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A qualitative study of the contribution of pharmacists to heart failure management in Scotland

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Abstract
Study objectives: (1) To identify the medication management needs of chronic heart failure (CHF) patients and their caregivers; (2) To examine the perceived support for medication management available to these people from health professionals; (3) To identify the actual and potential perceived contribution of pharmacists to medication management.
Setting: A mixed urban/ rural region in the west of Scotland.
Design: Semi-structured qualitative research interviews.
Participants: A total of 50 people with CHF (NYHA Class II and III) due to left ventricular systolic dysfunction (33 males; mean age 67 years, 17 females; mean age 68 years) and 30 nominated caregivers recruited from the outpatient departments of two hospitals in the West of Scotland. Sampling was purposive to include patients from a range of CHF severity, ages and sexes.
Main results: Managing medications was a responsibility shared by both the patients with CHF and caregivers. Treatment regimens were reported to be difficult to comply with. Health professionals were seen to provide little support for medication management. Pharmacists were viewed as being a good and accessible source of practical assistance who were also knowledgeable about the individual's heart health history. Participants reported valuing advice from pharmacists about the side effects of medications and for their assistance in reducing the complex logistics of medication management and in having medications delivered.
Conclusions: Patients with CHF and caregivers voiced a willingness to try to manage their medication regimen accurately but had a limited capacity to do so. Pharmacists were viewed as providing valuable support to patients with CHF and their caregivers, in terms of medication management. The extended role of pharmacists in medication management of CHF should be encouraged.

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Introduction

Chronic heart failure (CHF) is a chronic disabling condition most commonly caused by left ventricular systolic dysfunction (LVSD)[1]. The incidence and prevalence of CHF have increased so markedly over recent decades, that it is considered to constitute an 'epidemic'[2]. Current estimates are that between 6% and 10% of people aged over 65 have CHF[3,4]. However, the majority of the cost of treating CHF arises from inpatient care as hospitalizations for CCHF are frequent, lengthy and costly[5] with around 16% of patients hospitalized more than once each year[6].

The potential to improve outcomes in CHF has increased markedly in recent decades. Patients should be offered a range of therapies including diuretics, ACE-inhibitors or/and angiotensin receptor blockers, beta blockers, aldosterone blockers and digoxin. Patients also receive support to make lifestyle changes such as increasing physical activity, restricting salt, stop smoking and reducing weight[7,8].

However, a significant proportion of adverse outcomes, particularly admission to hospital with decompensated CHF, have been attributed to patient factors, especially poor self management of medications[9]. The psycho-motor and cognitive changes that are a common consequence of CHF have been associated with this low compliance[10,11]. Patients have also been shown to have a limited knowledge of CHF and its management[12,13]. Psycho-social factors can also negatively influence the use of health services and CHF outcomes[14–16]. Health professionals appear to do little to address these multiple barriers[12,17], and in particular, patients with CHF receive limited help in medication management[18,19].

New models of care for chronic diseases have led to health professionals being urged to work more effectively in multi-disciplinary teams and to provide more accessible support for home-based management[20,21]. As a part of that team, pharmacists in the United Kingdom have been encouraged to become more involved in medication self-management in priority areas such as heart disease[22–24]. Studies have reported the positive effect of supportive interventions provided by pharmacists on the quality of care and other outcomes in CHF[25–30]. However, while policy suggests that pharmacy services may be well suited to provide help to those with CHF in the community[22,24], current research has focused on more compliant patients[29] and little is known about how the pharmacist can optimally support patients' and caregivers' medication needs. It is also not known how patients with CHF and caregivers currently use pharmacists and how willing they would be to accept greater pharmacist input to their care in the future. We therefore examined these issues further in a qualitative study of CHF patients and their caregivers from the West of Scotland.

Methods

We undertook a qualitative study exploring the perspectives of 50 people with CHF (33 males: mean age 67 years; 17 females: mean age 68 years), and 30 of their nominated principal caregivers. Participants were recruited from the outpatient departments of

Table 1 *Main interview themes*

Patient questions
Views of heart failure
Biological effects of CHF
Personal effects of CHF on life
Medication /Symptom management
Decision making
Caregiver issues
Caregivers questions
Own views
Biological
Personal effects of heart failure
Health Professionals
Care-giving role

Table 2 *Core questions in the interview*

Views of heart failure
When did the breathlessness/ fluid retention/ fatigue start?
What was going on to cause this?
Personal effects of CHF on life
How is your life now different than before the heart failure?
What things did you like to do but now find difficult?
Medication/ Symptom management
What helps your symptoms/ heart failure?
How do you think your tablets work? What do they do?
What are the main things you find difficult about the tablets?
How often have you forgotten to take them? What happens if you stop taking them?
What do you do when you forget to take them?
Do you ever change the doses? In what situations do you do this?
What do you do when you run out of a prescription? (if applicable)

two hospitals serving urban/ rural populations in the West of Scotland. Purposive sampling included individuals from a range of severity of CHF, age and sex. Sample size was determined by the need to have sufficient numbers of each sex and NYHA class to allow meaningful comparisons[31]. Inclusion criteria of the sample were less than 80 years of age, one or more hospital admissions for CHF due to LVSD, NYHA Class II or III CHF (i.e. mild to moderately severe symptoms) and no known dementia. The study was passed by the relevant ethics committees.

Patient perspectives were explored using a semi-structured interview that examined knowledge and management of CHF, experience of symptoms and views of health needs, health professionals and health services (Table 1) with a series of core questions included in the schedule (Table 2). With the exception of two interviews undertaken at a University, all interviews were undertaken in participants' homes.

With participants' permission, all interviews were audio-taped. Participants were advised that they could withdraw at any time, their identities would remain confidential and their care would not be affected by their participation. Data were transcribed by a secretary and to ensure reliability, were initially analyzed independently by AMC and MER who then compared interpretations for each interview.

Based on data collected during the first 10 interviews, a coding framework was developed that could subsume all the current themes. The framework was discussed and entered into qualitative analysis software (NUDIST) and used to categorize subsequent interviews. It was essential that all relevant data should be subsumed into the analytical framework and that the framework, which was modified by the research team, was organized accurately into appropriate themes and sub-themes. In this paper abbreviations have been used based on pseudonyms of patients and their caregiver.

Results

Patients and caregivers reported at length the steps that they took daily to cope with and manage CHF. The main management tasks undertaken every day included regulating activity levels, monitoring the body for troublesome signs of worsening CHF and managing the medication regimen. The regimen contained treatments commonly recommended for CHF, with the most common drugs prescribed being loop diuretics and ACE-inhibitors. A mean number of 8.96 drugs (range: 4–21 tablets) were consumed daily.

Participants frequently voiced how important it was to manage their condition on an ongoing basis, but though they recognized that managing medication was integral to this, they had little knowledge of how the medications affected the CHF (this aspect is discussed in more detail elsewhere)[32]. In most instances, patients reported that taking tablets in accordance with their prescription was important because of the perceived moral obligations they felt to their health professionals and the faith they had in their cardiologists' expertise. However, the practical task of managing medications in accordance with the prescribed regimen was seen widely as being very challenging. The most common difficulty was avoiding running out of supplies of particular tablets (Box 1).

Role of health professionals

With the exception of dealing with acute episodes of symptom exacerbation, most health professionals (primarily family physicians and cardiologists) were viewed by patients as making little contribution to educate patients about CHF and had limited insight into management and information needs (Box 2a). Caregivers were also unable to provide much support in these areas as they too shared these deficits (Box 2b).

Two-thirds of patients interviewed used commercial or home-made pill boxes to organize medications for each day, but the use of these devices had been suggested by other family members or friends rather than by health care professionals. While family physicians and cardiologists were consulted about symptoms which persisted, the professionals' role was perceived mainly to be in designing and adjusting the medication regimen, rather than supporting or

Box 1 ***Perceived difficulties with managing heart failure medications***

Running out of supplies of tablets

Probably the longest (that I was without medications) was over a weekend because the surgery is shut...and I have been too late for handing in for my repeat prescription. And you can't get the prescription until the following Monday. Because the pills are all over the place...they are all staggered because you have got them started at different times. So you are maybe running out of the aspirin, and you have still got plenty of the frusemide left.

(Mr G, 45 years old, NYHA Class II)

I was running out (of tablets). But then I worked with my doctor and I am getting the whole lot at once. I told the doctor 'It's too many (tablets)'...There might be a couple of days difference between a couple of them, but I could go down and get my new prescription and I might have a couple of days left in that tablet, four days left on that, a day left on that.

(Mr B, 66 years old NYHA Class III)

Box 2a ***Health professionals and CHF management (Patients)***

They (health professionals) never told me a thing, then one doctor said to me 'You have got this heart disease which is incurable and you will just have to live with it. There is no cure for it. You can't get an operation, you can't get nothing.' ...He just told me to take things easy. He would never explain anything to me, he was very negative...But that was all I got out of him.

(Mr B, 67 years old, NYHA Class III)

I felt at times that I would go to my doctor and I said 'I am not coping well with this or that.' He said 'Well, what do you expect? You have got a bad heart.' And before I knew it, I was out the door. I said (to myself) 'Wait a minute I didn't even get a chance to ask him anything!' I could have done with a bit more advice on how to cope. I felt sometimes as soon as you went in he sorts of looked at his watch...Within a minute I was out that door. This isn't right, I was disappointed...I wasn't too happy about that, I went up the road thinking 'This was a waste of time, it wasn't worth the effort me going down there out in the cold air.'

(Mr R, 68 years old, NYHA Class III)

My heart is not pumping. My heart is not going fast enough to pump the water away and I wasn't taking my water pills the way I should have. I didn't realise how important the water pills were. One day the doctor said 'Are you still taking them?' and I said 'No.' He said 'You are off your head!' I said: 'Nobody was asking me, so I didn't bother with them, just through ignorance...' Nobody explained how important it was to me. I just got fed up taking them, running to the toilet, running to the toilet. If I had realized how important it was, I wouldn't have stopped it. I just didn't bother because nobody else was bothering so I didn't bother.

(Mr L, 70 years old, NYHA Class II)

Box 2b ***Health professionals and CHF management (Caregivers)***

He [patient] has been in and out of hospital that often and I took the doctor down to the door [to see him out]. And he said to me 'Has anybody ever told you, Mrs L, how serious this is?' I said 'No,' well they *hadn't*. He said 'Well it's very serious...'

(Mrs W, NYHA Class III, spouse).

Mrs H: No I am quite an independent person, I would (contact the doctor) myself because he (husband) doesn't like going into hospitals, so he would try and talk me out of it. No I take the decision – I will make (it) myself.

(Mrs H, NYHA Class III spouse)

Mrs J (caregiver) : I said (to partner with CHF): 'Go to the doctors,' and he said 'No,' and I said I would get the doctor and he said that he would see how he was on Monday. So on Monday he said 'Oh if I am not better by Tuesday phone the doctor.' Well by Monday night... he couldn't get up because he couldn't breath and he had difficulty getting up the stairs.

Mr J: I don't like going to the doctor...I just feel they have got enough to do with people that have really bad problems. I have never had anything like that, so I thought it was just trivial, just a cold.

(Mrs J, NYHA Class II spouse)

guiding their daily consumption. Even during periods in which symptoms worsened, access to a family doctor, especially one who knew them, was reported as being slow. Many patients also reported not wishing to 'trouble' their doctor, and deliberately delayed or avoided consulting. Their view was that their problems were relatively minor compared to others that the busy physicians faced.

Box 3a *Pharmacists role in CHF medication management*

An accessible first point of contact

I tend to go to the doctor if there is something wrong that I think might be serious. You read things in the newspapers and you add them all up and think 'I may have that'...I had a cough for 2 weeks, a dry cough and I went to the chemist and she said you should go to the doctor and it turned out to be pleurisy. That cleared up after two lots of antibiotics...

(Mr J, 69 year old, NYHA Class II)

Mr C: I usually check with the chemist because one time we were going to take something – a flu treatment – and he told us not to, because of the tablet I was on. I checked with him because he has got a note of all the tablets I am on. He would tell us: 'Is this for yourself? Oh I don't advise it.'

(Mr B, 67 years old, NYHA Class III)

I went on a certain tablet a while ago – my doctor put me on it. And I had a rash, so I went and asked the chemist. And she told us (caregiver also) something that the doctor hadn't, that is something to do with the heart I am not blaming the doctor but it happened and the chemist is able to say something.

(Mrs Y, 51 years old, NYHA Class II)

A good source of knowledge

The chemist I go to, if I go in there and ask for a tablet that is not on my prescription, they have got me on record on the computer. And they say 'Wait and I will see if you can get that Mr H.' And they will say 'no', they say 'You can't get that you will need to see your doctor.'

(Mr H, 77 years old, NYHA Class III)

If I have a cough, I take a cough bottle or I take an antibiotic from the doctor...the chemist I go to, if I go there and ask for something off the prescription, they have got me on the computer. And they say 'Wait and I will see if you can get that. Oh you can't get that, you will need to see your doctor.'

(Mrs O, 72 years old, NYHA Class III)

Close relationships with pharmacists

I have on occasions run out of tablets, not often but on occasion. Fortunately I have been going to the same chemist for years. He knows me and will give me medication. I will in turn phone up the surgery and say I ran out, and I owe the chemist whatever, and they will sort it out.

(Mrs A, 60 years old, NYHA Class II)

Mr D: I get the repeat prescription at that small chemist round the corner there.

Mrs D (caregiver) We are well known round there so if there was an emergency he would give us it straight away. So if he ever ran out we have never been without a tablet. We have always went round and said 'Can I get a couple until we get the prescription...' We did it as he was on over 20-odd tablets...

(Mr D, 76 years old, NYHA Class II)

Box 3b *Practical support*

I got a new set of tablets and I just got the other ones [as well] and I said 'What the hell am I going to do with them?' So I took them back to the chemist. They lay there for a while and then I took them to the chemist...I would always take them to the chemist, I wouldn't throw them in the bin.

(Mr B, 67 years old, NYHA Class III)

Mrs S: If I only have got another week of tablets left, then I will phone in for my prescription. I never leave myself any less than a week that I have got to fill in that.

Mr S (caregiver): We did go short. Then if you were short the chemist would give you something...

Mrs S: That was just recently I did it I got five tablets off the chemist and then he would get that off my prescription, I got five. If you go to the same chemist, they know you and they know what tablets you are on.

(Mr S, 75 years old, NYHA Class III)

The chemist...if for any reason I ran out of tablets...there is the odd time I have got stuck like that. So I said to (the pharmacist) 'I have run out of these I should be taking them this morning.' He says 'Right, are you putting your prescription in?' and I say 'Yes it is already in,' but it might have been a weekend or something like that. He would maybe give [me] ten and say 'Right, I will write this in my book, and when you get your prescription, bring it in' and he takes ten off your prescription. He wouldn't see me stuck, that is quite reassuring. I suppose strictly speaking, he shouldn't do that.

(Mr R., 68 years old, NYHA Class III)

We can get the tablets delivered, the chemist actually deliver them to your door so it's quite easy that way... Probably the longest I have been without tablets is over the weekend because the surgery is shut. I have done that...when I have been too late for handing in for my repeat prescription. And you can't get it until the following Monday. Again, you're only talking about one tablet, because the pills are all over the place...they are all staggered because you have got them started at different times.

(Mr G. 45 years old, NYHA Class II)

The support offered by pharmacists

In contrast to other health professionals, participants identified pharmacists as being a first point of call for questions related to CHF and management (Box 3a). Easy access was important and they felt they could more readily gain advice from their local pharmacist. No appointment was needed and no other professional or geographical barriers were seen to inhibit a rapid 'consultation'. Advice was sought most often on the possible side effects of medications, possible drug interactions or contra-indications between existing and new prescribed or ''over-the-counter'' medications and for symptom management. Pharmacists were seen as having a good knowledge of each of these areas. Because relationships with the same pharmacist had often been established over considerable time, the pharmacist was seen as being knowledgeable both about CHF and individual's heart health history in a similar way to that of the family physician.

Participants also reported that pharmacists provided practical support that was particularly useful in easing the complex logistics involved in medication management (Box 3b). Three types of support provided by pharmacists were particularly valued.

First, the most common management difficulty cited by participants was avoiding running out of medication. In some instances patients did inadvertently run out of stocks of medications before repeat prescriptions could be ordered. In these cases, if the patient was known to pharmacist, he or she often supplied a small number of tablets until the repeat prescription arrived. While the ethics of such a practice might be debated, it did prevent distress and reduced the likelihood of symptom exacerbation and rehospitalization.

Secondly, participants reported taking medications that were expired or left-over from previous prescriptions back to pharmacists for disposal. By disposing of these medications, pharmacists acted to limit the volume of additional medications that had to be retained and 'managed' in the home.

Finally, participants reported that some pharmacies would deliver medications to their homes. Both patients and caregivers reported that they found this service reassuring, knowing that in the event of a sudden change in their circumstances (e.g. symptom worsening or illness) they would not be left without their medication.

Discussion

This study demonstrates that patients with CHF and their caregivers have a range of unmet needs related to medication, including poor knowledge, lack of support and poor access to health professionals. Participants demonstrated a willingness to undertake home-based management of CHF but reported a limited capacity to deal with the logistical complexity of their medication regimens. While most participants responded proactively to their difficulties, such as by using commercial or home-made pill boxes, many would have benefited from more practical support and education about CHF and its management.

A range of personal and organizational factors may limit physicians' capacity to provide effective CHF management including awareness of evidence[33], sectorial boundaries[33] and the lack of social and palliative care services to supplement stretched medical care. Pharmacists constitute a professional group well placed to address these challenges. In this study, pharmacists were seen as being accessible and helpful. This group was also seen as being knowledgeable about CHF, its management and, importantly, about the individual. Unlike some family physicians, the pharmacist was seen to be approachable and interacted co-operatively and productively with patients and caregivers.

Low compliance with medication regimens is an international problem that has significant and negative consequences for patients and health systems[34,35]. Participants implicitly recognized that pharmacists could contribute effectively to home-based disease management as part of the wider health care team. This more collaborative and multi-disciplinary approach to health care is highly congruent with current health policy[20,23], models of chronic disease management[36,37] and contemporary approaches to medication management[23,34,35]. Physicians should work collaboratively with local pharmacists as part of health care teams to improve support for patients with CHF and their caregivers.

In terms of method, the interview was effective at eliciting participants' beliefs about CHF, and the reported medication management. Furthermore, it was successful in identifying salient themes the researchers had not anticipated, most notably with the role of pharmacists in assisting their care. Due to the high rates of premature heart disease in the West of Scotland, the patients may be slightly younger than elsewhere and patients over 80 years of age were excluded due to possible co-morbidity in this group. The transferability of the findings to other settings is increased by the relatively large sample size for a qualitative study, the balanced nature of the sample across sex and NYHA classification and the lack of a local specialist service for CHF support at the time of the study.

Conclusion

The positive view of patients about pharmacists in this study suggests that these professionals have a considerable potential to play an extended role in the management of CHF. They are seen by patients and caregivers as accessible and a useful source of support for medication management.

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Possible conflict of interests

None.

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