BMJ Open

What do patients with heart failure disclose about medication adherence at home to their hospital and primary care doctors? Exploratory interaction-based observational cohort study

Christine Frigaard ,[1,2] Julia Menichetti ,[2] Henrik Schirmer ,[1,3] Herman Bjørnstad,[1,2] Tone Breines Simonsen ,[2] Torbjørn Wisløff ,[1,2] Pål Gulbrandsen ,[1,2] Jennifer Gerwing [2]

To cite: Frigaard C, Menichetti J, Schirmer H, *et al*. What do patients with heart failure disclose about medication adherence at home to their hospital and primary care doctors? Exploratory interaction-based observational cohort study. *BMJ Open* 2024;**14**:e086440. doi:10.1136/bmjopen-2024-086440

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2024-086440).

Received 17 March 2024
Accepted 01 July 2024

[1]Institute of Clinical Medicine, University of Oslo Faculty of Medicine, Oslo, Norway
[2]Health Services Research Unit, Akershus University Hospital, Lørenskog, Norway
[3]Department (Dept) of Cardiology, Akershus University Hospital, Lørenskog, Norway

Correspondence to
Christine Frigaard;
christine.frigaard@medisin.uio.no

ABSTRACT

Objectives The main objective of this study was twofold: to investigate what kind of information patients with heart failure (HF) tell their doctors about their medication adherence at home, and how often such information is provided in consultations where medication reconciliation is recommended. To meet these objectives, we developed an analysis to recognise, define, and count (1) patient utterances including medication adherence disclosures in clinical interactions (MADICI), (2) MADICI including red-flags for non-adherence, and (3) MADICI initiated by patients without prompts from their doctor.

Design Exploratory interaction-based observational cohort study. Inductive microanalysis of authentic patient–doctor consultations, audio-recorded at three time-points for each patient: (1) first ward visit in hospital, (2) discharge visit from hospital, and (3) follow-up visit with general practitioner (GP).

Setting Norway (2022–2023).

Participants 25 patients with HF (+65 years) and their attending doctors (23 hospital doctors, 25 GPs).

Results We recognised MADICI by two criteria: (1) they are about medication prescribed for use at home, AND (2) they involve patients' action, experience, or stance regarding medications. Using these criteria, we identified 427 MADICIs in 25 patient trajectories: 143 (34%) at first ward visit (min–max=0–35, median=3), 57 (13%) at discharge visit (min–max=0–8, median=2), 227 (53%) at GP-visit (min–max=2–24, median=7). Of 427 MADICIs, 235 (55%) included red-flags for non-adherence. Bumetanide and atorvastatin were most frequently mentioned as problematic. Patients initiated 146 (34%) of 427 MADICIs. Of 235 'red-flag MADICIs', 101 (43%) were initiated by patients.

Conclusions Self-managing older patients with HF disclosed information about their use of medications at home, often including red-flags for non-adherence. Patients who disclosed information that signals adherence problems tended to do so unprompted. Such disclosures generate opportunities for doctors to assess and support patients' medication adherence at home.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Detailed and comprehensive description of patient's contributions to adherence discussions observed in authentic medical consultations.
⇒ Analysis of three key consultations for each patient as they transition from hospital to home.
⇒ Participant reactivity to the study situation may have led to more talk about medications and 'best practice behaviour'.
⇒ Limited generalisability.

INTRODUCTION

Patients with heart failure (HF) are a large and growing patient group who experience frequent hospital admissions and high mortality rates.[1 2] To alleviate symptoms, reduce hospital admissions and extend life expectancy, guidelines recommend a combination of four or more medications as core treatment.[3 4] Studies focused on whether patients actually take their medication as prescribed have reported troublingly low adherence rates (reviews report rates between 40% and 60%).[5 6] Patients' reasons for not taking their medications are complex and multifaceted[7 8] and result in: (1) not filling prescriptions, (2) not initiating treatment at the recommended time, (3) taking medications improperly, and (4) discontinuing medications prematurely.[9 10] Patients' failure to take medications as prescribed can be a conscious decision or not (eg, forgetting, misunderstanding).[11] When asked what makes it difficult to take their medications as prescribed, HF patients report a lack of understanding about the aetiology, prognosis, and symptoms of HF as well as complex

medication schedules, adverse drug effects, and perceptions of overmedication.[12 13]

Good communication between patients and doctors improves treatment adherence,[14] as it is key for exchanging information, responding to emotions, managing uncertainty, fostering relationships, making decisions, and enabling self-management.[15] While doctors need information about their patients' ability and motivation to take their medications to support adherence,[16] such information remains unknown unless patients disclose it to their doctor. For doctors to improve communication around assessing, addressing, and supporting older HF-patients to take their medications, they require research on how patients discuss it with their doctors, both inside and outside the hospital. Regarding self-care and medication use, HF patients emphasise the need for (more) effective communication with providers.[12 13 17–21] However, little research has focused on how patients and doctors talk together about medication adherence, resulting in a lack of knowledge about how patients contribute to adherence discussions during medical encounters and what kind of information they provide. While some studies used recorded consultations between patients and doctors to investigate talk about medications,[22–28] none targeted patients with HF, nor how adherence discussions changed over time.

The main objective of this study was to investigate what kind of information patients with HF tell their doctors about their medication adherence at home, and how often such information is provided in real-life consultation settings in which medication reconciliation is recommended as patients transition from hospital to home. To meet this objective, we developed an analysis to recognise, define, and count (1) patient utterances including *medication adherence disclosures in clinical interactions* (MADICI), (2) MADICI including red-flags for non-adherence (information indicating a potential risk for non-adherence or clear non-adherence), and (3) MADICI initiated by patients without prompts from their doctor.

METHODS

Overview of study design, participants, and setting

This is an exploratory interaction-based observational cohort study. Three consultations were recorded for each patient as they transitioned from hospital to home. We used Microanalysis of Clinical Interaction (MCI)[29] inductively to explore what patients say about how they use their medications at home. Data were audio-recorded consultations between self-managing older patients with HF and their doctors at (1) first heart ward visit in hospital, (2) discharge visit from hospital, and (3) follow-up visit with their general practitioner (GP).

Recruitment of participants

We recruited patients admitted to Akershus University Hospital (Ahus), Norway. Our inclusion criteria were patients, diagnosed with HF, 65 years or older, recently admitted to the hospital, competent to consent according to medical records, currently living at home within the catchment area of the hospital and managing their own medications. We excluded patients who required an interpreter or had a temporarily reduced ability to consent according to the ward nurse.

We identified and invited eligible patients to participate in the study from February 2022 to February 2023, Monday to Friday, using the following three steps: (1) the project assistant (TBS) screened admission records from the heart ward every morning, (2) two researchers (CF and HB) verified inclusion and exclusion criteria with the ward nurse and (3) recruited the attending hospital doctor (HD).

Eligible doctors included the attending physician of the patient, either the HD or the GP. We informed all doctors about the study prior to recruiting patients. The GPs of patients who had agreed to participate and had already been audio-recorded in the hospital were notified and received additional information in the patient discharge letter.

Data collection

Two researchers (CF and HB) collected all the data and were present during the consultations. The researchers collected audio-recordings using Olympus DS-9000 and used Livescribe Echo2Pen to make synchronised observation notes. This combined solution was selected to (1) make data collection more feasible than it would have been with video-recordings, especially in the hospital setting and (2) still be able to record crucial information missing from the audio-recordings that might influence how we would interpret the speech (eg, what happened during periods of silence, objects patients or doctors pointed to or showed each other, who was present and how they were positioned in the room).

In addition, medical records (hospital admission note, discharge documents and list of prescriptions from GP-record) were collected to extract HF history and current prescriptions.

Audio-recorded consultations were transcribed verbatim and entered into Microsoft Excel, adding observation notes when these provided relevant additional information (eg, 'the clinician hands the discharge letter to the patient, who is reading it'). All coding was done in the Excel worksheets.

Data analysis

The MCI consisted of two analytical steps: (1) identifying MADICIs and (2) characterising them. Both steps were initiated by two researchers (CF and JG) working together to develop inductive, data-driven operational definitions for how to (1) recognise utterances about the use of prescription medication at home pertaining to their initiation, implementation, or discontinuation (MADICI), and (2) characterise them according to their content pertaining to non-adherence, and whether patients offered information unprompted. We

purposefully selected a subset of recordings to start each step, consisting of data from three recently diagnosed patients and three previously diagnosed patients. We worked iteratively, including more recordings gradually and discussing difficult cases until consensus. Final operational definitions are documented in a detailed codebook (available from first author on request).

To support characterising MADICI for content indicating either a potential risk for non-adherence or clear non-adherence, jointly referred to as *red-flag MADICI,* we drew on the ABC Taxonomy,[9] EMERGE guidelines,[30] and PaPA Framework.[31] We developed operational definitions to differentiate between six types of red-flags observable in speech as well as for when the patient initiated the MADICI without a prompt from their doctor. Each MADICI was therefore characterised using dichotomous coding for all six types of red-flags and how it was initiated. In addition, we noted the name(s) of active ingredient(s) of medications when referenced in the dialogue.

During analysis, we consulted with a senior heart failure specialist (HS) to discuss the clinical relevance of our approach. As an additional validity step, we brought questions, analytical choices, examples, and preliminary findings to our multidisciplinary group (linguistics, psychology, and healthcare) of MCI researchers.

This study aims to provide first evidence of how adherence talk works in order to generate ideas and hypotheses for future experimental studies. Choices regarding sample size and analytical methods were influenced by the inductive, exploratory nature of the study. To investigate qualitative aspects of adherence talk, a sample of 74 authentic audio-recorded consultations from 25 patient trajectories has high information power.[32] Such a sample also allows for descriptive statistical methods to explore observations quantitatively, providing insight that can be useful when estimating parameters for future quantitative studies. Since analyses are exploratory, our reporting focuses more on confidence intervals (CI) than p-values, further signifying that we are not testing hypotheses. We performed three different generalised linear mixed effects regressions with random effects on patient level: (1) Poisson regression with number of MADICI as outcome and consultation setting as explanatory variable, (2) Poisson regression on rates of MADICI as outcome and consultation setting as explanatory variable, and finally (3) logistic regression with red-flag MADICI as the outcome and whether the MADICI was prompted as the explanatory variable, also controlling for consultation setting. Analyses were performed using R (V. 4.3.0) in Rstudio (V. 2023.09.1).

Ethical and privacy considerations

This is one of several studies within the MAPINFOTRANS research project (MAPINFOTRANS), funded by the Norwegian Research Council 31 August 2021. The Regional committee for medical and health research ethics reviewed the project and concluded that the project was exempt from review (ref. 273688). The Data Protection Officer at Ahus has approved data collection, handling, and storage for MAPINFOTRANS (ref 2021_146). All participants gave written informed consent before taking part.

Patient and public involvement

The MAPINFOTRANS project was planned with contributions from a user panel consisting of Ahus patient representatives. One user representative participated in MAPINFORTRANS Advisory Board and was consulted to discuss objectives for this analysis.

RESULTS

Data collection

We recruited 48 patients; only the 25 patients with data sets from all settings were included in this analysis, consisting of 74 audio-recorded consultations with their attending doctors (note one patient's ward visit was also the discharge visit). Along these patient trajectories, 23 HDs and 25 GPs participated. A flowchart of our sampling process is available online (online supplemental file 1).

Patients had a median age of 76 years with varying types of HF and comorbidities. Ten patients received their HF diagnosis within 3 months of the first visit of this study. All patients were living at home and self-managing. Patients had a prescription for a median of six regular medications on admission and eight medications on discharge from hospital.

The median work experience among doctors was 2.8 years for HDs and 16 years for GPs.

See table 1 for participant characteristics. Additional participant details are available online (online supplemental file 2).

The selected 74 consultations consisted of 1228 min of audio-recordings, 352 of which were during the first hospital ward visit (duration mean=14.7, min–max=6–23), 305 during the discharge visit (duration mean=12.2, min–max=5–25), and 571 during the follow-up visit with the GP (duration mean=22.8, min–max=10–44). Medical records matching these audio-recordings documented a total volume of 168 medications on hospital admission, and 223 at discharge.

Identifying MADICI

Following inductive analysis, we identified MADICI in patient utterances by two criteria: (1) they include talk about medication prescribed for use by the patient at home AND (2) they involve the patients' action, experience, or stance regarding using medications. We excluded patient utterances about intentions to do something in the future, and utterances limited to a 'yes', 'no', 'mm' response. The latter choice was conservative, but we deemed it necessary due to the ambiguity of the meaning of minimal verbal responses on audio-recordings, where any accompanying facial displays or co-speech gestures were missing. A flowchart of our analytical decisions is available online (online supplemental file 3) together

Table 1 Demographic information for study population

Patients: persons (+65 years) diagnosed with heart failure	n=25
Female, n (%)	8 (32%)
Age, median (min–max)	76 (67–90)
Cognitive function*, median score (min–max)	23 (16–30)
Diagnosed with HF more than 3 months ago, n (%)	15 (60%)
Ejection fraction†, EF% below 35%	11 (44%)
Number of medications at hospital admission†‡, median (min–max)	6 (0–14)
Number of medications†‡ at hospital discharge, median (min–max)	8 (4–16)
Diagnoses according to discharge letter, median (min–max)	3 (1–6)
Days from hospital admission to hospital discharge, median (min–max)	6 (1–20)
Days between hospital discharge and follow-up visit with GP, median (min–max)	10 (2–43)
Hospital doctors	**n=23**
Female, n (%)	17 (74%)
Age, median (min–max)	31 (24–50)
Professional role as junior doctor, n (%)	22 (96%)
Years of work experience, median (min–max)	2.8 (0–17)
General practitioners	**n=25**
Female, n (%)	8 (32%)
Age, median (min–max)	50 (35–71)
Professional role as junior doctor, n (%)	5 (20%)
Years of work experience, median (min–max)	16 (1–44)

*Cognitive function measured with MoCA assessment V.8.1,[48] median score (range).
†According to medical records.
‡Prescribed for regular use.
GP, general practitioner; HF, heart failure; MoCA, Montreal Cognitive Assessment.

with examples of our coding sheets (online supplemental file 4A,B).

We present some quotes to exemplify how we applied our criteria. Essential elements are underlined in the transcript. Original quotes in Norwegian with translation to English are provided online (online supplemental file 5). Information previously provided in the dialogue and required for comprehension is included in [square brackets] and names removed for anonymity are replaced in *italics*.

Talk about medications was recognisable from brand and generic names, colloquial terms, patients' visual descriptions or mispronunciations of their medications, or tools to administer medications at home. After medications or tools had been introduced in the dialogue, subsequent MADICIs could be identified when they included anaphoric references (eg, 'it', 'them', 'one').

We identified *patients' actions* pertaining to initiating, implementing, or discontinuing using medications when the utterance referred to the patient as the agent (eg, 'I') together with an action verb (eg, 'take', 'swallow', 'use', 'forget', 'stop', 'omit'). An example of a MADICI including patients' actions:'No, not really, because now I take the medications I should take at the correct times. And I try to keep it just within 40 minutes morning and evening'. In addition, we included specific patient questions that implied their actions with medication at home (eg, requesting repeat prescriptions, checking drug–drug interactions, challenging the necessity to take current medications). In this MADICI, the patient challenges the GP about the necessity to continue taking statins, thereby signalling he is currently taking it: 'So, then I can stop taking these cholesterol pills [atorvastatin]?'

We identified *patients' experiences* in utterances where they reported the presence or absence of symptoms, effects, or side-effects regarding their medication use: 'I tolerate it [medications] apparently well as I see it myself. I did not become nauseous, and I have not felt poorly due to it [starting with medications]'.

Finally, we identified *patients' stance* in utterances that included a positive or negative belief or point of view regarding medication use. In this MADICI, the patient expresses a negative stance to using diuretics: 'Yes yes, I will continue to take them [diuretics]. But I do not like it'.

Patient utterances in one speech turn were the unit of analysis for one MADICI. This choice is exemplified in this MADICI that includes experience, action, and stance: 'Yes, but she [the hospital doctor] has given me two [bumetanide tablets] a day, and that does not work

Table 2 Differences between consultation settings (Poisson regression)

	Number of MADICI		Rate of MADICI	
	Rate ratio	95% CI	Rate ratio	95% CI
Discharge visit from hospital vs first heart ward visit in hospital	0.39	(0.28 to 0.52)	0.46	(0.34 to 0.63)
Follow-up visit with GP vs first heart ward visit in hospital	1.54	(1.25 to 1.91)	0.95	(0.77 to 1.18)

GP, general practitioner; MADICI, medication adherence disclosures in clinical interactions.

you know. No so… I take one [bumetanide] when I am home. And if I am doing something then I cannot take it [bumetanide]'.

Frequency and rate of MADICI along patient trajectories

We identified 427 MADICI in 25 HF patient trajectories following microanalysis of three consultations per patient in settings where their medical treatment was transferred from hospital to primary care. Three first ward visits (13%) and nine discharge visits (36%) had no MADICI, while all GP-visits included two or more. Of 427 MADICI, 34% were in first ward visits (n=143, median=3, min–max=0–35), 13% in discharge visits (n=57, median=2, min–max=0–8), and 53% in GP-visits (n=227, median=7, min–max=2–24).

The duration of consultation times varied between the three settings, thus MADICI rates per min would be a more appropriate measure to compare than raw frequencies. We found the median rate of MADICI to be 0.32 MADICI/min for first ward visits (min–max=0–1.91), 0.15 MADICI/min for discharge visits (min–max=0–0.6) and 0.33 MADICI/min for GP-visits (min-max=0.1–1.3). Details per patient trajectory are available online (online supplemental file 6).

We observed differences between the three consultation settings and investigated these further using Poisson regression (table 2). Compared with first ward visits, discharge visits had 61% lower frequency of MADICI and GP-visits had 54% higher frequency of MADICI. When looking at rates per min, the discharge visits had 54% lower rates of MADICI, while GP-visits had only 5% lower rates of MADICI compared with first ward visits.

MADICI including red-flags for non-adherence

We recognised content including different types of red-flags ranging from potential adherence risks (types 1–3) to clear non-adherence (types 4–6), see table 3 for the specific red-flag definitions and examples.

Of the 427 MADICI, 235 (55%) referenced one or more types of red-flags; 143 were disclosed during GP-visits, 65 during first ward visits, and 27 during discharge visits. Patients disclosed potential adherence risks (types 1–3) more frequently than clear non-adherence (types 4–6) in all three settings. At discharge and GP-visits, most 'red-flag MADICIs' were type 1. Regardless of setting, nearly all patients disclosed worries, concerns, fear or negative stance to using medications. Sixteen patients (64%) reported clear non-adherence either at initiation, implementation, and/or discontinuation (types 4–6). Table 4 provides an overview of which red-flags we identified among patients and their distribution across consultation settings.

Of the 235 'red-flag MADICIs', 149 singled out specific medications. Bumetanide was the most problematic medication, mentioned as an issue 37 times by eight patients to their doctors. Atorvastatin was also commonly mentioned as problematic. Overview of medications mentioned is available online (online supplemental file 7).

Unprompted MADICI

Following inductive analysis, we identified when patients initiated the MADICI without being prompted by their doctor either (1) when the information was provided spontaneously 'out of the blue' (eg, after an audible pause in the conversation, or did not logically follow from the flow of the conversation), or (2) when the patient stayed on the same topic, but mid-utterance added information that steered the conversation in a new direction.

The following excerpt from a GP-visit exemplifies a MADICI that was initiated spontaneously by the patient since the patient utterance did not logically follow from the flow of the conversation. Here the GP is talking about a newly started blood pressure tablet when the patient chooses instead to bring up 'these diuretic pills' and continues to ask about how long they work in the body:

GP: "'So now you have received another heart failure medication called [brand name of blood pressure medication with valsartan], but that one you have …yes that one you have also started on now'"

Patient: "'Yes, but these diuretic pills, when I take them in the morning from 9 o'clock … or I can also get up at 7 o'clock also to take them. How long do they work during the day? I have a feeling that they work at least for 4 to 5 hours. Is that correct?"'

Of the 427 MADICIs, 146 (34%) were initiated by patients. Among the 235 'red-flag MADICIs', 101 (43%) were initiated by patients. MADICIs initiated by patients without prompts from their doctors included more often red-flags for non-adherence than MADICIs elicited by doctors (Odds ratio: 2.88, 95% CI: 1.82 to 4.67).

DISCUSSION

To the best of our knowledge, this is the first study to undertake a microanalysis of adherence discussions between patients with heart failure (HF) and doctors in a series of three medical encounters along the patient

Table 3 Red-flags for non-adherence in MADICI

	What kind of red-flag for non-adherence is provided in the MADICI?	Defined and coded as present when:	Examples (patient-pseudonym, setting)
Type 1	Indication of potential adherence risk specifically due to *patient's perceptions (eg, medication necessity beliefs, concerns, and emotions*).	The MADICI includes patient's concerns, worries, fears, or a negative stance towards: ► side-effects, ► the volume or choice of medications, or ► using medications generally.	'But it [taking bumetanide] is no fun. I cannot get anything done before noon, I was about to say'. (*Carl*, GP-visit) 'But if I'm in a normal condition and there are side-effects then I would like to remove it [cholesterol lowering medication]'. (*Daniel*, GP-visit)
Type 2	Indication of potential adherence risk due to practicalities, specifically due to *patient's difficulties identifying or keeping overview of medications (eg, resources and capabilities*).	The MADICI indicates that the patient: ► is unsure or unable to name own medications, or ► cannot verify medications taken based on descriptions provided by doctor.	'I do not remember. It has been a lot back and forth with exchanging old medications and getting some new ones and the like, so it is not clear to me'. (*Ken*, First ward visit) 'It's not exactly easy names on those things there. I know that I have an anticoagulant and…I do not remember…I just take those that I have'. (*Martin*, First ward visit)
Type 3	Indication of potential adherence risk due to practicalities, specifically due to *patient's difficulties dispensing own medications*.	The MADICI provides information about relying on assistance from next of kin with medications to ensure correct dispensing.	'It is *girlfriend's name* …she does it [dispensing medications] and puts into the boxes according to that list that we have. So if I have that bumetanide tablet, that it is on that list there, then I probably take it'. (*Eric*, GP-visit) 'That [dispensing in weekly pill organiser] is what I'm struggling with, because I called the home-nurse-team if they could come and dispense. But they did not have enough capacity, so I'm sitting now with the tongue in my mouth as I'm dispensing'. (*Benjamin's daughter*, GP-visit)
Type 4	Indication of non-adherence in the *initiation phase*	The MADICI provides information about the patient not taking the first dose of a medication prescribed for regular use.	'I was supposed to start on tablets for that [osteoporosis] too, but I cannot stand…I cannot stand more tablets'. (*Jane*, GP-visit) 'Never been using those [prescription strength tablets with calcium with vitamin D], so that is wrong'. (*Jane*, GP-visit)
Type 5	Indication of non-adherence in the *implementation phase*	The MADICI provides information about the patient omitting, delaying, or taking too many doses of medication.	'Pfh… I forget it [taking medications] probably once a week'. (*David*, GP-visit) 'Because I struggled to fall asleep so that I sat a lot in the sofa at home and fell asleep. And then when I got out of bed 3 or 4 o'clock at night then it was kind of not the time to take that tablet. And then I forgot to take it afterwards'. (*Brad*, First ward visit)
Type 6	Indication of non-adherence in the *persistence phase*.	The MADICI provides information about the patient intentionally discontinuing a medication that has not been deprescribed.	'I've stopped taking that, because that one [bumetanide]… I could not use it'. (*Carl,* First ward visit) 'That one [chlorprotixene] I took away myself when I was on the *island*.' (*Babette*, Discharge visit)

GP, general practitioner; MADICI, medication adherence disclosures in clinical interactions.

trajectory from hospital to home. Therefore, it offers an 'inside view' to what information doctors receive during consultations, each of which creates an opportunity for doctors to assess, address, and support patient adherence.

The findings showed that 25 self-managing HF patients disclosed information to their doctors pertaining to their medication adherence at home 427 times, more than half of which were presented at the GP visit. In our study, the presence of adherence discussions in GP-visits is higher than previously reported from outpatient settings. Previous studies, using audio-recordings collected more than 20 years ago, found that 10%–40% of visits did not include any talk about medication management.[23 26 33] That we observed more talk about patients' medication use in primary care may be attributed to HF patients having more complex regimens than patients in previous studies.[34] Policy changes[35] and healthcare services[36 37] that urge doctors to elicit patient preferences and encourage patients to engage in treatment discussions may also have played a part during this period. Though our results are encouraging, there is reason to reflect on the volume of disclosures compared with the number of prescribed medications; it suggests that doctors and patients did not discuss patients' medication use in detail. The present

Table 4 Frequency of red-flag MADICI along patient trajectories

MADICI contains information about patients'…	First heart ward visit in hospital (n=24)		Discharge visit from hospital (n=25)		Follow-up visit with GP (n=25)		All consultations (n=74)	
	Number of red-flags (n)	Number of patients reporting this red-flag (n)	Number of red-flags (n)	Number of patients reporting this red-flag (n)	Number of red-flags (n)	Number of patients reporting this red-flag (n)	Number of red-flags (n)	Number of patients reporting this red-flag (n)
Type 1: concern, worry, fears, or negative stance towards the use of medications	31	10	25	9	120	24	176	24
Type 2: difficulties identifying or keeping overview of medications	39	10	5	3	24	11	68	16
Type 3: relying on assistance from next of kin to ensure correct dispensing	1	1	0	0	3	2	4	2
Type 4: not starting to use medication	3	1	0	0	5	3	8	4
Type 5: omitting, delaying, or taking extra doses	11	5	1	1	14	6	26	9
Type 6: intentionally discontinuing medication	8	2	3	2	7	4	18	5
Adherence issues disclosed*	**93 in 65 MADICI**	**12**	**34 in 27 MADICI**	**10**	**173 in 143 MADICI**	**24**	**300 in 235 MADICI**	**25**

*One MADICI (analytic unit) may contain several utterances about patient actions, experiences, and/or stance conveying different types of red-flags; they are not mutually exclusive.
MADICI, medication adherence disclosures in clinical interactions.

study has not investigated which actions doctors used to elicit information about patients' medication use at home. Further work is needed to describe these actions and assess their efficiency to generate necessary insight into patients' intake of prescribed medications.

A second key finding was that we observed a large variation in what patients disclosed to their doctors within the same consultation type and across settings. Patient participation in adherence discussions was highest during GP-visits, followed by first hospital ward visits and discharge visits from hospital. This pattern can indicate that patients use their communicative resources differently between settings to seek optimal care in accordance with their preferences and concerns. Examples of patient communicative resources are: making direct requests, the choice of words when describing their illness history, actions influencing doctors before the diagnosis is presented, or resisting after the diagnosis or treatment plan is presented.[38] Also, one has to consider that the institutional context constrains admissible contributions to engage in different activities.[39] Therefore, admissible patient contributions may significantly change between type of visits, with GP-visits covering a wider range of possible contributions from the patient. That the institutional context limits patients adherence discussions to resisting recommended treatment might explain why we observed fewer adherence disclosures at discharge visits. Our findings are consistent with recent studies that found patients to be passive during discharge visits.[25 28 40 41] We found that a majority of 'red-flag MADICIs' at discharge visits and GP-visits included concerns, worries, fears, and negative stance, which can indicate resistance. Patients who wish to resist recommended treatment may choose to negotiate changes with the current doctor or choose a path of less resistance by bringing up issues with another doctor. Patients who feel better after their hospital stay may prefer to defer treatment negotiations until they see their GP a few days later, especially if they have an established and trusting relationship.[17 18] These initial results therefore suggest that the differences in adherence disclosures between these settings are influenced by how the institutional context provides opportunities (or constraints) for discussions about medications, how patients orient to their doctors, and patients' sense of urgency to negotiate prescriptions.

A third key finding was that more than half of the MADICIs included a red-flag for non-adherence, especially related to medications containing bumetanide

and atorvastatin. Both these medications have also previously been demonstrated to be problematic for adherence.[6 42 43] Patients disclosed more potential risks for non-adherence (eg, concerns, negative stances, need for assistance) and struggles with their intake (eg, forgetting, omitting, delaying), than outright non-adherence (not starting, discontinuing). Hence, a majority of problems disclosed in MADICIs pertained to only a potential risk. Such disclosures provide doctors with the opportunity to explore further and consider appropriate changes to alleviate the situation before it escalates to outright non-adherence. As expected, we found that explicit non-adherence disclosures were lower than concerns and negative beliefs about medications in general.[22 33] We also observed that many medications and frequent changes were a challenge for patients in all three settings. Such issues were also previously reported in patient interview-based studies.[12 13]

Finally, this study revealed that doctors initiated two-thirds of all adherence disclosures. However, when patients offered information spontaneously, it was more likely to include a red-flag for non-adherence compared with when doctors asked. These findings align with previous research reporting that doctors feel responsible and take a leading role when asking patients about their adherence.[22 25–27 44] Tarn *et al* found that patients initiated approximately one-third of adherence related discussions when they analysed 100 outpatient visits.[22] Two studies that investigated non-adherence disclosures found that patients provided half of the instances spontaneously,[22 24] which aligns with the results in our study.

The findings in this study constitute a point of departure for increasing our understanding of why patients with heart failure might fail to use their medications as prescribed, even when those medications are needed to achieve full benefit from pharmacotherapy. While patients and clinicians often fail to communicate efficiently about medication use,[20 44 45] this study cannot elucidate the quality of communication, as it focused only on patient disclosures. Further research is needed to explore how doctors follow up patients' adherence disclosures during consultations to shed light on how doctors work to support patient adherence.

Strengths and limitations

The main strengths of this study are as follows: (1) Our findings are observed in authentic consultations, well suited to studying adherence discussions in practice. The three selected timepoints coincide with when medication reconciliation is recommended for patients transitioning between primary and secondary care.[36 37] (2) Our analytical decisions are documented in a detailed codebook to ensure transparency and consistency in coding, and to encourage reproducibility.[46] (3) Access to medical records enabled verification of current prescriptions at all timepoints.

Main limitations of this study include the following: (1) Limited generalisability since patients are recruited from one hospital ward. Also, patients likely to be less frail than the average HF patient on the heart ward due to our inclusion/exclusion criteria and recruitment process (MAPINFOTRANS, which included an extended home interview and several eligible patients indicated they felt too poorly to receive visitors when declining study participation). (2) Participant reactivity[47] to the study situation, especially due to an observer present during the consultation, may have led to more talk about medications and 'best practice behaviour'. (3) Many patient–doctor interactions were not recorded (eg, admission to hospital, daily ward visits, informal conversations). Therefore our findings do not provide a comprehensive picture of the information exchanged about medication adherence during the study period.

CONCLUSION

We set out to investigate the quality and quantity of information about medication adherence that 25 self-managing older patients with HF disclosed to their doctors in a series of three clinical interactions as they transitioned from hospital to home. Microanalysis of the 74 authentic consultations produced a precise, detailed, and comprehensive description of patient's contributions to adherence discussions in settings in which medication reconciliation is recommended. We found that HF patients disclosed information about their use of medications at home, often including red-flags for non-adherence. Patients who disclosed information that signals adherence problems tended to do so unprompted. Such disclosures generate opportunities for doctors to assess and support patients' medication adherence at home.

Acknowledgements We extend our gratitude to patients and doctors who participated in this study for their time and contributions, and to hospital staff on the Ahus heart ward for facilitating the study. Also, warm thanks to Ivar Bakke for transcriptions and MAPINFOTRANS Advisory Board members and colleagues at HØKH for advice and support.

Contributors PG, HS, JG and JM conceptualised the MAPINFOTRANS study and applied for funding and ethics approval. HB, CF and TBS conducted the data collection. CF and JG conceptualised the present study, analysed the data and developed the codebook. TW performed all statistical analyses. CF drafted the manuscript with major contributions to the writing, review and editing from JG, PG, TW and JM. All authors have read and approved the final manuscript submitted for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted. The guarantor (CF) affirms that this manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

Funding The study was funded by the Norwegian Research Council. The funders had no role in considering the study design or in the collection, analysis, interpretation of data, writing of the report or decision to submit the article for publication. See methods for further details.

Competing interests All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: No support from any organisation for the submitted work; HS has received lecture fees from Novartis, Novo-Nordisk and Boehringer Ingelheim; PG has received lecture fees from Norwegian Brain Tumor Society, Pfizer and Takeda; JM is a member of Advisory Committee and Board of Trustees for the International Association for Communication in Healthcare EACH (unpaid), and received lecture fees from Oslo

Metropolitan University and EACH; no other relationships or activities that could appear to have influenced the submitted work.

Patient and public involvement The MAPINFOTRANS project was planned with contributions from a user panel consisting of Ahus patient representatives. One user representative participated in MAPINFORTRANS Advisory Board and was consulted to discuss objectives for this analysis.

Patient consent for publication All participants gave written informed consent before taking part.

Ethics approval This study involves human participants but The Regional committee for medical and health research ethics reviewed the project and concluded that the project was exempt from review (ref. 273688). The Data Protection Officer at Ahus has approved data collection, handling and storage for MAPINFOTRANS (ref 2021_146). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

ORCID iDs
Christine Frigaard http://orcid.org/0009-0007-3956-972X
Julia Menichetti http://orcid.org/0000-0002-9445-987X
Henrik Schirmer http://orcid.org/0000-0002-9348-3149
Tone Breines Simonsen http://orcid.org/0000-0002-4103-9011
Torbjørn Wisløff http://orcid.org/0000-0002-7539-082X
Pål Gulbrandsen http://orcid.org/0000-0001-7434-5392
Jennifer Gerwing http://orcid.org/0000-0001-6211-8723

REFERENCES

1 Vasan RS, Wilson PWF. Epidemiology of heart failure. UpToDate: Wolters Kluwe; 2022. Available: https://www.uptodate.com/contents/epidemiology-of-heart-failure [Accessed 29 Feb 2024].
2 Norsk legemiddelhåndbok. Hjertesvikt: Norsk legemiddelhåndbok, 2023. Available: https://www.legemiddelhandboka.no/T8.6/Hjertesvikt [Accessed 29 Feb 2024].
3 Heidenreich PA, Bozkurt B, Aguilar D, *et al*. 2022 AHA/ACC/HFSA guideline for the management of heart failure: a report of the american college of cardiology/american heart association joint committee on clinical practice guidelines. *J Am Coll Cardiol* 2022;79:e263–421.
4 McDonagh TA, Metra M, Adamo M, *et al*. 2023 focused update of the 2021 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure: developed by the task force for the diagnosis and treatment of acute and chronic heart failure of the european society of cardiology (ESC) with the special contribution of the heart failure association (HFA) of the ESC. *Eur J Heart Fail* 2024;26:5–17.
5 Wu J-R, Moser DK, Lennie TA, *et al*. Medication adherence in patients who have heart failure: a review of the literature. *Nurs Clin North Am* 2008;43:133–53; .
6 Jankowska-Polańska B, Świątoniowska-Lonc N, Sławuta A, *et al*. Patient-reported compliance in older age patients with chronic heart failure. *PLoS One* 2020;15:e0231076.
7 Sabaté E. *Adherence to Long-Term Therapies: Evidence for Action*. Geneva: World Health Organization, 2003.
8 Yap AF, Thirumoorthy T, Kwan YH. Systematic review of the barriers affecting medication adherence in older adults. *Geriatr Gerontol Int* 2016;16:1093–101.
9 Vrijens B, De Geest S, Hughes DA, *et al*. A new taxonomy for describing and defining adherence to medications. *Br J Clin Pharmacol* 2012;73:691–705.
10 Jin J, Sklar GE, Min Sen Oh V, *et al*. Factors affecting therapeutic compliance: a review from the patient's perspective. *Ther Clin Risk Manag* 2008;4:269–86.
11 Riegel B, Dickson V. A qualitative secondary data analysis of intentional and unintentional medication nonadherence in adults with chronic heart failure. *Heart Lung* 2016;45:468–74.
12 Farmer SA, Magasi S, Block P, *et al*. Patient, caregiver, and physician work in heart failure disease management: a qualitative study of issues that undermine wellness. *Mayo Clin Proc* 2016;91:1056–65.
13 Klindtworth K, Oster P, Hager K, *et al*. Living with and dying from advanced heart failure: understanding the needs of older patients at the end of life. *BMC Geriatr* 2015;15:125.
14 Zolnierek KBH, Dimatteo MR. Physician communication and patient adherence to treatment: a meta-analysis. *Med Care* 2009;47:826–34.
15 Street RL Jr, Makoul G, Arora NK, *et al*. How does communication heal? pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns* 2009;74:295–301.
16 Stewart S-J, Moon Z, Horne R. Medication nonadherence: health impact, prevalence, correlates and interventions. *Psychology & Health* 2023;38:726–65.
17 Myers SL, Siegel EO, Hyson DA, *et al*. A qualitative study exploring the perceptions and motivations of patients with heart failure who transitioned from non-adherence to adherence. *Heart Lung* 2020;49:817–23.
18 Clark AM, Spaling M, Harkness K, *et al*. Determinants of effective heart failure self-care: a systematic review of patients' and caregivers' perceptions. *Heart* 2014;100:716–21.
19 Eckerblad J, Klompstra L, Heinola L, *et al*. What frail, older patients talk about when they talk about self-care-a qualitative study in heart failure care. *BMC Geriatr* 2023;23:818.
20 Hayashi T, Morita Y, Mitani H, *et al*. Burden of heart failure on patient daily life and patient-physician discordance in disease management - results from a cross-sectional survey in japan. *Circ Rep* 2020;2:722–9.
21 Barello S, Graffigna G, Vegni E, *et al*. "Engage me in taking care of my heart": a grounded theory study on patient-cardiologist relationship in the hospital management of heart failure. *BMJ Open* 2015;5:e005582.
22 Tarn DM, Mattimore TJ, Bell DS, *et al*. Provider views about responsibility for medication adherence and content of physician-older patient discussions. *J Am Geriatr Soc* 2012;60:1019–26.
23 Tarn DM, Paterniti DA, Kravitz RL, *et al*. How do physicians conduct medication reviews? *J Gen Intern Med* 2009;24:1296–302.
24 Bergen C, Stivers T. Patient disclosure of medical misdeeds. *J Health Soc Behav* 2013;54:221–40.
25 Tobiano G, Manias E, Thalib L, *et al*. Older patient participation in discharge medication communication: an observational study. *BMJ Open* 2023;13:e064750.
26 Bokhour BG, Berlowitz DR, Long JA, *et al*. How do providers assess antihypertensive medication adherence in medical encounters? *J Gen Intern Med* 2006;21:577–83.
27 Schoenthaler A, Knafl GJ, Fiscella K, *et al*. Addressing the social needs of hypertensive patients: the role of patient-provider communication as a predictor of medication adherence. *Circ Cardiovasc Qual Outcomes* 2017;10:e003659.
28 van Dijk LM, van Eikenhorst L, Karapinar-Çarkit F, *et al*. Patient participation during discharge medication counselling: observing real-life communication between healthcare professionals and patients. *Res Soc Adm Pharm* 2023;19:1228–35.
29 Gerwing J, Healing S, Menichetti J. *A Pragmatic Agenda for Healthcare: Fostering Inclusion and Active Participation through Shared Understanding*. John Benjamins Publishing Company, 2023:43–74.
30 De Geest S, Zullig LL, Dunbar-Jacob J, *et al*. Improving medication adherence research reporting: ESPACOMP medication adherence reporting guideline (EMERGE). *Ann Intern Med* 2018;169:30–5.
31 Horne R, Cooper V, Wileman V, *et al*. Supporting adherence to medicines for long-term conditions: a perceptions and practicalities approach based on an extended common-sense model. *Eur Psychol* 2019;24:82–96.
32 Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res* 2016;26:1753–60.
33 Richard C, Lussier M-T. Nature and frequency of exchanges on medications during primary care encounters. *Patient Educ Couns* 2006;64:207–16.

34 Beezer J, Al Hatrushi M, Husband A, *et al*. Polypharmacy definition and prevalence in heart failure: a systematic review (jul, 10.1007/s10741-021-10135-4, 2021). *Heart Fail Rev* 2022;27:739–39.
35 Norwegian Ministry of Health and Care services. Principles for priority setting in health care; Meld. St. 34 (2015–2016), Principles for priority setting in health care, 2016. Available: https://www.regjeringen.no/no/dokumenter/meld.-st.-34-20152016/id2502758/?ch=1
36 National Institute for Health and Care Excellence. Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes. NICE; 2015. Available: https://www.nice.org.uk/guidance/ng5/chapter/1-Recommendations#medicines-related-communication-systems-when-patients-move-from-one-care-setting-to-another
37 Helsedirektoratet. Nasjonale faglige råd for legemiddelsamstemming og legemiddelgjennomgang. Helsedirektoratet; 2022. Available: https://www.helsedirektoratet.no/faglige-rad/legemiddelsamstemming-og-legemiddelgjennomgang [Accessed 29 Sep 2022].
38 Stivers T, Tate A. The role of health care communication in treatment outcomes. *Annu Rev Linguist* 2023;9:233–52.
39 Bigi S. *Communicating (with) Care*. IOS Press, 2016:37–55.
40 Rognan SE, Kälvemark-Sporrong S, Bengtsson KR, *et al*. Empowering the patient? medication communication during hospital discharge: a qualitative study at an internal medicines ward in norway. *BMJ Open* 2021;11:e044850.
41 Ho T, Campos BS, Tarn DM. Post-visit patient understanding about newly prescribed medications. *J Gen Intern Med* 2021;36:3307–10.
42 Simpson SH, Farris KB, Johnson JA, *et al*. Using focus groups to identify barriers to drug use in patients with congestive heart failure. *Pharmacotherapy* 2000;20:823–9.
43 Tarn DM, Barrientos M, Pletcher MJ, *et al*. Perceptions of patients with primary nonadherence to statin medications. *J Am Board Fam Med* 2021;34:123–31.
44 Hines R, Stone NJ. Patients and physicians beliefs and practices regarding adherence to cardiovascular medication. *JAMA Cardiol* 2016;1:470–3.
45 Sarkar U, Schillinger D, Bibbins-Domingo K, *et al*. Patient-physicians' information exchange in outpatient cardiac care: time for a heart to heart? *Patient Educ Couns* 2011;85:173–9.
46 Nordfalk JM, Menichetti J, Thomas O, *et al*. Three strategies when physicians provide complex information in interactions with patients: how to recognize and measure them. *Patient Educ Couns* 2022;105:1552–60.
47 Paradis E, Sutkin G. Beyond a good story: from hawthorne effect to reactivity in health professions education research. *Med Educ* 2017;51:31–9.
48 MoCA Test Inc. MoCA full (original paper format). MoCA Test Inc; 2024. Available: https://mocacognition.com/paper/