

## **Cardiology patients' medicines management networks after hospital discharge: a mixed methods analysis of a complex adaptive system**

### **Abstract**

#### **Introduction**

The complex healthcare system that provides patients with medicines places them at risk when care is transferred between healthcare organisations, for example discharge from hospital. Consequently, understanding and improving medicines management, particularly at care transfers, is a priority.

#### **Objectives**

This study aimed to explore the medicines management system as patients experience it and determine differences in the patient-perceived importance of people in the system.

#### **Methods**

We used a Social Network Analysis framework, collecting ego-net data about the importance of people patients had contact with concerning their medicines after hospital discharge. Single- and multi-level logistic regression models of patients' networks were constructed, and model residuals were explored at the patient level. This enabled us to identify patients' ego-nets with support tie patterns different from the general patterns suggested by the model results. Qualitative data for those patients were then analysed to understand their differing experiences.

#### **Results**

Ego-nets comprised clinical and administrative healthcare staff and friends and family members. Ego-nets were highly individual and the perceived importance of alters varied both within and between patients. Ties to spouses were significantly more likely to be rated as highly important and ties to community pharmacy staff (other than pharmacists) and to GP receptionists were less likely to be highly rated. Patients with low-value medicines management networks described having limited information about their medicines and a lack of understanding or help. Patients with high-value networks described appreciating support and having confidence in staff.

#### **Conclusions**

Patients experience medicines management as individual systems within which they interacted with healthcare staff and informal support to manage their treatment. Multilevel models indicated that there are unexplained variables impacting on patients' assessments of

their medicines management networks. Qualitative exploration of the model residuals can offer an understanding of networks that do not have the typical range of support ties.

Keywords: medication management; social network analysis; medication error; multilevel models; patient safety; healthcare systems.

## **Introduction**

The healthcare system that provides patients with their medicines can also place them at risk, especially when their care is transferred between healthcare providers, for example, at hospital discharge.<sup>1</sup> Among the risks to patient safety in the transfer of care are poor communication between care providers about changes to prescribed medicines during the hospital admission,<sup>2 3</sup> the insufficient provision of information to patients about their medicines when they leave hospital,<sup>4</sup> and deficits in the quality of medicines reconciliation.<sup>5</sup>

Medicines management is the UK healthcare system that supports the prescribing, dispensing, monitoring, reviewing and use of medicines.<sup>6-8</sup> It is a multi-professional, socio-technical system within which patients interact with different healthcare professionals.<sup>9</sup> These professionals often work from different sites and settings such as hospitals, GP practices, specialist clinics and community pharmacies, and use different technical systems to support care. People in the system may operate independently yet concurrently and the system can be unpredictable. For example, patient responses to changes to medicines may not be as expected and one organisation may not respond to instructions or communications made by another, for example not implementing recommendations for changed medicines by specialists. In this way the medicines management system can be considered a complex adaptive system. Complex adaptive systems thinking recognises complexity, accepting that linear 'cause and effect' models of healthcare are too simple and do not take into account the decentralised structure of care and dispersed system controls.<sup>10</sup> System performance or behaviours in complex adaptive systems are unpredictable, networks of 'agents' in the system react to the actions of others and connections between agents in the system are critical to success or survival.<sup>11</sup>

Fraser and Greenhalgh (2001) described several properties of complex adaptive systems, which we have considered in the context of medicines management and presented in Table 1.

**Table 1: Examples of the features of complex adaptive systems applied to medicines management adapted from Fraser and Greenhalgh 2001<sup>12</sup>**

<b>Features of complex adaptive systems</b>	<b>Examples in medicines management</b>
The system and its external environment are not constant	People – such as clinicians or spouses – in the system change depending on patients’ access to services and informal support, health condition, and co-morbidities. The environment in which medicines are taken also varies.
Individuals in the system are independent and creative decision makers	Each patient and clinician makes decisions about which medicines are prescribed and taken, how they are titrated, how they are monitored and how they are managed in the home.
Uncertainty and paradox are inherent	Patient responses to treatment vary and treatment for one condition may impact on another condition.
Problems cannot always be solved but they can be improved	Many chronic conditions cannot be cured, only managed with medicines.  The inherent risks in the transfer of care can be reduced but not eliminated.
Effective solutions can emerge from minimum specification	A small improvement to document the reason why a medicine has changed is not difficult to achieve yet it can substantially improve safety.
Small changes can have big effects	Changes made to treat one health condition may have adverse impacts on patients’ co-morbidities. Actions taken or not taken by one person in the system can cause a safety incident which can manifest in a different part of the system.
Behaviour exhibits patterns (can be termed ‘attractors’)	Patients order medicines through their GP practices and would normally have them dispensed in the same community pharmacy.  GP practices would usually have a process for processing discharge summaries.  Patients may have an established routine or process for managing their medicines.
Change is more easily adopted when it taps into these patterns	Co-design with existing patients of self-management routines would tap into their existing management patterns.

In the UK, the National Health Service (NHS) aspires to healthcare that is person-centred,<sup>13</sup> taking into account their individual needs and preferences. Medicines management is characterised by a focus on personal interactions,<sup>14</sup> and as care recipients, patients have a view of care interactions that may not be afforded to others in the system. However, many patients’ experiences of navigating this system are less than optimal: they can be confused by the information they have (or have not) been given about their medicines,<sup>4 15</sup> and they spend time actively monitoring for errors made by healthcare professionals.<sup>16 17</sup>

Patients are usually discharged from the hospital in the UK with a supply of medicines of up to 4 weeks and information about the patient's new list of medicines is sent to their primary care practice. Information is not routinely sent to community pharmacy unless the patient uses a multi-compartment compliance aid. Their next prescription will be issued by their GP and either sent to their community pharmacist or collected by the patient and taken to the community pharmacy to be dispensed. Many cardiology patients are referred by the hospital to cardiac rehabilitation and heart failure nursing services, which provide care for a specified period. Waiting times for these services are increasing nationally and the number of patients with co-morbidities that access them is also increasing.<sup>18</sup>

Given the evident complexity in the medicines management system and the impact this has on patients, this study aimed to explore and appraise the composition of the medicines management system from the patient viewpoint to understand how this healthcare system operated after hospital discharge and the range of different healthcare professionals who comprise the system that patients must navigate. Viewing healthcare systems as social networks allows the type and value of care and support patients receive from healthcare professionals and patients' own informal contacts to be considered. Consequently, a Social Network Analysis (SNA) framework was judged to be the most suitable methodology.

The overall objectives of the study were to:

- 1 Describe the medicines management system from the patient perspective.
- 2 Understand which professional and personal ties, such as community pharmacy, GPs and administrative staff, perform important functions for patients.

### **Theoretical model**

We characterised the medicines management system as a personal network (an ego-net), in which the patients were the 'egos' and the people they interacted with concerning their following their discharge were their network members. The ties between patients and network members were patient assessments of the importance of that person to them in managing their medicines, and these ties were the units of analysis.

### **Ego-net analysis of medicines management**

There are few published studies using ego-net or personal network approaches to explore how medicines are managed. Qualitatively, Kjos et al. (2011) explored medicines information seeking personal networks, finding that patients sought medicines information from both HCPs and informal network members, such as their family and friends, some of whom had healthcare experience.<sup>19</sup> A further study used an ego-net approach to explore roles in

multidisciplinary care teams, describing and comparing patients' health networks, gaining an understanding of their interactions, and identifying the community pharmacists' roles within asthma patients' networks.<sup>20</sup> More recently, Cheraghi-Sohi et al. (2015) explored how personal network members influenced medicines-taking amongst 20 people with long-term conditions.<sup>17</sup> The authors used the concept of 'medicines work' to explore the roles of others in enabling medicines taking. They found that personal network members performed tasks such as collecting and monitoring medicines, offering emotional support, and providing information to patients.

## **Methods**

### **Study setting and recruitment**

We collected data about the people cardiology patients had contact with relating to their medicines via diaries and face-to-face semi-structured interviews during a six-week period following their discharge from two hospitals in the North of England. Site 1 was a 900-bed hospital forming part of an NHS teaching hospital foundation trust serving a population of approximately 0.5 million people in 100,000 households. According to Public Health England, over a quarter of adults in the areas were classified as obese and smoking related deaths were worse than the English average. Early deaths (people under 75 years of age) from heart disease and stroke had been consistently higher than the English average. Site 2 was a 690-bed hospital which forms part of a NHS trust, again serving a population of just over 0.5 million people. It covered the populations of several different unitary authorities and districts, most of which are highly deprived. Indeed, in all but one area served by the site, life expectancy for men and women was lower than the national average and the rates of cardiovascular disease and obesity were higher than the national average.<sup>21</sup> A quota sample of 60 patients was constructed to ensure patients with different characteristics – socio-economic status measured by the Index of Multiple Deprivation value of the patient's postcode, gender and age – were present in the final sample.

Eligible patients were approached on the day of discharge by one experienced healthcare researcher (BF) who explained the study to them, gave them the patient information leaflet, which they were given time to read and to discuss with friends or family if they wished to do so. Patients who were willing to take part completed and signed a consent form. The researcher explained to the patient how to keep the diary records and agreed that the patient would be contacted by telephone after few days to see how they were managing their diaries and to arrange set-up of the subsequent interview. NHS Research Ethics Committee approval was obtained (13/NI/0118).

## Data collection

Data were collected between November 2013 and June 2014. During the six weeks following their discharge, patients were asked to keep paper diary records of the people they had had contact with concerning their medicines. They were asked to record each day in their diaries the contacts that had been made, the role of the person or relationship to them. There was space in the diary for the purpose and the mode (e.g. telephone) of the contact to be noted. We did not predefine who they should include, however patients were given examples of the types of contact they might record, for example GPs, nurses, pharmacists, friends and family. They were also given example diary records as shown in Table 2 and given the researcher's contact details to use if they had queries.

**Table 2: Example diary records given to patients in the study**

<b>Date</b>	<b>People I contacted</b>	<b>People who contacted me</b>	<b>Role / relationship to me</b>	<b>Contact type</b>	<b>What happened</b>
15/09/13		<i>Helen</i>	<i>Sister-in-law</i>	<i>Telephone</i>	<i>Told me to follow my discharge medicines instructions carefully</i>
16/09/13	<i>No contact</i>	<i>No contact</i>			
17/09/13	<i>Pharmacist (supermarket)</i>		<i>Pharmacist</i>	<i>In person</i>	<i>I asked for indigestion tablets</i>
18/09/13	<i>Pharmacist (Helen)</i>		<i>Pharmacist</i>	<i>In person</i>	<i>Reviewed my medicines – She said she would write to my GP to suggest some changes</i>

Diaries were used as prompts during semi-structured interviews held approximately six weeks following discharge from hospital. The interview schedule was constructed so that contact data could be collected during interviews if patients did not wish to keep a diary or did not feel able to do so. The semi-structured interview schedule comprised questions, probes and prompts exploring patients' experiences with their medicines since leaving the hospital and the contact they had had with healthcare professionals and others concerning their medicines. During interviews a hierarchical personal network tool was used to collect data about patients' medicines networks following previously applied methods.<sup>20 22</sup> This was done by showing patients a circular diagram with numbered concentric circles which was used to position their network members (shown in Figure 1). The circle nearest the centre was labelled '1' and outer circles 2, 3 and 4. The interviewer explained to the patient that they should indicate where each of the people identified in their networks should be

positioned based on how important the patient thought that person was to managing their medicines. A ranking of 1 was the most important and 4 the least important so the closer they placed them to the middle of the diagram, the more important the patient perceived that person to be. Patients were asked 'How would you rate the contacts involved in your medicines?' 'Why do these people play a bigger role than others in your medicines?', 'Why are these people not so important?' and 'How much do you feel each of these people listen to you? And understand you?' The names and positions of patients' medicines contacts formed their ego-nets for quantitative analysis. An example of the tool used is shown in Figure 1.

**Figure 1: An example of the hierarchical network tool used to capture patients' networks**

### **Data analysis**

Members of patients' networks were categorised into ten types based on their professional role or their relationship with the patient. There were eight professional types and two personal types. Tie values (recorded as 1 = highest value; 4 = lowest value) were reversed. Tie values were then dichotomised: for each network member the highest value was recorded as '1' values of '1-3' were recorded as '0'.

Data were analysed in SPSS v.22 using descriptive statistics to explore the composition of patients' networks and the importance of the types of network members. Data were then analysed using inferential statistics to explore the variation in importance for different network member types and whether network ties varied from patient to patient as well as by type of tie. This was also done to give insight into whether experiences of medicines management were different for each patient regardless of their network composition. A single-level logistic regression model was fitted in the statistical programme R<sup>23</sup> linked to MLWIN v 2.35.<sup>24-26</sup> The outcome variable was the dichotomised importance value. Explanatory variables were the site, the patient's age, the patient's gender, and the role or relationship of the network member. The reference category for patient gender was male, site was Site 1 and the reference category for network member type was the GP. A multi-level version of the models was then fitted adding a patient level to the data to explore the extent of the tie value variation between patients. These allowed inference about whether the perceived importance of network ties varied from patient to patient as well as by type. The data were prepared in a multi-level structure with the patient at level 2 and their network members at level 1.

The multi-level logistic regression model can be summarised as:

$$\text{logit}(\pi_{ij}) = \mathbf{X}'_{ij} \boldsymbol{\beta} + u_j$$

The dependent variable is whether the network member is highly important to the patient, therefore  $\pi_{ij}$  is the probability that the tie between the network member  $i$  and patient  $j$  is of high importance.  $\mathbf{X}'_{ij} \boldsymbol{\beta}$  model fixed effects that may be characteristics of the patient (e.g. age or gender) or the network member (e.g. professional role).  $u_j$  is a normally distributed random effect for the intercept of the regression model at the patient level (Level 2), where  $u_j \sim N(0, \sigma_u^2)$ . Level 1 variation between network members of the same patient (with the same fixed factors) is Bernoulli.

Following previous applications of this method,<sup>27 28</sup> we have assumed no overlap between networks; no member of one patient's network was assumed to be a member of another patient's network. Model estimation was achieved via a Markov Chain Monte Carlo method (MCMC), and the goodness of fit of the various models was compared using the Bayesian Deviance Information Criterion (DIC). The residuals of the best fitting model were analysed and extreme cases, not following the typical patterns of ties expected by the model, were explored qualitatively to understand more about their post-discharge experiences. This sequential mixed methods analysis combining interview data with quantitative network analysis allowed in-depth interpretation of the networks data and offered contextual information to the network structures.<sup>29</sup>

## Results

75 patients were recruited to the study; 15 were lost to follow-up because: the study team could not contact them (3), they did not wish to take part (3), they were ill (7), and two patients died. 60 patients were retained in the study, 39 of whom kept diary records and 60 took part in interviews. One patient was interviewed 12 weeks following discharge because he had been readmitted for surgery. Patients' ages ranged from 35–80 (m 62; SD 10.3), 42 were male and 18 were female.

## Descriptive analysis

In total, 60 patients reported 383 medicines contacts with a mean network size of 6.47 people (SD 2.72) and a range of 1–15. Overall, patients reported more professional than personal contacts (friends and family and spouses) in their networks. Most professionals were clinical, including GPs, GP practice nurses, hospital nurses, hospital doctors, community pharmacists and specialist cardiology nurses. Each patient had contact with at



least one healthcare professional or support staff member. In total, 60 patients had 273 such contacts. GPs (n=56) were the most commonly reported healthcare professional type, although a quarter of the sample had no direct GP contact. There were 53 nurses (other than specialist cardiology nurses) who were GP practice-based, clinic-based, and also hospital-based. Just over half of patients (43) recounted contact with community pharmacists. Cardiac rehabilitation nurses or heart failure nurses were present in the networks of 35 patients. Informal contacts included spouses (8% of all network members) and other family members and friends (20%) such as children, parents and siblings, friends and neighbours. Relatives, such as in-laws and cousins, also featured along with other people patients knew but were not close to, for example acquaintances at church. Some of these informal contacts had healthcare experience, e.g. they were GPs, current and former nurses, and healthcare assistants.

Patients attributed the highest importance to over two fifths of their network members (44%) and spouses commonly attracted the highest ratings. GP receptionists attracted the most negative assessments by patients with nearly half being placed in the lowest value category by patients. Table 3 shows the number of people in each category and the importance placed on them by patients.

**Table 3: Network member types and importance ratings. Numbers are reversed so that 4 in the highest importance and 1 is the lowest importance.**

Type of network member	Number (reversed) in each importance rating (%)				Total
	1	2	3	4	
<b>GPs</b>	10 (17.9)	6 (10.7)	12 (21.4)	28 (50)	<b>56</b>
<b>Friends/Family</b>	9 (11.5)	17 (21.8)	20 (25.6)	32 (41)	<b>78</b>
<b>Hospital doctors</b>	1 (4.5)	7 (31.8)	5 (22.7)	9 (40.9)	<b>22</b>
<b>Spouses</b>	2 (6.3)	2 (6.3)	5 (15.6%)	23 (71.9)	<b>32</b>
<b>Specialist cardiology nurses</b>	2 (5.7)	3 (8.6)	8 (22.9)	22 (62.9)	<b>35</b>
<b>Other nurses</b>	4 (7.5)	9 (17)	15 (28.3)	25 (47.2)	<b>53</b>
<b>Community pharmacy staff</b>	5 (15.2)	10 (30.3)	12 (36.4)	6 (18.2)	<b>33</b>
<b>Community pharmacists</b>	3 (7)	11 (25.6)	13 (30.2)	16 (37.2)	<b>43</b>
<b>Others</b>	1 (12.5)	1 (12.5)	2 (25)	4 (50)	<b>8</b>
<b>GP receptionists</b>	11 (47.8)	3 (13)	6 (26.1)	3 (13)	<b>23</b>
<b>Total</b>	<b>48</b>	<b>69</b>	<b>98</b>	<b>168</b>	<b>383</b>
<b>Total (%)</b>	<b>12.5%</b>	<b>18%</b>	<b>25.6%</b>	<b>43.9%</b>	<b>100%</b>

### Single-level model of the network ties

Model 1 in Table 4 was a single-level logistic regression of the likelihood of a network member being highly important to the patient – fitted mainly as a baseline model to be compared for goodness of fit with the more realistically complex multi-level model.

Compared with GPs, all healthcare staff network members were less likely to be highly important members of patients' networks. Patients' spouses were significantly more likely to be highly important network members ( $p < 0.05$  (CI 0.03 – 1.971)). Increase in age was also significantly more likely to positively impact on network ratings ( $p < 0.01$  (CI 0.008 – 0.0516)). GP reception staff ( $p < 0.01$  (CI -3.658 – -0.813) and community pharmacy staff (not pharmacists) ( $p < 0.01$  (CI -2.755 – -0.589)) were significantly less likely to be highly rated.

### Multi-level model of the network ties

Multi-level models better represent these patient networks and allow the nature and extent of variation in ties between and within patient networks. Model 2 in Table 5 is a multi-level logistic regression of the likelihood of a tie being highly rated by the patient. It has a reduced DIC of 495.29, indicating that controlling for patient-level variation improves the statistical model fit. In this model, increasing age still significantly increases the likelihood that network ties will be highly important to patients ( $p < 0.05$  (CI 0.003 – 0.065)). Spouses are also still significantly more likely than GPs to be highly important network members ( $p < 0.05$  (CI 0.112 – 2.218)) and the likelihood of ties to community pharmacy staff ( $p = 0.001$  (CI -3.247 – -0.827)) and to GP receptionists ( $p < 0.01$  (CI -4.147 – -1.032)) being highly rated is reduced compared to GPs.

**Table 4: Model 1 – Single-level logistic regression of the likelihood of a network tie being of high value to the patient. Reference categories: male patient; site 1; GP network member.**

Deviation Information Criteria (DIC) = 505.645 ** $p < 0.01$ * $p < 0.05$					
	Co-efficient	SE	P	CI lower	CI Upper
<b>Intercept</b>	-1.645	0.727	0.0236 *	-3.065	-0.242
<b>Patient age</b>	0.030	0.011	0.008 **	0.008	0.052
<b>Patient female</b>	0.199	0.241	0.409	-0.270	0.670
<b>Site 2</b>	-0.413	0.361	0.080	-0.881	0.045
<b>Friend / family</b>	-0.437	0.528	0.407	-1.479	0.573
<b>Hospital doctor</b>	-0.518	0.503	0.303	-1.511	0.484
<b>Spouse</b>	0.981	0.496	0.048 *	0.030	1.971
<b>Specialist cardio nurse</b>	0.513	0.449	0.253	-0.359	1.401
<b>Other nurse</b>	-0.120	0.399	0.763	-0.905	0.663
<b>Community pharmacy staff</b>	-1.608	0.549	0.003 **	-2.755	-0.589
<b>Community pharmacist</b>	-0.644	0.430	0.134	-1.498	0.203
<b>Other</b>	-0.063	0.803	0.937	-1.534	1.642
<b>GP reception</b>	-2.123	0.726	0.003 **	-3.657	-0.813

staff					
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Table 5: Model 2 – Multi-level logistic regression of the likelihood of a network tie being of high importance to the patient. Level 1 network members; level 2 patients. Reference categories: male patient; site 1; network member GP.

Deviation Information Criteria (DIC) = 495.293 ** p<0.01 *p<0.05					
Fixed part estimates					
	Co-efficient	SE	P	CI lower	CI upper
Intercept	-1.863	1.028	0.070	-3.858	0.110
Patient age	0.034	0.016	0.032 *	0.003	0.065
Patient female	0.159	0.349	0.650	-0.533	0.851
Site 2	-0.447	0.321	0.163	-1.086	0.194
Friend / family	-0.339	0.402	0.399	-1.130	0.439
Hospital doctor	-0.268	0.580	0.644	-1.405	0.860
Spouse	1.129	0.537	0.036 *	0.112	2.218
Specialist cardio nurse	0.600	0.500	0.230	-0.371	1.581
Other nurse	-0.117	0.437	0.789	-0.976	0.750
Community pharmacy staff	-1.973	0.620	0.001 **	-3.247	-0.827
Community pharmacist	-0.738	0.463	0.111	-1.659	0.157
Other	0.064	0.884	0.942	-1.674	1.809
GP reception staff	-2.451	0.790	0.002 **	-4.147	-1.032
Random part estimates at the patient level					
	Co-efficient	SE		CI lower	CI upper
Intercept	0.5636	0.404		0.002	1.561

### Analysis of the model residuals

We analysed the residuals for the best fitting model (Model 2) to see, having controlled for the explanatory variables in the model, which patients valued their networks on average more highly than others and which patients attributed lower values on average (extreme cases). A caterpillar plot of the residuals for Model 2 is in Figure 2 and the extreme residuals are presented in Tables 6 and 7 for the tail and head of the residuals plot. We then explored the composition of those networks and the patients' experiences of managing their medicines. Cases with extreme residuals indicated the patients for whom tie variation cannot

be explained well by the model and further qualitative assessment of these cases was carried out.

**Figure 2: Caterpillar plot of the residuals of Model 2**

**Table 6: Extreme residuals for Model 2 (Head)**

Patient ID	Residuals	Lower 95% CI	Upper 95% CI
18	-1.9	-3.4	-0.39
13	-1.7	-2.9	-0.61
50	-1.6	-3.1	-0.14

**Table 7: Extreme residuals for Model 2 (Tail)**

Patient ID	Residuals	Lower 95% CI	Upper 95% CI
54	1.3	0.1	2.4
48	1.6	0.3	2.9
47	1.7	0.2	3.2
25	2.5	0.9	4.2

After fitting Model 2, three patients recorded lower values for their network ties than other patients. Here we describe their experiences in more depth. Patient 18 had no spouse or other friends or family support with medicines and felt that little information had been given to her in the hospital about newly prescribed medicines. Overall, this patient described being frustrated with the levels of medicines-related care she had experienced. She described feeling “like I’m 50%, I’m not 100%”. She had been given incorrect information by the hospital about discontinuing a medicine in advance of a test, which had annoyed her, and described having low levels of confidence in the efficacy of her medicines and that her health conditions and response to her medicines were not being effectively managed.

*“I believe that they [health professionals] should think, ‘well she’s still got the hypertension, which I’ll have but it’s ridiculously high, she’s maxed out on all of her blood pressure tablets and the majority of the angina medication, she’s already had a heart attack, the angina is more prevalent than it was before the heart attack, we should really be getting her sorted out.’” (Patient 18)*

Patient 13 had a large medicines management network with six friends and family members and a range of staff from different healthcare organisations providing medicines management functions for the patient’s cardiology conditions and other co-morbidities. He did consider some of his healthcare professionals, such as his GP, to be important; however none of his informal network, including his spouse, was highly valued. This patient ordered

his medicines himself using the GP practice's online system and checked for himself the list of available medicines against the hospital discharge note. He attributed the highest value to his GP and hospital cardiologist and perceived much less value in the rest of his care team. In particular his usual community pharmacist was given the lowest value because he appraised their function and availability to be limited.

*"Well, I don't always see the chemist when I go... I may be wrong, but they can't change [the medicines], they have to go through a GP, or a consultant anyhow." (Patient 13)*

Patient 50 described discontinuing two of her medicines during the immediate post-discharge period because she didn't understand why she needed to take them. She had asked for help from her spouse in organising her supplies but this had not been forthcoming. She also felt that healthcare staff had not taken into account her preferences, for example not wishing to take statins. She described perceiving the need to be given more explanation about the function of medicines and the reason for needing to take them.

*"Regards medicines, I think what would have been nice, is somebody with communication skills to sit in a private room, just you and them, and work through what had happened to you, what you need and why you need it basically, a bit like a proper GP consultation, but with a pharmacist who's got some good communication and people skills." (Patient 50)*

Four patients recorded higher values for their network ties than others. Their experiences are laid out below.

Patient 25 attributed high importance to everyone in her network. She had unanswered questions about her medicines but blamed herself for not asking anyone about them. This patient valued the role of GP receptionists and pharmacy staff in supplying her with medicines and communicating efficiently. She also appreciated the relationship she had developed over time with the GP reception staff.

*"Well I have known them for a long time, I have been with them for years, so when I phone up they actually know who I am to start with. They just seem to know what you want when I am phoning for my medication. Like we will send it to the chemist, they are really good." (Patient 25)*

Patient 47 had a small network comprising her GP, community pharmacist, the pharmacy delivery driver and her sister. She described having no problems with her medicines since

leaving the hospital and explained that the services of her community pharmacist and pharmacy delivery driver were important and she valued them for their reliability and the convenience of having medicines delivered.

*“He [the pharmacy delivery driver] delivers them, doesn’t he? Without him I’d have to go find them myself, wouldn’t I?” (Patient 47)*

Patient 48 had a network of seven people, six of whom were healthcare staff. She described her daughter as acting as her advocate with the healthcare team. She had experienced side-effects whilst taking a beta-blocker but her GP had taken action and she described not needing to talk with anyone about her medicines because *“I just take them and get on with it”*. Nevertheless she felt confident that her GP, other practice staff and staff at her community pharmacy were approachable if she had problems with her medicines.

*“No, they always say, any problems at all you’re not wasting [our time]...because I always think I’m wasting their time. [My GP] has talked to me on the phone before, he did last time when I told him about [my problems with] these beta-blockers.” (Patient 48)*

Patient 54 had a network of six people, five of whom were members of the healthcare team. He placed importance on a pacemaker technician who advised him to take the prescribed dose of beta-blocker after the patient had told him he had decided to take half the dose. He felt he had a good relationship with his GP, however, he was critical of the GP practice receptionist staff who he thought provided poor service and his new medicines had also been missing from his repeat prescription. This patient, however, praised the staff at his community pharmacy for their helpfulness.

*“They [community pharmacy staff] are brilliant, they are really good, they are and extremely helpful, they make you feel that you need... that you know they are there to help you.” (Patient 54)*

## **Discussion**

We found that patients discharged from cardiology wards have individual medicines management networks with different compositions and different sizes that included clinical and non-clinical staff and friends and family members. Over two fifths of the people in patients’ networks were perceived to be highly important in managing medicines. We also found that not all patients had contact with GPs and community pharmacists following their

discharge, however all patients did have contact with at least one formal healthcare staff member. Older patients were more likely to perceive highly important network ties. Patients' spouses were significantly more likely than other network members to be highly important whilst community pharmacy staff and GP reception staff were less likely to be highly rated. By analysing the residuals of the best fitting model it was possible to identify patients who did not have the typical range of tie values. Some of these patients described not having enough information about their medicines and needing support in organising them once home from hospital. Others lacked confidence in their efficacy and had stopped taking them. Patients with more positive assessments of their networks described valuing the relationships they had developed over time with their care team.

In common with other studies, patients had medicines network members who were friends or family members.<sup>17 19</sup> Not all patients had this type of informal support, although each patient did have contact with at least one healthcare professional or healthcare support staff member. In our sample, increase in age positively impacted on the likelihood of patients perceiving their network members as highly important. Older patients have previously been found to have high expectations of their care team and to have those expectations met,<sup>30</sup> however older patients and their carers have also reported poor experiences of the medicines care they receive after leaving hospital, and to lack knowledge of their medicines.<sup>4 31</sup> This may result in older patients perceiving their care and informal support networks to be more important to them as they require more input post-discharge.

All network members were on average less likely to be highly valued by patients than GPs apart from their spouse and their specialist cardiology nurses, although the latter not significantly so. This emphasises the continued, perceived importance of patients' GPs in managing their medicines after a period in hospital, despite the reports some patients make about not being able to access GP services easily. GP receptionists and community pharmacy staff were not highly valued by the patients that came into contact with them. This contradicts evidence that patients tend to be satisfied with primary care experiences and they have confidence and trust in their healthcare teams.<sup>32</sup> It might also reflect views that non-clinical staff play less important roles in healthcare, However GP receptionists perform pivotal medicines management functions,<sup>33 34</sup> albeit not always patient-facing functions, which demand problem-solving, good judgement and a focus on patient safety. Receptionists often need to make decisions balancing patient needs with the availability of services, which can appear as 'gatekeeping' to the patient.<sup>33</sup> Patients engage with pharmacy delivery drivers delivering to their homes and community pharmacy staff who may act as a proxy for contact with a community pharmacist and they may not see a pharmacist in

person. Because patients do not automatically have contact with a community pharmacist after their discharge and many do not see their GP, opportunities to support their medicines use may be missed.

### **The ego-net approach to exploring a complex system**

Using the ego-net approach we were able to construct patients' networks as patients experienced them, rather than how this healthcare system was designed to be delivered. Here, the patient was in the role of perceiver of their system in the form of ties to others concerning their medicines, rather than simply those that routinely and explicitly appear between professionals in care delivery. The networks reflect patient access of formal healthcare services and the availability of informal social support resources to access medicines. The multi-level model was able to reflect how individual patients' networks were valued differently at the individual level; and that every person's experience of healthcare is different. During the study, exploring personal interactions was invaluable in understanding how the system manifested itself to patients. The networks patients described were sets of independent actors working in parallel to meet the goal of managing medicines.<sup>10</sup> In our study membership of each patient-described network varied and changed according to their needs, preferences and ability to adapt following their admission to the hospital, and the availability of services and support. The systems patients described were embedded within other systems and by nature would overlap with other systems, for example one GP would treat many patients but each of those patients would have different specialist clinicians managing their medicines and different people providing informal support. These medicines management systems also co-existed and interacted with other healthcare systems, for example those that commission healthcare services, or run primary care or hospital services.<sup>11</sup> Moreover, patients themselves are complex, and are faced with social, economic, personal, biological, and clinical circumstances which are also variable and unpredictable and these combined forces impact on how they respond to or manage treatment and care services.<sup>35 36</sup>

### **Implications for policy**

An important measure of the quality of healthcare is whether it provides care designed to meet individual patient's needs.<sup>37</sup> This research has demonstrated that every person's experience of medicines management is individual, however, the extent to which the care that patients experience is individualised or tailored to their needs and values is questionable. Patient-centred approaches are key to the successful optimisation of medicines.<sup>38</sup> It is undeniable that patients access the services of many different healthcare practitioners during this period of their recovery and in this sense they are managing one-to-



many relationships with their care teams in the course of their medicines self-management. Patients in other research have described this as burdensome,<sup>4</sup> and even if patients experienced individual, patient-centred encounters with a clinician, such as a cardiac rehabilitation nurse, the overall system itself may not have been calibrated to deliver patient-centred medicines management. Interventions have attempted to enhance the patient-centredness of medicines management, although few have been delivered by multidisciplinary teams.<sup>39</sup> Policy must address, therefore, how an integrated patient-centred medicines management process could be designed and embedded to make it an actionable goal for all care providers within healthcare economies.

The data suggest that there are inconsistencies in the support patients access to manage their medicines once they leave the hospital. Whilst this in part reflects individual variation in patients' care needs and the complexity in the system, after leaving the hospital one in four patients had no contact with a GP who may be expected to have an overview of the care patients receive from different healthcare professionals and the different treatments prescribed for different chronic conditions. The UK NICE guidance stresses how medicines optimisation should be focussed on the involvement of all HCPs and social care professionals involved in the patient's care and that professional collaboration across healthcare settings is required.<sup>38</sup> It is difficult to ascertain what consideration is given to patients' hospital discharge and medicines by somebody in primary care looking across patients' co-morbidities and their subsequent appointments with specialists in their different health conditions. Given that changes to medicines made by one clinician can impact on the patient's co-morbidities, consideration needs to be given to drug-condition interactions.

Policy has attempted to extend and expand the role of community pharmacists in supporting patients with their medicines and build patient knowledge of their medicines over time to complement the care they receive from their GP and reduce the demand for GP services.<sup>40</sup>

<sup>41</sup> In the UK patients usually receive a supply of medicines in hospital to take home and then receive a follow-up prescription from their GP, which they then would access a community pharmacy to dispense. This differs from the way care is organised in other countries, for example in the USA where patients are not given supplies at discharge. Community pharmacists have also been commissioned to provide a Medicines Use Review and Prescription Intervention Service (MURs) in England and Wales since 2005 which aims to ensure that patients understand their medicines, identify problems patients might be experiencing and provide feedback to the prescriber. There are currently four target groups for MURs, which include those who have recently been discharged from the hospital with changes made to their medicines and patients with cardiovascular conditions. In this study

community pharmacists were not universally present in patients' networks and, compared with GPs, they were not important network members. Our findings suggest that community pharmacy services could be better integrated into the post-discharge pathway to support patients in using their medicines following a period in hospital, especially as their information and support needs may change after discharge.<sup>42</sup> In addition the increase in GP practice-based pharmacists may provide an additional resource to optimise treatment across health conditions and clinical specialisms.<sup>43</sup>

### **Implications for further research**

The research has expanded our understanding that informal contacts are leveraged by many patients to gain support in medicines management. Spouses in particular played highly valued roles for patients. It is accepted that people's social networks impact on their health and wellbeing,<sup>44 45</sup> our study has shown the informal networks surrounding patients are as important to them as more formal healthcare practitioners and that people's health and treatment is experienced through social ties, either through personal contacts supporting and facilitating recovery and access to treatment, or through the social context in which people experience socio-technical healthcare systems. There is a clear opportunity for SNA to explore and understand more about people's behaviours and experiences with their medicines. Whole network approaches can be adopted to explore healthcare systems which include patients.<sup>46</sup>

### **Limitations**

This work focused on a single health condition, and although the findings from this study cannot be generalised to the broader patient population, patients with a range of different health conditions are likely to share some of the same experiences in the post-discharge management of their medicines. The necessity to conduct a relatively small sample study to determine the extent of patients' networks through face-to-face interview methods meant that the quantitative data analysis does not aim to be statistically inferential. This was a cross-sectional study that mapped patients' networks and is subject to some of the inherent biases of this approach. This approach did not allow us to take into account the temporal order of medicines management care or support patients were able to access. In theory, this data might have been available in patient diaries, however not all patients felt able to keep a diary. The networks represented patients' views of the medicines management system and this project did not attempt to corroborate their views with other sources of data such as their medical records or the views of healthcare professionals and informal carers. Patients' experiences of healthcare systems are, however, important data in determining the quality

and safety of care. Networks were recorded or described by patients who may not have accurately noted or recalled their medicines management interactions.

## Conclusion

Patients experience medicines management as individual systems comprising healthcare staff and personal contacts and patients value system components individually. Analysing the model residuals from the quantitative analysis, and exploring patients' experiences qualitatively was a novel application of mixed methods to network data. There are opportunities to improve how medicines are managed to reflect the care and support needs of individuals so that it is person-centred. Using this ego-net approach it is possible to understand this complex healthcare system as patients experienced it, rather than how policy suggests it is delivered.

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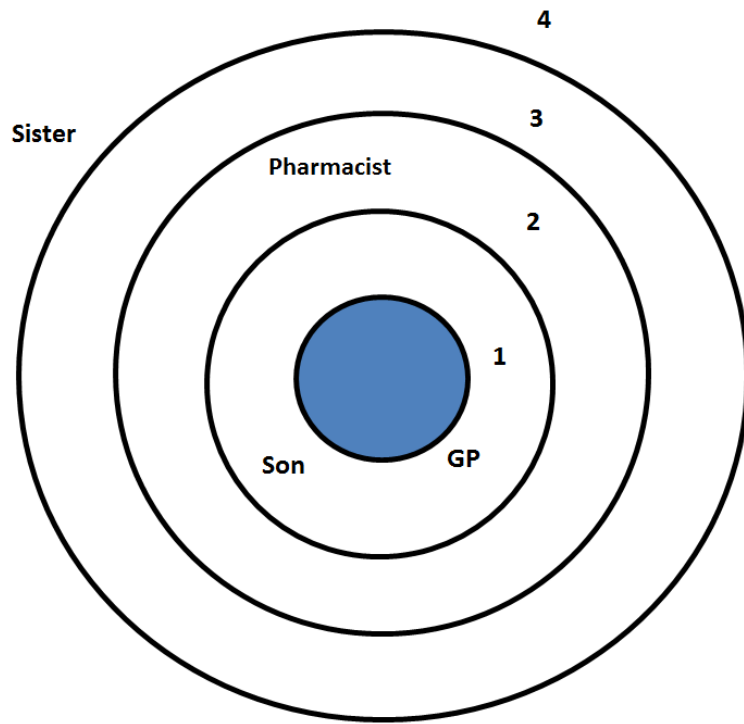


Figure 1: An example of the hierarchical network tool used to capture patients' ego-nets

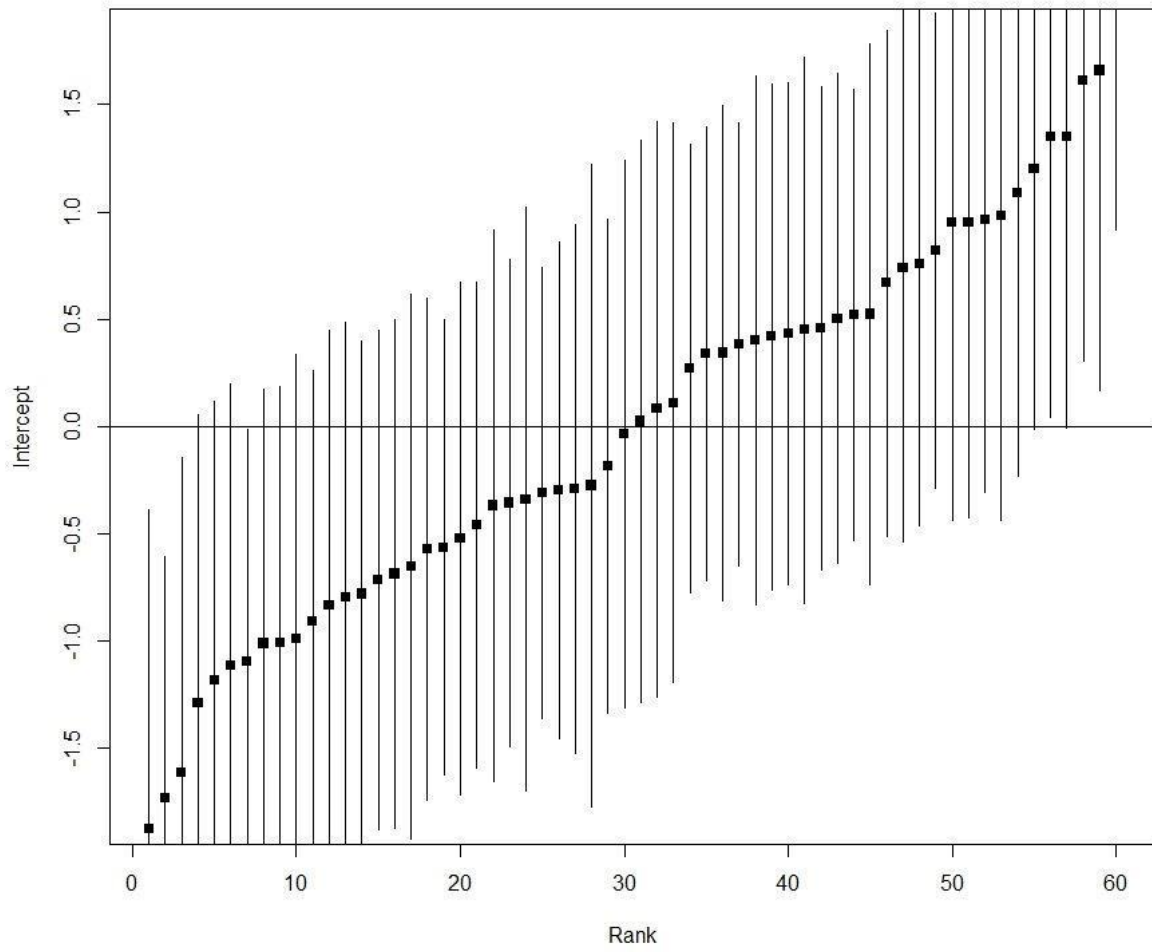


Figure 2: Caterpillar plot of the residuals of Model 2