatorio infermieristico nella gestione dei pazienti con scompenso cardiaco. Risultati clinici a sei mesi e costi relativi. Ital Heart J Suppl, 2002; 3: 532–538.

26. Green CP, Porter CB, Bresnahan DR et al Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: A new health status measure for heart failure. J Am Coll Cardiol, 2000; 35: 1245–1255.

27. Ware JE, Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36): Conceptual framework and item selection. Medical Care, 1992; 30: 473–483.

28. Miani D, Rozbowsky P, Gregori D et al. The Kansas City Cardiomyopathy Questionnaire: Italian translation and validation. Ital Heart J, 2003; 4: 620–626.

29. Rector T, Kubo S, Cohn J. Patient's self-assessment of their congestive heart failure. Part 2: Content, reliability and validity of a new measure, the Minnesota Living with Heart Failure Questionnaire. Heart Fail, 1987; 3: 198–209.

30. Apolone G, Mosconi P, Ware EJ. Questionario sullo stato di salute SF-36. Manuale d'uso e guida. Guerini e associati Editrice, Milano 1997.

31. Ballatori E. I fondamenti della medicina scientifica. Margiacchi-Galeno Editrice, Perugia 2006.

32. Shively M, Kodiath M, Smith TL et al. Effect of behavioural management on quality of life in mild heart failure: A randomized controlled trial. Patient Ed Couns, 2005; 58: 27–34.

33. Hunt SA et al. ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult. A report of the American College Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Update the 2001 Guidelines for the Evaluation and Management of Heart Failure; www.acc.org) 2005.

34. Heo S, Moser DK, Riegel B, Hall AL, Christman N. Testing the psychometric properties of the Minnesota Living with Heart Failure Questionnaire. Nurs Res, 2005; 54: 265–272.

35. Weinberger M, Oddone EZ, Henderson WG. Does increased access to primary care reduce hospital readmission? N Engl J Med, 1996; 334: 1441–1447.

36. Kutzleb J, Reiner D. The impact of nurse-directed patient education on quality of life and functional capacity in people with heart failure. J Am Acad Nurs Pract, 2006; 18: 116–123.

37. Kelly DT. Our future society: A global challenge. Circulation, 1997; 95: 2459–2464.

STRUCTURED INTERVIEW

Please read and answer the following questions, which refer to the aspects of healthcare and everyday life about which you think you need further information. There are no 'right' or 'wrong' answers. Just cross the answer that best describes your situation.

HEALTHCARE NEEDS

1. How do you judge the nursing care you have received?
   Put an **X** in one box in each line

Place	Inadequate	Sufficient	Fair	Good	Very good	Excellent
Hospital	☐	☐	☐	☐	☐	☐
Home	☐	☐	☐	☐	☐	☐

2. Would you rather be treated:
a) at home
   By relatives ☐   **By specialist nurses** ☐   **By both** ☐

b) in hospital
   Day hospital ☐   **Normal admission** ☐   **Long-stay admission** ☐

c) in a protected facility
   AHR (Assisted Healthcare Residence) ☐

3. What is the order of importance of your healthcare needs?
   Number the boxes from 1 (the most important need) to 5 or 6 (the least important). Leave the box blank if you do not feel the need for that particular assistance.

Priority physical needs

Support for everyday activities	Physiotherapy	Assistance in moving around	Skin care (lower limbs)	Diuresis and catheter care
☐	☐	☐	☐	☐

Priority relational needs

Support for relatives	Support for marital relations	Support for social relations	Support in terms of information	Psychological support	Support for drug self-administration
☐	☐	☐	☐	☐	☐

Priority management needs

Managing the disease as a whole	Managing treatment	Managing diet	Managing the assistance of relatives	Managing relations with healthcare professionals	Managing disease-related bureaucratic requirements
☐	☐	☐	☐	☐	☐

INFORMATION NEEDS

SUBJECTS

4. What type of information have you received?
    Number the boxes from 1 (the most important need) to 5 or 6 (the least important). Leave the box blank if you do not feel the need for that particular information.

Anatomy and physiology of the heart	Physiopa-thology of heart failure	Routine diagnostic examinations	Conventional therapy	Non-pharma-cological therapy	Changes in lifestyle
☐	☐	☐	☐	☐	☐

5. What type of information would you like to receive?
    Number the boxes from 1 (the most important need) to 5 or 6 (the least important). Leave the box blank if you do not feel the need for that particular information.

Anatomy and physiology of the heart	Physiopa-thology of heart failure	Routine diagnostic examinations	Conventional therapy	Non-pharma-cological therapy	Changes in lifestyle
☐	☐	☐	☐	☐	☐

HEALTHCARE PROFESSIONALS

6. Who have you asked for information?
    Number the boxes from 1 (the most important need) to 5 or 6 (the least important). Leave the box blank if you have not asked that particular person.

GP	Cardiologist	Internist	IDC (Integrated Domiciliary Care)	Clinic nurse	Specialised nurse
☐	☐	☐	☐	☐	☐

7. Who would you like to receive information from?
    Number the boxes from 1 (the most important need) to 5 or 6 (the least important). Leave the box blank if you do not feel the need for information from that particular person.

GP	Cardiologist	Internist	IDC (Integrated Domiciliary Care)	Clinic nurse	Specialised nurse
☐	☐	☐	☐	☐	☐

8. How much more information do you need about the following aspects of everyday life?

	None	Not very much more	A little more	Quite a lot more	A lot more	Very much more
Diet	☐	☐	☐	☐	☐	☐
Physical exercise	☐	☐	☐	☐	☐	☐
Sexual relations	☐	☐	☐	☐	☐	☐
Free time	☐	☐	☐	☐	☐	☐
Therapies	☐	☐	☐	☐	☐	☐
Sleep	☐	☐	☐	☐	☐	☐