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CROSS-SECTIONAL SURVEY OF PATIENTS' NEED FOR INFORMATION AND SUPPORT WITH MEDICINES AFTER DISCHARGE FROM HOSPITAL

Adam J Mackridge^a, Ruth Rodgers^b, Dan Lee^b, Charles W Morecroft^c, Janet Krska^b

a - Betsi Cadwaladr University Health Board, Wrexham

b - Medway School of Pharmacy, Universities of Greenwich and Kent, Chatham Maritime, Kent

c - School of Pharmacy and Biomolecular Sciences, Liverpool John Moores University, Byrom Street, Liverpool

Corresponding author:

Adam Mackridge, Reader in Public Health Pharmacy, School of Pharmacy and Biomolecular Sciences, Liverpool John Moores University, Byrom Street, Liverpool, L3 3AF, UK Telephone: +44 151 231 2261 Email: A.Mackridge@ljmu.ac.uk

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ABSTRACT

Background

Most patients experience changes to prescribed medicines during a hospital stay. Ensuring they understand such changes is important for preventing adverse events post-discharge and optimising patient understanding. However, little work has explored the information that patients receive about medicines or their perceived needs for information and support after discharge.

Aim

To determine information that hospital in-patients who experience medicines changes receive about their medicines during admission and their needs and preferences for, and use of, post-discharge support.

Methods

Cross-sectional survey with adult medical in-patients experiencing medicines changes in six English hospitals, with telephone follow-up 2-3 weeks post-discharge.

Results

A total of 444 in-patients completed surveys and 99 of these were followed-up postdischarge. Of the 444, 44 (10%) were unaware of changes to medicines and 65 (16%) did not recall discussing them with a health professional, but 305 (77%) reported understanding the changes. Type of information provided and patients' perceived need for post-discharge support differed between hospitals. Information about changes was most frequently provided by consultant medical staff (157; 39%) with pharmacists providing information least often (71; 17%). One-third of patients surveyed considered community pharmacists as potential sources of information about medicines and associated support post-discharge. Post-discharge, just 5% had spoken to a pharmacist, although 35% reported medicinesrelated problems.

Conclusion

In North-West England, patient inclusion in treatment decisions could be improved, but provision of information prior to discharge is reasonable. There is scope to develop hospital and community pharmacists' role in medicines optimisation to maximise safety and effectiveness of care.

INTRODUCTION

Patients' medicines are often changed during a hospital stay, with over 90% of elderly medical patients experiencing a change to their prescribed medication during an in-patient stay (1) and medication discrepancies at discharge being associated with increased risk of re-admission (2). Leading on from this, medicines optimisation guidance issued by the UK National Institute for Health and Care Excellence (NICE) recommends that changes to medicines (including reasons) be communicated between treatment settings (3). Further, NICE guidance on medicines adherence (4) recommends that patients are involved in decisions about their medicines, including discussing why they may benefit and the treatment options, including the pros and cons. However, it is not clear how this guidance translates to practice at the point of discharge, when patients, or their carers, assume responsibility for managing their medicines.

In 2015, 72% of patients surveyed in English hospitals reported they had received completely clear written or printed information about the medicines they were given to take home (5). However, other work found that only 44% of in-patients felt fully informed about their medicines (6). Concerns around defective post-discharge medicines reconciliation processes (7) led, in part, to recommendations for community pharmacy led Medicines Use Reviews (MURs) to be targeted at patients discharged from hospital with two or more medicines (8). These discharge MURs (dMUR), and the New Medicines Service (NMS) which is also provided across English community pharmacies (8), involve discussion between a community pharmacist and the patient regarding their medicines to promote understanding of their treatment and support medicines adherence (9,10). However, uptake of such services amongst discharged patients may be suboptimal (11).

Previous studies have explored patients' needs regarding information about medicines on discharge in relation to myocardial infarction (12) or post-surgical wounds (13) but few have investigated information provided to patients regarding changes to medicines during hospitalisation. A small study in one UK hospital found that patients were more satisfied with the information provided relating to the purpose and use of medicines than that about the potential problems that they may experience with their medicines (14). A New Zealand Page 3

study showed that although older people often experience medicine changes during hospitalisation, they were often unaware of the details (15). A qualitative study in the Netherlands found that patients wanted more detailed information, particularly regarding alternatives to prescribed medication and adverse effects (16), while an Australian survey found 37% wanted more time to talk about their medications during their hospital stay or post-discharge (17).

This study aimed to determine information that hospital in-patients who experience medicines changes receive about their medicines during admission and their needs and preferences for, and use of, post-discharge support.

METHOD

This cross-sectional study involved two stages: (1) a face-to-face survey of adult medical inpatients in a convenience sample of three teaching hospitals and three district general hospitals in Northwest England, followed by (2) a telephone survey approximately two weeks after discharge. Teacher-practitioner pharmacists working at the selected hospitals were approached to support running of the study within their organisation. Data were collected between January 2015 and March 2015. In common with hospitals across the UK, all hospitals had a ward based pharmacy service, which includes pharmacist clinical input into patient care and pharmacist-patient interaction.

Consent was obtained from the nurse in charge for each ward to allow data collection and in-patients were screened against the below criteria by a pharmacist or nurse from the ward team as part of discharge planning. Inclusion criteria were: in-patient on a participating ward; currently prescribed medicines, with a prescribing change made during the hospital stay (including initiation); ready for discharge from hospital; stable and well enough to participate (in the opinion of the nurse in charge); and able to communicate in English. Exclusion criteria were: aged under 18 years; cognitive impairment or confusion adversely affecting ability to communicate in the opinion of the screening healthcare professional; planned discharged to a nursing home or palliative care; or any other patient judged unsuitable by the nurse-in-charge. Twelve final-year pharmacy students provided written study information to patients identified through screening and gave 30 minutes to decide on participation. Written consent was then taken from willing patients, who then self-completed a questionnaire, with students helping with this if necessary. Patients were then invited to participate in stage 2, with further written consent and contact details being taken from those who agreed. Prior to data collection, all students completed Good Clinical Practice training offered by the UK National Institute for Health Research.

The Stage 2 telephone survey was carried out by an experienced research associate approximately two weeks after discharge with responses documented on a pro forma using written notes.

The stage 1 questionnaire was developed by the research team, based on a previous study (6), and adapted using the NICE Audit tool for medicines adherence (18). Face validity was evaluated by the research team, drawing on expertise in provision of information about medicines and health psychology. Questionnaires comprised 52 questions on: demographics and medicines use; changes to, and information received about, medicines during hospital stay; use of, and preferences for, information about medicines; and anticipated needs and preferences for support post-discharge (copies of the questionnaire are available from the corresponding author).

The stage 2 telephone survey comprised seven closed questions with follow-up questions to explore experiences more fully. The questions allowed structured information to be gathered in a short (five minutes) discussion, giving regard to respondents' recent discharge from hospital. Questions covered: information and support needed since discharge; knowledge about medicines changed during admission; problems (including supply) with medicines since discharge; and interactions with health professionals since discharge.

The methods and questions were piloted with 32 in-patients (13 of whom were followed up by telephone) in two NHS hospitals, which were not included in the main study, to assess

feasibility, estimate recruitment and refine the instruments. Minor amendments were made to the stage 1 questionnaire to reduce repetition and overall length.

NHS research ethics committee approval (reference 13/WM/0420) and NHS Trust governance approvals were obtained for this study.

Stage 1 data and responses to closed questions from stage 2 were collated and analysed in SPSS Version 22. Frequencies and descriptive statistics are reported, with percentages calculated from the total number of responses to individual questions. Chi-squared tests were used for differences between sub-groups and Spearman's correlation coefficient for correlations between responses to questions. An a priori value of p<0.05 was set for significance. To protect confidentiality, hospitals have been allocated a code letter (A-F) where individual sites are listed in the results.

Descriptions of post-discharge experiences from follow-up questions were independently coded by two researchers, against a basic framework , designed prior to data collection and exploring to key elements of information needs relating to medicines, derived from stage 1 and prior work. Following initial independent coding, agreement on final coding was reached through discussion.

RESULTS

A total of 444 patients from the six hospitals completed the stage 1 survey, 171 (38.5%) of whom agreed to follow-up and 99 of these completed the stage 2 survey. Among stage 1 respondents 233 (52.8%; missing=3) were female, 233 (53.1%; missing=5) were aged over 65, and 387 (87.6%; missing=2) reported using prescribed medicines prior to admission (Table 1).

Stage 1: Face-to-face survey

Almost all respondents who reported using medicines prior to admission had a regular pharmacy (371/387; 95.6%) and 179 (n=387; 46.3%) reporting having discussed their medicines with a pharmacist in a community pharmacy consultation room, of whom 149 (83%; n=179) indicated this related to their regular medicines.

Although one or more medicines had been changed or initiated for all patients invited to join the study, only 400 (90.1%, n=444) participants reported being aware of changes, with Page 6

36 (8.1%) believing no change had been made and the remainder being unable to remember a change. Changes recalled were: new medicine started (331/400; 82.8%), existing medicine stopped (162/400; 40.5%); and changes to prescribed medicines (146/400; 36.5%). Almost two-fifths (156/405; 38.5%) reported feeling involved in decisions to make changes, 318/419 (75.9%) had received enough information about their medicines and 305/397 (76.8%) felt that they understood the changes to their medicines. There were no differences in these proportions with respect to age, sex or education of the patient or their previous use of medicines, but there was important variation between the six hospitals in the proportion: feeling involved in decisions; receiving enough information; and understanding the changes (Table 2). Across the hospitals, the proportions of patients reporting that they felt involved in decisions correlated with the proportions of those who felt that they received enough information (ρ =0.829; p=0.042) and that they understood information received (ρ =0.886; p=0.019).

Overall, 208 (51.2%) patients recalled discussing their medicines with individuals from one healthcare professional group during their hospital stay, but a further 133 (30.0%) discussed medicines with individuals from more than one group, whilst 65 (16.0%) did not recall discussing medicines with any health professional. Again, meaningful differences were found between hospitals (Table 2). Patients most frequently recalled discussing medicines with consultant medical staff (157; 38.7%), followed by non-consultant medical staff (155; 34.9%), nurses (147; 33.1%), and pharmacists (71; 17.4%).

Of those who recalled discussing medicine changes, the majority felt informed about the benefits and drawbacks of treatment (282; 72.3%), were encouraged to ask questions (245; 62.8%) and were told how the medicine may help their condition (220; 59.1%), although only half (191; 49.6%) reported being asked what difference they hoped the medicine would make. Even where received, information was not always provided in the best possible way, with only 38.6% (149/386) recalling being offered information before a medicine was prescribed. Of these, 112/135 (83.0%) found information clear and easy to understand, 108/134 (80.6%) reported their understanding having been checked, and 60.4% (81/134) reported that staff gave information on where to find additional information or help.

There was variation in the proportions of patients across hospitals reporting receiving information on what their medicines were for, side effects, how to obtain further supplies, and how to use them (Table 3).

Most patients reported preferring to obtain information about medicines from health professionals, followed by patient information leaflets (PILs) supplied with medicines (Figure 1). The most common source of information about medicines was the GP (342; 78.4%), followed by community pharmacists (129; 29.7%), consultants/hospital doctors (68; 15.7%) and practice/community nurses (48; 11.6%), with family or friends, the internet and media being little used as sources. A significantly higher proportion of respondents who had previously had a consultation with a pharmacist reported pharmacists as a likely source of information (76/179; 42.5%) compared to those who had not experienced a consultation (42/209; 20.1%), p<0.001.

Expectations of support needed after discharge in a number of areas again varied across hospitals (Table 3). The perceived need for help/support was not related to age, gender, educational level or number of medicines taken pre-admission. Of those who did not receive enough information about their medicines during their hospital stay, 69.7% (69/99) considered they would need support regarding what their medicine was for and if it was working following discharge, compared to just 54.2% (167/308) of those who had received sufficient information (Chi-square; p=0.001). The desire for support with medicine-related worries was also higher in those who did not receive enough information (72/100; 72.0%) compared to those who did (162/309; 52%) (Chi-square; p=0.001).

Stage 2: Post-discharge telephone survey

Of the 171 patients whoe agreed to interview, 99 were successfully followed up within 3 weeks of discharge (58% successful follow-up). Main reasons for failed follow up included not contactable, changed mind, and unwell/returned to hospital since discharge. Of those who were interviewed, 31 (31%) reported needing support with their medicines after discharge. The type of issues described included: not knowing which medicines to continue taking, how long to take newly prescribed medicines, dose queries, side effect queries and wanting more information in general, particularly with respect to newly prescribed medicines or significantly changed regimens. Two interviewees reported not receiving a PIL

with their medicines, one of whom wanted to look up potential side effects. Help with these issues was most frequently sought from GPs (14) or hospital staff (8).

Over one-third (35%) of interviewees described specific problems with medicines since discharge, the majority of these (22; 63%) were adverse effects, but others included lack of efficacy, difficulty maintaining the new routine and confusion about which medicines to take or how long to take them.

While most respondents (59; 59%) had spoken to someone about their medicines since discharge, experiences differed considerably and, although the majority (82; 83%) said they knew enough about their medicines, it was apparent from some interviews that this may be inaccurate (Table 4).

Only five (5%) of those interviewed recalled having a conversation with a community pharmacist since discharge, only two (2%) of which appeared to be formal consultations.

DISCUSSION

In our study, many patients did not feel involved in prescribing decisions made during their hospital stay, with two-fifths reporting information being offered before medicines were prescribed and a significant minority not recalling ever discussing medicines with any health professional. Indeed, some were not even aware of changes having been made. There was variation between hospitals in the numbers of health professional groups with whom patients recalled discussing medicines, the information provided and feeling of involvement in prescribing decisions. Patients who felt that information was insufficient were more likely to report needing post-discharge support.

The present study is the first to our knowledge to cover pre- and post-discharge, collecting detailed information at the time of discharge to minimise recall bias and using questions aligned to NICE audit criteria to maximise relevance. Also, the post-discharge telephone survey was conducted within three weeks of discharge to minimise bias. The study data are patient self-reports and may not fully reflect true practice. However, these reports reflected the extent to which patients felt supported and this is important for concordance and adherence in medicines prescribing and use. The number of patients screened or approached to participate in the survey was not documented and response rates are not available. The proportion followed-up by telephone was just over half of those who consented to participate, representing 22% of the total participants, but they were

distributed across the hospitals and are broadly similar in demographic characteristics to the stage 1 study sample.

The variation observed between hospital sites in terms of both involvement in decisions about care and receipt of information about medicines points to different approaches to this element of care in different organisations. NICE guidance relating to medicines adherence (4), which addresses many of these points, was published around the time of data collection, so it is likely that practice has developed in this respect over the past few years. However, successful initiation of medicines, promoting maximal patient adherence, is important to effective treatment and prevention of disease. Therefore, further work is needed to examine this variation in more detail and consider the implications in terms of patient outcomes.

While almost all patients used a regular community pharmacy and many had previously experienced a consultation with a pharmacist about their medicines, only one in ten considered the community pharmacists as a source of information and support regarding medicines post-discharge. This was confirmed in the post-discharge interviews, where just 2% of interviewees reported that they had discussed their medicines with a pharmacist in a private area. Many participants had a problem with one or more medicines post-discharge, mostly relating to adverse drug effects, where it is important for the patient to be wellinformed such that they are equipped to appropriately handle the situation.

Previous work in other countries has identified the need and desire for more information to be provided to patients prior to discharge, particularly when medicines have been changed, to prevent problems occurring (15–17). Medicines reconciliation during transfer of care, information provision during hospital stays, post-discharge contact or community pharmacy post-discharge medicines reconciliation have all been explored as mechanisms for reducing problems with medicines after discharge (19–22). One USA study reported an average 3.85 medicines discrepancies following discharge and emphasised the possible role of community pharmacists in supporting patients post-discharge (23). However, other work suggests that US community pharmacists do not routinely or consistently follow-up patients after discharge (24).

Our findings contrast with the Adult In-patient Survey (AIS) (5), in that only 39% felt involved in decisions about medicines versus 59% in the AIS. This may be as a result of the different

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wording used in the two studies – in the present work, patients were asked if they were "involved in the decisions to change their medicines", whilst in the AIS, they were asked whether they were "involved as much as they wanted to be in decisions about their care and treatment" – suggesting that a large proportion of these patients may not wish to be involved in decisions about their care. However, our findings are broadly comparable with the AIS in regard to the information that patients received about their medicines. The differences may arise from the emphasis in the present study on patients with medicines changes during hospital stays and the detailed level of questioning, which contrasts with the comprehensive inclusion criteria and general questions used in the AIS.

Although over half the patients discussed changes with individuals from more than one professional group, around one in six did not recall discussing medicines with any healthcare professional - this was comparable with a previous survey (20%), involving many of the same hospitals (6).

Although pharmacists are viewed by some health professionals as primary providers of information to patients about medicines (28), they were cited least frequently as having discussed medicines with patients. Although it is possible that a pharmacist had spoken to many of these patients, but had not been recognised as such, it is possible that patients chose to talk to doctors about all aspects of their care.

In 2012, the Royal Pharmaceutical Society launched guidance to improve transfer of information between primary and secondary care (25) and there have been several attempts to increase uptake of dMURs (26), with mixed result (11,27,29). However, anecdotally, there is a perception that patients remain unaware of this service and the potential benefit it, and NMS, could offer. Although the low uptake seen in the present study appears to confirm this, around one third of patients did recognise pharmacists as a useful source of information, showing a possible change in patient knowledge. Post-discharge services are however still some way off meeting the NICE standards regarding medicines optimisation (3), so information provided during hospital stays remains a key mechanism to ensuring patient understanding of medicines changes.

CONCLUSION

The degree to which adult hospital in-patients involved in this study felt involved in decisions about their care was suboptimal and did not align with prevailing guidance. Four in Page 11

five patients were satisfied with information provided about medicines at the point of discharge but patient use of follow-up support post-discharge such as dMURs and NMS was limited and an opportunity to identify and resolve issues relating to medicines may be being missed. There was variation between hospitals in the way in which information about medicines was provided to patients, including the staff providing such information and further work is needed to explore this. Pharmacists appear to have had a limited role both in hospital and community settings and there is considerable scope for development of their role in supporting patients around care transition.

Characteristic		Stage 1 (n=444)	Stage 2 (n=99)
	Female	233 (52.8%)	42 (45%)
Sex	Male	208 (46.8%)	47 (47%)
	40 and under	40 (9.1%)	14 (15%)
Ago group	41 – 65	166 (37.8%)	43 (46%)
Age group	66 – 75	99 (22.6%)	22 (24%)
	76 or over	134 (30.5%)	14 (15%)
	None/primary	65 (14.9%)	10 (11%)
Educational level	Secondary	211 (48.5%)	33 (36%)
Educational level	College/further education	98 (22.5%)	29 (32%)
	Higher education	61 (14.0%)	19 (21%)
Ethnicity	White	421 (95.9%)	88 (96%)
	Full or part-time employed	101 (23.3%)	31 (34%)
Work status	Retired	253 (58.3%)	40 (44%)
	Not working	80 (18.4%)	19 (21%)
Prescribed	Any medicines	387 (87.6%)	85 (90%)
medicines prior to admission	4 or fewer	134 (34.8%)	36 (38%)
	5 to 7	112 (29.1%)	21 (22%)
	8 or more	139 (36.1%)	28 (30%)

Table 1 Demographic details (missing data for each item excluded from analysis)

Table 2 Differences in patient experiences between hospitals

Number (% of those responding to the question) of patients who responded 'yes' to					ponded 'yes' to
	questions regarding whether they				
Hospital	Felt involved	Received enough information about medicines	Understood information about	Discussed medicines with health professional groups	
	in decisions		medicines changes	One only	More than one
A (n=93)	31 (36%)	74 (81%)	66 (73%)	34 (40%)	44 (51%)
B (n=100)	34 (40%)	70 (73%)	67 (86%)	47 (58%)	24 (30%)
C (n=70)	16 (23%)	43 (61%)	47 (67%)	28 (41%)	30 (43%)
D (n=52)	13 (30%)	33 (66%)	23 (59%)	21 (43%)	3 (6%)
E (n=61)	28 (50%)	39 (68%)	40 (76%)	30 (53%)	17 (30%)
F (n=68)	34 (53%)	59 (88%)	62 (94%)	48 (75%)	15 (23%)
Overall (n=444)	156 (39%)	318 (76%)	305 (77%)	208 (51%)	133 (31%)
P value (Chi Square test)	<0.005	<0.001	<0.001	<0	.001

Number (% of those responding to the question) of patients who anticipated needing						
Hospital	What medicine is for and how well it is working	Help with any worries	General help with medicines	Sorting out which medicines to take	Help organising further supplies	Support with practical problems
A (n=93)	44 (47%)	41 (46%)	33 (37%)	31 (35%)	30 (34%)	25 (29%)
B (n=100)	53 (59%)	51 (57%)	46 (51%)	44 (48%)	55 (61%)	33 (37%)
C (n=70)	45 (64%)	42 (60%)	32 (46%)	33 (48%)	27 (39%)	16 (23%)
D (n=52)	30 (58%)	30 (58%)	9 (18%)	7 (15%)	6 (12%)	7 (14%)
E (n=61)	30 (50%)	35 (58%)	25 (42%)	31 (52%)	19 (32%)	23 (39%)
F (n=68)	47 (69%)	44 (65%)	41 (60%)	37 (54%)	21 (31%)	16 (24%)
Overall (n=444)	247 (57.7%)	243 (56.8%)	186 (43.3%)	183 (43.1%)	158 (37.0%)	120 (28.2%)
p-value*	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001

Table 3 Expectations for support required after discharge

Differences between hospital trusts: *Chi-square test

Table 4 p	ost-discharge	interview	findings
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Type of	Interview findings	Patient
experience		characteristics
Good support provided	Had GP appointment to review changes – agreed to continue medicines as prescribed in hospital. Good chat over everything, any questions answered.	Female, 40 or under
	Pharmacist visited ward regularly in hospital, so knew enough about medicines. Cardiac nurse visits to review weekly. She's very good - can ask any questions and concerns.	Female, 76-85
	You can never know enough, but what they explained was enough. Saw pharmacist when went to collect medicines and was taken to one side and told about strength of medicine (morphine), expected side effects. Pharmacist asked if he wanted to go into private room but was OK to talk in public. GP re-iterated these, checked through questions and told what to expect. Did experience dizziness and nausea.	Male, 41-65
Inadequate	Changed antidepressant and wanted to know more about it.	Female, 41-65
support provided	Tried to speak to GP but got put through to the practice nurse - but she wasn't able to answer queries. GP never rang back.	
	had quick review with GP, is continuing medicines as prescribed in hospital - was short appointment so didn't feel she had chance to discuss questions/concerns.	Female, 66-75
	Medicines are delivered from pharmacy, assumed they had the report from the GP, but was missing 5 of the 6 tablets prescribed while in hospital. Had GP check-up last Thursday, changed some of the medicines had from hospital (on 15 so unsure which ones). Patient asked questions but still confused, although reassured doing okay.	Female, 86 or over
Actual or potential adverse events	saw locum GP who wasn't familiar with patients' medical history - left medicine it is, but patient stopped taking (because of a suspected adverse reaction experienced – hives, itch).	Male, 41-65
	Felt knew enough about medicines, but was taking a medicine daily for which information stated: "one to be taken weekly or as advised by your health professional" and he was also unsure for how long the medicine would be needed. Not attempted to see GP as had sufficient medicines supply.	Male, 66-75
	Felt had no information at all about change. Saw GP who took blood pressure and wasn't happy and reversed the dose change instigated by the hospital.	Male, 41-65



Figure 1 - Patient preferences for sources of information about their medicines

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CONFLICT OF INTEREST

AJM, RR, DL, CWM & JK declare that they have no conflict of interest relevant to this work.

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