

Heart failure and COPD multimorbidity at hospital discharge transition: a study of patient and carer experience

ABSTRACT:

Objectives: The main objective of our 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.

Methods: Mixed-methods were applied to collect data using patient self-completion questionnaire from an adopted version of the HCAHPS survey and in depth interviews. 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: 14 out of 29 (48%) completed HCAHPS questionnaires were returned. Overall, nurses scored better (84%) than doctors (64%) in listening to patients. There were problems in communication about medication with 73% not aware of the reasons for new medication and 64% never been informed of their side effects.

In-depth interviews were carried out with 6 patients and 5 carers in the home setting one to two weeks following hospital discharge. Interviewees' descriptions of their experiences on hospital discharge fell into four main themes: clarity of information, communication, continuity of care after discharge and issues with medication.

Conclusion: Our study showed that gaps and delays in communication between healthcare professionals and poor discharge documentation continue to be recurring issues in caring for patients with multimorbidity of HF and COPD. It further points to the need for a comprehensive, coordinated and integrated care that incorporates patients and carers preferences in order to improve the outcomes for multimorbidity.

INTRODUCTION:

Multimorbidity is defined as the coexistence of two or more chronic conditions and is associated with increased number of hospital admissions, increased use of health care resources, higher mortality and higher healthcare costs (Bayliss et al 2008, Fortin et al 2007, Vyas et al,2012, Van den Akker et al 1998). As a result, care for patients with multimorbidity represents a major challenge not only to patients and their carers but also to healthcare systems (Fried et al 2008, Vyas et al 2012). In the current ageing population, it is estimated that two thirds of older people are living with two or more chronic conditions (Van den Akker et al 1998, Newbould et al 2012).

Patients with multimorbidity frequently require more structured and complex care from a range of healthcare professionals, which needs to be coordinated and integrated by different healthcare teams (Kadam 2012). Yet, current evidence and structure has focused to the delivery of healthcare along single disease pathways. This creates problems from patient perspective, and there is qualitative evidence on problems created by the experience of multimorbidity, which shows a lack of consistency of clinical information and co-ordination between healthcare teams (Noel, Bayliss and Rogers). These problems may further amplify at the time of transitions in care, when information and clinical management may be changing. One key transition process is the discharge planning. With the current health care system discharging elderly patients "quicker" and "sicker" from acute care facilities (laugaland et al 2012), there is a need for an effective discharge planning and discharge support for such frail people.

There are recurring problems in the interface between hospitals and primary care, observed at the time of hospital discharge (Day et al, 2009; McKenna et al, 2000) but as a consequence of poor interface during discharge planning. These include communication problems between professionals and services within hospital and primary care organisations. In the absence of robust communication, assumptions may be made about care, contacts and, sometimes, medication, resulting in a higher risk of hospital readmissions and unsafe patient care (McKeown, 2007, Balaban et al 2008, Hesselink et al 2012).

With current national healthcare policy increasingly focusing on shorter hospital stays and care provided closer to home, transition care points are a critical point for

the delivery of quality care (Bauer et al 2009), for the provision of robust communication about plans for care post-discharge to service users and carers, and to enhance service user and carer satisfaction with services.

Discharges are currently organised along single disease pathways. One example of this is the UK Quality and Outcomes Framework (QOF) which provides financial rewards for clinicians who achieve specific targets which relate to the monitoring of conditions such as diabetes, coronary heart disease and asthma (Morris et al 2011). In acute care settings this has led to a focus on individual disease pathways at the expense of the needs of patients with multimorbidity (Rushton et al 2011). Two of the commonest reasons for hospital admissions are heart failure (HF) and chronic obstructive pulmonary disease (COPD) (Titler et al 2008). There is evidence that HF and COPD co-occur in the older population. The prevalence of COPD ranges from 20% to 30% in patients with CHF (Le Jemtel et al, 2007) and nearly one fifth of elderly patients with known COPD, have unrecognised coexistent HF (Padeletti et al 2008). As such, these conditions exert a large financial burden for NHS services, particularly when they co-exist. Specialist teams and separate pathways have developed for the management of these two costly conditions (NICE 2010 & 2011). Currently, many of the possible interactions between both syndromes are still unclear, and more extensive knowledge is important in view of the potential increasing prevalence of both diseases in the near future and the possibly common existence (Rutten et al 2006). Using the COPD and HF as the basis for defining multimorbidity, we investigated in a large regional hospital, patient and carer experience on how their discharge had been planned using quantitative and qualitative approaches. This first patient-centred studies were planned as part of a larger project to develop a communication framework for multimorbidity at hospital discharge transition, which included subsequent healthcare team (clinical and manager) interviews with multi-disciplinary teams drawn from the hospital, community and primary care.

METHODS:

Design

A mixed-methods approach was used, both quantitative and qualitative, in order to gain a rich understanding of patient and carer views on hospital discharge. Data were gathered from patients admitted to a large acute teaching hospital and interviews were conducted post-discharge. Participation was invited from both patients and their carers at each phase of the study. Research ethical approval was granted by the National Research Ethics Service Committee London –Dulwich (REC 11/LO/1767) and R&D approval granted by the NHS Trust.

Setting and sampling

Participants were recruited from two cardiology and respiratory wards at a large regional hospital which covers a population of 500,000 by one of the research team (LD) with the help from the medical team on the ward. Recruitment was conducted according to the inclusion and exclusion criteria for the study. Participants included adults who had been admitted for either COPD or HF, but had both, and had been in hospital for a minimum of at least one night stay. Exclusion criteria included patients judged to be too physically unwell or frail to participate by healthcare professionals, those who were unable to give informed consent, or those with severe cognition difficulties. Potential participants were approached nearer to the time of their discharge to provide with study information, survey questionnaire and obtain patient consent to participation in the study. Participants were asked to complete the questionnaire after their discharge. Arrangements for interviews were made when patients were discharged.

Data collection

The quantitative approach to obtain patient and carer experience at hospital discharge was carried out using an adopted version of Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) questionnaire, which is widely used in the United States (HCAHPS 2012). It consists of 17 questions, which covers communication with doctors, and nurses and information on medication issues (Appendix 1). The final two questions within the questionnaire, relate to overall satisfaction with the hospital stay as well as a recommendation on the hospital. The questionnaire also provided the context for the following semi-

structured interviews. The themes for the semi-structured interviews were drawn from a literature review synthesis, and utilised modified questions from the HHCAHPS questionnaire.

Interview schedules were put together to provide a topic guide for the semi-structured interviews (see Appendix 2). Interviews were essentially participant-led, with opportunities provided for participants to introduce new topics for discussion during the interviews. All interviews took place at patients' homes between April and June 2012. Written consent was gathered from participants to utilise anonymised extracts from transcribed interviews.

Five out of six patient interviewees had a carer present at the interview, and all carers consented to participate in the study. Participants were offered the opportunity for a separate patient and carer interview, but all carers and patients opted to be interviewed together. Interviews were conducted by two qualitative researchers (EB and LD), one of whom facilitated the interview, while the other observed the conversation, took secondary notes and followed-up any responses or discussion with prompts and additional questions when appropriate. Interviews were digitally recorded with the participants' permission and lasted between 60 and 90 minutes. Handwritten notes made at the time of interview were reviewed shortly afterwards and the interviewers debriefed immediately following the interviews to highlight key themes observed during the interviews.

Interviews were initiated by inviting participants to describe (1) their medical history focusing on multimorbidity of COPD and HF and (2) their experience during hospitalisation. Participants were also asked to put their views and suggestions on (1) the process of hospital discharge, (2) the quality of information they received and (3) issues related to communication with clinical teams and between clinicians from different teams. During the interview, the researchers helped the participants to develop their narratives by posing questions.

Data analysis

All recorded interviews were transcribed verbatim, but without the use of names or identifiers. Transcripts were read and re-read by the research team (EB and LD) in order to identify key concepts and emerging themes. The principles of grounded

theory (Henwood, K. and Pidgeon, N. 1992), most notably constant comparison, were utilised throughout the data analysis. Analysis of the interviews took place throughout the period of data collection. The conduct of analysis during the data collection period enabled the interviewers to focus on themes of key interest, in order to challenge and test-out emerging theories. Discussion with clinicians, which took place as part of the larger study, also enabled early ideas and theories to be explored and tested. The transcripts were analysed utilising traditional grounded theory principles, with line-by-line coding and labelling of initial concepts. Early concepts were then grouped thematically, with re-labelling when necessary. Finally, overarching categories emerged and links to existing theory and literature were explored. Through this process, the analytic process was informed by regular email correspondence and 1-1 meetings between the researchers undertaking the analysis, feedback of emerging findings to the larger research steering group, and relation of patterns and conceptual work to existing research literature (to guide modelling). To promote both the transparency and validity of this process, quotations were utilised to demonstrate key concepts and themes as well as to highlight contrasts within existing themes. A running memo, accessible to both researchers (EB and LD) was kept to demonstrate how key ideas evolved from the interview data and as a mechanism to inform discussion within 1-1 meetings.

RESULTS:

Hospital Discharge questionnaire

There was an eligible sample of 35 patients over a recruitment period of 3 months, and 14 out of 29 handed questionnaires (48%) were returned. Overall responses are given in **Table 1**. The average age of the sample was 74 years (range 58 to 91 years) and there were equal numbers of women and men. Most patients were in poor health (62%) and all had been discharged to home. The overall satisfaction score was 6 out of 10 and 43% would recommend or possibly recommend (36%) the hospital. Nearly two thirds of the patients (64%) didn't receive a copy of the discharge letter and only 40% of those who received it were provide with information on 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 participants were lacking knowledge about potential side effects to their prescribed medication.

Interview sample characteristics

Six in-depth interviews were carried out with 6 patients and 5 carers in the home setting. Of the 6 patient participants, 3 were male and 3 were female. Of the five carer participants, four were female. The mean age of the patients was 79 years (range 62 to 91 years), the average hospital stay was 12 days (range 1 - 30 days), and all patients had multimorbidity diagnosis of COPD and HF. Although the total sample size for the interview study was small, no new themes emerged from the final interview, suggesting that the data had reached saturation.

Interview Themes:

The quantitative results from the survey questionnaire all support the qualitative findings. Interviewees' descriptions of their experiences on discharge from hospital were generated into four main themes: clarity of information, issues with communication, continuity of care and information about medication (**Table 2**).

Theme 1: Clarity of information

Participants talked throughout the interviews about their need for more good quality, clear information when they were discharged from hospital. Information was felt to be important to clarify exactly what symptoms meant, to provide guidance about how to respond to any symptoms once at home and how to take medication.

Uncertainty about diagnosis:

The majority of participants (four patients and one carer) recalled receiving very little information about their diagnosis. *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* (P2).

Bearing in mind the participants in this study all had multiple conditions; it was evident that they were unclear about their different diagnoses and any possible relationship between their two diagnoses. This confusion had a particular impact

when participants left the hospital, when they felt they had little guidance about what their symptoms meant, their (often newly instigated/altered) medication regimen, how to respond to symptoms, which medicines related to which symptoms/condition, or how to avoid a future admission. In the absence of guidance or information about symptoms, or the implications of their diagnoses, participants had constructed common sense understandings about their experience.

Inconsistent information:

Some participants did recall having received information about their conditions, however this had commonly been provided from multiple sources (nurses, junior doctors and specialist consultants) on multiple occasions, and as a consequence could appear contradictory, 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 (C4).* With respect to decisions about discharge, participants also reported some confusion and disagreement amongst hospital clinicians with respect to dates for discharge and planning.

Discharge information:

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 the previous day the doctor had been to see me, and he said I think we might be sending you home today. But it didn't happen that day, it was the next day (P2). Well they could have explained something but this particular doctor said to me, you're going home on Tuesday. Tuesday come I was still there, Wednesday I was send down to ward 81(P5).*

None of the participants had been 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, as well as prevent misunderstandings with their community healthcare teams (including their GP).

Carer's information:

Carer participants talked about wanting more information when patients were in hospital, particularly in relation to any movement between wards during an admission. Carers 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* (P6).

There was a clear feeling that further involvement with carers in planning would help carer participants to provide further support to the patient, as well as encourage an advocacy role and enhance communication between carers/ patients and their healthcare team.

Theme 2: Communication

Participants revealed a number of concerns about the communication between themselves and their clinical teams (both hospital and community healthcare professionals), usually aggravated by a lack of clear information. They also highlighted a number of issues in relation to the way that healthcare professionals communicate with each other.

Between healthcare professionals:

Information exchange between clinicians who care for the same patient is essential to maintain continuity of care. Participants were asked to comment on the quality of communication between healthcare professionals, most of them felt that this was poor and a source of confusion about discharge plans: *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* (C4).

There were lots of reports from participants about the need to repeat the same information to hospital staff on repeated occasions, furthering the sense of uncertainty and anxiety about information transfer within the care team. Carer participants 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 out of ten the same nurse doesn't come in (C5).

Despite this, the majority of participants described feeling satisfied with the care they received from their community healthcare teams, most notably the care provided by community nurses who they came to know well.

Between patients and clinicians:

Whilst nurses were described as being good at listening and talking to patients, nearly all participants felt that time pressure was a major obstacle to the communication they had with their doctors. There was an apparent hierarchy for communication within the ward environment, with participants feeling more comfortable asking questions to, and spending time with nurses than with doctors. Doctors were less familiar to the patients as they didn't 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 communicate actively with the patient: *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 (C4). They don't stay around, do they; they go away when they go and talk. They don't stand around and let you listen to what they're talking about (P6).* 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.

Perceived lack of communication between hospital and primary care:

All participants had expected to be contacted by their GP soon after their discharge (as 'routine'). However, none of the participants had been contacted by their GP post-discharge and were both surprised and disappointed. For this group of patients,

the GP is a key source of reassurance and the lack of contact post-discharge suggested to participants the possibility of a failure in communication between the hospital and GP practice: *I would like to see somebody from the GP's surgery to explain to her what is going on with her health medically. And I know she hasn't seen a doctor for her - oh before she was admitted to hospital, at least any information passed from the hospital to the GP, I thought would be essential (C2). Oh to be honest I expected a note to give my own doctor, which is what they always used to do. But they didn't, no (P1).*

In an age of technology, a number of participants talked about a presumed 'invisible' electronic communication between their hospital and community team. Despite making an assumption that this communication was 'probably' happening, participants weren't sure exactly how teams were communicating with each other, or whether this communication had occurred, creating a further sense of uncertainty about information transfer.

Special communication needs of elderly patients:

Patients with multimorbidity tend to be older and within this group a number had communication needs which needed to be taken into consideration during their consultation: *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.

Theme 3: Discharge process and continuity of care after discharge

Discharge process:

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. One consequence of this was that participants could be left waiting in the discharge lounge for some time whilst their carer organised transport back home. 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. So I'd have probably been better off staying in till the next day (P4).* Participants felt they received very little information about how to cope at home and

that the hospital team disengaged immediately post-discharge: *They don't seem to explain anything to you, you're going home, that's it, they forgot, you're forgot* (P 4).

Follow up and availability of a contact point:

During interviews, carer participants had concerns about the symptoms experienced by the patients, how to manage these at home, and how to respond if symptoms worsened: *Her breathing problem hadn't been solved, it was concerning me quite a bit and it still does* (C2). *We've had nothing from the hospital, you know, that if anything happens or...no, no one 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* (C3). Due to the nature of these long-term, co-morbid conditions, all participants were discharged with ongoing symptoms, so information provided to both patients and carers about how to cope with these at home was vitally important. Despite this, none of the participants in this study 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 that a telephone contact number or helpline would have been a helpful reassurance.

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, and suggested a high risk of re-admission as a consequence. Despite community teams being available out-of-hours, the majority of participants planned to ring an ambulance if symptoms worsened during these time periods.

Theme 4: Issues with medications

The patients in this sample were all living with multimorbidity, managing complex treatment regimens and in contact with various specialist teams to oversee their care. Despite this, 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 knowledge about the potential for their diseases and treatments to interact. This lack of information and 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. This is in direct contrast to the provision of services for these separate conditions, which are diagnostically-specific rather than looking at the whole person.

Although some participants had received information about their medication, the knowledge amongst the group overall about their medicines was poor and participants didn't feel confident about their medicines regimen. Where carer support was available, carer participants commonly took a lead role in assuring compliance with medication regimen. Support was provided from community pharmacy and community nursing teams with respect to the provision of compliance aids. 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 and re-admission to hospital: *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 (P5). 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 (P4).*

DISCUSSION

Research on multimorbidity is still in its early stages and most of it has focused on the epidemiology of multimorbidity particularly in primary care settings. So far much less studies have focused on what constitutes "best care" for multimorbid patients (Fortin et al 2007 BMJ) and few studies have investigated challenges of multimorbidity from patients' views with particular focus on enablers and barriers to self-management (Noel et al 2007). In this paper we focused on an area which has so far widely unexplored. Our study provided an opportunity to elicit the views of patients with multi-morbidity and their carers about their experiences of discharge

from hospital following a recent admission. Using mixed methods of research adds to the strength of this study. Patients completed the questionnaire and were interviewed recently after they were discharged from the hospital, which is seen as advantageous, because the experiences are still fresh and not biased by feeling obliged to answer more positively.

Although a small study, the experiences of those interviewed and answered the survey questionnaire reflected those of Efraimsson et al (2006), demonstrating that this group are at risk of feeling un-affiliated to their care and treatment planning, are 'outsiders' with respect to discharge and treatment plans and commonly feel unprepared at the point of discharge from hospital. It is important to consider how patients, carers and healthcare professionals working with this complex group could encourage further involvement, concordance and satisfaction with care at this key point of care provision. From our study it emerges that the main potential problems are related to discharge information, communication, issues with medication and continuity of care after discharge.

Discharge information and documentation

The feeling of not adequately informed is a very common post-discharge problem (Mistiaen et al 1997). The findings from both the survey and interviews have reaffirmed that this problem still exists among patients with multimorbidity. The literature showed that discharge-related information is often poorly documented and discharge summaries often fail to provide important administrative and medical information, such as the primary diagnosis and follow up plans (Kripalani et al 2007). A large national survey of hospital care in the USA revealed that only 50% of patients with congestive heart failure received written information at the time of discharge (Schoen et al 2006). Other research has demonstrated that most patients do not know their diagnosis on discharge, misunderstand their medication regimen, and receive inadequate post-discharge care (Balaban et al 2008).

It is well recognised that patients generate common-sense understandings about their symptoms and illness time-lines, based on information and prior experiences (Leventhal et al, 1995). These common-sense understandings then shape responses to symptoms and proposed treatment regimens, including concordance and adherence. As such, it is important for healthcare 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. Robust communication and information, delivered in a format to promote understanding, has a role in shaping common-sense models of illness, as well as potentially improving responses to symptoms post-discharge (reducing emergency re-admission).

Communication

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 (McKeen et al 2000, Walvaren et al 2008). 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 (Van Walvaren et al 2008, Noel et al 2005), with some focusing on patients with multimorbidity (Luihks et al 2012).

Concerns about the communication between the members of various healthcare teams suggest that the care for those with multi-morbidity is poorly co-ordinated, with little 'team' involvement. The transition from hospital to home was not described as seamless and the discharge planning in place did not appear to be proactive, with patients and carers describing a passive, rather than active, role during this time. In fact exchange of information is an integral component of continuity of health care (Van Walvaren et al 2008). Effective co-ordination and communication between different teams is essential to achieve a seamless interface of care between hospitals and primary care (McKeen et al 2000).

Grimmer et al (2000) describe key requirements for seamless transitions, including timeliness of decision making, recognition of impediments to discharge, technical efficiency. Within our study, there was room for improvement with respect to each of these factors and further carer involvement at points of decision-making would be a key starting point. Patients and carers expressed frustration at the need to repeatedly provide the same information to multiple professionals, even whilst in hospital. This suggests poor communication within and between care teams and

reduces the potential for technical efficiency, particularly at transition. The long-term nature of COPD and HF means that participants are likely to have prolonged, multiple contacts from multiple teams and professions – it is a key issue for healthcare service provision to consider how to ensure that communication for those people with multi-morbid conditions remains consistent, compassionate and streamlined.

Medication

Similar to the findings by Fried et al 2008, participants in our study didn't show concerns that one condition's treatment might affect the treatment for the other condition, suggesting that they had little understanding regarding the potential interaction between their diseases and treatments.

Echoing previous research (O' Brien et al 2011, Noel et al 2005, Jowsey et al 2009), this study found that patients with multimorbidity have experienced difficulties in understanding medication. Our findings are in line with those from Jowsey et al 2009 who found that patients in their study expressed limited understanding of their medication. They also added that managing medication for their numerous conditions was complicated and confusing. Similarly, medication-related problems were among issues raised in focus group meetings with patients with multimorbidity in Noel et al study 2005. Patients in their study expressed difficulties in understanding their medication regimen due to the lack of information on medication. Moore and colleagues (2003) found that nearly half of adults (49%) experience a medical error after hospital discharge; of these, medication discrepancies were the most frequent concerns (42%). This medication errors most commonly involved cardiovascular and pulmonary conditions (Moore et al 2003).

Issues with medication should be taken seriously because it could be associated with adherence to care and contribute to recurrent hospitalisations and survival rates (Tran et al 2012). The fact that multimorbid patients reported confusion about medication highlights one important aspect of the set of problems related to medication error and stresses the importance of interventions to improve medication reconciliation at the interface of care for patients with multimorbidity.

Role of carer

Given the frailty of patients with multimorbidity of COPD and HF, it is essential to recognise the role of carers in caring for such patients. Our findings agreed with those from Grimmer et al 2004 who found that lack of information left carers feeling unprepared to take on new and/or additional tasks including patient care and support. Research indicates that carers' involvement is one of the most significant factors influencing the success of discharge planning for frail older patients (Bauer et al 2009). 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.

Unless effective discharge planning for patients with multimorbidity is conducted in a comprehensive way to meet the need of such patients and their carers after hospital discharge, hospital readmissions as a result of adverse outcomes will increase. Current study indicates that an effective discharge planning for frail patients with COPD and HF multimorbidity should address carers' information.

Follow up

There are pressures on hospital to reduce length of stay and consequently patients with complex needs might be discharged earlier (Naylor et al 1999). With the trend towards shorter hospital admissions, patients will increasingly be discharged home earlier, and their symptoms may not have fully resolved when they return back home. As hospital stays reduce and the number of people with long-term chronic conditions increases, there is a need for health services to consider their role in educating, informing and support people within their homes, to co-ordinate care provision outside or traditional, profession-specific 'silos' and to provide holistic, compassionate care with patient and carers at the centre. Unlike the health professionals, participants appeared to lack essential knowledge about their symptoms and future care. Persons' interpretation and reaction to their experiences is based on pre-understanding and knowledge (Leventhal et al, 1995). As such, patient and carer understandings must be aligned with, and understood by, the healthcare professionals providing care as they can be a key source to enable concordance and self-management within the community. Further awareness about the availability of out-of-hours services within the community is important to prevent

unnecessary hospital re-admissions, particularly via emergency department. However, aligning the perceptions and expectations of patients, carers and healthcare professionals with respect to symptoms and anticipated disease progression could help patients and carers to better prevent unnecessary crises, or to access timely 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, utilising existing models of communication and theories of health behaviour (McKeown, 2007). Information is increasingly important to support patients in these situations to self-manage, to promote self-management within the home, and to prevent multiple crisis re-admissions. 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.

LIMITATIONS

This mixed methods study was conducted with a small sample of patients with a specific set of multi-morbidity (COPD and HF) and their carers. The qualitative study involved both patients and carers, where possible, and provided an opportunity for a full exploration of experiences and views. The aim of the interviews was to provide participants with an opportunity to express as personal narratives their experiences of being discharged from hospital and living with multi-morbid conditions. It was not an aim of this study to provide generalisable findings, however as the interview data reached saturation with a small sample, it is hoped that the findings will be transferable. To promote transferability, rich, detailed quotes have been utilised. It was beyond the scope of this study to explore the views of healthcare professionals providing care in the hospital and community to people with long-term multi-morbid conditions. However, the views of healthcare professionals delivering care within challenging environments warrants further exploration, including views about how to promote effective communication with patients and carers, within and across healthcare teams.

It is understandable that not all of the identified problems were unique to patients with multimorbidity of COPD and HF but multimorbidity seems to intensify these problems or increase their probability of occurrence.

CONCLUSION

Finally, our findings highlighted that patients with multimorbidity have clinical needs that distinguish them from those with a single chronic disease. Therefore, policy makers who are responsible for developing clinical guidelines should recognise the needs of such patients and incorporate protocols for the treatment of multimorbidity (Wolff et al 2002). These guidelines should be designed to improve the quality of care of patients with multimorbidity by improving care coordination and empowering shared decision making based on patients and carers' circumstances and preferences (Boyd et al 2005). There is a need for tailored intervention programmes to ensure the continuity of care across the hospital, primary care, home and community for patients with multimorbidity and to make transition of care across these settings smooth and safe.

Given the importance and frequency of multimorbidity of COPD and HF, future clinical policy initiatives need to move away from single disease management towards strategies that address the needs of patients with multimorbidity of COPD and HF together their carers particularly at the time of care transition.

AUTHOR DISCLOURE STATEMENT

No competing interests exist.

AUTHORS' CONTRIBUTION

LD was responsible for recruiting study participants, data collection and analysis of the survey. LD and EB conducted the interviews, analysed and interpreted the data and drafted the manuscript. UK designed the study and critically reviewed drafts of the article. SD was responsible for critical revisions of the final drafts of the manuscript for important intellectual content.

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Table 1: Quantitative findings from the survey questionnaire

Variable	Frequency (%)
Sex	
Male	7 (50)
Female	7 (50)
How often doctors listen	
Never	1 (7.1)
Sometimes	4 (28.6)
Usually	4 (28.6)
Always	5 (35.7)
How often doctors explain	
Never	1 (7.1)
Sometimes	4 (28.6)
Usually	3 (21.4)
Always	6 (42.9)
How often nurses listen	
Never	1 (7.1)
Sometimes	1 (7.1)
Usually	7 (50%)
Always	5 (35.7)
How often nurses explain	
Never	2 (14.3)
Sometimes	3 (21.4)
Usually	4 (28.6)
Always	5 (35.7)
Have you been given a new medicine	
No	3 (21.4)
Yes	11 (78.6)
How often did hospital staff tell you what the medicine was for	
Never	2 (18.2)
Sometimes	6 (54.5)
Usually	3 (27.3)
Always	0 (0.0)
How often did hospital staff describe possible side effects	
Never	7 (63.6)
Sometimes	2 (18.2)

Usually	2 (18.2)
Always	
Do you understand your medication	
No	3 (27.3)
Yes	8 (72.7)
Discharge destination	
Home	14 (100)
Others	
Did hospital staff talk with you about the help you needed	
No	2 (14.3)
Yes	12 (85.7)
Did you get information in writing	
No	9 (64.3)
Yes	5 (35.7)
Have you received a copy of discharge letter	
No	9 (64.3)
Yes	5 (35.7)
Does the letter explain to you who you need to contact if you need information	
No	3 (60)
Yes	2 (40)
Was the information on managing your condition and medication clear	
No	1 (20)
Yes	4 (80)
Will you recommend the hospital	
Definitely no	1 (7.1)
Probably no	2 (14.3)
Probably yes	5 (35.7)
Definitely yes	6 (42.9)
Rate your health	
Poor	8 (61.5)
Fair	4 (30.8)
Good	1 (7.7)

Age	
Mean	74.3 (SD=9.9)
Median	75
Minimum	58
Maximum	91
Hospital Rate	
Mean	6.15 (SD=2.9)
Median	7
Minimum	1
Maximum	10

Table 2: Main themes and sub-themes from participants' interviews

Main theme	Sub-theme
1-Clarity of information	-Diagnosis uncertainty -Inconsistent information -Discharge information -Carer's information
2-Communication	-Between healthcare professionals -Between patients and clinicians -Perceived lack of communication between hospital and primary care -Special communication needs of elderly patients
3-Discharge process and continuity of care after discharge	-Discharge process -Follow up after discharge and availability of a contact point
4-Medication	-Better information on medication changes (regimen, dose, side effects)

Appendix 1

Survey Questionnaire (HCAHPS 2012)

1. During this hospital stay, how often did doctors listen carefully to you?

Never Sometimes Usually Always

2. During this hospital stay, how often did doctors explain things in a way you could understand?

Never Sometimes Usually Always

3. During this hospital stay, how often did nurses listen carefully to you?

Never Sometimes Usually Always

4. During this hospital stay, how often did nurses explain things in a way you could understand?

Never Sometimes Usually Always

5. During this hospital stay, were you given any medicine that you had not taken before?

Yes No → If No, Go to Question 8

6. Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?

Never Sometimes Usually Always

7. Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?

Never Sometimes Usually Always

8. After you left the hospital, do you think that you can understand how to take your medication (if any) correctly?

Yes No I am not sure

9. After you left the hospital, did you go directly to your own home, to someone else's home, or to another health facility?

Own home Someone else's home Another health facility

10. During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?

Yes N

11. During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?

Yes No

12. During this hospital stay, have you received a copy of your discharge letter?

Yes No → If No, Go to Question 15

13. Does the letter explain to you who you need to contact if you need further information about your conditions?

Yes No → If No, Go to Question 15

14. Was the information on managing your condition and medication clear enough to you?

Yes No

15. Using any number from 0 to 10, where 0 is the worst hospital possible and 10 is the best hospital possible, what number would you use to rate the process of discharge at this hospital?

0 Worst hospital possible

1

2

3

4

5

6

7

8

9

10 Best hospital possible

16. Would you recommend this hospital to your friends and family?

Definitely no Probably no

Probably yes Definitely yes

17. In general, how would you rate your overall health?

Excellent Very good

Good Fair Poor