

# Perspectives from Geriatric In-patients with Heart Failure, and their Caregivers, on Gaps in Care Quality



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## ABSTRACT

### Background

Evidence indicates that care experiences for complex HF patients could be improved by simple organizational and process changes, rather than complex clinical mechanisms. This survey identifies care gaps and recommends simple changes.

### Methods

The study utilized both quantitative and qualitative methods at The Ottawa Hospital, Geriatric Medical Unit during a three-month period.

### Results

Nineteen patients (average age 85, 12 female) surveyed. Twelve participants lived alone. Fourteen lived in own home. Four patients had formal home-care services. Fifteen relied on family. Gaps were identified in in-patient practice, discharge plan, and discharge summary implementation feedback. Only five participants had seen cardiologist or specialist. Half of patients did not know if they were on a special HF diet. Participants did not recall receiving information on life expectancy but were comfortable discussing EoL care and dying. HF-specific management recommendations were mentioned in only 37% of discharge summaries to PCPs.

### Conclusion

The results provide the starting point for a quality assurance and process re-engineering program in GMU. Organization change is needed to develop and integrate a cardiogeriatric clinical framework to allow the cardiologist, geriatrician, and PCP to actively work as a team with the patient/caregiver to develop the optimal care plan pre- and post-discharge.

**Key words:** in-patient survey, patient experience, caregiver experience, quality improvement, re-engineering

## INTRODUCTION

Heart failure (HF) is the most common cause of hospitalization for people over 65.<sup>(1)</sup> The presence of multi-morbidity and frailty in older people with HF is associated with a decreased quality of life (QoL), a 92% increased risk for ED visits, and a 65% increased risk for hospitalizations.<sup>(2)</sup>

HF prognosis follows a progressive, albeit non-linear course, whereby patients can die suddenly or progress to end-stage HF over time.<sup>(3)</sup> There is an escalation in the care needs of these patients as the disease progresses. At system level, these patients rely on the coordination of several health-care providers in addition to informal services.<sup>(4)</sup> It has been shown that quality gaps and decreased patient safety often result from fragmented care caused by the lack of coordination and integration amongst these services.<sup>(5)</sup> Moreover, suboptimal ambulatory care and in-home support services have also been identified.<sup>(6)</sup>

The literature highlights challenges with both patients and their caregivers understanding the importance of self-efficacy in chronic disease management such as HF. In fact, the majority of hospital admissions are due to the lack of self-care support, medication management, and dietary adherence.<sup>(7)</sup> Patient-level barriers to self-care include regimen complexity, undesirable medication effects, and inadequate knowledge, tools and support. Even in advanced stages, HF patients and their caregivers are heavily and unnecessarily burdened by fragmented health-care services.<sup>(8)</sup> Most importantly, there is evidence that these poor experiences could be dramatically improved by simple organizational and process changes, rather than complex clinical mechanisms.<sup>(5,6)</sup> Understanding the perspectives of the patient, the caregiver, and the professional is crucial for the development of these organizational and process changes, leading to an optimal patient experience.<sup>(9)</sup>

The objectives of this study were to determine both the patients' and their caregivers' perspectives and experiences with HF care; and to explore the barriers to high-quality care at the Geriatric Medical Unit (GMU) of The Ottawa Hospital. This investigation would identify both the organizational and process changes needed to enable optimal HF management,

resulting in improved patient satisfaction. The focus included adherence to the GAP (Guidelines Applied in Practice) Tool<sup>(10)</sup> for patient HF education, better communication in self-care training, addressing advance directives, case coordination at the time of discharge (DC), and transitional care planning.

GMU is a 20-bed unit that primarily receives patients on transfer from other acute care services at The Ottawa Hospital following a triage by the Geriatric Consult Team. These patients have a variety of medical, functional, cognitive, and psychosocial issues, resulting in challenging DC planning. The GMU team consists of geriatric, nursing, physiotherapy, occupational therapy, pharmacist, dietician, and social worker services. The mandate of GMU is the assessment and optimization of conditions suitable for further rehab, transition to community living, or relocation to a facility. Patients may be followed post-DC at the ambulatory geriatric clinic.

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## METHODS

The study took place in the GMU from June 2015 to September 2015. Of the 36 eligible HF patients admitted during that period, 19 consented to participate in the study in addition to 18 caregivers. A mixed methodology was used.

Quantitative data were gathered through chart reviews and electronic medical records (EMR) including: age, ethnicity, educational level, marital status, gender, mental and physical function, multi-morbidities, and advance directives including decisions on end-of-life care. Medications upon admission and DC, as well as medications found on the Beer's list<sup>(11)</sup> were documented. Echocardiogram reports, including ejection fraction and diastolic dysfunction, were recorded. The presence of dementia, delirium in hospital, and falls were also documented.

Additional data were gathered by using assessment tools: function (Barthel & Lawton scales),<sup>(12,13)</sup> cognition (MoCA & CAM),<sup>(14,15)</sup> mobility (gait speed),<sup>(16)</sup> balance (Berg's scale),<sup>(17)</sup> multi-morbidity (Charlson index),<sup>(18)</sup> and depression (GDS).<sup>(19)</sup> Adherence to the GAP Tool<sup>(10)</sup> was established by chart reviews. Data analysis was done using Fischer Exact test for categorical variables and Mann-Whitney testing for continuous variables.

In the qualitative part of the project, a research assistant interviewed the patients and their caregivers administering semi-structured questionnaires. Interviews took place in person during the hospital stay and over the phone two weeks post-DC. In these exploratory interviews, patient experiences and preferences with HF care delivery were audio-recorded and transcribed verbatim for analysis. Content analysis was performed to identify recurrent themes, first performed by one researcher then verified for accuracy by a second researcher. QoL was measured by using the 'Minnesota Living with HF Questionnaire'.<sup>(20)</sup>

## RESULTS

Quantitative data analysis of the 19 consenting patients showed an average age of 85 (63% were female). Demographic details can be found in Table 1. Most participants lived alone (65%) and 74% were living in their own home. Only four of these patients had formal home services. The rest were relying on family for support. Diastolic dysfunction was present in 73% of these in-patients and was significantly more common in females. The NYHA Functional class assessment showed that 69% were Class III. Falls were experienced in 100% of these patients. The other common multi-morbidities included: delirium in 74%, anemia in 74%, CKD in 68%, and atrial fibrillation in 47%.

HF care quality measures are presented in Table 2. All patients previously had an echocardiogram. The HF education (GAP Tool) had been ordered by the MD in 74% of the HF patients.

Discharge (DC) summary from MD to the primary care physician (PCP) mentioned the patient's chosen code status in only 58% of the cases. Patients were discharged with an average of 10 medications. HF medications were prescribed such as Beta Blockers (in 74%), and ACEI (in 47%) at the time of DC. HF-specific future management recommendations were only mentioned in 37% of the summaries.

Qualitative data analysis focused on evaluating three domains: service utilization, self-care teaching/communication, and End-of-Life (EoL) care (see Table 3).

Participants reported that fatigue, dyspnea, and edema were barriers to function and self-care, but only a minority of patients had community support in place to assist them. Most were living alone or relying on family members for help to remain as independent as possible. Six patients (31%) reported having asymptomatic HF. Only five participants (26%) had a cardiologist involved in their care. Notable challenges were reported by the patients in accessing their family physician, both in follow-up after DC and on an urgent basis leading to emergency room visits or readmissions.

Most participants reported communication with the GMU team as courteous and concise. Three were unhappy with communication as "people were in and out of their room but not providing enough medical information", "information was only provided to family and the patient did not appreciate it", and "information provided was too quick". Most participants did not recall getting any instruction on HF management (i.e., medications, diet, exercises). The majority of patients recalled getting weighed and doing exercises everyday but were not sure why these were done: "Staff does things but do not explain what they do". Participants did not recall receiving information on the life expectancy and prognosis.

EoL care discussions rarely occurred with the hospital health-care team. Code status was Do Not Resuscitate (DNR) for most participants, but for the ones who wanted to be resuscitated, "they wanted this as long as there was a good chance of recovery". The majority of participants were comfortable

TABLE 1.  
Patients' characteristics

	<i>Percentage of sample</i>	<i>No. of patients (n=19)</i>
Gender	63% Female	12 Female
Age	85 Mean (SD±8)	19
Ethnicity	95% Caucasian	18
Living situation	65% alone, 74% at home	12 alone, 14 at home
Falls over last year	100%	19
Delirium during hospital stay	74%	14/19
Dementia	69%	11/19
CKD	68%	13
A fib	47%	9
Anemia	74%	14
MoCA score	Mean 20 (SD±5.5)	14/19
Charlson Index (age adjusted)	7.9 (2.4)	19
Gait speed (timed 5 meters' walk)	0.39 m/s (0.2)	15/19
ADL score (Barthel)	4 (2.5)	19/19
iADL score (Lawton)	7.9 (2.4)	19/19
NYHA class II	19%	3/19
NYHA class III	69%	11/19

TABLE 2.  
HF care quality measures

Echo performed	100%	19/19
Diastolic Dysfunction	73%	14/19
Minnesota QoL score	39.5 from 105	18/19
Gap Tool ordered	74%	14/19
Code status and EoL discussion on DC summary	58%	11/19
HF management recommendations to PCP on DC summary	37%	7/19
ACEi prescribed	47%	9/19
BB prescribed	74%	14/19
Seen by Cardiology	25%	5/19

to discuss EoL care and dying. Family presence at EoL was described as important, but the concept of palliative care was new to most participants. Participants who received the HF information booklet were grateful and wanted to receive more education in the presence of their families.

Other comments were related to patients' feeling they did not receive enough nursing supervision, response to call bells, and help with toileting. Issues related to managing patients' expectations, isolation, and communication were noted.

Follow-up phone interviews within two weeks post-DC did not happen for five of the patients, as they were too sick to participate in the interviews. The majority of patients (89%) reported that they had a good relationship with their PCP but

had not seen their doctors yet. Half of the patients reported that they did not know if they were on a special HF diet and were eating whatever was provided at their residence.

Of the 18 caregivers interviewed, 14 (73%) were directly involved with providing daily patient care (3 experienced heavy burden). They reported rarely being included in discussions with GMU disciplines such as physiotherapy. There was a concern about diet recommendations not being carried over to the retirement home upon DC. Caregivers did not appreciate being given too many written pamphlets as "it goes all in a pile and never gets read". Seven caregivers (37%) had concerns about the current DC plan since the majority of these patients (68%) had prior poor experiences with hospital readmissions and ED visits. Premature DC and a lack of care coordination created resistance and uncertainty with the current DC plan.

## DISCUSSION

The phenotype of patients with HF has substantially changed over the last two decades.<sup>(21,22)</sup> Most notably, these patients have a higher percentage of very old individuals with multi-morbidities and polypharmacy. Functional limitations and cognitive changes are prevalent. Although we need a great deal more clinical research with older people, it should come as no surprise that conducting this type of research can be problematic. A review of the literature in this area provides some indication of the challenges of doing qualitative studies.<sup>(23)</sup> One major challenge involves recruitment and consent. Our survey project was no different. Of the 36 patients eligible for our study, only 19 consented.

TABLE 3.  
Qualitative data

<i>In-Hospital Interview</i>	<i>Patient (N=19)</i>
What symptoms affect your function the most?	Fatigue, dyspnea & edema
Are you able to see PCP post discharge in 7-10 days?	No
Did you know you have HF?	20% said yes (majority knew they have heart problem)
Is there a cardiologist involved in your care?	26% said yes
Have you received information on HF management & diagnosis during your hospital stay?	Majority said did not recall
Did you receive information about medications and life style changes?	Yes, but did not know the reasons
Did you find the HF information booklet helpful	Yes
Were End-of-Life (EOL) discussions offered to you?	Rarely
Anything to improve in the care received?	74% said we need to improve
Are you fearful or have concerns about EOL discussion?	No
Did you receive any teaching on HF?	74% did not recall
Was Palliative Care discussed with you?	No
How do you find the communication by your health providers?	Not enough
<i>Post-discharge Phone Interview</i>	<i>Patient (N=19)</i>
Inability to complete because patient was too sick	26%
Good Access and relationship to PCP?	89% yes
Are you aware if you are on a special diet?	50% not aware
	<i>Caregiver (N=19)</i>
Direct involvement with daily patient care	73%
Involved with discussions with therapists or instructions given?	rarely involved
Had concerns about current discharge plan	37% due to previous negative experiences
Experience with prior admissions, ED Visits & readmissions	68% (some remembered negative experience)

The patients in our study are typical of hospitalized patients with HF. Our findings will apply to the many health-care systems with a similar structure for cardiogeriatric care.

The discussion below leads to key systemic and clinical recommendations. The GMU is comprised of many clinical disciplines that utilize a complex network/web of care processes tuned over the years to provide the current results. However this survey indicates many significant care gaps exist. If we are serious about improving clinical results, we must accept that the system must change. A quality assurance program should be developed to re-engineer processes to ensure they are both focused on the patient's goals and preferences while being compliant with best clinical practice. A focus on optimal patient satisfaction will drive change back through the GMU system.

Based on patient feedback, our discussion focuses on two areas: GMU items and Patient/Caregiver items.

### GMU Items

We identified specific clinical recommendations that should be implemented immediately and should be part of any process

re-engineering and quality assurance program. For example, the Gap Tool was ordered in only 74% of the cases by MDs when the patient was admitted to GMU. This can be rectified by a better orientation of physicians and trainees to achieve a rate of 100% compliance. Discussion of code status, prognosis, and documentation in the chart in addressing advance care planning (ACP) can also be enhanced from 58% of the cases to 100% during the EoL discussions.

In addition to clinical process re-engineering, survey results recommend organizational changes between the Geriatric Consult and the GMU teams leading to better selection of patients for GMU transfer. Direct transfer to palliative care would better serve some candidate patients. In this study five patients continued to do poorly during their GMU stay and post-DC, too ill to even participate in a survey phone interview. Unfortunately for these patients, the appropriate focus on symptom management and EoL issues was not done. Inappropriate patient selection for the GMU results in suboptimal use of GMU skills and resources, blocking access for other better suited patients.

Next consider DC summary and planning items. Consistent with the literature,<sup>(24)</sup> this study noted many addressable

factors that contribute to undesirable DC preparation. These include inadequate attention to QoL issues; poor symptom management; caregiver burden and their competency; complex medication regimen with a high potential of error and duplication; discharged too quickly.

Important gaps on the transition of care from hospital to home were identified. Improved provider-to-provider communication can be achieved by better documentation of medical goals of care, clarity on HF specific recommendations such as achieving targets (e.g., DC weight, BP & HR), management of weight, sodium restrictions, diuretic use, and evidence-based medications. Furthermore, changes in HF medications from pre- to post- hospital stay should be in the summary letter to PCP. Finally, planning for advanced directives, life expectancy discussion, and total status reconciliation of cognitive, function, social support and expectation post-acute care are also needed in the DC summary.<sup>(25)</sup>

In our survey, we found that only 37% had HF-specific recommendations included in DC summaries to PCP. The GMU needs to provide job aids/tools to rotating MDs to establish consistency in required information dictated in DC letters and minimize the variability in the quality of DC summaries. This is particularly important because only 25% of patients had seen a cardiologist.

EoL issues and prognosis were not discussed. The concept of palliative care was foreign to almost all participants. The Canadian and the American consensus guidelines strongly recommend that clinicians should initiate and facilitate regular discussions with patients and family regarding advance care planning (ACP).<sup>(26,27)</sup> Inadequate preparation for EoL care often results in inappropriate use of acute care. This discussion can be planned as part of a DC plan checklist, with early follow-up and discussion based on the PaTH model.<sup>(28)</sup>

Regardless of the quality of the DC plan, GMU does not track the success of the plan. Consequently, GMU does not receive vital performance feedback. GMU organization should be extended to encompass outpatient cardiogeriatric clinics to follow HF patients and to receive feedback from the patient, caregiver, cardiologist, and PCP post-DC. The DC plan implementation would be owned by GMU and prevent difficulties accessing PCP care post-DC. In our study, none of the patients was seen within the first two weeks post-DC.

### Patient/Caregiver Items

We need to enhance patient/caregiver recollection of the HF diagnosis, management, and self-care. Only 20% of patients remembered that they had a HF diagnosis. We should provide better explanations regarding what patients must get right in their self-care, such as weight monitoring, adherence to HF diet, and exercise. This can be achieved by providing a medical information package to both patient and caregiver that includes simple information about the diagnosis and easy-to-follow instructions.

Unfortunately, cognitive impairment (CI) is often under-recognized in this population.<sup>(29)</sup> CI diminishes the ability to follow lifestyle changes such as salt/fluid restriction, and following medication regimen and activities. The presence of CI in our patients added more complexity to the communication. Therefore, a systematic review of the medical information package with the caregiver can enhance adherence to the team's recommendations.

The use of phone calls from a hospital designated individual can be used to reinforce and offer clinical support for the DC plan recommendations and promote adherence to the plan. Again, a quality assurance program would help ensure optimal results for DC plan compliance.

Effective HF self-care can help optimize clinical outcomes. However, this is dependent on the patient undertaking a number of complex self-care behaviours. Research into the effectiveness of HF self-care management programs demonstrates mixed results.<sup>(30)</sup> This survey indicates HF self-care remains a challenge. Consequently, there is a need to improve the understanding of patient perspectives and challenges related to self-care in order to enhance supportive interventions. The way health-care professionals interact and communicate with patients strongly influences their understanding of their condition and subsequent behaviors.<sup>(30)</sup> Effective self-care was more evident when patients perceived that their health-care professional was responsive, interested in their individual needs, and shared information.

These challenges suggest a need for new research and practice strategies that accommodate the increasing complexity of this frail population with HF. Improved HF management needs to be tailored to make optimal use of enhanced HF self-care utilizing community resources, ambulatory care, and in-home support services.<sup>(31)</sup> A key component of this change is establishing novel cardiogeriatric clinics<sup>(32)</sup> to facilitate geriatrician, cardiologist, and PCP teamwork, resulting in better ambulatory care management of multi-morbidity in HF<sup>(33)</sup> and constructive feedback to inpatient GMU services.

### Limitation of Our Survey

The small sample size raises the question of generalizability. However, our sample size was not different from the current literature for a qualitative study<sup>(5)</sup> and is acceptable for a quality improvement project. Other limitations include the interview time period (the interviews were conducted based on the patient's ability to answer questions). Language barriers existed; some patients required an English translator or simplified questions.

We learned that it is crucial to plan strategies that accommodate the special circumstances of frail older patients with HF. We had to allow more time for patients to adjust to their new environment and to be patient with them. We had to engage the family in the discussion. We used visual cues and repetition to assist patients with cognitive impairment to conduct the interviews. We made the interviews short in duration and simplified specific questions.

## CONCLUSION/ FUTURE DIRECTION

This study found that the quality of care, from the perspective of HF patient/caregiver experiences and preferences, was not optimal. The survey identified many care gaps both within GMU and with the DC summary hand-off. These results will provide the ‘current state’ and starting point for a major quality assurance program. The first step in this program is to perform a root cause analysis to determine the source of these quality gaps. The second step is an organization change to move the DC summary implementation via a cardiogeriatric clinic to GMU to provide direct performance feedback. The root cause analysis and this direct DC summary implementation feedback will provide input to drive the necessary process re-engineering. In this and similar cardiogeriatric settings, the key is to provide a clinical framework that allows the cardiologist, geriatrician, PCP, patient, and caregiver to actively work together as a team to develop the optimal DC plan.

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## CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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