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Patient Experiences using a Novel Tool to Improve Care Transitions in Patients with Heart Failure: The Patient Oriented Discharge Summary (PODS-HF).

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4 **Patient Experiences using a Novel Tool to Improve Care Transitions in Patients**
5 **with Heart Failure: The Patient Oriented Discharge Summary (PODS-HF).**
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- 52 • Heart failure, care transitions, quality improvement, patient centered, education
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Abstract

Objective. Improving discharge instructions so that they are patient-centered may improve patient experience, understanding and adherence to discharge instructions following an admission for heart failure (HF).

Design. Semi-structured interviews assessed the utility of a novel discharge tool adapted for HF; Patient-Oriented Discharge Summary (PODS-HF) in the first 30-days after leaving hospital. Three investigators used grounded theory to determine themes from the narrative data.

Setting. The cardiology ward of an urban academic institution.

Participants. 13 patients and caregivers completed 24 interviews.

Results. Analysis revealed 6 interconnected themes:

1) *Utility of discharge instructions*; how patients perceive and use written and verbal instructions. Patients receiving PODS-HF identified value in the patient-centered summarised content.

2) *Adherence*; strategies used by patients to enhance adherence to medications, diet and lifestyle changes. PODS-HF provides a strong visual reminder, particularly early post-discharge.

3) *Adaptation*; how patients incorporate changes into 'new norms.' This was more evident by 30 days, and those using PODS-HF had less unscheduled visits and readmissions.

4) *Relationships with healthcare providers*; patients' perceptions of the roles of family physicians and specialists in follow-up care.

5) *Role of family and caregivers*; the role of caregivers in supporting adherence and adaptation.

6) *Follow-up phone calls*; the utility of follow-up calls, particularly early after discharge as a means of providing clarification, reassurance, and education.

Conclusion. PODS-HF is a useful tool that increases patients' confidence to self-manage and facilitates adherence by providing relevant written information to reference after discharge.

Article Summary.

- A novel patient-centered discharge instruction tool was adapted for heart failure and piloted on a cardiology ward in an urban academic institution.
- Qualitative patient experience data was collected at 72hrs and 30 days post discharge using semi-structured telephone interviews and analyzed using grounded theory.
- The patient population was predominantly young, male and educated and may limit the generalizability of findings to a wider HF population.

- The emerging 6 interconnected themes provide a unique insight into how patients and caregivers perceive and use discharge instructions and how tools such as PODS HF may facilitate adherence

Introduction

The final pathway of all cardiac disease, heart failure (HF) prevalence is increasing. There are over 5 million Canadians living with HF and 50,000 new diagnoses each year¹. Of the patients with HF discharged from hospital, 25% will be readmitted within 30-days and 50% within 6-months. Unplanned readmissions cost the Canadian healthcare service around \$35M annually and it is estimated that up to a quarter may be preventable^{2,3}. Much has been invested in interventions to improve the management and uptake of evidence-based therapies for HF, both in the inpatient and outpatient setting^{4,5,6}. While mortality benefits and modest reductions in hospitalisations have been realised over time, they have plateaued and the focus is shifting to improving transitions of care and new models of service delivery following discharge.

Efforts to understand readmissions have shifted to a more patient-centric approach for understanding the experiences of patients and their families as they transition from hospital to home. Patients are vulnerable in transitions of care, have poor recall of verbal instructions and discharge summary quality impacts patients' ability to adhere to discharge instructions^{7,8,9}. Canadian, American and European HF Guidelines recommend teaching patients self-management strategies to control sodium and fluid intake, weigh themselves daily and recognize symptoms of worsening HF¹⁰⁻¹². The findings from these studies, along with government incentives to reduce readmissions, length of stay and improve follow-up as part of health system funding reform has led to the development of more patient-centered discharge tools designed with patients and caregivers¹³.

A Canadian group recently partnered with patients and caregivers to co-design an individualised, freely-available, written discharge instruction tool, the patient-oriented discharge summary (PODS), which can be used to engage patients when reviewing discharge instructions¹⁴. While an early adopter study was encouraging,¹⁵ the utility of PODS to improve transitions of care for patients with heart failure is still not known. We adapted PODS for HF and in this paper, describe the utility of this tool based on patient experiences in a 30-day period following a hospitalisation for HF.

Methods

Design

A qualitative design methodology was used employing grounded theory.¹⁶ Three independent researchers participated in an iterative process of coding, reviewing and analyzing the interviews. Research ethics approval was obtained from UHN Research Ethics Board in December 2016 and patient data stored in accordance with institutional policies. This manuscript is prepared in line with the Standards for Reporting Qualitative Research (SRQR).

Patient and Public Involvement

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2
3 Patients and caregivers were involved in the design process of the original PODS content
4 and in the adaptation of PODS-HF, its delivery and evaluation through the semi-structured
5 telephone interviews. All participants consented in writing to the study, including the
6 publication of findings.
7

8 9 **Participants**

10 Patients >18 years with a primary diagnosis of HF admitted to the general
11 cardiology ward of an academic institution were included. Patients were excluded if they
12 had cognitive impairment, did not speak English, did not have a telephone, were
13 transferred to another ward, service or facility or had a survival prognosis less than 3-
14 months.
15

16 17 **Approach**

18 The project took place between December 2016 and June 2017 and used the
19 Model for Improvement¹⁷ to adapt and implement PODS for HF in a pre-post design
20 (Schofield T. Improving transitions of care for patients with Heart Failure: Feasibility and
21 performance of a patient-oriented discharge instruction tool. Article under review).
22

23 Patients meeting inclusion criteria were identified at daily huddles and approached
24 for informed consent. All participants received a copy of PODS-HF (Figure 1) on
25 admission and follow-up telephone calls were performed at 72 hours and 30 days
26 following discharge. The electronic patient record was accessed for missing outcome data
27 when patients could not be reached.
28

29 Patient demographics included; age, sex, date of admission, education level, who
30 they live with, use of home-care services, and a measure of health literacy based on a
31 patient's capacity to understand health information and fill out health related forms¹⁸.
32

33 The telephone calls consisted of a structured and semi-structured qualitative
34 interview component at 72 hours and 30 days following discharge. The structured
35 interview assessed items related to the delivery of PODS HF, patients' understanding of
36 instructions given at time of discharge as well as a subjective Likert scale of satisfaction.
37 The semi-structured questions elicited experiences related to understanding and use of
38 discharge instructions with the PODS HF and was designed by the research team based
39 on previous qualitative work and literature review.¹⁵
40

41 All telephone interviews were audio-taped and transcribed verbatim. Emerging
42 themes from the interviews were analyzed using grounded theory¹⁶. The research team
43 met to discuss themes emerging from the transcripts and modified the interview guide
44 iteratively to provide more directed focus on these themes. Two investigators
45 independently reviewed transcripts to develop a coding scheme and a secondary analysis
46 was performed to determine consistency and breadth before coding all interviews to
47 determine recurrent and emerging subthemes. Quotations within the transcripts
48 highlighting each theme and subtheme were coded, reviewed and analysed. Triple coding
49 of the data with a third investigator ensured agreement of major themes and subthemes.
50 All investigators used a process of manual coding. Inter-rater reliability was achieved
51 using investigator triangulation by cross comparison of the emergent themes for all team
52 members at each meeting¹⁹.
53

54 55 **Results**

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Study Population

Overall, 24 telephone interviews were conducted with 13 patients recruited to the study (5 patients in the pre-intervention group and 9 in the post intervention group). Seventy-two hour interviews were conducted a mean of 3.8 +/- 1.4 days following discharge and 30-day interviews were conducted on average 33 +/- 4.8 days following discharge. One set of interviews were conducted with a caregiver (patient's spouse). Characteristics of the study group are summarised in *Table 1*. Three patients received a new diagnosis of HF, the majority had a pre-existing diagnosis. The study cohort was predominantly male (85%), young (average 58 years.) and mostly educated at a college or university level. Only 2 of the post-intervention cohort lived alone, the remainder lived with spouses and described themselves as independent (80% of the pre-PODS and 75% of the post-PODS group).

Descriptive analyses comparing pre- and post-intervention quantitative data have been described in detail in another article by T Schofield entitled 'Improving transitions of care for patients with Heart Failure: Feasibility and performance of a patient-oriented discharge instruction tool' currently under review. Importantly, post-intervention patients reported a higher rate of having received information in writing about signs and symptoms to watch out for and what to do about them (100% vs 40% pre-intervention, $p=0.045$). The post intervention group also reported higher rates of adherence with diet (100% vs 60%) and exercise (100% vs 67%) at 30 days and the need for unscheduled visits also reduced in the post-intervention group (29% vs 40%) but were not statistically significant.

Qualitative Themes

The narrative dataset from the semi-structured interview questions revealed 6 key interconnected themes and subthemes in relation to the utility of discharge instructions for patients with HF (*Figure 2*).

1. Utility of discharge instructions

The first theme refers to the utility of discharge instructions during usual care (pre-PODS HF) in comparison to the utility of the PODS HF instructions. Verbal instructions at our institution are not standardized and delivered at the discretion of the healthcare provider, usually on the day of discharge. Written instructions consist of a printed electronic discharge summary created from an electronic template, which can 'pull' laboratory investigations and imaging results directly from the reporting software. There is a section for patient instructions, however, this is buried within a detailed 5-7-page document containing acronyms and medical jargon. In contrast, the PODS HF is a short document with instructions directed to the patient.

Verbal discharge instructions, making up the first subtheme on this topic, were frequently perceived as rushed, overwhelming, or incomplete, with several patients in the pre-intervention group reporting feeling as though staff could take extra time to explain things more fully at the time of discharge, as illustrated in this excerpt;

"maybe if somebody would kind of sit down and spend 5 or 10 minutes to go through the things, sort of separately, that would be a good thing." (72hrs Pre-PODS HF)

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4 The second subtheme of **written instructions**, were perceived by 60% of pre-
5 intervention patients as being more directed at the next healthcare provider, with several
6 patients commenting that the written content was not relevant to them or contained things
7 they could not understand:
8

9
10 *“There’s a lot of stuff they put on here that’s stuff I don’t understand, but it’s for*
11 *someone else to look at like my doctor so...?” (72hrs pre-PODS HF)*
12

13 This perceived lack of relevance was reflected in a third subtheme of **how patients use**
14 **the written discharge instructions**. Patients reported filing their paperwork away once
15 home. In contrast, in the group receiving PODS HF, particularly, the 2 patients with a new
16 diagnosis of HF, found the PODS format of written discharge instructions particularly
17 useful, as is illustrated by this excerpt;
18

19
20 *“you know the best piece of paper they gave me, the one that is colourful. That’s very*
21 *important for people who never had any kind of heart failure, who don’t even know what*
22 *symptoms to look out for, when to call 911 when you’re not doing well.... Because if*
23 *people never had any kind of heart failure, then they don’t know..., so it’s what you gave*
24 *me it’s very helpful for someone who leaves the hospital, in one piece of paper, they*
25 *can see.” (72hrs post-PODS-HF)*
26
27

28 This subtheme links to the themes of Adherence and Adaptation discussed below.
29 Patients in both groups reported keeping written materials, though often did not refer to
30 them within the first few days. By 30-days the majority of patients had looked over their
31 discharge papers.
32

33
34 Patients in the PODS-HF group more often described using them as a visual reminder,
35 particularly within 72hrs; placing the sheet in a prominent place, such as on a refrigerator,
36 a bedside table or kitchen bench. Additionally, 2 patients in the PODS-HF group planned
37 to take the sheet with them to their family doctor to facilitate the visit, anticipating, that the
38 doctor would not have received a copy of the discharge information.
39

40 41 **2. Adherence**

42 This theme highlights the ways in which patients use and follow-through with discharge
43 instructions and links to the next theme of *Adapting*. Though PODS-HF provides an
44 additional area for notes on medications to be written, this area was not used by our
45 patients, and it was the additional medication chart provided (routinely) to patients that
46 was most often commented on in aiding in post-discharge adherence. The majority of
47 patients reported using this medication list, particularly in the early post-discharge period,
48 while they are in the process of adapting their routine. By 30-days, however, the reliance
49 on this visual reminder for medication adherence was less; *“I know what to take, I don’t*
50 *really have to look at the chart anymore.”*
51
52

53
54 Changes to diet and fluid intake are key principles in the non-pharmacological
55 management of HF, and are arguably, the elements most under the influence of the
56
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1
2
3 patient and caregiver. All patients in both pre-and post-intervention groups discussed
4 dietary modifications at length in the early follow-up calls, and it dominated the narrative
5 of newly diagnosed patients. It was also a frequent topic in the 30-day calls, but from a
6 more reflective standpoint. Our data suggests it was the individual teaching received on
7 the ward which had the greatest influence on dietary adherence, with a strong visual
8 reminder provided by PODS-HF of the maximum recommended total daily sodium intake
9 and overall daily fluid restriction. Patients recall the group or individual teaching they
10 receive on the ward and become more aware of the salt content of foods they consume
11 as illustrated in this excerpt;
12
13

14
15 “it’s just opened my eyes to the amount of sodium and places I used to go like X...and I
16 was just appalled when I saw that their nutrition information, this breaded chicken patty
17 had like, 2000mg of salt, which to me is unbelievable” (72hrs post PODS-HF)
18

19 Patients admitted experiencing difficulties with food preparation because most of the
20 packaged food they previously relied upon as being too salty and have learned to cook
21 from ‘scratch’. Others reported avoiding some foods completely in order to reduce salt
22 intake.
23

24
25 This theme also links to the *Role of family and Caregivers* theme discussed below.
26 Patients with support often draw on them in early stages after discharge with help with
27 medications and dietary modifications. Moreover, younger patients reported feeling anti-
28 social effects of dietary restriction more readily. A patient reported avoiding recreational
29 events after discharge, because of the temptation, and feeling socially isolated as a
30 consequence. Frequently reflected in our cohort, was a desire to be compliant with the
31 recommendations provided by the hospital, with all patients detailing the concessions
32 they were making at the early interviews and proudly reflecting on the sustainable
33 changes they had discovered by trial and error at the 30-day calls.
34
35

36
37 *“I enjoy it, I guess you could say, looking for recipes that are within it and finding ways*
38 *of making things tasty without the salt...I see it as a bit of a challenge and I like to do it.*
39 *I’ve got my husband on board there to eating similarly, as it’s a good diet for anybody*
40 *really.” (30 day pre-PODS-HF)*
41

42 **3. Adaptation**

43 Newly diagnosed patients and pre-intervention patients reflected a sense of anxiety
44 around going home, as illustrated in the excerpt below;
45

46
47 *“that’s the one thing I knew about being in the hospital, as yukky as I was feeling, I*
48 *always knew that help was just...you know...pressing the button... So, I was kind of*
49 *nervous about going home, because I thought what if that happens and there’s no*
50 *medical staff around. That was the first day or so after, and then I started to feel a little*
51 *better. I started to worry about that less.” (72hrs pre-PODS HF)*
52

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54 Adapting to new routines was most challenging for newly diagnosed patients, as
55 they have to make the most accommodations. **Factors that influence** patients’ ability to
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3 make these shifts in routine, was a subtheme and included things such as the support of
4 family and caregivers and time off work to establish new routines. Early in transitions,
5 patients describe being busy adjusting to being home. Often, they hadn't looked over their
6 discharge papers, instead making arrangements for medications and resting after their
7 hospital stay. Several patients related how sleeping patterns had shifted as they catch up
8 on sleep once home: *"I'm sleeping really well, I haven't really slept well in 6 months!"* For
9 other patients, the memory of the hospitalisation or the gravity of the diagnosis can be
10 traumatic.
11

12 Most patients described needing to change their routine to accommodate
13 medication schedules, either due to altered sleeping habits (improvement in HF
14 symptoms, catching up on sleep lost in hospital) or by returning to work.
15

16
17 *"...I'm taking my medications, but I don't take them exactly on time...I was up half the*
18 *night...because I just couldn't sleep and then I was sleeping 'til noon and I just took my*
19 *medications at that time...and I only just took my weight..." (72hrs pre-PODS-HF)*
20

21 At 30-days many patients reflected how they had adapted their routines to support
22 necessary changes, by **developing new norms** which emerged as a second subtheme.
23 A patient described how he now walks to a pharmacy every day in order to check his
24 blood pressure and weight whilst simultaneously getting the exercise recommended by
25 his physician.
26

27
28 *"... it gives me a reason to go out walking...it's a good thing. And then I can email the*
29 *result to my computer and keep it" (30 days post PODS-HF)*
30

31 Patients who were most successful in making changes and developing new norms had a
32 sense of gravity about their condition:
33

34
35 *"what choice do I have? Half my heart is dead..." (30 days post PODS-HF)*
36

37 **4. Role of family and caregivers**

38 None of our patient population received publically funded homecare and the majority (11
39 of 13) of patients lived with spouses or other family members. These informal caregivers
40 play an integral role supporting the other themes of adaptation and adherence by helping
41 obtain, dispense and supervise medications, helping to prepare salt restricted meals,
42 coaching and reassurance, as illustrated in the following excerpts:
43
44

45
46 *"I feel very fortunate, because I've got my husband here all the time and he's just,*
47 *picked up the slack when I just couldn't do it." (72hrs pre-PODS-HF)*
48

49 *"...basically, ...cooking... ..washing my clothes, you know, keeping an eye on me,*
50 *making sure I'm ok. Sometimes I'm in the washroom and she'll come and check on me,*
51 *make sure I'm ok, something like that." (72hrs post PODS-HF)*
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Caregivers have a pivotal role in helping patients get to follow-up appointments and providing another set of ears while listening to verbal instructions. The caregiver we interviewed supported a role for PODS HF as an important reference for the caregiver;

“I know that you can be quite scattered when you get home and you’ve been in a structured environment, and someone else has been looking after all the meds and looking after everything, and if it’s a first experience for you it could be quite un-nerving.... I could quite see how something like this, where you could jot it down, you would need a little info, you know, when you got out of there” (72hrs post PODS-HF caregiver)

Caregivers also play a crucial and active role early on in ‘picking up the slack’ in the first few days post discharge, and subsequently have a more supportive role towards 30 days.

5. Relationship with Healthcare Providers

Many patients in our study when asked about adherence to post-discharge follow-ups perceived their specialist to be the most important person to follow-up with, as opposed to other scheduled or recommended providers in the patients’ circle of care, as illustrated by this statement; *“...he’s not really specialised in the stuff (the cardiologist) are specialised in, you know, he’s specialised in general stuff...”* Several patients reported in the early post discharge period if they were not feeling well, that the first point of contact would be their specialist. Other patients expressed feelings of dissatisfaction with post-discharge primary care, either with their ability to get a timely appointment; *“to follow up with my family doctor is not the easiest thing”*, obtain a family doctor after a period of good health; *“He told me I can’t really visit, as I am not a patient anymore. I went there once 4 years ago to follow up on shots.”* Or of greater concern, regarding a poor relationship; *“I’m kind of fed up with my family doctor...he doesn’t care about anything, I don’t know why I bother going to see him.”*

A subtheme of **factors that influence satisfaction** with their healthcare providers emerged and included topics such as ease of communication, ability to make appointments in a timely fashion and clinicians taking the time to explain medical terms and provide additional information were highly valued. Patients were highly satisfied with their hospital care, as reflected in the consistently high satisfaction scores (>8 on a scale of 1-10). Patients enjoyed and learned from the in-house dietician and education sessions and appreciated the one-on-one pharmacist teaching and medication lists. Continuity of care appeared to be a factor associated with satisfaction. This was particularly true for patients who had follow-up clearly arranged and written down before leaving the hospital and in those who received follow-up calls, leading to the next major theme.

6. Follow-Up Calls

The additional role of a telephone call for conducting interviews for data-collection was not identified a priori, but emerged as an important major theme in our HF cohort. Three distinct subthemes emerged from the transcribed data on this theme: **Clarification**, **Education**, and **Risk Assessment**. The interviewer is a cardiologist with expertise in HF who was asked during the majority of calls to clarify medical terminology and educate, as

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2
3 illustrated in this excerpt discussing the implications of a reduced ejection fraction and
4 subsequent follow-up written on the discharge summary;
5

6
7 *“Oh, that’s kind of what I needed, someone to explain how long it will take (for heart*
8 *function to recover), It’s nice to have somebody explain that to me. The medical team*
9 *was too busy by the time I go” (72hr post PODS-HF and new diagnosis)*
10

11 There were also opportunities to clarify instructions for follow-up, despite our policy
12 of writing follow-up appointment information²⁰. In several instances, details of scheduled
13 follow-up on the electronic system were confirmed during the call and clarification given
14 to clinic and investigation locations. In one case, this averted a potential clinic no-show.
15 Some issues that arose with clarification provided opportunity for process improvement;
16 *“on the discharge paper, there is the number to call back. But I called that number and it*
17 *is not in service…”* Additionally, there were also many opportunities to clarify medication
18 doses with real-time medication reconciliation and clarify and educate around fluid
19 restrictions. Follow-up calls also had the effect of providing additional information and in
20 several cases enabled a **risk assessment** to be carried out for symptoms of recurrent
21 heart failure.
22

23
24 Follow-up calls were able to provide reassurance and coaching for patients, linking
25 with other themes of adaptation, adherence and relationship with healthcare providers.
26 Though the interviewer introduced the interview as being for data collection purposes, all
27 patients expressed that they found the phone call useful.
28

29
30 *“Yes! I am very glad we had this conversation with you and talking to you and the tips*
31 *and the advice, you know, and the questions themselves, I am really glad you called it*
32 *was great”*
33 *(30-day post PODS-HF and new diagnosis)*
34

35 There was a temporal distinction between the type of information being provided
36 during the calls. At the 72hr call, more clarification was being provided as to discharge
37 instructions, follow-up plans and medication, as well as reinforcement of dietary and fluid
38 restrictions. The need for such reinforcement was less at the 30-day call.
39
40

41 42 **Discussion**

43 Our study revealed 6 interconnected themes and subthemes which highlight the
44 utility and limitations of PODS-HF for patients transitioning home from an admission for
45 HF; 1) Utility of discharge instructions, 2) Adherence, 3) Adapting, 4) Role of family and
46 caregivers, 5) Relationship with healthcare providers and 6) Follow-up phone calls. These
47 findings add to the growing literature focussing on patient experiences in the transition
48 from hospital to home. Our results provide granularity to the needs of patients with HF as
49 they adjust to life outside the hospital and how they acquire the necessary self-
50 management skills using information they are provided with at, or just after, discharge.
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54 The content and quality of discharge information has been shown to be crucial,
55 and its perceived relevance can impact adherence and readmission rates.^{9, 21} The day
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3 of discharge is busy and often overwhelming for patients and a significant proportion of
4 verbal information provided at the time of discharge is poorly retained ⁸. This study
5 highlights 6 major themes in a novel analysis of patient experience in transitions of care
6 after a hospitalisation for HF. The first theme, '*utility of written discharge instructions*',
7 supports the use of written, summarised individualised discharge instructions for HF, that
8 are patient-centered and relevant to issues faced by patients after discharge; namely
9 those of managing medications, assessing symptoms and deciding what to do about
10 them, organising follow-up and navigating the health system ²². Patients in our cohort
11 liked the coloured single page summary and used PODS-HF along with their separate
12 medication chart as visual aids to help them adhere to discharge instructions, as reflected
13 in our second theme. The use of PODS-HF for improving self-reported adherence to diet
14 and exercise recommendations and confidence to self-manage may facilitate successful
15 and early adaptation to new norms. Adaptation, and role of caregivers, our third and fourth
16 major themes, have been reported by previous authors as important steps facilitating self-
17 management for patients with heart failure ^{23 24}.

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20
21 Lastly, the role of the follow-up telephone calls, though not intended as part of the
22 PODS-HF intervention, emerged as an important and potentially therapeutic adjunct to
23 post-discharge follow-up in our HF cohort. In our study, the call provided an additional
24 point of clarification and education in 100% of calls at 72hrs. The calls also afforded an
25 opportunity to provide additional resources and conduct risk assessment for patients still
26 experiencing symptoms. The effect of follow-up calls in fostering the relationship with
27 healthcare providers, providing early access and enhancing continuity of care and
28 adherence has been previously described ^{25 26}, however, their impact on health outcomes
29 has been inconclusive ²⁷ and not well described in patients transitioning home with HF.
30 Additionally, the calls highlighted opportunities for process improvement, for example, the
31 provision of out of service telephone numbers, and issues with medication dispensation
32 that could be more patient-centered. This links with the shift to patient-centric care models
33 that mandate patient and family feedback to refine and improve healthcare delivery. This
34 last theme when taken together with the other 5 themes suggest the usefulness of PODS-
35 HF may be influenced by individual adaptation, the role of family or other caregivers,
36 health-care relationship and access to post-discharge care.

37
38
39 Previous studies have examined the quality of discharge summaries from the
40 limited perspective of the healthcare provider ^{9 28}. A strength of this study is that we looked
41 specifically at the utility of written discharge instructions from the patient and caregiver
42 perspective. This study identifies themes which have been previously described to
43 influence a successful patient-centered transition, including the role of written information,
44 adaptation, family or caregivers and the relationship with health-care providers^{22 29}. This
45 study also highlights ways in which patients may use written materials such as PODS-HF
46 to adhere to post-discharge instructions and to effectively self-manage. We also
47 discovered opportunities for process optimisation at our institution and others who do not
48 have these in place routinely, such as the potential benefits of early telephone follow-up.
49 Additionally, our patients highlighted the value of the medication charts as well as the
50 group education around salt and fluids and used the information as a visual reminder
51 along with PODS-HF after discharge to adhere to lifestyle changes. Guidelines, such as
52 the AHA statement on transitions of care in HF, highlight the importance of education,
53 self-management strategies, sodium restriction, medication and timely follow-up in the
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context of more individualised management programs³⁰. PODS-HF together with early follow up calls incorporate these elements in a patient-centered way to facilitate adherence and adaptation as patients transition to life at home after a hospitalisation.

Limitations of the study include its non-randomized design, small size, implementation on one specialized ward and the strict eligibility criteria. This may have led to the inclusion of patients more likely to succeed after a hospitalisation, limiting generalisability to patients who may stand to benefit even more from the intervention, for example, those with cognitive impairment or requiring additional support to transition home. Our adaptation of PODS-HF did not contain a medication list as one was provided separately. The medication chart was a theme in our narrative data that facilitated adherence to medications and so may be a useful addition to PODS in an environment that did not already provide a separate patient centered medication chart. Lastly, the individual effect of the post-discharge phone call as an emerging theme needs further clarification in patients receiving the PODS-HF.

Conclusion

Themes identified in this paper highlight new insights into the challenges, adaptive behaviours and opportunities to improve transitional care for patients and families living with HF, particularly through the use of patient-centered written instructions. PODS-HF provides patients and caregivers with a patient-centered reference of relevant information for HF. Together with early follow-up calls, PODS-HF may facilitate patients to make changes that are timely, sustainable and effective. Further study with a larger and broader range of patients with HF is required to determine PODS-HF ability to reduce post-discharge healthcare utilisation when compared to usual discharge processes.

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Competing Interest Statement

The authors declare no competing interests.

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Author Contributions

TS is a HF cardiologist who obtained, analyzed and interpreted data and participated in study design.

1
2
3 CY is a research assistant who participated in data analysis and interpretation of narrative
4 transcripts.

5 KO is a general internist who provided substantial contribution to the conception and
6 design of the study, analysed data and was involved in the drafting and revision of the
7 manuscript.

8 SH-G is a researcher who participated in data analysis and drafting and revision of the
9 manuscript.

10 SB is a cardiologist who provided substantial contribution to the drafting and critical
11 revision of the manuscript and was involved in the study design.

12 All authors read and approved the final manuscript.
13
14

15 **Data Sharing Statement**

16 The datasets used and analyzed during the current study are available from the
17 corresponding author on reasonable request.
18
19

20 **Figure Legends.**

21 Figure 1. Final PODS HF design (front on left, back on right).


22 Figure 2. Interconnected themes derived from the narrative data.
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UHN

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COURAGE LIVES HERE

_____’s **Heart Failure Care Guide**




I came to hospital on _____ and left on _____

I came into hospital because I have _____ My Notes

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
 <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Enjoy feeling well Keep active
 <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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
 <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Please call 911 Do not drive yourself to hospital Sit upright and try to take slow deep breaths If you have chest pain: <ol style="list-style-type: none"> 1. Rest 2. Take nitroglycerin as prescribed 3. Get help

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. Final PODS HF design (front on left, back on right).

88x57mm (300 x 300 DPI)



279x215mm (300 x 300 DPI)

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3
Purpose or research question	#4 Purpose of the study and specific objectives or questions	3
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and	3

guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.

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14	Researcher	#6	Researchers' characteristics that may influence the	12
15	characteristics and		research, including personal attributes, qualifications /	
16	reflexivity		experience, relationship with participants, assumptions	
17			and / or presuppositions; potential or actual interaction	
18			between researchers' characteristics and the research	
19			questions, approach, methods, results and / or	
20			transferability	
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25	Context	#7	Setting / site and salient contextual factors; rationale	4
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28	Sampling strategy	#8	How and why research participants, documents, or	4
29			events were selected; criteria for deciding when no	
30			further sampling was necessary (e.g. sampling	
31			saturation); rationale	
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35	Ethical issues pertaining	#9	Documentation of approval by an appropriate ethics	4
36	to human subjects		review board and participant consent, or explanation for	
37			lack thereof; other confidentiality and data security issues	
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40	Data collection methods	#10	Types of data collected; details of data collection	4
41			procedures including (as appropriate) start and stop	
42			dates of data collection and analysis, iterative process,	
43			triangulation of sources / methods, and modification of	
44			procedures in response to evolving study findings;	
45			rationale	
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50	Data collection	#11	Description of instruments (e.g. interview guides,	4
51	instruments and		questionnaires) and devices (e.g. audio recorders) used	
52	technologies		for data collection; if / how the instruments(s) changed	
53			over the course of the study	
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57	Units of study	#12	Number and relevant characteristics of participants,	5
58			documents, or events included in the study; level of	
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		participation (could be reported in results)	
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3	Data processing	#13 Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	4
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9	Data analysis	#14 Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	4
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16	Techniques to enhance trustworthiness	#15 Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	4
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21	Syntheses and interpretation	#16 Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5
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27	Links to empirical data	#17 Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-10
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31	Intergration with prior work, implications, transferability and contribution(s) to the field	#18 Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	10
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40	Limitations	#19 Trustworthiness and limitations of findings	12
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43	Conflicts of interest	#20 Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12
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48	Funding	#21 Sources of funding and other support; role of funders in data collection, interpretation and reporting	12
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BMJ Open

Patient Experiences using a Novel Tool to Improve Care Transitions in Patients with Heart Failure: A Qualitative analysis.

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Primary Subject Heading:	Cardiovascular medicine
Secondary Subject Heading:	Patient-centred medicine, Qualitative research
Keywords:	Heart failure < CARDIOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Cardiology < INTERNAL MEDICINE, QUALITATIVE RESEARCH

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4 **Patient Experiences using a Novel Tool to Improve Care Transitions in Patients**
5 **with Heart Failure: A Qualitative analysis.**
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51 **Keywords**

- 52 • Heart failure, care transitions, quality improvement, patient-centered, education
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Abstract

Objective. To evaluate the utility of a novel discharge tool adapted for heart failure (HF) on patient experience.

Design. Semi-structured interviews assessed the utility of a novel discharge tool adapted for HF; Patient-Oriented Discharge Summary (PODS-HF) at 72hrs and 30-days after leaving hospital. Interviews were recorded and transcribed verbatim. Three investigators used directed content analysis to determine themes and subthemes from the narrative data.

Setting. The cardiology ward of an urban academic institution in Canada.

Participants. 13 patients and caregivers completed 24 interviews. Eligible patients were >18 years and admitted with a diagnosis of HF.

Results. Analysis revealed 6 interconnected themes:

1) *Utility of discharge instructions*; how patients perceive and use written and verbal instructions. Patients receiving PODS-HF identified value in the patient-centered summarized content.

2) *Adherence*; strategies used by patients to enhance adherence to medications, diet and lifestyle changes. PODS-HF provides a strong visual reminder, particularly early post-discharge.

3) *Adaptation*; how patients incorporate changes into 'new norms.' This was more evident by 30-days, and those using PODS-HF had less unscheduled visits and readmissions.

4) *Relationships with healthcare providers*; patients' perceptions of the roles of family physicians and specialists in follow-up care.

5) *Role of family and caregivers*; the pivotal role of caregivers in supporting adherence and adaptation.

6) *Follow-up phone calls*; the utility of follow-up calls, particularly early after discharge as a means of providing clarification, reassurance, and education.

Conclusion. PODS-HF is a useful tool that increases patients' confidence to self-manage and facilitates adherence by providing relevant written information to reference after discharge.

Strengths and Limitations of the Study

- This study explores patient experiences following discharge using a novel patient-centered discharge instruction tool; the Patient Oriented Discharge Summary for Heart Failure (PODS-HF) using directed content analysis.
- The original PODS tool was co-created with patients and families and adapted for heart failure.
- Our study presents a unique insight into how patients and caregivers perceive and use discharge instructions.
- Our study highlights the potential limitations of written instructions and what modifications may be needed to the PODS-HF tool to meet the needs of the heart failure population.

- The study was conducted with patients discharged from a cardiology ward in an urban academic hospital in Canada, thus, generalizability to the wider heart failure population may be limited.

Introduction

There are over 5 million Canadians living with heart failure (HF) and 50,000 new diagnoses each year¹. Of the patients with HF discharged from hospital, 25% will be readmitted within 30-days and 50% within 6-months. Unplanned readmissions cost the Canadian healthcare service around \$35M annually and it is estimated that up to a quarter may be preventable^{2 3}. Much has been invested in interventions to improve the management and uptake of evidence-based therapies for HF, both in the inpatient and outpatient setting^{4 5 6}. While mortality benefits and modest reductions in hospitalizations have been realized over time, they have plateaued and the focus is shifting to improve transitions of care and new models of service delivery following discharge.

Canadian, American and European HF Guidelines recommend teaching patients self-management strategies to control sodium and fluid intake, weigh themselves daily and recognize symptoms of worsening HF⁷⁻⁹. However, patients are vulnerable during transitions of care and have poor recall of verbal instructions^{10 11}. Moreover, discharge summary quality has been found to impact adherence to discharge instructions¹². More recently, efforts to understand readmissions have shifted to a more patient-centric approach for understanding the experiences of patients and their families as they transition from hospital to home^{13 14}. Government incentives to reduce readmissions, length of stay and improve follow-up care, have formed part of health system funding reform¹⁵. Such incentives, alongside research studies, have led to the development of discharge tools designed with patients and caregivers to improve patient experience. While patient engagement and self-efficacy can be improved through the use of media or visual aids, few studies have examined the impact of such interventions on adherence, healthcare utilization and patient experience¹⁶.

A Canadian group recently partnered with patients and caregivers to co-design an individualized, freely-available, written discharge instruction tool, the patient-oriented discharge summary (PODS), which can be used to engage patients when reviewing discharge instructions¹⁷. An early adopter study demonstrated usability and feasibility with PODS currently in use across healthcare institutions in Ontario¹⁸. The utility of PODS to improve transitions of care for patients with HF however, is still not known. We adapted PODS for HF and in this paper, describe the utility of this tool based on patient experiences in a 30-day period following a hospitalization for HF.

Methods

Design

Directed content analysis was used to determine themes from transcripts of telephone interviews conducted with patients discharged after an admission with HF. Directed content analysis draws on existing theory or research to develop an initial coding scheme prior to analysis and then the scheme is refined by adding additional codes and

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3 themes as the analysis proceeds. In this way, existing theory can be supported and
4 extended¹⁹. Three independent researchers participated in an iterative process of coding,
5 reviewing and analyzing the interviews.
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8 Formal research ethics approval was waived by the University Hospital Network
9 Research Ethics Board in December 2016 and patient data stored in accordance with
10 institutional policies. This manuscript is prepared in accordance with the Standards for
11 Reporting Qualitative Research (SRQR)²⁰.
12

13 **Patient and Public Involvement**

14 Patients and caregivers were involved in the design process of the original PODS
15 content and in the adaptation of PODS-HF; the categories it contained; colours and the
16 timing of its delivery. All participants consented in writing to the study, including the
17 publication of findings.
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19

20 **Approach**

21 This qualitative analysis is part of a larger mixed methods project which took place
22 between December 2016 and June 2017 which used the Model for Improvement to adapt
23 and implement PODS for HF²¹. Only the qualitative results are presented in this paper
24 and the descriptive analyses comparing pre-and post-intervention quantitative data are
25 described in detail elsewhere. (Schofield T. Improving transitions of care for patients with
26 Heart Failure: Feasibility and performance of a patient-oriented discharge instruction tool.
27 Article under review). The first author (TS) was a cardiology fellow undergoing graduate
28 level studies in quality improvement. Other authors are experts in care transitions (KO),
29 qualitative research (SHG, CXY) and complex care models and improvement (SB). Two
30 of the authors were involved in the original PODS design and evaluation for usability and
31 feasibility (KO and SHG)^{16 18}. Eligible patients were unknown to all study authors and only
32 TS had contact with participants.
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36 **Participants**

37 A purposeful sampling strategy was used where study participants who met
38 eligibility criteria were identified and approached face to face by the study lead (TS).
39 Eligible participants included patients >18 years with a primary diagnosis of HF admitted
40 to the general cardiology ward of an academic institution. Patients were excluded if they
41 had cognitive impairment, did not speak English, did not have a telephone, were
42 transferred to another ward, service or facility or had a survival prognosis less than 3-
43 months.
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46 All participants received a copy of PODS-HF (Figure 1) on admission and follow-
47 up telephone calls were performed at 72 hours and 30-days following discharge by TS.
48 The electronic patient record was accessed for missing outcome data when patients could
49 not be reached.
50

51 Patient demographics included; age, sex, date of admission, education level, who
52 they live with, use of homecare services, and a measure of health literacy based on a
53 patient's capacity to understand health information and fill out health related forms²².

54 The telephone calls consisted of a structured and semi-structured qualitative
55 interview component at 72 hours and 30-days following discharge. Questions were
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3 designed in accordance with a previous care transition study²³. The structured interview
4 collected for use in the quantitative study assessed items related to the delivery of PODS-
5 HF; patients' understanding of instructions given at time of discharge as well as a
6 subjective Likert scale of satisfaction. The semi-structured questions used for the
7 qualitative piece of this study elicited experiences related to understanding and use of
8 discharge instructions with the PODS-HF. All telephone interviews were audio-taped and
9 transcribed verbatim. Initial and emerging themes from the interviews were analyzed
10 using directed content analysis¹⁹. The research team met to discuss themes emerging
11 from the transcripts and modified the interview guide iteratively to provide more directed
12 focus on these themes. Two investigators (TS and CXY) independently reviewed
13 transcripts to develop a coding scheme and a secondary analysis was performed to
14 determine consistency and breadth before coding all interviews to determine recurrent
15 and emerging subthemes. Quotations within the transcripts highlighting each theme and
16 subtheme were coded, reviewed and analyzed. Triple coding of the data with a third
17 investigator (KO) with all original transcripts ensured agreement of major themes and
18 subthemes. All investigators used a process of manual coding. As a final step to decrease
19 bias, inter-rater reliability was achieved using investigator triangulation by cross
20 comparison of themes for all team members at each meeting²⁴.

25 Results

26 Participant characteristics.

27 Overall, 24 telephone interviews were conducted with 13 patients recruited to the
28 study (5 patients in the pre-intervention group and 8 in the post-intervention group). One
29 patient underwent cardiac transplantation before 30-days and another could not be
30 contacted for the 72hr interview. Interviews conducted within 72 hours following discharge
31 were undertaken a mean of 3.8 +/- 1.4 days following discharge and 30-day interviews
32 were conducted on average 33 +/- 4.8 days following discharge. One set of interviews
33 were conducted with a caregiver. Three patients received a new diagnosis of HF, the
34 majority had a pre-existing diagnosis. Respondents were predominantly male (85%),
35 young (average 58 years.) and mostly educated at a college or university level. Only 2 of
36 the post-intervention cohort lived alone, the remainder lived with spouses and described
37 themselves as independent (80% of the pre-PODS and 75% of the post-PODS group).

38 Importantly, post-intervention patients reported a higher rate of having received
39 information in writing about signs and symptoms to watch out for and what to do about
40 them (100% vs 40% pre-intervention, $p= 0.045$). The post-intervention group also
41 reported higher rates of adherence with diet (100% vs 60%) and exercise (100% vs 67%)
42 at 30-days and the need for unscheduled visits also reduced in the post-intervention
43 group (29% vs 40%) but were not statistically significant.

48 Qualitative Themes

49 The narrative dataset from the semi-structured interview questions revealed 6 key
50 interconnected themes (in *italics*) and subthemes (in **bold**) in relation to the utility of
51 discharge instructions for patients with HF (*Figure 2*).

54 1. *Utility of discharge instructions*

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2
3
4 The first theme refers to the utility of discharge instructions during usual care (pre-
5 PODS-HF) in comparison to the utility of the PODS-HF instructions. Verbal instructions
6 at our institution are not standardized and delivered at the discretion of the healthcare
7 provider, on the day of discharge. Written instructions consist of a printed electronic
8 discharge summary created from an electronic template, which can 'pull' laboratory
9 investigations and imaging results directly from the reporting software. There is a section
10 for patient instructions, however, this is buried within a detailed 5-7-page document
11 containing acronyms and medical jargon. In contrast, the PODS-HF is a short document
12 with instructions directed to the patient.
13

14
15 **Verbal discharge instructions**, make up the first subtheme on this topic and were
16 frequently perceived as rushed, overwhelming, or incomplete. Several patients in the pre-
17 intervention group reported feeling as though staff could take extra time to explain things
18 more fully at the time of discharge, as illustrated in this excerpt;
19

20
21 *"maybe if somebody would kind of sit down and spend 5 or 10 minutes to go through*
22 *the things, sort of separately, that would be a good thing." (72hrs Pre-PODS-HF)*
23

24 The second subtheme of **written instructions**, were perceived by 60% of pre-
25 intervention patients as being more directed at the next healthcare provider, with several
26 patients commenting that the written content was not relevant to them or contained things
27 they could not understand:
28

29
30 *"There's a lot of stuff they put on here that's stuff I don't understand, but it's for*
31 *someone else to look at like my doctor so...?" (72hrs pre-PODS-HF)*
32

33 This perceived lack of relevance was reflected in a third subtheme of **how patients use**
34 **the written discharge instructions**. Patients reported filing their paperwork away once
35 home. In contrast, in the group receiving PODS-HF, particularly, the 2 patients with a new
36 diagnosis of HF, found the PODS format of written discharge instructions particularly
37 useful, as is illustrated by this excerpt:
38

39
40 *"you know the best piece of paper they gave me, the one that is colourful. That's very*
41 *important for people who never had any kind of heart failure, who don't even know what*
42 *symptoms to look out for, when to call 911 when you're not doing well.... Because if*
43 *people never had any kind of heart failure, then they don't know..., so it's what you gave*
44 *me it's very helpful for someone who leaves the hospital, in one piece of paper, they*
45 *can see." (72hrs post-PODS-HF)*
46
47

48 This subtheme links to the themes of Adherence and Adaptation discussed below.
49 Patients in both groups reported keeping written materials, though often did not refer to
50 them within the first few days. By 30-days the majority of patients had looked over their
51 discharge papers. Patients in the PODS-HF group more often described using them as a
52 visual reminder, particularly within 72hrs; placing the sheet in a prominent place, such as
53 on a refrigerator, a bedside table or kitchen bench. Additionally, two patients in the PODS-
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3 HF group planned to take the sheet with them to their family doctor to facilitate the visit,
4 anticipating, that the doctor would not have received a copy of the discharge information.
5

6 7 **2. Adherence**

8 This theme highlights the ways in which patients use and follow-through with
9 discharge instructions and links to the next theme of **Adaptation**. Though PODS-HF
10 provides an additional area for notes on medications to be written, this area was not used
11 frequently. It was the additional medication chart provided (routinely) to patients that was
12 most often commented on in aiding in post-discharge adherence. The majority of patients
13 reported using this medication list, particularly in the early post-discharge period, while
14 they are in the process of adapting their routine. By 30-days, however, the reliance on
15 this visual reminder for medication adherence was less;
16

17
18 *“I know what to take, I don’t really have to look at the chart anymore.”*
19

20 Changes to diet and fluid intake are key principles in the non-pharmacological
21 management of HF, and are arguably, the elements most under the influence of the
22 patient and caregiver. All patients in both pre-and post-intervention groups discussed
23 dietary modifications at length in the early follow-up calls, and it dominated the narrative
24 of newly diagnosed patients. It was also a frequent topic in the 30-day calls, but from a
25 more reflective standpoint. Our data suggests it was the individual teaching received on
26 the ward which had the greatest influence on dietary adherence, with a strong visual
27 reminder provided by PODS-HF of the maximum recommended total daily sodium intake
28 and overall daily fluid restriction. Patients recalled the group or individual teaching they
29 received on the ward and became more aware of the salt content of foods they consumed
30 as illustrated in this excerpt;
31
32

33
34 *“it’s just opened my eyes to the amount of sodium and places I used to go like X...and I*
35 *was just appalled when I saw that their nutrition information, this breaded chicken patty*
36 *had like, 2000mg of salt, which to me is unbelievable” (72hrs post PODS-HF)*
37

38
39 Patients voiced difficulties with food preparation because most of the packaged food they
40 previously relied upon as being too salty and have learned to cook from ‘scratch’. Others
41 reported avoiding some foods completely in order to reduce salt intake. This theme also
42 links to the **Role of family and Caregivers** theme discussed below. Patients with support
43 often drew on them in early stages after discharge to help with medications and dietary
44 modifications. Moreover, younger patients reported feeling anti-social effects of dietary
45 restriction more readily. A patient reported avoiding recreational events after discharge,
46 because of the temptation, and feeling socially isolated as a consequence. Frequently
47 reflected in our cohort, was a desire to be compliant with the recommendations provided
48 by the hospital, with all patients detailing the concessions they were making at the early
49 interviews and proudly reflecting on the sustainable changes they had discovered by trial
50 and error at the 30-day calls;
51
52

53
54 *“I enjoy it, I guess you could say, looking for recipes that are within it and finding ways*
55 *of making things tasty without the salt...I see it as a bit of a challenge and I like to do it.*
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3 *I've got my husband on board there to eating similarly, as it's a good diet for anybody*
4 *really." (30-day pre-PODS-HF)*
5
6

7 **3. Adaptation**

8 Newly diagnosed patients and pre-intervention patients reflected a sense of
9 anxiety around going home, as illustrated in the excerpt below;
10

11 *"that's the one thing I knew about being in the hospital, as yukky as I was feeling, I*
12 *always knew that help was just...you know...pressing the button... So, I was kind of*
13 *nervous about going home, because I thought what if that happens and there's no*
14 *medical staff around. That was the first day or so after, and then I started to feel a little*
15 *better. I started to worry about that less." (72hrs pre-PODS-HF)*
16
17

18 Adapting to new routines was most challenging for newly diagnosed patients, as they
19 have to make the most accommodations. The subtheme of **factors that influence**
20 patients' ability to make these shifts in routine, included things such as the support of
21 family and caregivers and time off work to establish new routines. Early in transitions,
22 patients described being busy adjusting to being home. Often, they had not looked over
23 their discharge papers, instead making arrangements for medications and resting after
24 their hospital stay. Several patients related how sleeping patterns had shifted as they
25 caught up on sleep once home;
26
27

28 *"I'm sleeping really well, I haven't really slept well in 6 months!"*
29
30

31 Most patients described needing to change their routine to accommodate medication
32 schedules, either due to altered sleeping habits (improvement in HF symptoms, catching
33 up on sleep lost in hospital) or by returning to work;
34

35 *"...I'm taking my medications, but I don't take them exactly on time...I was up half the*
36 *night...because I just couldn't sleep and then I was sleeping 'til noon and I just took my*
37 *medications at that time...and I only just took my weight..." (72hrs pre-PODS-HF)*
38
39

40 At 30-days many patients reflected how they had adapted their routines to support
41 necessary changes, by **developing new norms** which emerged as a second subtheme.
42 One patient described how he now walks to a pharmacy every day in order to check his
43 blood pressure and weight whilst simultaneously getting the exercise recommended by
44 his physician;
45

46
47 *"... it gives me a reason to go out walking...it's a good thing. And then I can email the*
48 *result to my computer and keep it" (30-days post PODS-HF)*
49
50

51 Patients who were most successful in making changes and developing new norms had a
52 sense of gravity about their condition;
53

54 *"what choice do I have? Half my heart is dead..." (30-days post PODS-HF)*
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4. Role of family and caregivers

None of our patient population received publicly funded homecare and the majority (11 of 13) of patients lived with spouses or other family members. These informal caregivers play an integral role supporting the other themes of adaptation and adherence by helping to obtain, dispense and supervise medications; helping to prepare salt restricted meals; coaching; and reassurance, as illustrated in the following excerpts:

"I feel very fortunate, because I've got my husband here all the time and he's just, picked up the slack when I just couldn't do it." (72hrs pre-PODS-HF)

"...basically, ...cooking... ...washing my clothes, you know, keeping an eye on me, making sure I'm ok. Sometimes I'm in the washroom and she'll come and check on me, make sure I'm ok, something like that." (72hrs post PODS-HF)

Caregivers have a pivotal role in helping patients get to follow-up appointments and providing another set of ears while listening to verbal instructions. The caregiver we interviewed supported a role for PODS-HF as an important reference for the caregiver;

"I know that you can be quite scattered when you get home and you've been in a structured environment, and someone else has been looking after all the meds and looking after everything, and if it's a first experience for you it could be quite un-nerving.... I could quite see how something like this, where you could jot it down, you would need a little info, you know, when you got out of there" (72hrs post PODS-HF caregiver)

Caregivers also play a crucial and active role early on in 'picking up the slack' in the first few days post-discharge, and subsequently have a more supportive role towards 30-days.

5. Relationship with Healthcare Providers

When asked about adherence to post-discharge follow-up many patients in our study perceived their specialist to be the most important person to follow-up with, as opposed to other scheduled or recommended providers in the patients' circle of care, as illustrated by this statement;

"...he's not really specialised in the stuff (the cardiologist) are specialised in, you know, he's specialised in general stuff..."

Several patients reported in the early post-discharge period if they were not feeling well, that the first point of contact would be their specialist. Other patients expressed feelings of dissatisfaction with post-discharge primary care, either with their ability to get a timely appointment, or obtain a family doctor after a period of good health;

;

"to follow up with my family doctor is not the easiest thing",

1
2
3 *"He told me I can't really visit, as I am not a patient anymore. I went there once 4 years*
4 *ago to follow up on shots."*
5

6
7 Or of greater concern, regarding a poor relationship;

8
9 *"I'm kind of fed up with my family doctor...he doesn't care about anything, I don't know*
10 *why I bother going to see him."*
11

12 A subtheme of **factors that influence satisfaction** with healthcare providers
13 emerged and included topics such as ease of communication and ability to make
14 appointments in a timely fashion. In addition, clinicians that took the time to explain
15 medical terms and provide additional information were highly valued. Patients were
16 highly satisfied with their hospital care, as reflected in the consistently high satisfaction
17 scores (>8 on a scale of 1-10). Patients benefitted from the in-house dietician and
18 education sessions and appreciated the one-on-one pharmacist teaching and medication
19 lists. Continuity of care appeared to be a factor associated with satisfaction. This was
20 particularly true for patients who had follow-up clearly arranged and written down before
21 leaving the hospital and in those who received follow-up calls.
22
23

24 25 **6. Follow-Up Calls**

26 The additional role of a telephone call for conducting interviews for data collection
27 was not identified a priori, but emerged as an important major theme in our HF cohort.
28 Three subthemes emerged from the transcribed data on this theme: **Clarification,**
29 **Education,** and **Risk Assessment.** The interviewer was a cardiologist with expertise in
30 HF who was asked to clarify medical terminology and educate during the majority of calls,
31 as illustrated in this excerpt discussing the implications of a reduced ejection fraction and
32 subsequent follow-up written on the discharge summary;
33
34

35 *"Oh, that's kind of what I needed, someone to explain how long it will take (for heart*
36 *function to recover), It's nice to have somebody explain that to me. The medical team*
37 *was too busy by the time I go" (72hr post PODS-HF and new diagnosis)*
38
39

40 There were also opportunities to clarify instructions for follow-up. In several instances,
41 details of scheduled follow-up on the electronic system were confirmed during the call
42 and clarification given to clinic and investigation locations. In one case, this averted a
43 potential clinic no-show. Some issues that arose with clarification provided opportunity for
44 process improvement;
45

46
47 *"on the discharge paper, there is the number to call back. But I called that number and it*
48 *is not in service..."*
49

50 Additionally, there were many opportunities for real-time medication reconciliation and to
51 clarify and educate around fluid restrictions. Follow-up calls also had the effect of
52 providing additional information and in several cases enabled a **risk assessment** to be
53 carried out for symptoms of recurrent HF.
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3 Follow-up calls also provided reassurance and coaching for patients, linking with
4 other themes of adaptation, adherence and relationship with healthcare providers.
5 Though the interviewer introduced the interview as being for data collection purposes, all
6 patients expressed that they found the phone call useful;
7

8
9 *“Yes! I am very glad we had this conversation with you and talking to you and the tips
10 and the advice, you know, and the questions themselves, I am really glad you called it
11 was great” (30-day post PODS-HF and new diagnosis)*
12

13
14 There was a temporal distinction between the type of information being provided
15 during the calls. At the 72hr call, more clarification was being provided as to discharge
16 instructions, follow-up plans and medication, as well as reinforcement of dietary and fluid
17 restrictions. The need for such reinforcement was less at the 30-day call.
18

19 20 21 **Discussion**

22 Our study revealed 6 interconnected themes which highlight the utility and
23 limitations of PODS-HF for patients transitioning home from an admission for HF. This
24 study identifies and supports themes which have been previously described to influence
25 a successful transition, including the role of written information, adaptation, family or
26 caregivers and the relationship with healthcare providers^{13 14 23}. Our results provide insight
27 into the needs of patients with HF as they adjust to life outside the hospital and how they
28 acquire the necessary self-management skills using information they are provided with
29 at, or just after, discharge.
30

31 The content and quality of discharge information has been shown to be crucial,
32 and its perceived relevance can impact adherence and readmission rates^{12, 25}. The day
33 of discharge is busy and often overwhelming for patients and a significant proportion of
34 verbal information provided at the time of discharge is poorly retained¹¹. Our first theme,
35 ‘utility of written discharge instructions’, supports the use of written, summarised
36 discharge instructions for HF, that are patient-centered, individualized and relevant to
37 issues faced by patients after discharge; namely those of managing medications,
38 assessing symptoms and deciding what to do about them, organizing follow-up and
39 navigating the health system¹⁴. Guidelines such as the AHA statement on transitions of
40 care in HF highlight the importance of education, self-management strategies, sodium
41 restriction, medication and timely follow-up in the context of more individualized
42 management programs²⁶. Patients in our cohort liked the coloured single page summary
43 and used PODS-HF along with their medication chart as visual aids to help them adhere
44 to discharge instructions, as reflected in our second theme. The use of PODS-HF for
45 improving self-reported adherence to diet and exercise recommendations and confidence
46 to self-manage may facilitate successful and early adaptation to new norms. ‘*Adaptation*,
47 and ‘*role of family and caregivers*’, our third and fourth major themes, have been
48 previously reported as important steps facilitating self-management for patients with HF²⁷
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53 Follow-up telephone calls, though not intended as part of the PODS-HF
54 intervention, emerged as an important and potentially therapeutic adjunct to post-
55 discharge follow-up. The calls provided additional clarification and education and afforded
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3 an opportunity to provide additional resources or conduct risk assessment for patients still
4 experiencing symptoms. The effect of follow-up calls in fostering the relationship with
5 healthcare providers, providing early access and enhancing continuity of care and
6 adherence has been previously described^{29 30}, however, their impact on health outcomes
7 has been inconclusive and not well described in patients transitioning home with HF³¹.
8 Additionally, the calls highlighted opportunities for process improvement, for example, the
9 provision of out of service telephone numbers, and issues with medication dispensation
10 that could be more patient-centered. This links with the shift to patient-centric care models
11 that mandate patient and family feedback to refine and improve healthcare delivery. This
12 theme, along with the other 5 themes, suggest the usefulness of PODS-HF may be
13 influenced by individual adaptation, the role of family or other caregivers, health-care
14 provider relationship and access to post-discharge care.

15
16
17 Previous studies have examined the quality of discharge summaries from the
18 limited perspective of the healthcare provider^{12 32}. A particular strength of this study is that
19 we looked specifically at the utility of written discharge instructions from the patient and
20 caregiver perspective. Moreover, the intervention is a novel tool designed and improved
21 on with patients and caregivers, which is a limitation of prior studies^{16 17}. Lastly, themes
22 identified strengthen previous quantitative studies by adding important context as to why
23 patient-centered interventions may improve post-discharge outcomes.

24
25 Limitations of the study include its non-randomized design, small size, and
26 implementation on one specialized ward. This may have led to the recruitment of patients
27 more likely to succeed after a hospitalization, limiting generalisability to patients who may
28 stand to benefit even more from the intervention, for example, those with cognitive
29 impairment or requiring additional support to transition home. In addition, the follow-up
30 call was provided by a specialist thus introducing a potential source of bias to the
31 participants' responses. Further study should clarify the independent effect of the post-
32 discharge phone call among participants receiving the PODS-HF.

33 34 35 **Conclusion**

36 Themes identified in this paper support previous findings and highlight new insights
37 into the challenges, adaptive behaviours and opportunities to improve transitional care
38 for patients and families living with HF, particularly through the use of individualized
39 written instructions. PODS-HF provides patients and caregivers with patient-centered
40 relevant information to reference for HF. Further study with a larger and broader range of
41 patients with HF is required to determine PODS-HF ability to reduce post-discharge
42 healthcare utilization when compared to usual discharge processes. Together with early
43 follow-up calls, PODS-HF may help patients to make changes that are timely, sustainable
44 and effective.

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Competing Interest Statement

The authors declare no competing interests.

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Author Contributions

TS is a HF cardiologist who obtained, analyzed and interpreted data and participated in study design.

CY is a research assistant who participated in data analysis and interpretation of narrative transcripts.

KO is a general internist who provided substantial contribution to the conception and design of the study, analyzed data and was involved in the drafting and revision of the manuscript.

SH-G is a researcher who participated in data analysis and drafting and revision of the manuscript.

SB is a cardiologist who provided substantial contribution to the drafting and critical revision of the manuscript and was involved in the study design.

All authors read and approved the final manuscript.

Data Sharing Statement

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Figure Legends.

Figure 1. Final PODS-HF design (front on left, back on right).

Figure 2. Interconnected themes derived from the narrative data.

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For peer review only

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UHN

University Health Network

COURAGE LIVES HERE

_____’s Heart Failure Care Guide

I came to hospital on _____ and left on _____




I came into hospital because I have _____

My Notes

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
 <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Enjoy feeling well Keep active
 <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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
 <ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Please call 911 Do not drive yourself to hospital Sit upright and try to take slow deep breaths If you have chest pain: <ol style="list-style-type: none"> 1. Rest 2. Take nitroglycerin as prescribed 3. Get help

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. Final PODS HF design (front on left, back on right).

88x57mm (300 x 300 DPI)



279x215mm (300 x 300 DPI)

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3
Purpose or research question	#4 Purpose of the study and specific objectives or questions	3
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and	3

1 guiding theory if appropriate; identifying the research
 2 paradigm (e.g. postpositivist, constructivist / interpretivist)
 3 is also recommended; rationale. The rationale should
 4 briefly discuss the justification for choosing that theory,
 5 approach, method or technique rather than other options
 6 available; the assumptions and limitations implicit in
 7 those choices and how those choices influence study
 8 conclusions and transferability. As appropriate the
 9 rationale for several items might be discussed together.
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14	Researcher	#6	Researchers' characteristics that may influence the	12
15	characteristics and		research, including personal attributes, qualifications /	
16	reflexivity		experience, relationship with participants, assumptions	
17			and / or presuppositions; potential or actual interaction	
18			between researchers' characteristics and the research	
19			questions, approach, methods, results and / or	
20			transferability	
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25	Context	#7	Setting / site and salient contextual factors; rationale	4
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28	Sampling strategy	#8	How and why research participants, documents, or	4
29			events were selected; criteria for deciding when no	
30			further sampling was necessary (e.g. sampling	
31			saturation); rationale	
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35	Ethical issues pertaining	#9	Documentation of approval by an appropriate ethics	4
36	to human subjects		review board and participant consent, or explanation for	
37			lack thereof; other confidentiality and data security issues	
38				
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40	Data collection methods	#10	Types of data collected; details of data collection	4
41			procedures including (as appropriate) start and stop	
42			dates of data collection and analysis, iterative process,	
43			triangulation of sources / methods, and modification of	
44			procedures in response to evolving study findings;	
45			rationale	
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50	Data collection	#11	Description of instruments (e.g. interview guides,	4
51	instruments and		questionnaires) and devices (e.g. audio recorders) used	
52	technologies		for data collection; if / how the instruments(s) changed	
53			over the course of the study	
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57	Units of study	#12	Number and relevant characteristics of participants,	5
58			documents, or events included in the study; level of	
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		participation (could be reported in results)	
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3	Data processing	#13 Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	4
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9	Data analysis	#14 Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	4
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16	Techniques to enhance trustworthiness	#15 Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	4
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21	Syntheses and interpretation	#16 Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5
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27	Links to empirical data	#17 Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-10
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31	Intergration with prior work, implications, transferability and contribution(s) to the field	#18 Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	10
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40	Limitations	#19 Trustworthiness and limitations of findings	12
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43	Conflicts of interest	#20 Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12
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48	Funding	#21 Sources of funding and other support; role of funders in data collection, interpretation and reporting	12
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