

## **A qualitative study of patient involvement in medicines management after hospital discharge: an under-recognised source of systems resilience**

### **ABSTRACT**

**Introduction** There are risks to the safety of medicines management when patient care is transferred between healthcare organisations, for example when a patient is discharged from hospital. Using the theoretical concept of resilience in healthcare, this study aimed to better understand the proactive role that patients can play in creating a safer, resilient medicines management at a common transition of care.

**Methods** Qualitative interviews with 60 cardiology patients six weeks after their discharge from two UK hospitals explored patients' experiences with their discharge medicines. Data were initially subjected to an inductive thematic analysis and a subsequent theory-guided deductive analysis.

**Results** During interviews twenty-three patients described medicines management resilience strategies in two main themes: identifying system vulnerabilities; and establishing self-management strategies. Patients could anticipate problems in the system that supplied them with medicines and took specific actions to prevent them. They also identified when errors had occurred both before and after medicines had been supplied and took corrective action to avoid harm. Some reported how they had not foreseen problems or experienced patient safety incidents. Patients recounted how they ensured information about medicines changes was correctly communicated and acted upon, and identified their strategies to enhance their own reliability in adherence and resource management.

**Conclusion** Patients experience the impact of vulnerabilities in the medicines management system across the secondary-primary care transition but many are able to enhance system resilience through developing strategies to reduce the risk of medicines errors occurring.

Consequently, there are opportunities – with caveats – to elicit, develop and formalise patients' capabilities which would contribute to safer patient care and more effective medicines management.

## **INTRODUCTION**

Despite a continued and worldwide focus on reducing avoidable harm caused to patients by healthcare systems, progress has been slow and a widespread reduction in adverse events has not materialised.<sup>1 2</sup> Furthermore, the under-reporting of errors remains a problem.<sup>3</sup> Risks to patient safety include those from healthcare systems that manage medicines and addressing the level of harm caused by medicines through unsafe practices and errors is an established global priority.<sup>4 5</sup>

In the UK, medicines management is the system that supports safe and cost-effective prescribing, supports patients' medicines use and helps patients gain the optimum benefit from medicines.<sup>6 7</sup> The inherent risks in this system are heightened when patient care is transferred between healthcare organisations, for example between a hospital and a family doctor (in the UK, General Practitioner or GP) when a patient is discharged.<sup>8-10</sup> The problems that patients experience as a result of how the system operates are well documented and include the lack of a definitive list of medicines which can lead to discrepancies between lists held by different care providers and the medicines that the patient actually takes when they are discharged.<sup>11-13</sup> Patients also report not receiving sufficient information about their discharge medicines,<sup>14</sup> lacking knowledge of their medicines,<sup>15 17</sup> and becoming confused or experiencing medicines taking as a burden.<sup>16 17</sup>

In the UK, the 2013 Berwick Review recommended that patients should be engaged and empowered to make healthcare safer.<sup>18</sup> UK policy also specifies that patients should have the opportunity to be fully involved in the safe management of their medicines when their care is transferred and in the reporting of medicines-related patient safety incidents.<sup>19</sup>

Indeed, there is some evidence in recent studies that, despite the complexity of the system, patient and family involvement in care transitions may enhance safety and continuity in medicines management.<sup>20 21</sup>

### **Resilience in healthcare systems**

Resilience is a protective and proactive system attribute that enables operational adjustments before, during or after disturbances or changes so that the system can continue functioning.<sup>22 23</sup> It values learning from successes – i.e. what went right – as well as from failures, such as adverse events. The proactive approach embodied in creating resilience contrasts with the reactive approach that retrospectively deconstructs events that have led to a loss and then adopts a curative strategy.<sup>24</sup> This latter approach is a Safety 1 approach and the former proactive approach is categorised as Safety 2, which accepts that successes in healthcare are more common than failures.<sup>25</sup> Hollnagel outlined the four abilities that systems need to be resilient: the ability to respond to events, monitor developments, anticipate threats and opportunities, and learn from failures and successes.<sup>23</sup> This allows the system to know what to expect, how to respond, and how to identify potential opportunities to make operational or environmental adjustments.

In healthcare, the concept of resilience has been used to propose how safety in single organisational settings can be enhanced. For example, how clinical handovers of care can be improved in individual, micro (e.g. ward level) and macro (organisation wide) contexts through foreseeing potential problems and taking action to avoid their impact, coping when disruptions occur to prevent them becoming worse, and recovering once disruptions have occurred.<sup>26</sup> Other studies have explored resilience in the context of how collaborative cross-checking can reduce the impact of medication errors,<sup>27</sup> and how the anticipatory and responsive strategies of nuclear medicines technologists could enhance resilience and therefore operational safety.<sup>28</sup> Resilience theory has also been applied to explore the strategies that patients might adopt to avoid unintentional non-adherence to their

medicines,<sup>29</sup> but beyond this work the notion of patients as agents of system resilience in medicines management has not been explored.

This study aimed to explore and categorise the proactive medicines safety strategies employed by patients discharged from two hospitals. The objectives were to establish an understanding of patients' experiences of the effectiveness of medicines management; to understand how patients act proactively in the medicines management system after hospital discharge; and to consider the implications for policy and practice based on an analysis of patients' narratives.

## **METHODS**

### **Sample and recruitment**

The sample for this qualitative study consisted of patients discharged with at least one medicine from the cardiology wards of two acute UK NHS hospitals in Northern England. Cardiology patients were selected as they take numerous medicines, are often prescribed new medicines, or experience multiple changes to medicines during hospitalisation. Patients were included in the research if they were between 18–80 years of age and were being discharged to their own home. A quota sample was developed based on age, socio-economic status (measured through postcode deprivation level) and gender to offset selection bias and promote variation into the sample. The quota guided the targeting of patients, particularly towards the end of recruitment. The achieved sample of sixty patients was assessed to be sufficient to allow for variations in subgroup experiences. Patients about to be discharged were identified on 36 randomly selected days in consultation with ward staff. One researcher approached patients and invited them to take part between November 2013–June 2014. Patients were given a patient information leaflet describing the research and their potential involvement. They were given time to read the leaflet and the researcher answered their questions about participation. Those who agreed to take part completed a consent form. NHS ethics approval was obtained (13/NI/0118).

## **Data collection**

A semi-structured interview schedule explored patients' experiences of the medicines management system from leaving hospital through to six weeks after their discharge and their medicines-specific interactions with other people. The schedule was developed by four researchers based on a review of the literature about patients' experiences with their medicines at and after hospital discharge. It was then reviewed by a patient representative and piloted with three patients, after which it was amended to reduce the potential duration. Each interview lasted approximately one hour and was conducted in the patient's home or an alternative venue of their choice. Interviews were audio recorded, transcribed verbatim and de-identified. Interviews were conducted by one experienced healthcare researcher (BF).

## **Data analysis**

Interview data for each patient were analysed using inductive thematic analysis,<sup>30</sup> to initially explore the data. Data were coded by one researcher (BF) and emerging themes were discussed by three researchers (BF, GA, AB) two of whom are from healthcare backgrounds. During the analysis it became clear that there were considerable data about threats to patient safety and the protective actions that patients took. A review of theories suggested that the literature about resilience engineering in healthcare would provide a useful guide. Therefore a theory-guided deductive analysis was undertaken, taking care to ensure the themes directly reflected patients' experiences.<sup>31</sup> Data were then coded into themes and subthemes describing patients' resilience strategies and compared to resilience frameworks and typologies.<sup>23 32 33</sup> This approach also informed the terminology for the themes. To ensure rigour, the data analysis strategy was developed by two members of the research team who then also reviewed the thematic grouping of data. There was an iterative process of data extraction, analysis and review. Events recounted by patients that had the potential for harm were also extracted and assessed by two researchers from a healthcare

background (GA, DN) who discussed the nature of each event guided by the National Patient Safety Agency definition and classified it as either a patient safety incident or not.<sup>34</sup>

## RESULTS

75 patients were recruited to the study; 15 were lost to follow-up because: they could not be contacted (3), they preferred not to take part (3), they felt too ill to continue (6), were not available for interview (1) and two patients died. Sixty cardiology patients aged 35–80 were interviewed about their post-discharge medicines management experiences. Participants' demographics are shown in Table 1. Twenty-three patients (aged 48–79; 18 male and 5 female) described strategies to maintain safe and effective medicines management which are presented by theme. Data extracts in the form of direct quotes from patients' interviews are included. The main themes identified were: Identifying system vulnerabilities; and establishing self-management strategies. Sixteen of the 60 patients also described experiencing patient safety incidents.

**Table 1: Characteristics of the study participants**

Sampling variable	Categories	Participant number			
1. Location	<i>Site 1</i>	29			
	<i>Site 2</i>	31			
2. Participant age	<i>&lt;64</i>				31
	<i>&gt;64</i>				29
3. Participant gender	<i>Male</i>			42	
	<i>Female</i>			18	
4. Level of deprivation	<i>Low</i>		10		
	<i>Medium</i>		18		
	<i>High</i>		32		
<b>Total participants</b>		<b>60</b>	<b>60</b>	<b>60</b>	<b>60</b>

### 1 Identifying system vulnerabilities

This theme describes how patients identified system vulnerabilities, experienced patient safety incidents and took corrective action. It is presented in three sub-themes: anticipating discrepancies; facilitating communication; and responding to errors and safety incidents.

#### 1.1 Anticipating discrepancies

Patients described the strategies they adopted to ensure they obtained the correct post-

discharge medicines. They explained how they would compare their post-discharge repeat prescription and supplies against the medicines list on their discharge summaries, check the medicines they received against those lists or compare the packaging and labels of new supplies with their hospital-dispensed medicines. Through these strategies, patients demonstrated how they and their informal carers anticipated discrepancies and took the final step in verifying that they had been supplied the correct medicines set.

*“I’ve kept the boxes from leaving hospital that the pills were in so [I] just check against them.” (Site 1 patient 33)*

*“[I] just go in [to the community pharmacy] for the tablets... but I always check to see what they’ve given me first.” (Site 1 patient 1)*

## 1.2 Facilitating communication

Patients ensured information from the hospital was communicated in a timely way to their primary care team. For example, they would take their hospital discharge summaries to their GP or tell their GP directly about the medicines changes made by the hospital. Some did this proactively after their discharge – deliberately going to their GP practice to give them details – and others did so during appointments.

Patients described how they would ensure the lists of their medicines held by their care providers were correct. For example, they would use their new list of medicines when telephoning their GP practice to order repeat medicines, ensuring the reception team were aware of changes. Others also took their new medicines lists to their community pharmacy which, in the UK, would not normally receive a medicines list from the hospital unless the patient was using a pharmacy-prepared compliance aid.

*“[I go to the community pharmacy] with the list [of medicines]. I’ve got my list with me. I write a list...I give the pharmacist that...I always double check.” (Site 2 patient 9)*

*“He [my GP] didn’t know [I was on new medicines] because [he did not have] the letter, the discharge notes that the hospital gave me...so I gave him them.” (Site 1 patient 27)*

*“The next time I rang the receptionist and we went through them, she said candesartan was still on the receptionists’ list as an available repeat and I said ‘no you can scrub that,’ [candesartan had been stopped during admission] so they ended up tidying a couple off.” (Site 1 patient 8)*

### 1.3 Responding to errors and safety incidents

Sixteen patients reported events that we categorised as patient safety incidents. Patients discussed how they had unearthed prescribing errors before and after medicines had been supplied. They also identified where medicines that were newly prescribed in hospital were missing from the sets of medicines they subsequently received. Some patients were able to respond when they discovered errors and took corrective action. For example, they described telephoning their GP practice or community pharmacy to alert them to the mistakes that had been made.

*“No, they [my new medicines] weren’t [supplied]. I had to ask for those. They are on [the prescription] now and they will be next time.” (Site 2 patient 52)*

Others had not noticed errors before experiencing their impact and were therefore unable to take action to mitigate them, for example they took incorrect doses of medicines. It is not known whether the system was able to learn and recover from these incidents because patients were not aware if the incidents had been reported.

## **2 Establishing self-management strategies**

This theme describes how discharged patients would establish or re-establish strategies to enhance the reliability of their own medicines management. It is presented in two sub-themes: post discharge learning and adapting; and implementing adherence cues.

### 2.1 Post-discharge learning and adapting

Some patients explained how they were not given adequate information about their medicines in the hospital before being discharged. In response, some patients sought information about their medicines from other sources once home, for example from friends and family members, some of whom had healthcare experience, the internet or patient



information leaflets.

*“I don’t think I was really given information [in the hospital], it was just a matter of, ‘Here are your tablets, sod off.’ It’s only when you open the tablets that you read the bit of paper that is in with them.”* (Site 1 patient 1)

*“Well [more information] would have been helpful...but I just did it myself. I came home [from hospital] and looked on the internet to find out what they [the medicines] were for and what they did.”* (Site 1 patient 27)

Once home, patients and their informal carers took action to obtain and organise their post-discharge supplies. Patients arranged collecting their new medicines supplies, for example asking family members to collect them. Some patients had created their own spreadsheets or tick lists of their medicines, or asked others to do so, and they used these lists to keep track of the medicines they had taken or were due to take and to remember their purpose. Patients and family members also spent time reorganising the medicines they had been given in hospital and their subsequent supplies.

*“She [my wife] does my tablets because they’re little...so it’s easier if I just stand there and say they’re for morning and they’re for evening and she’ll put them in my [multi-compartment compliance aid].”* (Site 1 patient 3)

## **2.2 Implementing adherence cues**

Patients described how after returning home from hospital they anticipated problems in their ability to adhere to their medicines. In response they would establish, re-establish or adapt strategies that supported adherence, for example visual or audio cues to help them remember to take medicines, such as leaving medicines in a visible place, leaving out a glass of water as a reminder to take their medicines, and setting alarms.

*“I mean what I tend to do now is put a glass of water on the table and if I haven’t had it I go, ‘I haven’t had my tablet...if I haven’t drunk the water I haven’t taken my tablets.’ ”* (Site 2 patient 18)

*“Well my memory is not that great so now I have a piece of paper with the dates on and I tick off when I’ve taken them.”* (Site 1 patient 33)

Patients also asked their family members to remind them to take their medicines, or noted

that family members regularly did so without being asked. Others bought and filled weekly multi-compartment compliance aids to guard against memory lapses, and some used discharge summaries as checklists to fill them. In one case, a patient explained that he and his wife struggled to identify their medicines once they had taken them out of their packets in order to fill a compliance aid, so his wife helped him to read what was printed on the tablets.

*“Looking at the pills once I’ve got them in these boxes, once you’ve taken them out they’re not very easy to identify on their own, and my wife has to have a magnifying glass to see them.” (Site 1 patient 4)*

*“We [my wife and I] had to re-write ourselves a list [of medicines] so we understood...and that’s where we ended up buying the box so we had a clear, separation of well what we were doing when. Because when you look at a bunch of [medicines] boxes like this, what do you do? So we wrote them down on a list and then transferred the list into a box so that you’ve got a clear week.” (Site 2 patient 35)*

## **DISCUSSION**

This study draws on the experiences of sixty patients after discharge from two hospitals to describe how patients and their informal caregivers enhance resilience in a complex system and demonstrate that they play a vital role and have valuable insights for safety. As found in other studies, our data confirm that the safety of care comes under threat during this care transfer and that patients and carers can adopt important roles in the continuity of care.<sup>20 21</sup>

<sup>35 36</sup> These data also demonstrate how patients’ actions contribute to medicines optimisation during care transfers, mapping onto one of the four principles of medicines optimisation – to ensure medicines use is as safe as possible.<sup>37</sup> Patients’ roles in crucial processes such as medicines reconciliation have not been explored in detail in the UK – despite guidelines recommending that the patient is spoken to whenever possible during this process,<sup>19</sup> and evidence from the USA that patients are able to enhance its accuracy following discharge.<sup>38</sup>

Like patients and carers in other UK studies, they were able to create medicines charts and establish routines after leaving hospital,<sup>14 39</sup> which contrasts with the experiences of some older patients who have described difficulties adapting routines following hospitalisation,<sup>17</sup> and to understand discharge information.<sup>40</sup> It was also clear that informal carers had

substantial influence in enhancing resilience, and in common with a recent study, medicines management roles were often undertaken by close family members.<sup>41</sup>

### **Patients as agents of system resilience**

Our findings emphasise the need to take into account the proactive current and potential roles of patients and their friends and families in identifying, avoiding and reporting system vulnerabilities. The basis of resilient system performance rests on four abilities: being able to respond to regular and irregular activity or disruption, monitor activity that might affect system performance, learn from experience, and anticipate potential disruptions.<sup>23</sup> We found that patients anticipated potential discrepancies and supply errors and monitored how the system supplied them with medicines. They responded when they noticed errors, by correcting HCP-held information or reporting errors. As outlined elsewhere,<sup>29</sup> patients anticipated their own potential adherence problems, and monitored their medicines taking through acquiring and using compliance aids and developing or adapting checklists and cues.

We also demonstrated how resilience elements previously described in relation to staff<sup>26</sup> – those of *foresight, coping, and recovery* – were evidenced by many patients in this study. Some demonstrated foresight in anticipating problems in the supply of their medicines and they were able to mitigate the impact of ‘resident pathogens’ in the system,<sup>42</sup> for example, well-established but inefficient processes for reconciling medicines. Coping was demonstrated by those patients who acted to prevent errors, for example taking action when they realised that they had received an incorrect set of medicines. Some who experienced a safety incident initiated system recovery through reporting errors. The impact of this recovery was less often evidenced, because the timing of the interview – six weeks after discharge – did not allow us to collect data about subsequent supplies of medicines.

### **Implications for policy and practice and theory**

Enhancing patients’ detection and adaptation strategies at transitions

Our findings suggest that bolstering resilience within the medicines system at care transition requires a renewed focus on patients' roles, accepting that many will play a vital part in maintaining safety. This begs a question – should patients be prepared to compensate for known weaknesses in the system?<sup>43</sup> We believe that there is potential in working with patients to better understand, enhance and formalise their roles,<sup>44-46</sup> whilst acknowledging that in some situations patients and their carers may be hesitant about challenging staff,<sup>47</sup> or believe that their involvement is not valued by staff.<sup>36</sup> Methods empowering patients in this role can be developed in practice settings, preferably using co-design methods.<sup>48 49</sup> Potential system modifications to enhance system resilience are shown in Table 2, developed based on patients' experiences described during this study. Modifications could be implemented through further co-operation between commissioners, care providers, and patients and should be fully evaluated. Commissioners in particular may be unaware of the often unseen roles that patients and carers adopt to enhance system safety. There will also likely be cost efficiencies in the more effective use of medicines.

**Table 2: Potential system modifications to enhance patient resilience elements adapted from Westrum<sup>33</sup> and Jeffcott et al.<sup>26</sup>**

<b>Resilience element</b>	<b>System modification to enhance patient resilience</b>
<b>Foresight</b> – to predict, foresee and avoid adverse events	<ul style="list-style-type: none"> <li>• Review guidelines and services, such as the UK's Medicines Optimisation guidelines and the Medicines Use Review service so that they support HCPs, patients and carers in working together to be active medicines management partners</li> <li>• Co-designed enhanced preparation for patients and / or their designated nominee to manage medicines once they are discharged including help to develop checklists and management systems</li> <li>• Enhanced guidance about informing HCPs in primary care about medicines changes</li> <li>• Preparing patients and carers to ask for help with their medicines once back in the community and signposting them to the relevant resources</li> </ul>
<b>Coping</b> – adapting and preventing situations from becoming worse	<ul style="list-style-type: none"> <li>• Working with patients and carers to further develop their problem solving, for example how to resolve supply errors if they occur and to ensure correct medicines are obtained.</li> <li>• Preparing and empowering patients and carers to identify patient safety incidents and take action should they occur</li> </ul>
<b>Recovery</b> – from an adverse event once it has occurred	<ul style="list-style-type: none"> <li>• Offering clear guidance about how safety incidents can be reported</li> <li>• Working with patients and carers to develop effective reporting systems capable of operating across care transitions</li> <li>• Feedback patient experiences to care providers, commissioners and policy makers to enhance system safety</li> </ul>

Patients and carers can enhance understanding about the safety of the medicines management system through their experiences and insight,<sup>45 50</sup> and especially valuable near-miss intelligence which can play a vital role in enhancing system resilience and preventing actual harm through a focus on how an adverse event was prevented.<sup>51</sup> Given the ability of patients here to recount unsafe care when asked about their experiences qualitatively, there may be opportunities to review the way that reporting systems collect information about safety incidents – firstly opening the system to patients, and then employing the language patients use to capture their concerns.<sup>52-55</sup> Such data can be hard to collect, for example because patients may feel uncomfortable reporting or challenging the care they have received.<sup>47 56</sup>

#### A new perspective on resilience in healthcare

This is a timely analysis of the role of patients as both policy makers and healthcare providers seek to increase public involvement in healthcare; and the patient safety movement embraces patient-led preventative approaches. Resilience is a system attribute and patients can be viewed as co-operators in that complex system, adapting and responding to threats. Resilience in healthcare has previously been described and understood mainly from organisational and staff perspectives.<sup>26-28 57</sup> This study has thus offered an increased understanding of patients as agents of resilience and we have highlighted where there are opportunities to strengthen resilience.<sup>58</sup> Using resilience as a theoretical concept to explore patient interventions to prevent errors has provided a view of patients as integral system components, rather than as recipients of treatment in a healthcare system. It has also allowed us to explore the system from a positive perspective: rather than deconstructing what went wrong for patients we were able to understand how things went right for many, despite the evident potential for errors and adverse events. Widening the use of this approach has the potential to further empower patients and carers as crucial components in healthcare systems through highlighting their positive contributions to safety.

## **LIMITATIONS**

This work was conducted with patients discharged from the cardiology wards of two UK hospitals; however the transferability of the findings to other patient groups is not clear. A member of the research team undertook recruitment and there was a possibility of selection bias. Also, if patients felt confident and well enough to take part in the research then they may have had more positive experiences than more vulnerable, sicker patients. A more extensive study involving multiple sites might enable a broader understanding of patients' proactive roles in maintaining safety, however the sites chosen served areas with highly varied demographics and the patients spanned a wide age range. The sample size was large for a qualitative study and provided considerable depth and authenticity.<sup>59</sup> We also analysed the data using the theoretical perspective of resilience as a guide, yet some patients did experience the effects of a poorly functioning system and did not demonstrate the ability to compensate for errors or rebalance the system, however we were able to report this within the presented themes. Finally, the study focussed on patients with one category of condition – cardiology; a broader focus on additional conditions may have offered alternative experiences, nevertheless cardiovascular disease continues to present a significant burden globally.<sup>60</sup>

## **CONCLUSION**

Patients experience the impact of vulnerabilities in the medicines management system across the secondary-primary care transition but many patients and their informal caregivers are able to enhance system resilience through developing strategies to reduce the risk of medicines errors occurring. Consequently, there are opportunities – with caveats – to elicit, develop and formalise patients' capabilities which would contribute to safer patient care and more effective medicines management.

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