Heart failure and chronic obstructive pulmonary disease multimorbidity at hospital discharge transition: a study of patient and carer experience

Lucy Doos MBBCh MSc PhD,* Eleanor Bradley BSc MSc PhD CPsych,† Claire A Rushton MA BA,‡ Duwarakan Satchithananda BSc MbChB MRCP FRCP,§ Simon J Davies BSc MBBS MRCP MD, and Umesh T Kadam MBChB MRCGP PhD FFPH**

*Research Fellow, NIHR Horizon Scanning Centre, Department of Public Health, Epidemiology and Biostatistics, University of Birmingham, Birmingham, †Professor of Health Psychology, Institute of Health and Society, Worcester University, Worcester, ‡NIHR Doctoral Research Fellow, Health Service Research Unit, Keele University, Staffordshire, §Consultant Cardiologist, Cardiology Department, University Hospital of North Staffordshire, Staffordshire, †Professor of Nephrology, Health Service Research Unit, Keele University, Staffordshire and **Senior Lecturer in GP Epidemiology, Health Service Research Unit, Keele University, Staffordshire, UK

Correspondence
Lucy Doos, MBBCh, MSc, PhD
NIHR Horizon Scanning Centre
Department of Public Health, Epidemiology and Biostatistics
University of Birmingham
Edgbaston
Birmingham
B15 2TT
UK
E-mail: l.doos@bham.ac.uk

Abstract

Background Care for patients with multimorbidity represents a major challenge not only for patients and carers but to health-care systems. Hospital discharge transition is a critical point at which challenges for multimorbidity may amplify.

Objectives The main objective of the study was to explore the experiences of heart failure (HF) and chronic obstructive pulmonary disease (COPD) multimorbid patients and their carers on hospital discharge. Secondary objectives included identification of gaps in the health care of multimorbidity and optimal solutions from patients and carers' perspectives.

Design Mixed methods were applied to collect data using patient self-completion questionnaire from an adapted version of the American Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey and in-depth interviews.

Setting Participants were recruited from two cardiology and respiratory wards at a large regional hospital in England, and all had a multimorbidity diagnosis of COPD and HF.

Results and conclusions Findings revealed that patients experienced difficulties in their communication with health-care professionals and there were specific challenges with information about medication. Qualitative descriptions revealed that experiences fell into two main categories: (i) information transfer to patients with multimorbidity in terms of issues with medication and clarity of information on diagnosis and (ii) communication and continuity of care after discharge. Respondents highlighted gaps in the management of patients with multimorbidity of HF and COPD at the critical time of care transition. They suggested the need for a comprehensive, coordinated and integrated approach to incorporate patients, carers and staff preferences for treatment on discharge from hospital.
Introduction

Multimorbidity is defined as the coexistence of two or more chronic conditions and is associated with increased number of hospital admissions, higher mortality and higher health-care costs.\textsuperscript{1-4} Care for patients with multimorbidity represents a major challenge to patients, carers and health-care systems.\textsuperscript{4,5} In the current ageing population, it is estimated that two-thirds of older people are living with two or more chronic conditions.\textsuperscript{6,7} Patients with multimorbidity frequently require structured and complex care from a range of health-care professionals, which needs to be coordinated and integrated by different health-care teams.\textsuperscript{8} Current evidence suggests that the structure of health care has focussed on provision along single-disease pathways, which results in challenges for multimorbid patients in receipt of care delivered via single-disease pathways, including poor consistency of clinical information and co-ordination between health-care teams.\textsuperscript{1,9,10} These problems may be amplified at the time of transitions in care, when information and clinical management may be changing. One key transition point is hospital discharge, and the process of discharge planning. Poor communication and coordination between health-care professionals at this transition point has clear implications for the ability of patients and carers to self-manage their multimorbid conditions at home, as well as their satisfaction with care delivered.

The literature suggests that there are recurring problems in the interface between secondary and primary care, observed at the time of hospital discharge\textsuperscript{11,12} as a consequence of poor interface during discharge planning. These include communication problems between professionals and services within secondary and primary care organizations. The absence of robust plans and communication at this key transition point increases the risks of hospital readmission and unsafe patient care.\textsuperscript{13-15}

Two of the commonest reasons for hospital admissions are heart failure (HF) and chronic obstructive pulmonary disease (COPD)\textsuperscript{16}, and there is evidence that these two conditions frequently co-occur in the older population. The prevalence of COPD ranges from 20 to 30\% in patients with HF\textsuperscript{17} and nearly one-fifth of elderly patients with known COPD have unrecognized coexistent HF.\textsuperscript{18} In the case of COPD and HF, separate pathways have been developed for the management of these two costly conditions.\textsuperscript{19,20}

In the light of the increasing prevalence of both COPD and HF, and their co-existence, more information is needed about the impact of being diagnosed with multimorbid COPD and HF, the impact of being treated for both conditions and any unmet information needs.

Within current health-care systems, patients are increasingly likely to be discharged ‘quicker and sicker’ from acute care facilities\textsuperscript{21}, and health-care professionals, patients and carers need to be able to develop shared plans for discharge, to enhance experience as well as access to appropriate care and support post-discharge. An important concept in explaining patients’ adaptation to their illness is coping strategies.\textsuperscript{22} Patients with multimorbidity need to cope with complex self-management tasks for coexisting and frequently interacting diseases.\textsuperscript{23} Crucial in self-management is that patients adhere to their treatment regimens and keep monitoring their symptoms,\textsuperscript{24} which in turn can affect disease outcomes such as recurrent hospital admissions and mortality.

This study was designed to explore the experiences of multimorbid COPD and HF patients during, and shortly after a hospital stay. Additionally, it was designed to focus on patient and carer information needs on transitions and any perceived gaps in relation to their multimorbidity. The qualitative component of this study was patient and carer-led, so the eventual focus of the interviews was shaped by patient and carer feedback and experiences.

Methods

Design

This study utilized a mixed methods approach to provide a rich understanding\textsuperscript{25} of multimorbid patient and carer’s views on hospital discharge. Mixed methods developed theories about hospi-
tal discharge from research grounded in data, rather than deducing hypotheses from existing themes in addition to the desire of the research team to ‘see lives from the inside’\textsuperscript{26}. Patients were approached during the hospital stay and quantitative data were collected from patients shortly after their hospital discharge to gather descriptive feedback about communication with, and information provided by, hospital staff. The quantitative phase was also utilized to test out the potential to conduct interviews with this group of frail patients, including their willingness to participate and to take account of any specific arrangements that would be necessary to support participation. It also allowed some patients to take part in the study at a minimum of a survey. As a vulnerable group, the research team agreed that gaining the trust of potential participants was crucial and the first point of contact (handing the questionnaire and obtaining consents) was utilized as an opportunity for potential participants to meet the subsequent interviewer, receive information about proposed interviews including an invitation to participation, as well as outline any requirements for practical support during interviews.

Research ethical approval was granted by a National Research Ethics Service Committee (REC 11/LO/1767).

Setting and sampling

Participants were recruited from two cardiology and respiratory wards at a large regional hospital in England. Participants included adults admitted to hospital for a minimum of at least one night and had both COPD and HF. Exclusion criteria included patients judged to be physically unwell to participate by health-care professionals, those unable to give informed consent, or those with severe cognition difficulties. Potential participants were approached near to the time of their discharge and provided with study information. Patient consent was obtained at this point and participants were asked to complete and return the postal self-completed questionnaire after their hospital discharge. All informed consents were securely kept in a university locked filing cabinet. Arrangements for home interviews were also made subsequent to discharge.

Data collection

The quantitative approach was carried out using an adapted version of the American Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)\textsuperscript{27} questionnaire. This consists of 17 questions covering communication with health-care professionals, information on medication issues, overall satisfaction with the hospital stay as well as patient recommendation on the hospital (Appendix S1). A topic guide was produced for the interview schedule (Appendix S2) to provide additional themes for exploration as identified by a literature review, but the interviews were predominantly participant-led to enable participants to share their stories about hospital discharge. Findings from the questionnaire survey were utilized to identify ‘points of departure’ to form proposed interview questions\textsuperscript{26} to explore areas of importance identified by participants.

All interviews took place at patients’ homes between April and June 2012. Written consent was gathered from participants to utilize anonymized extracts from transcribed interviews. Interviews were conducted by two qualitative researchers (EB and LD), one of whom facilitated the interview, whilst the other observed the conversation, took detailed notes, made observations and followed up any discussion with prompts and additional questions when appropriate. This written information was utilized during the analysis of the interview data, to make sense of the information and further understand the experiences of participants. The interview data reached saturation in relation to questions about discharge experiences and although the final interview provided additional information to support our understanding of ‘insider experiences’, no new theoretical insights were sparked and no new properties of existing themes were revealed.\textsuperscript{26} Interviews were digitally recorded with the participants’ permission and lasted between 60 and 90 min.
Data analysis

All recorded interviews were transcribed verbatim, but without the use of names or identifiers. Transcripts were read by two researchers (EB and LD) to identify key concepts and emerging themes. The principles of grounded theory, most notably constant comparison, were utilized throughout the data analysis, with line-by-line coding and labelling of initial concepts. Early concepts were grouped thematically, with relabelling when necessary. Finally, overarching categories emerged and links to existing theory and literature were explored. Analysis of the interviews took place throughout the period of data collection, and the topic guide was amended as appropriate to account for, and further explore, key themes. To promote both the transparency and validity of this process, quotations were utilized to demonstrate key concepts and themes as well as to highlight contrasts within existing themes.

Results

Hospital discharge questionnaire

There were 29 eligible patients who agreed to take part in the study, and 14 (48%) completed the survey, two died, and three were unable to complete the survey as their condition severely deteriorated. Overall responses are given in Table 1. The average age of the sample was 74 years (range 58–91 years), and there were equal numbers of women and men. Most patients rated themselves as being in poor health (62%) and all had been discharged to home. The overall satisfaction score was six out of 10, and 43% would recommend or possibly recommend (36%) the hospital. Nearly two-thirds of the patients (64%) had not received a copy of their discharge letter, and only 40% of those who had received it were provided with information about a contact point when help is needed. There was also a room for improvement with respect to communication about prescribed medication, with 73% of participants unaware of the reasons for medication being prescribed and 64% of par-

Table 1 Quantitative findings from the survey questionnaire

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (50)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (50)</td>
</tr>
<tr>
<td>How often doctors listen</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4 (28.6)</td>
</tr>
<tr>
<td>Usually</td>
<td>4 (28.6)</td>
</tr>
<tr>
<td>Always</td>
<td>5 (35.7)</td>
</tr>
<tr>
<td>How often doctors explain</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4 (28.6)</td>
</tr>
<tr>
<td>Usually</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Always</td>
<td>6 (42.9)</td>
</tr>
<tr>
<td>How often nurses listen</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Usually</td>
<td>7 (50)</td>
</tr>
<tr>
<td>Always</td>
<td>5 (35.7)</td>
</tr>
<tr>
<td>How often nurses explain</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Usually</td>
<td>4 (28.6)</td>
</tr>
<tr>
<td>Always</td>
<td>5 (35.7)</td>
</tr>
<tr>
<td>Have you been given a new medicine</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Yes</td>
<td>11 (78.6)</td>
</tr>
<tr>
<td>How often did hospital staff tell you what the medicine was for</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>2 (18.2)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>6 (54.5)</td>
</tr>
<tr>
<td>Usually</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Always</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>How often did hospital staff describe possible side-effects</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>7 (63.6)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>2 (18.2)</td>
</tr>
<tr>
<td>Usually</td>
<td>2 (18.2)</td>
</tr>
<tr>
<td>Always</td>
<td>2 (18.2)</td>
</tr>
<tr>
<td>Do you understand your medication</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Yes</td>
<td>8 (72.7)</td>
</tr>
<tr>
<td>Discharge destination</td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>14 (100)</td>
</tr>
<tr>
<td>Others</td>
<td></td>
</tr>
<tr>
<td>Did hospital staff talk with you about the help you needed</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Yes</td>
<td>12 (85.7)</td>
</tr>
<tr>
<td>Did you get information in writing</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>9 (64.3)</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (35.7)</td>
</tr>
<tr>
<td>Have you received a copy of discharge letter</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>9 (64.3)</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (35.7)</td>
</tr>
</tbody>
</table>
Participants were lacking knowledge about potential side-effects to their prescribed medication.

Patient and carer interviews

Sample characteristics

In-depth interviews were carried out with six patients and five carers. There were equal numbers of male and female patients, and four of the five carers were women. The mean age of patient interviewees was 79 years (range 62–91 years), and the average hospital stay was 12 days (range 1–30 days).

Interview themes

The overarching categories derived from the interview analysis were related to information transfer and communication. There were a number of subthemes which fell within these two categories including: (i) clarity of information on diagnosis and compatible symptoms, (ii) issues with medication, (iii) communication within and between team members and (iv) communication between healthcare professionals, patients and carers in hospital and post-discharge.

Clarity of information on diagnosis and compatible symptoms: The majority of participants (four patients and one carer) recalled receiving very little information about their diagnosis and some were very confused about the sources of their experiences:

I don’t know exactly what it is yet. Well I would imagine it’s the heart. But I haven’t been told that yet … You lie in the hospital for three weeks and you’re are confused … well a bit disappointed I would have liked an explanation of some sort, to talk to me, to tell me why (Patient 2).

Bearing in mind that all patients had multimorbidity, it was evident that they were unclear about their different diagnoses and any possible relationship between them. This confusion had a particular impact when participants left the hospital, when they felt they had little guidance about what their symptoms meant, which medicines related to which symptoms/condition, or how to respond to symptoms to avoid a further hospital admission. In the absence of guidance or information about symptoms, or the implications of their diagnoses, participants drew their own conclusions about the origins of their symptoms:

And nobody has spoken to me there. Well a bit disappointed because I would have erm … I would have liked an explanation of some sort, to talk to me, to tell me why – well, why I was having the reactions I was having and erm - but no, nobody’s said a word about it. I was confused, and I’m just as confused now about it (Patient 2).

Some participants received contradicting information causing further confusion:

When he’s been in hospital, he’s got heart trouble, then you go again, no he hasn’t got heart trouble. It’s very confusing … See one says he has, one says he hasn’t (Carer 4).

In addition to uncertainty about specific diagnoses, participants were unsure if reacting to the symptoms of one condition could impact on the

<table>
<thead>
<tr>
<th>Table 1. Continued</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
</tr>
<tr>
<td>Does the letter explain to you who you need to contact if you need information</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Was the information on managing your condition and medication clear</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Will you recommend the hospital</td>
</tr>
<tr>
<td>Definitely no</td>
</tr>
<tr>
<td>Probably no</td>
</tr>
<tr>
<td>Probably yes</td>
</tr>
<tr>
<td>Definitely yes</td>
</tr>
<tr>
<td>Rate your health</td>
</tr>
<tr>
<td>Poor</td>
</tr>
<tr>
<td>Fair</td>
</tr>
<tr>
<td>Good</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Median</td>
</tr>
<tr>
<td>Minimum</td>
</tr>
<tr>
<td>Maximum</td>
</tr>
<tr>
<td>Hospital Rate</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Median</td>
</tr>
<tr>
<td>Minimum</td>
</tr>
<tr>
<td>Maximum</td>
</tr>
</tbody>
</table>

ª 2014 John Wiley & Sons Ltd

Health Expectations
other and wanted to be provided with information to help them respond to one condition without detrimental impact on the second. They suggested that health-care professionals need to deal with the patient as a whole individual:

Yeah you can’t have that because it – because of the other complaint or do you know what I mean? [yeah] I think they’ve got to find something that would go with both (Carer 1).

Issues with medication. Participants were all living with multimorbidity, managing complex treatment regimens and in contact with various specialist teams to oversee their care. However, there were few concerns raised about the impact that one condition or its treatment could have on a second condition. This suggests that participants had little understanding about the potential for their treatments to interact. This lack of knowledge undermines the ability of participants to self-manage and respond to their symptoms and experiences autonomously. This also demonstrates that patients do not regard their multimorbid conditions in silos, but understand their symptoms and experiences holistically.

Although some participants had received information about their medication, the knowledge amongst the group overall about their medicines was poor and participants did not feel confident about their treatment regimen. Where carer support was available, carers commonly took a lead role in assuring compliance with medication regimen. However, the level of knowledge and understanding about medication undermined the potential for full concordance or self-management in the event of crises or side-effects, increasing the risk of emergency events:

Haven’t a clue, nothing to do about my medication. Well … well vaguely they’re for the heart, for (Patient 2).

They didn’t tell me what treatment I was going to have or nothing. No information whatsoever. Have I got to take one or have I got to take any of anything, I don’t know, I’m just taking one one day and two another day (Patient 5).

I just can’t understand why they haven’t cut this water tablet down. I’m running to the toilet 50, 60 times a day. So … maybe you could try and cut them down, you know. Cut them down and see how I go on, I mean if it come to that, just put me back on them again (Patient 4).

Communication with and between team members. Information exchange between clinicians who care for the same patient is essential to maintain continuity of care. In hospital, participants commonly received conflicting messages from clinicians about expected discharge dates, and some received little notice about imminent discharge:

Well I can’t understand why one doctor can say he’s to stop in and one says he can go home. Why are two doctors so different? I mean they should both agree whether he goes home or whether he stops in (Carer 4).

Carers placed particular importance on the need for effective communication between different community nurses, post-discharge:

One nurse is coming in, the next day another nurse is coming, she said, well what is it we’ve done, let me have a look at your notes what they did yesterday. She should already know that without looking at any notes they should communicate with one another. Because nine times of ten the same nurse doesn’t come in (Carer 5).

There was a good deal of uncertainty expressed by patients and carers in relation to the quality of information transfer between hospital-based and community teams. None of the participants could claim with any certainty that information had been accurately passed from their hospital team to their GP practice. In the absence of any ‘concrete’ evidence that this communication had taken place, a number of participants talked about a presumed ‘invisible’ electronic communication between their hospital and community team:

They have computers over there. So the information should be on each other’s screens I thought (Carer 2).

Communication between professionals, patients and carers: in hospital. Participants talked about the information they were given from ward staff whilst they were inpatients. There
was an apparent hierarchy for communication within the ward environment, with participants feeling more comfortable asking questions to nurses than with doctors. Doctors were less familiar to the patients as they did not spend as much time on the ward as the nurses. Further to this, there was a perception that doctors tended to have discussions about the patient with their medical colleagues, rather than actively with patients or carers:

I think the doctors ought to tell you more, give you more information, which they never do, do they? The nurses do that come in. You can ask them anything and they’ll tell you everything, they’ll explain everything to you, you know (Carer 4).

Despite this criticism, participants felt that the limitations in their communication with doctors were due to environmental constraints, with doctors seen to be particularly busy.

Carers talked about wanting more information when patients were in hospital, particularly in relation to any movement between wards during an admission. They also wanted to be more involved in discussions between patients and hospital clinicians about treatment and discharge plans, as well as to be kept informed about the times when these discussions and decisions were going to happen:

There was one doctor there that my daughter wanted to see, but they were only there until 5 o’clock and then they went. But with her working, they weren’t getting there until about half past five (Patient 6).

Whilst in hospital, participants described the process for discharge as a particularly uncertain and confusing period. Participants felt there was a need for more information about the procedure for discharge from hospital, including plans for a specified discharge date. Three patients in this sample had received rapidly changing information about their date for discharge and their forecasted length of stay:

Well they could have explained something but this particular doctor said to me, you’re going home on Tuesday. Tuesday came I was still there, Wednesday I was sent down to another ward (Patient 5).

Despite perceived uncertainty about discharge and discharge plans during the hospital stay, when a discharge decision was made, participants felt rushed out of the ward. Many of the participants in this study would have preferred a longer-stay in hospital:

I prefer stopping in hospital if I’m not well. I don’t want to go home for the sake of going home (Patient 4).

Furthermore, there was a feeling that the hospital care team disengaged immediately once the patient left the hospital ward, leaving patients feeling abandoned:

They don’t seem to explain anything to you, you’re going home, that’s it, they forgot, you’re forgot (Patient 4).

With respect to decisions about plans for care post-discharge, carers described a desire to be further involved in discussions about treatment plans, future support provision and the logistics of discharge whilst patients were still in hospital. One of the proposed benefits to carer involvement at this stage of care was the ability of carers to act in an advocacy role for the patients, particularly for those patients who experienced difficulties in their communication with the clinical teams. Patients with multimorbidity tend to be older and within this group a number had communication needs which needed to be taken into consideration: If you don’t speak up or speak slowly you can’t tell what they say I can’t hear a word anybody says, unless they come up to me (91-year-old patient). These considerations were vitally important when key discussions (e.g. specific plans for discharge) happened without a carer being present.

Communication between professionals, patients and carers: post-discharge. Participants talked about their need for better quality and clear information from health-care professionals at hospital discharge. They were commonly uncertain about their new treatment regimens, with little knowledge about side-effects to be
anticipated, tolerated, or when to seek further medical assistance:

But the blood tests haven’t come back, they haven’t, they come back to do his blood, they took it away yesterday, said they would have the results have back today, nobody’s phoned, now it’s twenty past ten, he’s got to take that tablet, whether he’s got to take one, two, what? We don’t know (Carer 5).

None of the participants could recall being given a copy of their discharge letter. Yet, most participants felt that having better information on discharge, both written and verbal, could reduce their feelings of apprehension about managing their conditions back home:

Yes, written down information. You can always fall back on it, can’t you? (Patient 1).

All participants had expected to be contacted by their GP soon after their discharge (as ‘routine’). However, none of them had been contacted by their GP and were both surprised and disappointed. For this group of patients, the GP is a key source of reassurance post-discharge:

I would like to see somebody from the GP’s surgery to explain to her what is going on with her health medically, at least any information passed from the hospital to the GP, I thought would be essential (Carer 2).

There were particular concerns about how to manage with, sometimes distressing, symptoms at home as well as how to respond if symptoms worsened. Participants described their plans for action if symptoms suggested the patient to be deteriorating, but these were commonly based on prior experience rather than guided by hospital or community team advice. Indeed, the majority of plans were reactive, emergency plans, which carried a high risk of readmission. Despite community teams being available out-of-hours, the majority of participants planned to ring an ambulance if symptoms worsened.

We’ve had nothing from the hospital, that if anything happens or… none said anything. I’d just ring an ambulance and like I say I’ve got the backup of all the district nurses but apart from that I don’t know (Carer 3).

None of the participants described receiving information about a contact point for help or advice about worsening symptoms. One participant would have liked a brief follow-up phone call from the hospital to review how well they were coping. Another participant suggested a telephone contact number or a helpline.

Discussion

Overall findings and context

In this paper, we focused on the critical healthcare transition point of hospital discharge in a group of frail patients, which has so far remained unexplored in terms of multimorbidity, and with consequent lack of integration of individual disease pathways. The findings in this study reflected those of Efraimsson et al., demonstrating that participants in this group are at risk of feeling unaffiliated to their care, are ‘outsiders’ with respect to discharge and treatment plans and commonly feel unprepared at the point of discharge from hospital. From our study, the main challenges to emerge included discharge information, issues with medication, communication and continuity of care after discharge.

Multimorbidity issues

Participants in our study did not focus their concerns on the fact that one condition’s treatment might affect the treatment for the other condition. This may reflect a limited understanding of diagnosis and treatment within this group (as found by Fried et al.) or confusion about the potential interaction between diagnoses and treatments. Consistent with previous research, we found that participants experienced difficulties when attempting to understand their medication and found their medication management to be both complicated and confusing. Moore and colleagues found that nearly half of adults (49%) experience a medical error; and of these, medication discrepancies were the most frequent concerns (42%). These medication errors most
commonly involved cardiovascular and pulmonary conditions.

Issues with medication should be taken seriously as they can be associated with adherence to care and contribute to recurrent hospitalizations and survival rates. The fact that multimorbid patients in this study reported confusion about medication highlights one important contributor to medication error, as well as the importance of interventions to improve medication reconciliation at the interface of care for patients with multimorbidity.

In the current hospital-orientated acute care, there are pressures on hospitals to reduce lengths of stay and consequently patients with complex needs might be discharged earlier and before their symptoms have fully resolved. As the number of people with long-term chronic conditions increase, and hospital stays reduce, there is a need for health services to consider their role in educating, informing and supporting people within their homes, to coordinate care provision outside the traditional, profession-specific ‘silos’ and to provide holistic, compassionate care with patient and carers at the centre.

Interpretation of, and reaction to, experiences is based on pre-understanding and knowledge. As such, patient and carer understandings must be aligned with, and understood by, the healthcare professionals providing care to enable concordance and self-management within the community. Further awareness about the availability of community out-of-hours services is important to prevent unnecessary hospital readmissions, particularly via the emergency department. It maybe, however, that education and support designed to align the perceptions and expectations of patients, carers and healthcare professionals with respect to symptoms and anticipated disease progression could help the prevention of unnecessary crises, and facilitate preventive help from across the community. It would be timely to consider the role of health promotion information and education within secondary care environments, to incorporate such information into routine contacts with patients in hospital, utilizing existing models of communication and theories of health behaviour. At a minimum, information should be tailored according to individual needs, be integrated to accommodate multiple conditions and treatment regimens, include information about both acute and community contact points, and to be provided in both verbal and written formats.

**Broader discharge planning**

This study adds to the growing body of evidence that communication gaps exist between healthcare teams, patients and carers at different stages of the discharge process. Poor communication surrounding hospital discharge has always been a problem. A number of studies have highlighted the problem of lack of communication between different specialists treating the same patient and stressed the importance of sharing decision making and application of an integrated approach, with some focusing on patients with multimorbidity.

Concerns about the communication between members of various health-care teams suggest that the care for those with multimorbidity is poorly coordinated, with little ‘team’ involvement. The transition from hospital to home was not described as seamless and discharge planning did not appear to be proactive, with patients and carers describing a passive role during this time. The exchange of information is an integral component of continuity of health care and effective coordination and communication between different teams is essential to achieve a seamless interface of care between hospitals and primary care.

The feeling of not being adequately informed is a very common post-discharge problem. Other
research has demonstrated that most patients do not know their diagnosis on discharge, misunderstand their medication regimen and receive inadequate post-discharge care.\textsuperscript{13}

It is well recognized that patients generate common-sense understandings about their symptoms and illness timelines, based on information and prior experiences.\textsuperscript{36} This, in turn, shapes responses to symptoms and proposed treatment regimens, including concordance and adherence. As such, it is important for health-care professionals, particularly at key points of transition, to talk with patients and carers about their understanding of their symptoms, their future plans to respond to symptoms and their plans to encourage adherence to treatment regimens.

Given the frailty of patients with multimorbidity of COPD and HF, it is essential to recognize the role of carers. Our study indicates that an effective discharge planning for frail patients with COPD and HF multimorbidity should address carers’ information. This finding is consistent with Grimmer \textit{et al.}\textsuperscript{41}, who found that lack of information left carers feeling unprepared to take on new and/or additional tasks. Carer involvement is one of the most significant factors influencing the success of discharge planning for frail older patients\textsuperscript{42}; therefore, time should be spent with carers to clarify their understanding of patients’ symptoms and experiences, as well as their knowledge about diagnoses and medication.

Limitations

This mixed methods study was conducted with a small sample of patients with a specific set of multimorbidity (COPD and HF) and their carers. This was a feasible approach in a complex acute healthcare environment and provided an opportunity for a full exploration of experiences and views, highlighting key and important issues in this emerging field. The interview data reached saturation in relation to questions about discharge experiences and although the final interview provided additional information to support our understanding of ‘insider experiences’, no new theoretical insights were sparked and no new properties of existing themes were revealed\textsuperscript{26}. This study was designed to construct new theory in the area of multimorbidity and hospital discharge, and whilst current evidence supports the idea that even small samples may be driven by the question\textsuperscript{43}, our findings are not representative of the widest population. However, due to the health difficulties experienced by people with these particular multimorbidity conditions, particularly shortly after hospital discharge, our interview sample provides new information and knowledge which warrants further exploration in a larger study.

It was originally planned to obtain information and discussion about the challenges of living with the specific multimorbid conditions of COPD and HF. It is notable that not all of the identified problems were unique to patients with multimorbidity of COPD and HF and these findings provide the generic implications from a common and important multimorbidity pair, which intensifies the problems at hospital discharge.

Conclusions

Our study findings provide the additional experiences of a vulnerable patient group with HF and COPD multimorbidity at the critical healthcare point of hospital discharge. In a sample who were difficult to access because of frailty, our findings suggest that multimorbid patients have clinical needs that distinguish them from those with a single chronic disease, but their needs focus on communication and clarity of clinical information which is not preoccupied with their diseases. These findings warrant further exploration in a larger study, but have important implications for delivery of healthcare that recognizes the specific needs of multimorbid patients at critical transition points.

Acknowledgements

The authors would like to express their gratitude to patients and carers who participated in the study and the hospital staff who supported the study. Specific thanks are given to Mr David Rushton and Dr John Mason Sneddon.
who provided advisory PPI into the study
design. We also should like to thank Professor
Gavin Russell, Ms Charlotte Aston and the
staff on the cardiology and respiratory wards
in helping with the study planning and recruit-
ment processes. Further thanks to staff within
the Research & Development department.

Funding

Project funding was supported by Health
Innovation & Education Cluster.

Conflict of interest

There is no conflict of interest.

Supporting Information

Additional Supporting Information may be
found in the online version of this article:
Appendix S1: Survey Questionnaire (HCA
HPS 2012).
Appendix S2: Interview schedule.
Data S1: Authors’ contribution.

References

1 Bayliss EA, Edwards AE, Steiner JF, Main DS.
Processes of care desired by elderly patients with
2 Fortin M, Soubhi H, Hudon C, Bayliss AE, van den
Akker M. Multimorbidity’s many challenges: time
to focus on the needs of this vulnerable and growing
population. British Medical Journal, 2007; 334:
1016–1017.
3 van Walraven C, Taljaard M, Bell CM et al.
Information exchange among physicians caring for
the same patient in the community. Canadian
4 Vyas A, Pan X, Sambamoothi U. Chronic condition
clusters and polypharmacy among Adults.
International Journal of Family Medicine, 2012;
2012: 193168.
5 Fried TR, McGraw S, Agostini JV, Tinetti ME.
Views of older persons with multiple morbidities on
competing outcomes and clinical decision-making.
Journal of the American Geriatrics Society, 2008; 56:
1839–1844.
6 Newbould J, Burt J, Bower P et al. Experiences of
care planning in England: interviews with patients
with long term conditions. BMC Family Practice,
7 van den Akker M, Buntinx F, Metsemakers JFM,
Roos S, Knottnerus JA. Multimorbidity in general
practice: prevalence, incidence, and determinants of
co-occurring chronic and recurrent diseases. Journal
of Clinical Epidemiology, 1998; 51: 367–375.
8 Kadam UT. Redesigning the general practice
consultation to improve care for patients with
multimorbidity. British Medical Journal, 2012; 345:
e6202–e6203.
9 Morris RL, Sanders C, Kennedy AP, Rogers A.
Shifting priorities in multimorbidity: a longitudinal
qualitative study of patient’s prioritization of multiple
10 Noel PH, Parchman ML, Williams JW et al. The
challenges of multimorbidity from the patient
perspective. Journal of General Internal Medicine,
2007; 22 (Suppl. 3): 419–424.
11 Day MR, McCarthy G, Coffey A. Discharge
planning: the role of discharge co-ordinator.
12 McKenna H, Keeny S, Glenn A, Gordon P.
Discharge planning: an exploratory study. Journal
13 Balaban RB, Weissman JS, Samuel PA,
Woolhandler S. Redefining and redesigning hospital
discharge to enhance patient care: a randomized
controlled study. Journal of General Internal
Medicine, 2008; 23: 228–1233.
14 Hesselin G, Schoonhoven L, Barach P et al.
Improving patient handover from hospital to
primary care: a systematic review. Annals of Internal
Medicine, 2012; 157: 417–428.
15 McKeown F. The experiences of older people on
discharge from hospital following assessment by the
public health nurse. Journal of Clinical Nursing,
16 Titler M, Jensen G, Dochterman J et al. Cost of
hospital care for older adults with heart failure:
medical, pharmaceutical and nursing costs. Health
17 Le Jemtel T, Padeletti M, Jelic S. Diagnostic and
therapeutic challenges in patients with coexistent
chronic obstructive pulmonary disease and chronic
heart failure. Journal of the American College of
18 Padeletti M, Jelic S, LeJemtel T. Coexistent chronic
obstructive pulmonary disease and heart failure in
the elderly. International Journal of Cardiology,
19 National Institute for Health and Clinical
Implementing NICE guideline, 2010. Available at:
http://www.nice.org.uk/nicemedia/live/13099/51015/


29 Efraimsson E, Sandman P, Rasmussen B. ‘They were talking about me’-elderly women’s experiences of taking part in discharge planning conference. Scandinavian Journal of Caring Sciences, 2006; 20: 68–78.


36 Leventhall EA, Easterling D, Leventhall H, Cameron L. Conservation of energy, uncertainty reduction, and swift utilization of medical care among the elderly: study II. Medical Care, 1995; 33: 988–1000.


