



Review Article

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

A.P. Rathbone, M.Pharm.^a, A. Todd, Ph.D.^a, K. Jamie, Ph.D.^b,
M. Bonam, B.Sc.^c, L. Banks, Ph.D.^c, A.K. Husband, D.Prof.^{a,*}

^aSchool of Medicine, Pharmacy and Health, Durham University, University Boulevard, Queen's Campus, Stockton-on-Tees TS17 6BH, United Kingdom

^bSchool of Applied Social Sciences, Durham University, 32 Old Elvet, Durham DH1 3HN, United Kingdom

^cAstraZeneca PLC, Charter Way, Macclesfield SK10 2NA, United Kingdom

Abstract

Background: Medicines non-adherence continues to be problematic in health care practice. After decades of research, few interventions have a robust evidence-based demonstrating their applicability to improve adherence. Phenomenology has a place within the health care research environment.

Objective: To explore patients' lived experiences of medicines adherence reported in the phenomenologic literature.

Methods: 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, health care professionals, the media and the medicine, itself. Health care 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.

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* Corresponding author. Tel.: +44 191 334 0102.

E-mail address: a.k.husband@durham.ac.uk (A.K. Husband).

Introduction

Medicines adherence, defined as ‘how well a patient takes their prescription medicines,’ continues to be problematic in health care 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 conceptualizations 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-centered 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 conceptualizations of adherence, for example Hess, Raebel, Conner, and 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 conceptualized ‘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, and 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 conceptualized 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 behaviors 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 overestimate adherence, suggesting these measures never to be used alone.⁷ Whilst it is well recognized no single method is preeminent and multiple methods of measuring the same phenomenon offer an element of triangulation and validity,⁸ these methods unintentionally conceptualize 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 behaviors located at the right time and date and finally; as a representation of patients’ own subjective beliefs about their behaviors when under investigation in research. These different conceptualizations 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 behavior or a long-term set of behaviors?) 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 conceptualized 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

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