

Article

Does symptom recognition improve self-care in patients with heart failure? A growth latent model

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Abstract: Patients with heart failure have difficulty in self-care management, as daily monitoring and recognizing symptoms do not readily triggers an action to avoid hospital admissions. The purpose of this study was to understand the impact of a nurse-led complex intervention on symptom recognition and fluid restriction. A latent growth model was designed to estimate self-care management and quality of life changes on patients with heart failure and assessed by a pilot study, for three months, to sixty-three patients (33 control, 30 intervention). Patients in the control group had a higher risk of hospitalisation (IRR 11.36; $p < .001$) and emergency admission (IRR 4.24; $p < .001$) at three-months follow-up. Analysis of the time scores demonstrated that the intervention group had a clear improvement in self-care behaviours (β Slope. Assignment_group = -.881; $p < .001$) and in the quality of life (β Slope. Assignment_group = 1.739; $p < .001$). This study supports that a nurse-led program on symptom recognition and fluid restriction can have a positive impact on self-care behaviours and quality of life in patients with heart failure.

Keywords: Heart failure; self-care behaviours; symptom recognition; nurse-led program.

1. Introduction

Symptom perception is a concept associated with self-care management, namely within the middle-range theory of self-care of chronic illness defined by Riegel, Jaarsma, and Strömberg [1]. In this paradigm, symptom perception includes both symptom monitoring and recognition, and is a challenging task to be taken by patients with heart failure (HF). Experiencing a symptom consists of awareness by a person of the body changes and how they can affect him/her [2]. This means that a person has to timely detect the symptom, evaluate its meaning, and finally, take action in response to symptom perception [3–5]. To be aware of body changes related to heart failure escalation symptoms, requires patients to have enough information about it. Previous studies suggest that this is frequently not the case [6,7]. Also, patients who experience an acute onset of symptoms, typically seek help earlier than those who experience a gradual worsening of symptoms, which will only seek help when symptoms are severe [8].

Symptom recognition therefore, seems to be a barrier to healthy self-care because patients fail to understand the signs and symptoms of heart failure after hospital discharge for heart failure exacerbation [6]. The most frequent symptoms reported by

patients are dyspnoea, weight gain, wake disturbance and oedema [6,9]. However, the association between two or more symptoms and daily symptoms fluctuation may lead patients to identify symptoms as usual, which may result on a stay at home, waiting for symptoms to disappear [6,10].

Heart failure disease management programs (HF-DMPs) allow a structured follow-up approach where patients receive education on major topics of HF, and where medical treatment and psychological support are optimised to the patients' disease condition [11–13]. As such, patients with HF are managed as a whole in concordance with European Society Cardiology (ESC) [14]. Besides HF-DMPs, nurse-led education programs also have demonstrated good results on patients with HF disease management, where education on disease knowledge and self-care behaviours are handled [15,16]. These programs enable patients to make conscious options and decisions about their health status.

Here, a pilot study centred on the development of a complex intervention on fluid management and its inclusion on a nurse-led program was designed to improve self-care behaviours and decrease hospitalisations on patients with HF.

The aims of this study were: (a) understand the longitudinal impact of a nurse-led program based on a complex intervention on fluid management, on HF patients' self-care management; and (b) analyse the quality of life (QoL) changes during nurse-led program.

2. Materials and Methods

In this pilot study, 63 patients in New York Heart Association (NYHA) functional class II-III were recruited in a hospital setting, after discharge from a heart failure intensive care unit. Inclusion criteria were adults aged >18 years old, with diagnosed HF and with no cognitive disability associated. Exclusion criteria included patients placed on the heart transplant waiting list.

Patients were allocated into a control group (CG, n=33) and an intervention group (IG, n=30) through the computerised random allocation generator available at <http://random.org>. Usual care was defined as the standard care provided for patients with HF. Patients were recruited during hospital admission on a Heart Failure Intensive Care Unit in a central hospital from a southern European country. The pilot study was performed during three months per patient, with four moments of assessment (baseline, first-week follow-up, first-month follow-up, third-month follow-up), starting on September of 2014 and ending in December of 2017, as depicted in figure 1.

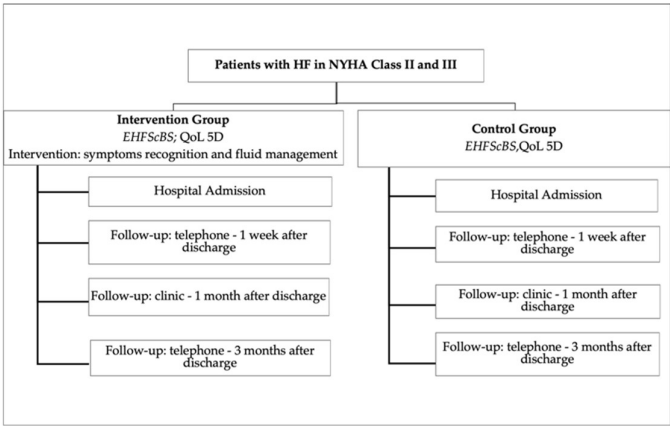


Figure 1 – Pilot study follow-ups

To understand the intervention’s impact on self-care behaviours and quality of life, classical statistical tests (independent samples t-test, Pearson’s correlation, Chi-squared test, Fisher’s exact test, U Mann Whitney) for each moment of assessment were carried out use IBM SPSS software v.24.0 (Armonk, NY: IBM Corp). Prerequisites for testing were carried out before the selection of the appropriate statistical test. As for the assessment of the impact of the intervention on all moments on self-care behaviours (Figure 2) and quality of life (Figure 3), two theoretical Conditional Latent Growth Curve Models [17] were tested through the use of the software IBM SPSS Amos for Structural Equation Modeling (Armonk, NY: IBM Corp). A p-value of .05 was considered for testing. Effect-size and confidence intervals were also calculated.

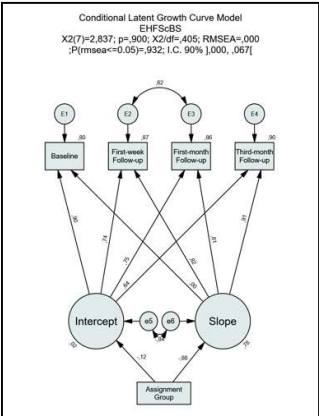


Figure 2 – Conditional Latent Growth Curve Model – EHfScBS

The study was approved by the Ethics Committee of Centro Hospitalar e Universitário de Coimbra (CHUC-032-14, approved on may 2014), with individual informed consent being obtained before the inclusion in the study, following the principles outlined in the Declaration of Helsinki [18], and the Declaration of Taipei [19]. Researchers had access to anonymised material, and this guaranteed the confidentiality of institutions. All rights regarding data protection were respected.

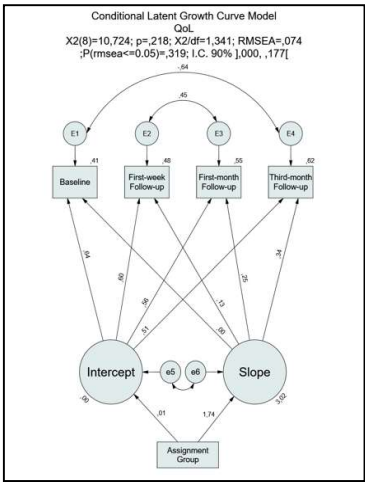


Figure 3 – Conditional Latent Growth Curve Model – QoL

2.1. Complex Intervention

The intervention developed for this pilot study, emerged from the aggregation of data from qualitative research [20] and data from a systematic literature review, according to complex intervention method by Medical Research Council (MRC) [21], as schemed in figure 4. The goal of the intervention is to improve HF patients’ ability to recognize symptom escalation, which, as discussed above, leads to clinical congestion. Although ESC guidelines describe educational topics [14] to be included on an HF-DMPs, the present study intended to focus on the educational topic that patients could more easily manage. This educational topic emerged from the results of a previous qualitative study, where fluid overload and symptom recognition were considered by HF patients as the most difficult to detect and manage [20].

This intervention was provided by a nurse with expertise in HF to participants in the IG, with reinforcements, through all moments of follow-up, and included: a) an explanation on signs and symptoms of HF and how to recognise them; b) importance on daily fluid restriction, by planning a maximum of 1.5-2 litres of liquids per day (e.g., soup, milk, coffee, water, tea and yoghurts); and c) when doctors or nurses should be contacted (when symptoms escalation or a weight gain of 2 kg in three days or 5 kg in a week were detected).

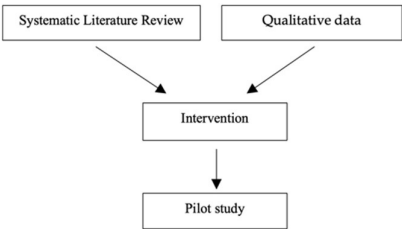


Figure 4 – Pilot study intervention development

2.2. Instruments

Self-care behaviours were measured using the *European Heart Failure Self-care Behaviour Scale (EHFScBS)* [22], and Quality of Life (QoL) was measured using the *EuroQol-5D (EQ-5D)* [23]. All participants (CG and IG) had to fill the instrument at all moments of contact: at time of study admission, one week after discharge follow-up, one month after discharge follow-up, and at three months after discharge follow-up.

3. Results

Sample characteristics showed a higher percentage of men (74.60%) living with a companion (69.84%). The mean age was 54.83 (10.28). Most had a NYHA functional class III (73.02%), with Implantable Cardioverter Defibrillator (52.38%). There were no differences in key variables between the two groups at baseline, as presented in Table 1.

Table 1 – Participants characteristics

Characteristics	Total (n=63)	CG (n=33)	IG(n=30)	Statistic	p-value	Cohen's d
Sex, men (%)	74.60	75.76	73.33	.049 ^a	.825	.056
Age, mean (SD)	54.83 (10.28)	54.42 (10.54)	55.27 (10.15)	460.0 ^b	.630	.122
Marital status, with companion (%)	69.84	69.69	70.0	.001 ^a	.979	.008
NYHA Class, III Class (%)	73.02	81.81	63.33	2.725 ^a	.099	.425
ICD, no (%)	47.62	48.48	46.67	.021 ^a	.885	.037
Initial Weight, mean (SD)	78.73 (15.04)	81.00 (15.56)	76.23 (14.28)	1.261 ^c	.212	.318
EHFScBS, mean (SD)	38.81 (10.91)	39.94 (8.27)	37.57 (13.26)	454.0 ^b	.572	.143
QoL, mean (SD)	67.86 (12.94)	68.18 (11.78)	67.50 (14.31)	.207 ^c	.837	.052

^a X²; ^b Mann Whitney's U; ^c Student's t

3.1. Symptom recognition

Patients with HF in the IG demonstrated a positive, progressive evolution on knowledge and explanation of what HF is, with an improvement on disease understanding at all moments of follow-up ($p < .05$; $\Phi > .5$). On symptom recognition, patients with HF could identify HF symptoms ($p < .05$), except the topic of sleeping seated or with pillows, with the presence of very high effect size on symptoms "Daily weight record", "Sudden weight gain", and "Fluid restriction accomplishment" ($\Phi > .5$), and high effect size on the other HF symptoms ($.25 < \Phi \leq .5$), on Table 2.

Table 2 – Symptom recognition by patients with HF

Symptoms recognition	Total (n=63)	CG (n=33)	IG (n=30)	Statistic	p-value	Effect Size
First-week follow-up						
Weight increase (>2kg/week), yes (%)	20.63	6.06	36.67	8.988 ^a	0.003	0.378 ^c
Oedema, yes (%)	39.68	48.48	30.00	2.243 ^a	0.134	-0.189 ^c
Shortness of breath, yes (%)	55.56	48.48	63.33	1.403 ^a	0.236	0.149 ^c
Fatigue to small efforts, yes (%)	49.21	45.45	53.33	0.390 ^a	0.532	0.079 ^c
Sleep seated or with pillows, yes (%)	9.52	3.03	16.67	3.391 ^b	0.094	0.232 ^c
Daily weight record, yes (%)	39.68	3.03	80.00	38.895 ^a	0.000	0.786 ^c
Recognizes rapid increase of weight, yes (%)	22.22	0.00	46.67	19.800 ^a	0.000	0.561 ^c
Fulfils fluid restriction, yes (%)	53.97	15.15	96.67	42.032 ^a	0.000	0.817 ^c
Calls doctor or nurse when detects symptoms early, to avoid hospitalization, yes (%)	3.17	0.00	6.67	2.272 ^b	0.223	0.190 ^c
First-month follow-up						
Weight increase (>2kg/week), yes (%)	19.05	6.06	33.33	7.580 ^a	0.006	0.347 ^c
Oedema, yes (%)	39.68	45.45	33.33	0.965 ^a	0.326	-0.124 ^c
Shortness of breath, yes (%)	65.08	54.54	76.67	3.384 ^a	0.066	0.232 ^c
Fatigue to small efforts, yes (%)	53.97	48.48	60.00	0.839 ^a	0.360	0.115 ^c
Sleeps seated or with pillows, yes (%)	4.76	0.00	10.00	3.465 ^b	0.102	0.235
Daily weight record, yes (%)	26.98	0.00	56.67	25.611 ^a	0.000	0.638
Recognizes rapid increase of weight, yes (%)	22.22	0.00	46.67	19.800 ^a	0.000	0.561
Fulfils fluid restriction, yes (%)	42.86	6.06	83.33	38.314 ^a	0.000	0.780
Calls doctor or nurse when detects symptoms early, to avoid hospitalization, yes (%)	11.11	3.03	20.00	4.582 ^b	0.047	0.270
Third-month follow-up						
Weight increase (>2kg/week), yes (%)	14.26	0.00	30.00	11.550 ^b	0.001	0.428 ^c
Oedema, yes (%)	68.25	51.51	86.67	8.961 ^a	0.003	0.377 ^c
Shortness of breath, yes (%)	66.67	48.48	86.67	10.309 ^a	0.001	0.405 ^c
Fatigue to small efforts, yes (%)	69.84	54.55	86.67	7.698 ^a	0.006	0.350 ^c
Sleeps seated or with pillows, yes (%)	6.35	3.03	10.00	1.284 ^b	0.340	0.143 ^c
Daily weight record, yes (%)	34.92	0.00	73.33	37.185 ^a	<.001	0.768 ^c
Recognizes rapid increase of weight, yes (%)	28.57	0.00	60.00	27.720 ^a	<.001	0.663 ^c

Fulfil fluid restriction, yes (%)	46.03	6.06	90.00	44.569 ^a	<.001	0.841 ^c
Calls doctor or nurse when detects symptoms early, to avoid hospitalization, yes (%)	26.98	15.15	40.00	4.925 ^a	0.026	0.280 ^c

3.2. Emergency and Hospital admissions

Patients with HF on CG went to the emergency department more often than those on IG, at one month (p=0.014; 95% CI 1.10-60.62) and three months follow-up (p<0.05; 95% CI 2.94-43.96), with an 8.18 higher risk at the end of the first month of discharge, and 11.36 higher risk at the three months follow-up. Regarding hospital admission, at one-month follow-up, patients on CG had a 3.64 higher risk of hospital admission, but no significant association between these variables was found (p=0.357; 95% CI 0.43-30.45). However, at three months follow-up, patients in CG had a 4.24 higher risk of being admitted into hospital (p<0.05; 95% CI 2.04-8.80), as presented in Table 3.

Table 3 – ER and Hospital admission during study time

ER and Hospital admissions	Total (n=63)	CG (n=33)	IG (n=30)	Statistic	p-value	RR (95% CI)*
<i>First-month follow-up</i>						
Resort to emergency room since last consult, yes (%)	15.87	27.27	3.33	6.744 ^b	0.014	8.18 (1.10, 60.82)
Hospitalization, yes (%)	7.94	12.12	3.33	1.661 ^b	0.357	3.64 (0.43, 30.45)
<i>Three-months follow-up</i>						
Resort to emergency room since last consult, yes (%)	42.86	75.76	6.67	30.630 ^b	<.001	11.36 (2.94, 43.96)
Hospitalization, yes (%)	53.97	84.85	20.00	26.601 ^a	<.001	4.24 (2.04, 8.80)

* For control Group
a Pearson's X² sig; b Fisher's Exact Test sig

3.3. Self-care behaviours

As the initial theoretical model did not present a good fit, analysis of the modification indices (MI>4, p<.05), and respective correlation of measurement errors demonstrated the need to remove the linear growth coefficients between the "first-week follow-up" and the "first-month follow-up". The global significance of the conditioning variables was assessed through the chi-square differences between the model with fixed effect of 0 and the model with random effects for the variable "Assignment Group" ($\Delta X^2(2)=115.57$; p<.001), with this variable being significant on the adjusted conditioned growth curve model.

Analysis of the final theoretical model (Figure 3) evidenced the presence of an excellent model fit to the variance structure, covariance and means of the sample under study ($X^2(7)=2.8$; p=.900; $X^2/df=.405$; RMSEA<.001 and P[rmsea≤.05]=.932; RMSEA IC

90% [.000;.067]). There was no evidence of the effect of the "Assignment Group" on the intercept ($\beta_{\text{Intercept.Assignment_group}} = -.125$; $p = .375$). Regarding the slope, there was a significant negative effect of the intervention ($\beta_{\text{Slope.Assignment_group}} = -.881$; $p < .001$) on the self-care behaviours' scores, indicating that the intervention positively influenced a progressive improvement on these behaviours. There was significant growth on self-care behaviours on the first-week follow-up ($M(\%) = .785$; $SE = .053$; $Z = 14.8$; $p < .001$), representing 78.5% of the total growth. Despite the significant growth on self-care behaviours on the first-month follow-up ($M(\%) = .762$; $SE = .053$; $Z = 14.4$; $p < .001$) when compared to the basal scores, with 76.2% of the total growth represented at this moment, the model suggested a slight stabilisation from the first-week follow-up to the first-month follow-up. The estimation of both parameters presented significant variances ($V(\text{Intercept}) = 94.08$; $SE = 21.24$; $p < .001$ and $V(\text{Slope}) = 43.04$; $SE = 16.71$; $p = .010$), indicating inter-variability on the basal scores of self-care behaviours, and on the growth rates. The mean basal score of self-care behaviours was 40.00 ($SE = 1.90$; $p < .001$), while the mean growth rate was 5.11 ($SE = 1.62$; $p = .002$).

3.4. Quality of Life

The initial theoretical model required the analysis of the modification indices ($MI > 4$, $p < .05$), as there was a violation of the fit indices. Through analysis of the correlation of measurement errors, we proceeded with the removal of the linear growth coefficients between the "baseline" and the "third-month follow-up", and between the "first-week follow-up" and the "first-month follow-up". The variable "Assignment Group" was significant on the adjusted conditioned growth curve model ($\Delta X^2(2) = 35.05$; $p < .001$).

Except for the RMSEA 90% CI upper limit ($> .10$), all the fit indices evidenced the presence of an almost perfect model fit to the variance structure, covariance and means of the sample under study ($X^2(8) = 10.7$; $p = .218$; $X^2/df = 1.341$; $RMSEA = .074$ and $P[rmsea \leq .05] = .319$; $RMSEA\ IC\ 90\% [.000;.177]$) of the final theoretical model (Figure 4). There was no evidence of the effect of the "Assignment Group" on the intercept ($\beta_{\text{Intercept.Assignment_group}} = -.008$; $p = .966$). Regarding the slope, there was a significant positive effect of the intervention ($\beta_{\text{Slope.Assignment_group}} = 1.739$; $p < .001$) on the quality of life scores, suggesting that the intervention positively influenced a progressive improvement on this variable. Overall growth was stable throughout the various moments of assessment ($p > .05$). The model also suggested inter-variability on the basal scores of QoL ($V(\text{Intercept}) = 65.93$; $SE = 27.40$; $p = .013$), but not on the growth rates ($V(\text{Slope}) = -6.04$; $SE = 6.11$; $p = .261$). The mean basal score of QoL was 68.76 ($SE = 2.10$; $p < .001$), while the mean growth rate was -2.49 ($SE = .79$; $p = .002$).

3.5. Self-care behaviours and Quality of Life

After hospital discharge, there was a significant positive improvement between self-care behaviours and QoL ($p < 0$; $p < 0.05$), as lower scores of *EHFScBS* (better self-care behaviours) relate to higher scores of EQ-5D (higher quality of life). Also, it

was noticeable a stronger relation between these groups at three months follow-up (Table 4).

Table 4 – Patients with HF QoL

		<i>EHFScBS</i>	<i>EHFScBS</i>	<i>EHFScBS</i>	<i>EHFScBS</i>
		baseline	1 week	1 month	3 months
QoL baseline	Pearson Correlation	0.214	0.166	0.096	0.183
	Sig. (2-tailed)	0.093	0.194	0.456	0.152
	n	63	63	63	63
QoL 1 week	Sig. (2-tailed)	0.022	-0.285	-0.253	-0.273
	n	0.862	0.024	0.045	0.030
	Sig. (2-tailed)	63	63	63	63
QoL 1 month	Sig. (2-tailed)	0.116	-0.275	-0.321	-0.321
	n	0.366	0.029	0.010	0.010
	Sig. (2-tailed)	63	63	63	63
QoL 3 months	Sig. (2-tailed)	0.024	-0.445	-0.480	-0.587
	n	0.852	<.001	<.001	<.001
	Sig. (2-tailed)	63	63	63	63

4. Discussion

On this pilot study a complex intervention on symptom recognition by patients with HF was tested. A latent growth model showed that patients in intervention group have improved self-care behaviours, as they could better interpret and recognize early signs and symptoms of HF decompensation, with better outcomes regarding the number of visits to the emergency room and hospital readmissions. Patients in intervention group also had better scores in quality of life at three-months study time.

HF patients from both groups had a variation of weight decrease between hospital admission and discharge, which reports clinical congestion. Throughout the study, when asked about symptoms of HF, ‘weight increase’ was mostly interpreted by patients in the IG, but symptoms interpretation had a slight decrease, at three months follow-up. This may suggest that weight gains linked to oedema are not interpreted as severe, possibly because congestion has a slow onset and does not immediately trigger patients symptom perception of disease decompensation [4,20,24]. Usually, patients that experience more severe symptoms are more engaged in self-care [25]. This gap between symptom recognition and taking action to promote health leads to a delay in care-seeking [8,10,26].

4.1. Hospital and ER admission

Patients in both groups were admitted into the ER. However, patients in the IG reported fewer ER visits, compared to patients at the CG, at one month and three months follow-up. Those who were admitted at the hospital had a considerable difference at three months follow-up between groups. Likewise, the literature indicates longer interventions

decrease mortality rate for each month of intervention, reduce the risk of hospitalisation and decrease hospital admission at the end of six months [27]. Also, when patients with HF are included in disease management programs, hospital readmissions are lower because of patients' knowledge improvement and, therefore, better self-care behaviours [15,28,29]. Our results support these findings, as patients are more engaged in self-care behaviours, as well as more committed to improve their health status, while avoiding hospitalisations and ER visits [28].

4.2. Self-care behaviours improvement

Patients in the IG had a more significant improvement on self-care, measured by *EHFScBS*. At baseline, both patients at the CG and the IG had similar scores of self-care behaviours. However, during the three months study period, combined with reinforcements at all moments in the IG, there was a progressive and robust improvement in the ability to explain what HF is. The intervention also allowed for improvement in the identification of most symptoms of HF, especially 'Weight diary', 'Sudden weight gain' and 'Fulfil with water restriction'. These results indicate that participants in the IG could understand HF symptoms, were competent in naming them, therefore improving their individual awareness of symptom recognition. Symptom interpretation and recognition are hard to detect. Patients who are not aware of them are more prone to demonstrate poor self-care [6]. In contrast, those who experience more severe symptoms are more engaged in self-care [25,30].

When symptom interpretation and recognition are integrated on a nurse-led program, with education reinforcements at all follow-up moments, patients with HF significantly improve their self-care [15]. These results support previous studies where educational programmes provided by nurses for patients with HF have increased their knowledge about the disease and self-care behaviors after a week, a month, and even after three months [15,31]. In our study this improvement was clear between baseline and the first-week follow-up, and between first-month and the third-month follow-ups, with stabilisation on self-care behaviours improvement between first-week and first-month follow-ups. One possible interpretation of these findings, is that until the first week of the study, patients were more engaged in the learning process and therefore were careful in monitoring daily symptoms (which stabilised). This is also in line with the results from the first-month follow-up, where educational reinforcements were crucial to aware patients on the need to keep symptom monitoring and therefore, engage in self-care behaviours.

4.3. Quality of life

The interventional program designed for this study supports a positive influence on QoL for patients with HF. Other studies have reported that nursing educational programs evaluating levels of fatigue, self-care education and training for 12 weeks were associated with improvements in levels of fatigue and QoL [34]. Nevertheless, shorter studies reported QoL improvement on patients with HF admitted into a multidisciplinary transition-to care program [35].

The findings from the present study are in line with the findings from these previous studies, where disease management programs or nurse-led programs have improved HF patients' quality of life, therapeutic regimen adherence, and better self-care behaviours.

HF is a chronic condition that patients must learn how to live with. Disease management programs, which include many topics for educating people about the disease, are intended to help such patients manage their health-disease status to change self-care behaviors. Focusing on symptom-recognition education as a major topic enable patients with HF to engage in better self-care and quality of life.

4.4. Limitations

The presented study consisted of a pilot study and therefore the main limitation to the interpretation of the present results is the sample size. Even though, as discussed above, our results are in line with previous reports on the effects of nurse-led HF management programs. In future studies we will repeat the present study with larger samples, multicentred research and also include a liaison between the hospital and community care for centred-patient management.

Furthermore, it will be important to study the effects of extending follow-up to: 12, 18 and 24 months. This will allow determining if the present intervention should be maintained as is or, eventually adapted to these specific time periods.

5. Conclusions

Disease management programs include several educational topics. Managing all those topics may be complex for patients with HF as they may misunderstand all information, at once, leading to difficulty in managing self-care. This study suggests that a nurse-led program focused on symptom recognition and fluid restriction helps patients with HF to improve and engage in self-care.

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