

A systematic review and thematic synthesis of patients' experience 1 of medicines adherence

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STRUCTURED ABSTRACT

Background: Medicines non-adherence continues to be problematic in healthcare practice. After decades of research, few interventions have a robust evidence base demonstrating their applicability to improve adherence. Phenomenology has a place within the healthcare research environment. To explore the patients' lived experiences of medicines adherence reported in the phenomenological literature?

Method: A systematic literature search was conducted to identify peer-reviewed and published phenomenological investigations in adults, that aimed to investigate patients' lived experiences of medicines adherence. Studies were appraised using the Critical Appraisal Skills Programme (CASP) Qualitative Research Tool. Thematic synthesis was conducted using a combination of manual coding and NVivo10 [QSR International, Melbourne] coding to aid data management.

Results: Descriptive themes identified included i) dislike for medicines, ii) survival iii) perceived need, including a) symptoms and side effects and b) cost, and iv) routine. Analytic themes identified were i) identity and ii) interaction.

Conclusions: This work describes adherence as a social interaction between the identity of patients and medicines, mediated by interaction with family, friends, healthcare professionals, the media and the medicine itself. Healthcare professionals and policy makers should seek to re-locate adherence as a social phenomenon, directing the development of interventions to exploit patient interaction with wider society, such that patients 'get to know' their medicines, and how they can be taken, throughout the life of the patient and the prescription.

Keywords: medicines adherence, treatment compliance, phenomenology, social pharmacy, qualitative research, thematic synthesis

Introduction

Medicines adherence, defined as 'how well a patient takes their prescription medicines', continues to be problematic in healthcare practice.¹ After decades of research, there is little consensus on improving poor adherence or tackling non-adherence.^{1, 2} Current approaches to research have resulted in numerous ways of measuring adherence, such as self-reported questionnaires, pill counts, and electronic packaging with more recent advances adding stomach-acid-activated microchips to medication dosage forms.^{1, 3} This has arguably led to multiple conceptualisations of the phenomenon, and has resulted in semantic confusion, from concordance, to compliance, to adherence. Often differences between definitions relate to varying degrees of patient-centred care, with changes often relating to how the patient 'fits into' the phenomenon, ranging from following the prescriber's orders, agreeing with the prescriber's decisions, and or making decisions supported by a prescriber, respectively.⁴

Methods of measuring adherence are heterogeneous, this has resulted in multiple conceptualisations of adherence, for example Hess, Raebel, Conner, Malone⁵ reviewed measures of adherence that were based on the number of times a medicine was collected from a pharmacy, this demonstrated a number of calculations that could be used to measure adherence and conceptualised 'adherence to medicines' as a function of prescription collection, that is to say that collecting the medicine from a pharmacy inferred patients' adherence to taking the medicine. Conversely van Onzenoort, Neef, Verberk, van Iperen, de Leeuw, van der Kuy⁶ investigated a product that measured adherence at the date and time a product was popped from its blister packaging, adherence here then is conceptualised as something precise, to do with using medicines at the right date and time, and represents a different way of thinking about adherence compared to Hess, Raebel et al. (2006), rather than 'adherence' meaning collecting a prescription once a month, 'adherence' becomes much more onerous, a set of behaviours enabling repetitive tasks to be carried out. In studies that use questionnaires, self-reports or interviews, adherence is measured as a function of the participants' memory (i.e. being able to remember that they had taken their medicines as they were prescribed) as well as being influenced by participants' own understanding of 'what it means to be adherent', that is to say, for some people missing a medicine by a few minutes is non-adherence, for others taking it within a few hours is still adherent. The variation in self report measures has been demonstrated to over-estimate adherence, suggesting these measures never to be used alone.⁷ Whilst it is well recognised no single method is preeminent and multiple methods of measuring the same phenomenon offer an element of triangulation and validity,⁸ these methods unintentionally conceptualise adherence as an epistemologically different phenomenon; as a representation of an ability to collect prescriptions once a month including elements of planning, and access to pharmacy services determined by wider, socio geographic determinants; as a representation of patient-specific, repetitious objective behaviours located at the right time and date and finally; as a representation of patients' own subjective beliefs about their behaviours when under investigation in research. These different conceptualisations of the functions of adherence, representations of adherence or 'ways of thinking about adherence' may have inhibited the understanding of adherence from moving forward. A significant majority of research investigating adherence is conducted within the quantitative, positivist paradigm. This paradigm relates to an underpinning ideology of what reality is and how reality can be experienced. Positivism describes reality as posited – essentially this means that reality and truth are 'out there in the world' waiting to be discovered. Positivist approaches often use quantitative methods to discover, identify and prove truths that exist 'out there in the world' waiting to be discovered. However, due to the nebulous nature of the adherence phenomenon (is it a belief, an attitude, a short-term behaviour or a long-term set of behaviours?) using a positivist approach might overlook essential aspects of what it is actually like to experience the phenomenon, thereby limiting how the phenomenon can be conceptualised and understood, measured and modified. An alternative approach to investigating the phenomenon may be required to deliver insights, generate new understanding, and direct practice. Qualitative research can provide an alternative approach, although disciplinary conventions, such as journal types and word length, can mean that research findings are not as pervasive in the field as they might be.⁹ Qualitative research includes multiple methods of data collection such as semi-structured or unstructured interviews; focus groups; ethnography; and observational studies.¹⁰ Qualitative research enables rich, detailed data to be collected and analysed, allowing novel perspectives to be generated and phenomenon to be explored at a fundamental level, ontologically and epistemologically. That is to say, qualitative research can help identify what a phenomenon 'is'. The need for this kind of fundamental qualitative research has been systematically identified in the adherence literature^{1, 2, 11}. Within the qualitative paradigm, phenomenology is positioned as a method and theoretical framework, based on the philosophical works of Heidegger and Husserl.¹² The approach has developed over the last century to embody a method of research, which can appear far removed from the scientific biomedical paradigm.¹³ Phenomenologists argue that phenomena, such as medicines use, are constructed through conscious interaction

between subjective humans and the objective physical world. Thus to understand phenomena, researchers must engage with those that have 'lived' through the phenomenon.¹² Collecting data is concerned with uncovering what others have experienced through interviews and focus groups – as well as collecting 'grey' data from photography, poetry, and studying other artifacts.¹² Data can be analysed through interpretative phenomenological analysis or descriptive 106 transcendental phenomenological reduction as well as more conventional thematic qualitative analysis.¹⁴ Phenomenology has a place within the healthcare research environment¹⁵ with methods adopted by nurse researchers to add unique insights to the literature,¹⁴ in areas such as heart failure and HIV, using medical devices to deliver continuous positive airway pressure (CPAP) and specific treatments, for example cholinesterase inhibitors in Alzheimer's disease.¹⁶⁻¹⁹ Phenomenological methods deliver insights into the 'lived experience' of healthcare phenomena of nursing, medical and pharmaceutical interest. Systematic reviews and meta-analysis are widely accepted by health professionals as a gold standard approach for pooling data from multiple studies. Formal statistical methods can quantitatively synthesise data from multiple sources in the literature, however where this is inappropriate, as is the case for qualitative data, a thematic or narrative synthesis can be an appropriate approach.²⁰ Thematic analysis of phenomenological research may provide insights into patients' lived experiences of medicines adherence and direct future strategies for adherence interventions based on patient experiences. The aim of this systematic review was to explore patients' lived experiences of medicines adherence reported in the phenomenological literature, through systematic review and thematic synthesis.

Objectives

To explore patients' lived experiences of medicines adherence reported in the phenomenological literature.

Methods

Protocol and Registration

This review follows PRISMA Guidelines for reporting systematic reviews.²¹ Methodological limitations were assessed following the CASP Qualitative Research Tool and summarised by i) medicines/health issue, ii) methods, iii) sample size, iv) sample characteristics, and iv) major findings.²² The review protocol is registered with PROSPERO [Registration number CRD42015029494].

Eligibility Criteria

The criteria for selecting records for inclusion in the review were i) was a phenomenological investigation ii) was in adults (defined as 18 years and older) iii) was published in a peer reviewed journal iv) aimed to investigate the patients' experiences of medicines adherence.

Exclusion Criteria

Excluded studies were not published in peer-reviewed journals; were not in adults; did not aim to investigate patients' experience of medicines adherence and were not phenomenological investigations.

Information Sources

A systematic search was performed to identify phenomenological articles that investigated patients' experiences of medicines adherence. CINAHL, PsychInfo, Web of Science, Sociological Abstracts, and MEDLINE were searched. Databases were searched individually 146 using the keywords displayed in Table 1 below. Additional records were identified via the snowball method through personal libraries of the authors, professional research networks and searching the references of the included records.

Search

As “adherence” is a relatively new term to describe medicines-taking behaviour, “concordance” and “compliance” were also used to identify articles. Database specific subject headings were used to broaden the search to include appropriately indexed subordinate subject headings. To focus the search to phenomenological inquiries “phenomen*” and “DE phenomenology” were added to the search strategy. Search terms were truncated, such as “phenomen*”, to include phenomenological and phenomenology. The search was limited to the English language.

Study Selection

Titles and abstracts resulting from the database search were reviewed by the first author (APR) and full-texts were retrieved for relevant articles or articles that did not provide enough information in the title or abstract. The full-texts of eligible articles were then systematically reviewed for information about patients’ experiences of medicines adherence. Articles that met the inclusion criteria were reviewed in their entirety using the CASP Qualitative Research Tool.

Data Collection and Synthesis of Results

Thematic analysis was conducted manually and with the use of Nvivo10 computer software [QSR International, Melbourne] to generate descriptive and analytical findings, according to the method outlined by Thomas and Harden.²⁰ Data was gathered for coding from articles by uploading full-text PDF files into an NVivo project, then coding the text within the PDFs at 6 different nodes. Text that was included in the analysis related 169 to the findings of the study, including participant numbers, evidence tables, quotes, as well as reported findings that were within the text.²⁰ When text in the abstract and discussion related to new concepts, this was also collected for coding. Nodes were clustered to generate descriptive themes and used to generate analytic themes. Coding was conducted iteratively by APR and verified through repeated discussions with the other authors, who had access to the full-text papers and NVivo coding reports to independently verify coding decisions. Analytic themes were generated through additional coding, reflection and discussion with all authors. Collected data was coded ‘line-by-line’ to develop descriptive clusters, which were used to generate analytic themes which ‘go beyond’ the primary studies.²⁰ Data was also collected from each study to tabulate i) medicines/health issue, ii) methods, iii) sample size, iv) sample characteristics, and v) major findings as shown in Table 1.²⁴

Risk of Bias in Individual Studies

Phenomenological and qualitative research is inherently subjective and often accused of bias. In phenomenological methodology, researchers are advised to avoid bias through a process of bracketing previously held presuppositions, referred to as epoché, prior to the investigation. As per the CASP Tool, bias was assessed based on the documentation of a reflective or epoché by the study authors.²³

Summary Measures and Synthesis of Results

Whilst there is not a principal summary measure, studies’ key characteristics and findings are summarised below in Table 1.

Risk of Bias across Studies

Risk of bias was not assessed formally across the studies.

Additional Analysis

No additional analysis was performed.

Results

Study Selection

The search strategy identified 47 records of phenomenological investigations into medicines adherence. 25 records did not meet the inclusion criteria. 22 articles were reviewed in their entirety using the CASP Qualitative Tool and included in a thematic synthesis.

Study Characteristics – size, Health Problem/Issue Investigated, Sample Characteristics

The majority of studies were set within the context of HIV,^{19, 25-30} other conditions including sickle cell disease,³¹ asthma,^{32, 33} tuberculosis,^{34, 35} mental health (including schizophrenia, depression),³⁶⁻³⁸ osteoporosis,^{39, 40} and diabetes.⁴¹ Two studies investigated the experience of adherence more generally^{42, 43} and two studies in multiple diseases, such as patients with life long dependency on medicines⁴⁴ and headaches.⁴⁵ Five studies investigated the experience in women only^{25, 29, 39, 41, 42} whilst no studies investigated the experience 211 of adherence specifically in men.

Sample sizes varied within the studies included in this review. The lowest sample size was 1, whilst the highest sample size was 149. The median number of participants was 14. In qualitative research, theoretical data saturation often dictates sample size however phenomenology appears to offer flexibility concerning appropriate sample sizes and emphasises the depth of analysis.⁴⁶ The majority of studies were from the US and Europe although there was a wide range of geographical locations including the UK,^{31, 32} Belgium,⁴⁴ America,^{19, 25-27, 37, 43, 45} Denmark,^{36, 42} Canada,^{39, 40} Iran,²⁸ Australia,^{30, 38, 41} South Africa,³⁴ Vietnam,²⁹ Sweden,³³ and Ethiopia.³⁵

Thematic Synthesis of Findings

Descriptive Themes (Results of Individual Studies)

The synthesis of results identified four descriptive themes. These were i) dislike of medicines, ii) survival, iii) perceived need including two sub-themes of a) symptoms and side-effects and b) cost, and iv) routine.

i) Dislike of medicines

Studies often reported a seemingly pre-predicative dislike for medicines engendered through fear of uncertainty,^{19, 25, 27, 33, 37, 38, 40, 42, 44} dependency,^{33, 37, 45} and illicit drug taking³⁸ tempered 230 only by hope.^{28, 34} Uncertainty was often described as experiencing a lack of knowledge^{19, 28, 32, 34, 36, 38-40, 42, 45} and related to patients accepting the biological causes of their illness^{30, 33, 35, 37} or adoption of natural or alternative therapies.^{27, 34, 35, 42, 45} Participants reported receiving knowledge,^{31, 39} obtaining knowledge,^{19, 32} and being 'convinced' to use medicines.^{30, 40}

ii) Survival

Survival, living and a readiness to adhere were reported extensively in the literature.^{19, 25-35, 37, 39} This was described as patients' 'choosing to live' and consequently being ready to adhere to treatment.^{27, 28, 30} Papers also described adherence as an experience of life-long commitment, highlighting the implications of routine, everyday life on long-term outcomes such as survival.^{19, 39}

iii) Perceived Needs

This theme relates to the frequently stated experience of weighing up 241 the advantages and disadvantages of using a medicine in relation to beliefs about 'need'^{27, 28, 32, 33, 37-39, 42, 45} and was constructed from two sub-themes.

a. Symptoms and Adverse Effects

Studies reported the experience of symptom relief, 'getting better' and the medicines 'doing what it was meant to do'. Papers often recounted a negotiation between the symptoms of a disease and the adverse effects of the medicine.^{27, 33-35, 38, 45} This relates to theme i) Dislike of medicines, in that adverse effects were often considered an inevitable part of the experience of adherence.

b. Cost

Six papers reported that the risk benefit analysis included considerations of the cost of the medicine.^{32, 35, 38, 39, 44, 45} The cost of travel to access the medicine was also conveyed in these studies as central to the experience of adherence in contexts where access to medicines was limited geographically or financially through insurance-based healthcare models.^{35, 38, 44, 45}

iv) Routine

Lifestyle,^{19, 25, 27, 28, 30-32, 34, 39, 40, 44, 45} time,^{19, 43, 45} memory,^{13, 15, 19, 20, 27, 40, 42, 47} and distraction⁴⁴ were found to be components of the experience of an adherence routine. Papers reported task based activities and the storage of medicines as structural components of the experience,^{30, 43, 45} as well as devices that might be used or prepared as part of the adherence experience.⁴⁸

Analytic Themes (Synthesis of results)

The descriptive themes were analysed further to construct analytic themes, which attempt to 'go beyond' the findings originally reported in the studies,²⁰ and deliver insights in the experiences of a phenomenon that transcend the contexts of the primary research. The analytical themes identified were i) identity and ii) interaction.

i) Identity

Pharmaceutical objects were reported to exist within the experience of adherence as embodied actors within a phenomenological life-world. Medicines were characterised by their efficacy to relieve symptoms; cause adverse effects; with costs associated with access; storage requirements; and how they should be taken. These identifying features of a medicine represented structural components of the experience and are demonstrated in the quotes below.

Most patients referred to penicillin as a 'very powerful medication' and this was demonstrated in their accounts that they believe that by taking the penicillin the threat and severity of getting serious infections would be reduced.³¹ For example, one participant considered his bisphosphonate to be a "minor medication...just more like supplements than medication"⁴⁰

The identity of the medicines also appeared to inform the participant's identity, as below,

And I think when Prozac came out somehow the brand name...I think Prozac became synonymous with crazy. For a lot of people. And so, people would say, "oh well, they're on Prozac"³⁷

As informed by the identity of the medicine, the identity of the patient emerged as part of the experience of adherence as noted in this quote,

Many participants expressed feelings, such as loss of identity, loss of roles within personal relationships and embarrassment in relation to their steroid treatment. Loss of identity included issues such as personality changes, feelings of 'not being themselves', being unable to fulfil their normal role within the family unit, or being perceived as different by friends or family.³²

Patient's identity and personal values influenced adherence as they constructed ideals of right and wrong and how to live a perceived healthy life.

These young women were determined to pursue a healthy lifestyle and considered medicine use to directly conflict with their health-related values. One informant felt it was "wrong" to take medicine, and shared her holistic view of healthy living:

"If you do the things, if you are healthy in your daily life, if you are less stressed out and stuff, then that makes it so that you have less of a need for medicine. Um. So I really try to avoid medicine, in every way".⁴²

A seemingly pre-predicative dislike of medicines as part of the patient's identity was renegotiated by perceptions of need, ultimately leading to the modification of the patient's identity and their ability to survive.

You know, I have been on medication now for 8 years and it's [sic] such a part of my life and the knowledge, the simple knowledge that if I had not taken my pills I would've been dead by now is enough to keep me taking the pills. I am healthy as anything. I'd probably never 303 been as healthy as I am right now but live and I assume I'd be dead so...³⁰

Identities of patients and of medicines appeared to be constructed through interaction with each other and wider social actors; this is expanded upon below.

ii) Interaction

Participants constructed identities of their medicines through interaction with their medicines; with healthcare professionals; with family members; the disease and with 'healthcare literature' (for example blood results and hospital charts). Instead of going to bars to find support, they began asking for this from their families, co-workers, healthcare providers and other HIV-positive people who were felt to be interested in their individual well-being.² Studies also reported interaction with medicines identities through health literature, In-depth research by participants paralleled the search for the 'right' health care provider and the 'right' HIV medication, and included activities such as reading magazines, looking for information about HIV treatment on the Internet, attending community HIV-related groups and listening to lectures about HIV disease²⁶ and through interaction with the medicine itself,

The metaphor that emerged from the data was Life in a Pill Bottle, which reflected the central focus of HAART in participants' lives and describes the complex relationships that evolve between among the person, the medications and the virus.²⁷

These interactions formed such a significant part of the experience of adherence, they often resulted in changes to the perceived identity of the medicine, particularly in relation to how it should be taken, which occasionally led to non-adherence, as demonstrated by the quote below,

When I got out of the hospital, he (health care provider) was really giving up on me. I thought, 'Well, this is not the person I want caring for me'. I decided, well, I want to live so I need to find a new doctor, which I did. "I took them (the HIV medications) about two months and stopped because I did not like him (health care provider)."²⁶

Interaction between patients' experience of symptom relief, adverse effects and their healthcare professional is demonstrated further in this quote, here the patient clearly modifies their medicines-taking to align with their beliefs about steroids,

I would be on my knees rather than take them, as time goes on and how I feel within myself, if I feel that I'm starting to come round. I will cut them down and maybe the consultant has said stay on two tablets until I see you in four weeks, but if I feel okay I won't stay on those two, I mean I probably will cut them down again, maybe I shouldn't but...³²

Interaction with expert healthcare professionals facilitated the construction of knowledge relating to the identity of the medicine congruent with adherence and consequently informed beliefs about 'need', this is demonstrated in the quote below,

“so then I started to feel better and I started actually to get involved in more self-help kinds of things and reading stuff that was critical of most of what I had experienced in the mental health system. They really try to convince you that the illnesses that you have are biological and that if you take the drugs and do what we think you need to do, then you’ll be okay.”³⁷

The construction of knowledge through interaction was often described as ‘convincing’ or ‘being convinced’ and related to the identity of the medicine including its perceived need to be taken, and the patients’ identity and in relation to how they should use medicines. This is demonstrated below,

“[the GP] that she automatically put women on bone density medication once they were fifty or over...So I was not convinced to take it because...I wasn’t convinced that I needed it. Not at all.” She was then referred to a specialist who gave her an in-depth explanation of her condition and about the medication itself. Following the visit with her specialist, this participant decided to take osteoporosis medication: “I felt very confident and secure once I spoke with her [the specialist] in detail about my concerns taking the drug. I just didn’t want to take any drug unless it was necessary. But she explained everything so thoroughly and had information to back it up from my charts. So she convinced me and she said she doesn’t mainly prescribe drugs either, nor does she like taking them herself unless it’s necessary.”⁴⁰

Bias was not assessed across the studies.

Discussion

Summary of Evidence

The findings from this synthesis suggest that a structural component of adherence is the interaction between the distinct, textual identities of social actors. Adherence was experienced as a dynamic routine, informed by knowledge about the patient and about the patients’ medicines, that patients gained from wider society. This work describes important structures of adherence as identity, of patients and medicines, and as interaction between the patient, their medicine and wider social interaction with friends, family, and health professionals. Knowledge and perceptions, constructed from social interaction, enabled patients to modify medicines-taking routines, ultimately resulting in normalised non adherence, i.e. patients ‘got to know’ their medicines to such an extent that they could confidently modify their medicine-taking routines despite prescribed regimens.

This work supports that conducted using other approaches, which identified the importance of perceived need.⁴⁹ Horne et al. argue that internal negotiations between the patient’s perceived need of a medicine and the patient’s concerns about adverse effects position adherence as a dichotomy. This was also seen in the reviewed phenomenological literature, as perceptions of need and of survival were explicitly described in relation to medicines taking. The construction of knowledge about the safety and efficacy of medicines, and hence the need of medicines, is also supported by other work.⁵⁰ Conceptualising medicines as social entities, as well as biochemical ones, is a well-supported position and supports the findings of this review, relating to the structures of adherence centred on social interaction.^{48, 51, 52} Particularly the work by Dingwall and Wilson, which reported the ‘symbolic transformation’ pharmacists perform when dispensing medicines, changing medicines from biochemical to social entities.⁵³ Framing interactional relationships as significant parts of the adherence experience is also supported by other work.^{54, 55} This highlights the importance of initial support and reinforcement when medicines are first prescribed and crucially, throughout the life of the prescription.

Relevance to HCPs and Position within Adherence Research

For healthcare professionals, these findings highlight the importance of social interaction on constructed patient beliefs, lay knowledge about medicines, and experiences of adherence. In clearer terms, this work highlights patients’ interaction with wider society as domain for novel

intervention development. Within this domain, healthcare professionals might consider their own role in generating patients' perspectives of medicines' identities, seeking to combine their scientific expertise with patients' lay knowledge and encouraging patients to 'get to know' their medicines over repeated clinical interactions. This might help patients consider the long-term outcomes of adherence and ultimately encourage patients to identify adherence within the context of wider societal norms. This work 402 can be located within the adherence research as a novel perspective of the adherence phenomenon. Adherence researchers might use this work to direct novel intervention development that positions adherence as a function of wider social interaction. The UK's National Institute of Health and Care Excellence's (NICE) guideline on medicines adherence⁵⁶ advocates that interventions are tailored to meet patients' individual needs, with an emphasis on patients being given an appropriate amount of information to make an informed decision. The guideline does not appropriately recognise medicines as tacit social objects and medicines adherence as a social phenomenon, where information to make an informed decision is often generated through social interaction with lay sources of knowledge. Policy makers must consider the wider social determinants of adherence, such as exposure to information in the mass media, newspaper headlines, on the Internet and generated through interaction with healthcare professionals. Interventions to improve adherence should therefore utilise these forms of social interaction, promoting adherence through public health campaigns. Additionally health professionals could highlight the need to scrutinise information about medicines that patients may be exposed to from other social interaction, such as interactions with family and friends, encouraging patients to discern between robust, scientifically-informed medicines' information and lay knowledge.

The findings also support the use of phenomenology as a theoretical framework and method to investigate adherence.

Limitations of this review

Synthesis of qualitative data is often controversial as qualitative findings are often deeply contextualised and so difficult to transfer from one setting to another. Thomas and Harden argue that "the act of synthesis could be viewed as similar to the role of a research user when reading a piece of qualitative research and deciding how useful it is to their own situation." ²⁰ They go on to argue that context can be preserved if aims, methods, sample characteristics and settings of the manuscripts synthesis are shared as part of the synthesis, as in Table 1.

Phenomenologists are encouraged to present their findings in creative and novel ways to engage wider public interest. Due to this varied nature of phenomenological research, it is possible some studies were not identified, such as those presented as art or poetry and not published in journals. Limiting the study to include only phenomenological studies limits the generalizability of the findings, however this was felt an appropriate way to manage differences in conceptual frameworks, philosophies and theoretical backgrounds to different types of qualitative research, maintaining a sense of conceptual congruity between the included studies. The authors are currently unaware of a method for identifying or assessing quality of this type of publication systematically and consequently 437 could not include this work in the review or thematic synthesis. A further limitation of this review is that we only included studies that explicitly aimed to investigate the experience of medicines adherence. This meant that studies investigating only a part of the experience of medicines adherence, for example investigating beliefs about treatment, or studies investigating the broader experience of healthcare, such as self-management of diabetes, were excluded from the study. It could be argued that these excluded papers may have included relevant extracts however as their primary aim was not investigating the experience of adherence per se, these extracts may have been hard to identify or contentious in their relevance to adherence.

Conclusion

This work describes adherence as a social interaction between the identity of patients and medicines, mediated by lay knowledge constructed through social interaction with family, friends, healthcare professionals, the media and the medicine itself. Patients 'got to know' their medicines to such an extent that interactions with the medicine could be modified to deviate from the prescription. Healthcare professionals and policy makers should seek to co-construct patient beliefs about medicines, through repeated interaction with expert knowledge from healthcare professionals, the mass media and the product, such that patients 'get to know' their medicines and how they can be taken to improve health outcomes safely, i.e. are prescribed, throughout the life of the patient and the prescription. The systematic review of phenomenological investigations of medicines adherence has shown that the method can deliver novel insights across a range of disease states. Further empirical research is needed to support these findings.

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Conflict of Interest

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468 References

- 469 **1.** Haynes RB, Ackloo E, Sahota N, et al. Interventions for Enhancing Medication
470 Adherence. *Cochrane Database Systematic Reviews*. 2008:CD000011.
- 471 **2.** Nieuwlaat R, Wilczynski N, Navarro T, et al. Interventions for enhancing medication
472 adherence. *Cochrane Database of Systematic Reviews*: John Wiley & Sons, Ltd; 2014.
- 473 **3.** Proteus Digital Health Inc. First Medical Device Cleared by FDA With Adherence
474 Claim. Redwood Shores, California: Proteus Digital Health, Inc; 2015.
- 475 **4.** Ahmed R, Aslani P. What is patient adherence? A terminology overview.
476 *International journal of clinical pharmacy*. 2014;36:4-7.
- 477 **5.** Hess LM, Raebel MA, Conner DA, Malone DC. Measurement of adherence in
478 pharmacy administrative databases: a proposal for standard definitions and preferred
479 measures. *The Annals of pharmacotherapy*. 2006;40:1280-1288.
- 480 **6.** van Onzenoort HA, Neef C, Verberk WW, van Iperen HP, de Leeuw PW, van der
481 Kuy P-HM. Determining the feasibility of objective adherence measurement with
482 blister packaging smart technology. *American Journal of Health-System Pharmacy*.
483 2012;69:872-879 878p.
- 484 **7.** Zeller A, Ramseier E, Teagtmeyer A, Battegay E. Patients' self-reported adherence to
485 cardiovascular medication using electronic monitors as comparators. *Hypertension
486 Research*. 2008;31:2037-2043.
- 487 **8.** Lam WY, Fresco P. Medication Adherence Measures: An Overview. *BioMed
488 Research International*. 2015;2015:12.
- 489 **9.** Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ : British Medical
490 Journal*. 2000;320:114-116.
- 491 **10.** Creswell J. *Qualitative Inquiry & Research Desig: Choosing among five approaches*.
492 2nd ed. California, United States of America: Sage Publications, Inc; 2007.
- 493 **11.** Vermeire E, Hearnshaw H, Van Royen P, Denekens J. Patient adherence to treatment:
494 three decades of research. A comprehensive review. *Journal of clinical pharmacy
495 and therapeutics*. 2001;26:331-342.
- 496 **12.** Moustakas C. *Phenomenological Research Methods*. London: Sage Publications Ltd.;
497 1994.

498 **13.** Keen E. *Doing Research Phenomenologically*. Lewisburg: Bucknell University; 1975.

499 **14.** Lopez KA, Willis DG. Descriptive Versus Interpretive Phenomenology: Their
500 Contributions to Nursing Knowledge. *Qualitative Health Research*. 2004;14:726-735.

501 **15.** Broekaert E, Autrique M, Vanderplasschen W, Colpaert K. 'The Human Prerogative':
502 A Critical Analysis of Evidence-Based and Other Paradigms of Care in Substance
503 Abuse Treatment. *Psychiatric Quarterly*. 2010;81:227-238.

504 **16.** Hutchings D, Vanoli A, McKeith I, Brotherton S, McNamee P, Bond J. Good days
505 and bad days: The lived experience and perceived impact of treatment with
506 cholinesterase inhibitors for Alzheimer's disease in the United Kingdom. *Dementia*
507 (14713012). 2010;9:409-425.

508 **17.** Shoukry G, Wong K, Bartlett D, Saini B. Treatment experience of people with
509 obstructive sleep apnoea seeking continuous positive airways pressure device
510 provision through community pharmacies: a role for pharmacists? *The International*
511 *Journal Of Pharmacy Practice*. 2011;19:318-327.

512 **18.** Scotto CJ. The lived experience of adherence for patients with heart failure. *Journal*
513 *of Cardiopulmonary Rehabilitation*. 2005;25:158-163.

514 **19.** Jones SG. The other side of the pill bottle: the lived experience of HIV-positive
515 nurses on HIV combination drug therapy. *JANAC: Journal of the Association of*
516 *Nurses in AIDS Care*. 2002;13:22-36.

517 **20.** Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in
518 systematic reviews. *BMC medical research methodology*. 2008;8:45.

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21. Moher D, Liberati A, Tetzlaff J, Altman D, Group TP. Preferred Reporting
519 items for
520 Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS medicine*.
521 2009;6.

522 **22.** Glenton C, Lewin S, Carlsen B, et al. Assessing the certainty of findings from
523 qualitative evidence syntheses: the cerqual approach 2013.

524 **23.** Critical Appraisal Skills Programme International Network. 10 questions to help you
525 make sense of qualitative research [Checklist] accessed at
526 [http://www.caspinternational.org/mod_product/uploads/CASP Qualitative Research](http://www.caspinternational.org/mod_product/uploads/CASP%20Qualitative%20Research%20Checklist%2031.05.13.pdf)
527 [Checklist 31.05.13.pdf](http://www.caspinternational.org/mod_product/uploads/CASP Qualitative Research Checklist 31.05.13.pdf) on 7th November 2013 2013.

528 **24.** Cooke A, Smith D, Booth A. Beyond PICO: The SPIDER Tool for Qualitative
529 Evidence Synthesis. *Qual Health Res*. 2012;22:1435-1443.

530 **25.** DeMoss M, Bonney L, Grant J, Klein R, del Rio C, Barker JC. Perspectives of
531 middle-aged African-American women in the Deep South on antiretroviral therapy
532 adherence. *AIDS care*. 2014;26:532-537.

533 **26.** Enriquez M, Lackey NR, O'Connor MC, McKinsey DS. Successful adherence after
534 multiple HIV treatment failures. *Journal of advanced nursing*. 2004;45:438-446.

535 **27.** Jones SG. Life in a pill bottle: the experience of taking HIV medications.
536 *International Journal for Human Caring*. 2003;7:57-65.

537 **28.** Mohammadpour A, Yekta ZP, Nasrabadi ARN. Hiv-infected patients' adherence to
538 highly active antiretroviral therapy: a phenomenological study. *Nursing & health*
539 *sciences*. 2010;12:464-469.

540 **29.** Nguyen NTT, Rasch V, Bygbjerg IC, Mogensen HO. Pursuing Treatment and Moral
541 Worth: HIV-Infected Women in a Northern Province of Vietnam Living With
542 Antiretroviral Therapy. *JANAC: Journal of the Association of Nurses in AIDS Care*.
543 2012;23:339-349.

544 **30.** Sidat M, Fairley C, Grierson J. Experiences and perceptions of patients with 100%
545 adherence to highly active antiretroviral therapy: a qualitative study. *AIDS Patient*
546 *Care & STDs*. 2007;21:509-520.

547 **31.** Abedian M, Howard J, Rawle H, Thomas V. A qualitative study of perceptions of
548 using prophylactic penicillin in patients with sickle cell disease. *Primary Health Care*.
549 2010;20:26-31.

550 **32.** Gamble J, Fitzsimons D, Lynes D, Heaney LG. Difficult asthma: people's

551 perspectives on taking corticosteroid therapy. *Journal of clinical nursing*.
552 2007;16:59-67.

553 **33.** Scherman MH, Löwhagen O. Drug compliance and identity: reasons for non554
555 compliance : experiences of medication from persons with asthma/allergy. *Patient
556 Education & Counseling*. 2004;54:3-9.

556 **34.** Naidoo P, Dick J, Cooper D. Exploring tuberculosis patients' adherence to treatment
557 regimens and prevention programs at a public health site. *Qual Health Res*.
558 2009;19:55-70.

559 **35.** Tadesse T, Demissie M, Berhane Y, Kebede Y, Abebe M. Long distance travelling
560 and financial burdens discourage tuberculosis DOTs treatment initiation and
561 compliance in Ethiopia: a qualitative study. *BMC public health*. 2013;13:424-424.

562 **36.** Henriksen MG, Parnas J. Self-disorders and schizophrenia: a phenomenological
563 reappraisal of poor insight and noncompliance. *Schizophrenia bulletin*. 2014;40:542-
564 547.

565 **37.** Kwinter M. Message in a bottle: the meanings of antidepressant medication for
566 psychotherapy patients. *Smith College Studies in Social Work (Haworth)*.
567 2005;75:27-52.

568 **38.** Muir-Cochrane E, Fereday J, Jureidini J, Drummond A, Darbyshire P. Self569
570 management of medication for mental health problems by homeless young people.
571 *International journal of mental health nursing*. 2006;15:163-170.

571 **39.** Lau E, Papaioannou A, Dolovich L, et al. Patients' adherence to osteoporosis therapy:
572 exploring the perceptions of postmenopausal women. *Canadian family physician
573 Medecin de famille canadien*. 2008;54:394-402.

19

40. Sale JEM, Gignac MA, Hawker G, et al. Decision to take osteoporosis 574 medication in
575 patients who have had a fracture and are 'high' risk for future fracture: a qualitative
576 study. *BMC musculoskeletal disorders*. 2011;12:92-92.

577 **41.** Tilden B, Charman D, Sharples J, Fosbury J. Identity and adherence in a diabetes
578 patient: transformations in psychotherapy. *Qualitative Health Research*.
579 2005;15:312-324.

580 **42.** Hansen DL, Holstein BE, Hansen EH. "I'd rather not take it, but . . .": young women's
581 perceptions of medicines. *Qualitative Health Research*. 2009;19:829-839.

582 **43.** Sanders MJ, Van Oss T. Using Daily Routines to Promote Medication Adherence in
583 Older Adults. *American Journal of Occupational Therapy*. 2013;67:91-99.

584 **44.** De Geest S, Abraham I, Gemmeke H, Evers G. Development of the long-term
585 medication behaviour self-efficacy scale: qualitative study for item development.
586 *Journal of advanced nursing*. 1994;19:233-238.

587 **45.** Seng EK, Holroyd KA. Optimal Use of Acute Headache Medication: A Qualitative
588 Examination of Behaviors and Barriers to Their Performance. *Headache: The
589 Journal of Head & Face Pain*. 2013;53:1438-1450.

590 **46.** Crotty M. *The Foundations of Social Research: Meaning and Perspective in the
591 Research Process*. Sydney: SAGE Publications Ltd.; 1998.

592 **47.** Usher K, Park T, Foster K. The experience of weight gain as a result of taking
593 second-generation antipsychotic medications: the mental health consumer perspective.
594 *Journal of psychiatric and mental health nursing*. 2013;20:801-806.

595 **48.** Whyte S, van der Geest S, Hardon A. *The Social Lives of Medicines*. United
596 Kingdom: Cambridge University Press; 2002.

597 **49.** Horne R, Chapman SCE, Parham R, Freemantle N, Forbes A, Cooper V.
598 Understanding patients' adherence-related Beliefs about Medicines prescribed for
599 long-term conditions: A meta-analytic review of the Necessity-Concerns Framework.
600 *PloS one*. 2013;8.

601 **50.** Webster A, Douglas C, Lewis G. Making Sense of Medicines: 'Lay Pharmacology'
602 and Narratives of Safety and Efficacy. *Science as Culture*. 2009;18:233-247.

603 **51.** Cohen D, McCubbin M, Collin J, Pérodeau G. Medicines as Social Phenomena.

604 Health. 2001;5:441-469.

605 **52.** Anderson C, Roy T. Patient experiences of taking antidepressants for depression: A
606 secondary qualitative analysis. Research in Social & Administrative Pharmacy.
607 2013;9:884-902.

608 **53.** Dingwall R, Wilson E. Is Pharmacy really an "incomplete profession". Perspectives
609 on Social Problems. 1995;7:111-128.

610 **54.** Chai J, Anderson C, Wong KT, Hussein Z. Social Stigma Affecting Non-adherence
611 of Insulin Therapy for Type 2 Diabetes Management in Malaysia. Research in Social
612 and Administrative Pharmacy. 2014;10:e53.

613 **55.** Laba T-L, Lehnbohm E, Brien J-a, Jan S. Understanding if, how and why non-adherent
614 decisions are made in an Australian community sample: A key to sustaining
615 medication adherence in chronic disease? Research in Social and Administrative
616 Pharmacy.11:154-162.

617 **56.** National Institute for Health and Clinical Excellence. Medicines adherence: involving
618 patients in decisions about prescribed medicines and supporting adherence. CG 76,
619 Medicines adherence. London 2009.

620

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