Feasibility and performance of a patient-oriented discharge instruction tool for heart failure

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ABSTRACT

Background The provision of patient-centred discharge instructions is a pivotal goal for improving quality of care for patients with heart failure (HF) during care transitions. We tested the feasibility and performance of a novel discharge instruction tool co-designed with patients and adapted for HF; the patient-oriented discharge summary (PODS-HF) with the aim of improving communication, comprehension and adherence to discharge instructions.

Methods An iterative process was used to adapt and implement an existing patient instruction tool for patients with HF (PODS-HF). A mixed methods approach was then used to explore patient experience, feasibility and performance using a pre-post study design among eligible patients admitted for HF over a 6-month period. Outcome measures included: the documentation of patient-centred instructions, a locally derived Average Discharge Score (ADS) based on the inclusion of instructions in nine key areas, patient satisfaction and understanding and adherence to instructions at 72 hours and 30 days determined using follow-up phone calls.

Results 19 patients were enrolled. The ADS increased by 68% with more consistent documentation. Patient satisfaction remained high. Patients provided PODS-HF reported receiving written information about HF related signs and symptoms to watch for (two out of five patients in the usual care group vs seven out of seven patients in the PODS-HF group; $p=0.045$). Patients also felt more confident to manage their own health and 30-day adherence to diet and exercise instructions improved while reducing the need for unscheduled visits. Quantitative results were supported by themes identified during follow-up calls, namely, the utility of written instructions and the importance of a follow-up call.

Conclusion PODS-HF is a feasible tool for the delivery of patient-centred discharge instructions for patients with HF. The individual benefits of clarification and reinforcement made during follow-up calls among patients receiving this tool remains to be clarified.

BACKGROUND

Heart failure (HF) prevalence is increasing, and as the most common reason for admission in those over 65 years, has a significant impact on healthcare resources.¹ Around 25% of patients are readmitted within 30 days of discharge² and up to a quarter of these readmissions may be avoidable.³ Some avoidable readmissions may result from

lack of patient-centred solutions and other challenges faced during the transition from hospital to home.^{4 5} A growing body of research highlights how patient engagement contributes to improved care,⁶ and for many institutions, improving patient engagement and developing patient-centred processes is a priority supported by Health System Funding reform.⁷ The American Heart Association Scientific Statement on Transitions of Care in HF highlights gaps in care related to the unmet needs of patients particularly in regard to managing unexpected symptoms and the challenges of an often-changing medication regime.⁸ Other studies have highlighted the vulnerabilities of patients in the postdischarge period and the poor retention of verbal instructions.^{9 10} The provision of high-quality education and written discharge instructions is crucial in patients' understanding of self-management strategies for HF, facilitating the transition from hospital to home and may prevent avoidable readmissions.^{11–14}

Canadian, American and European HF guidelines recommend teaching patients to control sodium and fluid intake, weigh themselves daily and recognise symptoms of worsening HF and emphasise the important role of self-management during the postdischarge period.^{15–17} A systematic review on patient-oriented discharge tools¹⁸ showed that most tools place emphasis on patient education in the context of bundled care incorporating home visits or early follow-up but lack enquiry as to the usability of discharge instructions once at home. The Transitions of Care Consensus Conference⁸ outlined categories of information that should be incorporated into the discharge summary.¹⁹ This was validated by a study whereby patients identified categories of information relevant to their care which are easy to understand and act on which were subsequently used to co-create a patient-oriented discharge summary (PODS) tool.²⁰ The PODS is one of the few published

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patient-instruction discharge tools we know of which was codeveloped with patients and which is adaptable to a wide range of patients and discharge practices.^{20 21}

We hypothesised that the PODS adapted specifically for patients with HF would be a feasible and high performing tool for delivering patient centred discharge instructions.

METHODS

This analysis is part of a larger mixed methods study which took place between December 2016 and June 2017. Only the quantitative results are presented in detail in this paper. The qualitative themes emerging from the interview data are published elsewhere.²² The first author (TS) was a cardiology fellow who completed this project as part of a quality improvement graduate degree and one of the authors was involved in the original PODS design and evaluation for usability and feasibility (KO).^{18 21} Eligible patients were unknown to all study authors and only TS had contact with participants. The Standards for Quality Improvement Reporting Excellence (SQUIRE V.2.0) were followed as a guideline for reporting throughout this manuscript.²³

Local context and study population

This study took place on the cardiology ward of a quaternary care academic health science centre. This ward discharges 10–20 patients with acute decompensated HF per month. Patient education resources include formal education sessions for patients and caregivers from a dietician and pharmacist prior to discharge. A prior audit demonstrated that education and self-management instructions were documented in <60% of discharge summaries and the provision of written discharge instructions to patients was non-standardised. Root cause analysis employing Ishikawa diagrams, multivoting and Pareto charts demonstrated that healthcare workers providing discharge instructions (predominantly nurses and junior doctors) identified a lack of knowledge and prompts in the electronic discharge template as key drivers of the omissions. Analysis of the current discharge process revealed that copies of the electronic discharge summaries were being provided to patients at discharge but their content directed towards healthcare providers and lacked any specific individualised instructions for the patient.

Eligible patients were admitted to the cardiology ward between December 2016 and June 2017 with a primary diagnosis of HF. Patients were excluded if they had cognitive impairment, did not speak English, did not have a phone, were transferred to another ward, service or facility or had a survival prognosis of less than 3 months.

Interventions

The PODS is a discharge instruction tool co-designed with patients and caregivers by another group of researchers that included one of our co-authors (KO).^{20 21} The PODS include a single page of individualised instructions, written for Grade 6 education level, which can be translated into multiple languages with design features such as

pictograms, large font and space for patient notes which improve retention.^{20 24} The six categories of instructions are (1) diagnosis; (2) medication instructions; (3) signs and symptoms and how to act on them; (4) follow-up appointments and telephone numbers; (5) diet and activity changes and (6) additional resources.

Original PODS content was subsequently adapted for HF in an iterative fashion, using a modified Delphi approach. A Delphi approach is a consensus-based technique providing a systematic method of collecting informed judgements from a group of experts via multiple iterations. The expert panel consisted of a HF nurse practitioner (NP), Physician Director of HF, three cardiologists, a data analyst, general internist and a quality expert. Iterations included a review of the AHA consensus guidelines for transitions of care,⁸ a ranking evaluation of those to include and a consensus meeting. Usability testing with patient volunteers provided refinements to the final design. The project team leading the implementation of the discharge instructions in both preintervention and postintervention groups comprised a clinical lead (HF physician), unit nursing director, educator, pharmacist, dietician and HF NP.

Plan-do-study-act cycles were conducted to determine the optimal time to provide the information to patients. Providing patients with the PODS-HF at the time of discharge was unsuccessful as it was frequently forgotten at this busy time on the ward. Another cycle attempting to provide PODS-HF at the time of formal education sessions also fell short, as not all patients are able to attend. Ultimately, a patient journal documenting information provided at various points of his emergency and in-patient journey provided a valuable 'experience map' that demonstrated peak information transfer occurred at the time of admission to the inpatient ward. This exercise, as well as patient feedback provided the rationale to provide PODS-HF to patients at the time of admission to the ward. PODS-HF were then provided to patients on admission to the ward to read and annotate during their stay and also provided the standard 'script' for day-of-discharge instructions provided by staff. Patients also received the usual electronic discharge summary. Patient and staff feedback along with direct observation were used to inform the delivery and the design. Staff education took place at daily huddles for 2 weeks before implementation.

Design

Patients recruited to the preintervention (usual care) cohort underwent usual education and discharge processes as described above. Patients recruited to the postintervention cohort received the PODS-HF (figure 1). The study was based on the Model for Improvement that asks three fundamental questions: what are we trying to accomplish, how will we know a change is an improvement and what changes can we make to result in an improvement utilising iterative cycles of planning, implementing and studying.²⁵ Additionally, we applied concepts from experience-based design²⁶ such as direct

_____’s **Heart Failure Care Guide**

I came to hospital on _____ and left on _____

I came into hospital because I have _____

Medications I need to take

My medications, their purpose and possible side effects, have been explained to me ☐

How I might feel and what to do

	How I am feeling	What to do
	- No shortness of breath or cough - Able to climb stairs and perform daily activities at home - No increased swelling in your feet, legs or stomach	- Enjoy feeling well - Keep active
	- Gained 3-4 pounds (2 kg) in 2 days or 5 pounds (2.5kg) in 1 week - Tired- unable to do usual activities - More short of breath than usual - More swelling - Reduced appetite	- Call family doctor to make an appointment in the next 1-2 days - You may adjust your lasix but only if you have been instructed on how to do so
	- Short of breath at rest - Dizzy or faint - My heart is racing even at rest - Feeling ‘foggy’ or confused - Having chest pains that do not go away with rest	- Please call 911 - Do not drive yourself to hospital - Sit upright and try to take slow deep breaths - If you have chest pain: - Rest - Take nitroglycerin as prescribed - Get help

My Notes

Changes to my routine

Activity	Instruction
Weigh yourself	Every day before breakfast and write it down to keep track My ideal weight is _____
Salt intake	Aim to eat less than 1500mg per day Look at food labels Don't add salt
Fluid	Drink less than 1.5-2L (6-8 cups) per day of ANY fluid (includes ice cream, yoghurt, soup, milk)
Exercise	Continue at a slower pace until you feel back to normal

Appointments I have to go to

Go see _____ for _____ on _____ at _____

Location: _____ Booked ☐

Go see _____ for _____ on _____ at _____

Location: _____ Booked ☐

Go see _____ for _____ on _____ at _____

Location: _____ Booked ☐

Where to go for more information

For	Call/See	Telephone/Address
Dietary advice	Amanda	
Information	Website	www.tedrogersheartfunction.ca

Figure 1 Patient-oriented discharge summary for heart failure (PODS-HF) final design (front and back).

observation, patient experience mapping and a combination of structured and semistructured postdischarge interviews to more fully understand the user experience.

Outcomes and other measures

Baseline data were collected at the time of enrolment and included sex, age, education level, self-reported health literacy,²⁷ dependence on family for care, length of stay of index hospitalisation and mean emergency room visits for HF in the 6 months prior to index hospitalisation.

Primary outcome measures related to feasibility and performance included: (1) Average Discharge Score (ADS), (2) the percentage of discharge summaries with patient education and provision of discharge instructions clearly documented per month and (3) patient satisfaction scores (based on a 1–10 Likert scale at 72 hours postdischarge). The ADS was a locally derived score based on findings from previous studies and adapted for HF.^{19 20} The ADS reflects the inclusion of nine key areas in the discharge summary: (1) medications; (2) signs and symptoms to be aware of; (3) what to do about worrying symptoms; (4) information on salt and (5) fluid restriction; (6) target weight; (7) follow-up appointment; (8) phone numbers and (9) provision of additional resources. All patients received 72 hours and 30-day follow-up telephone calls by a HF physician and consisted of both structured and semistructured interviewing. A structured validated patient-experience survey

for transitions of care provided the secondary outcomes: understanding of condition, what to do if worried, medications, follow-up appointments and confidence in self-management was used at 72 hours.²⁸ Additionally, self-reported adherence to discharge instructions, particularly medications, diet, exercise and follow-up appointments, along with readmission or other unscheduled visits was also recorded at 30-day follow-up.

Analysis

Run charts and statistical process control (SPC) charts were used to display the primary outcome measures of ADS, rate of documentation of education and patient satisfaction. Standard rules for the interpretation of run charts and SPC charts were used to determine significance and association of interventions with outcomes.²⁹ Preintervention and postintervention aggregate data were used in the event of detecting special cause variation from a chart. Additionally, all patients completed structured and semistructured interviews during the telephone calls regarding their understanding of the instructions, adherence and other experiences (secondary outcomes).

Fisher's exact test was used to compare preintervention and postintervention baseline data using JMP SAS software V.12. Each telephone interview was transcribed and qualitative themes from interviews determined by thematic coding using grounded theory.³⁰ A coding framework

Table 1 Baseline characteristics

	Preintervention (%) n=5	Postintervention (%) n=8	Overall (%) n=13
Male gender	4 (80)	7 (87)	11 (85)
Age	58±10	58±15	
Education			
High school or less	0	1 (13)	1 (8)
Trade/diploma	5 (100)	0	5 (22)
University	0	7 (87)	7 (54)
Limited health literacy	1 (20)	2 (25)	3 (20)
Lives alone	0	2 (25)	2 (15)
Depends on family for			
Self-care	0	0	0
Food preparation	1 (20)	0	1 (8)
Medication administration	0	0	0
Transportation	0	1 (13)	1 (8)
Length of stay of index hospitalisation	19±14 (median 13)	13±4 (median 15)	
Emergency room visits for heart failure in last 6 months	2 (40)	1 (12.5)	3 (23)

was developed by the clinical lead and secondary analysis performed by a coinvestigator to determine consistency and breadth before coding all interviews to determine recurrent and emerging subthemes. Triple coding of the data with a third investigator ensured agreement of major themes and subthemes.

RESULTS

Over the course of the initiative, 19 eligible patients were enrolled. Five formed the preintervention (usual care)

cohort and 14 were provided the PODS-HF intervention. Six patients from the intervention cohort were subsequently excluded as they no longer met inclusion criteria. The study cohort was predominantly male, young and educated ([table 1](#)).

Only two of the postintervention cohort lived alone, the remainder lived with spouses and described themselves as independent (very few relied on family for self-care, food preparation, medication administration or transportation). Less than half of our preintervention and

Figure 2 X-bar Shewhart chart displaying ADS by month. The control limits represent a spread of six-sigma, three above and three below the CL where sigma is the estimated standard deviation of the statistic, and hence, where most of the data would be expected to lie, Health Care Data Guide p 114). ADS, Average Discharge Score; CL, centreline; LCL, lower control limit; PODS-HF, patient-oriented discharge summary for heart failure; UCL, upper control limit.

Figure 3 Run chart showing rate of documentation of education and instructions in the discharge summary. PODS-HF, patient-oriented discharge summary for heart failure.

postintervention group had had an ER visit for HF in the last 6 months.

ADS improved by 68% following the interventions. The [figure 2](#) shows an X-bar chart displaying ADS over time. There is special cause variation in the data prior to January 2017 (eight consecutive points below the centre line and three data points on the chart within the outer third of the control limits). The percentage of patients with documentation of education and discharge information is demonstrated in the run chart in [figure 3](#). There is no special cause noted on the run chart, however, it appears that the average rate may be improving. Patient satisfaction was high (ratings >8/10) in the preintervention cohort and remained high throughout ([figure 4](#)).

Twelve of 13 patients received 72 hours and 30-day follow-up calls. Patient experience data and understanding of discharge instructions are summarised in [table 2](#).

Missing data for the patient that could not be contacted by telephone was obtained from the electronic patient record. Preintervention, the majority of the participants reported a high level of understanding of their condition, medications and what follow-up was required. Postintervention, patients reported a significantly higher level of having received information in writing about warning signs and symptoms to watch for (100% compared with 40%; $p < 0.05$). Patients receiving the PODS-HF also reported better understanding of their condition and higher confidence in self-management though this did not reach significance.

At 30 days, adherence to medication instructions and follow-up appointments was high in both groups; however, adherence to instructions for diet and exercise increased in the post-intervention group and the need for unscheduled visits decreased, though was not statistically significant. There was one readmission in the postintervention group and this occurred in the patient with whom telephone follow-up could not be achieved.

Several themes emerged from the qualitative analysis of the patient interviews which highlight the impact of the PODS and support the quantitative findings. The first was the utility of having written discharge instructions to refer to, particularly for increasing confidence, ability to self-manage and increasing self-reported adherence with medications, diet and exercise among those receiving PODS-HF for the first time. The second theme was the 'importance of the follow-up call', which provided an opportunity in almost every case for clarification and repetition of discharge instructions and follow-up, as well as provide reassurance and risk assessment.²²

DISCUSSION

In summary, we found PODS-HF to be a feasible discharge instruction tool which improved the delivery of patient-centred discharge instructions for patients with HF. Patient satisfaction for discharge experience remained high and both the ADS and the rate of documentation of instructions and patient education increased after the PODS-HF was implemented. Moreover, PODS-HF was

Figure 4 Run chart of Patient Satisfaction Scores. Ranking 1 (worst) to 10 (best).

found to improve patient reports of receiving written information about signs and symptoms to watch out for, a measure of quality and patient experience which is reported nationally and has been found to be linked with improved health outcomes.³¹ While other measures of patient understanding and adherence to instructions did not reach statistical significance, this study shows promising performance for improving and standardising communication of discharge instructions to patients with HF.

Education is an intervention considered low on the hierarchy of effectiveness,³² though was identified as a key driver of the problem during root cause analysis and therefore necessary to address. Repeated reminders of project goals at daily huddles and the presence on the unit of the clinical lead and other team members may have contributed to a Hawthorne effect; the modification of behaviour in response to an awareness of being observed.³³ The combined elements of the PODS-HF study, that is, the provision of patient-centred discharge instructions, written self-management information, early follow-up with phone calls and risk assessment are aligned with previous published data and validated tools used in transitional care models. The Naylor Transitional Care Model is centered around nine components including, but not limited to education and the promotion of self-management, assessing and managing risks and symptoms, fostering coordination and the engagement of patients and caregivers.³⁴ Additionally, the Coleman Care Transitions Intervention is aimed at performing medication reconciliation in the home, telephone calls, self-management coaching and care coordination.³⁵

‘Missing pieces’ of information have been described in another study looking at functional social and environmental barriers to recovery at home in vulnerable post-discharge patients.³⁶ Our study demonstrates how the use of patient-centred tools like the PODS-HF can improve understanding of key elements of discharge instructions.

In this study, we documented an improvement in the ADS, a locally derived measure of the quality of discharge instructions that includes information on nine key elements within the discharge summary related to the information patients value and those recommended by guidelines.^{15 20} This improvement is, however, unlikely to be attributable to any single intervention. The timeline of the initiative coincided with an institution-wide upgrade of the electronic discharge template in November 2016, which may have affected the validity of findings. Patient satisfaction was found to be reliably high and did not change after implementation of the PODS-HF. Patient satisfaction scores, however, are an insensitive measure of the success of an intervention, as are often subject to response bias among respondents.³⁷

The direct impact of follow-up calls was not anticipated or formally assessed, though was revealed to play an important mitigating role to review discharge instructions. The authors acknowledge that the ongoing provision of specialist physician-led calls is not feasible or sustainable. Previous studies looking at the impact of follow-up calls after discharge by healthcare practitioners directly involved in the patients’ care like pharmacists or nurses have yielded mixed results.^{38–41} Our qualitative analysis and patient feedback would suggest a role for their continued use when combined with the

Table 2 Patient experience and understanding of discharge instructions

	Preintervention (%) N=5	Postintervention (%) N=7	Overall (%) N=12
Did you have a better understanding of your condition when you left the hospital? (Completely/quite a bit)	4 (80)	6 (85)	10 (83)
Did staff talk to you about whether you would have the help needed when you left the hospital? (Yes)	4 (80)	5 (71)	9 (75)
Did you get information in writing about warning signs and symptoms to watch out for in monitoring your heart failure? (Yes)	2 (40)	7 (100)*	9 (75)
Did you receive enough information about what to do if you were worried about your condition or treatment after you left the hospital? (Completely/quite a bit)†	3 (60)	3 (43)	6 (50)
Did you have a clear understanding of all your prescribed medications? (Yes)	5 (100)	7 (100)	12 (100)
Did you have a clear understanding about your follow-up appointments and investigations? (Strongly agree/agree)‡	5 (100)	7 (100)	12 (100)
Were you confident that you could actually do the things you needed to do to take care of your health?	4 (80)	7 (100)	11 (92)
What number would you rate this hospital during your stay? (Scale of 0–10 where 10 is the best hospital) (≥8)	5 (100)	7 (100)	12 (100)
30-day adherence to discharge instructions			
Medications	5 (100)	7 (100)	12 (100)
Diet	3 (60)	7 (100)	10 (83)
Exercise§	2 (67)	1 (100)	3 (75)
Follow-up with GP or specialist¶	5 (100)	7 (100)	12 (100)
Unscheduled visits	2 (40)	2 (29)	4 (33)
Readmission (no deaths)	0	1**	1**

*Significant by Fisher's exact test, $p=0.045$.

†None out of five individuals answered 'completely' in the preintervention phase versus three out of seven in the postintervention phase.

‡Two out of five individuals answered 'completely' in the preintervention phase versus four out of seven in the postintervention phase.

§Of the three individuals who were provided with exercise prescriptions.

¶Most individuals had seen their specialist (92%) by 30-day follow-up but not their GP (50%).

**The readmitted patient was the only one who was unable to be contacted after discharge.

GP, general practitioner.

PODS-HF or similar patient instruction tools.²² The follow-up phone calls unexpectedly ‘intervened’ as often as they were carried out, by reinforcing discharge instructions, carrying out medication reconciliation, clarifying follow-up plans or providing relevant phone numbers. Feedback from staff using the PODS-HF identified it as an additional task for them and another item to give the patients. It is now planned that PODS-HF will be a patient-oriented ‘face-sheet’ to the rest of the electronic discharge summary and will ‘pull’ patient relevant information from other sections of the summary, thus reducing the need for ‘extra work’.

We acknowledge that technological advances may allow for the more generalised use of digital solutions to replace paper-based interventions. Web-based applications for handheld devices that enable bluetooth integration of biometric data to enable certain groups of patients to self-monitor and manage remotely with their healthcare teams are in development. Cohealth, a Toronto-based technology company specialising in digital solutions is adapting PODS for iPhone app use.⁴²

This study’s feasibility rests on the use of a multifaceted and collaborative approach to improve the provision of standardised patient-oriented discharge instructions and patient education to patients discharged with HF. Strengths of this study lay in its controlled unit-based environment, team approach and the use of patient feedback at multiple points to inform rapid cycle changes to its delivery.

A major limitation of the study was the small number of patients enrolled affecting the generalisability of the conclusions to institutions with a different demographic and ability to demonstrate statistical significance. Though many patients were excluded on the basis of language barriers and cognitive impairment, recruitment of participants from one specialised unit inherently meant many of the participants were predominantly male, young, independent and well educated. Moreover, as a quaternary institution, the cardiology ward is often populated by patients with late stage heart disease being assessed and evaluated for advanced therapies. This may also account for the preintervention high level of understanding of their condition, medications and follow-up.

CONCLUSION

The PODS-HF project used quality improvement methodology to adapt an existing tool and provided insight into the processes of education and delivery of discharge instructions. Our study helps highlight the intrinsic benefits of transitional care interventions which centre on high quality and patient-centred written discharge instructions and patient education among patients with HF. The individual benefits of follow-up phone calls in patients receiving this or similar tools needs to be clarified in further studies.

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