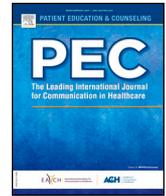




Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pec

Do patients and family carers have different concerns about the use of medicines compared with healthcare professionals? A quantitative secondary analysis of healthcare concerns relating to adults with complex needs

Sara Garfield^{a,b,c,*}, Aisha Begum^c, Kah Ling Toh^c, Anna Lawrence-Jones^b, Kristina Staley^d, Bryony D. Franklin^{a,b,c}

^a Imperial College Healthcare NHS Trust, London, UK

^b NIHR Imperial Patient Safety Translational Research Centre, London, UK

^c UCL School of Pharmacy, London, UK

^d TwoCan Associates, Ross on Wye, UK

ARTICLE INFO

Article history:

Received 20 January 2021

Received in revised form 10 May 2021

Accepted 11 May 2021

Available online xxx

Keywords:

Medication

Concerns

Adherence

Patients

Family carers

Health professionals

Communication

ABSTRACT

Objective: To identify concerns related to the use of medicines for adults with complex needs and explore whether these differed between healthcare professionals and patients/carers, in order to inform development of interventions to increase medication adherence.

Methods: A quantitative secondary analysis of a database of healthcare professionals' and patients'/carers' healthcare concerns, related to adults with complex needs. Categories of concerns related to medicines use were identified and concerns related to medication use coded against these. Data were analysed descriptively, and a Chi-square test conducted to test for differences in responses from healthcare professionals versus patients/carers.

Results: There was a significant difference in the types of medication concern raised by healthcare professionals versus those raised by patients/carers. Patients/carers expressed more concerns about side effects and interactions; healthcare professionals identified more concerns related to patient support and carers' knowledge/training.

Conclusion: Healthcare professionals had significantly different concerns about medicines to patients; this may be a potential barrier to medication adherence.

Practice implications: Healthcare professionals may need to adopt an approach to non-adherence that goes beyond education and counselling and adopts a wider patient perspective. Findings suggest that a greater focus on addressing side effects and interactions may be beneficial in increasing medication adherence.

© 2021 The Author(s). Published by Elsevier B.V.

CC_BY_NC_ND_4.0

1. Background

Non-adherence to medication (i.e. patient's behaviour not matching agreed recommendations from the prescriber) is estimated to affect approximately 30–50% of patients with long term conditions [1]. The consequences include a missed opportunity for treatment effect, poor health outcomes and an increased use of healthcare resources. For example, it has been estimated that medication non-adherence is responsible for 48% of asthma deaths, an

80% increased risk of death in diabetes and a 3.8-fold increased risk of death in the year following a heart attack [2]. The World Health Organization has recognised that increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments [3].

A large number of interventions have been developed to address non-adherence but systematic reviews have found the effects of these on adherence and improved clinical outcomes to be limited [1,4]. A Cochrane review found that only five of the included randomised controlled trials, with the lowest risk of bias, reported improvements in both adherence and clinical outcomes and that even the most effective interventions did not lead to large

* Correspondence to: UCL School of Pharmacy, 29-39 Brunswick Square, London WC1N 1AX, UK.

E-mail address: s.garfield@ucl.ac.uk (S. Garfield).

<https://doi.org/10.1016/j.pec.2021.05.020>

0738-3991/© 2021 The Author(s). Published by Elsevier B.V.

CC_BY_NC_ND_4.0

improvements in adherence or clinical outcomes [1]. A more recent review [4], focussed specifically on older people taking four or more medicines, found that there was low quality evidence that interventions incorporating a behavioural element may increase the proportions of people who are adherent but that educational interventions only did not.

The healthcare professional-patient relationship has been shown to be one of the factors affecting adherence [5,6]. There has been increasing recognition of the importance of building concordant relationships where patients and healthcare professionals are equal partners in decisions made about medicines [7]. A meta-analysis has demonstrated that patients' general beliefs about medicines, for example whether or not medicines are generally harmful, and their beliefs about the specific medicines that have been prescribed have also been shown to affect adherence [8].

However, there has been little work comparing patients' beliefs and concerns about medicines with those of healthcare professionals. Exploring this may inform the factors that need to be addressed in order to improve shared decision making about medicines and subsequent adherence to treatment. The objectives of this study were therefore to identify concerns related to the use of medicines for adults with complex needs and explore whether these differed between healthcare professionals and patients/family carers, in order to inform development of interventions to increase medication adherence.

2. Methods

2.1. Study design

A secondary quantitative analysis [9] of a database of healthcare professionals' and patients'/family carers' healthcare concerns, related to adults with complex needs, was conducted to explore responses related to concerns related to medication use.

2.2. Data source

The primary data collection was conducted by the NIHR Imperial Patient Safety Translational Research Centre as part of a James Lind Alliance (JLA) priority setting partnership [10]. A survey was developed and distributed, asking UK patients/family carers and healthcare staff for their concerns and questions about safe care for adults with complex health needs. Adults with complex health needs were defined as those who had more than one condition or received care in more than one healthcare setting. Two questions were asked concerning healthcare: "Based on your experiences of receiving, giving or observing healthcare, tell us about any times when something went wrong or nearly went wrong, or when you felt the care was unsafe" and "Based on your experiences and concerns, please could you suggest some questions that you would like researchers to answer in order to make care safer for adults with complex health needs?" In addition, some optional demographic questions were asked. These included a request for information about whether participants identified as patients with complex needs, family carers of patients with complex needs, members of the public, employed carers, or healthcare staff.

The survey was disseminated using two approaches. The first was based on the standard JLA method, via relevant networks and social media. Specifically, the survey was circulated online between August 2017 and February 2018 by means of contacts of the project steering group, via Twitter, and via organisations such as INVOLVE [11]. Paper copies with free return envelopes were also distributed to patient and carer groups. Strategies were put in place to reach minority groups, for example a translator facilitated discussions with a group of Somali women. Those under the age of sixteen, working in full time medical research or in the pharmaceutical or health technology

industries were excluded as participants. The second approach was via YouGov, [12] a global public opinion and data company, who were commissioned to distribute the survey to a sample of respondents representative of the UK general population.

2.3. Identification of concerns related to medication use

Responses to the two survey questions were text-filtered on an Excel spreadsheet using the truncated terms: medic*, drug* and pharmac*. Each of the top 100 drugs used in UK practice, as identified by Hitchings et al. [13], were also used as specific search terms. The responses identified were then reviewed to ensure that they described a concern related to medication use. The remaining responses were then briefly reviewed manually to identify any other concerns related to medication use. Responses that did not relate to the use of medication were excluded from further analysis.

2.4. Data analysis

Categories of medication use concerns raised in the survey were inductively identified from this subset of responses. Each response was then coded deductively into the type of medication use concern. For responses with multiple concerns related to medication use, each concern was treated independently.

Two researchers coded the data. A third researcher initially independently coded 10% of the data. Discrepancies were resolved through discussion and consensus reached. As there were a number of discrepancies at this stage, the first two researchers reviewed the coding for the full data set and revised it where needed. The third reviewer then independently coded a further 10%, with fewer discrepancies.

Following coding, data were analysed descriptively and verbatim responses were included to illustrate the categories. A chi-square test was then carried out to test for differences between responses from healthcare professionals/employed carers and patients/family carers. As there was no option in the original survey for people to categorise themselves as patients without complex needs, and the responses from participants identifying themselves as members of the public indicated they were drawing on their experience of being a patient or a carer, for this secondary analysis concerns from members of the public were included in the patients/family carers category. One medication related concern was raised by an employed carer and was included in the healthcare professionals' category. We excluded concerns raised by respondents who did not identify which category they belonged to.

2.5. Ethical considerations

The Health Research Authority confirmed that NHS ethical approval was not required for the original JLA study. All survey responses were fully anonymised before access to the data was granted for the present study.

3. Results

One thousand, six hundred and forty eight people responded to the original survey; these comprised 923 (56%) patients/family carers, 215 (13%) healthcare professionals, 28 (2%) employed carers and 482 respondents (29%) for whom this information was unavailable. Overall, 884 concerns related to medication use were identified: 97 by healthcare professionals/employed carers and 787 by patients/family carers. Twenty three categories of concerns related to medication use were inductively identified (Table 1).

The chi-square test demonstrated that the types of medication-related concerns raised by healthcare professionals were significantly different ($p = 0.01$) to those raised by patients and family

Table 1
Definitions of categories identified for the different types of concerns related to medication use identified.

Type of issue	Definition(s)
Categories	Subcategories
Adherence	Patients intentionally or non-intentionally not taking prescribed medication.
Administration	Concerns identified by patients during medicines administration (but that do not result in medication errors).
Allergies	Patients being prescribed medications that they are allergic to.
Communication	Communication between HCPs ^a and patients Lack of, or unclear, communication to patients/patient's family (who are not responsible for patient care) by HCPs responsible for their care regarding their medication. Communication between two or more HCPs HCPs being unaware of changes to patient medication made by other HCPs. Communication between HCPs and carers Poor/delayed communication between two or more HCPs regarding patient medicines. Lack of, or unclear, communication to carers by HCPs regarding their medication.
Delayed Medicines	Patients having to wait for prolonged periods of time to receive their medication.
Ethical	Ethical issues regarding medicine use, such as availability of medicines on the NHS.
Interactions	Concerns about medicines prescribed to patients which are unsuitable to take with their other medicines or comorbidities.
Medication cost	Concerns relating to medicines cost to patients
Medication errors	Errors made by healthcare professionals in the process of prescribing, dispensing, administration and monitoring of medications.
Medication records	Lack of consulting medication records, or patient medication. Dissatisfaction with the way records are kept.
Medication review	Lack of/inadequate review of patient medication.
Patient understanding	Patients being confused about their medication or any changes that have occurred in their medicines.
Patient support	Patient needing support of HCPs to manage their own medication or gain knowledge of their treatment and the need for patient support to help them manage their medicines. Lack of medicines support for vulnerable groups (i.e. disabled, elderly, those who cannot advocate for themselves) regarding support in medication.
Research	Patient suggesting or requesting more research or studies on medicines to be carried out. Concerns relating to a lack of research on new medicines for a specific medical condition.
Suggested practice intervention	Identifying a change in the way medicines can be initiated, documented, administered, and regulated in order to improve patient care.
Side effects	Concerns related to adverse drug reactions.
Training and knowledge	Training and knowledge – HCPs Concerns related to lack of training/ support to HCPs regarding medicines. Perception of HCPs having inadequate knowledge on patient medicines or associated conditions. Training and knowledge - Carer Perception of carers (including employed carers) having inadequate knowledge on patient medicines or associated conditions for which the medicine is being taken
Patient-identified errors made by HCP	Patients or family members identifying medication errors made by HCP.

^a HCPs = healthcare professionals

carers. Fig. 1 shows the key areas of difference. Although all types of concerns were raised by both groups, more patients and family carers identified concerns relating to side effects and interactions than healthcare professionals.

“Doctor prescribed me pregabalin for a bad back but made it sound as though the side effects were minimal. They turned out to be absolutely horrendous and even worse it was highly addictive.” (patient)

“I take many medications which interact with each other, and no one knows why I am on some medications.” (patient)

Conversely, more healthcare professionals than patients/family carers identified concerns related to lack of carer knowledge and training regarding medicines and the need for more support for patients to enable them to manage their medicines effectively.

“There is an issue with the administration of medicines via a peg [percutaneous endoscopic gastrostomy tube] as the NICE [National Institute for Health and Care Excellence] guidelines state this can be done by a home carer with training. It would be good to set some standards for these types of specialist tasks.” (healthcare professional)

“How can we identify people likely to run into problems with their medicines? How can we make sure that the people identified get the necessary support to keep them safe wherever their care is?” (healthcare professional)

Healthcare professionals were also more likely to suggest interventions to improve medication-related patient care.

“Would carrying a smart card with the patient's existing conditions and medications loaded into it that could be read at any NHS establishment be a feasible option?” (healthcare professional)

Despite these differences, there were also some areas of similarity with both patients/family carers and healthcare professionals being more likely to raise concerns about medication errors than any other concerns related to medication use.

“My newborn was given twenty times the dose required of a drug at birth by accident by the midwife.” (patient)

“On numerous occasions I have seen evidence of medication errors in care homes or social care settings often causing hospitalisation of the patient. A common cause of missed doses seen is by delayed medicines transferred from hospital to care home setting or not transferred at all when the patient is discharged.” (healthcare professional).

However, patients/family carers were more likely to identify a role that they had played in identifying and correcting errors.

“A family member has drugs in blister packs and they were not correct, thankfully he noticed.” (carer).

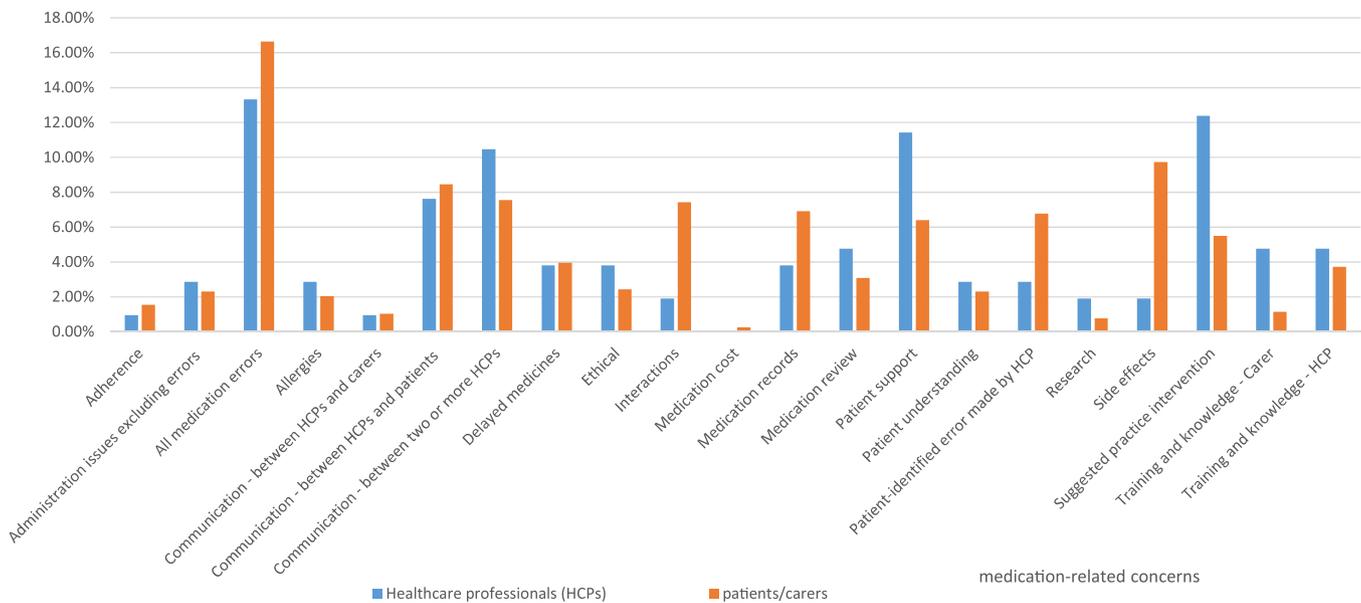


Fig. 1. Healthcare professionals and patients'/family carers' medication related concerns SG 29.04.01.

4. Discussion and conclusion

4.1. Discussion

There was a significant difference in the types of health concerns raised by healthcare professionals to those raised by patients and family carers. Patients and family carers expressed more concerns about side effects and interactions than healthcare professionals, whereas healthcare professionals identified more concerns related to patients needing support and carers needing more knowledge and training. Both groups identified concerns related to medication errors more often than any other concerns related to medication use but the emphasis of these was different, with patients much more likely to focus on the role that they had played in preventing errors. Previous research has also shown that concerns about side effects are common among patients, even when medication is well tolerated, and that they are often related to more general beliefs about the negative effects of medication as a class of treatment perceived to be intrinsically harmful and over-prescribed [8].

These differences between patients/ family carers and healthcare professionals may contribute to our understanding of the impact of different adherence interventions and how to potentially increase this. Interventions incorporating education and counselling alone may fit more into the healthcare professionals' model of concerns, which focuses on patient/carer support and training. This may explain why those incorporating a wider behaviour perspective seem to be more effective [4]. Such interventions may be even more effective if they address healthcare professionals' behaviours as well as patients' behaviours. Previous research has shown that few adherence interventions incorporate training for doctors and pharmacists on how to provide adherence support [14]. Having an understanding of potential differences in patients' and healthcare professionals' concerns relating to medicines may help drive such support.

4.1.1. Strengths and limitations

A key strength of this study is that it has added to the adherence literature by highlighting differences between healthcare professionals' and patients' concerns about medicines and considering the impact that this may have on interventions to increase adherence. A

limitation of our analysis is that we quantitatively coded open responses and this may have led to some errors of interpretation. However, reliability checks were carried out to mitigate this. There were also a larger number of responses from patients and family carers than healthcare professionals. Survey questions were framed around patient safety and this may have led respondents to be more likely to discuss errors as a concern. In addition, the questions were asked in the context of the needs of patients with complex needs, rather than the general population that uses medicines. Data concerning whether respondents identified as patients/family carers or healthcare professionals was missing from 29% respondents; thus their data could not be included.

4.2. Conclusion

Healthcare professionals have significantly different concerns about the use of medicines compared with patients. Findings suggest that a greater focus on addressing side effects and interactions may be beneficial in increasing medication adherence.

4.3. Practice implications

The study findings suggest that healthcare professionals may need to adopt an approach to non-adherence that goes beyond education and counselling and adopts a wider patient perspective. Interventions that are tailored to individual patient needs are likely to be more effective [15]. However, a general understanding of the issues that patients may be concerned about may help towards effective conversations and subsequent tailoring of interventions. Healthcare professionals may feel that discussing side effects might discourage patients from taking medicines. However, if patients have concerns about these that are not addressed, then this may be more likely to lead to non-adherence, than having an open conversation. It is generally part of healthcare professionals' protocols to check for interactions when prescribing or dispensing medicines and clinical decision support in electronic prescribing and dispensing systems may also assist with this. Being explicit about having carried out these checks such as stating that 'These can be taken together with the other medicines that you are taking.' could therefore be beneficial.

In addition, the finding that healthcare professionals and patients have significantly different concerns related to medication use supports the involvement of patients in partnership with healthcare professionals on research relating to medication safety.

CRediT authorship contribution statement

ALJ and KS led initial data collection and analysis for the main dataset. BDF conceived the study described in this paper. SG, AB and BDF were involved in study design. SG, AB, KT and BDF analysed the data. SG, AB and KT wrote the paper. All authors were involved in editing the paper and approved the final version.

Declarations of interest

none.

Acknowledgements

This work was supported by the National Institute for Health Research (NIHR) Imperial Patient Safety Translational Research Centre (PSTRC-2016-004). This report presents independent research. The views expressed in this publication are those of the authors, not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. We also acknowledge Anusha Mathur's contribution to the analysis.

References

- [1] Ieuwlaet R, Wilczynski N, Navarro T, Hobson N, Jeffery R, Keepanasseril A, Agoritsas T, Mistry N, Lorio A, Jack S, Sivaramalingam B, Iserman E, Mustaf RA, Jedraszewski D, Cotoi C, Haynes RB. Interventions for enhancing medication adherence. *Cochrane Database Syst Rev* 2014;000011 <https://doi.org/10.1002/14651858.CD000011.pub4>
- [2] Elliot R. Non-adherence to medicines - not solved but solvable. *J Health Serv Res Policy* 2009;14:58–61. <https://doi.org/10.1258/jhsrp.2008.008088>
- [3] World Health Organization. Adherence to Long Term Therapies: Evidence for Action. Geneva: World Health Organization; 2003 https://www.who.int/chp/knowledge/publications/adherence_full_report.pdf.
- [4] Cross AJ, Elliott RA, Petrie K, Kuruvilla L, George J. L. Interventions for improving medication-taking ability and adherence in older adults prescribed multiple medications. *Cochrane Database Syst Rev* 2020;5:012419 <https://doi.org/10.1002/14651858.CD012419.pub2>
- [5] National Institute for Health and Clinical Excellence (NICE). Medicines Adherence: Involving Patients in Decisions about Prescribed Medicines and Supporting Adherence. NICE, London, 2009. Available from: <http://www.nice.org.uk/nicemedia/pdf/CG76NICEGuideline.pdf>. [Accessed 4 December 2020].
- [6] Mahmoudian A, Zamani A, Tavakol N, Farajzadegan Z, Fathollahi- Dehkordi F. Medication adherence in patients with hypertension: Does satisfaction with doctor-patient relationship work? *J Res Med Sci* 2017;26:22–48. https://doi.org/10.4103/jrms.JRMS_205_16. PMID: 28567067; PMCID: PMC5426097.
- [7] A. Cribb. Involvement, Shared decision-making and Medicines. Royal Pharmaceutical Society of Great Britain, 2011.
- [8] Horne R, Chapman SC, SC, Parham R, Freemantle N, Forbes A, Cooper V. Understanding patients' adherence-related beliefs about medicines prescribed for long-term conditions: a meta-analytic review of the Necessity-Concerns Framework. *PLoS One* 2013;8:80633. <https://doi.org/10.1371/journal.pone.0080633>. PMID: 24312488; PMCID: PMC3846635.
- [9] Johnston MP. Secondary data analysis: a method of which the time has come. *Qual Quant Methods Libr* 2017;3:619–26.
- [10] <https://www.jla.nihr.ac.uk/priority-setting-partnerships/safe-care-for-adults-with-complex-health-needs/>. [Accessed 9 April 2021].
- [11] <https://www.involve.org.uk/>. [Accessed 9 April 2021].
- [12] <https://youngov.co.uk/>. [Accessed 9 April 2021].
- [13] Hitchings A, Lonsdale D, Burrage D, Baker E. *The Top 100 Drugs: Clinical Pharmacology and Practical Prescribing*. Elsevier; 2018.
- [14] Andersson M, Garfield S, Eliasson L, Jackson C, Raynor D. C. Delivery of patient adherence support: a systematic review of the role of pharmacists and doctors. *Patient Intell* 2014;6:31–42. <https://doi.org/10.2147/PLS46647>
- [15] Clifford S, Garfield S S, Eliasson L, Barber N. Medication adherence and community pharmacy: a review of education, policy and research in England. *Pharm Pract* 2010;8:77–88.