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Let’s Talk Numbers – A Qualitative Study to Understand the Role of Numeracy in the Management of Heart Failure

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Title: Let's Talk Numbers – A Qualitative Study to Understand the Role of Numeracy in the Management of Heart Failure

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Abstract

Objective: To examine the perspectives of adults with heart failure (HF) about numerical concepts integral to HF self-care.

Setting: This qualitative study took place at an urban academic primary care practice.

Participants: Thirty men and women aged 47 to 89 years with a history of HF were recruited to participate. Eligibility criteria included: a history of HF (≥ 1 year), seen at the clinic within the last year, and a HF hospitalization within the last 6 months. Non-English speakers and those with severe cognitive impairment were excluded.

Methods: In-depth semi-structured interviews were conducted. Participants were interviewed about numeracy across three domains of HF self-care: 1) monitoring weight; 2) maintaining a diet low in salt; and 3) monitoring blood pressure. Interviews were audiotaped, transcribed verbatim, and analyzed using grounded theory and word cloud techniques.

Results: Five key themes reflecting participants' attitudes towards numerical concepts pertaining to weight, diet, and blood pressure were identified: (1) Communication between healthcare providers and patients is a complex, multi-stage process (2) Patients possess a wide range of knowledge and understanding (3) Social and caregiver support is critical for the application of numerical concepts (4) Prior health experiences shape outlook towards numerical concepts and instructions (5) Fear serves as a barrier and a facilitator to carrying out HF self-care tasks that involve numbers. The findings informed a theoretical framework of health numeracy in HF.

Conclusion: Many HF patients lack basic understanding and skills of numeracy required for adequate self-care. In addition, they rely on caregivers who may lack training in HF self-care. Patient-provider communication and HF-specific training of caregivers may be more important influences on successful HF self-care than individual patient numeracy.

Strengths and Limitations

- This is the first study to examine heart failure (HF) patients' perspectives towards numerical concepts of HF self-care and significantly adds to the literature.
- The findings have direct implications for clinical care.
- A purposive sampling strategy was used to recruit a diverse group of patients, which is more methodologically rigorous than convenience sampling, a method used by many qualitative studies.
- Interviews were thoroughly analyzed using a grounded theory approach.
- The study is limited in generalizability due to its qualitative nature and small sample size.

Introduction

There are 1 million heart failure (HF) hospitalizations each year and 25% of patients admitted for HF are readmitted within 30 days.[1,2] Part of this unplanned healthcare utilization is thought to be preventable by improved HF self-care.[3] Prior studies have found social and cognitive factors to be associated with HF self-care, including health literacy,[4] HF knowledge,[5,6] social support,[7,8] and cognitive impairment.[9,10] Yet, little is known about health numeracy in the context of HF.[11,12]

Health numeracy is the ability to access, understand, and apply numerical data to health-related decisions.[13] Although poor numeracy skills can coexist with low health literacy, numeracy and literacy measure different constructs and many adults tend to have worse quantitative skills.[13-16] With respect to chronic diseases, low numeracy is associated with worse glycemic control among adults with diabetes,[14,17,18] poor anti-coagulation control among patients on warfarin,[19] worse medication adherence[20] among adults with HIV/AIDS, and poor blood pressure control among adults with hypertension.[21]

Similar to these conditions, the management of HF requires numerical skill. Patients are expected to maintain a diet low in salt (often less than 2,000 mg a day), monitor their blood pressure, and weigh themselves daily. However, the role of numeracy in the management of HF has not been studied. Herein we addressed this gap by examining how numerical information is viewed and used among HF patients.

Methods

Participant Selection and Study Setting

We conducted one-on-one semi-structured interviews with 30 adults with a history of HF, from December 2016 through March 2017. Patients were recruited from a hospital-based ambulatory clinic in New York, NY. To be considered eligible, patients must have had a diagnosis of HF for at least one year, had an office visit at the clinic within the last year, and must have been admitted to the hospital with a primary diagnosis of HF within the last 6 months. Non-English speakers, those with severe visual, hearing, or cognitive impairment were excluded. The Six-Item Screener (SIS)[22] was used to assess cognition.

The electronic health record was used to identify HF patients who met our eligibility criteria. Among those who were eligible, purposive sampling[23] was used to achieve a balanced sample with respect to gender, race/ethnicity, and duration of HF (years). Eligible patients were called by telephone to gauge their interested in participating. At their next clinic visit they were approached by one author (A.F.S.), who detailed the consent process.

Of the 72 patients who were eligible to participate, 32 refused and 4 were excluded for cognitive impairment (Supplemental Figure 1). Of the 36 participants who provided written consent, 6 withdrew. Overall, our study included 30 participants.

Data Collection

One author (M.R.S.) conducted in-person semi-structured interviews with each participant which lasted 20 to 40 minutes. The interview topic guide inquired about numeracy across three domains of HF self-care: 1) monitoring weight and fluid; 2) maintaining a low salt diet; and 3) monitoring blood pressure (Appendix 1). It was piloted for ease and comprehensibility with 5 participants who were not included in the final study. Data saturation, or the point at which no new themes emerged, was achieved by the 17th interview, however additional interviews were conducted to maximize the robustness of the findings.

Participants completed a socio-demographic questionnaire following the interview. Medication use was ascertained through pill bottle review. The 10-item Center for

Epidemiologic Studies Depression Scale (C-DES-10) was used to measure of depressive symptoms.[24] To assess subjective numeracy skill, participants completed the Subjective Numeracy Scale (SNS)[25], a validated 8-item instrument which measures numeracy on a scale of 6-48 with higher scores indicating higher numeracy skills.

Participants received a $25.00 gift card for their participation. The study was approved by the Institutional Review Board of the Weill Cornell Medical College.

Data Analysis

Interviews were audio-taped and professionally transcribed. Interview data were managed with ATLAS.ti Software and analyzed using grounded theory.[26,27] Two investigators (M.R.S. and A.F.S.) independently reviewed the first five transcripts and drafted preliminary codes according to their independent review. Codes were applied to segments of text, usually defined by one or more relevant concepts. A third investigator (L.R.) reviewed the first five transcripts and both code lists before consolidating the lists into a final codebook. The investigators then reviewed the transcripts a second time, coding the data using the uniform codebook, which was subsequently applied to the remaining transcripts. The resulting unique initial codes were entered into a word cloud using ATLAS.ti. Common codes were consolidated into categories and were compared and revised by all three investigators. Finally, categories were consolidated into common unifying themes, which a fourth investigator reviewed (M.M.S.). Since little is known about numeracy in the context of HF, and since the data did not fit well with existing numeracy frameworks,[28-30] a new theoretical framework was generated from the analysis.

Quality Assurance and Patient Involvement

The study adhered to the Consolidated Criteria for Reporting Qualitative research (COREQ).[31] Additionally, to ensure that our study had the ability to investigate the HF patients' perspective on numeracy, the semi-structured interview guide and the post-interview survey were piloted for ease and comprehensibility with five HF patients who were not included in the final study. At the conclusion of the study, the findings were shared with the study participants and with HF patients at the clinic in which the study was conducted.

Results

Characteristics of Study Population

The 30 participants were mean age of 67 years (SD 10), 17 (56.7%) were female, 7 (23.3%) were White, 15 (50%) were Black, 6 (20%) were Hispanic, and 2 (6.7%) were Asian/Pacific Islander (Table 1). Twenty-one (70%) had at least a high school education and 12 (40%) had Medicare or Medicaid. On average, participants had HF for 11 years (SD 7.8) and 22 (73.3%) were considered to have New York Heart Association (NYHA) classes two and three. The mean SNS was 27 (SD 10.3).

Major Themes

Interviews resulted in 501 initial codes which were then grouped into 13 categories, from which five key themes emerged, discussed next.

Theme 1: Communication between health care providers and patients is a complex, multi-stage process

Six distinct categories comprised this theme: (1) receiving information, (2) receiving explanations, (3) barriers to receiving information and explanations, (4) the role of non-physicians, (5) reliance on in-person communication with physicians, and (6) asking questions.

Receiving Information

The receipt of numerical information pertaining to HF self-care was highly variable. While some participants received information and instructions about weighing themselves, following a low salt diet, or monitoring their blood pressure, others did not receive information on any of these topics. This variation in communication is represented by the following two quotations:

"Every doctor at the office and in the hospital told me I need to follow a low salt diet."

"This is the first time I've ever heard that I'm supposed to weigh myself at home. Should I be doing that?"

Receiving Explanations

Among those who received information about HF self-care, few participants received explanations or real-life examples of how to apply these concepts, along with the information. This is illustrated in the following quotations:

"Yeah, I take the 40-dose of the water pill every day. But, no one explained to me why I take it, or why 40."

"2,000 mg – what does that even mean? What does that number represent? Nobody has explained that to me."

Barriers to Receiving Information and Explanations

Sensory impairments were cited as barriers to communicating with providers. Among them were memory, hearing loss, and visual impairment. Additionally, many participants conveyed that they go to the doctor's office without their reading glasses.

"I'm not sure if anyone gave me instructions about a 2,000-mg salt diet. I forget things. Maybe they did and I don't remember?"

"I'm embarrassed when I can't hear the doctor. My hearing aids broke a while back."

The Role of Non-physicians

More than half of the participants spoke of non-physicians (nurse practitioners, dieticians, and pharmacists) as critical to communication:

"I take my blood pressure at the drugstore. I tell the pharmacist what it is and he tells me what to do."

Reliance on in-person Communication with Physicians

Participants frequently described weighing themselves and checking their blood pressure at the doctor's office, and less often in their homes:

"I only get weighed at the doctor's office – and I go there every 4 to 5 months."

Among those who did carry out these tasks at home, many preferred to report abnormal values at their next office visit, rather than call their physician.

"When my blood pressure is very high, I write it down and tell my doctor at my next appointment."

Some went directly to the ER when they saw abnormal values at home, rather than first calling their physician:

"When my blood pressure is out of control, I go straight to the hospital. Nothin' my doctor can do when I'm home."

Asking Questions

The patient-provider relationship affected their willingness to ask physicians questions about numerical concepts. Here, one participant expresses comfort and trust:

"I always ask my doctor questions. Especially if I see a funny number on my pressure cuff. He's a wonderful man -- easy to talk to."

On the contrary, distrust, lack of provider continuity, and fear of being judged by the provider were barriers to asking questions:

"Every office visit I get a new doctor. They hardly know me. Why would I ask questions?"

"He told me about weighing myself…. It confused me, but I didn't wanna seem dumb, so I never asked him to explain it again."

Theme 2: Patients possess a wide range of knowledge and understanding

Three distinct categories comprised this theme: (1) understanding numeric concepts and instructions, (2) applying numeric concepts correctly, and (3) resources.

Understanding Numeric Concepts and Instructions

While some participants understood the reasoning behind monitoring weight and salt intake, others struggled to grasp concepts, particularly blood pressure.

"I understand why my doctor told me to weigh myself. He doesn't want me to gain weight because it's a sign of water build up."

"I still don't understand blood pressure. The doctors have tried to explain it, but it's a concept I just can't handle."

Applying Numeric Concepts Correctly

Despite expressing an understanding of numerical concepts, many participants struggled to apply them correctly. When given scenarios about abnormal values, many participants failed to act.

"Last month my weight went up on the scale and my legs got really swollen. But I didn't do nothing. I waited until the shortness of breath came."

While some were aware of their shortcomings, others were not. Instead, they were confident in their incorrect knowledge and actions. Below are two quotations which represent the "strong and wrong" patient:

"I hardly ever eat salt. Take yesterday -- I had two pancakes for breakfast, a can of sardines for lunch, and then soup for dinner."

"My blood pressure is usually 170/100. That's bad because the 100 is high --the bottom number is the important one."

Overall, participants' statements suggest that there is a mismatch between self-perceived and actual ability and that they struggle to apply concepts correctly in their day-to-day lives.

<u>Resources</u>

Finances were commonly cited as barriers to blood pressure and weight monitoring and health eating. In addition, chronic pain was a barrier to grocery shopping and standing on a scale.

"I'm on meals on wheels. I eat what they give me."

Theme 3: Social and caregiver support is critical for the application of numerical concepts

The role of social and caregiver support was prominent throughout the interviews. The majority of participants reported that someone in their life helped them manage their HF. Family caregivers (spouses, grown children, and relatives) and paid caregivers (home health aides, home attendants, and care managers), provided participants with emotional and functional support. In addition to helping with weight monitoring, diet, and blood pressure control, caregivers assisted with grocery shopping, meal preparation, and transportation.

Participants frequently asked caregivers to interpret and explain numerical concepts at home, as illustrated here:

"When we leave the office, I ask my daughter what the doctor meant with those blood pressure numbers."

"I get so many questions in my head when I get on the bus, so I call my care manager. She's good at explaining."

This heavy reliance on caregivers had both positive and negative effects on patients' ability to apply numerical concepts and information correctly, as demonstrated by the following two quotations:

"My wife looks at every single label and adds up what I can eat in terms of salt. She comes to every visit and hounds the doctor with so many questions."

"I don't know if I have a low-salt diet. Whatever my health aide cooks me, is what I eat."

Finally, while being described as critical to their ability to engage in self-care, caregivers were not always in the room with them and the doctor. Yet, despite not being present, participants recounted that caregivers are often responsible for calling the physician for further clarification of numerical instructions.

Theme 4: Prior health experiences shape outlook towards numerical concepts and instructions

Two categories comprised this theme: (1) attitudes towards HF and (2) experience with chronic disease and the healthcare system.

Attitudes Towards HF

For the majority of participants, attitudes and pre-existing beliefs towards HF informed their outlook towards numerical concepts associated with HF. Their ability to process and carry out numerical instructions was affected by duration of HF and their ability to adjust to the diagnosis:

"I didn't like getting all of them directions at first. It depressed me, 'weigh yourself and drink only this amount.' But then I came to terms with it."

For some, the longer they had HF, the better they were at HF self-care, while for others, a longer duration of illness led to less engagement. Some participants spoke about relying on their symptoms to signal an acute worsening of their HF, rather than weighing themselves, which is a view is represented here:

"Look I've had this disease for years now. I don't needa' do any of this. I know when a flair up is coming."

In addition, personal and cultural beliefs shaped behavior.

"People at my Church get sick with this heart failure. They told me I better stay on top of this stuff, so I do."

Experience with Chronic Disease and the Healthcare System

Overall, participants on dialysis, those taking warfarin, and those with insulin-dependent diabetes seemed relatively comfortable with numerical concepts and instructions pertaining to HF.

"Following a low salt diet is pretty easy. I've been on Coumadin for years and I learned to limit foods because of the 'K' issue."

Theme 5: Fear serves as a barrier and a facilitator to carrying out HF self-care tasks that involve numbers.

Interviews revealed that fear played a dual role. Some participants expressed fear of abnormal results, which hindered their willingness to carry out numeric instructions:

"I don't take my blood pressure because it's better if I don't know my numbers. If I know, I'll worry sick."

For others, however, the fear of death served as a facilitator in carrying out HF self-care tasks:

"I follow all of these instructions. Always. I want to be here for my children."

In addition to death, the fear of shortness of breath, being hospitalized, readmitted, and dying served as facilitators in carrying out self-care tasks at home.

"I really try and stay away from salt. Not being able to breathe, is a nasty symptom."

Theoretical Framework

Our findings were used to develop a theoretical framework that elucidates the role of numeracy in the larger context of HF self-care from the patients' perspective (Figure 1). To develop this framework, we first created a visualization of the codes from all of the initial codes which emerged directly from the interview transcripts (Supplemental Figure 2). In this word cloud, the size of a code represents the frequency in which it appeared throughout the 30 interview transcripts; the larger the size, the more often the code appeared.[32] This approach enabled us to get a preliminary sense of what concepts were discussed most often, by the participants. Our initial framework retained the properties of the word cloud, but also incorporated the categories and themes which we identified (Supplemental Figure 3). The large directional arrow represents how participants described the process of interacting with numeric information to carry out HF self-care tasks. After feedback from study participants, we developed a more unified theoretical framework that shows how distinct factors influence the effective used of numbers in HF self-care (Figure 1). Here, the themes are in white boxes, however their size demonstrates the extent to which they emerged from the analysis. Social and caregiver support and patient-provider communication appear the largest in size, since the codes and categories that comprised them appeared most often. One overarching arrow (left to right) as well as smaller ones detail the relationship between themes and categories.

Discussion

To our knowledge, this is the first study to evaluate the role of numeracy in the context of HF from the patients' perspective. Our findings add to the literature in several key ways. First, we found that among a socio-economically and racially diverse group of HF patients, many lacked basic understanding and skills required for adequate self-care. Second, the study participants relied heavily on caregivers to help them understand and carry out self-care tasks which required numeracy skills. Third, we found that the communication of numerical concepts between health care providers and patients was complex and highly variable. Finally, as depicted in our theoretical framework, we found that while patient numeracy skills are important in HF, they may not be as critical as patient-provider communication and caregiver support were to understanding and applying numerical concepts pertaining to HF self-care.

Like other studies[33,34] that found that HF patients struggle with HF self-care, our findings suggest that patients have difficulty integrating and applying numerical concepts and instructions home. For example, while many participants reported receiving information about a low sodium diet, few were able to correctly navigate real-life scenarios that asked them to calculate the sodium content in a meal. This deficit is consistent with a study by Rothman et al (2006), which highlighted patient shortfalls with nutrition label comprehension.[35] In addition, many participants struggled with understanding the implications of abnormal blood pressure values. This mismatch was also seen with SNS scores; many of the participants who rated themselves as above average with respect to numeracy, were unable to correctly apply numerical concepts during their interview. Notably, some participants, were unaware that they possessed incorrect information. This was further compounded by ill-informed caregivers on whom they relied. While others have shown that perceived numerical abilities differ from actual abilities,[36,37] ours is the first to report on this in HF.

While we intended to examine patient numeracy in the context of HF self-care, we found that HF patients relied heavily on family and paid caregivers to receive, understand, and perform HF self-care tasks that require numeracy skills. Notably, this differs from the existing body of numeracy literature in other chronic diseases, which has focused on individual patient numeracy.[14-16,19,21] This may be because HF patients differ from adults with other chronic diseases -- they are often older adults with multiple chronic conditions, who are frequently hospitalized, and many have sensory impairments, including cognitive impairment, which may hinder their ability to self-manage, particularly with respect to numerical tasks.[38,39] Consistent with prior studies,[40,41] our findings suggest that relying on caregivers may have inconsistent effects on patients' disease management; we found that caregivers equipped with HF knowledge who communicated with providers were able to help patients, whereas those with incorrect knowledge and little contact with the physician were detrimental.

In addition, we found that the communication of numerical concepts and instructions between providers and patients is a multi-stage process, which can go awry at several points. Receiving numerical information required that providers offer it and that patients were able to hear, see, and mentally process it. This, more often than not, required explanations and real-life examples, as well as adequate time for questions. Addressing these elements will require interventions that can overcome the constraints of contemporary office visits, which are often too short to allow this kind of interaction.

Notably, many participants preferred to ask caregivers or go to the emergency room when they received abnormal numerical results at home, rather than calling their physician. There are a few possible reasons for why this is. First, barriers in the healthcare system may discourage them from calling. Second, the patient-provider relationship may be an important determinant, since we found that those who called their physician reported feeling "close" to them. Third, patient characteristics like hearing loss and language barriers may deter phone communication.

Interestingly, while participants asked caregivers for help interpreting numerical instructions, they reported that caregivers were not often included in physician office visits. Although research has shown that family caregivers of HF patients often feel ignored by the healthcare system,[42] it is currently unknown how paid caregivers feel. Nonetheless, given the degree to which patients rely on caregiver knowledge and numeracy skills, it may be prudent for providers to include them in the visit if the patient agrees.

Strengths and Limitations

Our study's strengths include that it is the first to examine numeracy from the HF patients' perspective. We used a purposive sampling strategy to recruit a diverse group of patients, which is more methodologically rigorous than convenience sampling, a method used by many qualitative studies. Despite purposive sampling, however, the study is limited in generalizability due to its qualitative nature and small sample size. Our focus was the patients' perspective, but given our findings, future studies should examine the perspectives of HF patients' caregivers on numeracy. Another limitation is that we did not formally assess participants' health literacy, since it is thought to be a similar but distinct concept from numeracy and a wealth of research has already focused on literacy in the context of HF. However, future studies may consider doing so. Finally, we excluded non-English speakers, who may experience numerical concepts differently than patients discussed here.[43]

Conclusion

Overall, our findings suggest that the communication of numerical concepts and instructions between providers and HF patients is a complex, multi-stage process which is often highly variable. In addition, receiving, understanding and applying numerical concepts integral to HF self-care is challenging for many adults with HF. We found that many rely heavily on caregivers to perform numerical tasks and interpret numerical results, yet the training of caregivers relative to these demands, is unclear. Ultimately, patient-provider communication and HF-specific training of caregivers may be more important influences on successful HF self-care than interventions aimed at individual patient numeracy.

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Author's Contributions:
Concept and Design of the Study (M.R.S., M.M.Sa., M.M.Sc., S.K.D.)
Acquisition of Data and Analysis (M.R.S., A.F.S., S.K.D., L.R., M.M.Sa.)
Drafting of the manuscript (M.R.S.)
Critical revision of the manuscript (M.R.S., A.F.S., M.M.Sc., L.R., M.M.Sa., S.K.D.)
Final approval of the manuscript (M.R.S., A.F.S., M.M.Sc., L.R., M.M.Sa., S.K.D.)

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Table 1. Characteristics of the Study Population

Patient Characteristics	All (N = 30)
Age, years (mean[SD])	67 (10)
Gender	
Female N(%)	17 (56.7%)
Race	
White N(%)	7 (23.3%)
Black N(%)	15 (50%)
Hispanic N(%)	6 (20%)
Asian/Pacific Islander N(%)	2 (6.7%)
Educational degree	
No degree N(%)	3 (10%)
Some HS N(%)	6 (20%)
GED or HS completed N(%)	6 (20%)
Some College N(%)	8 (26.7%)
4 year College Degree N(%)	3 (10%)
Graduate Degree N(%)	4 (13.3%)
Insurance type	
None N(%)	5 (20.8%)
Private N(%)	7 (29.2%)
Medicare N(%)	5 (20.8%)
Medicaid N(%)	6 (25%)
Medicare and Medicaid N(%)	1 (5.6%)
NYHA Class	
1	8 (26.7%)
2	11 (36.7%)
3	11 (36.7%)
Number of years with HF diagnosis, years (mean[SD])	10.9 (7.8)
Number of medications taking for HF	
Don't know N(%)	2 (6.7%)
1 -5 N(%)	25 (83.3%)
6-10 N(%)	3 (10%)
>10 N(%)	0 (%)
Number of medications taking overall	
Don't know N(%)	0 (%)
1-5 N(%)	3 (10%)
6-10 N(%)	19 (63.3%)
>10 N(%)	8 (26.7%)
Depressed symptoms	
C-DES-10, mean(SD)	12.3 (5.3)
Subjective numeracy	
SNS-8, mean(SD)	27 (10.3)

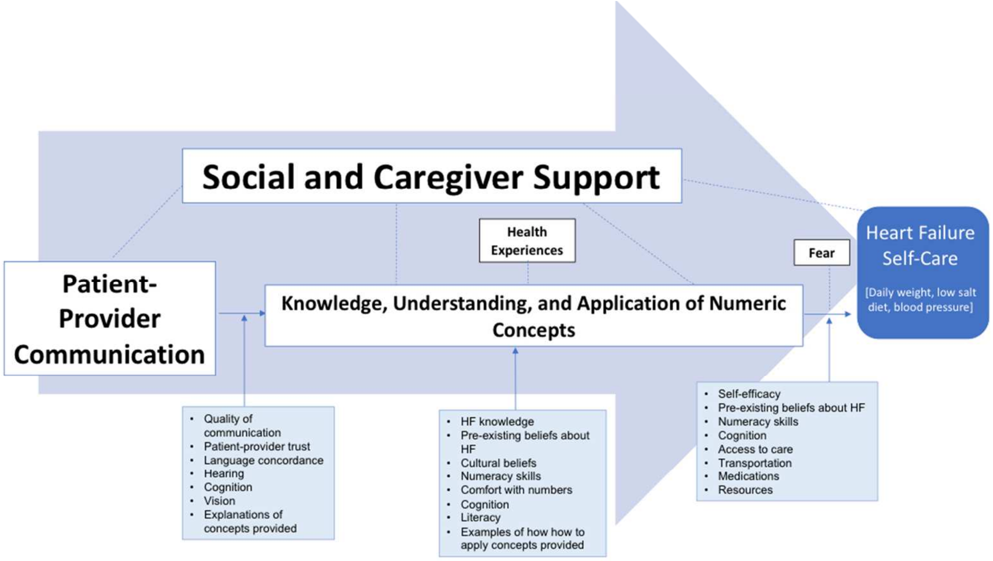


Figure 1. Theoretical Framework of Factors Influencing Effective Use of Numbers in HF self-care

Figure Legend: The final theoretical framework is a summation of the thematic content derived from grounded theory, along with features of the word cloud. As shown by their size, social and caregiver support and patient-provider communication emerged as the two most dominant themes. One overarching arrow (left to right), as well as smaller ones, detail the relationship between themes, categories, and prominent codes. Solid lines represent unidirectional relationships, whereas dashed lines represent bidirectional relationships. Input from study participants was incorporated into this final conceptual framework.

Supplemental Figure 1. Study Flow Diagram

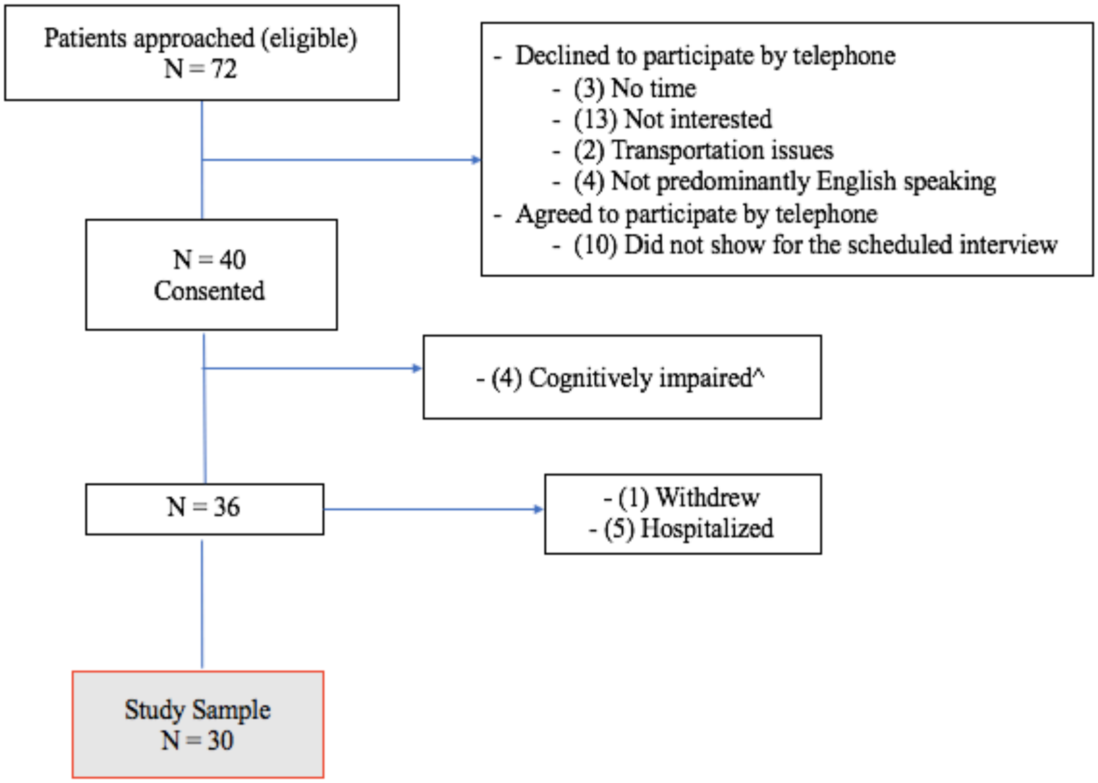
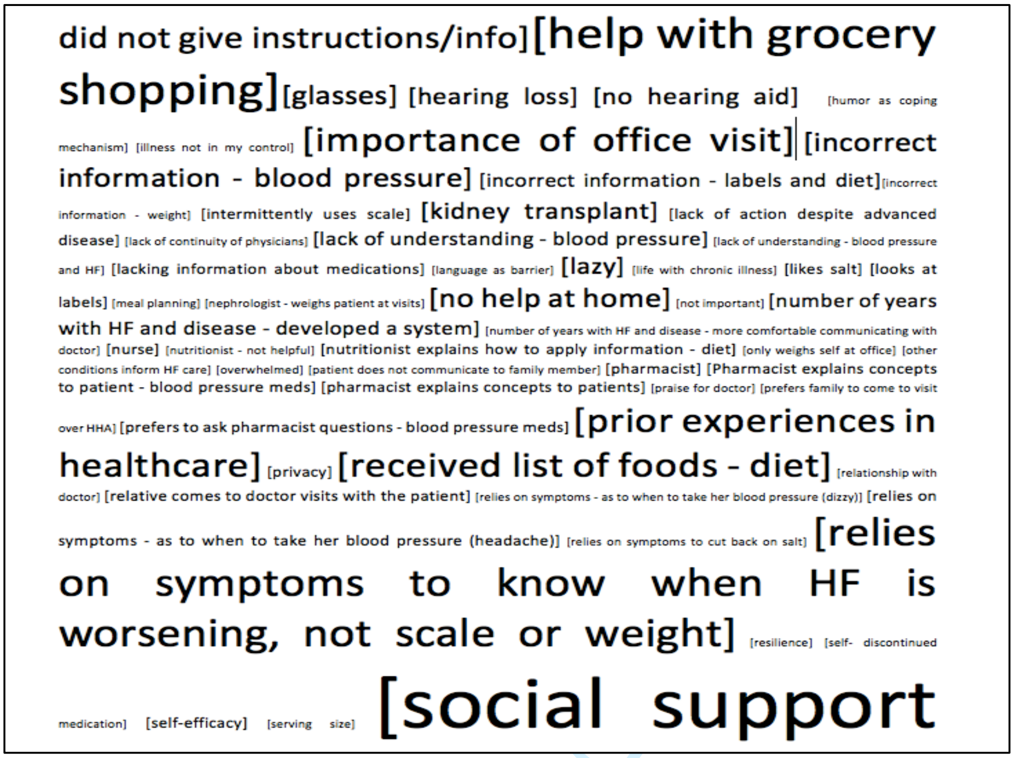


Figure Legend: Overview of study population. ^Cognitive impairment was assessed using the Six Item Screener by Callahan et al (2002), a well validated instrument which assesses global cognitive impairment. Cognitive impairment was defined as a score of 0 – 4 (correct) and intact cognitive function was defined as a score of 5 or 6 (correct).

Supplemental Figure 2. Excerpt from the Word Cloud Derived from Codes Applied to Interview Transcripts

Figure Legend: The size of the codes represents the frequency in which they appeared throughout the 30 interview transcripts; the larger the size, the more often the code was used. ATLAS.ti software was used to generate the Word Cloud.



did not give instructions/info] [help with grocery shopping] [glasses] [hearing loss] [no hearing aid] [humor as coping mechanism] [illness not in my control] [importance of office visit] [incorrect information - blood pressure] [incorrect information - labels and diet] [incorrect information - weight] [intermittently uses scale] [kidney transplant] [lack of action despite advanced disease] [lack of continuity of physicians] [lack of understanding - blood pressure] [lack of understanding - blood pressure and HF] [lacking information about medications] [language as barrier] [lazy] [life with chronic illness] [likes salt] [looks at labels] [meal planning] [nephrologist - weighs patient at visits] [no help at home] [not important] [number of years with HF and disease - developed a system] [number of years with HF and disease - more comfortable communicating with doctor] [nurse] [nutritionist - not helpful] [nutritionist explains how to apply information - diet] [only weighs self at office] [other conditions inform HF care] [overwhelmed] [patient does not communicate to family member] [pharmacist] [Pharmacist explains concepts to patient - blood pressure meds] [pharmacist explains concepts to patients] [praise for doctor] [prefers family to come to visit over HHA] [prefers to ask pharmacist questions - blood pressure meds] [prior experiences in healthcare] [privacy] [received list of foods - diet] [relationship with doctor] [relative comes to doctor visits with the patient] [relies on symptoms - as to when to take her blood pressure (dizzy)] [relies on symptoms - as to when to take her blood pressure (headache)] [relies on symptoms to cut back on salt] [relies on symptoms to know when HF is worsening, not scale or weight] [resilience] [self- discontinued medication] [self-efficacy] [serving size] [social support

Supplemental Figure 3. Initial Conceptual Framework

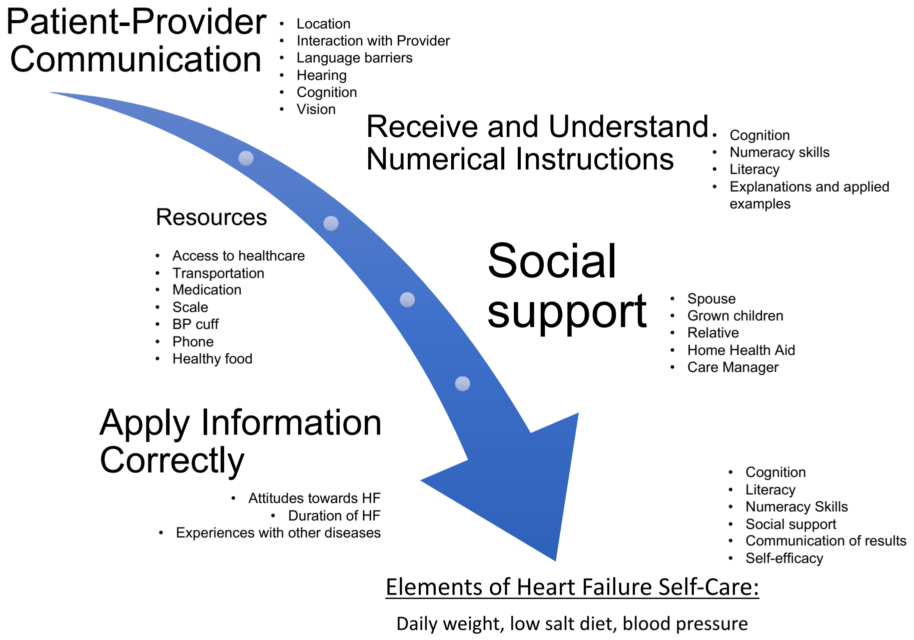


Figure Legend: This initial conceptual framework combines features of the word cloud with results from our grounded theory approach to represent the patient's perspective on numeracy across three domains of heart failure self-care: daily weight monitoring, maintaining a diet low in salt, and monitoring blood pressure.

The Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

No. Item	Guide questions/description	Considered
Domain 1: Research team and reflexivity		
	Personal Characteristics	
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group? M.R.S., page 5	Yes
2. Credentials	What were the researcher's credentials? MD, MPH, page 1	Yes
3. Occupation	What was their occupation at the time of the study? Physician-researcher, page 1	Yes
4. Gender	Was the researcher male or female? Female, page 1	Yes
5. Experience and training	What experience or training did the researcher have? M.R.S. is a AHRQ research fellow (qualitative training is mandatory), page 1; A.F.S. Trained in qualitative study coding; L.R. Qualitative expert; page 1	Yes
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement? No Participants who were deemed eligible were approached to gauge interest in participating, page 5	No
7. Participant knowledge of the interviewer	What did the participants know about the researcher? They her title, research experience, and motivation for doing the study (consent form), page 6	Yes
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? Title, research experience, and motivation for doing the study, page 6	Yes
Domain 2: Study design		
	Theoretical framework	
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? Grounded theory, page 6	Yes
Participant selection		
10. Sampling	How were participants selected? Purposive sampling, page 5	Yes
11. Method of approach	How were participants approached? Telephone, followed by face-to-face by A.F.S., page 5	Yes
12. Sample size	How many participants were in the study? 30, page 5	Yes
13. Non-participation	How many people refused to participate or dropped out? 42 (see study flow diagram for reasons), page 5 and supplemental figure.	Yes
	Setting	
14. Setting of data collection	Where was the data collected? Clinic, page 6	Yes
15. Presence of non-participants	Was anyone else present besides the participants and researchers? No, page N/A	Yes
16. Description of sample	What are the important characteristics of the sample? Demographics (age, sex, race/ethnicity, education, insurance), clinical (HF duration, severity of HF, medications) and health system characteristics (provider type, utilization), page 6.	Yes
	Data collection	

17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? Yes (topic guide available with questions and prompts), Yes, it was pilot tested, page 5 and page 7	Yes
18. Repeat interviews	Were repeat interviews carried out? If yes, how many? No	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data? Interviews were audio-recorded, page 6	Yes
20. Field notes	Were field notes made during and/or after the interview or focus group? Yes, no page	Yes
21. Duration	What was the duration of the inter views or focus group? 20- 40 minutes, page 5	Yes
22. Data saturation	Was data saturation discussed? Yes, it was reached at 17 participants, page 5	Yes
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? Main results were shared with participants for feedback but not transcripts, page 7	Yes
Domain 3: Analysis and findings		
	Data analysis	
24. Number of data coders	How many data coders coded the data? Three, page 6	Yes
25. Description of the coding tree	Did authors provide a description of the coding tree? No	No
26. Derivation of themes	Were themes identified in advance or derived from the data? Derived from the data, page 6.	Yes
27. Software	What software, if applicable, was used to manage the data? ATLAS.Ti, page 6	Yes
28. Participant checking	Did participants provide feedback on the findings? Yes, feedback was received from study participants, page 7	Yes
	Reporting	
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? Yes, by participant ID number – pages 8 - 14	Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings? Yes	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings? Yes, page 7 - 14	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? Yes	Yes

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Let's Talk Numbers – A Qualitative Study of Community-dwelling US Adults to Understand the Role of Numeracy in the Management of Heart Failure

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Title: Let's Talk Numbers – A Qualitative Study of Community-dwelling US Adults to Understand the Role of Numeracy in the Management of Heart Failure

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Figures: 1
Supplemental Figures: 3
COREQ Checklist Included (to assess quality of qualitative studies)

Keywords: heart failure, health numeracy, chronic disease management, qualitative study, health services research

Abstract

Objective: To examine the perspectives of adults with heart failure (HF) about numerical concepts integral to HF self-care.

Setting: This qualitative study took place at an urban academic primary care practice.

Participants: Thirty men and women aged 47 to 89 years with a history of HF were recruited to participate. Eligibility criteria included: a history of HF (≥ 1 year), seen at the clinic within the last year, and a HF hospitalization within the last 6 months. Non-English speakers and those with severe cognitive impairment were excluded.

Methods: In-depth semi-structured interviews were conducted. Participants were interviewed about numeracy across three domains of HF self-care: 1) monitoring weight; 2) maintaining a diet low in salt; and 3) monitoring blood pressure. Interviews were audiotaped, transcribed verbatim, and analyzed using grounded theory and word cloud techniques.

Results: Five key themes reflecting participants' attitudes towards numerical concepts pertaining to weight, diet, and blood pressure were identified: (1) Communication between healthcare providers and patients is a complex, multi-stage process (2) Patients possess a wide range of knowledge and understanding (3) Social and caregiver support is critical for the application of numerical concepts (4) Prior health experiences shape outlook towards numerical concepts and instructions (5) Fear serves as a barrier and a facilitator to carrying out HF self-care tasks that involve numbers. The findings informed a theoretical framework of health numeracy in HF.

Conclusion: _Effective communication of numerical concepts which pertain to HF self-care is highly variable. Many HF patients lack basic understanding and numeracy skills required for adequate self-care. As such, patients rely on caregivers who may lack HF training. HF specific training of caregivers and research that seeks to elucidate the intricacies of the patient-caregiver relationship in the context of health numeracy and HF self-care, are warranted.

Strengths and Limitations

- This is the first study to examine heart failure (HF) patients' perspectives towards numerical concepts of HF self-care; the main results and theoretical framework which emerged add to the literature and have implications for future research and clinical care.
- A purposive sampling strategy was used to recruit a diverse group of patients, which is more methodologically rigorous than other sampling strategies.
- Interviews were thoroughly analyzed using grounded theory.
- The study is limited in generalizability since it took place at one academic urban medical center.
- The study only included English speaking HF patients, which also limits the generalizability of the findings.

Introduction

There are 1 million heart failure (HF) hospitalizations each year and 25% of patients admitted for HF are readmitted within 30 days.[1,2] Part of this unplanned healthcare utilization is thought to be preventable by improved HF self-care.[3] Prior studies have found social and cognitive factors to be associated with HF self-care, including health literacy,[4] HF knowledge,[5,6] social support,[7,8] and cognitive impairment.[9,10] Yet, little is known about health numeracy in the context of HF.[11,12]

Health numeracy is the ability to access, understand, and apply numerical data to health-related decisions.[13] Although poor numeracy skills can coexist with low health literacy, numeracy and literacy measure different constructs and many adults tend to have worse quantitative skills.[13-16] With respect to chronic diseases, low numeracy is associated with worse glycemic control among adults with diabetes,[14,17,18] poor anti-coagulation control among patients on warfarin,[19] worse medication adherence[20] among adults with HIV/AIDS, and poor blood pressure control among adults with hypertension.[21]

Similar to these conditions, the management of HF requires numerical skill. Patients are expected to maintain a diet low in salt (often less than 2,000 mg/day), monitor their blood pressure, and weigh themselves daily. However, despite the degree to which numerical skills are needed for adequate HF self-care, to date only two studies have examined numeracy in the context of HF and they have done so by investigating the association between numeracy and the risk of readmission among adults hospitalized for HF.[11,12] Although informative, the results of these studies were conflicting, and neither investigated the role of numeracy in the management of HF or from the patients' perspective. Herein we addressed this gap by examining how numerical information is viewed and used among community-dwelling adults with HF.

Methods

Participant Selection and Study Setting

We conducted one-on-one semi-structured interviews with 30 adults with a history of HF, from December 2016 through March 2017. Patients were recruited from a hospital-based ambulatory clinic in New York, NY. To be considered eligible, patients must have had a diagnosis of HF for at least one year, had an office visit at the clinic within the last year, and must have been admitted to the hospital with a primary diagnosis of HF within the last 6 months. Non-English speakers, those with severe visual, hearing, or cognitive impairment were excluded. The Six-Item Screener (SIS)[22] was used to assess cognition. The electronic health record was used to identify HF patients who met our eligibility criteria.

Among those who were eligible, purposive sampling[23] was used to achieve a balanced sample with respect to gender, race/ethnicity, and duration of HF (years), as prior qualitative studies have shown variation across these characteristics with respect to self-care.[24] Purposive sampling is a technique widely used in qualitative research for the identification and selection of information-rich informants that cover the range of variation.[23] Eligible patients were called by telephone to gauge their interested in participating. At their next clinic visit they were approached by one author (A.F.S.), who detailed the consent process.

Of the 72 patients who were eligible to participate, 32 refused and 4 were excluded for cognitive impairment (Supplemental Figure 1). Of the 36 participants who provided written consent, 6 withdrew. Overall, our study included 30 participants.

Data Collection

One author (M.R.S.) with qualitative research experience conducted the in-person semi-structured interviews with each participant which lasted up to 40 minutes. Interviews were conducted using a standard interview guide, which included probes to elicit clarification and additional detail from participants. This approach is the most common in qualitative studies which seek to understand patients' perspectives on self-care in chronic diseases.[25-27] The interview topic guide, which was informed by the numeracy literature (in other chronic diseases) as well as our clinical experience with HF patients, allowed us to focus on numeracy in HF self-care, but also allowed for participant responses' to drive the direction and tone of the interview. The interview topic guide inquired about numeracy across three domains of HF self-care: 1) monitoring weight and fluid; 2) maintaining a low salt diet; and 3) monitoring blood pressure (Appendix 1). Data saturation, or the point at which no new themes emerged,[28] was achieved by the 17th interview, however additional interviews were conducted to maximize the robustness of the findings.

Participants completed a socio-demographic questionnaire following the interview. Medication use was ascertained through pill bottle review. The 10-item Center for Epidemiologic Studies Depression Scale (C-DES-10) was used to measure of depressive symptoms.[29] To assess subjective numeracy skill, participants completed the Subjective Numeracy Scale (SNS)[30], a validated 8-item instrument which measures numeracy on a scale of 6-48 with higher scores indicating higher numeracy skills.

Participants received a $25.00 gift card for their participation. The study was approved by the Institutional Review Board of the Weill Cornell Medical College.

Data Analysis

Interviews were audio-taped, professionally transcribed, and data were managed with ATLAS.ti Software. The data were analyzed using grounded theory.[31,32] To ensure methodological rigor, a constant comparative approach was used at each stage of the analysis.[33,34] First, two investigators (M.R.S. and A.F.S.) independently reviewed and open coded the first five transcripts, each drafting a preliminary coding schema which totaled 551 codes. Codes were applied to segments of text, usually defined by one or more relevant concepts. A third investigator (L.R.) reviewed the first five transcripts and both code lists before consolidating the lists into a final codebook, which was comprised of 77 unique codes. The investigators then reviewed the transcripts a second time, coding the data using the uniform codebook, which was subsequently applied to the remaining transcripts. During this process, the two coders met to revise the codebook, removing some codes while adding others. Once all transcripts were coded, the three investigators then compared common codes using dimensions and properties and consolidated them into 13 categories by consensus. The categories were then consolidated into five unifying themes, which a fourth investigator reviewed (M.M.S.). Quotations from each theme were anonymized and selected for presentation.

Theoretical framework

Since little is known about numeracy in the context of HF, and since existing frameworks did not incorporate the scope of the themes that emerged herein,[35-37] a new theoretical framework was generated from the analysis. To develop this framework, we first created a visualization of all of the initial codes which emerged directly from the interview transcripts using word cloud software in ATLAS.ti (Supplemental Figure 2). In this word cloud, the size of a code represented the frequency in which it appeared; the larger the size, the more often the code appeared.[38] This enabled us to get a preliminary sense of what concepts were discussed most often, by the participants. Our initial framework retained the properties of the word cloud, but also incorporated the categories and themes which emerged during the analytic process (Supplemental Figure 3). After feedback from study participants and health services researchers, we developed a more unified theoretical framework (Figure 1).

Quality Assurance

The study adhered to the Consolidated Criteria for Reporting Qualitative research (COREQ).[39]

Patient and Public involvement

Additionally, to ensure that our study had the ability to investigate HF patients' perspective on health numeracy, the semi-structured interview guide and the post-interview survey were piloted for ease and comprehensibility with five HF patients who were not included in the final study. At the conclusion of the study, the findings were shared with the study participants. Findings were also disseminated to the scientific community at two research conferences in 2017.

Results

Characteristics of Study Population

The 30 participants were mean age of 67 years (SD 10), 17 (57%) were female, 7 (23%) were White, 15 (50%) were Black, 6 (20%) were Hispanic, and 2 (7%) were Asian/Pacific Islander (Table 1). Twenty-one (70%) had at least a high school education and 12 (40%) had

Medicare or Medicaid. On average, participants had HF for 11 years (SD 7.8) and 22 (73%) were considered to have New York Heart Association (NYHA) classes two and three. The mean SNS was 27 (SD 10.3).

Major Themes

Five key themes emerged from our study, which are subsequently described and illustrated with anonymized quotes.

Theme 1: Communication between health care providers and patients is a complex, multi-stage process

Participants described the process of receiving numerical information about HF self-care to be a highly variable. one. While some HF patients had received information and instructions about weighing themselves, following a low salt diet, and monitoring their blood pressure during the course of their disease, others had not. This variation in communication is represented by the following two quotations:

"Every doctor at the office and in the hospital told me I need to follow a low salt diet."

"This is the first time I've ever heard that I'm supposed to weigh myself at home. Should I be doing that?"

Among those who did receive this information, few reported receiving accompanying explanations or real-life examples of how to apply numerical concepts and instructions, as shown here:

"Yeah, I take the 40-dose of the water pill every day. But, no one explained to me why I take it, or why 40."

"2,000 mg – what does that even mean? What does that number represent? Nobody has explained that to me."

Participants revealed that common barriers to communicating about these topics with providers in the clinic and the hospital included memory loss and hearing loss and visual impairment:

"I'm not sure if anyone gave me instructions about a 2,000-mg salt diet. I forget things. Maybe they did and I don't remember?"

"I'm embarrassed when I can't hear the doctor. My hearing aids broke a while back."

In addition to not having hearing aids, several participants conveyed that they go to the doctor's office without their reading glasses.

Notably, many participants spoke of non-physicians, particularly nurse practitioners, dieticians, and pharmacists, as critical to the communication and understanding of numerical information and instructions in HF.   However, when they received abnormal numerical results many preferred to speak directly with physicians:

"When my blood pressure is very high, I write it down and tell my doctor at my next appointment."

Some went directly to the emergency department when they saw abnormal values at home, rather than first calling their physician:

"When my blood pressure is out of control, I go straight to the hospital. Nothin' my doctor can do when I'm home."

Finally, participants spoke about the importance of the patient-provider relationship in communication. Specifically, many felt that this relationship affected their willingness to ask physicians questions about numerical concepts. Here, one participant expresses comfort and trust:

"I always ask my doctor questions. Especially if I see a funny number on my pressure cuff. He's a wonderful man -- easy to talk to."

On the contrary, distrust, lack of provider continuity, and fear of being judged by the provider were barriers to asking questions:

"He told me about weighing myself…. It confused me, but I didn't wanna seem dumb, so I never asked him to explain it again."

Theme 2: Patients possess a wide range of knowledge and understanding

While some participants understood the reason for monitoring weight, blood pressure, and salt intake, others struggled to grasp these concepts:

"I understand why my doctor told me to weigh myself. He doesn't want me to gain weight because it's a sign of water build up."

"I still don't understand blood pressure. The doctors have tried to explain it, but it's a concept I just can't handle."

Among those who expressed an understanding of numerical concepts associated with HF self-care, many participants struggled to apply them correctly. In fact, when given scenarios about abnormal values, many failed to interpret them and answer correctly:

"Last month my weight went up on the scale and my legs got really swollen. But I didn't do nothing. I waited until the shortness of breath came."

While some participants were aware of their shortcomings, others were not. Instead, they were confident in their incorrect knowledge and actions. The following two quotations represent the "strong and wrong" patient:

"I hardly ever eat salt. Take yesterday -- I had two pancakes for breakfast, a can of sardines for lunch, and then soup for dinner."

"My blood pressure is usually 170/100. That's bad because the 100 is high --the bottom number is the important one."

Overall, participants' statements suggest that there is a mismatch between self-perceived and actual ability and that they struggle to apply concepts correctly in their day-to-day lives.

Finally, participants cited a lack of financial resources as a main barrier to monitoring blood pressure and eating healthy:

"I'm on meals on wheels. I eat what they give me."

In addition, chronic pain was cited as a barrier to grocery shopping and standing on a scale during weight measurement.

Theme 3: Social and caregiver support is critical for the application of numerical concepts

The role of social and caregiver support was prominent throughout the interviews. The majority of participants reported that someone in their life helped them manage their HF. Family caregivers (spouses, grown children, and relatives) and paid caregivers (home health aides, home attendants, and care managers), provided participants with emotional and functional support. In addition to helping with weight monitoring, diet, and blood pressure control, caregivers assisted with grocery shopping, meal preparation, and transportation.

Participants frequently asked caregivers to interpret and explain numerical concepts at home, as illustrated here:

"When we leave the office, I ask my daughter what the doctor meant with those blood pressure numbers."

"I get so many questions in my head when I get on the bus, so I call my care manager. She's good at explaining."

This heavy reliance on caregivers had both positive and negative effects on patients' ability to apply numerical concepts and information correctly, as demonstrated by the following two quotations:

"My wife looks at every single label and adds up what I can eat in terms of salt. She comes to every visit and hounds the doctor with so many questions."

"I don't know if I have a low-salt diet. Whatever my health aide cooks me, is what I eat."

Finally, while being described as critical to their ability to engage in self-care, caregivers were not always in the room them and the doctor. Yet, despite not being present, participants recounted that caregivers are often responsible for calling the physician for further clarification of numerical instructions.

Theme 4: Prior health experiences shape outlook towards numerical concepts and instructions

For many participants, attitudes and pre-existing beliefs towards HF informed their outlook towards numerical concepts associated with HF. Their ability to process and carry out numerical instructions was affected by duration of HF and their ability to adjust to the diagnosis:

"I didn't like getting all of them directions at first. It depressed me, 'weigh yourself and drink only this amount.' But then I came to terms with it."

For some, the longer they had HF, the better they were at HF self-care, while for others, a longer duration of illness led to less engagement. Some participants spoke about relying on their symptoms to signal an acute worsening of their HF, rather than weighing themselves, which is a view is represented here:

"Look I've had this disease for years now. I don't needa' do any of this. I know when a flair up is coming."

In addition, personal and cultural beliefs shaped behavior.

"People at my Church get sick with this heart failure. They told me I better stay on top of this stuff, so I do."

In addition to their attitudes towards HF, experience with other chronic diseases and the healthcare system seemed to affect their comfort with numeracy skills integral to HF self-care. For example, participants on dialysis, those taking warfarin, and those with insulin-dependent diabetes seemed relatively comfortable with numerical concepts and instructions pertaining to HF:

"Following a low salt diet is pretty easy. I've been on Coumadin for years and I learned to limit foods because of the 'K' issue."

Theme 5: Fear serves as a barrier and a facilitator to carrying out HF self-care tasks that involve numbers.

Interviews revealed that fear played a dual role. Some participants expressed fear of abnormal results, which hindered their willingness to carry out numeric instructions:

"I don't take my blood pressure because it's better if I don't know my numbers. If I know, I'll worry sick."

For others, however, the fear of death served as a facilitator in carrying out HF self-care tasks:

"I follow all of these instructions. Always. I want to be here for my children."

In addition to death, the fear of shortness of breath, being hospitalized, readmitted, and dying served as facilitators in carrying out self-care tasks at home.

"I really try and stay away from salt. Not being able to breathe, is a nasty symptom."

Theoretical Framework

The theoretical framework that emerged from these results elucidates the role of numeracy in the context of HF self-care from the patients' perspective (Figure 1). Here, the main themes that emerged from our study are in white boxes and are scaled to the size in which they affected HF self-care, from the patients' perspective. The size of the themes reflects both the degree to which they appeared in the word cloud, but also from the interpretation of the quotations in the interview transcripts. As such, social and caregiver support and patient-provider communication appear the largest in size, since these themes were most dominant in influencing outcomes, from the patients' perspectives. Blue boxes contain factors, or sub-themes, which could mediate the relationship between themes. One overarching arrow (left to right), as well as smaller arrows, detail the relationship between the themes and the other factors identified.

Discussion

To our knowledge, this is the first study to evaluate the role of numeracy in the context of HF from the patients' perspective. Our findings add to the literature in several key ways. First, we found that among a socio-economically and racially diverse group of HF patients, many lacked basic numerical understanding and numeracy skills required for adequate self-care. Second, we found that the communication of numerical concepts between health care providers and patients is a complex and highly variable process. Third, participants relied heavily on caregivers to help them understand and carry out self-care tasks which required numeracy skills. Finally, as depicted in our theoretical framework, we found that while patient numeracy skills are important, they may not be as critical as patient-provider communication and caregiver support are to understanding and applying numerical concepts pertaining to HF self-care.

Like other studies that found that HF patients struggle with HF self-care,[40,41] our findings suggest that patients have difficulty integrating and applying numerical concepts and instructions home. For example, while many participants reported receiving information about a low sodium diet, few were able to correctly navigate real-life scenarios that asked them to calculate the sodium content in a meal. This deficit is consistent with a study by Rothman et al (2006), which highlighted patient shortfalls with nutrition label comprehension.[42] In addition, many participants struggled with understanding the implications of abnormal blood pressure values. This mismatch was also seen with SNS scores; many of the participants who rated themselves as above average with respect to numeracy, were unable to correctly apply numerical concepts during the in-person interview. Notably, some participants, were unaware that they possessed incorrect information. While others have shown that perceived numerical abilities differ from actual abilities,[43,44] ours is the first to report on this in HF, which has important implications for hospital discharge planning and clinic visits.

While our goal was to examine numeracy from the HF patients' perspective, many of the patients we interviewed relied heavily on family and paid caregivers to understand and perform HF self-care tasks that required numeracy skills. Notably, this finding differs from the existing body of numeracy literature in other chronic diseases, which has focused on individual patient numeracy.[14-16,19,21] Plausible explanations include that HF requires a high degree of self-care, they are frequently hospitalized, and they tend to be older, have multiple functional and cognitive deficits, all of which may lead them needing more help with respect to numerical tasks.[45,46] This may have both positive and negative implications though, as prior studies suggest that relying on caregivers has inconsistent effects on patients' disease management.[47,48] The numeracy skill level of caregivers in HF has not been investigated and is potentially warranted.

In addition, we found that the communication of numerical concepts and instructions between providers and patients is a multi-stage process, which can go awry at several points. As depicted by our theoretical framework, receiving numerical information requires that providers offer it and that patients are able to hear, see, and cognitively process the information. Recent data suggests that in the US, 75% of older adults with HF have mild or greater hearing loss,[49] 1 out of 4 adults with HF have trouble seeing up close,[50] and many are cognitively impaired.[51] In addition to these cognitive and sensory deficits, we found that comprehension and application of numerical concepts more often than not, required explanations and real-life examples, as well as adequate time for questions. Addressing these elements will require interventions that can overcome the constraints of contemporary office visits, which are often too short to allow this kind of interaction. Given the degree to which participants relied on non-physicians for information, it is likely that a multi-disciplinary team of healthcare providers could address some of these needs.

Interestingly, we found that when participants received an abnormal numerical result at home, such as a high blood pressure reading, they preferred to discuss it with their physician in the office, ask caregivers for help, or go directly to the emergency department, rather than call their physician. There are a few possible reasons for why this may be. First, barriers in the healthcare system may discourage them from calling. Second, the patient-provider relationship may be an important determinant, since we found that those who called their physician reported feeling “close” to them. Third, patient characteristics like hearing loss and language barriers may deter phone communication. Of note, none of our participants reported having telehealth devices which are known to transmit numerical results to the physician directly. It may be prudent for interventions to design flexible decision support tools which allow for varying knowledge, support in the home, and practice characteristics.

Finally, as depicted by our theoretical framework, we found that several patient level factors influenced how numerical information was perceived and acted upon. Participants who had other conditions which required them to manipulate numbers, and those who feared negative consequences of not following numerical instructions, were more willing to carry out more numerically burdensome HF self-care tasks. Additionally, as shown in our framework, self-efficacy, financial resources (owning a scale and being able to buy food low in salt), and the ability to access care, were factors that affected this willingness to engage. Thus, in addition to providers being aware of patients' outlook, beliefs, and attitudes, interventions which could address some of these more modifiable factors ought to be examined.

Strengths and Limitations

Our study's strengths include that it is the first qualitative study to examine numeracy in the context of HF. We used a purposive sampling strategy to recruit a diverse group of patients to seek a range of perspectives across gender, race/ethnicity, and chronicity of HF. Finally, we develop a novel theoretical framework from our findings which can guide future research and interventions on numeracy in HF. Despite purposive sampling, however, the study is limited in generalizability due to recruitment from a single clinical cite. Our focus was the patients' perspective, but given our findings, future studies should examine the perspectives of HF patients' caregivers on numeracy. Another limitation is that we did not formally assess participants' health literacy, since it is thought to be a similar but distinct concept from numeracy and a wealth of research has already focused on literacy in the context of HF. However, future studies may consider doing so since health literacy is likely to affect many aspects of HF self-care. Finally, we excluded non-English speakers, who may experience numerical concepts differently than patients discussed here.[52]

Conclusion

Overall, our findings suggest that the communication of numerical concepts and instructions between providers and HF patients is a complex, multi-stage process and the numerical information which is transmitted to patients may be highly variable. In addition, receiving, understanding and applying numerical concepts integral to HF self-care is challenging for many adults with HF. Perhaps owing to this, we found that many HF patients rely heavily on caregivers to perform numerical tasks and interpret numerical results. Since our study focused on HF patients, future studies ought to assess the numeracy skills of caregivers relative to these demands. As depicted by our theoretical framework, patient-provider communication and HF-specific training of caregivers may be important influences on successful HF self-care, rather than interventions aimed at individual patient numeracy alone. In addition, several patient-level factors, such as sensory impairments, prior experiences with other chronic diseases, access to resources, and the quality of patient-provider relationship, have the ability to affect the degree to which numerical concepts are understood and applied correctly. Healthcare providers ought to be mindful of these issues when counseling patients on numerical tasks, as a one-size fits all approach is not likely to successful.

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Data Sharing: Due to the qualitative nature of this study, the data are written transcripts of patient interviews. Although participant information is de-identified, some made references to their experiences with individual physicians, healthcare providers, and hospitals during the interviews, thus we prefer to not make these transcripts publically available.

Author's Contributions:
Concept and Design of the Study (M.R.S., M.M.Sa., M.M.Sc., S.K.D.)
Acquisition of Data and Analysis (M.R.S., A.F.S., S.K.D., L.R., M.M.Sa.)
Drafting of the manuscript (M.R.S.)
Critical revision of the manuscript (M.R.S., M.M.Sc., M.M.Sa.)
Final approval of the manuscript (M.R.S., A.F.S., M.M.Sc., L.R., M.M.Sa., S.K.D.)

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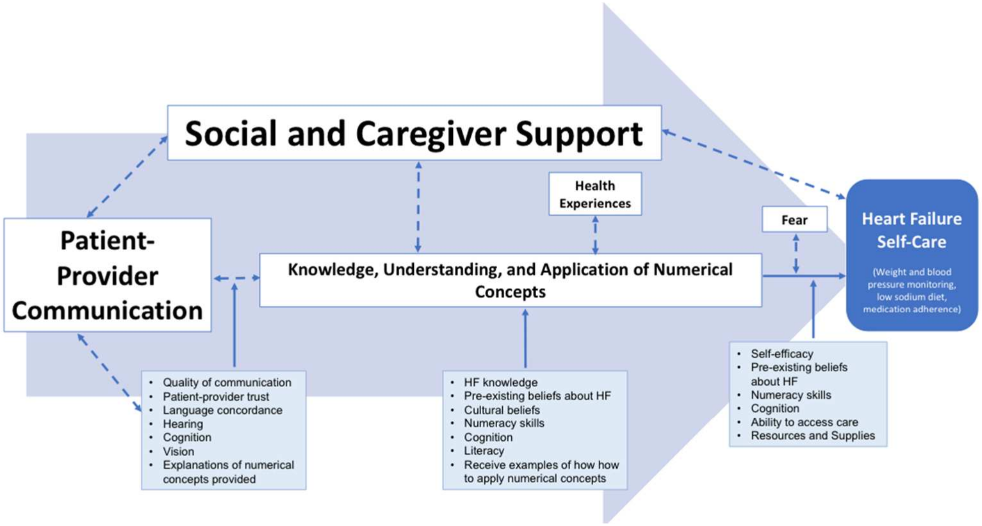
Table 1. Characteristics of the Study Population

Participant Characteristics	All (N = 30)
Age, years (mean[SD])	67 (10)
Gender	
Female N (%)	17 (57%)
Race	
White N (%)	7 (23%)
Black N (%)	15 (50%)
Hispanic N (%)	6 (20%)
Asian/Pacific Islander N (%)	2 (7%)
Educational degree	
No degree N (%)	3 (10%)
Some HS N (%)	6 (20%)
GED or HS completed N (%)	6 (20%)
Some College N (%)	8 (27%)
4 year College Degree N (%)	3 (10%)
Graduate Degree N (%)	4 (13%)
Insurance type	
None N (%)	5 (21%)
Private N (%)	7 (29%)
Medicare N (%)	5 (21%)
Medicaid N (%)	6 (25%)
Medicare and Medicaid N (%)	1 (6%)
NYHA Class	
1	8 (27%)
2	11 (37%)
3	11 (37%)
Number of years with HF diagnosis, years (mean[SD])	10.9 (7.8)
Number of medications taking for HF	
Don't know N (%)	2 (7%)
1 -5 N (%)	25 (83%)
6-10 N (%)	3 (10%)
>10 N (%)	0 (%)
Number of medications taking overall	
Don't know N (%)	0 (%)
1-5 N (%)	3 (10%)
6-10 N (%)	19 (63%)
>10 N (%)	8 (27%)
Depressed symptoms	
C-DES-10, mean(SD)	12.3 (5.3)
Subjective numeracy	
SNS-8, mean(SD)	27 (10.3)

The 10-item Center for Epidemiologic Studies Depression Scale (C-DES-10) was used to measure of depressive symptoms, with higher scores indicating more depressive symptoms. The Subjective Numeracy Scale (SNS-8) assessed patients' numeracy. The SNS-8 is a validated 8-item instrument which measures numeracy on a scale of 6-48 with higher scores indicating higher numeracy skills.

Figure 1 Legend. Theoretical Framework of Factors Influencing Effective Use of Numbers in Heart Failure Self-Care.

Figure Legend: The theoretical framework is a summation of the thematic content derived from grounded theory, along with features of the word cloud. As shown by their size, social and caregiver support and patient-provider communication emerged as the two most dominant themes. One overarching arrow (left to right), as well as smaller ones, detail the relationship between themes, categories, and prominent codes. Solid arrows represent unidirectional relationships, whereas dashed bi-directional arrows represent bidirectional relationships. Input from study participants was incorporated into this final conceptual framework.



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Supplemental Figure 1. Study Flow Diagram

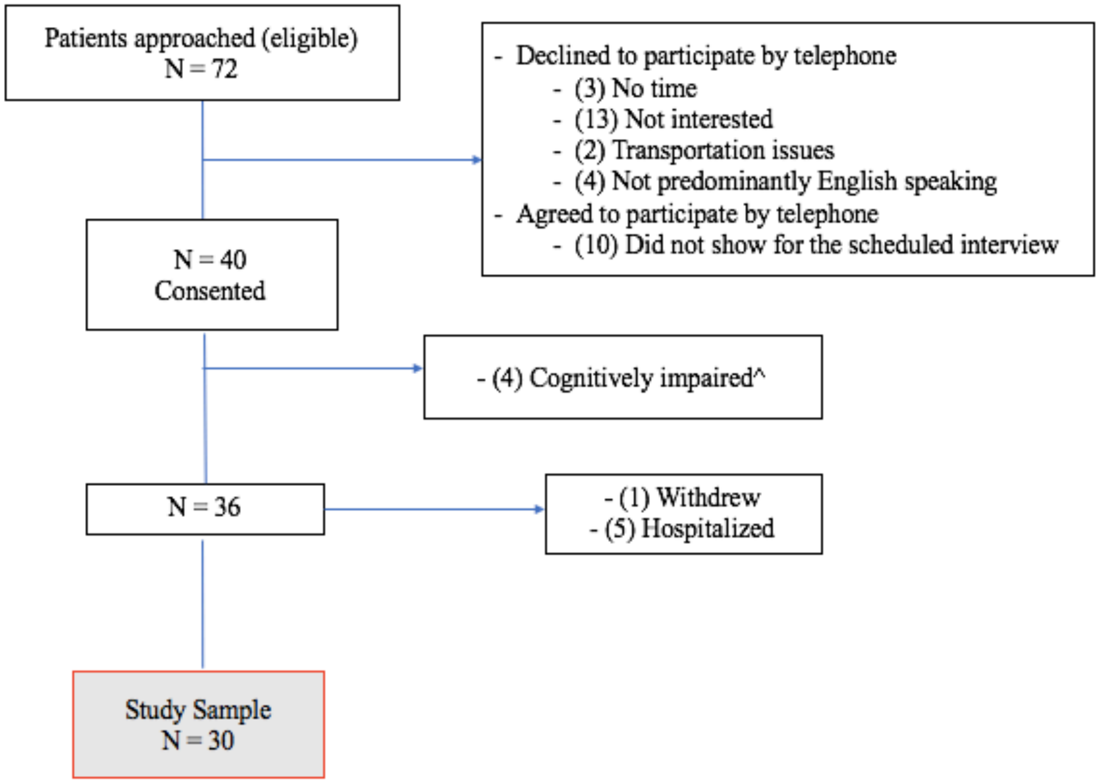
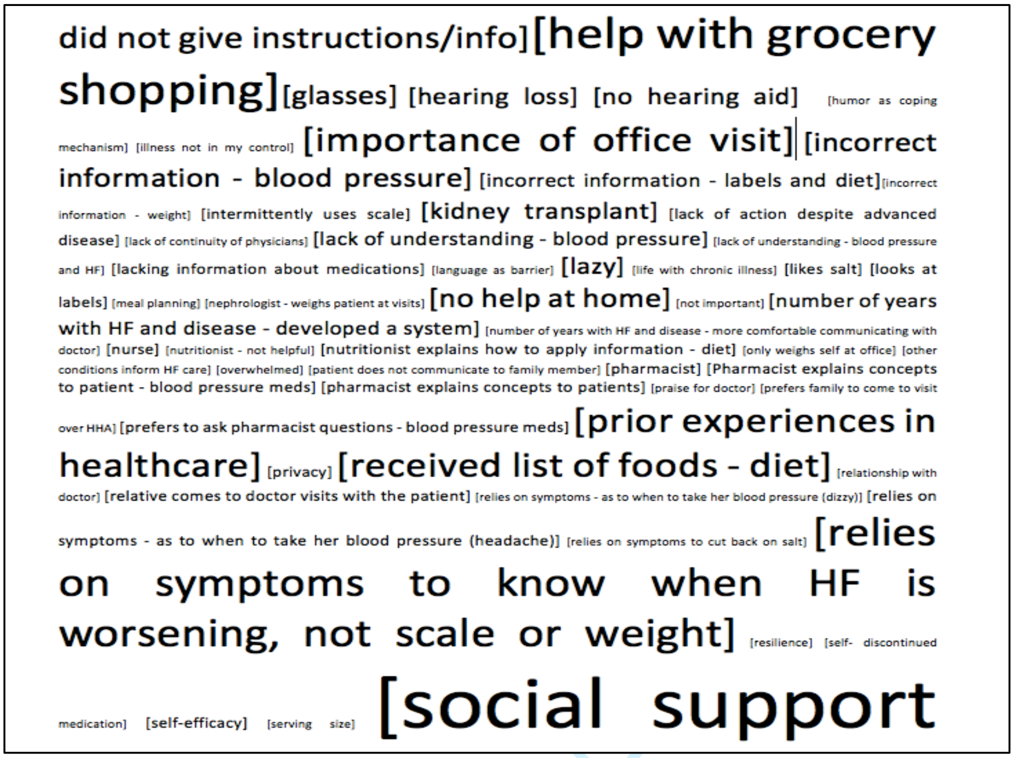


Figure Legend: Overview of study population. ^Cognitive impairment was assessed using the Six Item Screener by Callahan et al (2002), a well validated instrument which assesses global cognitive impairment. Cognitive impairment was defined as a score of 0 – 4 (correct) and intact cognitive function was defined as a score of 5 or 6 (correct).

Supplemental Figure 2. Excerpt from the Word Cloud Derived from Codes Applied to Interview Transcripts

Figure Legend: The size of the codes represents the frequency in which they appeared throughout the 30 interview transcripts; the larger the size, the more often the code was used. ATLAS.ti software was used to generate the Word Cloud.



did not give instructions/info] [help with grocery shopping] [glasses] [hearing loss] [no hearing aid] [humor as coping mechanism] [illness not in my control] [importance of office visit] [incorrect information - blood pressure] [incorrect information - labels and diet] [incorrect information - weight] [intermittently uses scale] [kidney transplant] [lack of action despite advanced disease] [lack of continuity of physicians] [lack of understanding - blood pressure] [lack of understanding - blood pressure and HF] [lacking information about medications] [language as barrier] [lazy] [life with chronic illness] [likes salt] [looks at labels] [meal planning] [nephrologist - weighs patient at visits] [no help at home] [not important] [number of years with HF and disease - developed a system] [number of years with HF and disease - more comfortable communicating with doctor] [nurse] [nutritionist - not helpful] [nutritionist explains how to apply information - diet] [only weighs self at office] [other conditions inform HF care] [overwhelmed] [patient does not communicate to family member] [pharmacist] [Pharmacist explains concepts to patient - blood pressure meds] [pharmacist explains concepts to patients] [praise for doctor] [prefers family to come to visit over HHA] [prefers to ask pharmacist questions - blood pressure meds] [prior experiences in healthcare] [privacy] [received list of foods - diet] [relationship with doctor] [relative comes to doctor visits with the patient] [relies on symptoms - as to when to take her blood pressure (dizzy)] [relies on symptoms - as to when to take her blood pressure (headache)] [relies on symptoms to cut back on salt] [relies on symptoms to know when HF is worsening, not scale or weight] [resilience] [self- discontinued medication] [self-efficacy] [serving size] [social support

Supplemental Figure 3. Initial Conceptual Framework

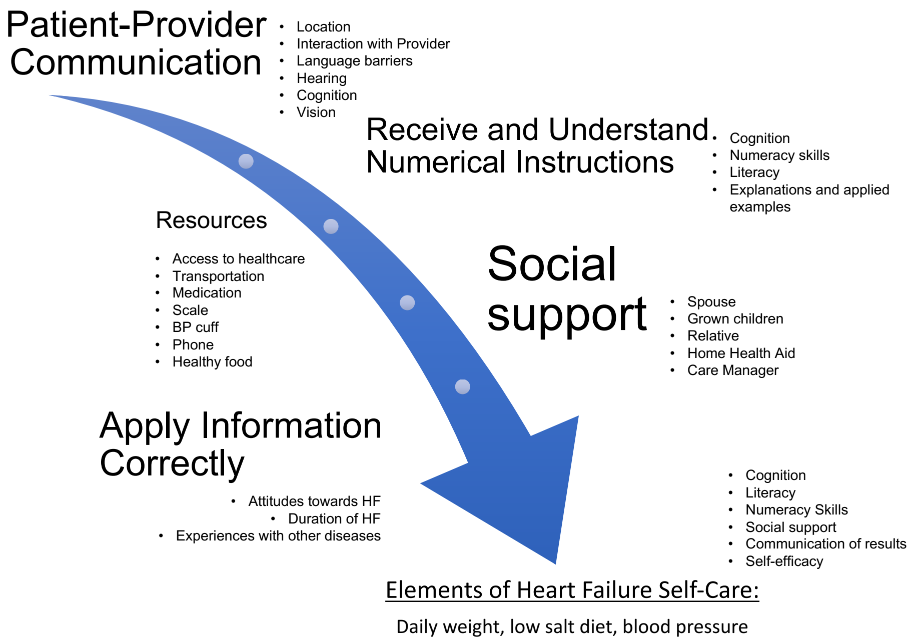


Figure Legend: This initial conceptual framework combines features of the word cloud with results from our grounded theory approach to represent the patient's perspective on numeracy across three domains of heart failure self-care: daily weight monitoring, maintaining a diet low in salt, and monitoring blood pressure.

Appendix 1. Interview Topic Guide

Introduction:

"Thank you for speaking with me today."

"The reason I am interviewing you is because I'm interested in understanding the role that numbers play in the management of Heart Failure." "Particularly, I would like to understand how patients (like you) feel about receiving and using numerical information in the context of managing your disease."

"What's important for you to know is there are no right or wrong answers. I am recording this interview, but you should know that your answers will remain confidential nor will they affect your medical care here or anywhere else. Your healthcare provider will not receive information about this interview or your responses. At the end of the study, I plan to follow-up and share my findings with you."

Opening question(s):

"Tell me, how long you've been coming to WCIMA?

"How long have you had HF?"

Introductory statement:

"Since the purpose of this study is to assess how comfortable you are with numbers (in the context of your HF), I am going to give you 3 scenarios and ask you a few questions which pertain to each.

Again, there are no right and wrong answers. I simply am trying to understand your attitudes and beliefs towards numerical concepts and instructions that you may come across during visits with your doctor about HF. "

"The first scenario is about weight and water pills."

Scenario 1

"Patients with HF are often asked to weigh themselves every day at home in order to monitor the amount of fluid in their body."

(pause)

"Doctors tell patients that if they weigh themselves and notice a weight gain of 2 to 3 pounds in 1 day or 5 pounds in 1 week, that is a problem and a sign of increased fluid in the body. When that occurs, they are often asked to take higher doses of their water pills."

(pause)

Question 1: What do you understand about the numerical instructions?

- Probe: Think back for a moment, has your doctor ever told you something like this?
- Probe: Think back to when you were in the hospital for HF, did doctors or nurses ever give you numerical instructions about monitoring your weight?

Question 2: How does it feel to use a scale at home to monitor your weight?

- Probe: When you step on a scale, what does the number mean to you?
- Probe: What is the first thing you think about if the number has changed?
- Probe: In terms of your HF, what should you do when you see that your weight has increased?
- Probe: Have you ever increased your water pill (or other medications) dose after noticing changes on the scale?
- Probe: Other than a scale, are there other ways that you keep track of your weight (or fluids in your body)?

Question 3: How confident are you that you could follow these numerical instructions?

- Probe: Why? Why not?
- Probe: Does monitoring your weight and adjusting your water pill doses feel like a difficult task to carry out?
- Probe: Would you require help to do so?
- Probe: Is there anything that might make recording your weight or noticing a significant gain or loss easier?

(pause)

"This next scenario I will read to you is about following a low salt diet."

(pause)

Scenario 2

Patients with HF need to limit the amount of salt (sodium) they eat in order to avoid fluid buildup. Often, they are asked to follow a low salt diet, which would allow you to eat up to 3,000mg of salt per day.

(pause)

Let's say you go to the deli for lunch and buy 1 bag of potato chips (which is 170mg of salt) and a can of chicken soup (which is 820 mg of salt).

At dinnertime, let's say you eat a hot dog (which is 470mg of salt).

Given your 3,000mg limit, would you be able to eat a second hot dog?

(pause)

<u>Question 1:</u> What do you understand about what I just told you?

- <u>Probe:</u> Think back for a moment, has your doctor ever spoke to you about a low salt diet?
- <u>Probe:</u> Think back to when you were in the hospital for HF, did doctors or nurses ever give you numerical instructions about following a low salt diet?

<u>Question 2:</u> How does it feel to have to keep track of how much salt you eat each day?

- <u>Probe:</u> How comfortable are you the reading nutrition labels of the food you eat?
- <u>Probe:</u> What do you think about when you make food choices?
- <u>Probe:</u> What system do you use for deciding whether a food is salty?
- <u>Probe</u>: How does counting and adding the salt in each of the foods make you feel?

<u>Question 3</u>: How confident are you that you could follow these numerical instructions and maintain a low salt diet?

- <u>Probe</u>: Why? Why not?
- <u>Probe:</u> Does maintaining a low salt diet feel like a difficult task to carry out?
- <u>Probe:</u> Would you require help to do so?
- <u>Probe:</u> Is there anything that might make following a low salt diet easier?

"The final scenario I will read to you is about blood pressure."

(pause)

Scenario 3:

Patients with HF often take medications for their blood pressure.

Doctors ask that patients with HF monitor their blood pressure at home with a blood pressure cuff and record it in a log.

(pause)

Yesterday, one of my patients called me because his blood pressure was 110/70. He thought the top number was too low and did not want to take his Coreg (also known as Carvedilol). I explained to him that if he felt well, it was OK to take the medication. I told him that patients with HF can tolerate lower blood pressures, but if the top number is less than 90mmHg or he is feeling lightheaded, he should not take his blood pressure medicine.

(pause)

Question 1: What do you understand about the numerical instructions?

- Probe: Think back for a moment, has your doctor ever told you something like this?
- Probe: Think back to when you were in the hospital for HF, did doctors or nurses ever give you numerical instructions about monitoring your blood pressure?

Question 2: What do you understand about the two numbers in a blood pressure measurement?

- Probe: As best as you can, tell me what the top and bottom number means to you?
- Probe: If you had to pay closer attention to one, which is more important for your HF and your health? (top or bottom). Why?

Question 2: How does it feel to use a blood pressure cuff at home to monitor your blood pressure?

- Probe: When your blood pressure is taken (or when you take it), what does the number mean to you?
- Probe: What blood pressure might be considered too high?

- Probe: What blood pressure might be considered too low?

- What is the first thing you think about when you see (or are told) what your blood pressure is?
- Probe: In terms of your HF, what should you do when you see that the top number is too high? Too low?

- Probe: Have you ever altered your medication regimen in response to seeing your blood pressure?

Question 3: How confident are you that you could follow these numerical instructions about blood pressure?

- Probe: Why? Why not?

- Probe: Does monitoring your blood pressure at home feel like a difficult task to carry out?

- Probe: Would you require help to do so?

- Probe: Is there anything that might make recording your blood pressure easier?

- Probe: Is there anything that might make taking (or adjusting) your blood pressure medications easier?

- Probe: How comfortable are you calling your doctor when you are unsure of what to do?

Ending question:

"I think what I heard today from you is_____________, _____________and _______.

(pause)

Over the next few weeks I will be interviewing other patients and will be sure to circle back to you at the end of the study to share my findings with you.

"Before we end today, is there anything you want to tell me that I didn't ask you?"

(pause)

END

The Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

No. Item	Guide questions/description	Considered
Domain 1: Research team and reflexivity		
	Personal Characteristics	
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group? M.R.S., page 5	Yes
2. Credentials	What were the researcher's credentials? MD, MPH, page 1	Yes
3. Occupation	What was their occupation at the time of the study? Physician-researcher, page 1	Yes
4. Gender	Was the researcher male or female? Female, page 1	Yes
5. Experience and training	What experience or training did the researcher have? M.R.S. is a AHRQ research fellow (qualitative training is mandatory), page 1; A.F.S. Trained in qualitative study coding; L.R. Qualitative expert; page 1	Yes
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement? No Participants who were deemed eligible were approached to gauge interest in participating, page 5	No
7. Participant knowledge of the interviewer	What did the participants know about the researcher? They her title, research experience, and motivation for doing the study (consent form), page 6	Yes
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? Title, research experience, and motivation for doing the study, page 6	Yes
Domain 2: Study design		
	Theoretical framework	
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? Grounded theory, page 6	Yes
Participant selection		
10. Sampling	How were participants selected? Purposive sampling, page 5	Yes
11. Method of approach	How were participants approached? Telephone, followed by face-to-face by A.F.S., page 5	Yes
12. Sample size	How many participants were in the study? 30, page 5	Yes
13. Non-participation	How many people refused to participate or dropped out? 42 (see study flow diagram for reasons), page 5 and supplemental figure.	Yes
	Setting	
14. Setting of data collection	Where was the data collected? Clinic, page 6	Yes
15. Presence of non-participants	Was anyone else present besides the participants and researchers? No, page N/A	Yes
16. Description of sample	What are the important characteristics of the sample? Demographics (age, sex, race/ethnicity, education, insurance), clinical (HF duration, severity of HF, medications) and health system characteristics (provider type, utilization), page 6.	Yes
	Data collection	

17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? Yes (topic guide available with questions and prompts), Yes, it was pilot tested, page 5 and page 7	Yes
18. Repeat interviews	Were repeat interviews carried out? If yes, how many? No	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data? Interviews were audio-recorded, page 6	Yes
20. Field notes	Were field notes made during and/or after the interview or focus group? Yes, no page	Yes
21. Duration	What was the duration of the inter views or focus group? 20- 40 minutes, page 5	Yes
22. Data saturation	Was data saturation discussed? Yes, it was reached at 17 participants, page 5	Yes
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? Main results were shared with participants for feedback but not transcripts, page 7	Yes
Domain 3: Analysis and findings		
	Data analysis	
24. Number of data coders	How many data coders coded the data? Three, page 6	Yes
25. Description of the coding tree	Did authors provide a description of the coding tree? No	No
26. Derivation of themes	Were themes identified in advance or derived from the data? Derived from the data, page 6.	Yes
27. Software	What software, if applicable, was used to manage the data? ATLAS.Ti, page 6	Yes
28. Participant checking	Did participants provide feedback on the findings? Yes, feedback was received from study participants, page 7	Yes
	Reporting	
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? Yes, by participant ID number – pages 8 - 14	Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings? Yes	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings? Yes, page 7 - 14	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? Yes	Yes