



City Research Online

City, University of London Institutional Repository

Citation: Cox, C. L. (2012). Adherence, compliance, persistence and concordance in the management of glaucoma, Part I. *International Journal of Ophthalmic Practice*, 2(6), pp. 260-264.

This is the unspecified version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/2346/>

Link to published version:

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

Title: Adherence: Compliance, Persistence and Concordance in the Management of Glaucoma Part I

Authors:

Raed Amro, MSc, BSc (Hons), RN
Emergency Nurse Practitioner, Accident and Emergency Department
Moorfields Eye Hospital NHS Foundation Trust
Address: 162 City Road, London EC1V 2PD
Telephone: 020 7566 2207
Fax: 020 7253 4696
E-mail: r.amro@moorfields.nhs.uk

Professor Carol L. Cox, PhD, MSc, MA Ed, P G Dip Ed, BSc (Hons), RN, FAHE
Professor of Nursing, Advanced Clinical Practice, Department of Applied Biological Sciences, City University London, and Nursing Research Lead, Moorfields Eye Hospital NHS Foundation Trust, London
Address: School of Community and Health Sciences, City University London, 20 Bartholomew Close, London EC1A 7QN
Telephone: 020 7040 5812
Fax: 020 7040 5717
E-mail: c.l.cox@city.ac.uk

Correspondence to: Professor Carol L. Cox

Key Points:

It is recognised by healthcare practitioners that adherence to long-term intraocular pressure (IOP) lowering medication is poor in patients with glaucoma, which is a significant factor in disease progression.

A significant problem associated with adherence is the patient's failure to recognise there is a need to administer their eye drops as prescribed.

Ocular hypotensive drugs are prescribed to patients with Chronic Open Angle Glaucoma to minimise the visual field loss by slowing the progression rate of the disease in individuals with high intraocular pressures (IOPs) and so preserving their vision.

There are three main techniques followed in assessing adherence. These are patient self-report, monitoring devices and renewing prescriptions.

Key Words: Adherence, compliance, persistence, concordance, intraocular pressure, glaucoma.

Adherence: Compliance, Persistence and Concordance in the Management of Glaucoma Part I

Abstract

Adherence is laden with difficulties in relation to the management of glaucoma. Perhaps a significant issue associated with a lack of the aforementioned is associated with the patient's failure to recognise there is a need to administer their eye drops as prescribed. Undoubtedly the greatest issue is that patients experience no pain with their debilitating eye disease. It is not until there is considerable loss of vision that awareness of the need to administer eye drops becomes a reality. Understanding the complexities of adherence and its association with compliance, persistence and concordance as discussed in this article can assist the healthcare practitioner in developing models of care that help the patient in self-management of their glaucoma. This article is published in two parts. Part I addresses the background to issues associated with adherence in glaucoma management including definition of terms, assessing adherence and barriers and interventions to improve adherence. Part II addresses the Theory of Adherence and Self-Management of Chronic Open Angle Glaucoma (COAG). It provides perspectives, theories and models that can be employed to improve adherence in the self-management of glaucoma.

Introduction

Adherence is a term that is frequently discussed by healthcare practitioners in relation to patients managing their health. It is recognised by healthcare practitioners that adherence to long-term intraocular pressure (IOP) lowering medication, in particular, is poor in patients with glaucoma, which is a significant factor in disease progression. The concept of adherence is recognised by healthcare practitioners as being laden with difficulties in relation to the management of glaucoma. A significant problem associated with adherence is the patient's failure to recognise there is a need to administer their eye drops as prescribed. Undoubtedly the greatest issue is that patients experience no pain with their debilitating eye disease (Amro et al, 2011). It is not until there is considerable loss of

vision that awareness of the need to administer eye drops becomes a reality. This article addresses the concept of adherence in association with compliance, persistence and concordance in the management of glaucoma. It provides the background associated with adherence in chronic conditions, explains the concepts of adherence, compliance, persistence and concordance, describes various mechanisms for assessing the concepts and delineates barriers and interventions to improve adherence.

Background:

Patient adherence with medical treatments for chronic conditions is known to be far from ideal (Schwartz and Quigley, 2008). Approximately 9% of all prescriptions written across all therapeutic areas are never filled; especially at initial stage of treatment (Lash and Harding, 1995). The scope of this issue is enormous throughout chronic condition literature. Diseases that are asymptomatic in nature like Chronic Open Angle Glaucoma (COAG) are more prone to poor adherence (Dimatteo et al, 2002) with studies suggesting it could be as high as 80% (Olthoff et al, 2005).

Ocular hypotensive drugs are prescribed to patients with COAG to minimise the visual field loss by slowing the progression rate of the disease in individuals with elevated intraocular pressures (IOPs) and so preserving their vision (Nordstrom et al, 2005). It is important that these drops are administered regularly on a daily basis for life (Gray et al, 2009). Failing to do so, could result in additional risks and costs because of the need for more hospital appointments and diagnostic tests, having to switch to other medications and/or wastage of unfinished pharmaceutical supplies, and ultimately needing to advance to surgical intervention (Bissell et al, 2004; Hoevenaars et al, 2008; Gray et al, 2009). It is important to note here that, according to some medical literature, medication such as Nitroglycerin may increase intraocular pressure and should be used with caution in patients that have glaucoma. However the effect of organic nitrates and nitrites on intraocular pressure has been found to be variable and that there is no evidence that these drugs cause narrow angle glaucoma (Drugs.Com, 2011)

The literature addressing glaucoma treatment adherence is vast, reflecting the variation in terminology used to describe it (such as compliance, persistence and concordance), its interventions and strategies designed to tackle poor adherence, barriers, and the way it is measured. Vermiere et al (2001) observed that during three decades of quantitative research into adherence 'non-compliance', more than 200 variables have been studied. However none can be considered as consistently predictive.

Terminology

The term adherence means to be consistent – to stick to a regimen. Therefore from an ophthalmic (medical) perspective adherence means to stick to a prescription, and is viewed as a measure of whether eye drops have been instilled. A lack of adherence refers to gaps in a therapy or treatment.

Although the term 'compliance' has been used extensively in the medical model to refer to the extent to which patients' behaviours correspond with providers' recommendations (Schwartz, 2005) and implies their obedience to the doctor's orders. Compliance views the patient as a passive recipient of instructions and directions of the superiorly experienced and knowledgeable doctor and reflects a paternalistic attitude. Unsurprisingly, this term has been abandoned for a more precise and less judgmental term, called adherence (Gray et al, 2009). Adherence in this sense is synonymous with compliance and has an association with concordance. Adherence was defined by (Lee et al, 2007) as consistency and accuracy with which a patient follows a recommended medical regimen. Compliance and adherence according to Britten (2001) have provided an ideological framework through which doctors can express their ideas about how patients *ought* to behave. This framework has justified blaming patients for not acting in accordance with doctors' instructions and expectations.

Mead and Bower (2002) highlighted the limitations of the compliance and adherence models in their application to health care relationships. The Independent Kings Fund report observed a "growing recognition" that the interests of those who provide health care do not necessarily coincide with the needs of those who use it. Where

interaction with patients based on this model is viewed as an opportunity to reinforce instructions and expectations, instead, Bissell et al (2004) have advocated for a more collaborative approach and open space where expertise of both patients and healthcare professionals can be pooled together to arrive at mutually agreed goals. In other words, healthcare professionals should seek to develop “concordance” with their patients attending the service (Working Party, 1997). Concordance was introduced in the 1997 by the Royal Pharmaceutical Society of Great Britain and intended to remove the implications of patient obedience or submissiveness to physician’s orders. Notwithstanding, what is the association with persistence?

Persistence is another term, not synonymous with compliance or adherence that is still in use as it refers to the length of time from commencement to discontinuation of a prescribed treatment (Reardon et al., 2004). Persistence can be considered to persevere such as in the continuous use of a medication. In this instance, the patient persists steadfastly in administering eye drops even though they sting and make the patient’s eyes red. The terms adherence and persistence are similar and yet have differences. For example, if a patient was prescribed a once-daily medication but actually takes the drug once every other day for an entire year; the patient would be 50% adherent and 100% persistent. Persistence leads on to a consideration of concordance.

According to a multidisciplinary group of healthcare professionals, academics and members of the pharmaceutical industry in the UK, concordance, as a new approach to glaucoma treatment and professional-patient interaction, has been defined as:

“Concordance is based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and the aim is therefore a therapeutic alliance between them. This alliance, may, in the end, include an agreement to differ. Its strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust and concealment”

Working Party (1997:8).

The principles of concordance are not new (Britten, 2001). The principles are increasingly referred to in health service research. In contrast to compliance and adherence, Williams and Calnan (1996) noted that concordance fits neatly with the political landscape of the NHS in the United Kingdom (UK) and is congruent with ideas such as shared clinical decision making, patient-centeredness and collaborative care (May and Mead, 1999). There are interesting studies that show the misunderstanding that arises between patients and doctors in the consultation around their treatment and the unvoiced patients' agenda in this consultation (Williams and Calnan, 1996). Nonetheless, there is a need for more empirical research which can shed light on concordance relevant to patients with chronic conditions like COAG (Bissell et al, 2004). Regardless of the aforementioned, Justis (2010) has argued that the concordance approach has not been widely adopted.

Assessing Adherence

Assessing adherence accurately poses a significant challenge in glaucoma treatment (Schwartz and Quigley, 2008). Throughout the literature, there are three main techniques followed in measuring adherence. These are patient self-report, monitoring devices and renewing prescriptions.

Patient Self-Report

Using a numerical scale that allows patients to mark along the scale where they thought their answers should be without judgmental or leading questions is called patient self-report (Gray et al, 2009). Although simple and inexpensive, self-report whether by self-administered questionnaire or by interview, tends to overestimate adherence (Kass et al, 1986). Although this technique is subjective to recall bias and the desire to please health professionals, Gray et al (2009) observed that self-report is the most utilised method for assessing adherence in glaucoma. Schwartz and Quigley (2008) draw attention to the selection bias of patients who are willing to complete a questionnaire or agreed to be interviewed may demonstrate higher rates of adherence. Patients with poor adherence tend not to return for follow up and thus are unable to participate in a study.

Monitoring Devices

In theory, an electronic monitoring device of dosing is considered the most reliable tool for assessment (Olthoff et al, 2005). An example of such monitoring devices that have been used is the Medication Events Monitoring System (MEMS) (Sleath et al, 2011). However, these devices cannot prove that a drop truly went in the patient's eye or on the cheek, floor or in the sink (Schwartz and Quigley, 2008). These devices have advanced considerably in recent years where the device itself has become smaller and even invisible in some cases (Hermann and Diestelhorst, 2006). However; it will be some time before more accurate and cost-effective devices are available for use (Gray et al, 2009).

Renewing Prescriptions

This method is an objective estimation of adherence and persistence by assessing patients' continuity of the therapy (Schwartz and Quigley, 2008). Gray et al (2009) argue that this method provides an accurate estimation of persistence; however, obtaining a repeat prescription of a particular drug does not necessarily mean that the drug will be used as prescribed or used at all.

Barriers and Interventions to Improve Adherence

Determining barriers to adherence relies primarily on patients' attitudes and thoughts which are well located in the merit of qualitative research (Lacey et al, 2009). Despite the call for further research relating to adherence with glaucoma therapy (Quigley et al, 2006) and the growing acceptance and use of qualitative methods in human behaviours (Green et al, 2002), there are few studies performed with in-depth qualitative perspectives (Taylor et al, 2002).

Adherence issues are complex. Tsai et al (2003) reported as many as 71 unique situational obstacles on patients in the United States of America (USA). Following this observation, Tsai et al (2003) grouped the obstacles into four separate categories: situational/environmental factors (35 of 71; 49%), medication regimen

factors (23 of 71; 32%), patient factors (11 of 71, 16%), and provider factors (2 of 71; 3%). For further details, refer to Table 1. The taxonomy formulated in this study could be useful in assisting healthcare professionals develop individualised interventions that optimise patient education and problem solving regarding their health care.

Table 1: Categories of Barriers to Adherence

<p>Situational/environmental factors</p> <p>Accountability and lack of support Major life events Travel/away from home Competing activities Change in routine</p>	<p>Treatment regimen</p> <p>Refill Cost of medication Complexity Change Side effects</p>
<p>Patient Factors</p> <p>Knowledge/skills Memory Motivation/health beliefs Co-morbidity</p>	<p>Providers factors</p> <p>Dissatisfaction Communication</p>

In another qualitative study Taylor et al (2002) explored poor adherence amongst glaucoma patients and revealed that forgetfulness was the main reason for poor adherence. Other reasons were inability to instil eye drops even though the patients thought they could, treatment side effects, complexity of the treatment regimen, level of glaucoma knowledge and education, trying new treatment options and the cost of treatment.

A more recent UK based study by Lacey et al (2009) revealed the following barriers: lack of knowledge and education, lack of faith in drop efficacy, problems with drop instilling, forgetting drops, practical problems (running out of drops, failing to reorder them, medication packaging, side effects and cost), age and individual differences (physical inability to instil drops, needing more assistance to instil drops, forgetting drops in the elderly population as compared to feeling depressed amongst the younger population as glaucoma is considered to be an elderly disorder).

Based on the above barriers, numerous studies have set out to improve treatment adherence in glaucoma patients by improving/removing one or more of the identified barriers. Broadly speaking, interventions that were designed to improve adherence comprised educational, drug comparison, and/or reminder devices.

Educational and Individualised Care Planning

These interventions are based on the belief that improving patients' glaucoma knowledge and their understanding of the condition will eventually improve their adherence levels. Patients receive basic information on glaucoma and available treatment regimens and then helped to identify suitable times for instilling and storing their eye drops. Examples of this intervention are Norell (1979) and Sheppard et al (2003). Educational interventions refer to cognitive didactic approaches where behavioural principles such as reinforcement and feedback are increasingly used (Leventhal et al, 1997). To be effective, educational interventions have to be tailored to the patient's particular needs, in addition to the quality of patient-provider interaction and the way information is passed (Van Dulmen et al, 2007).

Drug Comparison (Technical Interventions)

Most adherence interventions studies in this domain are aimed at simplification and reducing the number of doses per day or reducing the number of different drugs in the regimen (Van Dulmen et al, 2007). Other studies compared the adherence levels amongst patients prescribed two different drugs (Gray et al, 2009). Leventhal and Cameron (1987) argued that these technical solutions reflect the biomedical perspective of using medical expertise to find solutions for patients' problems without engaging with patients.

Reminder Devices (Behavioural Interventions)

These interventions are based on the fact that forgetfulness is the main barrier to adherence and shares the assumption that reminding patients to take their eye drops will improve their adherence. There are different devices being used: a cap attached to the bottle that digitally displays the time and the day of the week the container was

last open and when was the last drop taken (Gray et al, 2009; Olthoff et al, 2005). Other studies have used a memory aid that provides an audible and visible reminder as to when a drop is due (Laster et al, 1996). In the USA, several studies have examined the use of incentives in which patients have been paid for taking their treatment. This intervention showed improvement in adherence levels in 10 out of the all trials reviewed (Giuffrida and Torgerson, 1997) and represents aspects of human behaviour theories where reminders can act as cues or stimuli and incentives as rewards.

The three reviews did not demonstrate any convincing evidence to advocate a particular intervention over the others. However, there have been reported significant yet small improvements in all interventions. Olthoff et al (2005) concluded that all the studies in his review lacked a thorough behavioural theory basis which is a conclusion shared by Van Dulmen et al (2007). Van Dulmen et al (2007) indicated that further studies are needed to explore the theoretical components of these interventions. Furthermore, Gray et al (2009) did not find convincing evidence to recommend any particular intervention for improving adherence amongst glaucoma patients.

Conclusion

This article has addressed the concept of adherence in association with compliance, persistence and concordance in the management of glaucoma. It has explained these concepts, described various mechanisms for assessing adherence and delineated barriers and interventions to improve adherence. Part II in this series will address the Theory of Adherence and Self-Management of Chronic Open Angle Glaucoma (COAG). It will provide perspectives, theories and models that can be employed to improve adherence in the self-management of glaucoma.

.

References

Amro, R., Cox, C., Waddington, K. and Siriwardena, D. (2011) Glaucoma Expert Patient Programme. *International Journal of Ophthalmic Practice*, 2(1): 32 – 38

Bissell, P., May, C. and Noyce, P. (2004) From compliance to adherence: barriers to accomplishing a re-framed model of health care interactions. *Social Science and Medicine*, 58:851-862.

Britten, N. (2001) Prescribing and the defence of clinical autonomy. *Sociology of Health and Illness*, 23 (4): 478-496.

DiMatteo, M., Giordani, P., Lepper, H., et al. (2002) Patient adherence and medical treatment outcomes: a meta-analysis. *Medical Care*, 40:794-811.

Drugs.Com (2011) Nitrates/Nitrics – Glaucoma. <http://www.drugs.com/disease-interactions/nitroglycerin.html#Glaucoma> (Accessed 2 November 2011).

Gray, T., Orton, L., Henson, D., Harper, R. and Waterman, H. (2009) Interventions for improving adherence to ocular Hypotensive therapy. *Cochrane Database of Systematic Reviews*, Is. 2, Art. No.: CD006132.

Green, J., Siddall, H. and Murdoch, I. (2002) Learning to live with glaucoma: a qualitative study of diagnosis and the impact of sight loss. *Social Science and Medicine*, 55:257-267.

Hoevenaars, J., Schouten, J., van den Borne, B., Beckers, H. and Webers, C. (2008) Will improvement of knowledge lead to improvement of compliance with glaucoma medication? *Acta Ophthalmologica*, 86:849-855.

Justis, P. (2010) *Does “non-compliance” have any place in patient-centred care? Patient-Centred Medical Home Collaborative*. Internet document, available on (<http://www.pcpcc.net/pilot/Washington-patient-centered-medical-home-collaborative>).

Kass, M., Gordon, M. and Meltzer, D. (1986) Can ophthalmologists correctly identify patients defaulting from Pilocarpine therapy? *American Journal of Ophthalmology*, 101:542-530.

Lacey, J., Cate, H. and Broadway, D. (2009) Barriers to adherence with glaucoma medications: a qualitative research study. *Eye*, 23:924-932.

Lash, S. and Harding, J. (1995) Noncompliance. *Journal of Managed Care Pharmacy*, 1: 193-9.

Lee, P., Walt, J., Chiang, T., Guckian, A. and Keener, J. (2007) A gap analysis approach to assess patient persistence with glaucoma medication. *American Journal of Ophthalmology*, 144:520-4.

Leventhal, E. and Cameron, L. (1987) Behavioural theories and the problem of compliance. *Patient Education and Counselling*, 10:117-38.

Leventhal, E., Falconer, L., Diefenbach, M. and Leventhal, E. (1997) *From compliance to social-self-regulation: Models of the compliance process. In treatment compliance and the therapeutic alliance*, edited by: Blackwell. Amsterdam: 17-33.

May, C. and Mead, N. (1999) Patient-centeredness: A history. In L. Frith and C. Dowrick (Eds.), *Ethical issues in general practice: uncertainty and responsibility*. London: Routledge.

Mead, N. and Bower, P. (2002) Patient-centred consultations and outcomes in primary care: A review of the literature. *Patient Education and Counselling*, 48; 51-61.

Nordstrom, B., Friedman, D., Mozaffari, E., Quigley, H. and Walker, A. (2005) Persistence and Adherence with Topical Glaucoma Therapy. *American Journal of Ophthalmology*, 140 (4): 598-606.

Norell, SE. (1979) Improving medication compliance: a randomised clinical trial. *British Medical Journal*, 2(6197):1031-3.

Olthoff, C., Schouten, J., van de Borne, B. and Webers, C. (2005) Noncompliance with Ocular Hypotensive Treatment in Patients with Glaucoma or Ocular Hypertension: An Evidence-Based Review. *Ophthalmology*, 112 (6):953-61.

Quigley, H., Goldberg, I., Kitazawa, Y., Halprin, R., Hitchings, R., et al. (2006) *Cooperation with medical therapy, report from the global AIGS committee on cooperation with therapy*. In: Greve EL (ed). *International Glaucoma Review, Supplement, Vol.7*. Kuglar Publications: The Netherlands, 2006, pp. 354-359.

Reardon, G., Schwartz, G. and Mozaffari, E. (2004) Patient persistency with topical ocular hypotensive therapy in a managed care population. *American Journal of Ophthalmology*, 137: S3-S12.

Schwartz, G. (2005) Compliance and persistency in glaucoma follow up treatment. *Current Opinion in Ophthalmology*, 16:141-121.

Schwartz, G. and Quigley, H. (2008) Adherence and Persistence with Glaucoma Therapy. *Survey of Ophthalmology*, 53 (1):S57-S68.

Sheppard, J., Warner, J. and Kelley, K. (2003) An evaluation of the effectiveness of a nurse-led glaucoma monitoring clinic. *Ophthalmic Nursing*, 7(2):15-21.

Sleath, B., Blalock, S., Covert, D., Stone, J. L., Skinner, A. C., Muir, K. and Robin, A. L. (2011) The Relationship between Glaucoma Medication Adherence, Eye Drop Technique, and Visual Field Defect Severity. *Ophthalmology*, Aug 17th, <http://www.ncbi.nlm.nih.gov/pubmed/21856009> (Accessed 3 November 2011).

Taylor, S., Galbraith, S. and Mills, R. (2002) Causes of non-compliance with drug regimens in glaucoma patients: a qualitative study. *Journal of Ocular Pharmacology and Therapeutics*, 18(5): 401-409.

Tsai, J., McClure, C., Ramos, S., Schlundt, D. and Pichert, J. (2003) Compliance barriers in glaucoma: A systematic classification. *Journal of Glaucoma*, 12:393-398.

Van Dulmen, S., Slujis, E., van Dijk., de Ridder, D., Heerdink, R. and Bensing, J. (2007) Patient adherence to medical treatment: a review of reviews. *BMC Health Service Research*, 7(55).

Vermiere, E., Hearnshaw, H., Van Royen, P. and Denekens, J. (2001) Patient adherence to treatment: three decades of research: a comprehensive review. *Journal of Clinical Pharmacology and Therapeutics*, 26:331-42.

Williams, S. and Calnan, M. (1996) *Modern Medicine: Lay Perspectives and Experiences*, London: UCL Press.

Working Party (1997) *From compliance to adherence: Achieving shared goals in medicine taking*. Report of the Working Party. London: Royal Pharmaceutical Society of Great Britain/Merck, Sharp and Dohme.