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Telephone follow-up of self-care behaviour after a single session education of patients with heart failure in primary health care.

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Abstract

Background: Improved self-care behaviour is a goal in educational programmes for patients with heart failure, especially in regard to daily self-weighing and salt and fluid restriction.

Aims: The objectives of present study were to: (1) describe self-care with special regard to daily self-weighing and salt and fluid restriction in patients with heart failure in primary health care, during one year of monthly telephone follow-up after a single session education, (2) to describe gender differences in regard to self-care and (3) to investigate if self-care was associated with health-related quality of life.

Methods: The present analysis is a subgroup analysis of a larger randomised trial. After one intensive educational session, a primary health care nurse evaluated 60 patients (mean age 79 years, 52% males, 60% in New York Heart Association class III-IV) by monthly telephone follow-up during 12 months.

Results: The intervention had no effect on quality of life measured by EuroQol 5D and no significant associations were found between quality of life and self-care behaviour. Self-care behaviour measured by The European Self-care Behaviour Scale remained unchanged throughout the study period. No significant gender differences were shown but women had a tendency to improve adherence to daily weight control between 3- and 12 months.

Conclusion: The self-care behaviour and quality of life in patients with heart failure did not change during one year of monthly telephone follow-up after a single session education and this indicate a need for more extensive interventions to obtain improved self-care behaviour in these patients.

Keywords: Heart failure, Self-care, Adherence, Self-weighing, Salt and Fluid Restriction.

1. Introduction

Chronic heart failure (HF) often develops slowly, affects a large number of persons and is associated with high morbidity and substantially shortened survival [1]. Heart failure considerably affects physical, psychological and social functions of the individual, often making normal daily life activity difficult [2-4]. Due to the frequent hospital admission, the costs for HF treatment is substantial and it is expected to rise [5]. Most patients with HF first present in primary health care. It has been found that the true prevalence of heart failure is underestimated among general practitioners which might influence the suspicion of heart failure as a presenting syndrome [6].

In order to adapt to the new life situation, HF patients have to make considerable adjustments. These should be based on knowledge, thus allowing for competent and confident informed choices. For this, education is necessary and nurses are often involved in developing educational programmes and act as teacher or coach [7]. An important goal of the education is to improve self-care behaviour. Self-care has been defined as the decisions and strategies undertaken by the individual in order to maintain life, healthy functioning and well-being [8]. The importance of improved self-care is illustrated by the high early readmission rate among elderly patients [9], and the fact that up to 50% of the hospital readmissions for HF could have been prevented if the patients had been able to recognise deterioration and undertake the appropriate self-care behaviour actions [10]. In order to perform self-care behaviour, knowledge must be improved about optimum fluid and salt intake, exercise, adherence to pharmacological treatment, monitoring symptoms and seeking assistance when symptoms of worsening HF occur [11-13].

Improved self-care has been shown to favourably affect morbidity. The effect on quality of life has been less studied. A recent review of multidisciplinary HF management programmes showed that, although not affecting survival, programmes only focusing on enhancing patients self-care activities and not e.g. optimising treatment, reduced hospitalisations due to HF and all-cause hospitalisation [14]. Therefore, it is important for health care professionals to know if patients adhere to self-care and what they base their actions on. In clinical practise, a questionnaire can be useful to identify specific educational and counselling needs, especially for the elderly and patients with functional and cognitive limitations [15-17]. Combined with other educational interventions telemonitoring is another way of monitoring and assessing self-care abilities in HF patients after discharge from hospital [7].

Adherence is defined by the World Health Organisation as the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes - corresponds with agreed recommendations from a health care provider [18]. Some studies have investigated adherence to self-weighing in patients with HF. Research from Bushnell [19] and Sulzbach-Hoke [20] showed that between 25 and 40% of the patients measure their body weight on a daily basis. In another study that evaluated if the self-weighing was regular (at least once a week), 67% declared that they measured body weight regularly [21]. Regarding adherence to fluid and salt restriction, several studies indicate that it is difficult for the patients to follow a low-salt diet [22] and restrict the fluid intake [23-25]. Ni and colleagues reported that less than 50% of the patients avoided salty food and restricted fluid intake, although the majority of the patients were aware of the importance of these restrictions. Reasons for this can be lack of motivation and self-control or other psychological factors [26]. In order to inspire to improved self-care behaviour educational programs needs to be developed and evaluated.

The objectives of the present study were to: (1) describe self-care with special regard to daily self-weighing and salt and fluid restriction in patients with HF in primary health care, during one year of monthly telephone follow-up after a single session education, (2) to describe gender differences in regard to self-care and (3) to investigate if self-care was associated with health-related quality of life.

2. Methods

2.1 Design and setting

The present analysis is a subgroup analysis of a larger randomised trial published elsewhere and the intervention in this study is in short described below [27]. The study was conducted at 4 primary health care centres in southern Sweden between April 1999 and April 2000. Approval was received from the Research Ethics Committee at Linköping University, Linköping, Sweden. The primary health care centres were screened for eligible patients through the Diagnosis Related Groups (DRGs) registry. The inclusion criteria were typical symptoms and signs of HF corresponding to New York Heart Association (NYHA) class II-IV [28], echocardiographic evidence of cardiac dysfunction and/or radiographic evidence of pulmonary congestion, and age > 18 years. Exclusion criteria were severe dementia or other serious psychiatric disease, not Swedish speaking, follow-up at a HF clinic in the hospital and concomitant severe disease judged to substantially affect prognosis. Eligible patients were invited to participate in the study through a letter and were one week later contacted by telephone for consent. In total 153 patients were randomised into either educational intervention or usual care by a multidisciplinary team. In present study it is only the patients from the intervention group that were analysed.

2.2. The educational intervention

The nurse-led intervention programme consisted of one intensive session with education and counselling in the home of the patient at the beginning of the study. The education was based on guidelines and aimed at improving the patient's understanding of HF and self-management [29,30]. The specific purpose was to optimise intake of fluids and sodium, body-weight monitoring, detection of early signs of sodium and water retention such as breathlessness and oedema, and adjustment of diuretics according to symptoms. The European guidelines states no specific recommended amount of salt in grams, but gives a more general recommendation to restrict salt intake and the same recommendation was given to the study patients. The CD-ROM for example states that salt should not be added at the table and salty food avoided. The recommended fluid restriction in the guidelines is 1.5-2L/day and that recommendation was given to the study patients[30]. The education included written, verbal and interactive educational material and focused on the individual patient's learning needs and skills. The interactive HF education included a multimedia program on CD-ROM[31]. The CD-ROM program was designed for elderly persons with large, clear illustrations and buttons, and has been shown to result in increased and longer lasting knowledge about heart failure compared to standard information [32].

2.3. Data collection

One experienced primary health care nurse at each primary health care centre was educated in heart failure through a course comprised of three sessions, each lasting tree hours. During this education the nurses were also trained on how to perform the educational intervention and to conduct the monthly telephone interviews. The use of the instrument were scrutinized and discussed extensively. At the time of enrolment, the patient was interviewed in his/her own home to collect sociodemographic data. Clinical data were collected from the medical chart and

included medical history, confirmation of the HF diagnosis, NYHA class, blood-pressure, and prescribed medication. The European Self-care behaviour Scale (EHFScBS) [15] and EuroQol (EQ-5D) [33] were completed in the home of the patient at the time of enrolment before the educational program, and after 3 and 12 months of follow-up. In order to evaluate the performed self-management regarding weighing, salt and fluid restriction and the status of the patients, standardised telephone interviews were carried out monthly during the one-year follow-up period (Fig.1).

2.4. Measurements

2.4.1 Quality of life instruments

EQ-5D is a questionnaire that measures health-related quality of life. In the five dimensions defining health the patients rated their health on a three level scale, 1=no problem, 2=some or moderate problems and 3=unable or extreme problems. The five dimensions are morbidity, self-care, usual activities, pain/discomfort and anxiety/depression. The answers on the five dimensions/ statements generate five digit numbers that are classified to a preference utility score, from -0.59 to 1, obtained from a sample of the general population [33].

2.4.2 Self-care behaviour instruments

EHFScBS is a 12-item questionnaire with a Likert-scale ranging from 1 (I completely agree) to 5 (I completely disagree) as scoring format (range 12 to 60). The reliability and validity has been tested and the internal consistency reliability measured by Cronbach´s alfa was 0.81 [15]. In the telephone interviews a standardised format and a 25-item questionnaire was used. The questionnaire was developed to probe for self-care management. Face validity was established through a review by an expert panel of experienced primary health care nurses, physicians, heart failure nurses and cardiologists. Minor revisions of the wording in the questionnaire were made

based on the recommendations of these reviewers. In the present study, 5 items related to the specific study aim were selected from the entire 25-item questionnaire used at the telephone interviews. The selected items are shown in Table 1.

2.5. Statistical analysis

EHFScBS and EQ-5D were analysed using non-parametric tests to detect variations (the Wilcoxon matched pair test for within group comparisons) and associations (Spearman´s rank correlation test) during the one-year follow-up period. Data are expressed as median [interquartile range]. A p value <0.05 was considered statistically significant. In the EHFScBS the items of interest selected for analysis were: I weigh myself every day; I limit the amount of fluids I drink; and I eat a low salt diet. The patients were considered to be adherent at scores 1 – 2 and non-adherent at scores 3 – 5. Likewise, the items of interest were selected from the questionnaire used at the telephone interviews (Table 1). Frequencies were run in order to determine the amount of missing data. Approximately five percent of the questionnaires used at the telephone interviews were missing in full and occasional missing data were, depending on the type and quantity of data, either eliminated from the analysis or estimated. Missing data from EHFScBS are accounted for in the results.

3. Results

3.1. Study patients

As shown in Figure 1, 18 of 78 patients were not included in the final analysis of the present study: 10 patients died during the 12-month follow-up period four were excluded due to other severe diseases, two withdrew their consent to participate and two were excluded due to missing data. The characteristics and clinical profile of the remaining 60 patients (Table 2) did not differ

from those of the 18 patients not included in the present data analysis (n=60). Similar to the typical clinical setting, the average age was high and co-morbidities were considerable in the study group.

3.2. Quality of life and Self-care behaviour

Quality of life measured by EQ-5D did not differ significantly between baseline (0.72, [0.62-0.77]), 3 (0.73, [0.63-0.80]) and 12 months (0.71, [0.62-0.80]). There were no significant gender differences regarding quality of life. Self-care behaviour did not change significantly from baseline (31, [23-39]) to 12 month (29 [22,5-37]). There were no gender differences in self-care behaviour measured by the EHFScBS between baseline and 12 months. However, between 3 and 12 months, the men decreased their self-care behaviour significantly (p=0,012), whereas women did not. No significant associations were found between quality of life and self-care behaviour.

3.3. Adherence to weight control

The portion of patients who stated that they measured body weight daily was at baseline 31% (17 of the 54 patients who gave a response), at 3 months 30% (17/56) and at 12 months 40% (24/60) (Figure 2). Forty-seven percent (25/53) did not weigh themselves regularly at any of the three occasions and 19 % (10/53) were adherent to daily weighing at all three time points. The remaining 34% (18/53) adhered at one or two time points. The majority of the patients answered that they measured body weight once a week or more during the 12 month follow up and mean for the whole follow-up period was 3 times/week. There were no significant differences between men and women in this regard, but women had a tendency to improve adherence to daily weight control in contrast to men, who did not change their adherence over the 12-month period (Figure 2). On average, only 20% of the patients (12/60) made a written record of the body weigh and,

consequently, many patients could not answer the question if they noticed any changes in their body weight. Of those 55-80% of patients who replied at the various monthly interviews, 64-84% had not noticed any body weight change during follow-up. No significant associations were found between adherence to weight control and background variables such as sex, age, NYHA class and education level.

3.4. Adherence to fluid and salt restriction

In contrast to weight control, considerably more patients stated that they adhered to the fluid restriction (Figure 3). At baseline 70% (38/54) of patients followed the recommendations and this proportion remained stable throughout the study period. Only 15% (8/52) did not adhere at any of the three occasions, 35% (18/52) were adherent at one or two time points, and 50% (26/52) followed the fluid restriction at all three points. There was no difference between men and women in this regard (Figure 3). At the various monthly interviews, most patients (80-95 %) reported unchanged fluid intake during the last month. Several patients did not answer this question; the missing data ranged between 18 and 42% at the 10 follow-up interviews. Some adjustments of fluid intake were made during the first month of follow-up and 14% (7/51) patients reduced their fluid intake. After the first month very few changes were made to decrease or increase the fluid intake.

Regarding the salt restriction, at baseline 50% of the patients answered that they had adhered to the salt recommendation, and this percentage remained unchanged throughout the study period. There were no significant gender differences in this regard (Figure 4). No significant associations were found between adherence to fluid or salt restriction and sex, age, NYHA class and education level.

4. Discussion

This study aimed to investigate self-care and specific issues regarding self-care behaviour in patients with HF, namely adherence to daily self-weighing and salt and fluid restriction. Often in studies, different questionnaires are used to assess self-care behaviour and the results are often presented as a score of all the questions together. We chose to also take a closer look at those self-care abilities that nurses in heart failure management programmes emphasize and educate on.

The setting for the present study was primary health care centres and as expected the average age was high and comorbidities were substantial. This corresponds well with clinical reality in primary health care. In the present study, adherence to daily self-weighing and salt and fluid restriction was not related to age. However, this does not preclude an impact of age on the results of educational intervention. In our study the mean age of 79 years was higher than in the studies by Jaarsma et al. [34] and Wright et al. [21] with mean ages of respectively 72 and 73 years. Both those studies showed that self-care behaviour could be improved by patient education, suggesting that it might be more difficult to obtain effects on self-care behaviour on the older patients. The educational programmes in those studies were more intensive than in our study, and perhaps we could have obtained an effect on self-care behaviour if our programme had been more comprehensive. With regard to gender differences, our study indicates that women are more likely to improve their self-care behaviour compared to men. This confirms by Ni et al.[26] who found a difference in favour of women, whereas Artinian et al. [35] found no gender differences. Although the present study is small and one should be careful to draw general conclusions, our results indicate that education about self-care behaviour maybe should be different for men and women.

Regarding the patients' weighing behaviour the results are similar to other studies [19,20,26]. A mean of tree times a week of body weight measurement could be considered satisfactory. One third of the patients in our study weighed themselves every day and after 12 months daily weighing had increased to 40%. However, only one out of five patients was continuously compliant throughout the year of follow up. Van der Wal et al. found that one third of the Dutch heart failure patients in their study weighed themselves three times a week or more [36]. Strömberg et al. found a similar result that 1/3 of Swedish patients hospitalised due to heart failure had weighed themselves regularly before hospitalisation. Three month after heart failure education and follow up at a nurse-led clinic, daily weighing had increased to 79% and the weighing behaviour was retained at 12 months follow up [37]. This rather good adherence to measuring body weight is naturally linked to the fact that most people had a scale at home and weighing could easily be fitted in to the morning routine. However, for the elderly HF patient with bad eyesight, vertigo or debility it can still be difficult.

It is noteworthy that only a small number of the patients in our study made a written record of the body weight, especially since the literature provides evidence of a significant association between HF and cognitive impairment, such as loss of short-term memory capacity and concentration difficulties [38]. In the light of these facts, it makes sense that the question "How has your body weight been the last month?" was often left unanswered. In the study by Sulzbach-Hoke´s [20] the results were slightly better, and 50% of the patients stated that they kept a record of weights. In that study, the patients were asked what they would do if they gained weight, and one third of the patients did not know that. We had a lot of missing data regarding change in fluid intake. This could indicate that daily control of body weight and fluid intake is difficult for HF patients without keeping record or other monitoring. This was shown in a

randomised trial were the patients in the intervention group received a HF diary including a list of medications, contact details for the clinic, schedule of appointment and a calendar-based record of daily body weight. In that study, the intervention-group demonstrated significantly better knowledge and self-care behaviour [21]. Telemonitoring, by standard telephone lines and by cable-networks or broadband technology, can be a successful way to assess self-care abilities in HF patients after discharge from hospital.

In the present study, adherence to fluid and salt restriction remained stable throughout the study period, and 50% of the patients restricted salt intake whereas 70% restricted fluid intake. This indicates that there might be a need for more than one intensive educational session and telephone follow-up to increase self-care behaviour regarding salt- and fluid intake. However, another aspect is that adherence, especially for restricted fluid intake was quite high already at baseline. In another study of hospitalised patients with heart failure, 33% restricted their fluid intake before education on self-care and three month after the education fluid restriction was raised to 67% and after 12 month it had decreased to 50% [37]. Van der Wal et al. found similar adherence to fluid restriction (73%) and a higher degree of adherence to salt restriction (78%) [36].

Patients need knowledge in order to improve their self-care behaviour. Van der Wal et al. found that adherence to salt and fluid restriction was associated with knowledge [36]. But knowledge alone does not always ensure improved self-care behaviour. Nurse-led HF programmes with education and follow-up have been shown to benefit the patient with improved self-care and survival, and fewer days spent in hospital [14]. These management programmes have also been proven cost saving and effective [5,39].

The study has some limitations. First the sample size of the study was small. However, the sample was a representative group of the elderly heart failure patients in primary health care. Secondly, there are limitations with self-report questionnaire. There is always a risk that the patients overestimate their self-care management. Either, because they want to act as desirable, are forgetful or perform the self-care differently from day to day.

In conclusion, the self-care behaviour in patients with heart failure did not change during one year of monthly telephone follow-up, indicating a need for more extensive interventions to obtain improved self-care behaviour in these patients. From our data we cannot deduce why there was so little change in self-care behaviour or why there is no association between self-care behaviour and quality of life. A possible explanation is that some patients already at baseline were quite knowledgeable in this respect, leaving little room for improvement among these. Moreover, the patients' cognitive function, personality and environment have to be taken in to account, as well as the fact that the education was not repeated. This indicates that more intensive education and telephone follow-up may be required to improve self-care behaviour in patients with HF, especially in the elderly, and this is a field for further development in the future.

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Table 1
Questionnaire used for the monthly telephone interviews.

Body weight
How many times per week do you measure your weight?……..

Do you keep a record of your body weight?
Yes ☐ No ☐

How has your body weight been the last month?
☐ Unchanged
☐ Lost weight
☐ Gained weight
☐ Unsure

Fluid intake
Do you restrict your fluid intake
Yes ☐ No ☐

How was your fluid intake during the last month?
☐ Unchanged
☐ Increased
☐ Decreased
☐ Unsure

Table 2. Demographic and clinical characteristics of the study group(n= 60).

Age	
Mean±SD	79±7
Gender	
Men	31 (52%)
Women	29 (48%)
NYHA	
II	24 (40%)
III	27 (45%)
IV	9 (15%)
Co-morbidity	
Ischaemic heart disease	39 (65%)
Cardiac infarction	21 (35%)
Hypertension	23 (38%)
Diabetes mellitus	15 (25%)

NYHA = New York Heart Association classification

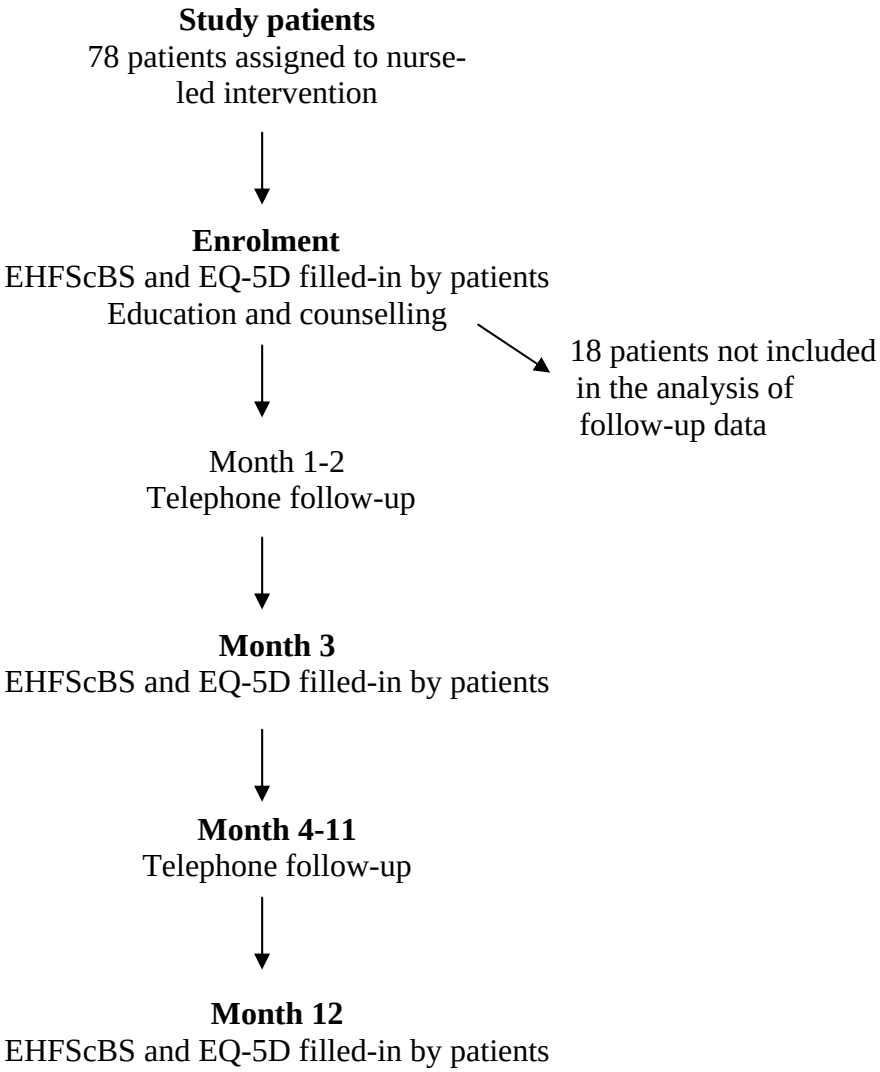

Figure 1. Flow chart describing the follow-up in the study.

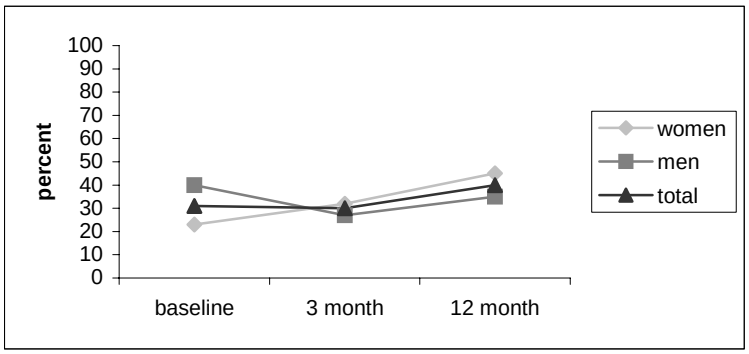

Figure 2. Adherence to daily weight control (n=54).

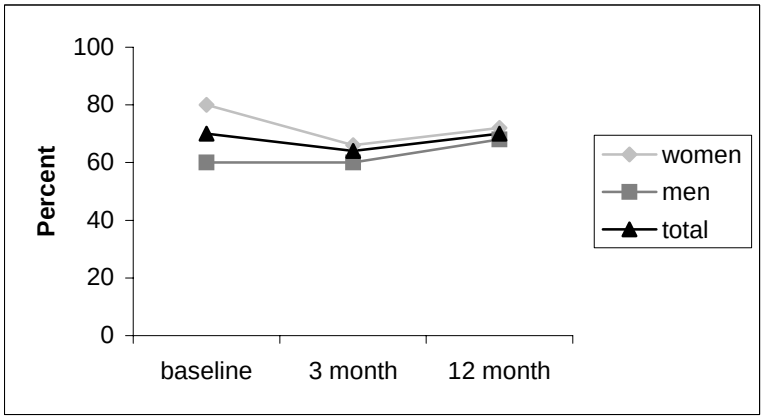

Figure 3. Adherence to fluid restriction (n=54).

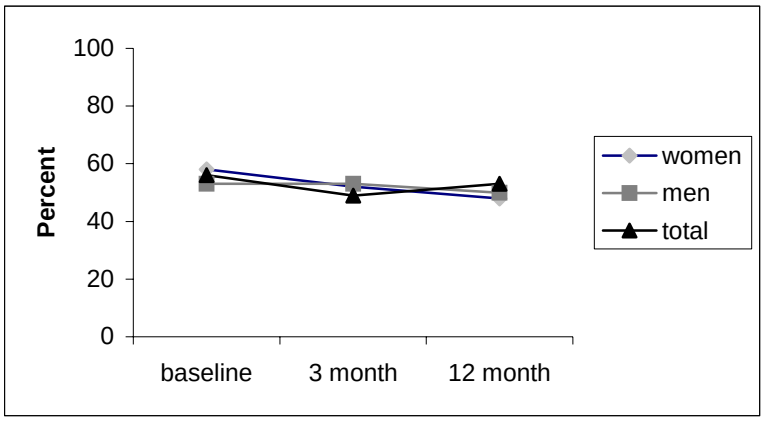

Figure 4. Adherence to salt restriction (n=56)