

Weight Monitoring Diaries to Improve Heart Failure Symptom Recognition

by

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THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco



Acknowledgements

The author wishes to thank her thesis committee, Kathleen A. Dracup, RN, FNP, DNSc, FAAN, Mary A. Caldwell, RN, MBA, PhD, Jill N. Howie, RN, MS, ACNP, and Nancy Stotts, RN, EdD, FAAN, for their continued guidance, encouragement and contribution to this manuscript, and Steven M. Paul, PhD for his statistical expertise.

The author also extends her love and gratitude to the two greatest heroes in her life, her mother and father.

Abstract

Background: Heart failure (HF) is a costly and highly disabling syndrome affecting nearly 5 million individuals yearly. Lifestyle changes are crucial to the successful management of HF and daily weight monitoring is an essential component of self care. Daily weights provide an objective indicator of fluid volume status in patients with heart failure. However, the practice of performing daily weights is underappreciated and infrequently implemented by patients. This may contribute to an inability to recognize worsening HF and ultimately delay in seeking medical care.

Objective: To evaluate weight monitoring diaries for adherence to daily weight monitoring, reasons for nonadherence, prevalence of weight gain of 3 or more pounds in one day, and medical advice-seeking behavior following weight gain in a sample of patients with documented heart failure.

Methods: A cohort study design was used to analyze data from twenty HF patients who participated in a tailored, one-on-one educational intervention. The analysis is part of a parent pilot study designed to improve symptom recognition and response to symptoms of fluid overload. Diary data were collected for 3 months following the intervention. The diaries provided information regarding symptoms participants experienced, daily weights, and a record of unplanned hospital or physician visits.

Results: Of 20 subjects in the study, 16 participants returned diaries for analysis. The mean adherence score for these 16 subjects was 79.4%. Seventy-five percent had weight gains of 3 or more pounds in one day and only one person contacted their physician for weight gain. Vacation time was the most common reason for weighing nonadherence.

Conclusion: This study revealed high adherence to daily weights. However, behavior related to daily weights did not lead to more appropriate use of physician or provider consultation. Diaries offer promise for symptom management and an opportunity for patients to engage in their own self-care; however clinicians need to encourage patients to use the diary data to seek prompt medical care.

Key Words: heart failure, self-care, patient diary, symptom management

Introduction

Chronic illnesses remain among the most devastating and costly in the United States (US) today. According to the Centers for Diseases Control and Prevention (CDC), chronic diseases result in 70% of all deaths in the US and 75% of health care costs each year.¹ Heart failure (HF) is one such syndrome that affects nearly 5 million people in the US with 550,000 new diagnoses each year.² The total estimated cost of HF in 2005 is \$27.9 billion dollars; in fact, more Medicare dollars are consumed on the diagnosis and treatment of HF than any other diagnosis.^{3,4} Heart failure presents individuals with the potential for disability and a significantly impaired quality of life, as well as an often indeterminate prognosis. Management, therefore, requires a constant and timely discourse between patient and healthcare provider. While this concept is well understood among those caring for patients with HF, there is evidence suggesting that patients themselves remain unclear about their role in disease management.^{5,6,7}

Heart failure evolves from the inability of the heart muscle to contract with enough force to generate adequate blood flow to the lungs and periphery. A vicious cycle ensues consisting of impaired emptying and relaxation, elevated filling pressures, ventricular hypertrophy, and ultimately failure of an overworked, stiffened heart muscle. These pathological changes manifest themselves in several classic ways. Symptoms include dyspnea, reflected by increased pulmonary congestion, hepatomegaly resulting from increased venous congestion, peripheral edema, and jugular venous distention. Each is an indicator of clinical deterioration that if not promptly recognized and managed may result in outright failure and possible death.

Successful management of HF requires balanced communication and action on the part of both patient and provider. However, patient lack of adherence to prescribed self-care strategies is well documented in the literature.^{5,7,8} Additionally, the hesitation patients exhibit to seeking medical care results in delay that is potentially harmful to patients and costly to society. Effective HF self-management has proven elusive for many patients who are perhaps either unknowing of their role or unwilling to partake in necessary self-care strategies. In response, HF programs have assumed the immense responsibility of counseling, managing, and educating HF patients, in an effort to teach patients effective self-management skills and prevent delays in care.

The most successful HF educational programs have been delivered in major academic centers where specialists are abundant and sophisticated resources are readily available.⁹ In addition, these programs are often multifaceted in nature; addressing several aspects of HF self-care. However, it is difficult to translate these programs to most physician offices where the majority of HF patients receive care^{10,11} because such settings often have fewer resources and must rely on less resource-intensive educational options. Therefore, we conducted a pilot study that tested a newly developed education and counseling program focusing on one aspect of HF self-care, the symptom of fluid volume overload, delivered in a rural community setting.¹² The study utilized weight and symptom monitoring diaries aimed at increasing patient confidence and ability with symptom identification. The value of weight diaries as a practical part of HF education has not been reported previously and is what made this study unique. This paper will focus on patient diaries as a resourceful option in increasing symptom recognition and prompting patients towards action-based behavior.

Aims

The *specific aims* of this diary analysis were to: 1) determine patient adherence to daily weight monitoring, 2) identify reasons for nonadherence to daily weight monitoring, 3) determine prevalence of weight gain ≥ 3 pounds in one day, and 4) establish the frequency with which participants sought medical advice for weight gain ≥ 3 pounds. The purpose of the analysis was to evaluate daily weight monitoring diaries, obtained from a larger parent pilot study, to determine the effectiveness of diaries on adherence to daily weighing behavior.

Review of the Literature

Adherence to Self-Care Behaviors

Heart failure is a complicated syndrome often requiring lifestyle modifications essential in the optimal management of the disease. Such modifications involve juggling complex medication regimens, ensuring adequate exercise and dietary discretion, and keeping a vigilant eye on daily weights. Adherence to these recommendations requires constant energy and attention, which alone presents a formidable challenge. While HF treatment incorporates the use of effective medications to maintain quality of life, equally important is expert self-management on the part of patients themselves.

Self-care has been defined as an active cognitive process undertaken by an individual to maintain health or manage illness and disease.¹³ Embracing this concept has proven difficult for patients with heart failure. A recent survey assessing knowledge of common HF symptoms revealed that of those patients who experienced rapid weight gain (n=139), 60% failed to recognize this sign as an indicator of worsening illness. In addition, more than half did not identify ankle swelling or fatigue as symptoms of HF.¹³

There is an apparent disconnect between symptom occurrence and one's ability to recognize decompensating HF. A qualitative study utilized transcribed interviews to assess the daily challenges of HF patients.⁸ Themes related to barriers to self-care were uncovered from the interviews and categorized as physical limitations; difficulty coping with the prescribed treatment plan; lack of knowledge about HF and its symptoms, and distressed emotions including being depressed, frustrated, and worried. Patients also described having to manage multiple comorbidities.

The importance of daily weight monitoring is a poorly accepted concept among HF patients. Ni and colleagues⁵ conducted a survey of HF patients (N=113) receiving care at a specialized HF clinic. Daily weighing and knowledge of the importance of daily weights was assessed. Results revealed that 22% of patients reported that weighing themselves daily was not important, and of those who *did* understand that daily weights were important (n=69), only 58% (n=40) actually weighed themselves daily.⁵ Research to date has demonstrated that patients have a poor understanding of the significance of weight monitoring and the relationship to volume status.^{5,13,14}

Heart Failure Delay

The inability of patients and their families to identify HF symptomatology results in delay to care. The concept of delay and the behavioral elements contributing to delay were addressed in a retrospective chart audit of 753 patients with heart failure. This study was novel from the standpoint that it was the first to examine duration of delay in the HF population. Fewer than 5% of participants sought care in the first 24 hours when symptoms worsened. The median time from onset of symptoms to hospital arrival in this group was 3 days and 30% waited up to 5 days to seek medical attention.¹⁰ Additionally,

dyspnea and edema were the most frequent presenting symptoms followed by fatigue and angina. Not surprisingly, the delay times among study patients with chest pain were shorter. One might speculate whether the symptom of chest pain presented a more acute, life-threatening warning, thus causing patients to respond to this symptom much sooner.

In another study designed to assess time of symptom onset and awareness of HF symptoms, most patients reported experiencing symptoms days to weeks before hospitalization.⁶ While 92% presented to the emergency department (ED) with worsened symptoms, only 17% had attempted to call their doctor for such symptoms. It appears that patients wait until their symptoms are so severe that it becomes necessary to seek help in the emergency department. This illustrates the fact that patients view HF as an acute illness, rather than one that is both chronic and progressive in nature.

An alternate explanation to account for delay in this population is the fact that signs of HF are often obscure. In other words, symptoms may be easily attributed to aging, or confused with symptoms of other comorbid conditions, whereas easily recognizable symptoms such as chest pain are associated readily with AMI. It is understandable that experiencing vague, ill-defined symptoms may cause patients to delay seeking care and perhaps become nonchalant towards their own self-care. In a qualitative study utilizing semi-structured interviews Horowitz and colleagues⁷ investigated self-management routines among HF patients (N=19). Few patients connected their symptoms with worsening HF, or related such symptoms to coexisting illness. Interestingly, the same study revealed that few participants felt that *they* could control their symptoms; instead they felt this was the responsibility of their doctor. Also, when study patients experienced symptoms, they often felt that they were not serious

enough to warrant a call to their doctor and would rather just 'wait it out' to see if the symptoms improved.

Friedman¹⁵ used an exploratory, correlational design to examine the length of time older adults (N=181) endured HF symptoms before seeking medical advice. Participants experienced dyspnea for a median of 3 days, while weight gain, edema, and cough were tolerated for a median of 7 days before hospitalization. Friedman¹⁵ suggests that delays may be attributable to the following reasons: patients may try to ignore the symptoms thinking they are not worthy of seeking assistance; or patients may try to seek help but are unsuccessful.

Educational Programs

To promote patient self-care knowledge, HF educational interventions attempt to help individuals with HF responsibly and confidently identify and manage their symptoms. A secondary but equally important goal in creating such programs is to decrease the number of unnecessary hospitalizations and healthcare costs. Educational strategies vary from hospital to home-based nurse-led programs, multi-disciplinary, group or individualized sessions.^{16,17} As reviewed by McAlister and colleagues,⁹ these management programs have met with success, however they often attempt to tackle several aspects of HF care, including clinical signs and symptoms, medications, dietary counseling, and fluid weight management. It is unclear what aspect of this specialized care is most valuable in containing costs and sustaining a quality of life that is both productive and fulfilling. The present pilot study¹² focused on the recognition of fluid volume overload in an educational intervention utilizing weight diaries to reinforce the education, improve symptom identification, and encourage active self-care.

Few investigators have utilized the patient diary in the HF population as a means to reinforce teaching or actively involve the patient in their own illness self-management. The concept of self-care was revisited by Wright and colleagues¹⁴ with the creative introduction of a HF diary for use by participants of the Auckland Heart Failure Management Study (AHFMS). The diaries were used to assess the incorporation of self-care strategies and weighing behavior among patients. A convenience sample (N = 179) with preexisting or new onset HF was randomized to receive either usual care or a nurse-led HF outpatient management program. Participants also received a diary that contained a calendar to record daily weights and a schedule of appointments. At follow-up, 76% of patients in the management group used the diaries. Those who used diaries were more likely to attend educational sessions and clinic visits, and were also more likely to weigh themselves at least once a week (67%). Furthermore, when compared at 12 months, the intervention group was more likely to understand the importance of weight management and more likely to take action if their weight changed.

Each of the studies reviewed utilized nurses specially trained in HF management to implement the educational component(s) of the intervention. However, it remains unclear what element of the intervention actually contributed to the outcomes. The pilot study described here represents a unique effort to isolate a component of standardized HF programs, in this case fluid management.¹² Furthermore, patient diaries were hypothesized to reinforce HF self-care and proactive healthcare-seeking behavior.

Theoretical Framework

Self-regulation has been described as conscious efforts used to direct and monitor thoughts, affect, and behavior; in this case within the context of illness.¹⁸ Many self-

regulatory theories operate on the premise that emotional processes influence cognition and behavior. Researchers have found theories of self-regulation useful in describing and understanding health-related behaviors. The Leventhal self-regulatory model of illness behavior provides the framework to help understand how patients with HF perceive their illness and subsequently how this perception influences their behavior.⁷ The theory is based on the understanding that individuals are active problem-solvers who, when faced with a health threat, develop cognitive representations of the threat, ultimately dictating their response to the threat.¹⁹

It is also necessary to recognize that individuals with chronic illness do not act in isolation; rather external or environmental stimuli such as family and the health care system influence the reaction to a health threat. In addition, the theory is helpful in elucidating the goal of the present intervention which is to promote successful self-regulation among study participants, enabling participants to identify symptoms of fluid volume excess and seek care without delay. According to self-regulatory theory, successful interventions are those that assist individuals in regulating their emotions and developing adaptive problem-focused strategies.¹⁸ Patients are given the knowledge to more readily identify their symptoms by connecting them to a specific decompensating disease process.

Methods

Study Design

The parent pilot study utilized a randomized two group experimental design to test a specialized nurse-administered educational intervention aimed at increasing symptom recognition of fluid overload in a population of HF patients.¹² Thirty-six

patients were randomized to an intervention group (n=20) and a care as usual group (n=16). The current study reports on the analysis of diaries limited to intervention group only data. The intervention was adapted from the National Heart, Lung, and Blood Institute (NHLBI) Working Group on Educational Strategies to Prevent Prehospital Delay in Patients at High Risk for Acute Myocardial Infarction,²⁰ and has been modified for the HF population. Education consisted of a one-to-one patient encounter highlighting content on HF and symptoms of fluid overload. Emphasis was placed on the prompt response to such symptoms including weight gain and lower extremity edema. The emotional responses that patients may experience to worsening HF symptoms were also explored in the educational session in an effort to address potential and perceived barriers to care. Participants were encouraged to bring their spouse or significant other to the intervention sessions to incorporate the social component of heart failure. At the conclusion of the session, patients in the intervention group were given a diary in which they were encouraged to record daily weights and symptoms, as well as document unplanned physician office or ER visits.

Study Sample and Setting

The study sample was recruited from a cardiology practice located in Santa Rosa, CA that serves a largely rural, agricultural community. The practice does not have an associated specialty HF clinic or program. Inclusion criteria were patients with a diagnosis of stable, symptomatic (New York Heart Association Class II, III, or IV) HF documented in the medical record and confirmed by the patient's physician. Patients with Class I failure were included if they had worsened symptoms that required an unplanned physician office or ER visit in the previous year. Patients also had to be living

independently. Patients were excluded if they had any of the following: a complicating serious comorbidity such as a psychiatric illness, an untreated malignancy or neurological disorder which impairs cognition; inability to understand spoken English and respond to English language questions; inability to complete the daily diary; or a major and uncorrected hearing or vision loss.

Instruments

Intervention group participants received diaries that included a calendar to record daily weights and symptoms, and space for the documentation of any unplanned physician or hospital visits (Figure 1). Diary instructions listed symptoms to record, including swollen ankles, hands, weight gain, shortness of breath, and reduced exercise capacity. Additional information provided in the diary reminded participants to weigh themselves daily and to call their physician for weight gain ≥ 3 pounds in a day or 5 pounds in a week. Sociodemographic information was obtained from a paper and pencil questionnaire and clinical history from the medical record.

Data Analysis

Diary data were analyzed three months following the intervention using SPSS statistical software version 12.0. Descriptive statistics were used to characterize the study sample, adherence to daily weight monitoring created by dividing the number of days a participant recorded their weight by the number of study days, and the reasons for weight monitoring noncompliance. Noncompliance was determined if the patient had made comments on the dairy calendar stating reasons they had not weighed themselves. Diaries were also reviewed to determine the prevalence of weight gain of 3 or more

pounds in one day and the frequency with which participants sought medical advice for weight gain.

Results

Of the 20 intervention group participants, 16 completed three month diaries. Two participants withdrew participation before the conclusion of the study and two patients who claimed to complete their diary never turned them in despite repeated reminders and phone calls. Demographic characteristics from the 16 subjects who completed diaries are outlined in Table 1. Patients in the intervention group ranged in age from 39 to 87 years with a mean age of 70 years (SD \pm 14.7) and the majority (75%) were men and Caucasian (94%). Baseline clinical characteristics included a mean ejection fraction of 48.7% (SD \pm 19.7) and mean brain natriuretic peptide (BNP) level of 197. Ischemic heart disease was the primary source of HF in approximately 44% of the sample. Hypertension and cardiomyopathy each accounted for 25% and 19% of HF causes, respectively. Thirty-one percent of the sample had diabetes, and 14% had history of stroke; however, 71% reported hyperlipidemia and 69% had hypertension. Seventy-five percent of participants were former smokers, while only 13% were currently smoking. Additionally, 40% reported having a sedentary lifestyle. Only 27% of the group reported weighing themselves daily at baseline, while 9% stated that they would contact their physician if they experienced weight gain.

Daily weight monitoring behavior following the intervention was characterized through the creation of an adherence score by dividing the number of days patients weighed themselves by the number of days in the three month period of follow-up. The mean adherence score was calculated as 79.4% (range 10.9% to 100%). Patients did not

weigh themselves primarily because of vacation, partaking in holiday meals, simply forgetting to weigh themselves, and reasons not otherwise specified. Figure 2 depicts the frequency of each reason. Seventy-five percent of the sample had weight gains of 3 or more pounds in a day, and of those who experienced weight gain 33% had 5 or more episodes of weight gain. Only one of the participants contacted his physician when weight gain occurred.

Discussion

The purpose of this diary analysis was to determine adherence to daily weight monitoring and advice-seeking behavior for notable weight gain in a population of HF patients utilizing daily diaries. The study demonstrated that patients participating in an education and counseling intervention had high adherence scores (almost 80%) to daily weight monitoring. These results are encouraging given other studies that have demonstrated low adherence to daily weights. Ni and colleagues⁵ showed that of those patients that believed daily weights were important, only 58% weighed themselves daily. Wright and colleagues¹⁴ also reported adherence to daily weight diary use in a group of patients who received an educational intervention. Of those 76 patients who utilized the diary, 51 (67%) weighed themselves regularly, defined as at least once a week. The present study revealed that vacation time was the most common reason that daily weighing was neglected. This finding suggests the need to stress the importance of daily weight monitoring even while on vacation and, to problem-solve ways that weights and/or symptom monitoring be done while away from home.

Seventy-five percent of the experimental group had weight gains of 3 or more pounds in one day. One third of that group had 5 or more episodes of weight gain;

however, only one patient contacted his doctor for weight gain. This result comes despite thorough education and diary prompts for patients to telephone their doctor for weight gain. This disappointing finding indicates that barriers remain to seeking care that were not explained fully by this study, but need to be explored in future research. The diaries in the current study did not provide the ability to analyze why participants did not seek medical advice more frequently when they documented a significant weight gain. Our findings are similar, however, to Schiff and colleagues,⁶ who reported that in a sample of 85 patients surveyed only 17% had attempted to call their doctor for worsening symptoms.

Daily pain management diaries have been successfully used by cancer patients to document degree and frequency of pain, as well as to assess effectiveness of treatments.²¹ In addition, the patient diary has long been a cornerstone of diabetes management in which blood glucose levels, dietary intake, activity level, and insulin use are continually monitored.²² The diary provides patients with an understanding of their disease and serves as a communication tool between patient and provider. The ongoing dialogue between the patient and nurse or physician centers on the elements recorded in the patient diary. Together patient and provider can attain strict glycemic control and ultimately improved quality of life. Diabetes experts are now analyzing the efficacy of electronic patient diaries.²² Improved adherence and ease of availability among healthcare providers are a few potential benefits to such technology.

A few limitations to this study should be noted. The small sample size and homogenous gender and race composition limits the external validity of the results. Attrition is a limiting factor as four participants did not complete the study or return their

diaries. A self-report instrument such as a patient diary is an effective data gathering tool, however, recall bias must be considered a risk. Diaries rely on sound recall and documentation of data. There is the potential for invalid diary recordings due to response bias. While the parent study ¹² was a randomized two group experimental design, the findings presented here represent analysis of the intervention group only and do not provide a test of the intervention.

Conclusion

Given the growing incidence of chronic HF, the education of HF patients with respect to self-care strategies has also become essential in the long-term management of this chronic disease. The significance of daily weight monitoring cannot be overemphasized as it has the potential to create effective patient self-management, yet is an uncommon practice and reporting of weight gain is even more infrequent among HF patients. This study in a small sample of HF patients demonstrated that high adherence to daily weight monitoring (80%) could be achieved with focused education and the utilization of diaries. This suggests that diaries represent an effective and resourceful self-monitoring tool, particularly in an environment where resources and educational tools are limited. Future studies must be carried out with larger sample sizes to confirm this finding. Diaries also have great potential in the HF population by facilitating patient involvement in illness management. Of concern is the fact that only one participant reported significant weight gain of 3 or more pounds to his doctor. There is a future need to improve our understanding of the reasons patients do not seek medical advice for weight gain and to develop methods to stimulate prompt responses.

Healthcare providers serve a valuable role in HF management through optimizing medical management and teaching self-care behavior, however, it is also imperative that patients themselves learn to actively engage in self-care practices. Heart failure education must emphasize the chronicity of the syndrome (as opposed to acute exacerbations) while reinforcing patient self-confidence in performing daily weights. Developing strong patient-provider relationships, engaging active patient learners, and encouraging team management of chronic HF will contribute to successful outcomes in this unique population.

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Figure 1: Sample of daily diary with instructions

Important Facts to Remember About Using This Diary:

- Weigh yourself on the same scale each morning after urinating and before eating
- Record your weight every day in this diary
- Also, note if your extremities become swollen or you need extra pillows
- Call your doctor if you gain more than 3 lbs in one day or 5 lbs in 1 week
- At the time you call your doctor, you might also report if the number of pillows you sleep on increased, your waistband is tighter, or your feet look swollen.

Month: April

| Sunday | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday |
|--------|--------|---------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|
| | | 245 | 243 Tired | 244 | 248.5 | 246 |
| 248.5 | 245 | 246 | 248 | 247 | 248 | 246 |
| 248 | 247.5 | 248 | 247.5 | 247.5 | 247 | 246.5 |
| 246 | 246.5 | 247 | 247 | 245 | 245 | 244 |
| 242.5 | 243 | 243.5 | 245 Shortness of breath | 243 Shortness of breath | 244 Shortness of breath | 245 Shortness of breath |

Month: May

| Sunday | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday |
|--|--------|--------------------------------|--|----------|--------|----------|
| 244 Shortness of breath - bad | 244 | 244 Chest xray normal | 244.5 | 244 | 242 | 243 |
| 243.5 | 243 | 243 | 243.5 | 243 | 243.5 | 245 |
| 246.5 | 247 | 248 | 249 | 249 | 247 | 246.5 |
| 245 | 246 | 247 | 245 Dr. adds Spironolactone – heart not elastic enough | 245.5 | 246 | 245 |
| 244 | 245 | 244 | 243.5 | 243 | 244.5 | 245 |

Table 1: Demographic characteristics of the experimental group (n = 16)

| Characteristic | N | Percentage |
|----------------------------|----------|-------------------|
| Gender | | |
| Male | 12 | 75.0% |
| Female | 4 | 25.0% |
| Ethnicity | | |
| Non-Hispanic | 15 | 93.8% |
| Hispanic | 1 | 6.3% |
| Level of education | | |
| Completed high school | 5 | 33.3% |
| Completed tech school | 2 | 13.3% |
| Completed college | 3 | 20.0% |
| Completed graduate school | 5 | 33.3% |
| Marital status | | |
| Never married | 2 | 12.5% |
| Single/divorced/widowed | 4 | 25.0% |
| Married | 10 | 62.5% |
| Currently employed | 4 | 25.0% |
| Level of income | | |
| Less than \$20,000 | 3 | 20.0% |
| \$20,001-\$40,000 | 5 | 33.3% |
| \$40,001-\$75,000 | 5 | 33.3% |
| Greater than \$75,000 | 2 | 13.3% |
| Principle provider | | |
| Cardiologist | 13 | 81.3% |
| Cardiologist in HF clinic | 1 | 6.3% |
| General/Family practice MD | 2 | 12.5% |

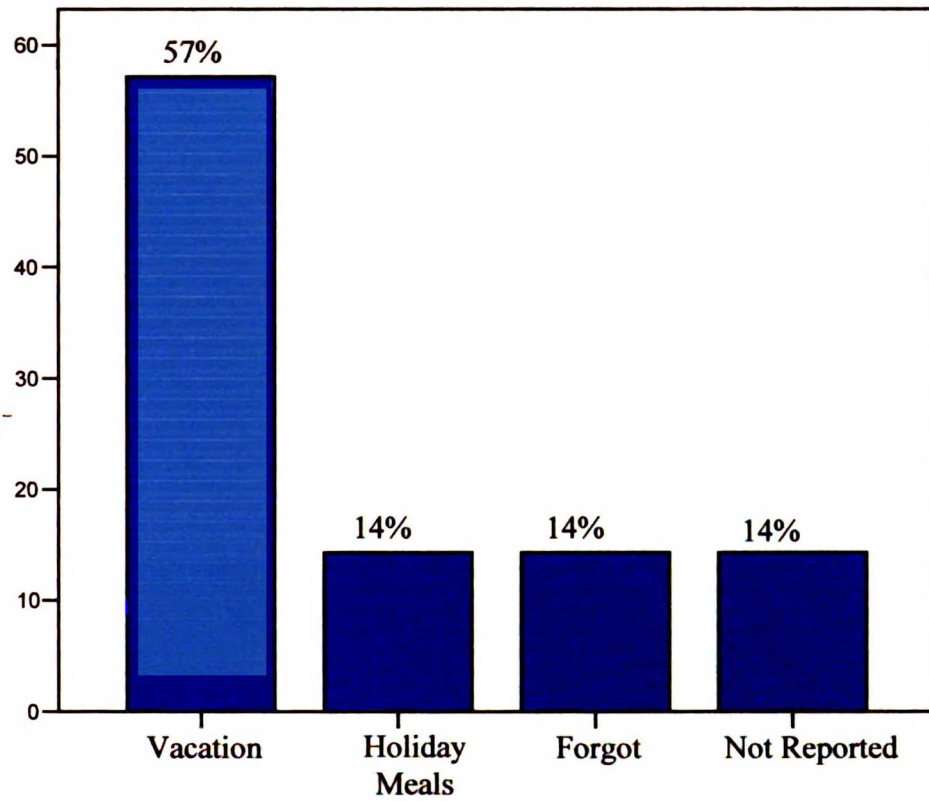
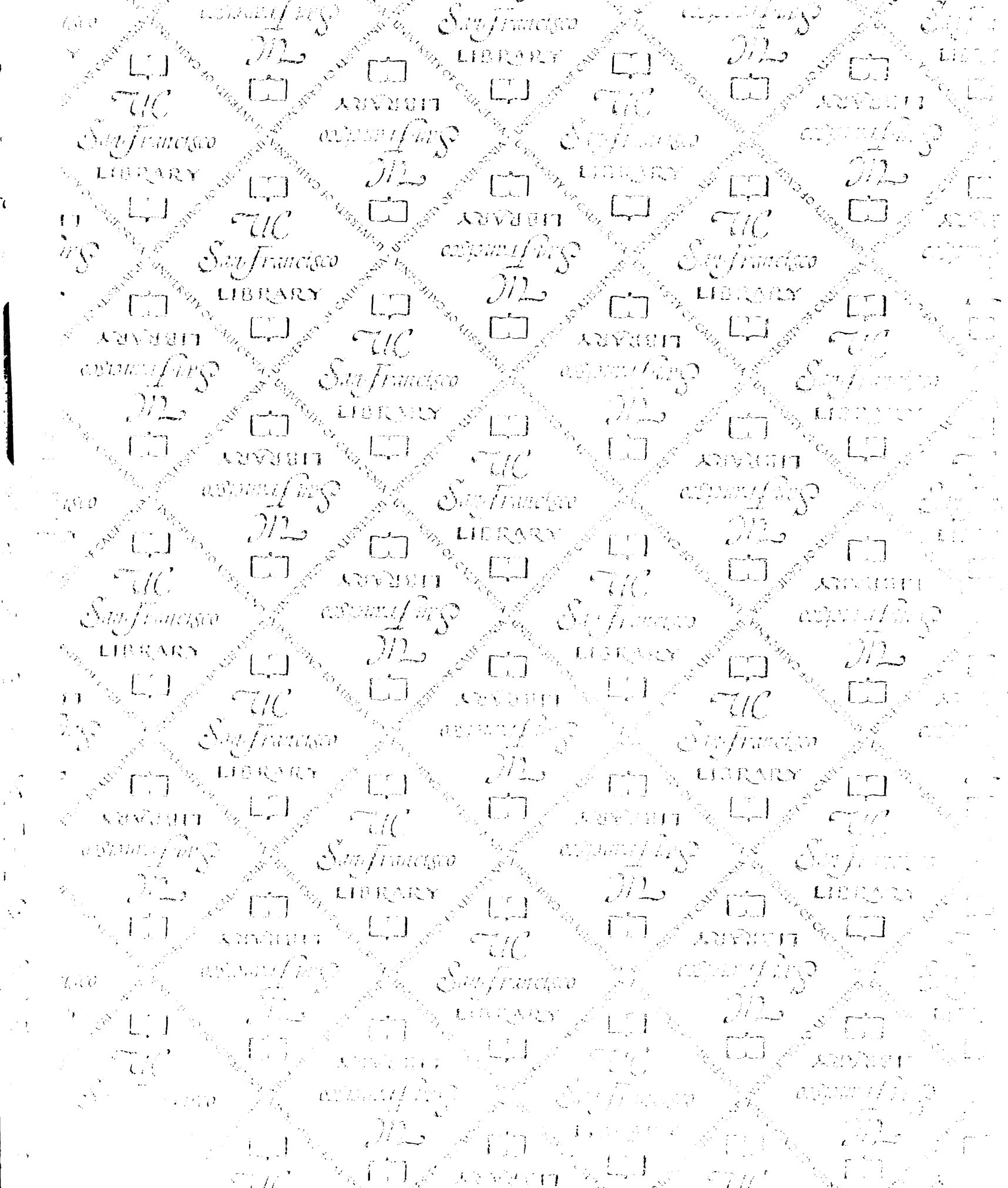


Figure 2: Reasons for daily weight nonadherence



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